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Dementia friendly flying: investigating the accessibility of air travel for people living with Dementia

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University of Plymouth

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**UNIVERSITY OF
PLYMOUTH**

**Dementia Friendly Flying: Investigating the
accessibility of air travel for people living with
Dementia**

by

Katherine Turner

A thesis submitted to the University of Plymouth
in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Health Professions

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Author's Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without the prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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Publications

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Presentations at Conferences

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Abstract

Katherine Anne Turner: Dementia friendly flying: investigating the accessibility of air travel for people living with Dementia

A diagnosis of dementia should not mean the end of a person's ability to participate in meaningful activities. However, accessibility for people living with dementia requires improvement across a range of settings. Anecdotal evidence and critical incident reporting suggests that air travel is not meeting the needs of people with dementia, although evidence-based research into air travel and dementia is extremely limited. This research bridges the gap in the evidence-base on the accessibility of air travel for people living with dementia from within the United Kingdom by:

- 1) Exploring the experiences of air travel of 10 people living with dementia and 10 travel companions of people living with dementia through a series of in-depth phenomenological interviews. Findings identified the importance of a positive social environment, airport special assistance as both a barrier *and* a facilitator, challenges within the general airport environment and the need for continuity of support at transit points and upon arrival at the destination.
- 2) Conducting a realist synthesis of the best practice elements of dementia awareness and support training outside of the field of healthcare. Core training components included the importance of sector specific leadership to facilitate engagement, the need for contact education to reduce fear of the unknown and to challenge stigma and the inclusion of ongoing peer support and evaluation to facilitate long-term change.

The findings from both studies are presented within a series of recommendations for how the air travel experience can be improved for people living with dementia and those who travel with them in the future. A detailed framework for the future design of context specific dementia awareness and support training is also outlined. The framework not only identifies what key mechanisms may work in such training, but also provides a rationale as to *why* these mechanisms may work.

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Abbreviations used throughout the thesis

ACI	Airports Council International
ADI	Alzheimer's Disease International
BAME	Black, Asian and minority ethnic communities
BBC	British Broadcasting Corporation
CAA	Civil Aviation Authority (UK)
COT	College of Occupational Therapists (UK) (pre 2017)
DEEP	Dementia Engagement and Empowerment Network
NEB	National Enforcement Body (of air travel legislation)
ICAO	International Civil Aviation Organisation
ICF	International Classification of Functioning
I-D-Air	International Dementia Air Travel Group
LGBT+	Lesbian, gay, bisexual and transgender+ communities
PRM	Passenger(s) with reduced mobility
RAMESES	Realist and Meta-Narrative Evidence Synthesis
RCOT	Royal College of Occupational Therapists (UK) (post 2017)
UK	United Kingdom
USA	United States of America
WFOT	World Federation of Occupational Therapists
WHO	World Health Organisation

Terms used throughout the thesis

Convention on International Civil Aviation	Otherwise known as the Chicago Convention. The convention was signed in December 1944 to regulate air travel for 52 member states (including the UK). The International Civil Aviation Organisation (ICAO) was formed to “implement, monitor and update this convention which is still in force today” (ICAO, 2021, p.16).
Hidden or invisible disabilities	“...an invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person’s movements, senses, or activities... the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions, and judgments”. (Invisible Disabilities Association, 2020)
Long haul flight	Any flight over 6 hours’ duration
Short haul flight	Any flight under 6 hours’ duration
Special assistance	“...a passenger with a disability or reduced mobility ...[is] legally entitled to support, commonly known as Special Assistance when travelling by air. This means airports and airlines must provide help and assistance, which is free of charge, and helps ensure [the passenger] has a less stressful journey” (Civil Aviation Authority [CAA], 2015b).
Travel Chain	“...all elements that make up a journey from starting point to destination – including the pedestrian access, the vehicles and the transfer points. If any link is inaccessible, the entire trip becomes difficult” (World Health Organisation [WHO], 2011)
Young onset dementia	A person who is <65 years of age at the time of their dementia diagnosis

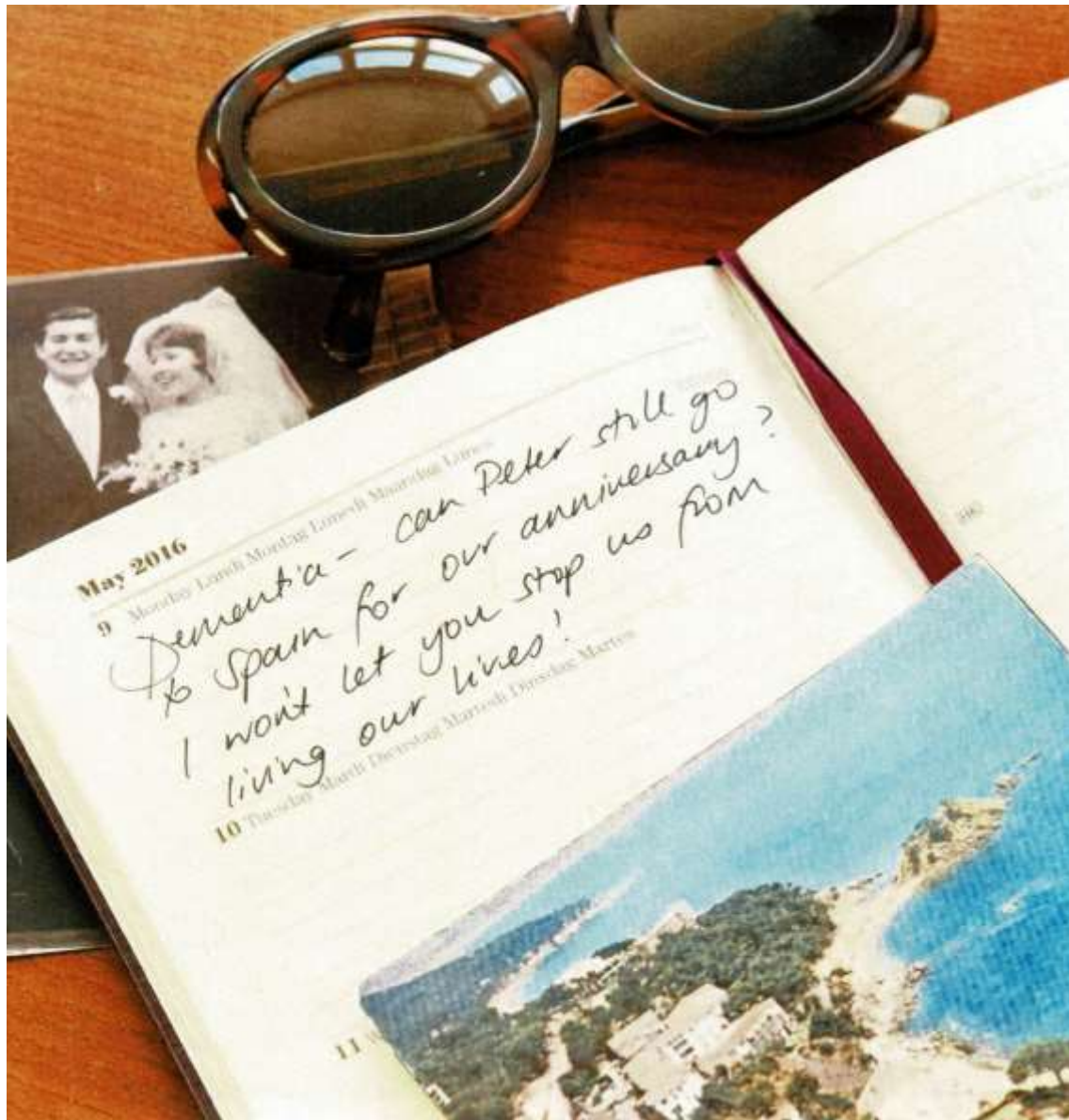


Figure 1 - What do you want to say to dementia?

**From Alzheimer's Society Dementia Awareness Week 2016.
Image reproduced with permission from Alzheimer's Society**

I placed this image on the wall by my desk soon after I began this Ph.D. For me it expresses the very human nature of, and rationale for, this research in that a diagnosis of dementia should not define a person. Nor should it prevent a person from living their life, their way, for as long as possible.

CHAPTER 1 – INTRODUCTION

“...always remember the answer to these two questions: if your mother developed dementia how would you want her to be treated by society? If you yourself developed dementia at some time in the future, how would you like to be treated by society?”

(McKillop in Alzheimer’s Disease International, 2016, p.7).

1.1 Introduction

Dementia is a global challenge. In 2015 Alzheimer’s Disease International (ADI) published a report that estimated 46.8 million people were living with dementia across the world, a figure they expect to increase to 75.7 million by 2030 and 131.5 million by 2050 (ADI, 2015). Whilst it is the latest available global report, it is now six years out of date. This is important given that ADI (2015) further stated that every year there are approximately 9.9 million new cases of dementia worldwide equating to one new case every three seconds (ADI, 2015). More recent estimates indicate that there are 885,000 people living with dementia in the United Kingdom (UK), a figure that is expected to rise to 1,000,000 by 2024 (London School of Economics, 2019). Connell and Page (2019b) suggest that over four percent of the UK population are directly affected by dementia, either by having dementia themselves or acting as a carer for someone living with the condition, a figure that is again likely to increase.

Whilst dementia affects all ages, it has been estimated that of those living with dementia in the UK at least 42,000 have young onset dementia (<65 years of age at

diagnosis) (Alzheimer's Society, 2021a). However, statistics for other sub-groups of the UK dementia population are more difficult to quantify. For example, while it is estimated that three percent of those living with dementia within the UK are from black, Asian and minority ethnic (BAME) communities, this statistic cannot be relied upon due to the purported barriers experienced by this group in both receiving a dementia diagnosis and obtaining access to services (Alzheimer's Society, 2019a). Similarly, it is unknown how many of those living with dementia are from the lesbian, gay, bisexual and transgender (LGBT+) community, despite the additional stigmatisation and social isolation likely to be experienced by those within this group (Dementia Action Alliance [DAA], 2017).

In recent years, air travel has received increased attention within the media as not meeting the needs of people living with dementia. High profile incidents include the case of Victoria Kong an 83 year old American woman who became disorientated and died just 200 yards from Reagan International Airport, Washington in the United States of America (USA) after she allegedly failed to connect with an airline representative (Washington Post, 2013). While Alois Dvorzak was detained by UK Border Force after arriving in the UK from Vancouver, Canada with no ticket for onward travel, no luggage and \$1,400 cash (The Globe and Mail, 2016). Reports suggest that Mr Dvorzak was trying to reunite with his daughter who lived in Slovenia and was merely using the UK as a transit point, but became caught up in the UK's immigration system due to his inability to provide details of onward travel and due to concerns over his health and welfare (The Globe and Mail, 2016). Tragically, Mr Dvorzak died in custody at Harmondsworth Immigration Detention Centre despite

medical advice that he was too frail and confused to be detained in this setting (The Guardian, 2015).

Clearly, these cases are extreme, but the worldwide occurrence of such anecdotal reporting demonstrates that air travel is not meeting the needs of people with disabilities in general (Darcy, 2012). There is also evidence that the appropriateness and safety of air travel for people living with dementia is being discussed on travel forums and advice is also being sought via these means (Alzheimer's Society, 2013a; Alzheimer's Society, 2018a; TripAdvisor, 2013).

One disability rights expert has even described air travel for people living with dementia as:

“... a ticking time bomb medical research and [the] travel industry are yet to address”

(Castiglioni, 2014)

While Castiglioni's comments are now over six years old, the number of passengers travelling by air who declare a disability and request assistance is increasing. In the financial year 2018/19 the UK Civil Aviation Authority (CAA) reported that “*a record*” 3.7m passengers were assisted through UK airports, an increase of 49% since 2014 (CAA, 2019a, p.4). The CAA's figures are not broken down into disability category, nor do they include figures for people with a disability who do not declare they need assistance to travel. However, the increasing prevalence of dementia would suggest that more people living with dementia are going to be travelling by air in the future

and airport and airline staff will need an appropriate level of understanding of the condition to enable them to do so safely.

1.2 Chapter Overview

This chapter sets the context for this doctoral thesis by providing a definition of dementia, together with an overview of how the most prevalent form of dementia, Alzheimer's Disease, can affect an individual's ability to participate in occupations that are meaningful to them. The stigmatisation of people living with dementia, and some of the work that has been undertaken to reduce this, will also be discussed. As the doctoral researcher is an occupational therapist the occupational therapy profession and its role in facilitating people to do the things they want and need to do within their lives will be explored. The chapter concludes with the research question, the aims of the study and an overview of how the research will be presented within this thesis, together with an outline of the researcher's positionality in view of the background of the research.

1.3 What is Dementia?

Dementia is an umbrella term for a range of conditions that cause progressive damage to brain function affecting memory, language, problem-solving and other skills necessary to carry out activities of daily living (Alzheimer's Association, 2019b). Whilst there are over 100 different types of dementia, the four most prevalent types are Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Frontotemporal Dementia, with Alzheimer's Disease and Vascular Dementia accounting for approximately 90% of all dementia cases (Warner & Graham, 2018).

Rarer forms of dementia may be associated with other diseases such as Parkinson's disease, Huntington's disease, Cruetzfeldt-Jakob disease and the human immunodeficiency virus (HIV) or may occur as a result of severe or sustained head injuries (Warner & Graham, 2018).

Whilst all dementias share commonalities due to progressive cognitive decline, the presentation of dementia will be dependent on the type of dementia a person has and the area of the brain that is affected. For example, typical symptoms within Alzheimer's Disease include short term memory recall difficulties, repetitive questioning, word finding difficulties and increased anxiety, while someone with Vascular Dementia may experience muscle weakness, difficulties with walking and movement and mood changes (Rahman & Howard, 2018).

When discussing dementia, some experts use a three-stage model of progression being: early stage, mid stage and end stage. However, Professor Barry Reisberg and colleagues have developed a more in-depth, seven stage, scale of how progressive dementias such as Alzheimer's Disease develop and their likely effect on an individual's daily life on a stage by stage basis (Reisberg *et al.*, 1982). Despite its age, the Reisberg *et al.* (1982) scale is still used for diagnostic and staging purposes in some settings today and helps to demonstrate that dementia is not a static condition, but one that deteriorates over time. Understanding this variable and individualised rate of progression is relevant and will be discussed further in Section 3.4.3 when determining the inclusion criteria for those living with dementia to the study.

Research into the cause of, and potential cure for, dementia is ongoing (Alzheimer's Society, 2021c). However, people are being diagnosed with pre-clinical dementia as many as eight years before they start to exhibit symptoms due to technological advances in brain scanning and other factors such as primary healthcare professionals being more alert to the long term risks of mild cognitive impairment (Rasmussen & Langerman, 2019). The purported advantage of this is that the person can access treatment at a much earlier stage which may preserve their functional ability and allow them to maintain their independence and quality of life for longer than if their diagnosis was not known (Rasmussen & Langerman, 2019).

Whilst early diagnosis is not the same as young onset dementia, it has already been noted that an estimated 42,000 people within the UK dementia population have received a diagnosis of dementia prior to their 65th birthday (Alzheimer's Society, 2021a). Earlier diagnosis in general, and being diagnosed at an earlier age in particular, are relevant for this research as it is recognised that people in the earlier stages of dementia and those diagnosed at a younger age are keen to live well with dementia for as long as possible post diagnosis (National Dementia Action Alliance, 2020). Although it is acknowledged that pervading stigmatisation of people living with dementia is frequently cited as one of the main reasons a person may not wish to receive an early diagnosis of dementia, despite the perceived benefits that may be derived from this (Social Care Institute for Excellence, 2020c).

1.3.1 Stigmatisation of people living with dementia within society

Those living with dementia have encountered stigmatisation within society and even within the medical professions. Kate Swaffer an academic and younger person with dementia from Australia recalls being told to cease all activities and to prepare her power of attorney at the time of her diagnosis, a process she has termed and trademarked as Prescribed Dis-Engagement™ (Swaffer, 2015). Whilst researchers in Poland assert that diagnostic labels such as dementia can lead to automatic stereotyping and stigmatisation within the medical profession (Urbańska, Szcześniak & Rymaszewska, 2015). The findings from Urbańska, Szcześniak and Rymaszewska (2015) are considered to be generalisable as such stigmatisation within the medical establishment appears to be prevalent in other countries. With one neurologist from the Republic of Ireland describing her profession's attitude to dementia as one of "[perceived] inability and invisibility" (Montague, 2018).

Other areas of purported stigmatisation towards those with dementia include detrimental changes within relationships, ignoring the person with dementia within conversation and an automatic assumption that the person living with dementia must have no quality of life (Alzheimer's Association, 2019a). It is also important to note that those living with dementia in minority groups such as the BAME or LGBT+ communities can experience additional stigmatisation and discrimination beyond their dementia diagnosis. Indeed, a recent survey of the LGBT community (n=5000) identified that one in seven people have actively avoided seeking medical treatment for fear of discrimination due to their sexual orientation (Bachmann & Gooch, 2018).

Stigma does not just affect the person with dementia however, with family members experiencing embarrassment and anxiety which can result in reduced contact with family, friends and acquaintances leading to social isolation of the family unit (Urbańska, Szczesniak & Rymaszewska, 2015). ADI (2016), in their capacity as the international federation of dementia organisations around the world, suggest that this pervading level of stigmatisation within society should not be surprising. Particularly given the historically neglectful treatment and routine institutionalisation of people living with dementia up to the turn of the last century (ADI, 2016). Indeed, it has been suggested that even as recently as the late 1990's, when Kitwood published his seminal book on dementia (Kitwood, 1997), the overwhelming public expectation was that people with dementia would be living in care (Brooker, 2019). Whereas the majority of people with dementia are now living in the community and need to be supported to do so (Brooker, 2019).

1.3.2 Legislation protecting the rights of people living with dementia

This ongoing stigmatisation is despite the right of people with dementia to remain active members of society and to be consulted on decisions that affect them being mandated in disability legislation. For example, the Mental Capacity Act 2005 which covers England and Wales holds that a person cannot be deemed to lack capacity on diagnosis alone and that an individual should always be assumed to have capacity unless it can be proved otherwise. However, a Parliamentary review of the Act demonstrated that pervading paternalism and risk aversion within health and social care meant that many people were interpreting the Act as a means of constraint, when the original intention of the Act was to provide people with greater choice and involvement in their own lives (House of Lords, 2014).

Further legislation of relevance includes the Equality Act 2010 which introduces disability in all its forms as one of a series of protected characteristics including (amongst others) age, sex, gender identity and marital status, making it unlawful to discriminate against someone as a result of these characteristics. Articles three, nine and 30 of the Convention on the Rights of Persons with Disabilities (2006) all have relevance to this research in that they provide for:

Article 3: The full and effective partnership and inclusion of persons with disabilities within society.

Article 9: The identification and elimination of barriers to accessibility within transportation.

Article 30: The right of persons with disabilities to have access to travel and tourism services.

To reinforce these rights, a nationwide group of people living with dementia have written five rights based statements with a view to reducing the stigma and lack of understanding surrounding the condition (DAA, 2018). Two of the five statements are particularly pertinent to this research as they emphasise the rights of people living with dementia in accessing community services and in being aware of, and taking part in, research that is relevant to them:

“We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness”

(DAA, 2018, p.9);

And:

“We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part”

(DAA, 2018, p.10).

Tackling the stigmatisation of dementia is important as those encountering stigmatisation may cease to communicate their needs or details of their diagnosis for fear of the response they will receive, leading to increased feelings of fear, loneliness and social isolation (Alzheimer's Association, 2019a). It has also been argued that people living with dementia wish to remain engaged in activities that are meaningful to them not just because they enjoy those activities, but also that their continued engagement acts as a form of resistance to pervading stereotypes giving them a level of power and control over their situation (Dupuis *et al.*, 2012).

However, a tourism study has shown that stigmatisation of people with dementia is still prevalent within that sector, with some tourism providers believing that having people living with dementia as part of their customer base would have a negative impact on customer retention and act as a limiting factor to the success of their businesses (Page, Innes & Cutler, 2015). This has led to the opinion that while positive anti-discriminatory legislation is in place, those living with dementia are almost a decade behind the interventions taken to address the needs of those with physical disabilities in terms of leisure and tourism access (Innes, Page and Cutler, 2016). Clearly, this research is now somewhat dated, particularly given the post Covid-19 world that we now live in (World Health Organisation [WHO], 2021). There

are also notable exceptions to the findings. For example, over 500 staff and volunteers at Beamish, a large open air museum in the north of England are dementia friends and actively utilise their period settings to welcome and engage people living with dementia (Beamish the Living Museum of the North, 2021b; Beamish the Living Museum of the North, 2021a). However the 2019 World Alzheimer Report suggested that societal expectations of, and attitudes to, people living with dementia are still generally very poor on a global scale and more needs to be done to reduce the stigma associated with this condition (ADI, 2019).

Inappropriate use of language about dementia and those living with the condition is considered to add to the stigmatisation of people with dementia in general society (The Dementia Engagement and Empowerment Project [DEEP], 2014). Therefore, the term *person living with dementia* has been consciously used throughout this thesis in accordance with positive language guidelines (DEEP, 2014). *Person* or *people living with dementia* have also been included in full and not abbreviated to PwD or PlwD as such abbreviations are considered to be reductionist (Alzheimer's Society, 2018b).

1.3.3 Dementia Friendly Initiatives

Such is the prevalence and concern regarding the impact of dementia that, in 2012, the then Prime Minister of the UK, The Rt. Hon. David Cameron, M.P., issued a challenge to improve the lives of people living with dementia through innovative health and care services, research and the creation of dementia-friendly communities (Department of Health, 2012). Dementia friendly communities aim to

empower people living with dementia to remain active participants in society and to reduce stigma and social isolation through increased understanding of the disease (Alzheimer's Society, 2013b). Key to the creation and success of dementia friendly communities is that the rights and capabilities of people living with dementia are recognised, with the long-term aim that dementia will become normalised within general society (ADI, 2016). As dementia friendly communities are constructed socially, they vary depending on locality or community response to their creation, but should all focus on improved engagement and participation for people living with dementia with a view to improved quality of life (ADI, 2016). However, the sheer variety of settings for dementia friendly communities locally, nationally and internationally, makes it extremely difficult to evaluate them and to compare their effectiveness (Lin, 2017).

A further initiative is Dementia Friends, an awareness programme which aims to transform the way people think, act and talk about dementia within society and how small actions can make a difference to a person living with dementia's engagement in everyday activity (Alzheimer's Society, 2017). The idea of changing the social and physical environment to reduce the effect of a disability is core to occupational therapy philosophy and forms the basis of the social model of disability (Oliver, 2004). The social model of disability moves away from the idea of personal deficits to recognise the impact on participation of hostile and oppressive environments (Darcy, 2012). In 2019 the Alzheimer's Society covering England, Wales, Guernsey, the Isle of Man and Northern Ireland celebrated reaching a significant milestone in their dementia friends awareness programme, with the creation of three million dementia

friends (Alzheimer's Society, 2019b). All dementia friends learn and pledge to share the five key messages of the programme, namely that:

“(1) Dementia is not a natural part of aging, (2) dementia is caused by diseases of the brain, (3) dementia is not just about losing your memory – it can affect thinking, communicating and doing everyday tasks, (4) it's possible to live well with dementia and (5) there is more to a person than the dementia”

(Alzheimer's Society, 2017)

These messages help to dispel common myths around dementia, with many people still believing that dementia is a natural result of old age, or what was termed for many years as senile dementia (ADI, 2016). It also dispels the myth that loss of memory must always be present, whereas in some forms of dementia, such as frontotemporal dementia for example, there may be no changes to working memory at all in the early stages of the condition (Rahman & Howard, 2018).

The Dementia Friends programme, while successful, is not without controversy, however. With one writer from Japan, where a forerunner of the Dementia Friends UK programme originated, noting that those living with dementia have not always been involved in the programme's design or delivery, effectively putting it at odds with its own ideals (Hayashi, 2017). Also, while the numbers of dementia friends are counted, the dementia friends programme itself has not been evaluated. Evaluating outcomes is important when seeking to improve how those living with dementia are treated within society. For example, by examining whether or not awareness and understanding of dementia has increased and by establishing the changes that have

been made to the physical and/or social environment to enable people living with dementia to engage in their chosen activities (ADI, 2016).

As part of the Prime Minister's Dementia Challenge, a number of specialist groups were established including the Prime Minister's Dementia Challenge Group for Air Transport which is chaired by Mr Ian Sherriff BEM, one of the supervisors to this doctoral research. The group involves people living with dementia and their travel companions¹, representatives from airports and airlines, dementia specialists, cabin crew trainers, legal experts and representatives from the UK CAA. The purpose of the group is to identify the challenges faced by people living with dementia when travelling by air and to seek to improve their air travel experiences. By including those with personal lived experience of dementia, together with representatives of governmental organisations with the power to instigate change such as the CAA, the group is actively embracing the top down, bottom up approach considered to be essential when creating successful dementia friendly initiatives (ADI 2016). This top down/bottom up approach to change has been successful in other settings, whereas utilising only one of the approaches can lead to limited results (Letens *et al.*, 2011).

Following the active involvement of Mr Ian Sherriff and Dr Alison Warren (the Director of Studies for this research), in their capacity as members of the Prime Minister's Dementia Challenge Group for Air Transport, the issue of air travel for people living with dementia and the urgent need for action and improvement has received further support at UK parliamentary level. This included a special debate on

¹ The term travel companion is used at the request of the Reference Group to this project.

the subject in the House of Commons (Hansard, 2016). During the debate Members of the House highlighted the legal obligation to provide special assistance to air passengers and gave examples of good practice in this area such as the Gatwick Airport hidden disability lanyard scheme. However, another Member of the House alleged his wife had been assaulted by a passenger with dementia on an overnight flight from the USA to the UK, an incident which had led him to make a formal complaint to the airline involved (Hansard, 2016). These two opposing viewpoints demonstrate that air travel for people living with dementia is a complex issue and consideration needs to be given on the safety and appropriateness of a person with dementia travelling on their own and the time at which this lone travel may no longer be deemed appropriate.

Arguably, while the aviation industry has a legal duty to accommodate people with a hidden disability such as dementia as previously noted, it also makes sound financial sense to increase accessibility for this group. In 2017, the number of UK air travel passengers totalled 284 million with aviation contributing an estimated £22 billion to the UK economy (Department for Transport, 2018). At the same time the number of UK passengers requiring assistance was increasing year on year, with four million assistance passengers travelling in the 2019/20 financial year - up from one point five million in 2013/14 (CAA, 2020). Clearly, this represents a significant potential market segment for the aviation industry, the implications of which has become even more relevant given the challenges faced by the sector with the advent of the Covid-19 pandemic which occurred during the latter stages of this research (WHO, 2021). The effect of Covid-19 will be discussed further in Chapter 8 (Section 8.4.5) when considering the strengths and limitations of this research.

1.4 Occupational therapy and its links to health and wellbeing

As mentioned in Section 1.2 the researcher for this doctoral research project is a registered occupational therapist. Occupational therapy celebrated its 100 year anniversary as a profession in the United States in 2017, with occupational therapy beginning in the UK in 1929 with the opening of the Dorset House School of Occupational Therapy in Bristol (Elizabeth Casson Trust, 2021). Occupational therapists are health and social care professionals, with their title protected by law. In order to practice occupational therapy within the UK a registration with the Health and Care Professions Council (HCPC) is required. The HCPC describe occupational therapists thus:

“An occupational therapist uses specific activities to limit the effects of disability and promote independence in all aspects of daily life”

(HCPC, 2019)

Indeed, the core premise of occupational therapy holds that engaging in meaningful activity is essential for an individual’s health and wellbeing. This sentiment is frequently expressed by quoting the words of eminent occupational therapist, Mary Reilly:

“that man, through the use of his hands as they are energised by mind and will, can influence the state of his own health”

(Reilly, 1962, p.2)

Policy makers have also adopted this concept of the health benefits derived from engaging in activity, as per this quote from the Ottawa Charter for health promotion.

“Health is created and lived by people within the settings of their everyday life; where they work, learn, play and love. . . . Health is created by caring for oneself and others, by being able to make decisions and have control over one’s life circumstances”

(WHO, 1986, p.4)

This quote is important as it recognises that people derive health and wellbeing from engaging in activities across all aspects of their lives, including those based within the community, and not just those that may be seen as traditionally health promoting. However, despite the health benefits derived from engaging in activities being core to occupational therapy practice, it has been argued that the profession needs to do more to provide evidence of the effect of participation on health and wellbeing outcomes in general (Hammell, 2009; Pizzi & Richards, 2017). It has been suggested that a person with dementia’s health and wellbeing is derived, at least in part, from their engagement in occupations that are meaningful to them (Kitwood, 1997). This study will therefore also seek to identify the meaning of air travel to those living with dementia as part of the wider study.

1.4.1 Defining occupation

When referring to everyday activities, occupational therapists use the term occupation, although defining this term has been the subject of much debate. One of the main challenges with a number of the proposed definitions is that they separate

everything we do as humans into three basic categories of self-care, productivity and leisure, with some occupations, such as caring for others, not appearing to fit into any of the three (Hammell, 2009). Pierce (2001) believes such attempts at categorisation of occupation are overly simplistic and lack the subjectivity of individual experience.

It has been further noted that engaging in occupations such as taking public transport may be undertaken in the company of significant others, thus potentially moving the occupation from the realms of pure doing to that of belonging (Hammell, 2009). This thesis will therefore utilise the World Federation of Occupational Therapists' (WFOT) definition of occupation as it not only provides a broader remit of what occupations are, but also acknowledges that occupations may not just be engaged in individually but jointly and not only occupy time but are meaningful and purposeful to those concerned:

“Occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do”.

(WFOT, 2019b)

1.4.2 The historical workplace for occupational therapists

As previously noted, occupational therapy was born out the belief that engaging in occupations is healing for both mind and body. Primarily used for the treatment of mental health conditions, occupational therapy became more widely known and

respected as a profession due to the benefits it brought to injured and disabled service personnel post World Wars I and II (Gordon, 2009). As a result, occupational therapists remained closely allied to the medical profession and thus the medical model of practice, with occupational therapy intervention being available primarily on prescription (Schwartz, 2018). However, concerns were raised that the continued focus on isolated functions or body parts was reductionist and at odds with the holistic roots of the profession (Gordon, 2009). This refocusing of the profession saw some occupational therapists move out in to the community to support people in their own environments. Such community work remains an important part of the occupational therapy role (Royal College of Occupational Therapists [RCOT], 2017).

In recent years, occupational therapists have been encouraged to take this community role further in seeking non-traditional or role-emerging opportunities by identifying areas where occupational therapists are able to provide support to meet clients' holistic needs (Withers & Shann, 2008). Indeed, Pizzi and Richards (2017) consider that the key to best practice in occupational therapy is to support individuals to engage in occupations that are the most meaningful to them in their own lives.

This concept is highly relevant to this research as those living with dementia, and those who travel with them, have begun to highlight challenges when undertaking travel by air and have expressed the wish to remain engaged with this occupation both prior to an official diagnosis of dementia and for as long as possible post diagnosis. Working within transport may be considered more role emerging than traditional practice for occupational therapy. However, Broome *et al.* (2009) suggest

that, due to our expertise in analysing activities and environments to detect specific challenges, occupational therapists are ideally qualified to investigate transport difficulties and can advocate for transport services to respond to the needs and abilities of those users whose needs are currently not being met. Membership of the Prime Minister's Dementia Challenge Group for Air Transport for occupational therapists and occupational therapy students provides exactly this opportunity in the case of this research.

1.4.3 The concept of occupational justice

When exploring the concept of occupation consideration must also be given to dimensions of inequality that affect such participation such as patriarchy and poverty (Hammell & Iwama, 2012). Indeed, it has been noted that occupational therapists can act as change agents by identifying and seeking to address underlying structural and contextual factors that result in a person's occupational rights to participation being upheld or denied (Pollard, Sakellariou & Kronenberg, 2009; Townsend & Polatajko, 2013). This concept has been termed occupational justice within occupational therapy and occupational science (Wilcock & Townsend, 2009).

A critique of occupational justice is that it has historically been associated with what Bailliard and Aldrich (2017, p.85) term as 'extreme situations' such as homelessness, forcibly displaced communities, modern slavery and imprisonment, rather than those injustices which occur within everyday occupation. With the classification of what constitutes these extreme life situations frequently based on

the social position and expectations of the most dominant group in any society (Bailliard & Aldrich, 2017).

In an attempt to differentiate between extreme and everyday occupational therapy practice, Whiteford *et al.* (2016) began to use the term critical occupational therapy to describe the occupational therapy practice that focusses on disadvantaged or oppressed populations. However, concern has been expressed that such differentiation only serves to make the concept of occupational justice appear even more remote from everyday occupations and occupational therapy practice, when it is, in fact, a common occurrence:

“occupational injustices arise when *any* person experiences *any* situation that prevents access to meaningful occupations”

(Bailliard & Aldrich, 2017, p.84, original emphasis)

The WFOT have also recognised the need for occupational justice measures to address the restrictions that limit people, particularly people with disabilities, when engaging with their chosen occupations. Indeed, research to address systemic barriers to participation are classed as a research priority for participation in everyday life (WFOT, 2016). Wilcock and Townsend (2009) go further by suggesting that the profession’s success not only rests on our focus on occupation, but by putting the concept of occupational injustice at the forefront of our practice. This research therefore seeks to identify the challenges faced by those living with dementia and those who usually travel with them when engaging in air travel in order

to highlight these difficulties. By adding to the current evidence base on this subject (see Chapter 2), it is anticipated that areas of occupational injustice will be highlighted and participation may consequently be increased for this group.

1.4.4 Air travel as a meaningful occupation for people with dementia

It is recognised that the risk of developing dementia increases with age rising from one in 688 in the under 65's to one in six in the over 80's (Alzheimer's Society, 2014). As people age they prioritise their occupations, potentially indicating that those occupations that they choose to remain engaged in are those that are the most meaningful and essential to them (Law, 2002). While Law's (2002) paper is now very dated, a more up to date reference on the prioritisation of occupations in later life has not been found. Remaining engaged in meaningful occupations is linked to improved quality of life, better health, reduced symptoms of depression and stress, life satisfaction and even longevity (Broome *et al.*, 2009; Wilz & Fink-Heitz, 2008). However, life events such as dementia can interrupt participation in meaningful occupations and thus have a detrimental impact on quality of life (Roberts, 2011). Quality of life for those living with dementia can be negatively affected if occupations that promoted social interaction and mental stimulation are reduced (Innes, Page & Cutler, 2016). As previously noted, the quality of life of those in minority groups such as BAME or LGBT+ can be even more severely impacted when their minority status is coupled with a dementia diagnosis (Alzheimer's Society, 2019a; Bachmann & Gooch, 2018). In order to maintain optimal quality of life all people living with dementia should be able to access the full range of occupations open to those in general society including travel (Edwards *et al.*, 2016).

It is suggested that being able to access transport in all its forms is a highly valued and meaningful occupation as it enables participation in society and facilitates access to people and places of meaning, with reduced access leading to social isolation and exclusion (Brown, 2009; Connell *et al.*, 2017; Ingle *et al.*, 2012). However, dementia can affect those skills necessary to access transport such as memory, language and visuospatial and executive functions (Atchison & Dirette, 2012). Accordingly, people with dementia are reportedly finding access to transport more and more difficult due to the complexities and levels of divided attention involved (Hedman *et al.*, 2016). It has also been noted that negotiating new environments can be confusing and anxiety provoking for people living with dementia and readjusting back to the home environment may be problematic for some people (Connell & Page, 2019b).

1.5 Rationale for the research

Due to anecdotal accounts of poor travel experiences for people living with dementia, and limited research evidence into this subject (see Chapter 2), this study will examine the barriers and facilitators to air travel for those travelling with a diagnosis of dementia. As per dementia friendly guidance and in keeping with social and occupational justice, people living with dementia will be directly involved in the interview process (ADI, 2016). As ADI state:

“If it is about us without us, it cannot be dementia friendly”

(ADI, 2016, p9).

By gaining a greater understanding of the barriers and facilitators to air travel for those living with dementia and those who usually travel with them, this research seeks to increase participation in air travel for people living with dementia and to address the potential injustice of non-participation due to factors outside an individual's control.

As noted within section 1.3.3 existing dementia awareness programmes such as dementia friends are not context specific. Therefore, this research will also seek to identify what constitutes good practice dementia awareness and support training in order that a series of recommendations may be created to support those working in the aviation industry when assisting passengers with dementia within this environment in the future.

1.5.1 Aims and Research Questions

Given the challenges identified by people living with dementia as identified within this chapter and the extremely limited evidence base for this topic as outlined in chapter 2, this doctoral study will answer the following overarching question:

What are the barriers and facilitators to air travel for people with dementia and how can participation be improved for this group?

As previously noted, this question will be answered by undertaking two separate but interlinked studies:

Study 1

The first aim of the research is to explore the air travel experiences of people living with dementia and their travel companions when travelling by air from within the UK. This will be achieved by holding phenomenological interviews with ten people living with dementia and ten travel companions of people with dementia. The question for this phenomenological study will be:

What are the lived experiences of people with dementia and their companions when travelling by air?

Study 2

As previously noted, the literature has shown that a lack of customer service training can be a significant barrier to participation in air travel for people with disabilities in general and dementia in particular. Therefore, the second aim of the research will be to establish what constitutes good practice for customer facing staff when meeting the needs of people living with dementia and their travel companions. This will be achieved by undertaking a realist synthesis of the literature on dementia awareness and support training outside of the field of healthcare. The question for the realist synthesis will be:

Dementia awareness and support training outside of healthcare: A realist synthesis of what works, for whom, in what circumstances and why?

The next section of this Chapter will outline the structure of the remainder of this thesis.

1.5.2 Thesis outline

To aid the reader, this thesis contains a further seven chapters which are set out as follows:

Chapter 2 – provides a narrative review of the existing literature on air travel and disability in general.

Chapter 3 – outlines the methodology for this doctoral research including the rationale for undertaking both qualitative phenomenological interviews for those living with dementia and those who travel with them and a realist synthesis of the evidence of dementia awareness and support training outside of the field of healthcare.

Chapter 4 – presents the key findings for the phenomenological interviews as undertaken with participants living with dementia.

Chapter 5 – presents the key findings for the phenomenological interviews as undertaken with companions of participants with dementia.

Chapter 6 – discusses the findings from the realist synthesis and presents a realist refined programme theory of key factors to be considered when designing a training programme for customer facing staff within aviation in the future.

Chapter 7 – synthesises and discusses the findings from Chapters 4, 5 and 6.

Chapter 8 – concludes the research by providing a recap of the key learning derived, outlines the research's unique contribution to the field of occupational therapy and makes a number of recommendations in relation to air travel for people living with dementia and those who travel with them. This chapter also identifies areas for further research and discusses the limitations to this research.

1.6 Reflexive statement - researcher positionality

Whilst the research will primarily be undertaken in my role as a research student, it is recognised that my life and work experiences and my personal and professional beliefs will, consciously or unconsciously, impact upon how the research is designed and undertaken (Durdella, 2019). This understanding of the impact of the *self* in and on the research is considered essential in order to aid transparency and to mitigate the potential for researcher bias (Gray, 2014). I, therefore, acknowledge that I will be bringing a number of key roles and perspectives to this research:

1.6.1 Occupational Therapist

The occupational therapist's role was discussed within this chapter. Consequently, as an occupational therapist, I recognise the link between engaging in occupations of necessity and meaning and the purported effect such participation, or conversely non-participation, has on an individual's health and wellbeing. This understanding of the importance of participation has driven me to seek to identify the points of the air travel journey that cause people living with dementia and their companions the most difficulty and to explore potential solutions to these challenges. Identifying these challenges seeks to address the potential injustice of non-participation due to factors outside an individual's control.

1.6.2 A supporter of the rights of people living with dementia

My reasons for wanting to be involved in this project go beyond those of a health professional however, as my maternal grandmother (Nan) was diagnosed with vascular dementia three years before her death in 2015. As previously noted, society

and even the medical profession can stigmatise, exclude and patronise people with dementia. This resonates deeply with my experience of how my Nan was treated, with many people around her, including health professionals, deeming her to be incapable of making her own decisions and attempting to exclude her from discussions concerning her care and welfare from the point of her diagnosis.

My Nan died six years ago but stigmatisation of people with dementia and a lack of understanding of dementia remains prevalent, with people assuming that a diagnosis of dementia must signal either the end of a person's life or the end of their right to live their life in their own way. On several occasions since starting this research, I have been asked whether people with dementia actually want to travel by air or continue to go on holiday. The questioners' rationale for this being that those living with dementia are unlikely to remember anything of their experiences when they return home. I firmly believe that, unless more research is undertaken that actually includes people with dementia, then the societal belief that people living with dementia automatically lack capacity and are incapable of valued input will perpetuate. It is therefore very important to me, on both a personal and professional level, that the voices of people living with dementia are not only heard, but also listened to, within this project.

1.6.3 A supporter of the rights of carers²

I have supported those caring for people living with chronic and terminal illnesses for over 18 years in my role as a Trustee of a National Respite Care Charity within the UK. When my Nan was diagnosed with vascular dementia I also supported my Mum who became both her main advocate and carer. This was a difficult time as my Mum described it as a ‘constant battle’ against a system she felt was frustrating her at every turn. A union representative during the majority of her working life, my Mum is a very experienced and capable advocate, but her constant fight for my Nan’s rights had a negative impact on her own mental and physical health and wellbeing.

Legislation recognises the adverse effect caring can have and requires that carers’ needs and wellbeing must also be taken into account in any given situation (Care Act 2014). Therefore, this study will also seek to include the views of people living with dementia’s usual travel companions. This is not to the detriment of hearing the voices of people living with dementia, but to better understand the participatory needs of people living with dementia when travelling with a companion or group.

1.6.4 Frequent Traveller

I have always loved travelling and I personally see air travel as a valued and extremely meaningful occupation to the extent that I feel not being able to participate in flying would be highly detrimental to my own quality of life. I, therefore, wish to reduce the barriers to participation for those who may wish to continue to travel by

²The term Carer is utilised to denote a person who supports a person living with dementia in the broadest sense. While Travel Companion is the Reference Group’s preferred term for this research, it is acknowledged that a Travel Companion may also be a Carer to varying degrees.

air, but who are no longer able to do so due to a lack of understanding and awareness of their participation needs.

1.6.5 Experience of travelling with a physical health condition

Over thirty years ago, I undertook my first holiday abroad without my parents and, due to contracting a serious form of food poisoning, ended up in hospital very sick and unable to walk unaided. I was allowed to fly back to the UK on the condition that I had assistance on and off the aircraft and a medical escort for the return journey. I was so unwell that I remember very little about the actual flight home, but what I do remember with absolute clarity was a standoff on the aeroplane between my medical escort (a UK nurse) and the lead member of the cabin crew. The cabin crew member was questioning in full view and earshot of all other passengers what exactly was wrong with me, with her main concern being the effect my presence was going to have on 'her passengers'. The fact that I was actually one of the paying passengers who she was there to assist seemed to pass her by entirely. The incident was a very long time ago, but the feeling of embarrassment at being the centre of attention in this very loud and public battle of wills stayed with me for a very long time. It made me realise that, while I had encountered the world of air travel and disability temporarily and briefly, other people were not as free as I usually was to travel by air without question or challenge.

1.6.6 Potential influence of researcher positionality

Clearly, my personal and professional roles and experiences bring both potential benefits and challenges to this research project. My desire to hear and include both the voices of people living with dementia and their carers is supported by legislation. However, I recognise that I also need to be mindful that my pre-existing personal and professional views that air travel is a meaningful, necessary, enjoyable and appropriate occupation does not adversely affect the research process. Accordingly, a number of strategies will be employed within the study in an attempt to mitigate this potential effect. This will include the recommended use of a reflexive diary to enable me to critically reflect on my decision-making and rationale throughout my research journey (Durdella, 2019). I will also discuss my assumptions and rationale for decision making with my supervisors throughout the research and have also included reflexive statements at the end of key chapters as a means of capturing my decision-making, thoughts and processes as the research developed.

1.7 Chapter summary

This chapter has introduced some of the challenges in engaging in air travel for people with dementia, alongside the idea that people living with dementia can feel excluded and stigmatised by society in general. The profession of occupational therapy was discussed together with the concept that engaging in occupations, or the things that we want or need to do, is directly linked to our quality of life. Air travel as a valued occupation was also considered, in that it helps us to stay connected to people and places that are meaningful in our lives.

The chapter concluded with how this research aims to add to the limited evidence base on this topic by investigating the barriers and facilitators to air travel for people living with dementia, and those who normally travel with them, within the UK thus providing new knowledge for the occupational therapy profession in this regard. A reflexive statement on the researcher's positionality was also provided. The next Chapter, Chapter 2, will examine the evidence base regarding air travel and disability in more detail.

CHAPTER 2: NARRATIVE LITERATURE REVIEW

“When travelling to speak at the European Parliament, I put in an application to an airline for assistance...I contacted the airline and the female staff member said she was very aware of Alzheimer’s and there was no way they could let someone with Alzheimer’s travel alone. I recall pleading, saying I travelled all the time and starting to cry...how can someone make a decision about the state of my illness on the basis of a phone call?”

(Rochford-Brennan in Rochford-Brennan & Jenkins, 2019, p.85).

2.1 Introduction

This chapter will identify and discuss the research evidence for people living with dementia when travelling by air in general, alongside the legislative framework covering those with disabilities when travelling by air from the perspective of the UK and the United States of America (USA). Details for the USA have been included not only to offer a comparison with the UK, but also as a potential indication of how the UK legislative framework for air travel may develop in the future. This is particularly pertinent given that the UK CAA intends to create an annual disability compliance report for airlines (Wicher, 2019), which is already in place in the USA (US Department of Transportation, 2018).

As a realist synthesis of best practice dementia awareness and support training outside of the field of healthcare has been included in this thesis (see Chapter 6), the literature presented in this Chapter is narrative in style. Narrative reviews discuss topics of interest in order to provide a detailed overview, but are less formal than systematic reviews and do not traditionally report methodology, search terms or

databases used (Jahan *et al.*, 2016). Therefore, this narrative review brings together and discusses the evidence around the topic of air travel for people with dementia.

2.2 Dementia and air travel – an area for further exploration

Whilst the incidents of the failure of the air travel industry for those with disabilities, including dementia, continue to make headlines around the world, a previous study of air travel and dementia found very little academic evidence on this subject (Edwards *et al.*, 2016). An unpublished systematic review undertaken a year later concurred with this finding, with the author stating that they expanded their search parameters to include public transport in all its forms and included mild cognitive impairment (MCI) as well as dementia in an attempt to identify a wider evidence base (Grice, 2017). Notwithstanding this, Grice (2017) reportedly only identified and included a total of six papers in the final systematic review on this topic.

Cridland *et al.* (2016) suggest that there is limited evidence on the lived experiences of people with dementia in general due, at least in part, to researchers' historical apprehension regarding interviewing this participant group due to the purported difficulties over receiving ethical clearance for such studies. Consequently, this lack of research involving people with dementia has had the effect that the needs of people with dementia are poorly understood (Connell & Page, 2019b). A further systematic review on cognitive impairment and public transport also noted that research on this topic was scarce and recommended that future studies identifying real world experiences for this group were essential (Risser *et al.*, 2015).

Whilst there are some basic guidelines on air travel for people living with dementia (Alzheimer's Society, 2016; Unforgettable, 2017), they do not appear to be based on research evidence. Only one study of air travel for people living with dementia has been identified to date, led by a research group from the Queensland University of Technology in Brisbane, Australia. Whilst it should be noted that the original aim of the study was to explore air travel for people living with dementia from multiple perspectives, only seven of the final 83 surveys were from people living with dementia with the remainder made up of companions (n=41), flight crew (n=22) and security staff (n=13) (Edwards *et al.*, 2016). The researchers further report that none of the 10 follow up qualitative interviews were held with people living with dementia, with companions being interviewed in all cases (Edwards *et al.*, 2016). Whilst the full study has not yet been published in a journal and thus peer-reviewed, their self-published findings available via a downloadable report from their website indicate that, on average, people living with dementia travel by air twice per year, with the most common difficulties being encountered landside in terms of orientation, check-in and security (Edwards *et al.*, 2016). Pre-flight difficulties included obtaining travel insurance, obtaining larger amounts of prescription medication and obtaining medical clearance to fly (Edwards *et al.*, 2016). However, it should be noted that these findings primarily come from the companions' strand of their study and may not represent the views and experiences of people living with dementia themselves.

While Edwards *et al.* (2016) have cautioned about generalisability of their findings to the wider national and international population, their findings have been echoed from a UK perspective. Presenting at the South West Dementia Conference (UK) representatives of the Prime Minister's Dementia Challenge Group for Air Transport

highlighted several travel chain difficulties for people with dementia. Namely, lack of awareness of entitlement to special assistance, poor communication and lack of training of key staff, the pressure of search and queuing and the stress caused to people living with dementia from being separated from their travel companions (Warren *et al.*, 2016). It should be noted, however, that the background information for the presentation by Warren *et al.* (2016) was based on anecdotal evidence.

In 2012 a survey was undertaken with 1293 patients with another hidden disability, chronic heart failure, to ascertain their experiences of air travel (Ingle *et al.*, 2012). The survey received a 39% response rate (n=464) with the patients reporting that they found air travel difficult due to the challenges of obtaining travel insurance, negotiating long walks and stairs at the airport, the amount of waiting time involved and the lack of comfort inflight (Ingle *et al.*, 2012). Whilst considering the experiences of other passengers with hidden disabilities provides useful background, it has been noted that the needs of people with disabilities can vary across the travel chain depending on the individual, their disability and the stage of their condition (Chang & Chen, 2012). Ingle *et al.* (2012) further caution that they believe selection bias may have affected their results in that only those with particularly strong positive or negative views tend to reply to online surveys. A trend recognised within the completion of surveys in general (Bryman, 2016).

Difficulties with the travel chain are not just limited to passengers with hidden disabilities. Passengers with physical disabilities report that the top three challenges they face when travelling by air are loss or damage to wheelchairs, lack of disability

awareness by aviation staff and the extensive waiting times during the air travel process (Major & Hubbard, 2019). Darcy (2012) utilised a range of secondary qualitative accounts including newspaper articles, complaints of human rights violations and interviews to identify challenges across the travel chain for people with disabilities from pre-travel, boarding and disembarking, seat allocation, on-board personal care, equipment handling and customer service. Whilst these findings are focussed on physical rather than hidden disabilities, Darcy's research is considered useful to this study as he is a wheelchair user himself and has lived experience of travelling by air with a disability. This dual perspective undoubtedly brings considerable insight to the accessibility research for which he is known. However, it could equally be argued that Darcy (2012) may, consciously or unconsciously, seek evidence that supports his own worldview. This challenge of insider researchers ensuring they maintain a professional rather than personal perspective is acknowledged in the literature (Fleming, 2018).

From the qualitative accounts studied, Darcy (2012) reports that some people with disabilities have been interrogated at the booking and pre-boarding stages by customer service staff who have frequently ventured into matters of medical privacy. This resonates with the experience of a person living with dementia who has written of her air travel experiences in a published book chapter on human rights legislation. Helen Rochford-Brennan's quotation on the distress that airline staff caused her when she tried to request special assistance to travel to the European Parliament in order to deliver a keynote speech opened this chapter (Rochford-Brennan & Jenkins, 2019).

Whilst special assistance is available to passengers with hidden disabilities at airports, awareness of this is reportedly low as reported by Ingle *et al.* (2012) in their study of passengers with chronic heart disease. It has also been suggested that when people living with dementia do request special assistance they may be advised they need to sit in a wheelchair, something that someone with dementia who has not got associated mobility problems may be unwilling to do (Edwards *et al.*, 2016; Rochford-Brennan & Jenkins, 2019). Having wheelchair assistance can also cause further problems as it adds time on to both the beginning and the end of the journey due to the need to pre-board the aircraft and then wait while other passengers disembark the aircraft before assistance arrives to help the person with the disability off the aircraft. Darcy (2012, p.96) has noted that this 'first on, last off syndrome' adds a minimum of one hour to the air travel journey time and when communication breaks down, may add as much as three hours leading to increased stress levels.

2.3 The need for improved training within aviation

As the numbers of passengers with disabilities has risen, so have the complaints. A recent mixed methods study of disability and non-disability complaints within the USA aviation sector demonstrated that in 2016 complaints were almost 100 times higher for passengers with disabilities (144.30 complaints per 100,000 passengers) than for passengers without disabilities (1.86 complaints per 100,000 passengers) (Major & Hubbard, 2019). A key recommendation from Major and Hubbard (2019) was that wide ranging disability training, including hidden disabilities, was essential to improve service standards within this sector.

While Major and Hubbard (2019) suggest that the increasing rate of complaints may be due to a reduction in service, they also note that greater awareness and ease of complaint filing or the fact that more people with disabilities are utilising air travel may also be contributory factors. The advent of social media may also be a factor in the rise in complaint numbers, as it allows high profile members of the disability community to highlight poor service and to remind their followers that this is unacceptable. For example, Frank Gardner a British news reporter who is a wheelchair user himself, used Twitter® to inform his followers he was trapped on an empty aircraft due to problems with the accessibility lift used for disembarkation (Gardner, 2018). In a later report to the British Broadcasting Corporation (BBC), Gardner said that whilst he appreciated the disembarkation delay was not deliberate he felt it was important to highlight and challenge such issues in an effort to make positive change for those living with disabilities (BBC, 2018).

When aiming to become dementia friendly, an organisation needs to identify the key parts of its business where more support is needed so that it can target training for staff at those key points (Connell & Page, 2019b). Consequently, it has been reported that aviation staff lack specific knowledge on disabilities with key areas of concern including the safe and correct use of specialist disability equipment and the attitudes and communication skills of key staff including those in security, third party stores and baggage handling (WHO, 2011; Major & Hubbard, 2019). Specific concerns within security include that people with dementia may not understand the questions being asked of them and that they may become agitated under pressure (Edwards *et al.*, 2016), so staff need to know how to recognise and respond to these difficulties. In their study, Edwards *et al.* (2016) found that around half of the security

staff who completed surveys (n=13 in total) were receptive to receiving disability training around dementia, while the majority of cabin crew (n=22 in total) felt that knowing how to identify someone who may have dementia would be useful. Therefore, Edwards *et al.* (2016) also recommended that bespoke dementia awareness and support training be developed for the aviation industry.

As with other forms of disability training, any training should include procedures and practices for how staff can empower passengers and should provide guidance on language use and upholding passengers' dignity and respect (Darcy, 2012). Despite the seven-year gap Darcy's (2012) findings echo an earlier study of attitudes to disability within the tourism sector. Daruwalla and Darcy (2005) found disability awareness training to be an effective approach for challenging and combatting personal attitudinal barriers, particularly when the training provided direct contact with a person with disabilities and was reinforced within the workplace. It should be noted, however, that Daruwalla and Darcy's (2005) study relied on evidence from as early as 1996. While their findings may be considered significantly out of date, they resonate with other more recent evidence of continued stereotyping and stigmatisation of people with disabilities within aviation (Rochford-Brennan & Jenkins, 2019), potentially indicating that changing attitudes in this area is extremely slow moving.

While staff may be receptive to training, the employing body may not be as Connell and Page (2019b) found in their dementia awareness and accessibility audit of tourism establishments. The audit consisted of reviewing the websites of destination

management organisations (DMO's) (n=127) with a follow up survey being sent to those DMO's that were still active (n=114). The survey response rate was 28% (n=32). Connell and Page (2019b) identified that the main challenge with providing disability training within tourism was the high level of staff turnover and employer concerns over the associated cost involved. Although, Connell and Page (2019b) noted most employers within tourism tend to hire staff on a seasonal basis so the level of staff turnover and associated costs may not be as great a concern within aviation. However, challenges around the financial cost of training do need to be considered as it has been previously noted that any new innovation needs to be both effective and economically sustainable (Broome *et al.*, 2009).

2.4 Travelling by air with a Disability – the UK context

Legislation covering inclusivity in air travel for those with disabilities does exist within the UK and includes Council Regulation (EU) 2006/1107 (2006), the Convention on the Rights of Persons with Disabilities (2006), which was formally adopted by the UK Government in 2009, and the Equality Act 2010 . In a paper outlining the rights of people living with dementia Hare (2016a) notes that those with dementia may not wish to consider themselves as being disabled because to do so may elicit further stigmatisation. However, dementia is a disability under legislation and seeing it and accepting it as such provides important protection of a person with dementia's rights (Butchard & Kinderman, 2019).

This is important as evidence from the tourism industry suggests that disability legislation is widely interpreted in favour of those with a physical, rather than a hidden, disability; reducing access for this large and growing group (Page, Innes and Cutler, 2015). Indeed, one of the purported challenges with Council Regulation (EU) 2006/1107 (2006), which is the main sector specific legislation relating to air travel and disabilities across Europe, is that it is known and referred to as the passengers with reduced mobility (PRM) or PRM regulation, with passengers travelling with a disability being widely referred to as PRM's. This emphasis on the term PRM within aviation has been criticised in an opinion piece by one author due to its potential reinforcement of the stereotypical image of disability as being overtly physical (Angrave, 2017). This is an important observation given that the UK Government estimate that 14.1 million people, or one in five, has some form of disability, but only 48% of these are mobility related (Department for Work & Pensions, 2020). Whilst this data is taken from a survey of just 19,000 UK households it accords with the trustworthiness and quality standards of the UK Statistics Authority and is deemed to be scalable and thus representative of the wider UK population (Department for Work & Pensions, 2020).

Interestingly, when publishing their handbook on implementing barrier free air travel for all passengers with additional needs, Airports Council International (ACI) explained that they were abandoning 'PRM' in favour of '*persons with disabilities*' in order to align their terminology with that of the Convention on the Rights of Persons with Disabilities (ACI, 2018). It remains to be seen however, if the term *persons with disabilities* adequately encompasses those with more hidden disabilities, like dementia, or whether it will still be interpreted in favour of those with more physical disabilities as it reportedly has been in the past.

As a result of concerns raised over the treatment of passengers with hidden disabilities the CAA, in their capacity as the UK National Enforcement Body (NEB) of Council Regulation (EU) 2006/1107 (2006), have issued guidance on how airports should be supporting passengers with hidden disabilities (CAA, 2016a). In 2018, the CAA published an update on how airports had responded to the 2016 airport guidelines for passengers with hidden disabilities (CAA, 2018b). One of the main innovations highlighted within this document was the implementation of a hidden disability lanyard scheme which originated at Gatwick Airport, UK and had been adopted nationwide (CAA, 2018b). The lanyard scheme enables those with hidden disabilities to receive additional support as they travel through the airport as staff can discreetly identify anyone wearing a lanyard as someone with additional needs (Gatwick Airport, 2016).

Reviews of the hidden disability lanyard scheme by people living with dementia have been both positive and negative. Dementia activist Helen Rochford-Brennan believes that disability lanyards could label and stigmatise the wearer and she should not need to wear one to obtain the assistance she needs to travel (Irish Dementia Working Group, 2019). While another dementia activist, Wendy Mitchell, states that wearing a lanyard aids her independence as it gives her the confidence to travel independently and can help those who might otherwise struggle to ask for help by acting as a discreet signifier that help may be required (Mitchell, 2019). Mitchell (2019) adds that while she wants to live in a world where everyone gets the help they require without the need to ask, that reality does not yet exist and the lanyards are an important intervention for people with disabilities in the meantime.

The report further noted, however, that whilst all airports have moved to improve their hidden disability provision, the innovations are largely uncoordinated and localised by airport, airport ownership or by the shared ground handler. For example, all airports using the Gatwick ground handling company OCS Group UK adopted the sunflower lanyard, while other airports adopted lanyards with different designs, wristbands, badges, or, in the case of one airport, a voucher system (CAA, 2018b).

The CAA utilises its national enforcement body status to publish an annual report on UK airport compliance for disability assistance, identifying and highlighting underperforming airports. Each airport is graded against three main criteria being special assistance waiting times, passenger satisfaction and effectiveness of their communication with the local disability community (CAA, 2019a). These reports demonstrate an apparent improvement in disability assistance over a three year period at the 31³ largest airports across the UK as per Table 1.

³ Note: only 30 airports assessed in 2015/16

Airport compliance ratings against disability criteria	2015/16 - Prior to the CAA (2016) hidden disability guidance being published	2018/19 – Most recent report post CAA (2016) hidden disability guidance being published
Very good	10	14
Good	7	16
Needs improvement	12	1
Poor	1	0

Table 1 - UK Airport Disability Compliance Ratings
(CAA, 2016b; CAA, 2019a).

When the hidden disability guidelines for airports were first published, the CAA estimated that up to seven percent of people with hidden disabilities such as dementia may have ceased travelling by air purely due to a lack of confidence (CAA, 2016a). However, as this statistic was derived from respondents to the CAA's annual PRM survey, it is unlikely to be representative of the wider hidden disability population and may, in fact, be an underestimate. This is because people with hidden disabilities are less likely to be aware of their right to access special assistance as previously noted and thus are much less likely to be aware of and complete the survey that assesses its performance. However, Graham and Metz (2017) concur in their research that having any form of disability leads to reduced engagement with air travel in general.

Despite the improvements that have been made by airports (CAA, 2018b), 1 in 15 special assistance passengers still indicate a lack of confidence that the support offered to them will meet their individual needs and that they will be treated with an appropriate level of dignity and respect (CAA, 2019a). However, this statistic is also

open to debate as special assistance passengers do not always provide feedback on the service they have received, positive or negative, as noted.

The CAA has also published separate guidelines, this time for airlines, on supporting passengers with hidden disabilities (CAA, 2018a). However, it is currently unclear whether the CAA will report on adherence to these guidelines in a similar way that they do for airports by identifying and highlighting those airlines who receive large amounts of complaints. When discussing the proposed new guidelines at a Reference Group meeting in Plymouth, a CAA representative stated that one of the challenges with identifying airlines who have provided poor disability service is that, frequently, it is the airport who has failed to provide the service to an accessible standard which is outside of the airline's control (Wicher, 2019). Identifying and highlighting airlines who are deemed to have provided a substandard service does already occur within the USA however, alongside the issuing of large-scale fines for failing to comply with disability legislation. Given that the UK is looking to increase legislation for airlines, and the USA has an advanced system of doing so which the UK may seek to emulate, the USA system is explored further in Section 2.5.

2.5 Legislation and violations in the United States

In 2009 US air travel legislation was amended to include provisions for passengers who needed to carry medical oxygen or breathing apparatus on board and passengers with hidden disabilities, together with clarification on the carriage of assistance animals such as hearing or sight dogs and emotional support animals who must now be

allowed into the aircraft cabin (McCloskey, 2008). Non-compliance with this legislation may result in US and foreign carriers' right to fly within the US being suspended (US Department of Transportation, 2009).

The 2009 changes to the US legislation enabled carriers to insist that passengers who could not physically assist in their own evacuation should travel with safety assistants (McCloskey, 2008). This requirement for safety assistants could also impact on passengers with dementia who would need to ensure that they could understand and comply with safety protocol if travelling alone when flying to, from, or within the USA. Whilst safety should be a priority, such legislation potentially runs the risk of all people with disabilities being asked to have a travelling companion based on diagnosis alone. Although making assumptions of capacity and ability based purely on diagnosis would put carriers in breach of both the Mental Capacity Act 2005 and the Equality Act 2010. It will therefore be important to monitor if such legislation is also introduced in the UK and any effect such legislation would have in practice, particularly around infringement of disability rights. It should be noted, however, that Edwards *et al.* (2016) identified that the more severe air travel incidents involving passengers with dementia have occurred when those passengers were travelling on their own and either failed to connect with special assistance services as planned or became confused during their stop over or connection with onward travel services. The alleged assault referred to in the UK Government Debate (see section 1.3.3) also involved a lone traveller with dementia (Hansard, 2016). So, clearly, this is an area for further consideration and review.

However, legislative violations have been very costly for the aviation industry within the US not only in terms of reputation but also in terms of airlines receiving severe fines. For example, million dollar fines have been reported for airlines failing to provide adequate assistance to passengers both at the airport and on embarking and disembarking flights as well as, in some cases, poor responses to, and underreporting of, passenger complaints (Major and Hubbard, 2019). In terms of reputation, The US Department of Transportation produces an annual report on disability related air travel complaints which shows the number of complaints per carrier. The latest report showed that 34,701 disability related complaints were reported by 190 airlines in 2017 (US Department of Transportation, 2018). Clearly, the UK aviation industry needs to be mindful of the lessons learned in the USA, particularly in terms of the reputational and financial damage that may be caused by non-compliance with legislation enacted to support this passenger group.

2.6 People living with dementia as consumers of goods and services

Understanding and responding to the needs of passengers with a range of disabilities, is considered to be essential, especially given that 3.7 million UK passengers requested assistance across the 2018/19 year, a rise of 80% from 2010 (CAA, 2019a). Darcy (2012) warned the aviation industry about the rise in passengers with disabilities and the need for them to not only comply with legislation, but to also recognise the opportunities supporting passengers with disabilities presented in an increasingly competitive market. Given the reported rise in passengers requesting special assistance since 2010, Darcy's (2012) warning for the aviation industry to recognise and respond to the needs of this passenger group seem somewhat prescient.

In their research related to accessible tourism Connell and Page (2019a) concur stating that people living with dementia were consumers of goods and services prior to their diagnosis and will continue to be so after their diagnosis. The Centre for Business Research and Economics (2014) have estimated that consumer expenditure related to dementia will rise from £11 billion in 2014 to £27.2 billion in 2030, arguably identifying that businesses and services need to be engaging with, and ready to support, this consumer group. Some airports have already begun to recognise the importance of catering to the disability market in general, with Heathrow Airport spending £23 million on disability enhancements after seeing an 8% increase in passengers requesting special assistance (Global Accessibility News, 2017).

2.7 Chapter summary

This chapter identified that existing research into air travel for people with dementia is extremely limited, with just one study on air travel for people with dementia having been conducted by researchers in Australia. An important knowledge gap has therefore been identified in that no research into air travel experiences for people living with dementia has been conducted in the UK to date. The authors of one systematic review into public transport for people with cognitive impairments support the imperative that future research should be designed to elicit lived experience viewpoints from those directly affected by the condition rather than relying on proxies (Risser *et al.*, 2015).

The next chapter, chapter 3, will outline the methodological framework utilised to undertake this research. This includes the phenomenological approach used to design, undertake and analyse the interviews element of the study and the procedure for the realist synthesis which examined 'what works, for whom, in what circumstances and why' within best practice dementia and awareness training outside of the field of healthcare.

CHAPTER 3: METHODOLOGY

“Where, after all, do human rights begin? In small places, close to home – so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere.”

(Eleanor Roosevelt, 1958)

3.0 Introduction

Within the previous chapters, a rationale for exploring the lived experiences of people with dementia and their travel companions when travelling by air from within the United Kingdom has been provided (see Section 2.2). The need to understand more about the training provision for individuals who support people with dementia has also been identified (see Section 2.3). This chapter will outline the methodological approaches undertaken for the two studies within this research, namely:

- **STUDY 1:** A phenomenological study to capture the lived experiences of both people with dementia and the companions of people with dementia when travelling by air; and
- **STUDY 2:** A realist synthesis to explore what constitutes best practice in dementia awareness and support training outside of the field of healthcare.

The chapter will discuss the ethical considerations that needed to be addressed both before and during the phenomenological study, together with the data collection and analysis methods used. The chapter will conclude with a reflexive account as in previous key chapters.

3.1 Methodological foundations

When designing and undertaking research it is important to understand the methodological foundations upon which the research is based in order to be able to understand and defend our own position and to understand the position of others (Grix, 2010). Uncovering and understanding personal beliefs and values is considered to be essential as they not only influence the study's design, but also determine how the researcher interprets and constructs their findings into new knowledge (Smith, Flowers & Larkin, 2009). Crotty (2010) identified four interrelated stages to the research design process: ontology, epistemology, methodology and method.

Ontology is concerned with the nature of reality, or more particularly with what the researcher *believes* is the nature of reality, and sits broadly between objectivism – the concept that reality is beyond and independent of our control and constructionism – the concept that reality is individually and socially constructed (Bryman, 2016). Epistemology is concerned with the theory of knowledge and our personal belief in what there is to know about a subject and how we can learn about it (Bryman, 2016). The two major epistemological standpoints are recognised as

positivism - which believes that knowledge can be observable and thus measured and interpretivism - which believes that knowledge is subjective (Grix, 2010).

Of the four main research paradigms outlined by Denzin and Lincoln (2018), the paradigm I most closely associate with is *constructivist-interpretivist*. Denzin and Lincoln (2018) propose that constructivist-interpretivists see the world as a social construct of multiple realities and that meaning is derived from interacting with those realities on a personal level. This stance is closely associated with the client centred frame of reference within occupational therapy, through which the therapist works with a client to enable them to engage in occupations and derive meaning from this engagement (Schell *et al.*, 2013). It is also congruent with the first aim of this study which is to identify the barriers and facilitators to air travel and the meaning that a person living with dementia subjectively ascribes to their engagement or non-engagement in air travel on an individual basis. The chosen methodology (descriptive phenomenology) and methods (semi-structured interviews) for uncovering the subjective experiences of people with dementia and those who travel with them will be explored further in Section 3.4.

Whilst the two major epistemological positions of positivism with its focus on structure and interpretivism with its focus on agency are widely cited in the literature as polar opposites, Grix (2010) suggests that epistemological standpoints are more of a continuum with a third position of post positivism sitting centrally between them. Realism is a form of post positivism in that it acknowledges the positivist standpoint of the need to understand structure and the interpretivist standpoint of the need to

understand agency are equally valid and thus attempts to bridge the gap between the two extremes (Pawson, 2013). I agree with this standpoint especially when attempting to understand complex interventions and thus a realist methodology was used to explore causal mechanisms at both the macro and micro level in best practice dementia training. As such a realist synthesis of the literature exploring what works in dementia awareness and support training outside of the field of healthcare will be discussed further in Section 3.6.

3.2 Stakeholder Involvement (Reference Group)

This doctoral research project has been strengthened by stakeholder involvement throughout in the form of a Reference Group. The Reference Group existed prior to the commencement of this doctoral research and had been convened as a sub-group of the wider Prime Minister's Dementia Challenge Group for Air Transport. The Reference Group was instrumental in guiding the need for this research and provided input into the funding bid for the doctoral studentship. The Reference Group is made up of people living with dementia, companions/carers of people living with dementia, dementia specialists, representatives from local dementia support groups and national dementia charities and experts in aviation customer service, such as a representative from a local airport and a cabin crew trainer.

Stakeholder involvement purportedly aids a study's relevance and credibility by providing input at key areas of the research process such as the development of a systematic research protocol and recruitment and dissemination strategies (Cottrell *et al.*, 2014). Having access to varying viewpoints and experience in this way is also

considered vital when seeking to address real world challenges (Schmidt *et al.*, 2020). Involving stakeholders was also in keeping with the researcher's commitment to social and occupational justice (Hocking, 2017), and the constructivist philosophy as the stakeholders were able to share their lived experience of dementia and air travel from a variety of perspectives and were able to shape and input into research in which they had a personal connection.

Despite the benefits of stakeholder involvement, it is not without its challenges in that it can be resource intensive, stakeholders may have competing interests and it may be difficult to ensure the stakeholders are truly representative of the community which the research seeks to assist (Cottrell *et al.*, 2014). As such, stakeholder involvement may be seen as burdensome to the research process, with any input being purely tokenistic as a result (Schmidt *et al.*, 2020). In this instance, the investment of time was considered essential given the benefits associated with stakeholder involvement and the researcher's own research position to ensure stakeholders' voices, particularly those of people living with dementia and their travel companions, were heard.

It has been further noted that clear objectives and positive communication can aid stakeholder group cohesion and efficacy (Schmidt *et al.*, 2020). To assist with this an initial meeting was held to agree the objectives of the Reference Group with regard to this research and an agenda setting out the objectives for each meeting was produced and circulated to all group members. Minutes of the meetings and actions taken as a result were also circulated to enable the Reference Group to see the

value of their input as the project progressed. As previously noted, the Reference Group was separate from, but informed, a larger Prime Minister's Dementia Challenge Group for Air Transport. The Prime Minister's Group contained Members of Parliament, legislators and policy makers, airport representatives, members of the media, and other interested parties. Information from the Reference Group was regularly disseminated to the Prime Minister's Group to inform policy making.

One challenge that did occur was ensuring the continued representation of people living with dementia on the Reference Group as, given the progressive nature of the condition, participant involvement varied over the duration of the research. Specific actions that were taken to improve participation were to encourage those who could not travel to meetings to participate by other means such as email, with one person living with dementia inputting into meetings this way. Contact was also made with an Alzheimer's Society support group in the South West of England and the project was discussed on two separate occasions with group members at their usual meeting venue to obtain their input and feedback on findings. A person living with dementia who was a member of this support group also volunteered to be part of the Reference Group during the later months of the study. A record of stakeholder involvement through the Reference Group is shown at Appendix A. Key elements of the Reference Group's involvement with the design and development of this research will also be discussed throughout this chapter.

3.3 STUDY 1: Exploring the lived experience of air travel

The aim of the first study was to explore the experiences of air travel for people living with dementia and their travel companions (see Section 2.2). As such this exploration of lived experiences needs to be framed by the interpretivist paradigm (Denscombe, 2014). Accordingly, in seeking to explore the participants' thoughts, feelings and experiences an overarching qualitative framework is required (Gray, 2014) to explore air travel as a valued sole or co-occupation. Co-occupation in the sense of this research means that people with dementia may fly with significant others for various reasons and derive meaning from this shared experience. Whilst researchers disagree on classification of traditions within qualitative enquiry (Durdella, 2019), evidence suggests those methodologies most closely associated with qualitative study in the health sciences are ethnography, phenomenology and grounded theory (Denzin & Lincoln, 2018; Patton, 2014; Smith, Flowers & Larkin, 2009).

Ethnography primarily focusses on immersive cultural experiences in order to learn about group feelings and behaviours in context (Durdella, 2019). Ethnography was therefore discounted because the study focussed on individual, rather than group, experience. Grounded theory seeks to develop explanatory theories of how social processes work in context (Durdella, 2019). Therefore, grounded theory was also discounted as the study aimed to explore the participants' lived experience of air travel, rather than develop a broader process theory on how air travel might work for this group (Starks & Trinidad, 2007).

Phenomenology, however, holds that the route to understanding a social phenomenon lies in a person's subjective understanding and experience of that phenomenon and, as such, accords with the constructionist/constructivist approach (Bryman, 2016). As it is increasingly recognised that the individual voices of people with dementia must be heard when attempting to improve services for this group (Cridland *et al.*, 2016; Pesonen, Remes & Isola, 2011), phenomenology was chosen as the methodological framework through which the qualitative interviews element of the study was undertaken.

3.3.1 History and evolution of phenomenology

Phenomenology stems from the pre-World War One schools of philosophy and psychology and was primarily designed as a response to reductionism within the scientific community (Dowling, 2007; Smith, 2013). Phenomenology aims to investigate people's experiences and the subjective meaning contained within them, consequently it has become a popular research method within the health sciences (Matua & Van der Wal, 2015). Traditionally, phenomenological inquiry has had two main standpoints, Husserl's descriptive phenomenology which aims to understand the true conscious nature of experience through the bracketing, or putting aside, of one's pre-existing beliefs and Heidegger's hermeneutic, or interpretative, phenomenology which aims to contextualise an individual's experience in terms of its historical, cultural and political landscape (Durdella, 2019). Dowling (2007) states these differing schools of thought can be associated with positivism (Husserl) and interpretivism (Heidegger). However, Denscombe (2014) asserts that a

phenomenological approach is anti-positivist as it focuses on subjective human experience.

More recently, a third approach of Interpretative Phenomenological Analysis (IPA) has evolved (Smith, Flowers & Larkin, 2009). Within IPA the intention is to interpret an individual's own interpretation of an event or series of events which hold meaning for them (Smith, Flowers & Larkin, 2009). As such, IPA may be considered to be an extension of Heidegger's work on phenomenological interpretivism (Davidsen, 2013).

3.3.2 Descriptive phenomenology

Within descriptive phenomenology the prime intention is to explore, analyse and describe an individual's experience of a phenomenon in such a way that the real life experience of the phenomenon is maintained (Matua & Van der Wal, 2015). This exploration of the experience as it was originally lived requires the researcher to put aside their own ideas and preconceptions of the phenomenon under review through a process known as bracketing or phenomenological epoché (van Manen, 2011). Dowling (2005, p132) states that epoché originates from the Greek language and means 'to refrain from judgment, or to stay away from the everyday way of looking at things'. Husserl termed this as being in the natural attitude (Van Manen, 2011).

As such, descriptive phenomenological research aims to discover and report what it is like to experience a certain phenomenon through faithful description of the information gathered (Matua & Van der Wal, 2015). This enables the reader to see,

feel and understand the lived experience without any reference to the socio-cultural or economic context of the person who experienced it (Dowling, 2007). In order that such descriptions remain faithful to the original experience, researchers should consider themselves unfamiliar to the phenomenon under review as this enables the reader to grasp what something is from the perspective of the person who has experienced it (Neubauer, Witkop & Varpio, 2019). It is recognised, however, that this is difficult for the doctoral researcher and the supervisory team who have prior knowledge of the subject under consideration. Indeed, the concept that we can truly ever bracket all presuppositions given our pre-existing knowledge and life experience is a critique of Husserl's work and that a level of interpretation cannot be avoided (Davidsen, 2013).

3.3.3 Interpretative phenomenology

Within interpretative phenomenology, the researcher is looking to gain a deeper understanding of the experience and the personal meaning that is associated with it (Dowling, 2007). Matua & Van der Wal (2015) suggest that the meaning associated with a phenomenon may be uncovered not only through an examination of the words spoken, but also by examining the language used. When utilising interpretative phenomenology the researcher does not bracket their own knowledge of the phenomenon under review and instead it is included within, and becomes part of, the research findings (Humble & Cross, 2010). Interpretative phenomenologists contend that when we describe a phenomenon we have already begun the process of interpretation thus making pure description difficult to achieve (Finlay, 2008). The findings of interpretative phenomenological research are, therefore, a combination of

a person's lived experiences and the researcher's own understanding and beliefs about the phenomenon (Matua & Van der Wal, 2015).

3.3.4 Critique of phenomenology

Aside from the use of bracketing purely at the point of data analysis, evidence of a wider phenomenological approach can sometimes be lacking within studies, especially those completed by novice researchers (Dowling, 2007). In order to remain connected to the philosophical standpoint, I have engaged in reflexivity throughout the study, included reflexive statements throughout the thesis and discussed assumptions during supervision and data analysis. The aim of reflexivity is for researchers to engage in a continual form of self-appraisal to provide an explanation of how their own experiences may, or conversely may not, have influenced the research process (Dowling, 2007). A further critique of phenomenology is that the early influencers of the methodology, such as Husserl, were purely philosophical and never actually gave a description of how their particular methods could be used in practice and the meaning of phenomenological phrases were never completely explained (Paley, 2017). Later descriptive phenomenologists such as Giorgi and Giorgi (2008) and interpretative phenomenologists such as Smith, Flowers and Larkin (2009) attempted to lay down guidelines for the research and analysis in order to fill this knowledge gap. It has also been suggested that descriptive phenomenological researchers should delay completing an in-depth literature review until after the primary data has been gathered in order to further mitigate any potential for data contamination (Finlay, 2008). As such, although the original intention was to run the realist synthesis

concurrently with the phenomenological analysis, the realist synthesis was paused until the interviews had been carried out, transcribed and analysed to reduce the risk of the data being contaminated in this way.

3.3.5 Rationale for choosing descriptive phenomenology

Descriptive phenomenology has been chosen for this research as the findings will allow for a general understanding of what it is like for both a person or group of people to experience a phenomenon (in this case the barriers and facilitators to air travel) (Lopez & Willis, 2004). Interpretative phenomenology also allows for a greater understanding of what it is like to experience a phenomenon, but Paley (2017) ascribes that interpretation is only possible if a background theory is already held on the topic in question. By utilising descriptive phenomenology, the underlying meanings experienced by each of the participants can be identified and named. In order to achieve this, the data analysis method of Giorgi and Giorgi (2008) was considered alongside a method from Colaizzi (1978). Both Giorgi and Giorgi's (2008) method and Colaizzi's (1978) data analysis frameworks are structured. Having a structure to follow aids rigour and moves these frameworks away from phenomenology as a philosophy to phenomenology as a method (Flood, 2010). Whilst Giorgi and Giorgi's (2008) method has evolved over several decades and remains popular within the health sciences, it does not include a form of participant validation within the framework (Dowling, 2007). It has been suggested that following a descriptive framework that allows for participant validation can strengthen a study's findings as it provides a means of checking that the researcher has accurately captured the phenomenon under investigation with those who have experienced it

(Edward & Welch, 2011). Colaizzi's (1978) method is purportedly very popular within nursing research (Dowling, 2007), a phenomenon which may in itself be explained by the member checking element of its design.

Therefore, Colaizzi's (1978) data analysis framework was chosen for this study as it closely follows Giorgi's framework, but allows for respondent validation and the implementation of any amendments as the final part of the analysis process. It is noted, however, that Colaizzi's (1978) method is not without critique as sending the dense framework statements devised by the researcher back to respondents to ask how closely they match the respondents' experiences acknowledges a form of interpretation has taken place (Dowling, 2007). Giorgi (2006) concurs that respondent validation is not appropriate as the researcher and participants will have differing views on the topic in that the researcher will be reviewing the phenomenon using phenomenological reduction, while the participant will be viewing the phenomenon in the natural attitude. However, as the aim of the study is to uncover the lived experiences of air travel as closely as possible and, as such, participants should be able to recognise their own experiences in the framework statements, inclusion of the respondent validation was considered an important and valuable step. The data analysis process which followed Colaizzi's (1978) method will be discussed further in Section 3.4.14.

3.4 Phenomenological method

3.4.1 Interviews

As this element of the study was to increase understanding of the lived experiences of air travel for people with dementia and their companions, the data collection method needed to be congruent with this aim (Durdella, 2019). Therefore, semi structured interviews were utilised as a means of capturing this information.

Interviews are the most widely used method of data collection within the social sciences (Manzano, 2016). Semi-structured interviews have a list of questions to be answered, however the participants are invited to give open and detailed responses as opposed to the inflexible and closed responses available in structured interviews (Denscombe, 2014). Semi-structured interviews also allow the interviewer to read verbal cues as the interview progresses and to follow up on any answers which might provide additional insight into the participant's experiences in real time (Gray, 2014). This was considered to be particularly useful for people living with dementia and their companions as it allowed scope for further exploration of topics and answers through prompts and probes (see Appendix B) and the face to face real-time interaction helped to ensure that the participants remained engaged with the interview process cognitively and physically. Semi structured interviews are also in keeping with the interpretivist epistemological standpoint of this research as they allow the participants the flexibility to share their subjective experience and highlight areas of the topic that are important to them (Grix, 2010).

Conversely, unstructured interviews were not deemed suitable for the participants living with dementia as once the topic has been introduced the interviewer should let

the participant develop their own ideas and pursue their own particular train of thought (Denscombe, 2014). Clearly, such a lack of structure would not provide participants living with dementia an adequate level of support to express their views on the topic of air travel and may lead to distractions. Focus groups of people with dementia and their companions were also considered. However research suggests that such groups may make capturing individual and in-depth experiences difficult as the researcher can be prevented from asking follow up questions as the conversation is moved forward by other members of the group (Denscombe, 2014). It has also been suggested that focus groups would place the research outside of the methodological sphere of phenomenology, where the intent is to capture and explore an individual's subjective experience of a phenomena (Dowling, 2007). However, Tomkins and Eatough (2010) found that utilising focus groups in an IPA study helped participants to identify and reflect on important aspects of their personal experience, rather than eclipse these.

3.4.2 Participants

As the study aimed to gather rich, in-depth, data; eight to ten people with dementia and eight to ten travel companions of people with dementia were sought to take part in the study. It is recognised that 16-20 participants is at the higher end of the recommended level of participants for phenomenological research according to Gray (2014), who cites 5-15 participants as being optimum. However, Gray (2014) is potentially basing his participant numbers on Seidman (2006) who suggested undertaking a progressive three interview cycle with each participant necessitating fewer participants overall. This three interview cycle included contextualising the person in light of the topic to be explored, examining the lived experience of the

person in relation to the topic and asking the person to reflect on their individual meaning of their experiences in relation to the topic (Seidman, 2006). Clearly, as half of the participant group were living with dementia and likely to experience challenges with short-term memory (Warner & Graham, 2018), repeat interviews that built on prior discussion were not considered a feasible option for data collection. Instead, data was gathered via single interviews with an increased number of participants.

3.4.3 Inclusion criteria

The study aimed to gather data from people living with dementia of any age who had:

- experience of travelling by air alone
- who usually travelled by air with a companion; or
- who were no longer able to travel by air for any reason

However, as per the pen portraits in Table 4 (see section 4.0) all participants identified in the living with dementia group usually travelled with a companion. No participants were identified who travelled by air alone or who were no longer able to travel by air. Ten participants living with dementia were interviewed for the study in total. As the interviews included a mixture of interview formats, Table 2 sets out the number of interviews conducted in each format to aid the reader.

Type of Interview conducted	Number
The person with Dementia was interviewed alone	1
The person with dementia was <i>supported</i> ⁴ by their travel companion	3
The person with dementia was <i>assisted</i> ⁵ by their travel companion	2
Joint interview – the person with dementia and their travel companion were interviewed for this study at the same time	4
Total Participants living with dementia	10

Table 2 - The formats of interviews conducted with participants living with dementia

In order to take part participants were asked if they had officially been diagnosed with dementia. Participants with dementia were verbally assessed by the researcher to ensure they had the mental capacity to take part in the interview at the time it was held in accordance with the requirements of the Mental Capacity Act 2005 (See Section 3.4.9). As England and Wales have separate Mental Capacity legislation to the rest of the UK and the researcher had no experience of working within these alternative legislative frameworks, participants were sought from across England and Wales only.

As previously noted in Section 1.6.3 the Care Act 2014 specifies that any intervention should include the perspective of the carer and therefore carers' views and experiences of air travel were also important to the study. At the request of the

⁴ 'Supported by' indicates the companion assisted with some factual corrections and additional information.

⁵ 'Assisted by' indicates that the companion provided more detailed help and advice.

Reference Group participants in this group have been called ‘companions’ rather than ‘carers’. The interviews with companions aimed to include companions who:

- were still travelling by air with a person with dementia
- may have stopped travelling by air with a person with dementia for any reason, but the person with dementia was still living; or
- had previously travelled by air with a person with dementia, but the person with dementia was now deceased

As per the pen portraits in Table 6 (see Section 5.0) the companions fell into all three categories. Although it was interesting to note that the one companion who had stopped travelling by air with a person with dementia who was still living, was initially reluctant to admit this was the case due to the finality of the statement.

Ten companions of people living with dementia were interviewed for the study in total. As with the participants living with dementia, the companion interviews were conducted in a range of formats. These are shown in Table 3 to aid the reader.

Type of Interview conducted	Number
The companion was interviewed alone and the person with dementia had died	2
The companion was interviewed with the person with dementia in the same room, but the person with dementia was not part of this study	2
The companion was interviewed alone and the person with dementia was alive but no longer travelling and was not part of this study	1
The companion was interviewed separately to the person living with dementia, but the person with dementia was also part of this study	1
Joint interview – the companion and the person living with dementia were interviewed for this study at the same time	4
Total participants who were companions of people with dementia	10

Table 3 - The formats of interviews undertaken with travel companions

This means that of the 20 participants, eight of the participants (four couples) took part in joint interviews with the remaining 12 participants taking part in interviews in the formats noted above.

3.4.4 Exclusion criteria

People without dementia were excluded from the study unless they have been a companion of someone travelling with dementia. As were those who had dementia, but who have not undertaken air travel since 2016. This is due to 2016 marking an important landmark in travel for those with hidden disabilities, as guidance for UK airports on their duty to support those with hidden disabilities, including dementia,

was published during this year (CAA, 2016a) (see Section 2.4) and any travel preceding this date may not accurately reflect current air travel experiences.

Participants in Scotland and Ireland were also excluded due to the study being informed by the Mental Capacity Act (2005) which covers England and Wales and these countries having their own Mental Capacity Legislation (Adults with Incapacity (Scotland) Act 2000; Mental Capacity Act (Northern Ireland) 2016) as previously noted. Importantly, participants who were unable to provide their consent under the Mental Capacity Act 2005 were also excluded, as were non-English speakers or those with communication difficulties as the researcher did not have the resources to engage the translation services required for this.

3.4.5 Sampling

As the study required participants to have both dementia and post 2016 experience of air travel, or be a travel companion of a person with dementia and have post 2016 experience of air travel, sampling was purposive in nature (Gray, 2014). Purposive sampling is commonly used in qualitative research to identify and engage participants with rich and in depth experience of the phenomenon under review (Bryman, 2016). However, a critique of purposive sampling is that the inclusion criteria is frequently unclear (Palinkas *et al.*, 2015). Therefore this section should be read in conjunction with Section 3.4.3 (inclusion criteria) for clarity.

Participants were sought across England and Wales in order to widen the potential sample population and capture diverse experiences from a range of airports.

Following ethical approval (see Section 3.4.10), recruitment was undertaken by advertising the study at dementia focussed conferences and events (including the Alzheimer's Society UK Conference 2018; the UK Dementia Congress 2018 and the Alzheimer Europe Conference 2018), via Twitter ® and in 'Dementia Together' a membership publication of the Alzheimer's Society. All forms of recruitment successfully produced participants with Twitter ® and the Dementia Together publication producing the highest response. Indeed, the recruitment strategy for the research led to a greater number of participants wishing to take part than places available, with a reserve list being held in case any participants dropped out. However, all interviews were completed as planned with no cancellations. The three potential participants on the reserve list were kept informed with regard to progress with the research and the reserve list ended when the final interview was completed.

3.4.6 Pilot interviews

When developing interview materials for people living with dementia it is recommended they are pilot tested for language and comprehension to highlight any areas of confusion or misinterpretation (Cridland *et al.*, 2016). Accordingly, the interview materials were pilot tested with a person with a hidden disability (cognitive issues) and minor amendments made. Following the amendments, the materials were further piloted with a person with a hidden disability (long-term effects of cancer treatment) and their travel companion. Denscombe (2014) suggests that pilot testing also allows for areas of omission to be recognised. Indeed, during the second pilot interview, it became evident that prompts on the inflight experience had been omitted from the interview schedule. The participants for the second pilot study suggested a

number of potential prompts relating to the inflight experience which were added to the schedule and utilised within the main interviews (see Appendix B).

3.4.7 Semi-structured interviews

Face to face interviews were arranged at a mutually agreed location within England and Wales for each participant. Interviews were completed over an eight-month period in 2018/19. The interview questions were based with permission from key researchers on the Australian 'Infrequent Flyers' study. This is the only other known research project on the experiences of people with dementia within aviation (Edwards *et al.*, 2016). See Section 2.2 for further details of this study. However, additional prompts, and probes that centred on the *feelings* attributed by the participants to certain phenomena, were included in order to enhance the phenomenological methodology through which the study was undertaken (Durdella, 2019). As it was recognised that people with dementia may become distracted during the interview, particularly by environmental cues and sensory overstimulation, the interviews were held in a quiet and familiar environment. The majority of the participants opted to be interviewed in their own home, with just two participants requesting to be interviewed in a hotel meeting room. A photographic visual aid on air travel was also designed for this study (see Appendix C), as these have also been found to facilitate a person with dementia's participation by acting as a refocus tool if needed (Allen *et al.*, 2017).

When meeting with potential participants, the relevant Participant Information Sheet and Consent Form were discussed to ensure that the participant fully understood the

purpose of the study and had the required level of information to enable them to consent to participate. The right to withdraw from the study was also clearly explained in the Participant Information Sheet, the Consent Form and reinforced verbally in person. It was made clear that, should the participant wish to withdraw from the study they were entirely free to do so at any point up to data analysis. To give the participant time to change their mind, all participants were informed that transcription would take place no sooner than one month from the date of the interview and a reminder of the participant's right to withdraw was included with the copy of the transcript for those who chose to receive it (see Section 3.4.13). The participant was also reminded that if they did decide to withdraw from the study, this would have no detrimental effect whatsoever on their relationship with the researcher, their current care provision or their support from any organisations.

3.4.8 Field notes

Completing field notes is deemed useful both as an aide memoir of the interviewee and the interview location and also for capturing personal reflections of the interview which can be useful for later reflexivity (Bryman, 2016). As such, following each interview, a structured field note was completed (see example of a completed field note at Appendix D). As is recommended, all field notes were written on the day the interview took place to avoid the risk of valuable data being lost (Gray, 2014).

3.4.9 Ethical considerations when interviewing People with Dementia

As with any research harm to participants should be minimised and, accordingly, due consideration was given to participants' dignity, safety and wellbeing as required by

the research framework of the professional body for occupational therapists in the UK (College of Occupational Therapists [COT], 2016). People living with dementia are considered to be vulnerable and, unfortunately, this vulnerability often precludes their involvement within research as researchers may choose to conduct research via a caregiver or proxy due to the perceived difficulty of obtaining ethical approval to work with the people with dementia themselves (Cridland *et al.*, 2016; Allen, *et al.*, 2017).

However, the right of inclusion by assuming capacity (unless it can be proven otherwise) is enshrined within legislation (Mental Capacity Act 2005; Equality Act 2010). Concentrated activism to give people with dementia a voice in research and service design has also been championed by user-led organisations such as the DEEP (Hare, 2016a) and the DAA (2018) as previously noted. Interestingly, the UK professional body for occupational therapy states that consideration of participants' rights should also be paramount in research design and delivery (COT, 2016). Accordingly, as this research aimed to discover the lived experiences of air travel for people with dementia and their travel companions and the researcher is a firm advocate of social and occupational justice, it was considered imperative that people with dementia were included throughout the study with the appropriate level of support.

Research has shown that overly complex documentation can be an example of an excluding factor for people living with dementia (Allen *et al.*, 2017). When designing the study's literature, the recommendations of Cridland *et al.*, (2016) were followed

to aid the informed consent process for people living with dementia; such recommendations included reminder statements within the participant information sheet and consent form as to the purpose of the research and the need to create and structure questions in the appropriate language and/or terminology. Guidance on creating dementia-friendly information was also considered and use of images, contrasting colours, key facts and presentation of information in short paragraphs all formed part of the literature design process (British Geriatrics Society, 2017; DEEP, 2013). The finalised interview materials incorporating this guidance are shown at Appendix E (people living with dementia) and Appendix F (travel companions).

As previously noted, the research also benefitted from the input of a Reference Group (see Section 3.2). The Reference Group were also asked to advise on the development of the documentation for this study and reviewed and commented on drafts of the interview materials in order to maximise readability and enable participation by the target participant group (see RG2 of Appendix A). Additionally, the study literature was checked for readability via Readable (2020) which utilises the Flesch Kincaid Grade Level within its computerised document checking system. Whilst there is no definitive reading grade for people with dementia, Readable (2020) state that 80 percent of the American population are able to read and understand documents that have a Flesch Kincaid Grade Level of 8 or below as this is the equivalent of an eighth grade student or someone who is 13-14 years of age. On first use of this system, the participant information sheet had a Flesch Kincaid Grade Level of 9.5. However, after several amendments and a final review by the Reference Group, the score had fallen to 7.9 putting it within the recommended range (Readable, 2020). This demonstrates the value of checking the readability of

documents as part of the informed consent process and is in keeping with the requirements of the Equality Act 2010 which legislates that participant information should be accessible to all.

The consent process was further enhanced at the time of interview by reading through the relevant forms and discussing any aspects of the study upon which the participant would like further information. It was recognised, however, that those with a diagnosis of dementia may have fluctuating capacity to consent (Social Care Institute for Excellence, 2020a) and this was assessed through verbal communication on an ongoing basis. Whilst capacity, or a lack of capacity, cannot be assumed on diagnosis alone, when meeting with prospective participants the researcher ensured that the participants met the criteria for capacity through an informal verbal assessment (and thus were deemed to have the ability to provide informed consent) in accordance with the Mental Capacity Act 2005. This recognises that the person's ability to provide informed consent to the study may have changed since they initially agreed to take part in the research and is in line with good practice. The Mental Capacity Act 2005 presumes capacity if a person is able to demonstrate that they can understand, retain and weigh up information provided to them in relation to *that particular decision at that particular moment in time* and can communicate their consent. All participants in both groups were able to demonstrate these key factors through general conversation, discussion of the participant information sheet and the completion of the consent form.

The researcher has practical experience of working with people with dementia and undertaking formal capacity assessments within the NHS as a Health and Care Professions Council (HCPC) registered occupational therapist. The researcher also attended an in-depth course on the Mental Capacity Act 2005 prior to commencing the interviews as a means of refreshing and updating this knowledge. Utilising prior experiential knowledge of working with people with dementia, supported by up-to-date training, the researcher was alert to people who were unable to provide appropriate verbal consent to participate at the time of interview or who showed signs of losing capacity to continue to proceed during the interview process.

Formal capacity assessments were not undertaken with participants due to these potentially detracting from the purpose of the visit. However, the opportunity was taken at the start of each interview to talk through the purpose of the visit and to discuss the interview materials and interview procedure with all participants. This process, together with general conversation concerning the person's home environment (such as looking at and discussing photographs of family members) allowed the researcher to both put the person at ease and to carry out the informal verbal capacity assessment to ensure the participants were able to meet the core capacity components as outlined by the Mental Capacity Act 2005 . All participants met the capacity criteria, however two people living with dementia who were present when their companions were interviewed did not. One was unable to retain, weigh up and make a decision on the interview information that was provided and the other did not communicate with the researcher at all falling asleep immediately after the researcher arrived. Whilst the people living with dementia were present in both

cases, the interviews focussed on the experiences of their usual travel companions as originally intended. See *Sections 4.0 and 5.0 for further details of the participants.*

3.4.10 Ethical approval

In keeping with the researcher's belief in social and occupational justice (Hocking, 2017) the ethical approval for this study was written from a rights based perspective. Considerable emphasis was placed on the rights of people with dementia particularly:

- that there has historically been an overuse of proxies in dementia research and the voices of people living with dementia should be heard wherever possible (Cridland *et al.*, 2016);
- that they should be supported to take part in research that was of interest and importance to them (DAA, 2018), and
- that capacity should always be assumed unless it can be proved otherwise (Mental Capacity Act 2005)

Ethical approval for this study was granted in March 2018 (under reference 17/18-899) by the Research Ethics and Integrity Committee for the Faculty of Health and Human Sciences at Plymouth University. As the ethical approval letter was marked

as being confidential, it has not been added as an appendix to this thesis in order to comply with data protection legislation (Data Protection Act 2018).

3.4.11 Financial information

Participants did not receive any payment for participating in this research as payments may have been seen as a form of coercion or caused people to feel they had no alternative but to participate (Largent *et al.*, 2012). Many of the participants elected to be interviewed in their own homes and, therefore, provided their own refreshments. Only two participants opted to be interviewed outside of their home environment. On this occasion, the joint interview took place during a break from a conference that all parties were attending. Consequently, refreshments and a quiet meeting space were freely available in this setting.

3.4.12 Confidentiality and security of data

All participants' details remain confidential and will be kept in accordance with the Data Protection Act 2018 . Only the researcher and Dr Alison Warren, as Director of Studies, know the contact details of the interviewees. Dr Warren was informed by email of the name and contact details of all participants, together with arrival and departure times from each location, in order to implement a tracing system and reduce the risks associated with researching as a lone worker (Suzy Lamplugh Trust, 2019). Once the interviews were conducted and the safety of the researcher established the emails were deleted.

Study literature that contains identifying details, such as consent sheets were kept in a locked filing cabinet in the researcher's University office. All digital interview recordings were given a pseudonym and stored on an encrypted USB flash drive which was also kept in the locked office filing cabinet when not in use. Transcription of the interviews was undertaken using a University owned and password-protected laptop with up to date security software. At the completion of the study all electronic data was transferred to the Director of Studies via the University's OneDrive system and paper records were lodged with the secure data storage facility on campus. Both sets of records will be kept for 10 years in accordance with the University of Plymouth's Research Ethics Policy (Pellowe, Tuczniak & Martin, 2018).

All participants were offered the opportunity to choose a pseudonym to assist with anonymity, with pseudonyms being allocated to those participants who opted not to do this. These pseudonyms have been utilised when disseminating the research findings in any form. Anonymity through the use of pseudonyms is considered to be important as the data also records other potential identifying factors such as the participants' age, geographical location, type of dementia and length of time post diagnosis (Braun & Clarke, 2013). As previously noted in Section 1.3, the challenges experienced by someone living with dementia will be dependent on the area of the brain that is affected (Rahman & Howard, 2018) so this information has been collected and is shown in Table 5 (see Section 4.0). However, due to some of the participants having a rarer form of dementia, the geographical areas in which the participants live have been purposefully omitted from the findings, together with other identifying details such as the person's local airport if they have mentioned it, as it is highly likely that this information could make people identifiable.

3.4.13 Transcription

The audio files from the interviews were transcribed verbatim using Express Scribe Professional (NCH Software, 2019). The researcher had previous experience of using this software for transcription purposes and found that it helped to speed up the transcription process. When transcribing, the guidelines of Braun and Clarke (2013) were followed in terms of highlighting turn taking so it was clear when the researcher and the participant(s) were speaking, non-verbal utterances such as 'mm hm' or 'erm' and when the participant laughed or paused for any significant length of time were also captured in the transcription document. Braun and Clarke (2013) also advocate that punctuation should not be used when transcribing as to do so may alter the meaning of the data. However, some light punctuation was included to aid with the analysis and readability of the text as both the researcher and the Director of Studies found an early unpunctuated transcript difficult to follow and analyse (a sample page of transcription is shown at Appendix G).

All participants were offered the opportunity of reviewing their final transcript as a means of respondent validation and to allow them the opportunity of deleting any of their data before analysis took place (Denscombe, 2014). Six of the twenty participants declined to receive a copy of their transcript. Of the remaining 14 participants, four had no amendments, one participant asked for a minor amendment to their transcript and nine participants did not reply. The one minor amendment requested (an identification error on who was speaking) was undertaken before data analysis commenced.

3.4.14 Data analysis

Once the audio recordings of the interviews were transcribed verbatim and participants had been given the opportunity to check their transcript for completeness via respondent validation, the transcripts were analysed using Colaizzi's (1978) method. See Section 3.3.5 for details of why this analysis was chosen.

Prior to any analysis taking place each transcript was copied into a basic word processing table designed to allow for a transparent record of data transformation to be kept. Each transcript was then read in order to take a holistic view of the phenomena under review - in this case the experience of air travel, both from the perspective of a person with dementia and the perspective of a travel companion as appropriate. No analysis or marks were made on the transcripts at the time of this first read through. All transcripts were then re-read to identify significant statements. Each significant statement was marked with a sequential number. An example of a transcript page annotated with significant statements is shown in column one of Appendix H.

The next step involved transforming what was *implicit* within the significant statements to a more *explicit* statement, allowing the lived, but not articulated meanings, to be revealed. An example page from this stage of analysis is shown in column 2 of Appendix H.

Once the meanings had been analysed, the next stage was to organise these into themes. NVivo (QSR International, 2017) was utilised for data management purposes during this element of the phenomenological analysis process due to its purported usefulness in coding and retrieving sub-sets of qualitative data under various headings or nodes (Bryman, 2016). Nodes were created for each of the themes as they developed and the evidence compiled within each node was then further reduced to get to the essence of their meaning. See column three of Appendix H.

The next step was to refer the final themes back to the original transcript to validate the findings and make sure that nothing had been omitted (Colaizzi, 1978). Once this check had taken place an exhaustive description was written for each individual's experience. See Section 4.1 for an exhaustive description of a person living with dementia's experience and Section 5.1 for an exhaustive description of a companion of a person living with dementia's experience.

The process was repeated for all transcripts in both participant groups. Once all transcripts had been analysed, the finalised themes for each participant were uploaded into NVivo and these were again organised by nodes so that similarities and differences across the group could be identified. As this procedure was complex and led to the final themes for each of the two groups being produced, the project Reference Group were invited to comment on this stage of the data analysis process as a means of validation. A meeting was held where each potential theme, the meaning units that underpinned them and extracts from individual exhaustive

descriptions were discussed (see RG9 and RG11 of Appendix A). The Reference Group were in agreement with all the themes, although they suggested a change of title for one of the themes for the companions of people living with dementia. Accordingly, the theme title was changed from 'Helping other people living with dementia to travel by air' to 'Sharing strategies for a positive air travel experience'. A final exhaustive statement for each group as a whole was then produced in draft form.

As noted in Section 3.3.5 a key reason for choosing Colaizzi's (1978) method was due to the final step of analysis – participant validation. Therefore, each exhaustive statement was discussed with the Reference Group who recommended a number of minor amendments on language use (see RG12 of Appendix A). The final statements were then sent to those participants who had agreed to be kept informed of the study and its findings. Of the 16 participants who were contacted⁶, 11 replied and seven suggested amendments. These amendments were incorporated into the final statements which are shown at Section 4.7 and section 5.6 respectively.

3.4.15 Reflexivity

It is recommended that when undertaking any form of qualitative research the researcher engages in reflexivity, or a reflective examination of one's own actions, observations and feelings, throughout the research process (Gray, 2014). This is in

⁶ Note: this figure differs to the number of participants who were sent a transcript in 3.4.13 as two participants did not want to receive a copy of their transcript, but did want to be kept informed of the research findings.

recognition that the researcher has an instrumental influence over the research and that by asking questions of the research process and the impact of interactions, this influence can be recognised and mitigated (Durdella, 2019). Evidence of ongoing reflexive enquiry began in Section 1.6 when my personal experiences associated with this research were explored in some depth.

Descriptive phenomenology also calls for the researcher to bracket one's own experiences and preconceptions with regard to the phenomenon under investigation (Giorgi and Giorgi, 2008; Smith, Flowers and Larkin, 2009). This bracketing of information is intended to allow the researcher to experience a greater connection with the essence of the individuals' lived experiences (Matua and Van Der Wald, 2015). It is also important, however, that I understood how my own experiences and feelings could potentially affect all aspects of the research process (Durdella, 2019). For this reason, I have kept a reflexive diary throughout the study and have completed reflexive field notes following each interview. I was also mindful that the interview schedule should not ask leading questions (Seidman, 2006) and that the participants should be encouraged to describe and explore their own thoughts and feelings on any given subject in order to enhance the phenomenological lens through which the interviews were designed and undertaken. Writing this thesis has also allowed for further reflexivity as each chapter ends with a reflexive statement to highlight some of the key interactions and the impact these may have had on the research process.

3.5 STUDY 2: Establishing what works in dementia training

The aim of the second study was to explore best practice in dementia training, to identify what could be learned from this for the field of aviation. Consideration of how this information should be captured was a key consideration for this element of the research. As social science interventions are multifaceted and complex, and involve human actors with differing behavioural patterns interacting within different contexts, undertaking a systematic review to understand the efficacy of an intervention is considered unlikely to generate any in-depth theory that will enable practical change (Pawson *et al.*, 2014; Pearson *et al.*, 2015). It is therefore suggested that some research commissioners are becoming increasingly receptive to alternative approaches to systematic reviews which focus on efficacy alone, due to the purported history of interventions built on this type of evidence having little to no real world effect (Jagosh, Tilley & Stern, 2016). There is an alternative approach, however, in the form of realist enquiry. Realist enquiry, or *realistic* enquiry as it was originally termed, falls broadly into two categories: realist evaluation which explores primary data, and realist synthesis which explores secondary data (Pawson and Tilley, 1997; Wong *et al.*, 2013).

As noted in Section 3.1 realist enquiry sits broadly between positivism - everything we know can be observed and constructivism - all that we know we interpret (Rycroft-Malone, 2018). Realists reject the positivist notion that interventions, in and of themselves, cause outcomes (Jagosh, Tilley and Stern, 2016). Instead, realists strive to understand the broader impact of the context in which the intervention is set and how human decisions and real world influences and choices can affect

intervention outcomes (Greenhalgh *et al.*, 2011). By identifying the mechanisms underpinning any intervention that are the catalyst for change, *whether they be favourable or unfavourable*, realists produce evidence as to how the appropriate mechanisms for engagement with an intervention can be triggered in order to give the desired outcome (Wong, 2018).

A key objective of this doctoral research is to produce information for the aviation industry on how they can best serve people with dementia and their travel companions in the future (see Section 8.2). It was therefore considered that utilising realist methodology to examine best practice dementia awareness and support training, in combination with the subjective findings from study one of the research, would help to maximise the impact and effectiveness of these guidelines in a relatively inexpensive way (Kastner *et al.*, 2011).

3.6 Realist synthesis method

3.6.1 Stakeholder involvement

Stakeholder involvement is key at all stages of a realist synthesis due to the stakeholders' extensive insider knowledge and ability to give clarity to the problem under consideration (Pawson *et al.*, 2005). As previously noted in Section 3.2 a Reference Group was associated with the research and this group was developed to maximise this insider knowledge by selecting a range of content experts (Wong, 2018). See Appendix A for details of Reference Group meetings and the topics discussed.

3.6.2 Publication of protocol

Ordinarily, when undertaking a systematic review, a protocol is devised in which the question and purpose of the review is outlined and published *before* the review commences. However, it is recommended that such protocols are not published within a realist syntheses until the study reaches at least the half way point (Pawson *et al.*, 2005). Realist training materials, known as the Realist and Meta-narrative Evidence Synthesis: Evolving Standards (RAMESES), were consulted and do not directly advise on this point (Wong *et al.*, 2014). However, they do caution that a realist synthesis is likely to generate a number of potential questions and theories and that the synthesis may need to be scaled down or amended after the initial exploratory searches have been completed (Wong *et al.*, 2014). Therefore, the protocol for this study was submitted in November 2018, once the study's question had been finalised and the working programme theories had been discussed and agreed with the project's Reference Group, a process that took approximately 11 months (see Appendix A). The protocol was accepted by PROSPERO and published on their website (Turner *et al.*, 2018).

3.6.3 Structure of the synthesis

Realism as advocated by Pawson and Tilley is relatively new, with their first book on realist evaluation only published in 1997 (Pawson & Tilley, 1997). Realist synthesis was not introduced until seven years later (Pawson *et al.*, 2004). The method has evolved since this date. Therefore, when undertaking the realist synthesis, the structure recommended by (Pawson *et al.*, 2004) and Booth, Wright and Briscoe (2018) was utilised alongside guidance from the RAMESES Projects (Greenhalgh *et*

al., 2015; Greenhalgh *et al.*, 2011; Wong *et al.*, 2014). Due to the complexities of realist research this combination of the latest thinking helped to provide clarity to what needed to be achieved in the form of a framework and consequently the following six steps were undertaken:

3.6.3.1 Step 1 - Question setting

Causality is the crux of realist enquiry (Pawson *et al.*, 2005). Whilst other research philosophies may also seek to understand causality, this is usually achieved by following the successionist viewpoint *that x follows y*; while realism follows a more generative viewpoint to understand *what is it about the underlying mechanisms that enables x to follow y within this context?* (Sridharan & Nakaima, 2020). This generative understanding is employed when setting realist questions in order to examine causality in its widest form (Pawson *et al.*, 2005). Therefore, when setting the question for the synthesis, key elements of the realist research question structure ‘what works, how, why, for whom, to what extent and in what circumstances, in what respects and over what duration?’ (Wong *et al.*, 2014) were utilised. This resulted in the proposed question:

Dementia awareness and support training outside of healthcare: A realist synthesis of what works, for whom, in what circumstances and why?

The emphasis on training outside of healthcare reflected the importance of context as it is recognised that what will work in one area of training may not work in another due to a range of contextual factors (Pawson, 2013). Such contextual factors may,

for example, include the differing legislative, political and managerial landscapes within a state funded healthcare environment to that of a profit driven commercial enterprise such as aviation. The Reference Group was consulted on the wording of this question and it was slightly amended (language only) in accordance with their advice (see RG4 of Appendix A).

3.6.3.2 Step 2 - Initial exploratory searches

Prior to undertaking the exploratory searches the PROSPERO international prospective register of systematic reviews (National Institute for Health Research, 2017) was checked to ensure that a similar review had not already been registered. No registration of a review on the topic of dementia awareness and support training outside of the field of healthcare was identified.

At the outset of the realist synthesis the project Reference Group were asked to contribute their practical wisdom to the study by taking part in a workshop on ‘what works’ and ‘what does not work’ within dementia awareness and support training from their experience (see Appendix I for the document produced as a result of the workshop). Such gathering of theories derived from practical wisdom is a recommended strategy when building working theories in realism (Pawson *et al.*, 2005). The doctoral research supervisory team were also asked if they could recommend any key papers that may act as a potential starting point for theory development. Proponents of realism consider requesting the assistance of sector specific experts in this way to be a useful strategy (Kastner *et al.*, 2011). This action proved to be very useful to the study as a key tourism paper (Connell *et al.*, 2017)

was identified and analysed for working or candidate programme theories. In the interests of transparency it should be noted that Mr Ian Sherriff, one of the supervisors of this doctoral research project, was the third author on this paper.

The candidate theories from the Reference Group and derived from Connell *et al.* (2017) were then combined to form one long list of candidate theories which were then grouped, with the assistance of the Reference Group (see RG6 of Appendix A), into six key areas:

1. Attitudes to, and knowledge of, dementia
2. Who should be involved in the training
3. What should be included in the training
4. Training delivery methods
5. Wider effects of training and
6. Training outcomes

See Appendix J for further details of the candidate theories under each heading.

Once the candidate theories had been produced the background search continued with the assistance of the Reference Group to further refine the theories under construction and to build a picture of the existing dementia awareness and support training terrain (Wong *et al.*, 2013). Building candidate theories in this way attempts

to define the key aspects of an intervention that are thought to lead to certain outcomes (Wong *et al.*, 2014).

When searching for background information Pawson *et al.* (2005) recommend the value of opportunistic searching. An example of this was the recommendation, by a delegate at a European dementia conference, for the researcher to read a chapter on air travel and human rights in an upcoming law book (Rochford-Brennan & Jenkins, 2019). A total of 12 key papers were identified within the background search. As recommended, a bespoke data extraction form was designed and utilised during this element of the realist synthesis (Pawson *et al.*, 2005). The data extraction forms were then populated with evidence to support, refute or amend the theories under consideration (Rycroft-Malone *et al.*, 2012). Due to their importance within the synthesis process, the data extraction forms were pilot tested with the aid of the project's reference group to establish if they are capturing the right information in order to build, refute, or refine, the programme theories before being utilised within the wider study (Rycroft-Malone *et al.*, 2012). A copy of a populated data extraction form is shown at Appendix K.

Unpacking the effect of context is also considered vital for realist enquiry as social programmes are highly unlikely to maintain equality of effectiveness when delivered in different settings (Pawson *et al.*, 2005). Context is more than mere physical location, however, and covers many considerations that are external to the intervention such as societal and organisational culture, geographical location, historical perspectives, political structures, leadership, resources and competing

priorities and influences amongst others (Greenhalgh *et al.*, 2015; Jagosh, 2018; Rycroft-Malone, 2018). Accordingly, the Reference Group were also asked to contribute to a list of key legislation and policies, together with their publication dates, to help to shape the context of the interventions under review within the study (see RG6 Appendix A and Appendix L).

3.6.3.3 Step 3 - Selecting the working theories for investigation

The Reference Group were asked to consider the results of the additional searches completed in step two alongside the original candidate theory list to produce the final long list of theories. As the list was lengthy, the Reference Group were asked to prioritise the list to enable their most important theories to be tested against the evidence base in step four of the process. This strategy of reducing potential theories to the most ‘fruitful’ is a recommendation from Pawson in response to another doctoral student’s query on the realistic management and scope of a realist synthesis (Pawson, 2019). Unfortunately, meeting RG8 (see Appendix A) at which this topic was discussed was poorly attended and, despite a post meeting email being sent to the whole Reference Group, only two group members completed the prioritisation exercise. However, the theories were edited and prioritised in accordance with the comments received.

3.6.3.4 Step 4 - The search for empirical evidence

An information specialist was contacted once the finalised list of candidate theories had been produced to seek advice on a draft search strategy. Obtaining such advice is recommended due to the diverse range of literature that may be included within a

realist synthesis (Wong, 2018). The advice was extremely helpful as the information specialist advised that the initial draft search strategy for this element of the synthesis was too lengthy, likely to produce a number of false leads and thus be unmanageable (see Appendix M for a copy of the initial draft search strategy). For example, the researcher was advised that utilising the word ‘memory’ was likely to produce some dementia related results, but also generic results around memorable events or people’s own personal memories on a range of subjects or settings. Consequently, a revised and abridged search strategy was developed for the study in accordance with this advice (see Appendix N).

A search was conducted in accordance with this strategy and, despite the fact that it was heavily edited from the original version, it still highlighted 7,070 potential results. Following removal of duplicates utilising EndNote reference management software (Clarivate Analytics, 2020) 4,958 abstracts remained. All 4,958 abstracts were uploaded to the online systematic review software Rayyan (Qatar Computing Research Institute, 2020) and were screened against inclusion/exclusion criteria which had been agreed in conjunction with the project’s Director of Studies (see Appendix O). Rayyan was chosen for the abstract screening as it allows multiple users to collaborate on the same dataset and has the functionality to blind inclusion and exclusion decisions made by the primary reviewer to any secondary reviewers until the secondary abstract screening decisions are complete (Ouzzani *et al.*, 2016).

Dr Alison Warren, the Director of Studies for this research, independently appraised 10% (n=496) of the abstracts on Rayyan for consistency. The 10% figure was

chosen in line with standard protocols for realism – see, for example, Wong *et al.* (2015). Once the 10% had been appraised Rayyan was ‘unblinded’ to reveal a conflict on just six papers. This was potentially due the fact that both the researcher and the Director of Studies had discussed the inclusion/exclusion criteria in some depth before this exercise. The six papers were then included or excluded through further debate and subsequent agreement between the doctoral researcher and Director of Studies in line with the inclusion and exclusion criteria shown at Appendix O. A further 137 papers on which the doctoral researcher had queries were also jointly appraised in the same manner until final agreement was reached.

Following the abstract appraisal process 104 papers remained and full texts were obtained for these where possible. Again as is recommended, a bespoke data extraction form was designed and utilised during this element of the synthesis (Pawson *et al.*, 2005). An extract from the populated data extraction form is shown at Appendix P. To assist the data collection process key words from the finalised working theories were also input into NVivo (QSR International, 2017) as nodes (see Appendix Q). These nodes were then populated with evidence to support, refute or amend the theories under consideration (Rycroft-Malone *et al.*, 2012).

As realist researchers are not just interested in whether or not interventions cause a specific outcome, but how the intervention’s context and underlying mechanisms interact to produce a specific outcome in a specific context (Jagosh, 2018), evidence gathered focussed on elements of the C (context) + M (Mechanism) + O (Outcome) configurations as developed by Pawson and Tilley (1997). Dr Alison Warren again reviewed 10% of studies in this element of the synthesis for consistency alongside

the information extracted using the hybrid system as detailed. Some minor changes were made to the NVivo coding as a result of comments received. Following the full text review process a final 41 papers were included in the realist synthesis. See Figure 2 for details of the full search results from step four of the realist synthesis.

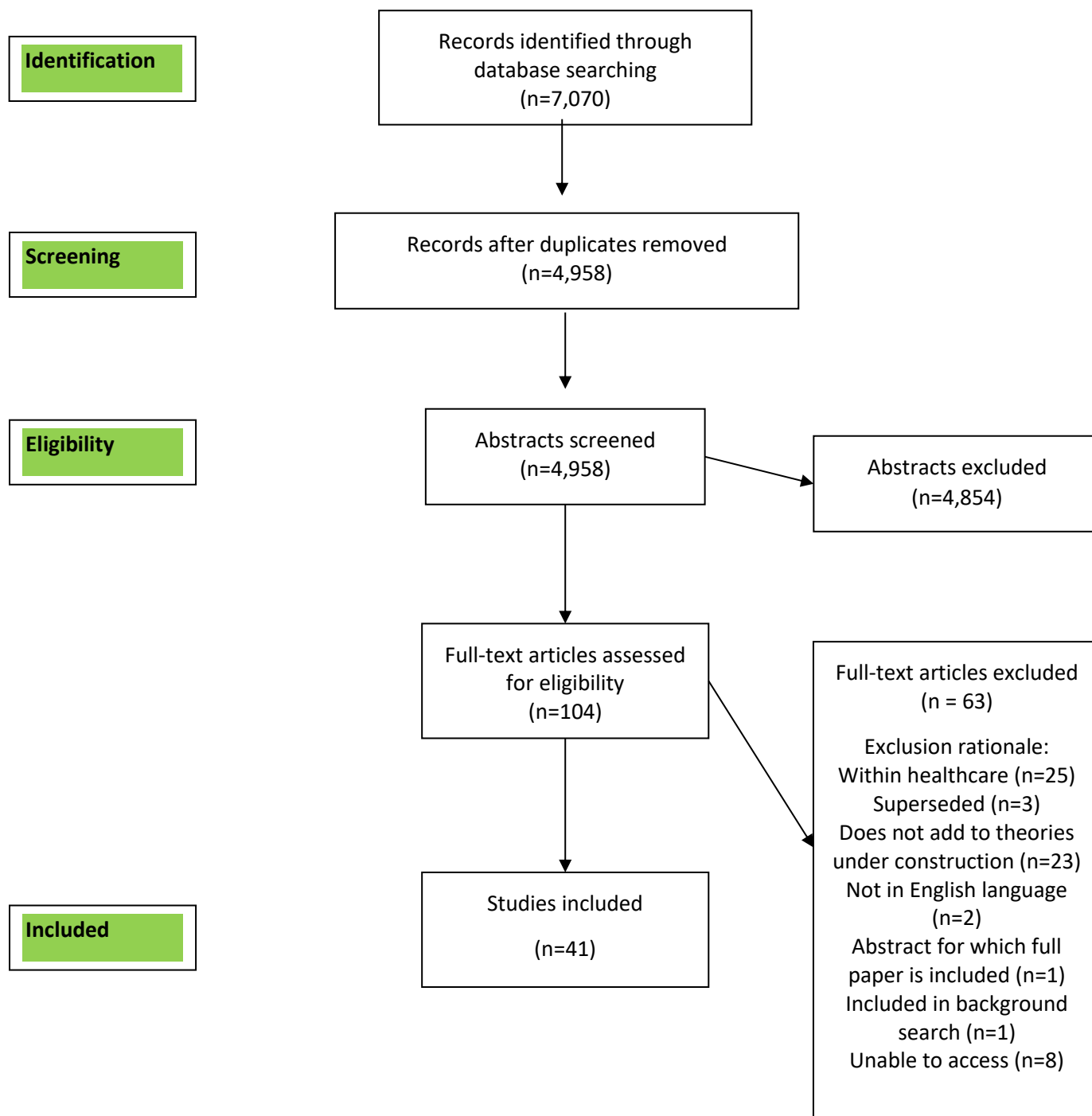


Figure 2 - Results of realist synthesis

Adapted from the Preferred Reporting Items for Systematic Reviews and Meta Analyses:

The PRISMA Statement. Moher *et al.* (2009)

3.6.3.5 Relevance and rigour

Inclusion of documents was primarily based on relevance. Within realism relevance is determined by how, and to what extent, studies support or refute the programme theories (hypotheses) under investigation (Kastner *et al.*, 2011). Realist synthesis should not be any less rigorous than a traditional review. Accordingly, an audit trail was kept of papers examined in order to demonstrate the rationale for their inclusion or exclusion (Pawson *et al.*, 2005; Rycroft-Malone *et al.*, 2012; Wong *et al.*, 2013) (see extract of data collection form at Appendix P). As the focus of the synthesis was on theory building, rather than theory testing, no quality assessment of each paper was undertaken. This is in line with Pawson *et al.* (2004) who maintain that realists may only choose to report on a small part of any study in order to build context, mechanism and outcome configurations making any quality appraisal of the entire study time consuming and potentially misleading for the reader. However, brief details of a study's perceived quality, as judged by the researcher, were included in the data extraction form for completeness – see Appendix P. Consistency checks were also undertaken by the Director of Studies on a 10% sample of abstracts and full text papers as outlined in Section 3.6.3.4 to aid trustworthiness and rigour throughout the theory building process.

In recognition of the advice from authors of existing realist studies, when the legitimacy of including a piece of evidence was in doubt, the evidence was *included* rather than *excluded* with the rationale for doing so being noted within the data extraction forms (Rycroft-Malone *et al.*, 2012). Due to the levels of complexity involved, it is recognised that it would be impossible for the realist synthesis to cover

every possible programme theory, thus emphasising the importance of prioritising the potential theories for investigation at an early stage (Wong *et al.*, 2013). Unlike traditional systematic reviews, realist syntheses are not intended to be exhaustive but to build theories from which the best possible explanation can be inferred. It is noted however that a different researcher reading the same set of materials may infer different explanations. As such realism is anti-positivist and accepts that there is no one true explanation for any phenomenon under study and that a level of interpretivism will always apply (Maxwell, 2012).

3.6.3.6 Step 5 - Refinement of the seven programme theories

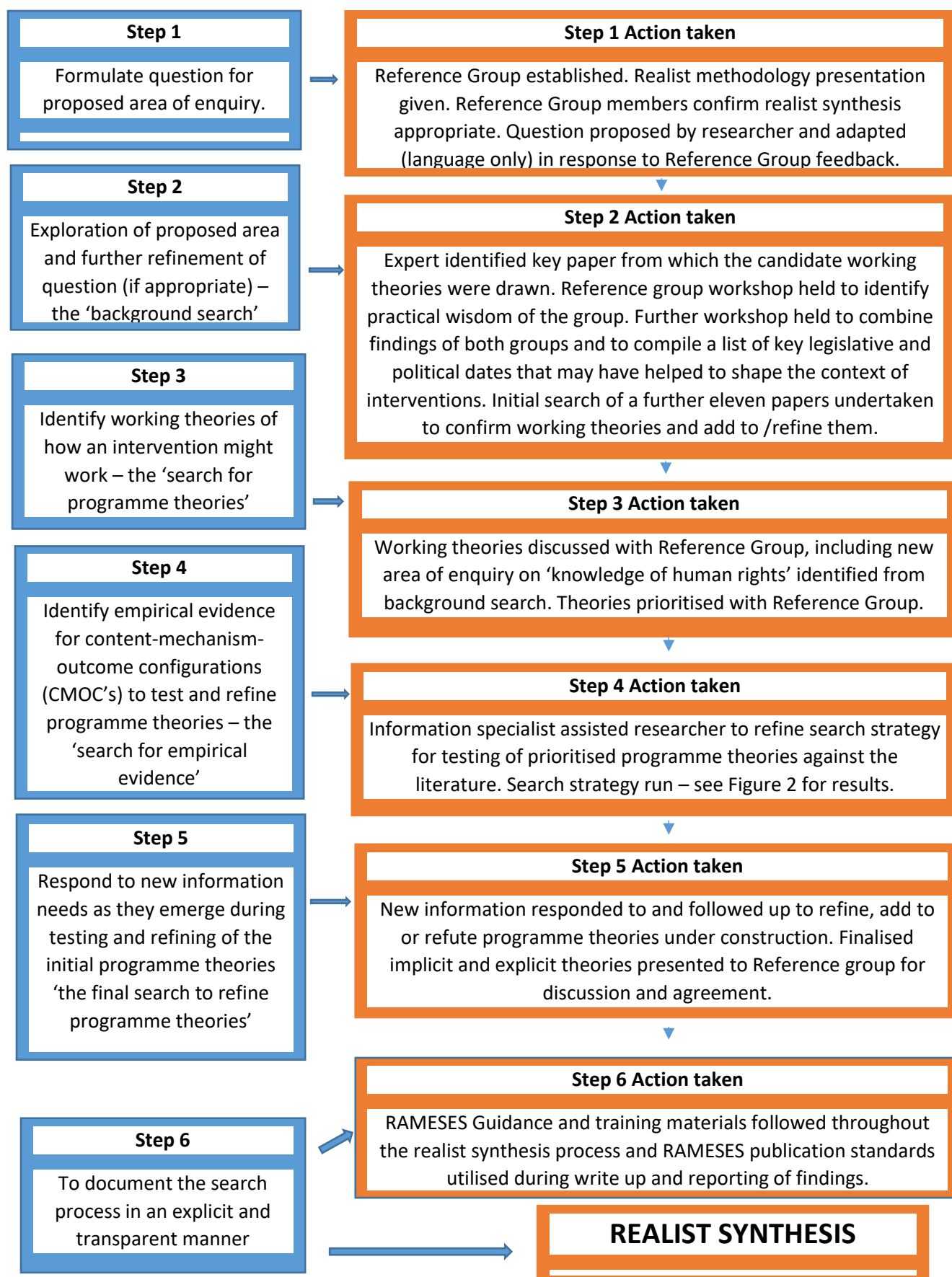
During the data refinement stage NVivo was used to compile the number of data sources that supported the programme theories being tested in order to increase the strength and relevance of any inferences made (Wong *et al.*, 2013). Once the programme theories were developed and refined, the finalised implicit and explicit theories emerging from the study were discussed and validated with the Reference Group (See RG13 of Appendix A). Having followed a realist framework to create a refined programme theory, it was emphasised to the Reference Group that the theory developed would not determine if there are certain dementia training interventions that work, but rather highlight how existing dementia support and awareness training might work, for whom, in what circumstances and why (Pawson and Tilley, 1997; Pawson, 2013). Pawson (2002) terms this a change in thinking from identifying de-contextualised best practice to the creation of tailored, transferable theory. The aim of such theory is to aid understanding of what has occurred in the past and to predict, at least in part, what may occur in the future if

key aspects of the theory are utilised in intervention planning (Wong, 2018). Once the programme theories were refined they were also tested against potential underlying transferable or substantive theory (Wong *et al.*, 2014). The examination of one underlying substantive theory for each of the seven programme theories again recognises the complexity involved and the advice that examining every potential substantive theory is unrealistic (Wong *et al.*, 2013). This element of the realist synthesis will be discussed in further detail in Chapter 7 (see section 6.0).

3.6.3.7 Step 6 - Dissemination of findings

During the study the RAMESES training materials and guidance were consulted to ensure that the realist synthesis was conducted to an appropriate standard (Wong *et al.*, 2014). The findings were also written up following the RAMESES publication guidelines for realist synthesis (Wong *et al.*, 2013). As well as providing a structure in which to capture the findings, following these guidelines increases the chance of future publication as they allow for an ongoing critical appraisal of the quality of realist syntheses submitted (Wong *et al.*, 2013).

Whilst these steps have attempted to offer a linear framework in order to explain how the realist synthesis element of the study was planned and undertaken, realist syntheses are, in fact, not linear in nature and the synthesis required cyclical search patterns to be undertaken over the study's entire duration (Wong *et al.*, 2014). A framework for the realist synthesis is shown in Figure 3.



Adapted from Booth, Wright and Briscoe (2018, p.153) and Pawson et al., (2005, p24)

Figure 3 - Flow chart of steps undertaken in realist synthesis

3.7 Critique of realist syntheses

As noted in Section 3.6.3 the Pawson and Tilley school of realist enquiry is relatively new (Pawson *et al.*, 2004; Pawson & Tilley, 1997). It is however considered to be very helpful in unpacking project complexity and can therefore be utilised to explore a wide range of subjects (Rycroft-Malone, 2018). However, it is recognised that realist researchers can become lost in this complexity (Pawson *et al.*, 2005). The varied use of realist synthesis across a range of disciplines and subjects prohibits the design of a one size fits all technical checklist (Wong *et al.*, 2013). However, as a novice in the realist field, I utilised the RAMESES guidance and reporting standards documents (Wong *et al.*, 2013; Wong *et al.*, 2014) together with published realist synthesis exemplars such as Pearson *et al.* (2015) in order to provide a framework and to maintain a focus when undertaking the synthesis (see Figure 3).

Writing about realist research in Pawson *et al.* (2005) suggested that realist syntheses should not be undertaken by novices. However, due to the number of realist studies that have been undertaken since this date, established realist researchers no longer consider this recommendation to be valid, provided new researchers actively engage with other members of the realist research community and seek advice where necessary (Rycroft-Malone, 2018). To help with this process of engagement I joined the RAMESES email exchange, where advice can be obtained from some of the key authors within realist enquiry and also attended a week's training course on realist evaluations and reviews at the University of Oxford, led by Dr Geoff Wong, one of the authors of the RAMESES research guidance. I also engaged with other realist researchers within the University through the Critical

Realist Group and arranged to meet with other realist researchers on a one to one basis to discuss my project. As a lone researcher attempting to get to grips with the complexities of undertaking a realist synthesis, I found making these links with other researchers extremely useful.

3.8 Combining the dual methodologies

As previously noted in Section 3.1 the phenomenological interviews in study one are compatible with the researcher's constructivist/interpretivist standpoint. The realist synthesis in study aim 2 moves towards post-positivist territory as it recognises the validity of both structure and agency when attempting to unpack complex interventions (Pawson, 2013). While Grix (2010) asserts that positivist and interpretivist epistemologies can not and should not be mixed as they are epistemologically incompatible, combining elements of interpretivism and realism (or indeed positivism and realism) can be very successful in answering both the how and why of any research question. Patton (2014) also notes the benefits of using different methodologies to complement each other and fill differing gaps in knowledge on the subject area under review (Patton, 2014). Using both interpretivist and realist methodologies also fits with the researcher's philosophy that understanding causality at both the macro and micro level is equally important. Once both studies were completed, the findings converged as demonstrated in Figure 4.

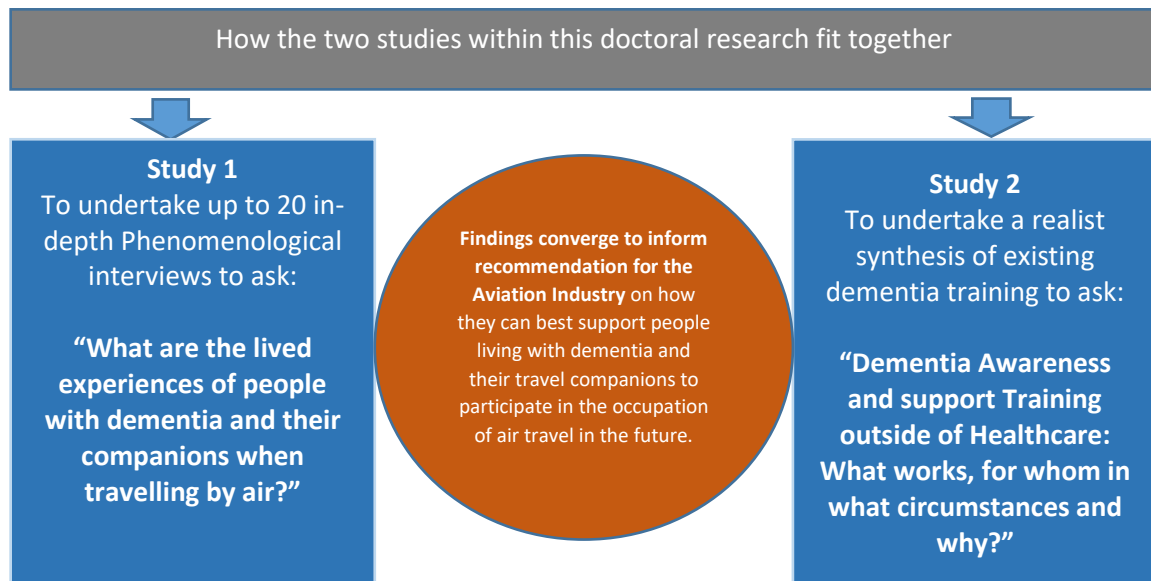


Figure 4 - How the two research studies fit together

3.9 Chapter summary

This chapter has detailed the methodologies that underpin the two studies within this research, together with the methods used. The following three chapters will examine the two research studies, and their respective findings, in more detail.

3.10 Reflexive commentary

Throughout this research I have been very keen to see people as individuals and not to try and put people into boxes, stances which are in keeping with my belief in the importance of social and occupational justice and seeing the value of subjective personal experience from as wide a range of people as possible. For example, when asked how I would stage the potential participants with dementia (on a continuum or scale from mild to severe), to identify who could participate in the study, my answer

has always been that I would not be staging the participants at all. Instead, a key inclusion strategy was that potential participants should be able to demonstrate that they could meet the capacity threshold as set out in the Mental Capacity Act 2005. In reality, this meant that the participants would be largely self-selecting from the earlier stages of the dementia continuum or, potentially, they would be situated more towards the middle of the continuum, if their travelling companion had instigated the contact for them to take part in the study and would be supporting them to take part. However, as an occupational therapist, I wanted to see each participant as an individual and ensure that I had respected this when designing the research.

Nevertheless, I had not allowed for the fact that by separating my interviews into 'people living with dementia' and 'travelling companions' I had effectively put participants into boxes anyway. Some of the participants I met who were still travelling as a couple did not want to be separated in this manner and insisted on being interviewed together. I obviously honoured the participants' wishes, which is why I have listed several interviews in Tables 2 and 3 as being 'joint'. This was an important lesson for me however as, sometimes, researchers can have strongly instilled values, such as my wish to be inclusive and treat everyone as an individual, but still miss the obvious. This was disappointing given my stance on the importance of upholding individual preference and social and occupational justice, but a positive learning point for the future.

When designing the interview materials, I followed a suggestion from evidence of including 'smiling' and 'frowning' faces on the consent form to indicate that the

person with dementia agreed with each statement or disagreed with each statement. Together with the Reference Group, we spent a long time discussing whether the faces were appropriate and whether they should be colour coded in some way to further increase the person living with dementia's understanding, eventually settling on grayscale. Without exception for both people with dementia and their companions, the participants did not understand the faces saying 'are these meant to mean yes or no?' 'They are? Why did you not just put that then?' This potentially indicates that I further assumed that the participants needed pictorial prompts to aid their understanding which proved to be unnecessary. The visual guide of the airport travel chain was very useful however, with both companions and people with dementia using it as a prompt within the interview process. However, the similarities in themes from both groups (see Figures 5 and 6) could be explained, at least in part, by the use of this procedural prompt and it may have also acted as a limitation to the study's findings (see Section 8.4.3 for further detail).

A further surprise came as a result of misunderstandings associated with an interview question from the Infrequent Flyers study (Edwards et al., 2016) that had been reused with permission from the study's authors as previously noted (see Section 2.2). The question was 'did you need to ask the flight staff for anything while you were on board the aircraft?' Answers to this question were somewhat generic like "water" or "snacks" or "drinks from the trolley" and it was only when a person living with dementia asked me to clarify what I meant that I realised the question was unclear, even to me as the researcher.

Lewis (p21/line219) asked “Anything relating to my dementia, or anything relating to anything?” I had to think for a moment what I actually meant and I answered “anything related to dementia specifically” to which the reply was “Yeah? No, not really” (Lewis, p21/221). I am not sure what the original researchers meant by this question and what they hoped to uncover as a result, but for me it was about problems with dementia in flight so from that point on I changed the question to make this clearer for all other participants. This made me realise that I had not adequately considered the purpose of the questions I was asking and that the participant’s query had required me to quickly consider the underlying meaning, potentially changing the purpose of the question in the process.

CHAPTER 4: FINDINGS – PEOPLE LIVING WITH DEMENTIA

4.0 Introduction

The aim of this study was to explore the lived experiences of air travel for people with dementia. Following the recruitment process set out in Section 3.4.2, 10 people living with dementia were recruited. Pen portraits of the participants are provided in Table 4 while the participants' diagnoses are shown separately in Table 5. The diagnoses have been separated from the pen portraits on the recommendation of the project Reference Group who reviewed the preliminary findings for this chapter and felt such separation was likely to further aid participant anonymity. Pseudonyms have been used for all participants to protect their anonymity. All participants were given the opportunity to choose their own pseudonym at the time of interview.

Participant pseudonym	Background information
Angela (Supported by⁷ husband Phil)	Angela was diagnosed 14 years ago. She has an associated medical condition that means she tires very easily. Angela takes medication for this condition and it dictates when she can do things such as travel. Angela believes that people do not understand how she feels and how physically exhausted she can get. Prior to having dementia, Angela would travel on her own for work, but does not feel she could travel by herself now. Angela is an avid traveller and she and Phil have travelled all over the World.
George (Supported by wife Millie)	George was diagnosed six years ago. He was initially diagnosed with work place stress, before tests indicated dementia. George's dementia means that he struggles with dim lighting, steps and thresholds. He is particularly keen to raise the issue that not all dementias are the same and people with different types of dementia will encounter different issues. George loves to travel especially to hot countries, but feels he could not travel without Millie.
Victoria (Supported by partner Gertie).	Victoria was diagnosed two years ago, but had been experiencing symptoms four to five years prior to that. A previously outgoing person, since receiving a diagnosis of dementia she has become more quiet and reserved. Victoria and Gertie had to push for a formal diagnosis on the basis that they wanted to organise their lives if dementia was the cause of Victoria's cognitive and physical difficulties. Following her diagnosis, Victoria and Gertie created a bucket list of all the places they wanted to travel to and embarked on a number of trips across the World. Victoria feels she could no longer travel on her own.

Table 4 - Pen portraits of participants living with dementia

⁷ Note: 'Supported by' indicates the companion assisted with some factual corrections and additional information, 'Assisted by' indicates that the companion provided more detailed help and advice and 'Joint interview' indicates that the person living with dementia and their companion were interviewed for the study at the same time.

Len (Interviewed by himself)	Len was diagnosed four years ago. He feels that support for people with dementia varies across regions and his GP can sometimes be unaware of recent treatments and developments. Len tries to keep up to date with research as he recognises that his GP is not a specialist. Len lives in the present and did not want to discuss what could happen in the future. Len has supported other members of his local dementia support group when they were in the later stages of their dementia and clearly finds the prospect of facing this himself distressing. Len does not currently travel on his own, but feels he could with the help of special assistance at his local airport if he needed to.
Billy (Assisted by wife Fi)	With the support of Fi, Billy was able to say that he was diagnosed four years ago. During the interview it became clear that Billy has a very dry sense of humour which Fi says he has not lost because of his dementia. Billy and Fi are regular travellers. They enjoy the mountainous regions of Europe, in particular, as Billy loves travelling on the cable cars and enjoys going to the cafés and restaurants the cable cars take him to. He also enjoys the rivers, the general cleanliness and the company of the people from this area. Billy would not travel without Fi. Billy worries that he may be stopped from flying by the aviation industry before he is ready, and says that he would want someone to explain to him very clearly why he was not allowed to travel.
Colin (Assisted by wife Sam)	Colin is unable to state his age, his diagnosis or the length of time he has been diagnosed without Sam's support. Sam confirms Colin was diagnosed three years ago and began experiencing symptoms three years prior to this. Colin enjoys going away and they do their best to continue travelling. Colin is happy to fly at the moment and is unsure what would make him stop. With Sam's support Colin says they have been away to three different European destinations within the past year. Colin feels that a positive attitude is important and is keen to try new things, although he accepts that it can take him quite a while to do something new. Colin would not travel with anyone other than Sam.
Pauline (Joint interview with partner Tommy)	While Pauline enjoys flying on occasion, she recognises that every experience is different. She also worries about the number of things that can go wrong in a machine that defies gravity. A particular concern is flying over water, as Pauline cannot swim. Pauline has flown long haul on a number of occasions and has once travelled in business class. Pauline clearly values and remembers the extra attention they were given when they were upgraded. Pauline and Tommy had a traumatic experience with special assistance that resulted in them missing an important connecting flight and are now afraid to use it, even though they are aware of new innovations such as the lanyards. Pauline feels that there will come a time when she does not want to carry on flying as it can feel like an ordeal.

Jack (Joint interview with wife Gill who assisted Jack on a number of occasions).	Jack was diagnosed three years ago and is one of several members of his family to be diagnosed with dementia. Jack believes the prevalence of dementia in his family is down to environmental factors. Gill confirms that dementia researchers are aware of the family history, but have not looked into the nature of the familial link and have not tested or commented on Jack's environmental theory. Jack has been married to Gill for many years and they have travelled extensively, spending months at a time away over the Winter. Jack says that since his diagnosis he and Gill have experienced a complete role reversal.
Lewis (Joint interview with Wife Rose)	Lewis was diagnosed nine years ago. Originally thinking he had an ear infection as he kept losing his balance, Lewis's GP referred him to a specialist as he was quietly concerned Lewis might have a brain tumour. Following scans, Lewis saw a neurologist which is when dementia was first mentioned. Despite Lewis's Mother having Alzheimer's Disease, neither Lewis or Rose considered dementia as a possibility due to Lewis's age, so the diagnosis came as a complete shock to them both. Lewis and Rose are seasoned travellers, flying long haul most years. At the point of diagnosis, Lewis had to advocate for his own right to travel and he continues to advocate for people with dementia and their rights in a range of settings.
Alan (Joint interview with Wife Judith)	Alan was in his early fifties when he was diagnosed. As he had an existing medical condition that caused periods of breathlessness, Alan originally felt that his memory problems were down to oxygen loss. It took just over a year for him to get his diagnosis. Alan said that when he was first diagnosed he and his family estimated that, when coupled with his existing medical condition, he was likely to be dead in four years. Consequently, they organised and went on their 'last' family holiday together six months into his diagnosis. Alan says that the only positive advice he was given at the point of diagnosis was to make his Power of Attorney. Alan now travels by air regularly, but feels he can no longer travel on his own.

Diagnosis type	Number of participants
Young onset Alzheimer's Disease (categorised as <65 years of age at time of diagnosis)	5
Alzheimer's Disease (categorised as >65 years of age at time of diagnosis)	2
Young onset Dementia other ⁸ (categorised as <65 years of age at time of diagnosis)	3

Table 5 - Participants living with dementia by diagnosis

4.1 Exhaustive description – Victoria

Following a descriptive phenomenological analysis utilising Colaizzi's (1978) method as outlined in Section 3.4.14 all interviews were initially analysed separately and an exhaustive description produced for each participant as per step five of the method. The exhaustive description created from Victoria's interview is outlined below by way of an example of this part of the analysis process.

Exhaustive Description from Victoria's Interview

After Victoria's diagnosis, she and Gertie created a bucket list of all the places they wanted to travel to. In the 12 months prior to the interview, they have completed all overseas elements of their list. Their remaining bucket list places are now UK based and they plan to drive as they want to take their dogs with them.

Victoria's dementia can cause her to feel anxious, particularly if she is under pressure. Victoria feels that some of this pressure is due to the dementia affecting her levels of confidence in her own abilities. If the pressure is intense, Victoria can lose the ability to communicate, so having someone around her who is calm is essential to Victoria's ability to function. Victoria says they have learned from

⁸ Including Posterior Cortico Atrophy (PCA), Mixed Dementia (Alzheimer's Disease and Vascular Dementia) and a rarer form of young onset Dementia (not specified to protect the anonymity of the participant).

previous holidays and now request special assistance, but acknowledges that Gertie makes all the arrangements for this.

The continued pressure, the need to stand around for long periods and the levels of divided attention required in navigating the airport are the main reasons Victoria finds airports challenging. Victoria's strategy in all situations is to try and remain calm. She is not afraid to ask for help and has not yet been in a situation she has been unable to resolve. Prior to her diagnosis, Victoria says she was an outgoing person who loved talking to others, but she now needs to be calm and quiet. Victoria does not feel she would consider travelling without Gertie to help her. She feels her reducing energy levels and increased tiredness will affect her ability to travel in the future.

Victoria has found special assistance to be helpful, but disliked having to use a wheelchair in order to get it. When at [Airport name withheld], the assistance consisted of a wheelchair, a lanyard with integral buzzer to alert them when they would be collected by the assistance buggy and an assistant to wheel Victoria through security. However, Victoria and her support assistant became separated during security as the assistant had to go through the security procedures herself. Victoria felt the assistance was very helpful, especially as they were carrying injections and medicinal liquids. Victoria confesses that she was not aware of any of the difficulties that Gertie has since relayed about the assistance process as Gertie had protected her from the anxieties associated with this. Whilst she realises she may have forgotten some facts, Victoria says her emotional memory of the experience was equally unaffected.

Victoria feels that special assistance should be provided for the entire passenger journey and not just certain points within it. She also feels that having a travelling companion should not preclude receiving support as the companion can also be put under considerable strain. Victoria feels that early boarding would be beneficial and was unaware they should have received this service. Victoria explains that using a wheelchair when she is not physically disabled can make her feel guilty, even though she experiences high levels of back pain when standing and walking as well as having dementia. She also feels some people with dementia will refuse the use of a wheelchair on principle.

Victoria confirms that when she is travelling with Gertie they do not need to be together all the time, but she does value having someone with her. Victoria is also keen to express how maintaining her independence and normal routine such as driving her car and going to the shops is valuable to her sense of achievement and self-esteem.

Victoria does not mind flying, but feels she can become bored just sitting on the plane. She has experienced first class and premium economy travel and feels the increased staff attention that came with the upgraded travel and associated peaceful lounge access were highly beneficial. Victoria and Gertie have not experienced the special assistance extending to the aircraft itself. The main challenges that Victoria has on board are finding her seat and putting her hand luggage in the overhead compartments. Victoria experienced high levels of anxiety on one flight, to the extent that Gertie was afraid she might try and open the

aircraft door, but the cabin crew were very obliging with her request for an alcoholic drink to help her sleep. Whilst Victoria says she did not openly become upset, Gertie knew her well enough to know how distressed and anxious she was and was glad she was able to get some rest.

One particularly unpleasant taxi journey on route to the airport led to a very stressful experience for Victoria as the driver was going very fast and she was being thrown around in the taxi. Victoria said this affected her whole airport experience due to retained anxiety. Due to this experience, Gertie now always drives them to the airport the night before so they can arrive calmly and get the lie of the land. Whilst this is helpful, it does mean their holidays are more expensive as a result.

Victoria and Gertie always try to have a goal in mind for their holidays and then stick to it (such as seeing a particular attraction) as this makes their holidays more manageable. Other strategies are to keep calm, have someone to help you, do not be afraid to ask for help, find a quiet area if there is one, travel light to reduce the fear of leaving something valuable behind and to regularly check in with your travel companion that you have the same amount of items you started with especially after returning from the toilets.

Victoria feels that having someone with her can help her to continue to participate in meaningful activities but that person must be approachable, calm, kind, patient, unhurried and have a positive attitude. Victoria feels the assistance person should stay with the person with dementia throughout the entire travel chain, even if they have a travel companion with them to reduce the strain on that person. The special assistance person should also understand that the person they are helping may have multiple disabilities (such as having dementia and being deaf). They also need to talk to the person they are helping.

Victoria finds automated systems such as biometric passport gates difficult to navigate and feels that locating her flight on the departure boards and finding her own way to the gate would be very difficult without support. If Victoria could speak to airport managers she would say that people with hidden disabilities also need support, but they should endeavour to see the person behind any diagnosis. When using a wheelchair within the airport, Victoria noticed that many of the key points, such as the fingerprint registration or eye scanners, were not set up for low-level use and these need to be accessible to all.

Victoria can find it difficult to navigate airport toilets, especially if Gertie has to stay in the seating area and look after the bags. Toilets can be a long way from a seating area and Gertie can become worried that Victoria will lose her way. Signage for toilets can be poor and the entrance can frequently not be sufficiently obvious from the surrounding area. To help, Gertie tends to visit the toilets first and then provide Victoria with detailed instructions (including visual landmarks to guide her there and back).

Whilst appreciating that airport staff have to maintain order, Gertie and Victoria report being shouted at and put under pressure by staff when they were clearly

struggling with the automatic aspects of the airport. Gertie feels she also cannot help Victoria to navigate areas of the airport she finds difficult for fear of being rebuked by airport staff at these points.

Once all 10 interviews had been analysed individually, the interviews were then analysed as a group. Five themes were identified across all participants in relation to the lived experiences of air travel for people with dementia (see Figure 5). Each of these themes will be discussed further and will culminate in an exhaustive description for the group as recommended by Colaizzi (1978). When introducing each theme a selection of the meaning units upon which each theme has been derived will be given, with a full list of all meaning units associated with each theme shown at Appendix R.

When describing the findings ‘one’ has been used to indicate the experiences and thoughts of one participant, ‘some’ to indicate two to five participants, ‘most’ to indicate six to nine participants and ‘all’ to indicate that the viewpoint is shared across the whole participant group of ten. As hearing the voices of people with dementia has always been a priority for this research, a number of quotations are included within the text to highlight key points. Where this occurs, the participant’s pseudonym is included together with the associated page and line number from the individual’s master analysis table.



Figure 5 - Five themes derived from participants living with dementia

Whilst Figure 5 portrays the themes as being separate, the reality is that they are interconnected with overlapping of the themes throughout the entire air travel journey. Whilst the themes are numbered this is for ease of reference and is not indicative of their order of importance as it is considered that the themes carry equal weight.

4.2 Theme 1: Importance of a positive social environment

This theme identified the participants' need for positivity and encouragement from those around them in order to facilitate their continued engagement in air travel. The concept of the social environment was broad, from family and friends, to medical

professionals, and those within associated industries such as travel insurance. Once at the airport, the attitudes and behaviours of aviation staff were considered to be essential to the participants' overall air travel experience and their ongoing participation. Meaning units associated with this theme include: companions as enablers, pervading ignorance and stigma within wider society and understanding the physical effects of dementia on activity (see Appendix R for a full list of meaning units).

For all participants the positive social environment started close to home with the support of a significant other; most participants stated that they would no longer travel alone. For some, the person they travelled with was not just a companion in the usual sense, but a reassuring and trusted presence in a chaotic environment.

She understands me and what I'm doing and watching and guiding me. Other people wouldn't. They'd just think 'oh well you're alright aren't you?' and you can't trust anybody, but I can trust her...to get me in the right place at the right time (Colin, p24, line 267)

The participants' views on medical professionals and their attitudes to dementia and remaining actively engaged in meaningful activities were mixed. Some participants reported professionals were supportive and encouraging, while others were not. One participant reported being devastated at his consultant's advice for him to cease travelling long haul on the same day he was diagnosed with dementia.

So in the context of you've just had this bombshell explode next to you that you never saw coming, the next bombshell was don't go [on holiday]...it was probably the worst day of our lives in some respects (Lewis, p3, line 30)

Whilst this participant successfully challenged his consultant and amended his travel plans rather than cancel them, he recognised that challenging those in authority is highly unusual and there is a risk that many people with dementia may take such advice at face value and cease travelling altogether. Some participants reported that poor expectations of people living with dementia are prevalent in wider society, with widespread stereotypes of what someone with dementia looks and acts like.

People don't know how to treat people with dementia. They have this image of...somebody sitting gaga in the corner of a room dribbling and they look at you gone out... They say 'you can't have dementia you speak too well' and I could thump them (Angela, p16, line 155)

One participant felt this sense of pervasive stigma and ignorance within wider society was adversely influencing those living with dementia in terms of their own perceived ability and expectations of what it is to live well with dementia.

An awful lot of people that I know with dementia in our circle, they're quite shocked to find they can still travel. They don't think they should anymore (Alan, p1, line 5)

Despite the lack of societal understanding of dementia, all of the participants spoke about how important remaining engaged in travel was to them. Going on holiday

helped to maintain a sense of normality and linked them to people and places of significant meaning and memories. While for some travel was a reinvigorating and restorative escape.

[Travel is] a great tonic as they used to say in the old days...but it really is, it really lifts your spirits ...I believe the sunshine is the gift of life for me... I love swimming, I love the saltwater ... that's what makes me happy. (Len, p62, line 560)

Difficulties with obtaining travel insurance were highlighted as a major barrier to participants' continued engagement in air travel. Some participants reported historical difficulties in finding anyone to insure them post diagnosis, despite having held policies for a number of years without claim, and the challenge of obtaining travel insurance came as a shock.

I had to explain to them 'I've got Alzheimer's'...So many doors closed from insurance companies...[they] wouldn't touch me for anything (Lewis, p22, line 227).

Whilst some participants report that the travel insurance market has improved over recent years, provider options remain limited. Policies now routinely only cover single trips and come with very strict conditions, including that the person with dementia must state that they will not be travelling on their own. This led some participants to question whether the insurance industry may curtail their travel plans sooner than their physical or cognitive health does.

During the interviews it became increasingly clear that both positive and negative interactions with aviation staff could have a lasting impact. For most, they wanted to let aviation staff know that even the smallest of changes in terms of being kind, calm, patient, good humoured and respectful, would make a major difference to airport accessibility and their continued engagement in air travel.

For me it's about people's attitude...it can make a huge difference how people speak to you... if you've got someone who speaks softly or kindly it can really make a big difference and that's the sort of thing I think people working in airports should know about. Because I'm sure it would help other passengers as well (Pauline, p46, line 600).

A lack of understanding of dementia was also a concern for participants, especially given the increasing prevalence within the general population. As some of the participants also had physical conditions such as hearing loss, having severe pain, extreme fatigue and breathlessness on exertion, they felt staff needed to be trained to check for, and be mindful of, this and not to make assumptions that dementia may be the only factor of concern with the person they are speaking to. However, aside from understanding that dementia is not just a disease of older age, some participants felt aviation training should focus more on how dementia can manifest in situational behaviours rather than focussing too heavily on the different types of dementia themselves. Core to this understanding was the participants' experiences of the adverse effect of pressure on their ability to communicate effectively.

I can't think of anything if I get anxious. In stress situations, you know? You can't think of anything. It all disappears. Then of course it's worse for you, because then you get anxious because you know you can't remember anything (Victoria, p34, Line 404).

Most participants struggled with the sensory overstimulation of the airport environment due to the large crowds, the high levels and different frequencies of noise, the bright lights and the scents emanating from shops. They felt this general overstimulation, combined with queueing and waiting, was likely to heighten their anxiety and impatience levels significantly. This could lead to repetitive behaviours such as seeking reassurance from their companions or the need to constantly check for information.

I look at the board three or four times and keep saying 'it's not ready yet, it's not ready, I'm just checking it, I'll have a walk up here'...cause I want to check to see ...[that] it's not gone and things like that (Colin, p32, line 352).

The use of positive communication techniques was described as very important to all the participants, with a request that instructions be given to them clearly, calmly, precisely and *one at a time*.

Well say...I need to think about three things all at once...sometimes, it only takes a couple of seconds, it could just go and I have to say 'can you do that again'? (Billy, p58, line 684).

For some, sensitivity to being touched, coupled with their heightened anxiety, could lead to them becoming distressed, for example if someone approached them without warning. Participants described that they would like staff to provide them with a clear explanation of the actions they are about to take to help to reduce their stress levels.

Some of them, they're like [demonstrates being patted down] and I think 'what's going on here'? (Jack, p17, line 183)

Whilst participants appreciated the importance of security protocols and the need to keep control and order within the airport environment, they were worried about being separated from their travel companions at key areas such as security and border control. For most, their companions acted as interpreters for complex instructions and provided much needed reassurance in those areas of the airport where the person with dementia was likely to become most distressed. However, this expert communication and enabling support frequently went unrecognised by the airport staff on duty, with the companions being described as being forced to keep moving.

The first time I went [into a body scanner] I was totally thrown and Judith was trying to come forward [shouts] 'WHOA, DON'T COME ANY CLOSER'. She said 'he's got dementia, I just want to explain to him how you stand' (Alan, p36, line 255)

The vitally important support role of the companions of people with dementia was something most participants would like to see highlighted in any future training guide for the aviation industry.

4.3 Theme 2: Special assistance as both a barrier and facilitator

This theme covered participants' experiences with special assistance as a service and their experiences of the hidden disability lanyard scheme (see Figure 11, section 7.2.2). When discussing special assistance, some participants suggested innovations for the future and these ideas were also captured within this theme.

Meaning units associated with this theme include: lack of knowledge of the services and facilities available, dominance of the wheelchair symbol and lack of understanding of the needs of passengers with dementia (see Appendix R for a list of meaning units).

Participants considered that special assistance was extremely helpful in negotiating complex areas of the airport when it worked well. However, experiences described varied from airport to airport, from terminal to terminal and even when visiting the same airports at different times. Some participants had not realised that they were eligible for special assistance with dementia and those who had used it were not aware of all the facilities available to them such as quiet routes and rooms. All participants felt that more needed to be done to highlight the rights of people with dementia to receive special assistance at the airport.

Whilst the move away from the name mobility assistance had been helpful, the continued dominance of the wheelchair symbol to advertise special assistance was considered by one participant to exacerbate the ongoing confusion around assistance eligibility.

If you didn't have mobility problems then people thought 'well they can't do anything for us' or they're not allowed and it's just a wheelchair sign. I think that's a terrible sign...[it's] very against the rights of other people I think. It makes it look like you can only have that [assistance] if you're in a wheelchair (Alan, p9, Line 61).

One participant was also concerned about asking for help in case this gave the airlines a reason to deny them boarding and there was some confusion around whether or not special assistance was a free service. Views on whether special assistance enabled independence, or marked a significant turning point in losing one's independence, also differed across the participant group.

I'd rather sort things out meself or try to until I need it you know? Because then that's thinking 'oh God this things kicking in'...and the fear starts then...I try to be independent as long as I can (Len, p20, line 208)

A major reported challenge with special assistance was actually finding the special assistance desk as this frequently involved a significant walk and some complex route finding, especially in some of the larger airports. For those with physical health conditions, they had been surprised that they were not met at the airport entrance and that the long walk to the assistance desk usually meant a long walk to find a wheelchair as these are not always kept by the airport entrance points.

Once at special assistance, some participants found that the special assistance was geared more towards those with physical, rather than hidden disabilities. For the

majority of participants who were physically well, a rejection of a wheelchair also meant the automatic rejection of the help of an assistant. This is despite some participants highlighting the fact that they needed someone to accompany them and steer them through the complexities of the airport travel chain. Most participants felt it was important for special assistance to know that, even if they did not require a wheelchair and were travelling with a companion, they would still benefit from additional support.

You just need someone to hold your hand metaphorically or actually (George, p32, Line 514).

Only one participant reported that their rejection of a wheelchair had resulted in them still receiving the personalised assistance through the airport that they needed. Although the rigidity of special assistance was described as leading to frustrations in some instances, especially at being asked to wait a considerable amount of time for an assistant to support them.

If you say you've got Alzheimer's and could you have special assistance they will say to you 'well you've got to go to [place] in about three hours' time ... and someone will collect you' ... I think 'well blow that, we'll go through on our own rather than sit in an area where there is nothing to do, nowhere to go, let's risk it' (Lewis, p16, Line 171).

Having to wait for special assistance resulted in one participant missing a vital connecting flight. The participant will now not even consider using special

assistance, as the trauma surrounding the incident remains deeply embedded in their emotional memory.

They wouldn't let me walk, you know? And they wouldn't let me get out of the chair because they said there were people who would...want to know why you can walk...so it was really frustrating because ...I could have run down the platform very easily and got there in plenty of time (Pauline, p32, line 437).

Some of the participants had experienced wearing the hidden disability lanyards, but the entire participant group felt that awareness surrounding the lanyard scheme was poor. No participant had been alerted to the lanyard scheme at the time of booking assistance and assistance desk staff at the airports had also not brought the lanyard scheme directly to the attention of any of the participants. Those who were aware of the scheme had learned about it purely by word of mouth, by seeing the lanyard cards at the assistance desk and making their own enquiries or by being part of their local airport disability advisory panel.

Where the lanyards had been worn the overall experience of the participants was positive and it was felt that they were a significant benefit in negotiating the complexities of the airport, particularly around security.

When I got up there...when he's seen me with the thing 'come on' and I was right out (Jack, p1, line 8)

However, participants reported reuse of the lanyards, as recommended by airport assistance staff, resulted in very poor service with a general lack of recognition of the person wearing the lanyard. Further investigation highlighted that those reusing the lanyards had not specifically booked special assistance on subsequent occasions, which may explain the decline in their overall service experience.

Opinions on the potential labelling of a person with dementia by wearing the lanyards were mixed among the group. Some participants felt people with dementia would not want to advertise the fact that they needed help or would not want to be treated differently. While those who had used the lanyards felt they were a subtle identifier that helped them to receive the support they needed and that their meaning went unnoticed by the majority of the general public.

I like subtlety, you know? I don't like display...I don't like being the centre of attention, but I like the fact that...people know who need to know (Lewis, p28, line 274).

All participants agreed that discretion was important when dealing with someone with dementia and all were opposed to wearing any form of identifier that openly stated they had a disability. Most participants also felt that it was important that the power to disclose the nature of their hidden disability should remain in the individual's control at all times.

One of the main challenges with the hidden disability lanyard scheme that some participants reported, was that it is not currently recognised outside of the United Kingdom. However, they felt there is scope for the lanyard scheme to be implemented within other Countries in order to create accessible air travel routes.

When considering innovations for the future, one participant felt that a film of the airport journey for passengers with hidden disabilities would be a valuable addition to airports' assistance pages. While those participants who were unaware that some airports already had quiet routes or rooms highlighted that the provision of these facilities would be very helpful to them in reducing the sensory overload of the airport environment. Some participants also felt that more could be done to recognise the important role of companions at the booking stage, potentially with an automatic means of indicating that the person with dementia needed to remain with their companion during the flight for reassurance and/or safety purposes.

Some participants also highlighted the need for an airport accessibility guide which could be automatically sent to any person booking special assistance. They suggested the guide should include the location of the assistance desk and other important facilities such as toilets, including the rights of those with hidden disabilities to use the accessible toilets as needed. Other hints and tips for the guide included the fact that toilet facilities on the aircraft could be used at the time of boarding up until the point the seat belt signs were illuminated and that passengers with disabilities were entitled to use toilets in a higher grade cabin if these were easier for them to access.

When designing an accessibility leaflet it was felt that visual landmarks should be used wherever possible to help with orientation.

Navigation is very, very important...you've got an automatic sign waiting for you there, you know? Say it's opposite the [coffee shop], it's on the left. 'Oh, there's [the coffee shop], there's the desk' (Len, p57, line 518).

A further suggested innovation, from one participant, was to put information signs and maps throughout the airport to help with passenger navigation.

There should be a little map, 'you are here' and then...if you are stuck and if you don't know where you are you can look at the map and go 'you are here', 'yeah, I want to be there, is this the way I need to go?' (Alan, p52, line 376).

It was felt by one participant that the provision of maps and 'you are here' signs would also reduce the burden on airport staff from people continually asking them for directions. The participant who suggested the maps had recently visited a European airport and had found these to be very useful.

4.4 Theme 3: Challenges within the general airport environment

This theme highlights the challenges the participants experienced in finding their way around the airport, negotiating environmental challenges such as sparkly floors and the specific challenges they encountered when transiting through the security process. Meaning units associated with this theme include: challenges with

directional and other signage, sensory overload in duty free and security as the perfect storm of environmental factors (see Appendix R for a list of meaning units).

Most of the participants used small, regional airports that were familiar to them. However if the airports changed in any way, such as during a structural remodel, participants described having to relearn the environment. Some participants cited change of this nature as being very difficult for them, especially as they found navigating airports challenging in general. The main navigational difficulty for most participants was poor signage, with high-level signage being a particular challenge.

The signs are all up in the air and I know they have to be so that people can see them, but it's very difficult to look for obstacles and hurdles to make sure you're walking correctly and look up (Alan, p29, line 204).

As well as having signage that is not at eye level, other signage difficulties described included signs that were too small, difficulty reading signs that were on shiny or reflective surfaces and directional signs. The main directional sign that caused some participants difficulty was the upward facing arrow indicating that passengers needed to go straight on, as they interpreted these signs as meaning to go upstairs.

[the upward facing arrow] totally confused me and [friend's name] I said 'well that's odd, the toilets must be upstairs' ...and he said 'well the toilets are down there aren't they?' And I said 'well I thought they were', but the sign was actually pointing up (Len, p12, line 128)

Other difficulties that occurred to the participants when negotiating the airport were around stairs and escalators. Those participants with depth perception difficulties interpreted escalators as a form of steep chute, while one participant had to use the tips of their shoes to literally feel the height and depth of steps when walking up or down them. Lifts were the preferred option for moving between floors, but signage for these was also described as being poor.

One participant reported that being unable to orientate himself within the airport had the potential to negatively affect his confidence levels.

You do get your black days ...and that's when the battle starts ...if you go to the airport in one of those moods then it's just going to get worse and worse and worse if you get confused. If you don't know where the loo is... if you don't know where the gate is, then it's all going to just start like a volcano rushing through (Len, p61, line 550)

Duty Free was an area that some participants frequently avoided, especially those with allergies and heightened senses. This was due to the bright lights, noise and overpowering scent levels. A further challenge within Duty Free and throughout the general airport environment, was when some participants encountered shiny or sparkly floors as these were perceived as pools of water or to be covered in ice crystals.

Shiny floors, that can be very distracting for people ... So you find people wandering off into a different direction to try to avoid certain things (Pauline, p14, line 186).

The increase in automated services was also a challenge for all the participants, many of whom would actively look for a person to interact with as a preference. The main challenges were around check-in machines, boarding pass barcode readers and the biometric passport gates. Poor instructions, not standing still long enough for photographs to be taken, incorrect placement of barcodes and passports on the readers and not moving through the barriers quickly enough once they had opened were common difficulties across the participant group.

Finding toilets in the airport was a further shared difficulty. Some of the participants reported that they found the differences in pictorial toilet signage too subtle for them to differentiate between and felt the addition of the words 'men' and 'women' to the existing signage would be very helpful. Whilst not in an airport, one participant reported difficulties with unisex toilets [participant's term] as he had not understood what the signage meant and had become very confused. He had wanted to point out this difficulty in terms of future airport design as he felt other participants living with dementia would have the same problems identifying unisex toilets as a toilet they could use. Some participants also feared becoming stuck in the toilets as the lack of exit signage frequently meant they could not find their way back out again.

I've been walking around ... just trying doors and then I've noticed someone else ... so I've followed them and the majority of time they have been going out, but I have followed someone in to their cubicle and they've got quite distressed with me (Alan, p50, line 362).

Waiting for long periods of time in the general noise and crowds of the airport was a particular challenge for all participants, as were negotiating and remaining calm in other very busy points of the airport travel chain, such as collecting luggage from the carousels. Security was reported as being the most difficult aspect of the airport for most of the participants, with some describing it as a trial they needed to overcome before they could relax and their holidays could truly begin.

Sometimes that's the only way to do it. Just put your head down and get on with it and get through. And know once you're through it then that's it ...it feels like you're popping through the other side (Angela, p10, line 101).

Negotiating the security process involved many of the aspects of the airport that the participants found challenging; from the noise, the impatience and increased anxiety of waiting and queuing, difficulties with complex multi-tasking and decreased functioning when they were put under pressure.

It just scrambles my brain cause I think 'oh God they're waiting' and I'm doing this and the more I get agitated the worse it gets (George, p11, line 163).

Despite some participants wearing the hidden disability lanyard, they frequently became separated from their companions during the security process. Participants recognised, however, that the majority of instances where separation occurred were down to the strict protocols of the security process itself, such as being separated

into male/female searching queues. This separation, however unintentional, was distressing for some participants.

They start pushing you around... 'you get over there and you get...', you know? I'm going down one thing and she's on another one... and when I'm there I'm looking [for Gill] (Jack, p7, line 67)

While separation during the actual search process was difficult, the challenges continued when participants had to find and retrieve their own belongings from the scanned security trays. Some found it hard to remember which items were theirs and became worried and upset that they might leave something valuable behind. On those occasions where their bags were removed from the security line for hand searching, participants reported that security staff did not always explain what was happening. This poor communication was considered by some participants to be down to a lack of training.

One gets the sense that the people manning those positions aren't always dementia friends or dementia aware or... have a clue to be honest with you. And we've had occasions where I've been put in situations and spoken to in ways that were totally inappropriate (Lewis, p15, line 165).

Whilst it was generally accepted by the participants that security staff needed to shout to keep order and make themselves heard above the background noise these shouted instructions could be unsettling or distressing. Some participants thought they had done something wrong and were being personally reprimanded. While

some participants reported that the act of being spoken to too loudly or too sharply could exacerbate their word finding difficulties.

Well the thing is I can't speak you know? If I get something like that at me, I can't get the words out which makes it worse (Billy, p17, line 216).

Many of the participants described they had developed coping strategies to help them transit security. These strategies included companions helping them to pack their hand luggage and carrying out a final pre-search of their bags and person for items likely to activate the alarms immediately prior to their entering the security channel.

4.5 Theme 4: Subtle differences from the usual inflight experiences

This theme covers the inflight experiences of participants. When advising on the preliminary findings, the project Reference Group felt some of the issues, such as participants becoming distressed at having someone kicking their seat, were challenges that any passenger might have. This theme therefore concentrates on the subtleties of participant experience, to highlight the aspects of flying that are particularly pertinent to those living with dementia. Meaning units associated with this theme include: value of priority boarding versus last on last off, aircraft toilets and disembarkation challenges (see Appendix R for a list of meaning units).

For those participants who had experienced the special assistance priority boarding process, this was found to be very useful in reducing the stress levels associated with the overcrowded and rushed transfer from the departure gate to the aircraft. However, for some participants with heightened sensitivity, boarding the aircraft first was something they would actively avoid.

I just sit and make sure there's nobody left...it [boarding last] means a lot to me ... cause I'm not hunched up in the seat ... and watching all the palaver and the slamming ... and all the movement (Len, p31, line 308)

Late arrival on the aircraft was not without difficulties, however, as this meant some participants became separated from their belongings which were either stored in a different overhead locker or in the hold, due to running out of storage space on the aircraft. Personal preferences were again evident when participants discussed seat choice and allocation. Some participants favoured the security of a window seat as being between the wall and their companion was comforting to them. However, for others, being seated by the aisle provided much needed reassurance if they needed to use the toilet urgently due to bladder weakness.

All of the participants were fearful of being separated from their companions in flight. The reassuring presence of companions was a major factor in flight facilitation from locating seats, to stowing luggage, interacting with the cabin crew and helping with seatbelts where needed.

I know all the time that Sam is there... we sit side by side (Colin, p32, line 350)

The participants reported that they had not had to ask the cabin crew for assistance related to their dementia as they were not travelling alone. Although those who had experienced special assistance to board the flight had found the cabin crew to be highly skilled and discreet in the way they assisted participants to find their seats, stow their luggage and to become settled within their surroundings.

You're placed quite subtly...you're not made to feel privileged or special or different, but you're given that subtle support to allow you to embark upon the aircraft early (Lewis, p9, line 87).

One participant had also used the lanyard as a means of identifying himself as a person who may need additional support during the flight. He was unclear, however, whether the cabin crew would know what the lanyard was without it being explained to them.

Aircraft toilets provided a challenge for many of the participants in terms of understanding how the toilet, hand washing facilities and door locks operated. One participant also reported how unsettling the unusual noise made by the aircraft toilets could be.

I fly four or five times a year and I still have such a fright when I find the flush ... if they just had 'flush – loud noise'...especially for people with Autism and Asperger's ...I mean I've fell against the door before now because of the noise (Alan, p57, line 417).

While one participant had changed his use of airline provider as he could not cope with the constant noise and distraction from the in-flight announcements.

The one thing I don't like with flying [Airline] is the adverts never stop. As soon as you're in the air 'we've got this today' you know, dead loud, 'we've got that today' ... it goes on and on and on ...that really gets me that so I try to go with [Airline] as much as I can (Len, p40, L396)

For those special assistance participants who appreciated the calmness of priority boarding, having to remain seated while other passengers disembarked was difficult. For some it was anxiety provoking as they became increasingly worried about not making their connections or that their onward transport would leave without them. Conversely, for one participant with altered depth perception crossing the temporary threshold to leave the aircraft was one final hurdle they had to overcome.

I always think it's dodgy trying to get off a plane cause there's a gap...as you're getting off...it seems huge, but I don't know, it probably isn't...but it does seem like really quite a wide gap (Pauline, p30, line 399)

It is evident from this quote that the participant questions her ability to judge distances as she knows that her brain can play tricks on her. She reported using a mind-over-matter strategy to overcome her fear of visual disturbances, but still finds these unsettling.

4.6 Theme 5: Recommended strategies for other air travellers with dementia

This theme covers hints and tips from participants of what they have found helpful when travelling by air (a similar hints and tips theme is included in Section 5.5 from the perspective of companions). Meaning units associated with this theme include: importance of knowing your rights, travel with a companion and adapt the way you travel (see Appendix R for a list of meaning units).

When discussing their experiences of air travel, all participants shared some of their strategies in the hope that these would help other people with dementia to continue travelling by air for as long as possible. Core to the participants' strategies was to remember that air travel with a diagnosis of dementia is possible, but that it helps to plan and also to investigate what help and support is available. A key recommendation was to request assistance at the time of booking and to investigate the assistance facilities at the airport that you plan to travel from by checking the assistance pages of the airport website. A further strategy was to make use of professional services, such as travel agents, for help with booking seats, organising inflight assistance and recommending hotels that were small and quiet. Participants were also keen to encourage other travellers to ask for help once at the airport if they needed it.

Don't be... afraid to ask people, people who are working there you know? If you get confused just stop and take a moment to analyse things and then ...try and get back on track and keep calm and help yourself ... you'll always get help off someone now in the airport (Len, p53, line 506).

Sharing the message that people with dementia had a right to access special assistance and to use the accessible facilities such as priority boarding, priority seating, accessible toilets and the hidden disability lanyards, was also important. Participants recognised that sensory overload was also a major problem for some passengers with dementia and suggested taking headphones to block out some of the noise and sunglasses to reduce the glare from the artificial light.

All of the participants suggested travelling with a trusted companion as a means of reducing anxiety if that was possible. Allowing plenty of time and trying to maintain a positive attitude were helpful in reducing anxiety levels.

I do have to be like a Zen master to keep my cool...otherwise I just get agitated and everything goes awry really (George, p12, line 191).

Staying overnight at the airport the night prior to departure was also considered a useful strategy by some participants as this helped to reduce the anxiety of travelling to the airport on the actual day of travel, although it was recognised that this did add to the overall cost of the holiday.

Minimising checked luggage and just taking one item of hand luggage was also a tried and tested strategy for some. For the female participants who carried additional items such as handbags and scarves, one participant suggested identifying how many items they were carrying at the start of travel and checking in with their companion at key points of the journey, such as after visiting the toilet, to make sure they still had the same number of items with them.

Most participants found that they had had to adapt the way they travelled depending on how their dementia had progressed. For some this meant a move to short haul travel from long haul, reducing the complexity of their travel arrangements or taking a different type of holiday altogether.

I can't do the type of travelling that we've done in the past where we've gone away...and we've had six weeks...driving around. I just can't cope with that anymore. I can't get hold of the bits and pieces and sort of keep them in my brain as to where we're going and how far we've got...it's just too complicated (Angela, p47, line 491).

For some participants building new routines around air travel helped them to embed patterns and routines into their procedural memory. This was described as helping to reduce their anxiety levels as they found the familiarity reassuring. Examples of routines were to always travel from the same small, regional airport or to book the same seats on the plane. Returning to the same travel destination was also considered to be helpful as the familiarity could help with memory recall and confidence building.

It's security really in your brain to think 'we can do alright here, cause we've done it before' ...and then when you get there it's a surprise if there's something that you've not thought of...it's nice to see something and say 'I remember that' (Colin, p4, line 43).

For one participant returning to familiar travel destinations included re-visiting three or four of his and his companion's favourite destinations on a rota system, while some participants visited the same destination, year after year, and considered it to be a second home for them.

4.7 Framework Statement

As per Section 3.4.14 the final stage of the analysis process using Colaizzi's (1978) method is to produce a dense framework statement that encapsulates the meaning derived from the experience across the whole participant group. The framework statement for participants living with dementia is shown below.

Air travel is an important activity for people living with dementia. It provides connections to family and friends and facilitates access to holidays, which are restful, restorative and important to an individual's sense of self.

A positive social environment is essential to facilitate air travel. People with dementia report that their diagnosis can have an immediate disabling effect on obtaining necessary travel services such as travel insurance, with some travel insurers refusing cover for any person with dementia at any stage post diagnosis particularly when travelling alone.

Travel companions are primarily seen as enabling air travel, while medical professionals and aviation staff can enable or disable a person with dementia depending on their attitudes and actions. In general, people with dementia find airports to be complex and overwhelming places with noise, crowds, queues, scents and poor design adding to the sensory overload they experience.

Security is seen as the most difficult aspect of the airport by people living with dementia, with the pressurised environment, crowds and complex and shouted instructions adding to the disabling effect. People with dementia consider themselves to be 'on holiday' only once the security process has been completed. Separating the person with dementia from their travel companion(s) at key points of the air travel journey can heighten their feelings of anxiety and overwhelm them. People with dementia can have particular difficulty in preparing for security screening and identifying and collecting their personal items post security screening if their companion is prevented from assisting them.

Some passengers with dementia find the special assistance hidden disability lanyard scheme helpful in negotiating the more challenging areas of the airport such as at check-in, security and automated areas such as the boarding pass and passport gates. However, awareness of the right to access this assistance is low, with special assistance being primarily seen as a service for those with physical disabilities.

People with dementia wish to continue travelling by air and adapt their journeys according to their ability. Such adaptations might include a move from long haul to short haul air travel or returning to familiar departure airports and destinations. Once in flight, passengers with dementia wish to remain seated with their travelling companions throughout the journey not just for reassurance and to aid communication with the cabin crew, but also for safety reasons such as assisting with seatbelts, emergency protocols and medication especially if travelling through any time zones. Using aircraft toilets can also be a cause of concern due to their small size, layout, noise and the perceived complexity of the flush, taps and door locks.

4.8 Chapter Summary

This chapter has highlighted the lived air travel experiences of 10 people with dementia, including the many barriers they face with regard to air travel and some suggested innovations for the future that participants would find helpful. Participants highlighted the importance of the encouragement and support of those within their social environment to facilitate air travel and the need for aviation staff to be aware that their actions and behaviours are key to a person living with dementia's overall experience of air travel once at the airport or on the plane. Utilising special assistance was considered by some to be an effective means of transiting the

airport, although knowledge of right of access to special assistance provision was considered to be low by the participant group. The emphasis on physical disability within special assistance signage and advertising was thought to be adding to this confusion. Participants felt that there was scope for special assistance to develop other resources such as an airport accessibility guide and improved location signage.

Greater recognition of the role of the travel companion was also seen as important and something that participants would like to see in the future. Challenges within the general airport environment were also discussed in terms of sensory overstimulation, unusual flooring, poor signage and the security process. While, inflight experiences shared some similarities and subtle differences from other travellers. The participants also shared a number of strategies for other travellers with dementia including requesting support, knowing their rights and investigating the help and support that was available to them before travel.

The participants' experiences of air travel will be discussed in more detail in Chapter 7, together with the implications of these findings for the aviation sector. While the following Chapter, Chapter 5, will explore the lived experiences of air travel from the perspective of the travel companions of people living with dementia.

4.9 Reflexive Statement

Undertaking the interviews element of the study was my favourite part of the process. Talking to people living with dementia was comfortable ground for me given my occupational therapy education and related work experience in this field. What I did not expect, however, was the level of emotion I would feel having undertaken the interviews. I think when I was carrying out the interviews I was caught up in the moment, talking and laughing, trying not to forget my questions and get distracted. It was only when I transcribed the interviews and had time to reflect on them that I discovered just how much they had affected me.

I was transcribing the interview with one of the younger people with dementia⁹ when the unfairness of his dementia diagnosis hit me. I heard the words on the tape and I was back in his living room chatting to him about his love of music. He had a number of musical instruments and I had asked him about them. He told me that his music was important to him and that it was an important part of who he was. Recently, though, he had started to forget how to play the instruments and the music he loved so much. The instruments sat there, too precious to give away but a constant reminder of how his life had changed. His demeanour throughout the interview, however, was one of absolute strength, independence and resilience. For some reason, this just made it worse when I heard our conversation over again. The more I transcribed, the more his words upset me. As I was getting nowhere, I left the transcribing and had a walk in the garden feeling somewhat helpless and confused.

⁹ Participant pseudonym purposefully not detailed here due to the potentially identifying nature of the content in this statement.

There is irony in the fact that I had thought very carefully about how the interviews might potentially harm my participants and had sought to reduce this by various means, but I had not really thought about the impact that the interviews might have on me personally. I had thought about safety, of course, and keeping in touch to protect me as a lone worker, but not about the emotion the interviews might generate. Why would I? Talking to people with dementia is something I have done on a number of occasions, sometimes in extremely difficult circumstances, but it had never upset me in this way or to this extent before.

Perhaps this particular participant reminded me of someone close to me, perhaps it highlighted the fragility of my own mortality, perhaps I was tired or perhaps it was a combination of all these things. When I went back to transcribing after my walk in the sunshine, I was fine and felt somewhat guilty and embarrassed about becoming so emotional and self-absorbed. I heard the laughter and strength in the interview and found it spurred me on. I could not do anything about the music, but this participant also loved to travel. He told me it made him feel like a child again. It made him feel [his words] normal again. It made me realise that improving travel might not help this particular participant, but that it might help others and I found comfort and renewed purpose for the research in that.

CHAPTER 5: FINDINGS - TRAVEL COMPANIONS

5.0 Introduction

The aim of this study was to explore the lived experiences of air travel from the perspective of the travel companions of people with dementia. Following the recruitment process (set out in Section 3.4.2), 10 travel companions were recruited. The travel companions' experiences were broad, representing those travelling with someone in the earlier stages of dementia, those who were travelling with a person with dementia who needed more support and those who had travelled with a person with advanced dementia.

The pen portraits of the companions are provided in Table 6, while their travel status as companions is shown separately in Table 7. As with the participants living with dementia, pseudonyms have been used to protect the participants' anonymity. All participants were given the opportunity to choose their own pseudonym at the time of interview.

<p>Arthur</p> <p>(Travel Companion to Louise who was not part of this study).</p>	<p>Arthur is married to Louise who, as well as having dementia, has a physical disability for which she needs to use a wheelchair. Following a recent hospital admission, Louise was provided with a package of care which has been helpful for Arthur, especially in terms of managing his stress levels. Arthur and Louise have a caravan and used to go on holiday to Europe in this for weeks at a time. They now only use their caravan in the UK and fly to Spain with their extended family at least once a year, returning to the same hotel each time. The familiarity of the destination is helpful to Louise and also to another family member who has autism. As Louise also has a physical disability, much of their experience of airports and air travel is from the perspective of a wheelchair user and Arthur is unsure how representative this is of travelling with someone with dementia as the primary diagnosis. Arthur's attitude to life is to look to the future and not to the past.</p>
<p>Heather</p> <p>(Travel Companion to Dave who was not part of this study)</p>	<p>Heather's husband Dave was diagnosed with dementia six years ago, but Heather says that he had been experiencing symptoms for a long time prior to this. Following his diagnosis, Dave's wish was to keep on travelling. Heather and Dave travelled all over the world on wildlife holidays, but, following a trip to Europe a year prior to his death, Heather feels that she could not have taken him away on holiday again. Indeed, Heather does not feel that Dave would have been able to have travelled on his own for the last seven years of his life, including the two years before he was diagnosed, due to the difficulties he was experiencing. At the time of interview, Heather had recently returned from her first holiday without Dave, a trip she had found emotionally challenging. Heather acknowledges that adjusting to being on her own after being with a partner for most of her adult life is going to take time. Heather is a supporter of dementia charities and helps other people living with dementia and those who care for them. When giving advice to others on how to travel with someone with dementia, Heather is conscious that everyone with dementia is different depending on the area of the brain that is affected.</p>

Table 6 - Pen portraits of travel companions

<p>Beryl</p> <p>(Travel Companion to Blake who was not part of this study)</p>	<p>Beryl is the wife and travel companion of Blake. Blake was diagnosed with dementia six years ago. Blake is on a 24 hour slow release medicated patch for the treatment of his dementia which Beryl believes is more effective than the six or 12 hour release tablets. Beryl and Blake travel long haul to see a family member and their trips can involve two or three flights, with them sometimes travelling for periods in excess of 24 hours. Their family member usually helps them to book their travel and they have always travelled economy class. Beryl says that Blake is finding it increasingly difficult to travel long haul as he cannot sleep on the plane and, consequently, neither can she. However, they are trying to balance this with their enjoyment of going to see their family and being in a place that they refer to as their home from home.</p>
<p>Caz</p> <p>(Travel Companion to Babe who was not part of this study)</p>	<p>Caz is the carer and a previous travel companion of her Mum, Babe. Babe was diagnosed with dementia seven years ago. Babe used to go on holiday once or twice a year and did not fly for any other reason. Caz last accompanied Babe and her Step Dad on holiday a year before the interview took place as she felt that they would not have gone away on their own at that stage. While Babe enjoyed going away on holiday, Caz does not think Babe liked flying seeing it more as a means to an end. Since their joint holiday, Babe's health has deteriorated to the extent that Caz no longer feels comfortable taking her away. They have also had to stop using public transport and most of their travelling from home is now by car. Due to her experiences of caring for her Mum, Caz volunteers to support those living with dementia and those who care for them.</p>
<p>Gill</p> <p>(Travel Company to Jack who was also interviewed as part of this study)</p>	<p>Gill is the wife and travel companion of Jack who has dementia. Gill and Jack have been married for many years and enjoy going on holiday. They have gone away at least twice a year since they were married and usually go away every Christmas. Gill feels that travelling through an airport is stressful for everyone and not just people with dementia. Jack's dementia has meant that he and Gill have experienced something of a role reversal in terms of financial and other responsibilities, a transition that Gill has found difficult. Gill feels that their holidays are coming to an end now due to Jack's deteriorating health, but they will keep going as long as they can.</p>

Judith (Travel Companion to Alan who was also interviewed as part of this study)	Judith is the partner and travel companion of Alan who has dementia. When Alan was diagnosed, Judith says that they were overwhelmed with information, most of which was irrelevant as it related to other conditions. Judith says that she does not want to go away without Alan and wants to go on holiday with him for as long as they can both travel. As advocates for people living with dementia, Judith and Alan share information on the help that is available when travelling by air. However, they were unaware of some elements of hidden disability entitlement such as the increased number of quiet rooms and accessible security lanes available at some airports.
Rose (Travel Companion to Lewis who was also interviewed as part of this study)	Rose is the wife and travel companion of Lewis who has dementia. Rose and Lewis are advocates for people living with dementia and have experience of travelling both short and long haul. Rose and Lewis have family members overseas who they travel to see on a regular basis. This involves them taking a series of flights and travelling in excess of 24 hours in total door to door. They have found using a travel agent very helpful when booking their trips as they can tell them what they would like to do and the agents will do all the planning and detailed arrangements for them. Rose and Lewis have been instrumental in encouraging the staff at the travel agency to become dementia friends.
Millie (Travel Companion to George who was also interviewed as part of this study).	Millie is the wife and travel companion of George who has dementia. Following George's diagnosis, Millie left her job to care for George as he was not managing on his own at home. Millie keeps up to date with dementia research and is active on dementia discussion boards. Millie and George enjoy their holidays and, while they are still travelling by air, Millie has begun to look at other means of travel for when they can no longer use air transport, such as going to Europe by train. As well as advocating for people with dementia and those who care for them, Millie also speaks to various groups on her experience of being a carer for someone living with dementia.

<p>Tommy (Travel Companion to Pauline who was also interviewed as part of this study)</p>	<p>Tommy is the partner and travel companion of Pauline who has dementia. Tommy and Pauline have travelled frequently and have experience of flying both long and short haul. Although, recently, their flights have been just a few hours in length and their next planned flight will be under one hour. Tommy and Pauline had a poor experience with special assistance in the past that contributed to them missing an important flight as they were held for disembarkation on the plane despite Pauline not needing wheelchair assistance. Tommy and Pauline will no longer request special assistance for themselves for this reason, but they are aware of new innovations such as the hidden disability lanyard scheme. Whilst they have given up some activities, Tommy feels that this is a sign of them both getting older and wanting to do different things and not just an effect of Pauline's dementia.</p>
<p>Mary (Travel Companion to Clifford who was not part of this study)</p>	<p>Mary is the wife of Clifford who died a year prior to the interview. At the time of his death, Clifford had been diagnosed with dementia for nine years and had been married to Mary for four. Mary and Clifford had known each other for most of their adult lives but, following his diagnosis, Clifford expressed the wish to get married which they did in one of his favourite places in Europe. Travel was important to both Mary and Clifford and they travelled up to the end of Clifford's life. At his funeral Mary prepared a series of photograph albums of all their holidays from their first to their last to share with family and friends. Clifford travelled independently for four years after his diagnosis, but Mary accompanied him on all trips after this date as he was denied boarding at a European Airport for failing to show the correct documentation.</p>

Travel status of the companions	Number of companions
Still travelling with a person with dementia.	7
No longer travelling with a person with dementia, but the person they travelled with is still living.	1
No longer travelling with a person with dementia, as the person they travelled with is now deceased.	2

Table 7 - Travel status of companions by number

5.1 Exhaustive description – Beryl

Following a descriptive phenomenological analysis utilising Colaizzi's (1978) method as outlined in Section 3.4.14, all interviews were initially analysed separately and an exhaustive description produced for each participant. The exhaustive description created from Beryl's interview is outlined below by way of an example:

When they travel long haul Beryl and Blake check in online from the UK and a family member checks them in online when they are departing from their overseas destination. Beryl says that Blake would have previously done the online check in, but they now do it together sitting side by side. Their chosen airline has a lot of automated systems but Beryl leads on this, once at the airport, and involves Blake as much as she can as Beryl says that Blake would not be able to manage the automated systems on his own. Beryl has never requested assistance and has been told that for a lot of airlines assistance is just wheelchair provision which she says they do not need as they are both quite physically fit and able.

Beryl says that she does try and start getting organised and begins packing a couple of weeks prior to travel, but this can sometimes cause confusion for Blake with him unpacking the suitcase and rehangng items in the wardrobe. Beryl says that she and Blake laugh a lot about things that happen and it is helpful to them.

Beryl says that she and Blake previously travelled to [name of airport withheld] by coach, but now feel this is too long a journey for Blake so their son takes them to the airport by car. Beryl feels that having to rely on their son in this way signifies a loss of their much-valued independence.

Once at the airport, Beryl and Blake have stopped going to the toilet at the same time, as Blake tries to find Beryl if she is not outside waiting for him when he comes out. Beryl now waits outside with the cases and they then swap places, which seems to work well for them.

Beryl says that Blake is normally quite good at waiting at the airport, but she has learnt to monitor his non-verbal cues for when he wants to be more active. Beryl says that they have not had any problems finding their way around the airports as they always allow plenty of time and read the signs together. If Blake feels rushed then it increases his anxiety levels.

Beryl says that she usually packs the hand luggage with Blake giving her anything he would like to go in the bag. Beryl says that she always stands at the side of Blake when they are in security so that she can prompt him on what items of clothing need to be removed and which items need to be placed in which position. Beryl keeps all the items needed to be kept separate for the security scanner, but frequently forgets that Blake carries a breathing spray in his pocket which sets the alarm off. Beryl says that the staff are always alright with this once they have read the label.

Beryl says that Blake cannot manage the automated passport gates and needs assistance to use them as the instructions are too complex and multiple actions are required at the same time. Beryl says that while staff will help Blake with automated systems most of the time a staff member on a recent trip redirected her to a different queue. Beryl states that she explained that Blake had dementia but the staff member did not register or respond to this and just redirected her. Beryl says that the staff member's tone made her feel embarrassed and like she had been naughty for getting in the wrong queue. While Beryl did not like the staff member's attitude she appreciated that staff member was busy and did not want to cause a scene.

When looking for their seats on the aircraft, Beryl will tell Blake what numbers they are looking for and then ask him to put the luggage in the overhead locker which he will do. When choosing their seats on a wide-bodied aircraft, Beryl will opt to sit in two of the middle four seats with Blake so that they can get up and down without disturbing anybody. Blake always sits on the inside seat, with Beryl sitting in the aisle seat as this way he cannot get out of his seat without her moving.

Beryl says that the most difficult aspect of air travel for Blake is that he does not sleep on the flight, even during night flights. As Blake likes drawing and colouring, Beryl bought him some stress relieving colouring books and football books for a recent flight but they were not used. Beryl says that she has also had to learn how Blake communicates and if he starts to fidget on the plane, she takes him for a walk up and down the aircraft.

One of the problems they have encountered in flight is when they are sitting in two of the middle three seats on a dual aisle aircraft as Blake can sometimes be asked what he wants to eat by a different member of the cabin crew to Beryl. Beryl says that the cabin crew have always been very good when she has asked if they can be served together and was impressed with how one member of staff dealt with the situation and included Blake in the conversation. Beryl said that she had not had to explain why they needed to be served together but, once she had asked, the cabin crew member remembered to speak to them both together on all future in flight meal and drink service runs on that particular flight. Beryl feels that when people are helpful and supportive it can make all the difference, especially if they realise that Beryl and Blake might need additional support without Beryl having to explain the situation for everyone to hear.

While Blake can go to the toilet on his own on the aircraft, Beryl needs to stand outside as he can forget how to open the door. As Blake struggles with toilet door locks in general, Beryl has applied for a radar key for him so that he can use all accessible toilets when on the ground but feels guilty about doing so as Blake is not physically disabled.

Beryl says that her advice to other companions would be to allow plenty of time and to be patient and calm. Beryl says that it is important for her to keep explaining to Blake what is happening to provide reassurance when they are travelling. Beryl reiterates a major difficulty for them is Blake's inability to sleep on an aircraft and Beryl wonders whether airlines would make any concessions for them to allow them to upgrade to a cabin with a seat that looks more like a bed to help him with this.

Beryl feels that it is very important to them both that they carry on travelling long haul to see their family and friends as when they get to their destination it is like a home from home. Beryl says that travelling to somewhere familiar is also helpful for Blake as he does not cope well in unfamiliar places.

Beryl says that obtaining travel insurance can be costly for Blake with a one off long haul trip for up to 90 days costing £400. They have been unable to obtain annual cover from any organisation, including those that support older adults. While Beryl understands that they have to have insurance, she does not understand why the premiums are so high for people with dementia, especially as Blake's other health conditions make little difference to the cost. Beryl has asked insurance companies why their premiums are so high for someone with dementia, but has been unable to find an answer. Beryl worries that the high price of insurance may curtail their travel as it will eventually become unaffordable for them.

Once all 10 interviews had been analysed individually, the interviews were then analysed as a group. Four themes were identified in relation to the lived experiences of air travel for the travel companions of people with dementia (see Figure 6). Each of these themes will be expanded upon and culminate in an exhaustive description for the group as recommended by Colaizzi (1978) and discussed in detail in Section 3.4.14. When introducing each theme a selection of the meaning units upon which each theme has been derived will be given, with a full list of all meaning units associated with each theme shown at Appendix S.

When describing the findings 'one' has been used to indicate the experiences and thoughts of one participant, 'some' to indicate two to five participants, 'most' to indicate six to nine participants and 'all' to indicate that the viewpoint is shared across the whole participant group. Quotations are included within the text to highlight the themes. Where this occurs, the participant's pseudonym is included together with the associated page and line number from the individual's master analysis table.

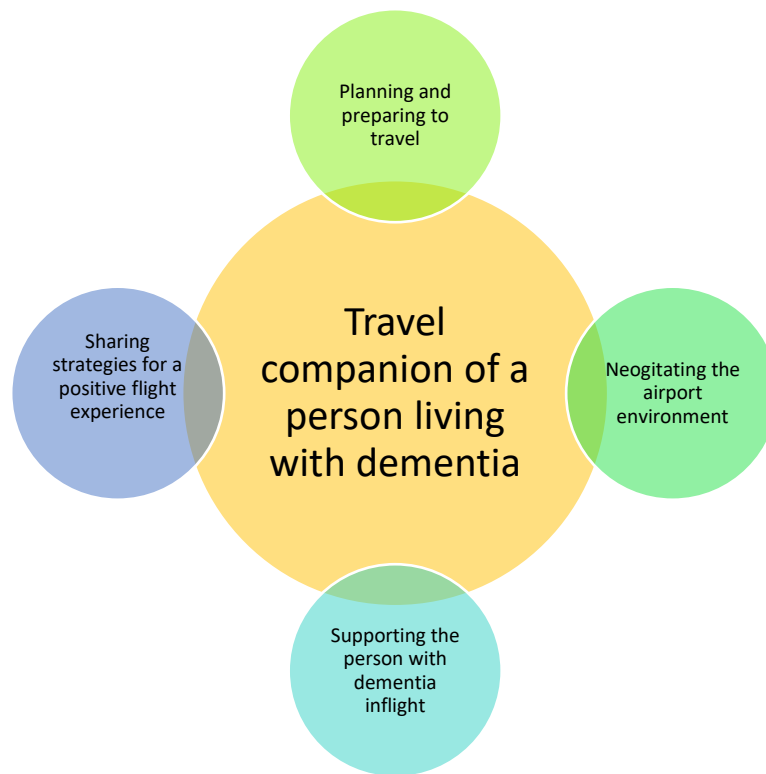


Figure 6 - Four themes revealed from travel companion interviews

Whilst Figure 6 portrays the themes as being separate, there is again some overlap throughout the entire air travel journey. As with the themes for the participants living with dementia, the themes are numbered purely for ease of reference and this is not indicative of their order of importance, with all themes being considered equally important.

5.2 Theme 1: Planning and preparing to travel

This theme covers the participants' experiences of planning and preparing for a trip away and some of the challenges they encounter in doing so. It also includes their thoughts on the importance of travel for, and societal expectations of, people living with dementia. Meaning units associated with this theme include finding a helpful travel agent, being aware of travel rights for diversion or delay and making the most of travel opportunities. A full list of all meaning units is shown at Appendix S.

Some companions felt that planning was more important when travelling with someone with dementia, but that travel was still possible with help. For some that help came right at the beginning of their holiday by meeting travel agents face to face to plan and arrange their trip.

We just go in there and say 'we want to do this, this and this' and they do it completely for us (Rose, p33, line 313).

A further participant reported that they had had a good experience with another travel agent who had made all their bookings and special requests, such as contacting the hotel to ask for an accessible room, for them. However, when booking with a different travel firm they had had to make all their special requests themselves.

Awareness of the help available via special assistance was mixed among the participants with some actively requesting it prior to travel, while others considered it to be still very much something for people with physical disabilities. Those who were aware of their right to request special assistance felt that more needed to be done to highlight that special assistance was available to passengers with dementia and their travel companions.

I didn't even know you could get half of this stuff, I only came across special assistance by chance (Heather, p59, line 484).

Some participants appreciated that increasing awareness of the right to use special assistance for those with hidden disabilities could lead to abuse of the system as it may lead those without a hidden disability to claim that they had one in order to receive priority treatment. However, it was felt that this was a risk that needed to be taken to ensure that people with dementia received the support they needed to travel by air.

When requesting special assistance, some participants reported that they had experienced difficulties booking this online as the airlines' websites did not always specifically cater to passengers with hidden disabilities.

When you go to register that you need special assistance they're set up around physical disability...so they want to know if you want a wheelchair...do you need this, do you need...and some of them you end up having to phone...because he just fell through the 'no, no, no...'. You drop out the bottom, you clearly don't need special assistance (Millie, p46, line 538).

For another participant, his family gave him the support and confidence to continue travelling long after he had stopped travelling with his wife on their own.

My son says 'are you coming on holiday this year...?' and I'm sitting there thinking, humming and hawing, and he'll say 'come on, it might be the last time you'll be able to go', you know?...we've booked to go next [Spring] ...but we haven't got a clue what's going to happen between now and [then] (Arthur, p34, line 205).

This feeling of approaching each holiday wondering if it could be their last was something shared by most of the participants. For one participant, going on holiday with her husband was becoming increasingly challenging due to the progression of his dementia and her family had started to express concern about their overseas trips.

The year before we'd had a two week in [Europe] and I came back and I went 'I'm not doing that again'...and the kids all went 'phew thank God for that'. And then, a few months later, I went 'ooh I've booked another holiday' and they went 'ooh where are you going?' And I went 'ooh [South America]' and they all went 'ooooooooohhhh who's going to go and get them if something happens', you know? (Heather, p13, line 114).

Obtaining travel insurance for the person living with dementia was also an issue for some of the participants. One participant reported that she had been unable to find annual cover from any broker, including from those firms specifically for older travellers. The participant queried why a diagnosis of dementia should increase the travel insurance premiums more than other health conditions and raised concerns that the cost of single trip cover, which was the only insurance they could now obtain, was becoming increasingly cost prohibitive for them when travelling long haul.

Will we have the money to be able to do it, you know? If you add that on to your holiday...you think sort of £400 plus my top up. At one time we found a company we thought was going to be cheaper and, by the time we finished, it was £800 for the pair of us (Beryl, p43, line 414).

For those participants who had travel insurance as part of a packaged bank account, they reported that their experience had been positive and their cover had been maintained after their partner's diagnosis. Although the situation had changed for one participant when they had reached their bank's maximum age limit for cover and they had needed to seek insurance elsewhere.

When packing for the journey, some of the participants only packed one item of hand luggage that they carried themselves. They felt that if the person with dementia did not have to carry hand luggage that this would help to reduce the person's anxiety at leaving something important behind. Some of the participants also packed their hand luggage with security in mind. For example, by making sure that any liquids or other

declarable items such as electronics were kept separately. They felt that this attention to detail helped them when transiting security and cut down on the need for them to be stopped, searched and separated from the person they were travelling with. Trying to get ahead with their packing was challenging for one participant however, as it led to confusion for her husband.

A couple of weeks before we get the suitcases out and I put them in the spare bedroom, and I used to find that I'd pack it and he'd unpack it. Because he's not registered the fact that, you know, we're going away, apart from the fact that they shouldn't be in there, they should be in the wardrobe. So he gets the hangers out and puts them back... 'I've just packed that!' (Beryl, p13, line 147).

Despite careful planning, some of the participants highlighted that they could not plan for everything and unforeseen difficulties could be very stressful for them. Examples of unforeseen events included adverse weather conditions which could delay travel by a few hours and impact on connecting flights, last minute changes to their holiday itinerary and being delayed to the extent that they had to stay overnight at the airport. One participant felt that not knowing her rights in these circumstances added to her stress levels.

Just lately I've heard that several...flights out of [a London Airport] have ended up in [a Midlands Airport] or somewhere and then basically you're on your own mate. I'm not quite sure what they would do with somebody like me...what would I do if we ended up in an airport we weren't expecting to be in? (Heather, p86, line 717).

For all participants travel remained an important and meaningful activity as it allowed them the opportunity to see family and friends, to have a break from their normal routine and to relax and enjoy themselves. However, despite the perceived importance of being able to continue travelling, some of the participants felt that societal expectations of those living with dementia were poor. With one participant feeling that if the person they travelled with had any other health condition their desire to continue travelling would be more accepted by the general public.

We're all limited ...by the things that have happened to us. For example, I've had [cancer] ...nobody puts any limits on me...they allow me or help me to cope with that...almost everything else we set about making it possible for people to carry on, but [with] dementia they're just expected to give up and I don't get that (Millie, p6, line 65).

The need to ask for help caused one participant to wonder if other people may think that she and her husband should still be travelling, but she felt that they still had the right to continue travelling if they wanted to.

These days you would probably get people saying 'well you just can't go away' but why should we not go away 'coz Jack's got dementia? You know there will be people that will say that. If you don't like what goes on (Gill, p22, line 236).

For the participants whose partners had subsequently died, remaining engaged in travel had provided them with important and lasting memories.

It's the emotional memories that stick, so right up to the end, when he'd forgotten everything else, he was still talking about birds and animals that we'd seen on holiday. Now they came in hallucinations, but...because I knew what we'd done together, I knew that they were his memories (Heather, p99, line 825).

Most participants acknowledged that while they were still travelling, or had continued travelling for as long as they could, they had had to adapt the holidays they had taken due to the progression of their travel partners' dementia. Adaptations included reducing the activity levels of their holidays, avoiding multi centred trips, returning to familiar destinations and reducing the duration of their flight times.

5.3 Theme 2: Negotiating the airport environment

This theme describes the participants' experiences when negotiating the airport environment with a person with dementia. It covers security which most participants considered to be a particularly difficult aspect of the air travel journey and also includes communication, both with airport staff and the person with dementia. Meaning units associated with this theme include one-size fits all approach to assistance provision, benefits of the hidden disability lanyards and distress at being separated at security. A full list of all meaning units is shown at Appendix S.

Views on travelling to the airport were mixed among the participants, with some preferring to park at the airport and others preferring to be driven to the airport as it was easier than them trying to park and find their way to the terminal themselves. For those parking at the airport, navigating the different types of car parks could be

confusing, with one participant reporting that she became stressed if she encountered roadworks or disruption as her in car satellite navigation system rarely worked and the person with dementia was unable to read a map.

On arriving at the terminal, some participants reported difficulty locating the special assistance desk. When they did arrive at the assistance desk, some participants found that their airline had not communicated their assistance requirements to the airport. When engaging with special assistance participant experiences varied, with some participants feeling that the special assistance staff were more comfortable assisting those with physical disabilities, rather than those with hidden disabilities such as dementia. One participant compared her husband's experience to that of her own when she requested assistance due to a physical injury.

I went through with a crutch and the service was unbelievable what I got. I was even given a chair 'sit there Madam, take your shoes off'...Jack it was sort of like, yes, they acknowledged it, but ...that was it (Gill, p4, line 42).

This perceived focus on supporting those with physical disabilities was raised by another participant, who had wanted more individualised help from the special assistance team.

You go... 'this is what I need you to do for me' and they go 'oh, we'll put him in a wheelchair'... 'No, this is what I need you to do for me and this is how I need you to behave..and...nobody is up for it. They're not helping you, you're having to tell them what to do and so...the onus is on you again (Heather, p91, line 765).

While another participant reported that when special assistance took his wife away in a wheelchair in order to try and make a connecting flight, they did not consider that she may be scared at being separated from him or that he might also need their help.

I saw your little face...and this woman just went 'whoosh' and you disappeared and I'm there with the suitcases and trying to keep up...it was a case of me just trying to stay as close as I could...just being reassuring (Tommy, p25, line 339).

Some participants had used the hidden disability lanyard scheme and had found them to be helpful when transiting difficult areas of the airport such as automated systems and security as they had been able to receive assistance at these points. However, it was felt that the special assistance staff could provide more information on the lanyards, especially around the re-use policy.

We thought 'oh they're gonna ask for it back, if we don't hand it back they're gonna email us'. But then we find out through conferences and things that actually no you keep the lanyard, because you can use it every time then...but this has all been by trial and error we've found this out (Judith, p17, line 115).

One participant had re-used their lanyard and reported receiving poor service. However, she had not requested special assistance on the subsequent occasion and had not been informed that she needed to do so. Some participants also felt that it would be beneficial if the lanyard scheme was standardised across the UK as some

airports used different identifiers and designs which could be confusing when re-using them. Some participants disclosed that they did not feel that their partner would wear a lanyard at all as they would not want to draw attention to themselves, however the companions in these instances were willing to wear the lanyard to identify they needed support as a couple if this was allowed.

It was also felt that it would be beneficial if the lanyards could be used in Europe or further afield to aid understanding of dementia in different cultures and to create dementia friendly travel routes. A further challenge of using special assistance overseas was that the assistance staff did not always speak English, but some participants felt that, in general, overseas staff, especially security staff, were more relaxed and amenable than their UK counterparts.

When communicating with airport staff, some participants felt that there was a lack of awareness of dementia with staff insisting that they needed to support the person with dementia, especially when using automated systems or in security searches. Despite this insistence, staff frequently did not know how to communicate with the person with dementia resulting in frustration on both sides. Suggestions for how airport staff could improve their communication were to look the person with dementia in the eye when speaking to them, and to give very precise instructions. Most participants also wanted to be able to help the person they were travelling with as they felt they were best placed to understand their individual needs. One participant explained that her husband no longer understands directional cues such

as here, there or ahead and she has to interpret instructions to enable her husband to understand and respond to them.

Sometimes when they say 'look straight ahead', if I look there might be a sign so I say ... 'Can you see that sign on the wall that says where the café is?' Or 'can you see...?' and he'll look (Millie, p28, line 305).

Some participants also tried to discreetly explain to staff that the person with dementia might need additional support, although this was generally when the person with dementia was not wearing a lanyard.

I think I'm quite good at somehow subtly letting people know there's a problem and that I need them on board. I just... even if I'm stood behind going [mouths] 'she's got dementia', which might sound really cruel but ... people cotton on very quickly (Caz, p35, line 227).

Some participants reported that passengers with dementia struggled to use the automated systems such as check in, boarding pass scanners and passport gates due to the complex instructions involved, the need to stand still for a certain amount of time and the need to move quickly when prompted to do so.

The new thing now as you know is that you put your passport in...and then the barrier opens and you can walk in and then they take a picture of you, you have to stand on the yellow thing. Well you try and tell Blake to do that...it doesn't register at all (Beryl, p19, line 212).

When transiting the airport some participants reported challenges with unusual flooring surfaces, particularly those that were shiny or sparkly.

Some of [the floors] have got little flecks in and you see people trying to pick them up... [they] worry about what it is (Tommy, p22, line 285).

Signage was also an issue that was reported by some, with the signs being considered too high up or too small. Some participants felt that the signs needed to be lower, preferably at eye level, with some additional signs on the floors. When replacing signs, one participant suggested that black writing on a yellow background is helpful for people with dementia. While another participant said that directional signs could be particularly confusing and care needed to be taken when using these.

Most participants considered that waiting in the airport and queueing led to increased anxiety for the person with dementia, due to the sensory overload of noise, crowds of people and scent levels. One participant felt that other passengers could sometimes fail to make allowances for someone with dementia when in crowded environments.

I always say to people 'when I'm walking along if you're holding a child's hand people walk round you, if you're holding an adult's hand they walk through you' (Heather, p65, line 534).

Some participants said that they had to be mindful of their own attitude to difficulties they encountered within the airport as the person with dementia would mirror their reactions. So if they became angry the person with dementia would become angry and when they were calm the person with dementia would remain calm. One participant suggested that monitoring her husband's non-verbal cues was an important way of helping her to reduce his anxiety and impatience levels.

It's understanding what he does and why he's doing whatever he's done, you know? He'll go [mimes rubbing the top of her legs back and forth when seated] and I'll say 'come on we'll go for a walk' and that's the way of him saying that he's fed up sitting here (Beryl, p14, line 162).

Due to the pressure of the airport environment, some participants opted to use the airport lounges as they felt these could be a quiet haven from the crowds and noise. Although they stated that the lounges cost extra and some lounges are only available to higher fare paying passengers.

For some, security was the most difficult aspect of the airport due to the fast pace and complex and shouted instructions. One participant whose wife was in a wheelchair reported positive experiences at security as they were always fast tracked, while another said that their partner did not understand the security process and would refuse to remove items like his shoes and belt which was difficult to deal with in such a busy environment. Some participants found it helpful if they assisted the person with dementia to remove items like belts and coats before entering the security channel. One participant reported that, even though her husband was

wearing a hidden disability lanyard, they were separated at security which was a distressing experience for them both.

I was ushered through [security] and Jack was still there and his bag was...so Jack was like the rabbit in the headlights. I couldn't believe how stressed he was (Gill, p3, line 30).

Some participants noted that when the person with dementia was separated from them, the person with dementia did not receive any support to identify and retrieve their items from the security belt which added to their distress. One participant stated that, even if the person with dementia and the companion are together when retrieving their items, it is difficult to locate and gather up all of their items and contend with the crowds, so additional support would be appreciated at this point. It was also noted that once they had retrieved their items there was frequently nowhere quiet to sit and re-dress.

Using the separate gender toilets at the same time as the person with dementia was difficult for some participants as their partner would go looking for them if they were not waiting for them when they came back out. A further challenge was the person with dementia could sometimes become stuck in the toilets due to the lack of exit signage as they found it difficult to find their way back out again. Some participants suggested that toilets needed a large 'exit' sign on the exit door and, for those toilets that had an exit corridor rather than a door, an exit arrow on the floor or the walls would be helpful.

The right of people with dementia to use accessible toilets was recognised by most participants. Although two participants reported that their partners found using the accessible toilets difficult, due to them having to bend down to use the low level hand dryers and also not recognising the accessible toilet as a toilet due to the level of adaptations around it.

He would open the door and it just looked so full of contraptions...it just horrified him...it didn't look like a toilet, he hated them (Mary, p47, line 568).

A further participant expressed some feelings of guilt at using the accessible toilets as her partner is not physically disabled. She felt that toilet awareness signs such as 'not every disability is visible' were very helpful in overcoming this concern.

Walking to, and waiting at, the airport gates also caused some participants difficulty in terms of the distances involved and the time the person with dementia needed to sit still for. Other reported challenges included not being able to hear the announcements and becoming anxious if the announcements were not clear. A further challenge noted by some participants was there are frequently not enough seats at the departure gate. One participant reported that she was entirely comfortable sitting in the priority seats with her husband, while another participant had felt uneasy about doing so due to the invisible nature of her husband's disability. It was again felt by some participants that signage indicating that not every disability is visible would be useful at this point.

On arrival at their destination, retrieving luggage from the carousel was something that the participants led on with support from the person with dementia. While the participant whose partner was in a wheelchair relied on the support of his family to help with this, stating that special assistance had never offered to help them and he was not sure how he would cope if it was just him and his partner on their own.

Two of the participants reported that their partners had experienced difficulties when travelling by air on their own. For one participant, her husband had been stopped at the boarding gate on a return flight to the UK as he kept showing his driving licence instead of his passport. Special assistance had been called to assist and the person transferred to a later flight once the passport could be located. While the participant considered that this incident had not adversely affected the person with dementia, she had found it very stressful and distressing, especially as she had needed to contact the Police when her husband did not arrive back into the UK as expected. It was at this point that the participant realised that her partner could no longer travel on his own.

I took the decision after that that I couldn't let him travel on his own I never said anything to him I just made a decision ... I didn't think it was fair on him... and I just thought it's too dangerous. It's not fair on the airport staff and also it was a pressure on me as well worrying about him (Mary, p16, line 209).

A further participant reported she had arranged to meet her husband at the airport, but he had become confused and they had struggled to locate each other. This

participant felt that the airport experiences of someone with dementia travelling on their own were likely to be very different to those who had someone to support them.

5.4 Theme 3: Supporting the person with dementia in flight

This theme captures the participants' inflight experiences of travelling with a person with dementia and some of the challenges that air travel can present. Meaning units associated with this theme include difficulties with using the aircraft toilets, keeping the person with dementia entertained when travelling and experiences of the inflight meal service. A full list of all meaning units is shown at Appendix S.

When entering the aircraft, some of the participants felt that priority boarding had been helpful to them as it had allowed them the extra time they needed to find their seats and stow their luggage in a calm way. However, some participants reported that one of the challenges with priority boarding was that other passengers may still need them to move so that they could access their own seats. One participant had tried boarding last to get around this issue, but found that when they did this there was no space left in the overhead lockers for the items they needed during the flight. They had raised this issue with their local airport during a disability event and had been assured that, if they did want to board the aircraft last, space in the overhead lockers could be reserved for them. However, the participant was unsure if this was general policy or just the policy of that one airport and airline.

Sitting together during the flight was something that all participants felt was important as it allowed them to support the person with dementia. Some participants had paid extra to ensure that this happened, while a further participant questioned whether the airlines should be doing more to keep companions and those with disabilities together.

Our daughter went on holiday [with her boyfriend]...and they were separated...so that a family could sit together with children. Well why can't they do that for disabled people? (Judith, p55, line 404).

Choosing the position of the seats was also considered to be important by some, as their partners did not like talking to other passengers or having to get up and move to allow other passengers to leave and return to their seats. While other participants needed seats with extra legroom, easy and constant access to the toilet or just wanted to be in a position that they were aware of their partner's movements during the flight.

I always have [Blake] on the inside so that he can't get out the seat without me moving (Beryl, p24, line 255).

Some of the participants reported that one of the main reasons they needed to sit together was to support the person with dementia with safety tasks such as fastening and unfastening their seatbelt. The increase in this type of difficulty and not

complying with instructions from the cabin crew was instrumental in one participant's realisation that their air travel days were coming to an end.

Putting on seatbelts was a nightmare. I had to help [Clifford], he couldn't do that and then again he couldn't understand 'yeah I'll do it, I know how to do it'...and of course he didn't know how to do it (Mary, p88, line 1027).

A further challenge once inflight was using the aircraft toilets, with most participants reporting issues with this to varying degrees. For some the issue was around the person with dementia not being familiar with how the toilet and door locks operated, while for others the toilets did not provide enough space to allow them to support the person they were travelling with in a dignified manner.

I would put [Dave] in the toilet, lift up the seat, I would close...semi close the door...play with his trousers and things, make sure he was pointing away from anybody else and hoping that it would end up in the toilet ...and people behind me they've got as much view of him as I have you know? (Heather, p41, line 343).

One participant reported that her husband had trapped himself in the toilet after he had engaged the lock and could not undo it from the inside. However, a member of the cabin crew had shown her how to release the toilet door lock from the outside, which she found very reassuring.

It never bothered me after that, because I knew it would be alright...the first time 'argh' and I thought 'this must happen all the time', you know? ...they must have a way of being able to open them and they do (Mary, p93, line 1087).

Another companion had expressed concern that travelling by air was starting to affect her husband's health in terms of increased confusion and tiredness following a flight, although these effects were usually short lived. The companion wondered whether there was a connection between these increased physical effects and her husband not wanting to use the toilet when on board.

It is possible that it's dehydration and the fact that we can't manage the toilets on the plane means that he doesn't drink on the plane...and of course the air in planes is very dry...it's incredibly dry. So I am wondering, even almost as we're talking, whether it could be a dehydration effect (Millie, p52, line 591).

One participant reported that they had been on a flight with an accessible toilet so they had been able to go in with the person with dementia and help them. They felt that knowing an aircraft had an accessible toilet on board would be a significant selling point for them flying with that airline.

Other reported challenges around the toilets were the difficulties of the people with dementia wanting to use these at awkward times such as when embarking or disembarking the aircraft or during the meal service. A further challenge was that the

person with dementia sometimes struggled to find their way back to their seat following their use of the toilet, especially on larger, dual aisled aircraft.

Some participants reported difficulties with keeping their partners entertained when on-board, especially during long flights. One participant reported that her husband had found using the on-board entertainment system particularly challenging.

He couldn't work out his screen so you're doing his screen, you're putting his headphones in, then he's taking them out going 'what are these?' ...That's what stopped me with long haul, I couldn't do ten hours of that (Heather, p76, line 636).

Another participant reported that her husband was unable to sleep on an aircraft no matter what time of the day it was and they would frequently be the only passengers still walking the aisles during a night flight. The participant wondered whether travelling in a lie flat bed would actually encourage her husband to go sleep, but felt that the cost of upgrading would be cost prohibitive for them.

Experiences of eating in flight were mixed among the participant group depending on the length of the flight, with some assisting their travel partners to order snacks and drinks if needed. Some participants reported difficulties with the main meal service however, such as challenges with opening the food containers and food going onto the aircraft floor. One participant had experienced an issue with the inflight meal service on a dual aisle flight, as their seat configuration meant that different

members of the cabin crew served her and her husband. Realising that her husband would have difficulty ordering his meal by himself, the participant asked for them both to be served together and was impressed by the cabin crew's attitude to their request.

I never said he'd got a problem or anything but ...after that first time when I said about it, she said 'what would you both like to eat?' not 'what would your husband like to eat?' you know? 'What would you *both* [participant's emphasis] like to eat?' She was very good... (Beryl, p31, line 314).

Some participants felt that the cabin crew were skilled at noticing and responding to people who needed additional support and were generally respectful of all passengers, whatever their needs.

I've always found the hostesses very good...I find them very good at just noticing the way he's progressed up the stairs or the way I've got my arm through his...I find it's the airport staff who are less aware (Millie, p13, line 142).

However, the pressure that is on the cabin crew to serve a large number of people meant that some participants were unsure if they could call on the cabin crew for support during the flight and did not know what they were, and were not, allowed to help them with.

Waiting for special assistance to help them to disembark the aircraft was a source of stress for some participants, especially if they had a deadline they needed to meet. While one criticism of cabin crew was they did not always explain what the procedure was for special assistance passengers once they had arrived at their travel destination.

You're getting off the flight at the other end and you're very aware that there's these people standing there with wheelchairs, but nobody's said 'oh when you get off ...they'll be someone there to meet you and they'll take you through and make sure you make your connection'...nobody says any of that and you're thinking 'oh God it's down to me, we're never gonna make that flight' (Heather, p92, line 767).

One participant felt that it would be helpful if the cabin crew could be briefed about the needs of their passengers requiring additional support before boarding, as this would help them to provide the individual support that was needed during the flight.

5.5 Theme 4: Sharing strategies for a positive flight experience

In keeping with the participants in Section 4.6 the travel companions shared strategies that had helped them to overcome some of the challenges they had experienced when travelling by air. They also discussed ideas for airport design, training of aviation staff and innovations for the future which are also captured within this theme. Meaning units associated with this theme include advantages of travelling from a local airport, being prepared for travel and not being afraid to ask for help. A full list of meaning units is provided at Appendix S.

Some of the participants recommended travelling from a local airport as it reduced travel time and avoided the need for an overnight stay. For one participant, travelling from the same local airport had allowed them to create a new routine which the person they travelled with found familiar and reassuring.

There is one particular restaurant we always go to, we always have Eggs Royale no matter what time of the day it is and we can sit and see a departure board without me having to get up and leave him (Millie, p19, line 212).

For those travelling to an unfamiliar airport, some participants suggested researching the airport before travel to identify where facilities such as the toilets were and where any challenges may be.

Get as much info as you can...I'm just talking from a carer's point of view...if it's local do a dry run, just have a look to see what the hurdles might be (Tommy, p38, line 516).

Careful planning of the actual departure and arrival times of their flights was also considered to be an important consideration for some.

I think timing of flights ... and trying not to time it that you arrive back in rush hour and you're caught in traffic and all things like that...I mean they're only minor things but they can all add to the stress of somebody (Mary, p105, line 1236).

For those preferring to drive to the airport, some participants recommended applying for a Blue Badge to allow for easier parking at the airport and to reduce the amount of walking time needed.

Allowing plenty of time to travel to the airport was another strategy employed by some of the participants, as it reduced the need for rushing and helped to maintain a sense of calm both for the companion and the person they travelled with.

Even if you get to the airport two, three hours before you need to...and just be patient with everything, just take it slow...you don't have to rush...that is the one thing that I would say that makes life a lot easier (Beryl, p35, line 344).

For some participants travelling with other people who could provide additional support at the airport and during the flight was important. This was particularly the case for the one participant whose partner had a physical disability as well as dementia.

I wouldn't even consider going on a flight on my own or with just the two of us...I'd take the car, I'd go abroad with the caravan but that's not going on a plane (Arthur, p29, line 174).

A key recommendation by some participants was to devise a plan for if they became separated from the person they were travelling with. One participant's strategy was to always meet at the exit.

It's the one thing [George] can ask for so if ... we get separated in a shop he can ask to be taken to the exit...it's a commonality everywhere's got an exit (Millie, p33, line 360).

Preparing for any eventualities of travel was also considered important for some who routinely carried tissues, moist wipes and spare items of clothing just in case these were needed on the journey. Some of the participants also suggested taking a rucksack as hand luggage rather than a handbag, as it frees up both hands if needed.

While recognising that not everyone could afford to upgrade their travel, the benefits of travelling business class were highlighted by some of the participants in terms of reduced queueing time, the use of an airport lounge, priority boarding and increased room and attention in flight. Some participants also recommended paying to use an airport lounge as they found that the lounges tended to be calmer and quieter than the general airport environment. Food and drinks were also freely available in the lounges often without the need to queue, the toilets were much easier to find and they could usually keep the person with dementia in their line of sight at all times.

Preparing for security was another strategy employed by some of the companions as this helped to reduce the likelihood of the person with dementia being stopped for wearing or carrying prohibited items.

Getting ready for security actually that would be a top tip...try and minimise what you're taking for hand luggage, you know? Anything like that, that you can reduce the sort of stress levels, yeah (Caz, p27, line 161).

Asking for help was a strategy that most of the participants recommended, although they recognised that this took courage.

One of the biggest ways to have help is to ask. Don't be afraid to ask and, yeah it's a private thing, but if you're going to be private about it, don't complain if you need the help and haven't asked. It has to be a two-way thing. We have the responsibility to say 'I need help' (Judith, p102, line 840).

For some of the participants, one of the major ways of asking for help was to request special assistance. Although one of the participants acknowledged that her husband would have declined assistance as he did not want to admit that he needed support in the later stages of his dementia. Had they continued travelling, the participant's strategy would have been to say that the assistance was for her, and not for her husband, as a means of getting him to engage with it.

For the two participants whose partners had died, they wanted to say that, although continuing to travel could be difficult with a person in the later stages of dementia, help was available. Their advice was to seek support and not to give up travelling too early due to the perceived enjoyment travel could bring.

I think the majority of people would have given up travelling way before I did, way before. They would not have wanted to put themselves through it...and I think that's what's sad because it's not that difficult you know? The moments of stress were not huge in comparison to the pleasure the holiday gives (Mary, p38, line 457).

When considering staff training, most of the participants felt that there was room for improvement. Recommendations included that security staff should always explain what actions they were about to undertake, that staff speak to and include the person with dementia in any conversation and that all staff should be kind and patient.

Be kind, that's the basic thing, take your time, there's loads of time. Yeah, just be kind, take your time, stay with them...patience is a big thing" (Tommy, p41, line 547).

Participants also felt that it would be beneficial if members of staff could have a basic understanding of the problems experienced by those with different disabilities including the different dementias. A further key point for training made by some companions was that people with dementia would mirror any attitudes or behaviours that the staff member displayed.

They will react however you are...so it has to be about dealing with them with respect and talking to them as another normal person (Heather, p98, line 815).

Some companions also considered it important that aviation staff be made aware that, even if the person with dementia did not remember what had been said to them, they would remember how the interaction made them feel, positively or negatively.

When considering training for cabin crew, one participant felt that it would be appreciated if the cabin crew could introduce themselves to the passengers requiring assistance and let them know they were there if they were needed. It was felt that this would be a way of them effectively giving their permission to be approached should their support be required.

When making suggestions for how airports could be improved for the future, some of the participants reported being members of their local airport disability committee where they had shared their ideas for improvements. While they acknowledged that some of their suggestions had resulted in positive change, others would take time and money to be implemented.

We went to [our local airport] to do a dementia friendly session with them ... and some of the things haven't been...put right, but they're more architectural and decorative things, you know? Sparkly floors and all that sort of stuff (Tommy, p13, line 182).

Good airport design was considered beneficial by some participants not just to the traveller, but also to the airport in terms of potentially giving them a commercial advantage. With one participant reporting that she had actively chosen to travel to

and from one particular airport terminal on a number of occasions as she considered it to be so user-friendly.

Other suggested innovations for the general airport environment were to have a quiet room as a way of avoiding the general noise and crowds of the airport and a security slow lane for people with dementia to allow them the extra space and time they needed.

In terms of special assistance, one person suggested that having the same person to escort you all the way through the airport would be beneficial as it would allow the person with dementia to build a rapport with the person helping them. While another suggestion for improving special assistance was for the assistant to be willing to wait with the person with dementia while their companion used the toilet.

One person also recommended that having a card that explained the person carrying it had dementia would be a very useful item to place in the person with dementia's passport, especially if the person with dementia and their companion became separated at the border. This suggestion came from the companion's experience that their partner would frequently forget answers to common questions such as 'where are you travelling from/to?' and considered a card containing this information may help to alleviate this difficulty as well as alerting the border official that the person may need additional support.

5.6 Framework Statement

As per Section 3.4.14 the final stage of the analysis process using Colaizzi's (1978) method is to produce a dense framework statement that encapsulates the meaning derived from the experience across the whole participant group. The framework statement for ten travel companions of people with dementia is shown below.

Travel companions of people living with dementia consider air travel to be important as it allows them to go on holiday or visit family with the person they usually care for and to take a break from their usual routines.

Companions report that planning and preparation is essential when travelling with someone with dementia, with unforeseen difficulties such as travel delays, bad weather and travel itinerary changes proving particularly challenging.

Companions also report that they need additional time to assist the person with dementia through the airport and that feeling rushed or pressurised can distress both the companion and the person with dementia and consequently impede both their progress. For this reason, Companions recommend allowing plenty of time to negotiate the airport and state that they would value additional time and a less pressurised atmosphere at key points in the airport journey, such as being able to access a security 'slow lane'.

Companions value the support of their family and friends when travelling or planning to travel with someone with dementia, but report that family and friends can sometimes be worried or become over protective when the companion plans to take the person with dementia overseas. Companions also report that societal expectations of people living with dementia can be poor, especially when compared to those living with other medical conditions.

Asking for help is considered important whether at the travel planning stage, during the journey or at the destination, although companions do not always know who to ask or what help they are entitled to especially at the airport and inflight. New special assistance initiatives for those with hidden disabilities, such as the hidden disability lanyard scheme, can be poorly advertised and some carers remain unaware that this help is available to them and the person they travel with. Those companions who are aware that they can access special assistance report that requesting this online can be challenging as some airlines' websites are designed to support passengers with physical disabilities over those with hidden disabilities such as dementia.

Companions also report that communication between airlines and airports can be poor with special assistance requests frequently not being correctly recorded or communicated. Companions also note that special assistance can be inconsistent, resulting in additional stress on arrival at the airport until the Companions can confirm what to expect in terms of support.

Companions can be skilled at adapting their travel plans to match the abilities of the person with dementia in order to provide an appropriate level of enjoyment and challenge. Companions also feel they are well placed to communicate with the person with dementia and support them to negotiate challenging and anxiety provoking areas of the airport such as security. However the companions state that this skill is not always recognised or utilised by aviation staff, with some companions reporting that they have been actively prevented from assisting the person with dementia when they have been struggling.

Separating the person living with dementia from their companion at key points of the air travel journey and inflight can cause anxiety and distress for the companion as well as the person with dementia. Keeping the person with dementia occupied during the flight itself can be challenging, especially when travelling with someone in the more advanced stages of dementia. Supporting a person living with dementia to use the aircraft toilets can also be difficult due to the limited space available.

Despite the challenges, companions of people with dementia are keen to keep travelling by air for as long as possible as it allows them to create memories with the person they travel with, which can be especially meaningful when the person with dementia is no longer able to travel.

5.7 Chapter Summary

This chapter has highlighted the lived air travel experiences of 10 travel companions of people with dementia. The companions discussed the challenges around awareness of, and obtaining access to, special assistance with the group taking the view that special assistance primarily focussed on the needs of those with physical disabilities. Challenges with obtaining travel insurance and how increasing insurance premiums could limit their future travel plans was also discussed as were the societal expectations of people living with dementia in general.

Security was seen as the most difficult aspect of air travel, with participants discussing the stress of the fast-paced environment and their distress at becoming separated from the person they were travelling with. Poor and ambiguous signage was also discussed, with the participants recommending that improved signage and increased use of hidden disability signage would be beneficial at key points.

Experiences of the hidden disability lanyard scheme were also discussed with participants recognising these as being helpful in negotiating difficult aspects of the airport such as automated transit points. However, participants felt that more information should be given when issuing the lanyards, especially around the procedure for their re-use.

Some of the challenges experienced inflight were discussed and participants felt that clarification of what they could and could not ask the cabin crew to assist them with would be appreciated, as would greater clarity of the special assistance process when they landed at their destination.

The participants shared their strategies for travelling with a person with dementia such as the benefits of flying from a local airport and visiting an airport prior to travel if the airport was unfamiliar. Ideas for staff training were also discussed, as was the need for much greater recognition of travel companions and the role they could play in providing assistance to aviation staff especially when communication difficulties were encountered.

The participants' experiences of air travel will be discussed in more detail in Chapter 7, together with the implications of these findings for the aviation sector.

5.8 Reflexive Statement

Talking to people about their experiences and learning from them is something I very much enjoy doing as previously noted. The dynamics of the interviews were interesting however, in that some interviews were carried out with companions on their own, some were joint interviews with the person with dementia (at their request) and some where the person with dementia sat in on the interview, but who did not take part in the interview due to issues with reduced mental capacity. For example, one person with dementia sat in the same room as their travel companion whilst they were interviewed but, after our initial greetings, fell asleep and slept through the entire interview, only waking as I was about to leave. On re-awakening they were initially very confused when they saw me, a complete stranger, sat in their living room but after a brief conversation and reassurance their concerns were averted.

One person with dementia who sat in on their partner's interview was animated and supportive of their companion's comments. Whilst I had not intended to interview this person with dementia, I automatically ran through the mental capacity assessment in my head and considered that he would not have passed the capacity threshold set out in my ethical application. However, he surprised me part way through the interview. His wife was explaining about automated passport machines and the difficulty they sometimes had with getting these to work. I must have looked puzzled for a moment because, quick as a flash, the husband mimed the action of placing the

passport on the machine perfectly. 'You know' he said 'you take the thing and turn it over and put it down like this'. This reminded me never to underestimate a person with dementia as he was following the conversation and responding to my non-verbal cues very well indeed.

Two of the companions were recently bereaved and I took some time talking to them about their partners before their interviews began. It was very important to me to get a sense of who their partners were as people. Taking the time to discuss the person who had died also helped me to build rapport with the companion and to contextualise the interview as I felt able to visualise the person with dementia more. It was a privilege to share stories and, in one case, photographs of their travel experiences. The companion in this instance had prepared a series of photo albums to share at their partner's funeral of all the holidays they had been on from their very first holiday together as a couple through to their last. The companion told me how precious these photographs were to her as she was able to look at them and remind herself of all the journeys they had shared. It was something she had received considerable comfort from doing.

I had written about this in my study diary and had not really thought much more about it, other than to reflect on how much joy having those photographs had brought to that companion after her husband died. However, it had a surprising and positive effect on me. As mentioned in my initial reflexive commentary in Section 1.6.4 I love travel and have been fortunate to go to a number of countries and experience some wonderful trips and sights. The one thing I have always been very

bad at, however, is having my photograph taken. I dislike it intensely and always have done. Consequently, we have a large number of photographs of landscapes or photographs of my husband on his own. However, on our last two trips abroad I have actively posed for pictures rather than always being the one behind the camera. It is just a small thing, but as I write this I am smiling because I had not realised why I had done this until now. It serves to demonstrate that sometimes when undertaking interviews we learn as much about ourselves as we do about other people.

CHAPTER 6: REALIST SYNTHESIS

6.0 Introduction

This Chapter discusses the findings of a systematic realist synthesis the question for which is:

“What works in dementia awareness and support training outside of the field of healthcare?”

The process for undertaking the realist synthesis is laid out in depth in Section 3.5. As some of the realist terms are interpreted differently by different researchers, the RAMESES guidance recommends including some of the key terms at the outset of any findings to aid reader understanding (Greenhalgh *et al.*, 2015). Therefore, the terms used in realism as they relate to this research *and as I understand them* are set out in Table 8.

Term and any abbreviation used	Meaning ascribed in this research
Context	The settings, structures or environments in which resources or responses are triggered.
Mechanism	Resources or reasoning that are triggered and potentially lead to a change in participants' behaviour.
Outcome	Expected result if the mechanism is fired. Both short term (proximal) and longer-term (distal) outcomes have been reported.
Context Mechanism Outcome Configurations (CMOCs)	Relationships between key factors are the building blocks of realist research. CMOCs report how mechanisms may potentially be triggered in certain conditions that result in certain outcomes.
Programme Theory	A theoretical explanation of <i>how</i> a particular intervention is likely to work.
Substantive or generalisable theory	Transferable theory from a range of disciplines that seeks to explain <i>why</i> an intervention is likely to work.

Table 8 - Realist terms and abbreviations used in this research

Analysis of the evidence gathered from the 41 articles (see Figure 2, section 3.6.3.4) led to seven programme theories being developed (see Table 9).

Theory	Description
Programme theory 1	<i>Where a dementia friendly initiative is being introduced to a particular sector (context) engaging leadership and flexible accreditation from a recognised body (mechanism) can lead to increased business engagement (proximal outcome) and maintenance of engagement in the longer term (distal outcome)</i>
Programme theory 2	<i>Where businesses within the commercial sector are ambivalent or resistant to investing resources into dementia training (context), understanding the challenges faced by consumers and the potential commercial and staff benefits associated with undertaking such a training scheme (mechanism), may lead to increased receptivity and uptake (proximal outcome) and a long term commitment to the training scheme (distal outcome).</i>
Programme theory 3	<i>Where trainees have limited or no personal experience of dementia (context), including people living with dementia in the design and delivery of training programmes (mechanism) can increase awareness and reduce fear of the unknown (proximal outcome) it can also aid project efficacy and challenge stigmatisation and prejudice surrounding the condition (distal outcome).</i>
Programme theory 4	<i>When designing a dementia awareness programme for a new setting (context) it is important to ensure that the programme is tailored to the organisation, is cost effective and (preferably) replicable in situ (mechanism). This will help to ensure that the training is taken up by the setting for which it has been designed (proximal outcome) and remains usable and relevant in the longer term due to resource and implementation barriers being identified and addressed within the bespoke design (distal outcome).</i>
Programme theory 5	<i>Where dementia awareness is a new topic to the prospective audience (context), learning can be maximised through the inclusion of key topic points such as what it is like to live with dementia, effective communication techniques and the importance of accessible physical and social environments (mechanism). This purposeful design helps to increase societal expectations of those living with dementia and challenges stigma and preconceptions (proximal outcome) while building confidence in staff to recognise and respond to a person with dementia's needs within their own context (distal outcome)</i>
Programme theory 6	<i>When a training programme is being introduced within an organisation (context) a wide network of employees across all levels of the organisation need to be personally introduced to the training programme and its potential benefits, with a particular advantage being derived from identifying and engaging those staff and volunteers with pre-existing experience of dementia (mechanism). Continued communication and involvement of those with personal experience of dementia helps to establish widespread understanding and buy in of the project (proximal outcome) and secures ongoing programme momentum (distal outcome).</i>
Programme theory 7	<i>When a training programme is being established (context) bespoke short and long term evaluation methods need to be designed and implemented alongside ongoing peer support systems (mechanism). This will help to identify any important gaps in knowledge and provide context specific problem solving and guidance (proximal outcome) and establish if the training is making the desired changes in practice (distal outcome)</i>

Table 9 - The seven programme theories from the realist synthesis

It should be noted, however, that while the findings have been reported within distinct areas, the programme theories are interlinked as demonstrated in the realist, refined programme theory presented at the end of this chapter. The mechanisms contained within this refined programme theory are considered to be important when creating and delivering dementia awareness and support training within the wider community, with the refined programme theory providing a realist informed framework to aid the design of such training.

A further recommended step within realism is to identify any substantive, or generalisable, theories underpinning the interventions examined. This is due to Pawson & Tilley (2004, p.3) asserting that interventions are ‘...theories incarnate’ and that all interventions are built on substantive theory or theories, implicitly or explicitly. Pawson & Tilley (2004) state that identifying and examining these underpinning theories will assist with the building of future interventions. Craig *et al.* (2008) concur stating that best practice interventions should always be evidence-based and theory driven. However, identifying substantive theory is not without its challenges, especially when the underpinning theory (or theories) is not expressly stated. Moore and Evans (2017, p.133) particularly caution about the risks of the researcher finding an ‘off the shelf’ theory that appears to fit the intervention as this could damage the findings of the synthesis if the chosen theory is incorrect. Moore and Evans (2017) further contend that the identification of underpinning theories should enhance and not constrain the research and that considerations of context and mechanism are equally important.

It is, however, usual practice within realism to explore and discuss at least some potential underpinning theories further and thus one potential substantive theory for each of the seven programme theories has been explored with a view to adding value to the synthesis undertaken. Investigating one potential underlying substantive theory for each of the programme theories has been taken as a pragmatic approach, given the critique that context and mechanisms can be equally informative (Moore & Evans, 2017). This decision is also consistent with the realist training materials that advise limiting potential avenues for investigation due to the complexity involved (Wong *et al.*, 2014). It is also important to recognise that other substantive theories may be at play and what is offered here are examples of inference to best explanation, a key tenet of realism whereby the researcher considers the most likely explanation from the evidence gathered (Eastwood, Jalaludin & Kemp, 2014).

6.1 Programme theory 1

Where a dementia friendly initiative is being introduced to a particular sector (context) engaging leadership and flexible accreditation from a recognised body (mechanism) can lead to increased business engagement (proximal outcome) and maintenance of engagement in the longer term (distal outcome)

6.1.1 Community and sector specific leadership and support

As well as seeking to enact change at an organisational level, Plunger *et al.* (2019) sought to leverage change at a national level when developing a dementia friendly community pharmacy network. One success of this project was the creation of a nationwide logo that participating pharmacies could adopt, the logo had the dual

benefit of aiding the visibility of the project and reinforcing professional status and pride in being part of the scheme (Plunger *et al.*, 2019).

The dementia friendly communities model (Alzheimer's Society, 2020) also demonstrates the value of engaging statutory bodies in collaboration with other agencies such as the local DAA to set up, manage and resource local initiatives (Buckner *et al.*, 2019). Further examples of this include the Chief Executive of York City Council pledging to support the creation of York as a dementia friendly city (Crampton & Eley, 2013) and planning and public health officials working together on creating a dementia friendly plan for Sheffield including the adoption of a dementia friendly project checklist (Mitchell, 2014). While the 'Unforgettable' accessible art project highlighted the importance of support for the project by key stakeholders both internally and externally to the organisation (Hendriks *et al.*, 2019).

Although connections between communities of interest are important, leadership at a more strategic level is considered vital to a project's longer-term success (Hare, 2016b). Strategic involvement from regulators can also help to ensure that changes become a normal and accepted part of everyday business (Fleming, Fay & Robinson, 2012). While governmental endorsement and national campaigns encouraging dementia friendly projects in Japan has seen a proliferation of long-term partnership projects between communities and statutory bodies (Buckner *et al.*, 2019). However, lack of funding and resources were perceived to be a major barrier to participation in community activities by local authorities and governmental agencies especially in times of austerity, while a cross-sectoral collaboration helped

to decrease such challenges by sharing overall project responsibility and amalgamating available resources (Buckner, 2018).

When evaluating a dementia friendly footballing initiative, Carone, Tischler and Denning (2016) identified that the reputation of the lead organisation, in this case the Notts County Football Club, had been a contributing factor in the success of the project. Carone, Tischler and Denning (2016) stated that the project had attracted coaching staff and people living with dementia because it was run by a well-known and well-respected football club, resulting in widespread positive attention whilst simultaneously decreasing stigma by demonstrating that those living with dementia could remain engaged in activities of interest within their wider community.

This concept of the power of pioneering organisations was reflected in an exploratory study of the dementia friendliness of tourism businesses. Connell and Page (2019b) discovered that businesses generally fell into one of four categories: pioneers (which tended to be larger organisations and those within the public sector), followers of the pioneers (who could learn from the pioneers' best practice), reluctant compliers (who were seeking to do the bare minimum) and the non-engaged. Connell and Page (2019b) concluded that, while there was a DAA in the locality in which the research was conducted, further success in engaging businesses was likely to be achieved by engaging a champion from within the tourism sector. Thus reflecting the need for *sector specific* leadership.

6.1.2 Counter effects of leadership organisations becoming overly prescriptive

One paper highlighted that while an accrediting organisation could be useful in terms of providing an internationally recognised logo and identity, over prescriptiveness could have a detrimental impact on initiative participation. The example comes from the Alzheimer Café movement whereby in order to call itself an Alzheimer Café the Café in question had to adopt the Alzheimer's Society official programme of content for materials that should be delivered (Randeria, 2012). The authors describe that those living with dementia in this particular locality considered some of the official programme content superfluous to their needs, but by deviating from the programme they were no longer allowed to call themselves an *Alzheimer* Café which, in turn, had a detrimental effect on both their marketing activities and prospective participant reach (Randeria, 2012). While, Fleming, Fay and Robinson (2012) in a study of evidence-based design, noted that architects frequently encounter challenges between designing to meet prescriptive regulatory standards and the practical needs of the organisation for whom the building was being designed and delivered .

The challenge of an accrediting organisation becoming overly prescriptive was alluded to in other research. For example, Connell and Page (2019b) identified that organisations such as a local DAA need to be flexible enough to allow members to set their own objectives and to work with organisations in their locale to manage converging and conflicting issues to effect change. While some commissioners of dementia projects are now moving away from a pre-specified service model in favour of projects specifically designed around local needs to reflect that those receiving the benefits are key to successful project design and outcomes (Buckner, 2018). This suggests that if a voluntary accreditation scheme is to be created, care needs to be

taken that any associated scheme does not become overly prescriptive and thus counter-productive to its original aims and objectives.

6.1.3 Substantive theory underpinning programme theory 1

While the evidence for this programme theory was somewhat limited, the reason why accreditation can lead to change has been explored in the literature. For example, Desveaux *et al.* (2017) propose that accreditation can act as an external quality check and allows an organisation to better meet the needs of its customers by changing its policies and performance to meet the required accreditation standard. However, Desveaux *et al.* (2017) further assert that, without appropriate staff buy-in, such accreditation can become little more than a tick box exercise that makes very little difference to an organisation's performance in the medium to long term.

6.2 Programme theory 2

Where businesses within the commercial sector are ambivalent or resistant to investing resources into dementia training (context), understanding the challenges faced by consumers and the potential commercial and staff benefits associated with undertaking such a training scheme (mechanism), may lead to increased receptivity and uptake (proximal outcome) and a long term commitment to the training scheme (distal outcome).

6.2.1 Raising awareness of the issue to be addressed

Fleming, Fay and Robinson (2012) posit that before change can be enacted those in the commercial sector need to be first made aware that there is a problem to be addressed with a credible explanation of what the problem is and how it may be resolved. Connell and Page (2019b) concur stating businesses need to understand any societal challenge to their business model, such as how changing customer needs can impact on their long term success, before concepts of benefit and shared value can be understood. Primetica *et al.* (2015) suggest that consideration of the problem leads to consideration of a solution and aids an organisation's readiness for participation in that they begin to consider who should be involved and who is ultimately likely to benefit from any intervention.

6.2.2 Engaging in training can create a competitive benefit/advantage

In their paper on creating dementia friendly businesses within the visitor economy, (Connell & Page, 2019a) suggest that businesses operate on a transactional basis, especially where their profit margins are low. Accordingly, once the background to a commercial issue has been established businesses need to understand the cost/benefit of any investment both in the short and long term in order that they may assess the viability of their engagement (Connell & Page, 2019a).

Investment of resources in terms of finance, staff and time are seen as being major barriers to an organisation engaging in training and becoming more dementia friendly (Connell & Page, 2019). Those conducting environmental adjustments for a particular consumer group have encountered similar barriers to an organisation's

partial or complete participation (Fleming, Fay & Robinson, 2012). It remains the case however, that dementia is not the limiting factor to a person's engagement with an activity, but the accessibility of the physical and social environment (Dupuis *et al.*, 2012; Mitchell, 2014). The provision of a positive social environment in terms of welcoming, patient and understanding service is considered of such importance to those living with dementia that they will frequently travel further in order to access shops and businesses where the staff are more dementia aware (Connell & Page, 2019; Crampton & Eley, 2013). This clearly gives those businesses that have become more dementia friendly an advantage over their competitors who are yet to engage with such initiatives.

It has been further suggested that investing in training, when coupled with other adjustments such as reducing environmental barriers, can lead to a reduction in operating costs overall as it negates or reduces resources spent on the management of critical incidents (Fleming, Fay & Robinson, 2012). This implies that while there is a cost associated in becoming dementia friendly, the training can save resource expenditure in the longer term. With evidence of such financial savings likely to encourage businesses to maintain their involvement in the longer term.

6.2.3 Training can have reciprocal benefits for staff and volunteers

Improving the social environment through staff training is beneficial to both customers living with dementia and those holding the customer facing roles, especially where contact with this consumer group is high (Plunger *et al.*, 2019). However, it is considered that the training produces a reciprocal and beneficial effect

for trainees that goes over and above achieving competency (Carone, Tischler & Denning, 2016; Chow *et al.*, 2018; Crampton & Eley, 2013). Additional reported benefits include greater self-awareness (McCurry & Drossel, 2011), improved self-esteem and empathy (Carone, Tischler & Denning, 2016), increased patience and increased compassion and problem solving skills (Chow *et al.*, 2018).

It was further reported by a group of older adult volunteers that participating in dementia awareness training had helped to allay some of their own fears of developing dementia and improved their positivity in terms of being grateful for their own health (Han, Brown & Richardson, 2019). The volunteers also reported benefitting from the altruistic feelings and increased social interaction associated with volunteering (Han, Brown & Richardson, 2019). While educating younger people on the importance of decreasing the stigma associated with dementia had the benefit of them being more empathetic and compassionate towards those with a variety of mental health conditions in general (Carone, Tischler & Denning, 2016). The older adult volunteer group also reported increased tolerance towards those experiencing cognitive changes within their own lives as a direct consequence of the training (Han, Brown & Richardson, 2019).

Feil and de Klerk-Rubin (2012) go further by explaining that those working to validate and help to resolve longstanding life issues of people living with dementia in the later stages of the disease, can help those individuals to consider how they can age successfully themselves. This includes recognising and resolving their own deeply

held thoughts and issues ‘...*while speech, logic, and social controls are intact and we have the capacity to change*’ (Feil & de Klerk-Rubin, 2012, p.xxxii).

Carone, Tischler and Denning (2016) report that their findings of the reciprocity of dementia training relate to findings from intergenerational studies that show clear benefits for all parties involved, not just those receiving the activity. While Tessier, Power and Croteau (2019) contend that, although more research is needed to understand the emotional impact of such training on trainees, those employees who are both confident and competent to interact with those living with dementia are generally more satisfied within their workplace. Again, this has the potential benefit of reducing operating costs in terms of the reduced expenditure associated with staff turnover (Fleming, Fay & Robinson, 2012).

6.2.4 Increased knowledge of disability legislation and rights may help to embed dementia training within the setting

When investigating customer service communication with customers with a disability Taylor *et al.* (2019) noted that while retailers have a legal responsibility to ensure that their staff do not stigmatise or discriminate against customers who need additional support, customers with a disability were frequently subjected to extremely poor service that involved them being stereotyped or ignored. As a result, customers tended to make their own adjustments to help them to remain engaged with shopping, rather than seeking support from the retail staff (Taylor *et al.*, 2019). Although, it is unclear from this study whether the retail staff involved had received any disability training to highlight their responsibilities under disability legislation. Whereas, following a scoping review of communication strategies for paid workers

and unfamiliar partners, Tessier, Power and Croteau (2019) advocated that customer facing staff should be provided with communication training to facilitate the rights of people with complex communication disorders to engage in everyday activities such as visiting coffee shops and restaurants.

Hare (2016b) states that dementia friendly communities must recognise and promote the right to equity of access for people living with dementia in any dementia friendly activity and provide guidance on how barriers to inclusion can be removed for this group. However, in their in-depth study of 100 dementia friendly communities in England, only two dementia friendly communities explicitly referenced that a rights based approach had informed their work (Buckner *et al.*, 2019). Buckner *et al.* (2019) further argue that some dementia friendly communities may unintentionally be helping to perpetuate the stigmatisation of people with dementia by offering dementia exclusive activities rather than campaigning for the rights of people with dementia to be actively included in activities of their choosing within the wider community.

6.2.5 People living with dementia are increasingly expecting their rights to be upheld

When reviewing evidence for the importance of incorporating rights into any training, an additional aspect of the theory became apparent. In that those living with dementia are increasingly becoming more aware of their rights and, importantly, are starting to expect those rights to be upheld (Butchard & Kinderman, 2019). With the support of Charities such as the Joseph Rowntree Foundation, user groups of people living with dementia are becoming more active in changing policy and

standards about what it is to live well with dementia, with such activism being described as being ‘the bedrock’ of any dementia friendly community or initiative (Hare, 2016b, p.134). Writing about her experiences of travel in a book on legal capacity reform dementia rights activist and young person living with dementia, Helen Rochford-Brennan, explained that despite requesting special assistance at an airport, the support to which she was legally entitled did not materialise:

‘I had a contract for specific support but instead was left to the kindness of strangers. This is not equal rights. I should not be dependant on charity nor friendliness’

(Rochford-Brennan & Jenkins, 2019, p85)

Ms Rochford-Brennan explains that she was advised-and considered-pursuing a discrimination case against the airport concerned but decided against this due to the level of distress she would experience, although she felt strongly that her rights had been breached and that the airport in question did have a case to answer (Rochford-Brennan & Jenkins, 2019).

Building on a previous randomised control trial and focus groups of people living with dementia in Liverpool, Butchard and Kinderman (2019) have developed a series of rights based practical steps that can be used to support people living with dementia to participate and remain engaged in activities of their choosing.

FREIDA Principle	Statements developed
Fairness	Do not make assumptions about me Give me time and space Do not exclude me because of my dementia
Respect	Listen to me Find out who's important to me Make a positive effort to get to know me Speak to me Look at me when you speak to me
Equality	Give me input into the care I receive Respect my culture, race, and religion I have the right to intimate relationships I have the right to vote
Identity	Respect my intelligence Recognise my skills and talents Respect my choices about how I want to live my life Let me live my life
Dignity	Do not embarrass me Ask my opinion Do not patronise me If you are helping me, explain what you are doing to me
Autonomy	Allow me to express my views Respect my personal freedom Give me the freedom to do what I want, which may include taking risks Provide assistance to make decisions for myself Take my significant others into account Give me advice but do not try to control me

Figure 7 - The FRIEDA Principles

The FRIEDA Principles developed by Butchard and Kinderman (2019) used by permission from *European Psychologist* (2019), 24(2), 159–168 ©2019 Hogrefe Publishing www.hogrefe.com <https://doi.org/10.1027/1016-9040/a000370>

The resulting FREIDA principles from this study have been replicated in Figure 7 as it is considered that they would be a valuable addition to any training materials due to their clarity on how rights can be translated into everyday practice. They are also an effective means of emphasising that equal participation of people with dementia is a right and responsibility that all staff members share.

6.2.6 Supporting people with dementia assists other consumer groups

Tessier, Power and Croteau (2019) suggest that if staff learn communication strategies this will be beneficial for people with a range of conditions, not just dementia. While environmental challenges such as replacing complex, confusing and copious signs with signage that is clear and straightforward would benefit most people in the older population (Mitchell, 2014). Indeed, the principles of the Dementia Friendly Communities Environmental Assessment Tool (DFC-EAT) were devised based on the requirements of a similar Environmental Assessment Tool (EAT) framework designed to meet the needs of older adults in general (Fleming *et al.*, 2017). While O'Malley *et al.* (2018) recognise that older adults can take longer to learn and navigate unfamiliar environments, an effect that becomes more pronounced in those with mild cognitive impairment (MCI) or dementia and that dementia friendly design principles can be seen as being user friendly for all.

Where dementia friendly initiatives have been established in areas such as art galleries and museums, the trainees have realised that key methods such as slower delivery style and increased time for participant reflection and contribution can be adapted to assist other consumer groups (MacPherson *et al.*, 2009). For example, the 'Unforgettable' interactive art programme for people with dementia and their caregivers is now being extended to other groups of people with disabilities, older people and for children (Hendriks *et al.*, 2019). It is therefore proposed that if benefits from dementia training can be expanded to engage other consumer groups then this may favourably influence the cost/benefit decisions that commercial businesses need to take prior to engaging in any new training activity.

6.2.7 Substantive theory underpinning programme theory 2

It could be argued that this programme theory is underpinned by the Attention, Interest, Desire, Action (AIDA) model which is widely associated with behavioural psychology, marketing and communication theory and which is used to attract people to either purchase products or to engage with specific concepts and ideas (Tuan, 2015). In a study of the use of the model to examine health related messages on social networking sites, it was found that utilising the model's four step framework of attracting attention, engaging people's interest, building their desire to make a change and providing them with a means of taking action had a positive effect on audience behaviours (Danaei & Sanei, 2019).

Despite its longevity within marketing, AIDA is not without its critics as it assumes that people act in a linear way and does not take into account spontaneous decision making (Tuan, 2015). Interestingly, a further critique of the model is that it does not take into account the importance of context (Tuan, 2015). As has been noted, context is a key consideration within realism and the context in this case – where an organisation may be ambivalent or resistant to investing resources – is an integral part of this programme theory.

The importance of raising the need for change and offering a credible solution to businesses is also consistent with the principles of knowledge translation which is also derived from behavioural theory (Fleming, Fay & Robinson, 2012). In their model Pathman *et al.* (1996) posit that there are four stages between receiving the new knowledge and the recommended changes becoming business as usual -

awareness of the issue, credibility and acceptance of the evidence, adoption of the recommended changes and continued adherence to that change. Newell *et al.* (2003) believe that the process of change is not as linear as this, but it is influenced by the context in which it is being delivered including the characteristics of the project team who will be implementing the changes and the knowledge and interest they have in those changes coming to fruition. This clearly fits with the tenets of realism that context and reasoning have an important part to play in the success or failure of interventions. It also demonstrates the overlapping of the programme theories as previously noted, as this also fits with the concept that having someone with personal experience of dementia acting as a change agent inside the business not only helps to encourage take up of the training but also has an important bearing on the training's long term success (see Section 6.6.2).

It is, of course, entirely reasonable that any business, commercial or otherwise, should look at the cost/benefit of engaging in a training scheme before deciding to adopt it. That due diligence is only likely to become more stringent in a post Covid-19 world, due to the extensive economic damage already caused and the continuing uncertainty associated with the pandemic (Harari & Keep, 2021). So limited expenditure for a positive return is going to remain a very high priority. In their study of dementia readiness within the visitor economy (Connell & Page, 2019a) found that while public sector businesses are more open to engaging in initiatives, smaller private sector businesses tended to make only limited changes due to their lack of available resources. Utilising a realist lens may suggest that this is not purely a matter of resources, however. With public sector businesses being potentially more

likely to engage in changes for which they have a legislative duty to comply such as the access requirements as outlined in the Equality Act 2010 .

6.3 Programme theory 3

Where trainees have limited or no personal experience of dementia (context), including people living with dementia in the design and delivery of training programmes (mechanism) can increase awareness and reduce fear of the unknown (proximal outcome) it can also aid project efficacy and challenge stigmatisation and prejudice surrounding the condition (distal outcome).

6.3.1 The importance of direct contact with people living with dementia

From their evaluation of a dementia awareness project for University students, Parveen *et al.* (2018) assert that when attempting to reduce stigma and prejudice about any condition, including direct contact with people within the stigmatised group is vital to the project's success, recommending co-delivery of any training with a person living with dementia wherever possible. Where direct contact with a person with dementia is not possible, Parveen *et al.* (2018) recommend the use of a video of people living with dementia stating that this was positively received by their project participants. In an art gallery project where educators had no prior experience of dementia, the educators reported experiencing anxiety about what people with dementia would be like and be capable of (MacPherson *et al.*, 2009). Direct personal contact with those living with dementia helped to allay such fears very quickly as trainees could begin to understand more about the participants' individuality, humour and residual capacity (MacPherson *et al.*, 2009).

Importance of directly addressing preconceptions to alleviate fear of the unknown was a key finding in a UK study assessing the impact of a dementia themed curriculum at 22 primary and secondary schools, whereby meeting a person with dementia was considered to be the most consistent factor in improving the children's confidence and understanding of dementia (Atkinson & Bray, 2016). A similar finding was emphasised in a study of high school students who felt that contact with people with dementia greatly increased the students' positivity towards older adults (Chow *et al.*, 2018). However, it should be noted that this study was very small scale with just four students taking part. Nevertheless, the concept of involving people with dementia and focussing on what they can do-rather than what they cannot do-is also seen as an important part of awareness raising and reducing negative stereotypes within dementia friendly communities (Crampton & Eley, 2013).

Crampton and Eley (2013) report that any awareness campaign should include people living with dementia as a means of challenging attitudes and behaviours that are reinforcing ideas about stigmatisation and prejudice. Such involvement is also in keeping with the ethos of the dementia friendly movement (Fleming *et al.*, 2017). (Hare, 2016b, p.136) goes further by saying that including people living with dementia within dementia friendly activities is the epitome of 'being the change we want to see in the world'.

Involving people living with dementia helps trainees to view the situation through the lens of the person living with dementia (Crampton & Eley, 2013). While, in a study of the accessibility of dementia friendly heritage settings, trainees felt that direct contact

with people with dementia helped them to adopt more effective strategies into their project delivery such as sensory approaches, listening, slowing down and being comfortable to move at the participants' pace (Sharma & Lee, 2019). A number of other studies indicated involving people living with dementia aided both the credibility and efficacy of the respective projects, as the interventions were more likely to be appropriate for those for whom they had been designed (Connell & Page, 2019a; Dupuis *et al.*, 2012; Young & Manthorp, 2009; Young *et al.*, 2011).

6.3.2 Strategies to aid the involvement of people living with dementia

Strategies to aid the involvement of people living with dementia within project planning and delivery include taking time to get to know one another, keeping in touch between official meetings and allowing varying means of participation including attending meetings in person or virtually via teleconferencing software (Dupuis *et al.*, 2012). Hare (2016b) further reports that thought needs to be given to how people living with dementia may continue to be involved in projects as their needs change to ensure that even those living with advanced dementia can continue to have their voices heard and their needs met. In an attempt to provide realism, one project used specially trained actors to play the role of people living with dementia when demonstrating communication strategies and techniques in a training film (Smith *et al.*, 2011). However, it was unclear whether those living with dementia were involved in setting the scenarios at any point. The impact on the attitudes of the trainees of using actors rather than those with lived experience of dementia was also not explored so it is unknown whether this strategy helped or hindered the trainees' overall attitudes of dementia (Smith *et al.*, 2011). Another project developed innovative ways of including the attitudes of people with dementia at all stages of the

dementia continuum through alternative mediums such as poetry, photographs, art, personal stories and quotations (Dupuis *et al.*, 2012). The authors report that for some professionals hearing a poem that evocatively captured the experiences of a person living with dementia was a significant turning point in their understanding of the condition (Dupuis *et al.*, 2012).

6.3.3 Substantive theory underpinning programme theory 3

Including people living with dementia in training sessions was identified as being important, in order to increase trainees' awareness of dementia and reduce fear of the unknown. Such contact-based education has been used in a variety of other settings. For example, contact-based education has historically been used when attempting to reduce in-group / out-group prejudice in areas such as race relations (Short, 1993), with contact theory being developed in the 1950's in an attempt to reduce prejudice associated with these groups (Allport, 1979).

More recently, the value of including people with lived experience of mental health conditions within educational programming has also gained momentum as a means of challenging the attitudes held by future health care professionals and reducing stigma. For example, a study comparing the value of contact with people with lived experience of bi-polar disorder and schizophrenia in pharmacy education, with non-contact educational strategies, found that the contact-based education session increased positivity towards those living with a mental health condition and significantly reduced stigma overall (Patten *et al.*, 2012). Indeed, contact-based education has been recognised as best practice by one study aiming to reduce the

stigma surrounding mental health conditions in Canada, where didactic education techniques are the norm particularly within healthcare education (Stuart *et al.*, 2014). In both studies, the contact involved the person with lived experience recounting their personal story, including any context specific experience, and answering facilitated questions about their condition. While Stuart *et al.* (2014) did not elaborate on a recommended duration for the contact sessions, Patten *et al.* (2012) highlighted that a single facilitated session of 60-90 minutes with a person with lived experience could significantly aid participants' understanding of what it is to live with that condition and to gain an understanding of the challenges faced. Interestingly, when conducting a meta-analysis of the mediators for how contact with someone with lived experience reduces prejudice, Pettigrew and Tropp (2008) discovered that anxiety and fear reduction and increased empathy had a greater effect on the attitudes of participants than increased knowledge.

Contact education has its critics however in that any positive emotions and beliefs generated from the contact with select individuals may not generalise to the whole of the so called outgroup, with wider stereotypes and beliefs about the outgroup as a whole remaining intact (Tropp & Pettigrew, 2005). One potential and longstanding solution to reduce this risk is to combine contact-based education with reinforcement of the risks of employing generalisations about the wider group (Short, 1993). While evaluating contact-based education to identify changes in positive and negative emotion towards the person with lived experience, as well as the impact on longstanding beliefs and potential stigma and prejudice associated with the wider group of which the person with lived experience is part, would be beneficial (Tropp & Pettigrew, 2005).

A further challenge is that contact-theory has a duality to it. This means that if a person has had a negative encounter with someone in the past this can increase their anxiety, prejudice and stereotypes to a greater degree than the decrease in anxiety and reduction in prejudice and stereotype for someone who has had a positive encounter with someone of the same group (Barlow *et al.*, 2012). This makes the case for people living with dementia to be part of training delivery all the more essential if airport staff have been negatively affected by past experiences in this way, due to a lack of awareness and training in how to recognise and communicate with a person living with dementia who may have needed their support.

6.4 Programme theory 4

When designing a dementia awareness programme for a new setting (context) it is important to ensure that the programme is tailored to the organisation, is cost effective and (preferably) replicable in situ (mechanism). This will help to ensure that the training is taken up by the setting for which it has been designed (proximal outcome) and remains usable and relevant in the longer term due to resource and implementation barriers being identified and addressed within the bespoke design (distal outcome).

6.4.1 Tailored training is more likely to be successful

When creating tools to enable a dementia positive community Maki and Endo (2018) recognised that in order for the tools to be effective they needed to be customised to the relevant audience, as the trainees found it difficult to make the theory to practice link when offered generic materials. When creating their accessible art training

programme for tour leaders in Australia, MacPherson *et al.* (2009) not only included what dementia is, common symptoms and impact on a person's quality of life, but also the presentation styles that were most likely to lead to effective group facilitation that the trainees could then adopt. While in a UK schools programme each participating school was able to develop their own curriculum (Atkinson & Bray, 2016).

Common approaches to raising awareness of dementia in primary schools included school assemblies, talks from invited professionals and forming links with local dementia groups, while secondary schools and colleges were able to take the training further and embed it into key learning areas such as science, health and social care (Atkinson & Bray, 2016). Timing and limitations of content of sessions was a consideration for projects involving young children given their limited attention span (Noble, Hedmann & Williams, 2015). For example, in their interactive dementia awareness programme for how to communicate with older people living with dementia, the training length was only one to two hours in total so content had to be prioritised accordingly (Murashima *et al.*, 2018). When dealing with different training recipients in an informal carers communication programme, Small and Perry (2012) also contextualised and tailored materials to their audience to ensure maximum relevance and impact. While Primetica *et al.* (2015) found that evaluating and accommodating barriers to organisational participation was an important and ongoing part of their training design.

6.4.2 Cost effective and replicable training may help to offset concerns around limited resources

When researching barriers and facilitators to the creation of dementia friendly businesses within tourism, Connell and Page (2019a) identified that training costs, finding the time to train staff and the challenges of staff turnover were all significant barriers to take up. Primetica *et al.* (2015) also recognised these challenges and offered a practical train-the-trainer style solution which included not only the main training content that could be cascaded to other employees and interested parties, but also information on recruitment, monitoring and evaluation of the wider programme. A training handbook was also provided to aid training replication, although Primetica *et al.* (2015) noted that more research needs to be undertaken as to the value of offering such training manuals as their use beyond the initial training session and the most preferred format for such a document is currently unknown.

6.4.3 Substantive theory underpinning programme theory 4

The basis of this programme theory is that any training should be context specific. Context is essential to realist enquiry and its effect is perhaps best explained by replicating a much quoted phrase from Pawson, one of the key theorists behind scientific realism:

“Why does a programme work in Wigan on a wet Wednesday and why does it then fail in Truro on a thunderous Thursday”?

(Pawson & Manzano-Santaella, 2012, p.178)

Such is the effect of context on intervention efficacy that some researchers within healthcare are increasingly asking us to take '[this] invisible rogue variable' into consideration (Bate, 2014, p.4). Robert and Fulop (2014) assert that the most important aspects of context include the organisation's prior experience or history on a topic, leadership at a local and national level, politics and priorities of senior organisational figures, the culture of the organisation, and relationships including the organisation's long-term commitment to change. Arguably, this supports the use of CMOCs as a framework for realist programme theories and, indeed, elements of all of the aspects of context as described by Robert and Fulop (2014) can be seen across the seven programme theories identified in this synthesis (see Table 9). Members of the Reference Group also echoed the importance of context specific training within aviation. For example, when the idea of utilising online or electronic learning was mooted the airport representatives on the group advised against it, stating that it was very difficult to find the time or the equipment to do this in an airport as all available computers are in constant use directing aspects of passenger flow (see Appendix I).

The realist synthesis also highlighted that the relevance of the training materials was an important aspect of the tailoring process to the applicable context as learners struggled to make the theory / practice link without this (Maki & Endo, 2018). Thus, Merrill's first principles of instructional design would seem to be an applicable underpinning theory here (Merrill, 2002). Merrill's first principles are based on problem-based learning theories and encompass five steps:

1. The learners need to be presented with real world challenges (e.g. case studies of the challenges a person living with dementia may face in an airport environment).
2. This allows the learners to identify what they already know on a topic (e.g. what they know about dementia or hidden disabilities and the element of the airport chain that the person with dementia is struggling with).
3. New knowledge can then be demonstrated to the learner (e.g. via a presentation on how dementia may affect a person's thoughts and actions).
4. The learner is then given the opportunity to apply the new knowledge (e.g. by discussing the case study again in light of what they have learnt).
5. The learner is then able to integrate that knowledge into their everyday practice (e.g. the learner is able to apply what they have learnt in the airport environment by recognising and responding to some of the real world issues that they have discussed in training).

(Adapted from Merrill, 2002)

Thus it is considered that, while awareness raising sessions like Dementia Friends (Alzheimer's Society, 2017) are highly beneficial as an introduction to the topic, context specific training is needed in addition to this to enable participants to make the theory / practice link and to allow real, practical, and long-term change to take place.

6.5 Programme theory 5

Where dementia awareness is a new topic to the prospective audience (context), learning can be maximised through the inclusion of key topic points such as what it is like to live with dementia, effective communication techniques and the importance of accessible physical and social environments (mechanism). This purposeful design helps to increase societal expectations of those living with dementia and challenges stigma and preconceptions (proximal outcome) while building confidence in staff to recognise and respond to a person with dementia's needs within their own context (distal outcome).

6.5.1 Awareness activities and training must seek to address stigma and preconceptions about dementia

In order to better meet the needs of people living with dementia Sharma and Lee (2019) suggest that it is important that any training develops an understanding of how dementia affects people, including how they might think and feel. Having staff who are trained to understand dementia and recognise and respond to some of the issues that individuals may be experiencing is considered to add to a person with dementia's feelings of safety and security in any given situation (Sharma & Lee, 2019). Indeed, Atkinson and Bray (2016) report that dementia friendly communities are built on people within the community understanding the challenges that people with dementia face and they emphasise the importance of supporting and respecting people with dementia of all ages and abilities to engage in meaningful activity.

Dementia awareness sessions provide an opportunity to enable participants to develop their understanding of what dementia is and how it affects the person living with it in an attempt to explore and challenge their own beliefs (Murashima *et al.*, 2018). Preconceptions and stigmatisation of dementia were reported in a number of studies that were attempting to raise awareness of the condition. Noble, Hedmann and Williams (2015) noted in their awareness raising session with children that very few could report at baseline what the symptoms of dementia were other than forgetfulness. A similar finding was reported when the baseline knowledge of coaching staff in a dementia friendly football activity was evaluated (Carone, Tischler & Denning, 2016). While university students demonstrated significant pre-session misconceptions about dementia including that it is a disease of old age, that people with dementia are aggressive, have a poor quality of life, and are unable to live well (Parveen *et al.*, 2018). In this case, naming the awareness session 'Dementia Detectives' was seen as being very valuable as the students were guided to uncover and dispel some of the myths surrounding the condition (Parveen *et al.*, 2018).

Unsurprisingly, given these findings, including some of the common symptoms of dementia within any dementia awareness session is considered to be important (Murashima *et al.*, 2018). It may also be helpful to include that dementia is a continuum, with the majority of people only entering residential care in the latter stages of the condition (Fleming *et al.*, 2017). Despite the challenges associated with having dementia, Dupuis *et al.* (2012) also feel it important to emphasise that people with dementia still want to engage in activities, have fun and find joy in those activities.

Atkinson and Bray (2016) also feel it is important that staff are aware that those living with dementia may frequently demonstrate behaviours that are rooted in their life history, advocating the importance of treating each person with dementia as an individual. For example, people in the later stages of dementia may attempt to use objects and people in the present to express and attempt to resolve conflict from their past (Feil & de Klerk-Rubin, 2012). Understanding a person's cultural context is a further consideration of life history. Beliefs about dementia in different cultures was explored in a study of Asian elders with the authors stating that breaking down barriers to dementia was particularly difficult, with some cultures still not accepting dementia as a condition and/or refusing to talk about it (Azam, 2010). This is potentially a useful subject to discuss where staff will be working with those from multicultural and multi-faith backgrounds. Azam (2010) suggests that where support is available for people living with dementia, information should be provided in a number of languages as a means of including people from, and potentially reducing stigma within, these hard to reach groups.

In a UK study of dementia friendly businesses, the majority were utilising the dementia friends programme which was perceived as an important first step in an organisation becoming dementia friendly (Connell & Page, 2019b). Arguably, the limited resources needed to engage in the dementia friends programme could explain its popularity as it is provided free of charge to the organisation, takes approximately one hour and has a recognised outcome in the form of the dementia friends lapel badge (Alzheimer's Society, 2017). The programme is not without its critics however. Perceived weaknesses are that it is generic rather than context specific (see also section 6.4.3), it has historically not included those living with

dementia in its design or delivery and it could be seen as being purely a badging exercise for those organisations wishing to become, or be seen to be, dementia friendly (Hayashi, 2017). The programme has purportedly also not been evaluated, with the primary success indicator of many dementia friends' projects being based on the number of friends created rather than the impact those friends have had on the lives of people living with dementia (Buckner *et al.*, 2019). Although the Alzheimer's Society does point out that the programme is designed to raise awareness in general and is not intended to be an accredited form of training (Alzheimer's Society, 2017).

6.5.2 Use of interactive activities helps to embed learning, especially when such activities include the lived experiences of people with dementia

Parveen *et al.* (2018) noted that their University participants engaged well and derived learning from more interactive activities, particularly group work and activities that uncovered and explored myths and preconceptions surrounding the condition. Role-play was also considered useful in reinforcing learning with children and was seen as an important part of fostering belief in their ability to act if they were faced with a similar scenario in real life (Noble, Hedmann & Williams, 2015). Activities that role-play two way communication were also seen as being essential for school children, with one study using a humanoid robot to teach children how to interact with a person with dementia (Murashima *et al.*, 2018). The robot was programmed to enact common behaviours that a person living with dementia might demonstrate such as forgetfulness and disorientation and to give an 'emotional' response depending on what the children said and how it was treated, encouraging the

children to consider why a person's reactions might change in line with their own actions (Murashima *et al.*, 2018).

Use of songs and mnemonics¹⁰ were considered to be very helpful for awareness information recall, with the authors of this study estimating that six to seven key knowledge elements could be included in such a mnemonic and it would still remain effective (Noble, Hedmann & Williams, 2015). In keeping with this finding, communication specialists have also used mnemonics as an evidence based aid for explaining and remembering key learning points for communication skills in dementia¹¹ (Smith *et al.*, 2011). Having reminders of the mnemonics in the form of comics, posters, display cards and lanyard cards helped to reinforce learning in the longer term in both studies (Noble, Hedmann & Williams, 2015; Smith *et al.*, 2011).

Films and/or short videos are seen as an accessible way of demonstrating key learning activities such as communication techniques and can be a useful tool for encouraging debate (Smith *et al.*, 2011; Tessier, Power & Croteau, 2019). Azam (2010) supported this finding in their study of supporting Asian elders with dementia as they found a video of people living with dementia helpful in getting the message across that dementia can affect anyone and does not respect cultural boundaries. While (Hare, 2016b) felt that it was imperative to include a focus on the lived

¹⁰ This study, which helped to raise awareness of dementia in young children, used the 'FLOW' mnemonic which translates to: Forgetting conversations, words and people's names; Losing objects, interest or one's way; Overlooking bills, hygiene, safety and Wandering).

¹¹ This study used two mnemonics RECAPS and MESSAGE which have been expanded upon in sections 6.2.5 and 6.5.4.

experience of dementia through a range of mediums including stories, short films, case studies, quotes, positive images and audio clips. (Hare, 2016b) considers that including lived experience helps to harness a person centred approach, complements the training and helps to challenge the status quo as well as amplifying the voices of those living with dementia. Whilst not using the voices of people living with dementia directly, using contrasting characters in a comic book format helped children to embed their learning on dementia awareness by discussing which character was showing signs of dementia and which character was showing signs of normal ageing (Noble, Hedmann & Williams, 2015).

6.5.3 Peer activities can be a useful training aid

Encouraging students to work in groups and consider what they could do to support someone with dementia can help with sharing of ideas on positive actions that they could take to help someone with dementia, such as providing reassurance, being mindful of talking speed and being polite and friendly (Parveen *et al.*, 2018). Group work was also used as a means of discussing and sharing individual key learning points from the training (Murashima *et al.*, 2018). While Small and Perry (2012) viewed group settings as being efficient in delivering training as they provide opportunities for peer learning and support, they noted that this was not the case for carers of people living with dementia as more individualised and person centred support was needed in this context.

6.5.4 The importance of effective communication techniques

Young and Manthorp (2009) state that effective communication with people with dementia is an important consideration for maintaining effective relationships. The communication difficulties experienced by someone living with dementia varies but may include word finding difficulties, the inability to recall recent events or challenges with expressing complex ideas (McCurry & Drossel, 2011). Young and Manthorp (2009) emphasise that even though it is sometimes difficult to recognise the meaning within a person living with dementia's conversation, limiting their communication has a detrimental effect on their confidence and wellbeing.

McCurry and Drossel (2011, p.16) note that as dementia progresses a person's language may become increasingly abstract and may require a certain amount of decoding; giving the example that someone with a headache may not be able to recall the word, but instead may describe how it feels to them such as 'the hairs on my head are fighting'. McCurry and Drossel (2011) further state that difficulties in expressing themselves may lead people living with dementia to become depressed or to withdraw entirely from the conversation. Conversely, frustration at not being able to communicate may purportedly manifest in physical or verbal aggression (McCurry & Drossel, 2011). Feil and de Klerk-Rubin (2012) agree that a person's behaviour is in itself a form of communication and useful techniques to support someone with dementia to communicate are to use calm, non-threatening language and to rephrase any points made with empathy. Feil and de Klerk-Rubin (2012) note that such empathetic listening can build trust, reduce anxiety and help to restore a person's dignity.

Banovic, Zunic and Sinanovic (2018) state that there are a number of factors that can help to promote effective communication with someone living with dementia such as reducing noise and distractions in the environment, speaking calmly and not too quickly, making eye contact and avoiding overly complex language. While McCurry and Drossel (2011) identified that trying to follow multiple speakers in a conversation may become increasingly overwhelming and anxiety provoking for a person with dementia.

When evaluating communication in an accessible art project, the educators reflected that they had more success when they paced their language and gave respondents time to reflect and contribute to the discussions (MacPherson *et al.*, 2009). This was confirmed in a study of those living with dementia who said that they want the person they are communicating with to give them more time to respond, to act patiently, to talk normally and to speak to them rather than the person with them (Tessier, Power & Croteau, 2019). However, carers of people with dementia may actually inhibit communication by answering before giving the person with dementia time to respond (Sharma & Lee, 2019). This propensity for some carers to speak for the person with dementia regardless of their ability was noted in another study, with the project educators needing to show diplomacy and skill to foster the independence of the person with dementia and encourage them to participate in the project (MacPherson *et al.*, 2009).

Young and Manthorp (2009) also highlight that communicators should be aware of their non-verbal communication, with a particular emphasis on facial expressions, as

a person living with dementia has the ability to understand this form of communication for much longer than they are able to understand the spoken word. Young and Manthorp (2009) hypothesise that this is potentially because non-verbal communication is learnt earlier than language in human development and thus is one of the last skills to be lost to dementia. While Fisher *et al.* (2018) suggest that it is equally important to monitor the non-verbal communication of the person with dementia, especially if the person with dementia is having difficulty in communicating verbally.

One study of communication support for caregivers resulted in the development of two mnemonics to aid communication (Smith *et al.*, 2011). One of these mnemonics RECAPS is largely centred on communication in the home so is not relevant for this study, however the MESSAGE mnemonic (see Figure 8) is considered more helpful for a commercial setting and encompasses many of the strategies highlighted in this section.

MAXIMISE attention	Attract attention Avoid distractions One at a time
Watch your EXPRESSION and body language	Relaxed and calm Show interest
Keep it SIMPLE	Short, simple and familiar Clear choices
SUPPORT their conversation	Give them time Find the word Repeat then rephrase Reminders of the topic
ASSIST with visual AIDS	Gesture and actions Objects and pictures
GET their message	Listen, watch and work out Behaviour and nonverbal messages
ENCOURAGE and ENGAGE in conversation	Interesting and familiar topics Family and friends

Figure 8 - The MESSAGE Communication Strategy

The MESSAGE communication strategy created by Smith *et al.* (2011) is reproduced with permission.

Whilst there are a number of communication strategies for people living with dementia, many of these require a speech and language therapist to interpret and utilise them (Young *et al.*, 2011). When considering the communication training required by drivers of adapted buses Tessier, Power and Croteau (2019) note that communication programmes targeting one disorder can be helpful to other people with communication difficulties. This recognises that learning multiple communication strategies for different conditions is likely to be time consuming and potentially ineffective as the person attempting communication may not be skilled enough to

identify which condition they are dealing with and thus which communication strategy they need (Tessier, Power & Croteau, 2019). Interestingly, the educators in the art project also wanted to highlight that people should not miss the obvious when encountering communication difficulties in that if someone forgets their glasses or hearing aids then, regardless of whether or not they have dementia, they are going to struggle to communicate (MacPherson *et al.*, 2009).

6.5.5 Understanding that the environment in all its forms can be a barrier to participation can lead to improvements

When sharing their practical wisdom (see section 3.6.3.2), the Reference Group suggested that increased knowledge of environmental barriers may lead to improvements in wider areas such as organisational websites, paperwork and booking systems. However, there was limited evidence to support this in the literature located. Such items were only mentioned briefly with McCurry and Drossel (2011) and Small and Perry (2012) noting that many people with dementia have difficulty with decision making and problem solving leading them to encounter difficulties with materials that offered a significant amount of information or choice such as restaurant menus or travel timetables. Instead, environmental concerns for people living with dementia focussed primarily on the physical environment in terms of buildings and the social environment in terms of people. Cost was reported as a barrier to environmental adaptation (Fisher *et al.*, 2018), however a number of supportive changes, many of which may be seen as low cost, were suggested in the literature as per Table 10.

Area of difficulty identified	Recommended solution	Supporting references
Difficulty with wayfinding and navigation	<ul style="list-style-type: none"> Clearly visible and identifiable building entrances Use of landmarks to aid orientation at key decision points - landmarks may be simple such as artworks, furniture or wall hangings. Mirrors should be avoided as people living with dementia may not recognise themselves and be startled by their reflection. Use of signage at key decision points Signage should be clear, preferably with large dark lettering on a light, non-reflective background Use of contrasting colours to demark different areas of a building such as contrasting doors and doorframes. Although it is noted that this does not necessarily work with flooring as patterns, thresholds and colour transitions can cause freezing for those with perception difficulties 	(Crampton & Eley, 2013; Houston, 2010; McCurry & Drossel, 2011; Mitchell, 2014; O'Malley <i>et al.</i> , 2018; O'Malley, Innes & Wiener, 2017)
Inability to recognise common objects such as the toilet	<ul style="list-style-type: none"> Increase stimuli through use of signage in areas such as toilet entrances and exits Use standard items in facility design such as traditional door locks, flushes and taps to facilitate behavioural cues. 	(Fleming, Fay & Robinson, 2012; McCurry & Drossel, 2011; Mitchell, 2014)
Effects of sensory amplification such as lighting, temperature and acoustics and difficulties with crowds and noise	<ul style="list-style-type: none"> Use of natural light or light that replicates natural light Acoustic barriers to reduce background noise Availability of quiet and calm areas and quieter and less congested routes 	(Ahrentzen & Tural, 2015; Fisher <i>et al.</i> , 2018; Houston, 2010; Mitchell, 2014; O'Malley <i>et al.</i> , 2018; Sharma & Lee, 2019)

Table 10 - Key environmental challenges identified with some suggested practical solutions

Reduced mobility	<ul style="list-style-type: none"> • Availability of seating every 100m • Flush thresholds and clearly marked level changes with guards and handrails • Automatic doors • Presence of accessible facilities such as toilets with grab bars • Exit points from lifts and stairwells should be well signed to orientate the person to the floor number 	(Ahrentzen & Tural, 2015; Fisher <i>et al.</i> , 2018; Mitchell, 2014; O'Malley <i>et al.</i> , 2018)
Loss of place identity	<ul style="list-style-type: none"> • Changes to an environment should preferably be small scale and incremental 	(Mitchell, 2014)

The information in Table 10 is not intended to be exhaustive due to the availability of existing evidence-based dementia friendly checklists such as the Dementia Friendly Communities Environmental Assessment Tool (Fleming *et al.*, 2017), but it intends to demonstrate some of the challenges and solutions as presented in the evidence reviewed. While some suggestions were widespread in the literature such as the use of memorable landmarks to aid wayfinding and navigation as they are thought to form cognitive beacon points, O'Malley *et al.* (2018) state that more research needs to be undertaken as to which type of landmark is most effective in guiding people living with dementia. O'Malley *et al.* (2018) further report that care also needs to be taken not to increase signage and landmarks to such a level that they become cluttered and unmanageable.

While some of the challenges identified are clearly related to just those living with dementia, it was noted that older and more frail people can also find negotiating built environments challenging, with poor and infrequent signage causing a particular difficulty (Mitchell, 2014). O'Malley *et al.* (2018) argue that if you are designing for people with dementia you are effectively designing for all. Recognition of this fact may help to support the fact that changes that help people with dementia are likely to help other user groups such as older adults thus making any changes more cost effective.

Further challenges were identified in specific environmental areas. For example, in a study of dementia friendly heritage settings, there was an ongoing conflict between preserving the integrity of the buildings and creating inclusive and accessible

environments (Sharma & Lee, 2019). While in a study of care homes, residents complained that all levels of the building looked the same with one resident offering the view that a simple change to the colour scheme floor by floor would dramatically help with their orientation (O'Malley *et al.*, 2018).

Despite the suggestions shown in Table 10, the evidence suggested that true environmental solutions can only be found by walking the route that a person living with dementia would need to take to identify any challenges as they experience them (Crampton & Eley, 2013). This is a strategy that has also been helpful when designing dementia friendly environments, as those living with dementia will frequently point out areas that act as important landmarks for them that may otherwise go unnoticed (Mitchell, 2014). Accompanying a person through the route also helps to identify all of the key touchpoints that need to be negotiated and to identify any particular challenges on a touchpoint by touchpoint basis (Connell & Page, 2019b).

The concept of unsupportive social environments promoting or inhibiting a person living with dementia's participation was reported in a number of papers (Butchard & Kinderman, 2019; Houston, 2010; Small & Perry, 2012). Therefore, those interacting with people with dementia need to understand the difference their own attitude can make to the life of someone with dementia, positively or negatively as a social environment can be as disabling or enabling as a physical environment. Whilst not specifically related to dementia, in their study of customer service for customers with a communication disability, Taylor *et al.* (2019) found that the behaviours of staff in

the retail environment created considerable barriers to participation. Particular barriers identified in this study included difficulties in attracting the attention of employees and employees displaying patronising and dictatorial attitudes (Taylor *et al.*, 2019).

Crampton and Eley (2013) consider that dementia friendly people are a cornerstone of any dementia friendly community, stating that such people are dementia aware, are understanding and empathetic, are non-judgmental and focus on what people with dementia can do rather than what they cannot. This individual level of dementia friendliness is evident in training design. For example, when reporting on their awareness training for school children, Atkinson and Bray (2016) highlighted the importance of including positive behaviours such as inclusivity, warmth, empathy and respect within any training package.

6.5.6 Substantive theory underpinning programme theory 5

There are a number of mechanisms within this section and therefore a number of potential avenues that could be pursued in terms of the substantive, or generisable, theory that may underpin them. However, given that the emphasis of this research is on best practice elements of training, one area that is worthy of further examination is the use of role-play. Role-play is similar to problem based learning in that it is underpinned by constructivist learning theory whereby the learner uses their prior knowledge as a form of scaffold for new knowledge (Hammer *et al.*, 2018).

Role-play attempts to simulate real life situations to enable the learner to apply their learning and deepen their understanding through doing (Waters, 2016). An integral part of the learning comes via a debrief session which is usually held at the end of the role-play exercise which allows learners to reflect on the role-play exercise and what they may do differently in the future (McAndrew & Phillips, 2005). Context is also important however as unrealistic role-play is considered to have limited effect on knowledge application and translation into practice (van Soeren *et al.*, 2011).

Due to its purported usefulness in practice preparedness, role-play has been used in medical education for over 50 years as a way of portraying and identifying fictional health problems and is also used in other settings such as the emergency services and the military (Hammer *et al.*, 2018). Some of the reasons role-play is thought to be effective are that learners can engage in unfamiliar scenarios in a safe environment, deeper learning may occur, skills can be developed and learners' confidence to engage in real world situations in the future may be increased (Waters, 2016). Role-play is also considered a useful means of improving communication skills, particularly in inter-professional settings (van Soeren *et al.*, 2011). Certainly, Reference Group members felt the ability to take part in role play was important as, from their practical experience, some staff members may otherwise avoid getting involved in helping a person with dementia for fear of saying or doing the wrong thing (see Appendix I). Therefore, role-play is considered helpful when designing future dementia awareness and support training packages within aviation to allow staff members who may be unfamiliar with a person living with dementia to practice what they may say and do in a situation where a person with dementia needs their support.

6.6 Programme theory 6

When a training programme is being introduced within an organisation (context) a wide network of employees across all levels of the organisation need to be personally introduced to the training programme and its potential benefits, with a particular advantage being derived from identifying and engaging those staff and volunteers with pre-existing experience of dementia (mechanism). Continued communication and involvement of those with personal experience of dementia helps to establish widespread understanding and buy in of the project (proximal outcome) and secures ongoing programme momentum (distal outcome).

6.6.1 Involve staff at all levels of the organisation to promote buy in

Where dementia awareness training was implemented in a museum setting, communication with staff across the entire organisation and encouraging them to personally experience a dementia friendly art session was key to the project's success (Hendriks *et al.*, 2019). Similarly, when replicating an established project in a new environment, internal promotion of the training using various sources was considered important in gaining the staff's interest both in taking part in and supporting the project (Primetica *et al.*, 2015). When creating a network of dementia friendly pharmacies in Austria, personal contact with staff members and staff groups to promote the training was considered vital (Plunger *et al.*, 2019). It is also suggested that contacting a wide range of staff may encourage further project buy in, by reaching those staff members who have interacted with people with dementia and their carers within their role and are actively looking to develop a solution- focussed approach to working with this consumer group (Plunger *et al.*, 2019).

There was limited evidence within the studies of the benefits of mandatory training over voluntary training. With one intervention discovering that where staff were given the opportunity to self-select to take part in training this was beneficial for both initial engagement and ongoing motivation (Hendriks *et al.*, 2019).

6.6.2 Staff members with personal experience of dementia may drive training engagement and delivery forward within the setting

Staff or volunteers with personal experience of dementia are potential assets to enacting change within an organisation. When delivering the ‘Unforgettable’ art programme Hendriks *et al.* (2019) identified educators who had previous experience of dementia as being important facilitators for successful implementation and delivery of their project. Volunteers with experience of dementia who engaged in a social programme for people with dementia cited wanting to help others in a similar situation as an important reason for their participation (Han, Brown & Richardson, 2019). Clearly, this motivation and drive can be harnessed at a local level by involving someone within the organisation who already knows, and can articulate to others, how important the project is. While not necessarily needing to be situated in house, having a local dementia leader was also seen as essential when creating dementia friendly businesses within tourism as the leaders could offer support and guidance on whether or not the businesses were meeting their intended commitments (Connell & Page, 2019a).

6.6.3 Substantive theory underpinning programme theory 6

Arguably, the substantive theory here is that of the change agent. The concept of change agents has recently been explored from a realist perspective within healthcare (Handley, Bunn & Goodman, 2017) and thus will not be further explored here. This is due to the fact that knowledge derived within realism should be transferable between situations, in this case inside and outside of healthcare. Whilst change agents can help to create organisational change, for this change to be meaningful the change agents need to build trust and to communicate with others (Battilana & Casciaro, 2012). Without such communication, change agents may fall victim to tunnel vision whereby change is enacted, but this change may not be entirely appropriate as it is ultimately based on what the change agent themselves deems important.

An example of this was alluded to in the qualitative interviews for this study, whereby a companion of a participant noted that an airport employee with personal experience of dementia had created an assisted travel programme at their local airport. This programme was designed almost exclusively on the experiences and needs of the airport employee's own family member, purportedly without reference to any other person living with dementia. The travel companion's view was that the assisted travel programme was absolutely perfect *for the one individual concerned*. As Kitwood said 'when you have met one person with dementia, you have met one person with dementia' (Social Care Institute for Excellence, 2020b). So while some positive change undoubtedly took place in this situation, it may not be helpful or indeed appropriate for everyone living with dementia due to the alleged rigidity of the

change agent's approach. As such, where those with lived experience of dementia are encouraged to enact change within their own working environments, emphasis needs to be made on the importance of communicating with others with similar experiences in order to create the best possible service for those with a range of needs.

6.7 Programme theory 7

When a training programme is being established (context) bespoke short and long term evaluation methods need to be designed and implemented alongside ongoing peer support systems (mechanism). This will help to identify any important gaps in knowledge and provide context specific problem solving and guidance (proximal outcome) and establish if the training is making the desired changes in practice (distal outcome)

6.7.1 Outcomes monitoring is needed to establish short and long term project effectiveness

Evaluation is considered to be an important aspect of any intervention, with decisions needing to be taken at an early stage as to how project impact will be measured (Primetica *et al.*, 2015). By evaluating the change in attitudes of 1850 school children as a result of dementia awareness training, Atkinson and Bray (2016) were able to see an increase in pupil confidence from 25% at the beginning of the project to 76% immediately post intervention. While in their dementia literacy programme for 75 school children, Noble, Hedmann and Williams (2015) concluded

that the use of mnemonics helped the children to retain what they had learned for at least three months' post intervention potentially indicating this project's success.

Through use of a pre and post test dementia knowledge questionnaire Parveen *et al.* (2018) were able to demonstrate that university students' perceptions of people living with dementia had moved from being demonstrably negative and stigmatised, to understanding how their own attitudes and behaviours could have a positive impact on a person with dementia's life. However, as noted in a further study of dementia awareness in high school students, the long term retention of learning derived from dementia awareness sessions is unknown and longitudinal follow up studies are therefore recommended for awareness raising projects (Chow *et al.*, 2018). A further critique of dementia awareness training is that very few studies have gone on to evaluate whether the training has led to any changes in attitudes and behaviour for the attendees (Murashima *et al.*, 2018). This has been a particular critique of the dementia friends' programme and the dementia friendly movement in general with success indicators focussed purely on the number of dementia friends created or the number of businesses involved, rather than on the difference those friends or businesses have made to the lives of people living with dementia (Buckner, 2018). A scoping study of dementia friendly communities in England only identified that three out of the one hundred projects studied in depth had sought feedback from people living with dementia on the impact of their projects (Buckner *et al.*, 2019). While only one dementia friendly community in the same study had completed a self-assessment to record their progress against recommended actions (Buckner *et al.*, 2019).

Parveen *et al.* (2018) acknowledge that while the students in their study were able to describe a range of behaviours and actions to improve the lives of people with dementia, this was not in itself indicative of positive behavioural change. Tessier, Power and Croteau (2019) concur that measures of increased awareness and confidence do not equate to an increase in skill, and evaluation measures should include an assessment of whether the participants have successfully integrated aspects of training within their work. When creating the dementia friendly pharmacy network in Austria, a self-rated competency scale pre and post intervention helped to support effectiveness of the programme (Plunger *et al.*, 2019). Indeed, Sharma and Lee (2019) suggest that the capturing of impact in this manner can help to substantiate the need for new training projects and may help to unlock resources to enable more training sessions to be delivered in the future.

Conversely, evaluation identifies project weaknesses as well as successes. For example, it was only through evaluation of their Alzheimer Café that organisers realised that, while the café was structured in adherence to official guidelines, it was not meeting the need of their local participants who wanted less information about dementia and more opportunities for companionship and peer learning (Randeria, 2012).

Methods of evaluation varied depending on the session and aims of the project. Murashima *et al.* (2018) used an interactive humanoid robot to both assess young children's learning and provide them with instant feedback on their actions and decisions. When creating a code of communication practice for people with

dementia, stakeholder consultation was considered vital throughout the development and refinement of the code, not only to ensure its contents met the needs of the relevant parties but also to instil continued ownership and involvement (Young & Manthorp, 2009). A sounding board event was held when creating a dementia friendly community to ensure that the issues that had been expressed had been appropriately captured and to seek the views of people living with dementia on the recommendations that had been made as a result of those initial findings (Crampton & Eley, 2013).

When seeking to capture evaluation evidence from school children, an interactive response system was used at the end of each training session to allow for real time projection of their anonymous answers on to a large screen (Noble, Hedmann & Williams, 2015). It was felt that this interactivity was helpful for this particular audience and improved participation and overall retention rates (Noble, Hedmann & Williams, 2015). Trainers attempting to replicate a programme in a new setting, worked with the key project partners to identify what information needed to be captured and agreed upon a realistic but informative data collection method (Primetica *et al.*, 2015). In this case a short anonymous post session questionnaire was utilised to capture the key skills learned and to identify any remaining training needs, with this information then informing the design of subsequent training materials and activities for the project (Primetica *et al.*, 2015).

6.7.2 Ongoing peer support can help to translate learning into practice

Ongoing peer support was viewed as an important part of integrating the dementia friendly pharmacy network training into practice (Plunger *et al.*, 2019). Reinforcement of training through peer and faculty support was seen as being integral to the success of a dementia awareness project for high school students (Chow *et al.*, 2018). When training accessible art tour hosts Hendriks *et al.* (2019) identified that an important aspect of training consolidation was to observe a tour led by a trained peer to see the method in action. Primetica *et al.* (2015) noted that ongoing support was essential to facilitate use of the training when facing real world situations. Of particular help to problem solving was regular informal supervision sessions with other programme staff, group calls with the original researcher and an annual in person refresher session on key aspects of the training (Primetica *et al.*, 2015).

6.7.3 Substantive theory underpinning programme theory 7

Clearly, the substantive theory underpinning programme theory 7 is evaluation theory. Evaluation is considered essential within many sectors, including occupational therapy research and practice (COT, 2016). One criticism of evaluation however is that there tends to be a greater focus on outputs (such as the number of activities undertaken) rather than outcomes (whether the desired change or effect has occurred) (Macnamara, 2020). As previously noted, the Dementia Friends programme is a case in point whereby the number of Dementia Friends created has been regularly reported (Alzheimer's Society, 2019b), but there is little reported evidence of the difference those Friends have made to people living with dementia in reality.

It is, therefore, considered essential that any future dementia awareness and support training identifies whether the intended outcomes have occurred in both the short and long term.

One model that is used within education is Kirkpatrick's four levels of evaluation (Kirkpatrick & Kirkpatrick, 2007). As the name suggests this model posits that there are four levels of evaluation that need to be considered:

1. Reaction: The degree to which participants have found the training relevant.
2. Learning: The degree to which participants have acquired the skills and confidence to put the learning into practice.
3. Behaviour: The degree to which participants have put the learning into practice within their everyday role.
4. Results: The degree to which the targeted outcomes have occurred as a result of the training.

(Kirkpatrick & Kirkpatrick, 2007)

Accordingly, this model has clear links to the programme theories discussed in this chapter (see section 6.0) and is considered to be an effective framework for the design of short, medium and long-term outcome measures for any future evaluation activity of the programme theories discussed.

6.8 What ‘works’ in Dementia Awareness and Support Training

The aim of the realist synthesis was to investigate what ‘works’ in dementia awareness and support training outside of the field of healthcare. Through the systematic examination of the literature, seven programme theories were created which have been examined in-depth. From these programme theories a number of mechanisms have been identified that can be helpful when creating dementia awareness and support training in the future. Underlying reasons as to why these mechanisms may work have also been examined through the examination of the substantive, or generalisable, theories that underpin the programme theories. The key mechanisms identified and the rationale for their inclusion are shown in Figure 9. Accordingly, Figure 9 may be seen as a checklist and/or guide for anyone wishing to create such a dementia awareness and support training package in the future.

Overarching factors that can influence change in the commercial sector <ul style="list-style-type: none"> Leadership from a sector specific body can promote the need for change and provide best practice examples from pioneering organisations Accreditation from a recognised body may act as an incentive to participate in the training programme 				
Training should actively demonstrate a rights based approach with people living with dementia involved at all stages of the project to reduce fear, stigmatisation and prejudice surrounding the condition and increase project efficacy				
Pre implementation stage	Training design considerations	Important items to include within training	Implementation stage	Post Delivery stage
<ul style="list-style-type: none"> ✓ The need for training should be clearly articulated; and ✓ Potential benefits to the organisation explained such as: ✓ Competitive benefit/advantage ✓ Reciprocity of training ✓ Transferability of training to attract and engage other consumer groups 	<ul style="list-style-type: none"> ✓ Training should be tailored to the respective audience with consideration given to time and resources available. ✓ In recognition of resource barriers, training should be cost effective and (preferably) replicable in situ 	<ul style="list-style-type: none"> ✓ Training should actively address stigma and preconceptions surrounding dementia by including lived experience either in person or through other accessible means. ✓ Interactive activities such as role play to facilitate peer and group learning should be key to training delivery ✓ Communication techniques and strategies can also help staff to engage with people with dementia ✓ The importance of an accessible physical and positive social environment should be discussed alongside potential low cost solutions for changes that can be made in the setting ✓ Where possible, those living with dementia should be invited to walk any key routes to identify, discuss and resolve any problematic touchpoints 	<ul style="list-style-type: none"> ✓ A wide variety of staff should be involved to encourage training 'buy in' ✓ Those with personal experience of dementia should be identified and encouraged to act as internal change agents to the project 	<ul style="list-style-type: none"> ✓ Ongoing peer support is needed to help trainees problem solve solutions in their own context ✓ Baseline and post training evaluations are needed to identify increased awareness of dementia and any gaps in training ✓ Longitudinal outcome measures also need to be in place to establish if training knowledge and skills have been retained and if the project has enacted the desired change in practice
<ul style="list-style-type: none"> Activism from people living with dementia expecting their rights to be upheld can encourage organisations to accommodate their needs Grass roots activism that can facilitate change in commercial sector				

Figure 9 - A realist programme theory of what 'works' in Dementia Awareness and Support training outside of healthcare

6.9 Chapter summary

This chapter has outlined a realist synthesis undertaken on ‘what works in dementia awareness and support training outside of the field of healthcare’. A realist refined programme theory has been developed as a result of the synthesis and the evidence underpinning this has been presented via a series of seven interlinked context, mechanism and outcome configurations.

The next chapter, Chapter 7, will discuss the findings of the realist synthesis in conjunction with the findings of the phenomenological interviews, to establish how this learning can be applied to the field of aviation to better support those living with dementia and those that travel with them.

6.10 Reflexive commentary

Completing a realist synthesis is more complex and confusing than I originally anticipated. I underestimated the advice that novice researchers may find realist research difficult and overwhelming. The sheer variety of realist papers on offer has led me both up and down the garden path and, at times, out of the garden gate and headfirst into the murky depths of Pawson’s Swamp. A place where I have stayed for varied periods of time, swimming in circles, as I have tried to understand what I ‘should’ be doing next. This is, it would appear, par for the realist course and an important part of progress in this discipline though it did not feel much like it at the time.

Having completed the realist synthesis, my next thought was ‘well isn’t this all just a little bit obvious’? On reflection, it is to a certain extent, but only to those who already know the answer. I have a longstanding background in the voluntary sector and I vividly remember a study being published many years ago about why people give (or more importantly do not give) to Charity. When the study was published fundraisers up and down the Country rushed to open their latest industry journal for the golden nugget of information that was going to help them do better in their jobs. The answer turned out to be surprisingly simple, the main reason people do not give to Charity is because no-one asks them to.

Whilst, like most things in life, there is no such thing as a black and white answer. This simple, and somewhat obvious, finding changed fundraising practice within the UK. Most fundraising communication letters are now written using AIDA (attention, interest, desire [to help], action) principles, which in turn are based on communication theory. It was a three am moment when I realised that this is what the underlying evidence for programme theory two was pointing to. I was on familiar territory here. It made, and continues to make, perfect sense to me that commercial businesses just like individuals are more likely to respond favourably if they are approached with a clear explanation of the issue, why action is needed, an overview of what is in it for them and the provision of a simple solution.

This familiarity helped me to develop my understanding of unpacking interventions in realism and the concept of interventions being ‘theories incarnate’ (Pawson & Tilley, 2004, p.3). There’s a risk here of course that I may be fitting the theory to the

evidence, but prior knowledge is always going to have an affect whatever we are seeking to investigate and address however much we seek to defend against it. Hence the need for reflexivity, openness and transparency.

I would argue that prior subject knowledge can also be incredibly helpful in realism. In this case I found the recollection and realisation that a programme theory was underpinned by communication theory both cheering and enlightening. It was a small but significant breakthrough. It helped me to understand that sometimes we need to spell out in very simple terms what we need to do to change the status quo. We need to go back to basics and uncover the nuts and bolts of how things work (or do not work) and why and use this transferable knowledge to our advantage. This left me feeling that, despite the difficulties and frustrations encountered along the way, undertaking this research has helped me to develop into ‘...some kind of realist’ (Pawson, 2013, p.xix).

CHAPTER 7: DISCUSSION

“Bob really enjoyed his holiday – he didn’t get his memories back but we made new ones”¹²

(Reference Group Member - Dorothy Tudor, 2019)

7.0 Introduction

This chapter will discuss the phenomenon of air travel for people living with dementia and their travel companions from the interview findings, alongside findings from the realist synthesis. However, as the realist synthesis had a specific focus, concentrating purely on best practice elements of dementia awareness and support training, the findings from the synthesis will only be applicable to certain elements of this discussion. A discussion on the importance of human rights and the concept of occupational justice will also be provided in order to frame the findings of this research.

7.0.1 Human rights and occupational justice

As noted in section 1.4.3, occupational scientists have introduced the concept of occupational justice in order to promote and enable equitable participation in occupations that contribute to a person’s health, wellbeing and potential (Durocher, Gibson & Rappolt, 2014). The concept of occupational justice as fair and equitable participation in necessary and meaningful occupation is something that I, as an occupational therapist, fully support. However, the five sub-terms of occupational

¹² Quote used with permission

justice—deprivation, marginalisation, alienation, imbalance and apartheid—have been criticised as being confusing due to their many and varied interpretations, their lack of academic thought and rigour and their tendency to be value-laden (Hammell & Beagan, 2017). It has also been argued that the tendency of occupational scientists to utilise and highlight occupational justice theory purely within extreme life situations has added to the mistaken belief that occupational justice is irrelevant to everyday occupational therapy practice (Bailliard & Aldrich, 2017). This is despite the fact that everyday occupational therapy practice incorporates the active pursuit of justice by challenging stigma, recognition and respect of difference and enabling clients to identify and engage in personally meaningful occupations (Bailliard & Aldrich, 2017). Conversely, occupational therapists can demonstrate everyday *injustices* within their practice. Indeed, transferable research from within the field of social work identified that unless we move away from the egocentric ideals of westernised practice to working in a truly person-centred way that respects each individual's personal needs and wants, our interventions will inevitably be imperialistic and oppressive (Caron, 2020).

In their position paper on this topic, the WFOT highlight that occupational justice should be seen and promoted as a series of individual rights to choose, participate and freely engage in occupation with breaches of occupational rights also being highlighted as breaches of human rights (WFOT, 2019a). Indeed, Hammell and Beagan (2017) suggest that confusion around occupational justice terminology can be reduced if access to an occupation is considered purely in terms of human rights legislation. With Mace *et al.* (2018) arguing that occupational justice should be no

more complex than considering whether a person has the right and freedom to do what they want and need to do and be who they want and need to be.

Dementia advocate Hare (2016a) suggests that focussing discussion around the rights of people living with dementia can help to facilitate a positive cultural shift on the perception of dementia. While, importantly, people living with dementia are beginning to utilise a rights-based approach to raise awareness of their entitlement to live fulfilling lives and to confidently voice where those rights have not been upheld (National Dementia Action Alliance, 2020). Recognising and upholding a person's human rights is also core to the values and standards of the occupational therapy profession (RCOT, 2021). Indeed, while the RCOT emphasises the importance of upholding a person's human rights within its revised professional standards documentation, it does not mention occupational justice or its sub-themes at all (RCOT, 2021).

When invited to give the Canadian Muriel Driver Memorial Lecture on the right to occupation, Hammell (2017) suggested that occupational therapists need to act on addressing occupational injustices rather than concentrating on the terminology to describe them. I agree with the stance taken by Hammell (2017). Therefore, this chapter will discuss barriers experienced by people living with dementia and those who travel with them throughout the air travel chain, but will not categorise them utilising occupational justice sub-themes or terminology. Instead, barriers to participation will be reported using headings outlined in the WHO world report on disability (WHO, 2011). The rationale for this is that these headings recognise the

impact of the environment in its broadest sense on reduced or restricted participation and have been directly informed by both the Convention on the Rights of Persons with Disabilities (2006) and the International Classification of Functioning (ICF) (WHO, 2002). The ICF is closely associated with occupational therapy practice, due to its global recognition of the role the external environment plays in a person's occupational participation (Abarghuei *et al.*, 2018). However, an important aspect of utilising a rights-based approach is to identify not only potential barriers to a person's participation in society, but also potential solutions to those barriers (Convention on the Rights of Persons with Disabilities, 2006). This stance correlates with the original aim of this research to identify both barriers and facilitators to engagement in air travel for these passenger groups. Therefore the final chapter, chapter 8, will build on the barriers and facilitators identified in this discussion chapter and provide a conclusion to this research by setting out a series of recommendations on how participation in air travel might be improved for people living with dementia and those who travel with them in the future.

7.1 Inadequate policies and standards

7.1.1 Imprecise risk profiling in the insurance industry

Difficulties in obtaining travel insurance were reported as a potential barrier to travel by both participant groups in terms of actually finding cover and the prohibitive cost of premiums (sections 4.2 and 5.2). Participants living with dementia also reported that where cover was available to them it was only granted if they declared that they would travel with a companion (section 4.2). This is a particularly interesting stance, given that capacity cannot be assumed on diagnosis alone and must always be

assumed unless it can be proven otherwise (Mental Capacity Act 2005). It also potentially assumes that the person's companion has capacity, when they may not.

A UK Charity reported that people living with heart disease were finding obtaining travel insurance cover equally difficult has suggested that imprecise risk profiling plays a significant part in insurance underwriting decisions and calculating premiums payable for this group (British Heart Foundation, 2020). Interestingly, insurance risk profiling is one of the few areas that is exempt from consideration of certain protected characteristics under equality legislation with both age and disability type being key considerations when calculating insurance rating risk factors (Groupe Consultatif Actuariel Européen, 2011). This could potentially explain why insurers are able to insist that a person living with dementia should travel with a companion without the need to assess their capacity as noted.

The challenge of obtaining insurance for people living with dementia has been recognised within the UK insurance industry who formed the Insurance United Against Dementia (IUAD) task group in 2017, in partnership with the Alzheimer's Society, to support industry staff and customers affected by the disease (Alzheimer's Society, 2021b). It is particularly interesting to note that the IUAD group was formed because senior insurance staff had become aware of the challenges of people living with dementia obtaining insurance directly through a close family member or friend (Matier & Hardy, 2020). Those insurance staff had then chosen to take action to improve this situation from inside the industry (Matier & Hardy, 2020). This example vividly highlights the role that employees with personal experience of dementia can

play in becoming organisational change agents for the dementia cause as identified in programme theory 6 of the realist synthesis (section 6.6.2).

Further research on the challenges associated with obtaining travel insurance for people living with dementia is outside the scope of this doctoral research study, but it does warrant further investigation. An exploration of the evidence insurance companies use to assess the risk of a person travelling with dementia and whether this applies to all stages of their diagnosis, and indeed pre-diagnosis, would be particularly helpful to those travelling with dementia in the future.

7.1.2 Policy changes and enforcement within aviation

A recognised barrier to improving services for people with disabilities is that policies frequently do not take their needs into account (WHO, 2011). As previously noted, while legislation is in place to support people with disabilities, including hidden disabilities, to travel by air, this legislation has historically been interpreted in favour of people with physical disabilities (Marchant, 2021). In an attempt to remedy this inequality the UK CAA as the recognised national enforcement body implemented guidance on how airports (CAA, 2016a) and airlines (CAA, 2018a) could support people with hidden disabilities when travelling by air. These policy changes have undoubtedly witnessed an increase in good practice and innovation within the airport environment, such as the implementation of the hidden disability lanyard scheme to identify those passengers who might need additional support (CAA, 2018b). However, awareness of the right to access the lanyards and to utilise special assistance in general was low amongst the participants in this research. It was also

interesting to note that those participants who were aware that they were entitled to access special assistance, including those participants who might describe themselves as dementia rights activists, were unaware of the CAA documents setting out what was expected of airports and airlines in assisting people with hidden disabilities (CAA, 2016a; CAA, 2018a).

All participants were also unaware that the CAA had produced a document outlining the steps that had been taken by all UK airports to engage with these policy documents which included a list of services and facilities that those travelling with a hidden disability might now expect to receive across the UK (CAA, 2018b). This suggests that more work needs to be undertaken by the CAA to highlight their role in upholding passenger rights for those with hidden disabilities and the help that should be available to this passenger group. This is particularly important given that the CAA has recognised that consumer confidence in the hidden disability passenger group is low (CAA, 2016a), with this research confirming that some passengers still expect to have difficulties when travelling by air. Some participants' went as far as to report that encountering an inaccessible air travel chain made them feel as if they had to go into battle with the environment, a feeling echoed by participants in other aviation research (Revealing Reality, 2021).

A further barrier identified by the world disability report was that even where disability standards do exist they may not be enforced (WHO, 2011). The CAA publishes an annual review of airports' compliance against the quality standards set down in Council Regulation (EU) 2006/1107 (2006), with each of the UK's airports being

awarded a ranking of very good, good, needs improvement or poor depending on their performance against a range of metrics (CAA, 2019b). While each airport's ranking is published via the CAA's website in the form of an annual airport accessibility report CAA (2020), airports are not required to publish these rankings on their own websites or at their special assistance desks. However, explicit publication of an airports ranking is recommended as accreditation schemes in other industries, such as the Food Standard Agency's 'Scores on the Doors' Campaign, have empowered customers to make informed choices as to which businesses they would support based on their performance standards (Food Standards Agency, 2008). Furthermore, evidence suggests that being part of such accreditation schemes and having a visible symbol of the scores received also encourages businesses to improve their compliance standards (Food Standards Agency, 2008). Whilst it focussed on a nationwide logo rather than a score, Programme theory 1 of the realist synthesis identified that having an overtly displayed sign or emblem reinforced staff's feelings of professional status and pride (Plunger *et al.*, 2019). Pride may well be the mechanism as to how overt accreditation signage improves compliance standards, as businesses are highly unlikely to want to display any indication of their apparent failings to the public.

7.2 Negative attitudes

Both those living with dementia and their travel companions highlighted that they felt societal expectations of people living with dementia were poor (sections 4.2 and 5.2). While the realist synthesis suggested that the rights of people living with dementia are not being upheld outside of the field of healthcare in terms of how they are seen, spoken to and treated (Butchard & Kinderman, 2019; Small & Perry, 2012; Taylor *et*

al., 2019). This confirms previous findings from other opinion pieces and studies on this topic (Alzheimer's Association, 2019a; Montague, 2018; Urbańska, Szcześniak & Rymaszewska, 2015). Indeed, when creating the dementia rights statements, participants living with dementia noted that much more needed to be done to recognise and uphold their rights, that are all enshrined within law, within general society (National Dementia Action Alliance, 2020).

7.2.1 Health Professionals

Some of the participants discussed the importance of having supportive health care professionals, including General Practitioners and Consultants, reporting that they received guidance to reduce or disengage with meaningful occupations at the point of diagnosis. These findings parallel with the experience of Swaffer (2015) who coined the phrase prescribed disengagement ® based on her experiences of being advised to withdraw from activities by a specialist within the Australian health service when receiving her own diagnosis of dementia. This finding is especially worrying given that the results of a systematic review on the concept of prescribed disengagement ® found limited evidence to support the idea that people with dementia were explicitly being told to withdraw from meaningful activities at the time of diagnosis (Low *et al.*, 2018). Although the authors of the systematic review, which explored the diagnostic and post-diagnostic experiences of 373 participants with dementia over 35 studies, suggest that the limited support available to people diagnosed with dementia may have exacerbated their feelings of disempowerment and self-stigmatisation and did not rule out that disengagement from meaningful activity may have been implied (Low *et al.*, 2018). Given the sensitive nature of prescribed disengagement ® further primary studies on this topic may be beneficial,

as it could be an under-reported factor in secondary data focussing on the wider diagnostic experience.

It has already been noted that in their post legislative scrutiny of the Mental Capacity Act 2005, the House of Lords (2014) expressed disappointment that the Act was frequently seen as a means of constraint and paternalism from within the NHS and that risk aversion was prevalent within social care. It has been argued that those within the NHS need to work within a difficult balance of patient autonomy and state paternalism as the NHS was established with the aim of caring for people across their lifespan (McCrae, 2013). However, a consultant nurse and expert witness on the rights of older people, has suggested that the dominance of health and safety has reduced patients' rights to take risks particularly in care settings and that a cultural shift is needed away from risk avoidance to risk reduction for this group (Phair, 2019).

Phair's (2019) opinion piece highlights the difficulty of balancing freedom of choice for those living with dementia with their continued overprotection. This is particularly noteworthy given that Phair was commenting on this matter nearly 10 years after the UK Government's publication of a key guidance document for the healthcare sector on the need for positive risk taking for this group (Department of Health, 2010b). The publication highlights the importance of respecting and/or permitting a person living with dementia's right to participate in an activity unless a risk analysis, capacity assessment and, if warranted, a best interests decision demonstrates that they

should not do so (Department of Health, 2010b). However, Phair's (2019) opinion piece suggests the report has had little impact in some settings.

It is fair to say that not all of the study participants' experiences with health professionals were poor, paternalistic, or risk averse, with some participants actively being encouraged to continue living their lives their way for as long as possible. However, the effect of health professionals' comments and actions on those living with dementia's wish to remain engaged in activities that are meaningful to them, including air travel, are a recommended area for further research.

7.2.2 Fear of angering other passengers due to hidden nature of dementia

Some of the participants reported that they had not used accessible facilities in the airport such as toilets or priority seating due to the hidden nature of dementia. While some participants understood that they had the right to use these facilities, others were fearful that they would be challenged for using them. These fears may be justified due to the public's perception of what someone with a disability should look like. For example, a survey led by a UK charity identified that one in two of the respondents had been openly criticised for using an accessible toilet due to the hidden nature of their disability (Crohn's & Colitis UK, 2019). Whilst this evidence appears to be compelling, it is noted that the survey has not been published in peer-reviewed journals and there are no details of how many people it involved, nor their ages. Ironically, the aforementioned study also identified that 93% of those challenging someone for using accessible facilities on the basis that they did not look disabled, actually believed that they were standing up for the rights of people with

disabilities by doing so (Crohn's & Colitis UK, 2019). The same caution applies to this evidence as previously noted however, in that the number of people interviewed is not transparent and the study has not been subject to peer review so not all details are available. Fear of angering other passengers may also be an issue for airport staff. Whilst it was only one reported incident, it was disappointing to note that a member of airport staff had insisted that a person living with dementia utilise a wheelchair so as not to upset other passengers who might not otherwise understand why they were receiving preferential treatment. This suggests that greater awareness of hidden disabilities is needed within society in general and within the airport environment in particular. While greater emphasis on managing conflict is needed for those in public facing roles.

One way of raising awareness of hidden disability is through a change to signage, so it is clear that accessible facilities are not just for those with physical disabilities. Grace Warnock, a young person living with Crohn's Disease, successfully campaigned for a change to accessible toilet signage after she was repeatedly questioned as to why she was using these facilities, a situation that she reports finding extremely difficult (Inclusive Design Scotland, 2016). Accordingly, versions of Grace's Sign indicating that not every disability is visible (see Figure 10) have become more prominent in recent years, particularly across community facilities in Scotland, and has been adopted by Edinburgh Airport (Sillitoe, 2017). The widespread community adoption of this sign resulted in Grace being recognised with an award by the UK Prime Minister (Points of Light, 2018).



Figure 10 - Not every disability is visible toilet signage

(Researcher's own image)

A further innovation to help airport staff to recognise someone who might need additional support was the introduction of the hidden disability sunflower lanyard (Gatwick Airport, 2016). This scheme has grown exponentially since its inception, with hidden disability lanyards now available and recognised in a wide range of UK settings including financial institutions, train and coach stations, the NHS, schools, colleges and universities, and supermarkets (Hidden Disabilities Sunflower Scheme Limited, 2020d) . See Figure 11 for an example of the hidden disability lanyard advertising board in a community setting.



Figure 11 – Advertising board for the hidden disabilities lanyard scheme

(Researcher's own image)

Whilst the lanyards were originally designed to discreetly highlight to airport staff that the wearer might need additional support throughout the air travel chain (CAA, 2018b), their meaning has changed in light of the Covid-19 pandemic. Some people with hidden disabilities are now choosing to wear the hidden disability lanyards to denote that they are exempt from wearing a face covering with explanatory cards available online for this specific purpose (see Figure 12).



Figure 12 - Face covering exempt hidden disabilities card

(Photograph Hiddendisabilities.com)

As a result of their increased use during the pandemic, the hidden disability lanyards are now being recognised around the world (Hidden Disabilities Sunflower Scheme Limited, 2020c). This increased recognition is undoubtedly positive as the more the sunflower lanyards are used, the more public perception and awareness of hidden disabilities like dementia should improve. However, there are potential downsides to this surge in demand with major online sales platforms now selling numerous versions of the hidden disability lanyard and accompanying identity cards in an attempt to capitalise on their increased popularity. This variation in design runs the risk of diluting the sunflower hidden disability brand and could impact on the level of service that is received if someone with a hidden disability uses a different version of the lanyard in an airport environment (Hidden Disabilities Sunflower Scheme Limited,

2020b). This is of particular concern given that none of the websites on which the hidden disability lanyards are advertised state that those needing additional support at airports should register for special assistance at least 48 hours prior to travel (CAA, 2015a). Lanyard use without requesting special assistance was raised as an issue in this research as the participants felt that the assistance service they had experienced was inferior as a result of using the sunflower lanyard alone (see Section 5.3), compared to declaring that they needed additional support through official channels.

The discreet nature of the hidden disability lanyards was also one of the factors that participants noted as helpful, as they wanted to remain in control of whom they told about their dementia diagnosis and did not want to identify themselves as being vulnerable. Some dementia activists have raised concerns over the wearing of lanyards as they potentially highlight a person's difference and may encourage the segregation, rather than integration, of people living with dementia within society (Rochford-Brennan & Jenkins, 2019; Swaffer, 2020a). One participant in this research raised similar concerns noting the need for a careful balance between a discreet way to highlight that a person may need additional support and labelling that person as something other. The participant's concern was that labels have been purposefully utilised throughout history to denigrate and isolate those who may be seen as different and he did not want to see a return to this. Certainly, the Reference Group to this research has always been opposed to overt labelling of any person. It is however noted that the main online store for sunflower products is now selling identification cards that state, for example, 'I am autistic', 'I have epilepsy', or 'I have diabetes' (Hidden Disabilities Sunflower Scheme Limited, 2020a). Although it is

recognised that some people with a hidden disability may choose to wear such an identifier as they may not be able to easily explain what help they may need (Mitchell, 2019).

One airport in Canada has considered an alternative solution to identifying those with autism without making this obvious to other passengers. Vancouver Airport now issues boarding cards with an autism access sticker on them to indicate to airport and airline staff that the person carrying this boarding card needs additional support (Vancouver International Airport, 2020). However, Vancouver Airport do not appear to offer this service to passengers with any other hidden disability at the current time. One architect specialising in airport accessibility has also suggested that embedding disability information into a boarding card so that it is visible to airport staff whenever it is scanned would be a useful addition to an airport's special assistance offering (Jones, 2020). However, while the suggestion from Jones (2020) may suit those who object to wearing a lanyard, the fact that a person's assistance needs is only visible when the card is scanned may result in the person not getting the help they need when they need it. While the boarding pass sticker offered by Vancouver International Airport (2020) may be more visible, this scheme also relies heavily on the person carrying it remembering to show it when additional support is needed-a potential challenge for people living with dementia.

7.2.3 Companions as enablers

It is important to note that some participants reported positive societal expectations, with companions being reported as a major enabler. All participants living with

dementia travelled with a companion, who provided support to the person living with dementia to various degrees. For some the companion was a form of reassurance, while for others their companion took on the responsibility for most of the planning and preparation involved in travelling and supported the person living with dementia extensively throughout the journey to their destination. Whilst having an enabling person is certainly a facilitator to travel for many people living with dementia, this can come at a cost for some companions. For example, those companions who had travelled with someone with more advanced dementia recounted experiences where they had begun to find negotiating the air travel experience highly stressful and difficult, especially if they were faced with unforeseen challenges like delays. This demonstrates a need for improved communication between special assistance staff and special assistance passengers when things do go wrong.

The physical, mental, social, and financial difficulties experienced by carers in providing a full time caring role for a significant other are widely recognised and documented (Carers UK, 2014) and thus will not be repeated here. However, travelling with someone with dementia brings additional responsibilities such as increased vigilance away from the safety and familiarity of the home environment. This was emphasised by a participant in a study by Innes, Page and Cutler (2016) who noted that the need to constantly monitor the person with dementia to ensure they were close by and safe when on a break away from home led to them not having a holiday themselves. Indeed, some of the companions in this study who had travelled with people with advanced dementia had found constant supervision and guidance tiring (see, for example, section 5.4). This demonstrates that even the same occupation, experienced at the same time, can have different meanings for

those engaging with it. This consideration is important given that an increased use of co-occupations tends to be used as a coping strategy by couples where one person has dementia (van Nes *et al.*, 2012). However, a qualitative study of 26 couples where one person had dementia demonstrated significant differences in meaning derived from such co-occupations, with people living with dementia seeing them as enabling while some carers saw them as burdensome (Vikstrom *et al.*, 2008). Interestingly, some of the participants living with dementia in this research demonstrated insight into the pressure their travel companions faced when negotiating the airport environment. With some participants with dementia indicating that special assistance should be provided whether or not a companion is present as both parties needed additional support. For example, staying with the person with dementia while the companion retrieves items from the luggage carousel or goes to the toilet.

Some of the companions also raised concerns about the risks of people living with dementia going missing when travelling, recounting situations where they had been temporarily separated and the distress that this had caused. Aside from the potentially serious risk to the person living with dementia as outlined in the critical incidents in Section 1.1, the fear of this happening added to the companions' stress. Whilst this risk is ever present as someone living with dementia may walk away from wherever they are for various reasons, such as confusion with time or place, to ease discomfort or for habitual reasons (Alzheimer Scotland, 2009), airports obviously lack some of the safeguards that can be installed in the home environment such as door alarm systems. Some companions in this research had created a number of strategies to help to deal with this fear such as arranging a meeting point or travelling

with other family members and friends. However, some travel companions reached the point where they felt they could no longer travel with a person living with dementia on their own as the constant vigilance was too much for them, leading to feelings of guilt and regret that they may be letting the person with dementia down. Such feelings of shame, guilt and regret are commonly expressed by those caring for a significant other living with dementia, particularly when there is a progression in the person's dementia, as this can be seen as a personal failure on the companion's behalf (Owen & Harrison Dening, 2019). One potential intervention that could enable continued access to overseas travel is assisted holidays. Assisted holidays do not just provide support for the carer, but can also help the person living with dementia as being separated from their usual carer for any period of time is thought to contribute to increased cognitive decline (Wilz & Fink-Heitz, 2008). Assisted holiday destinations for people with disabilities and their companions are relatively rare but do exist. However, assisted holidays tend to be based within the UK rather than overseas - see for example Revitalise Respite Holidays (2020) and Dementia Adventure (2019). The absence of an assisted service for overseas travel provides scope for further research as to why this may be the case and/or the opportunity for the development of such a service in the future.

7.3 Lack of provision of services

Whilst special assistance is available to passengers with dementia, most of the participants were unaware of their right to access this service. Some participants felt the dominance of the wheelchair symbol within special assistance was a potential barrier for those with hidden disabilities as they thought that it indicated that special

assistance is only for those with physical disabilities. The fact that one participant felt strongly that the continued use of wheelchair signage was against his rights as a person with a hidden disability bears repeating here (see section 4.3). Indeed, the continued appropriateness of the wheelchair symbol as the international standard of disability is open to debate. Particularly given that a mapping exercise of disability statistics from across the UK has concluded that just 5-7% of the disability population in England uses a wheelchair (Sport England, 2016).

While the statistics in Sport England's (2016) report are considered credible as they were undertaken by the Office of Public Management, it is noted that they are now five years old so may no longer be representative. However, a recent survey on the support needs of passengers at a UK airport has helped to highlight that the wheelchair symbol no longer accurately reflects special assistance passengers.

Revealing Reality (2021, p.6) specifically refer to the phrase 'personal circumstances', to recognise that not everyone requiring support will have a permanent disability and that passengers not only need support with physical circumstances, but also sensory, cognitive, psychological and cultural circumstances. Just 1.4% of the 11,400 passengers surveyed reported issues with reduced mobility, compared to 39% of passengers who have another type of support need (Revealing Reality, 2021). The disparity between the potential percentage of wheelchair users in these two studies [5-7% (Sport England, 2016) and 1.4% (Revealing Reality, 2021)] is potentially due to Sport England using a much larger dataset of multiple statistics and voluntary sector reports across a specific period. Whereas the Revealing Reality data is likely to be more of a snapshot of a much

small number of travellers within a much shorter timeframe. Therefore, the Sport England figures may be considered more representative, even given their age.

Despite this, the wheelchair symbol still dominates disability services. For example, on a recent trip to a [purposefully unnamed¹³] airport the wheelchair symbol was very prominent at the special assistance desk compared to the small and partially obscured information on the support available to those with hidden disabilities as seen in the photograph at Figure 13.

¹³ It is not the intention of this research to ‘name and shame’ airports where it is perceived that poor practice has been experienced or witnessed, but to discuss potential issues with a view to improving the special assistance service for people living with dementia in the future.

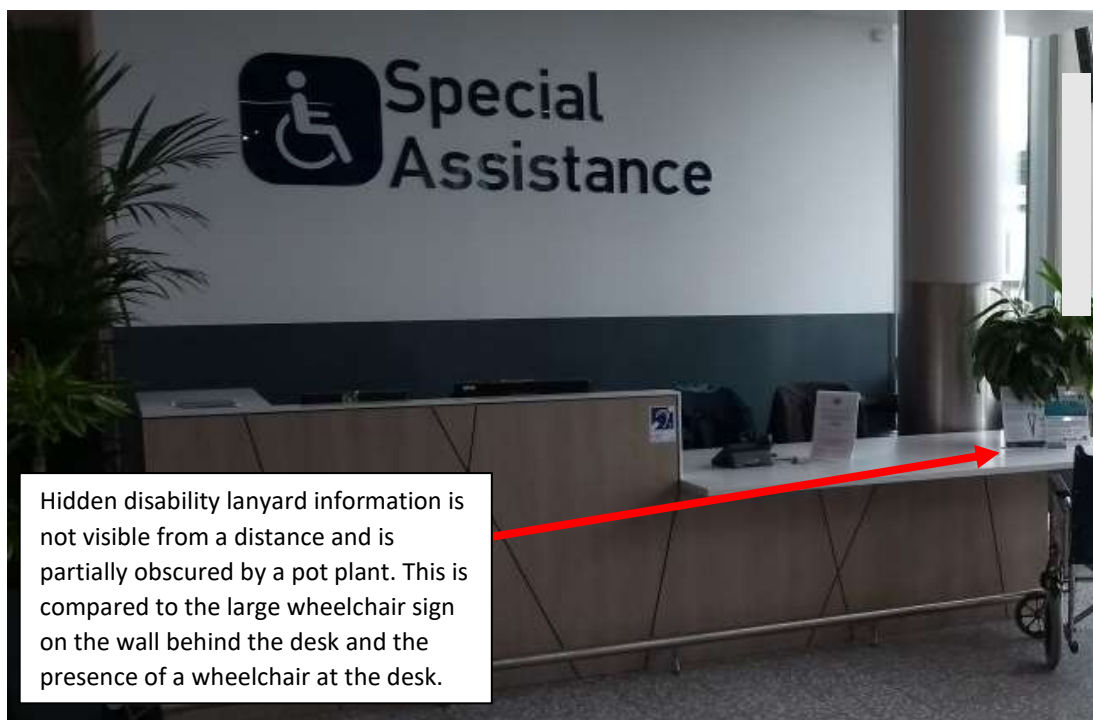


Figure 13 - Disparity between physical and hidden disability symbolism at a UK airport

(Researcher's own image)

In an attempt to increase diversity within their service, some airports have adopted the United Nations symbol of accessibility within their special assistance signage alongside the traditional wheelchair symbol (see Figure 14).



Figure 14 - The United Nations symbol of accessibility within special assistance signage

(Researcher's own image)

While it is unclear how many people in the general public would recognise and understand the meaning of the United Nations Symbol of Accessibility, it has been adopted by organisations campaigning for more accessible air travel. For example, Reduced Mobility Rights Limited (2018) adopted the United Nations symbol as they considered the international standard image of a person in a wheelchair to be demeaning. Given the perceived lack of recognition of the United Nations Symbol of Accessibility, it would be an interesting exercise for airports using it within their signage to survey the general population to identify how many people can recognise it. It would also be useful to ascertain data as to whether its presence on signage would encourage them to ask for assistance if they did not have an obvious physical disability.

Researchers from the Life Changes Trust and the University of Stirling recognised that the UK did not have a standard sign to represent people with any disability and have created, with the aid of focus groups of people with lived experience, a new any disability symbol (Richards, 2019). The new any disability symbol was launched as part of a wider debate on hidden disabilities in the UK House of Commons in 2019, with the ultimate aim that the symbol will be adopted by the British Standards Institution (BSI) (StudioLR, 2019a). It is anticipated that if the new any disability symbol is recognised by the BSI, it could become the UK standard for all accessible facilities, including accessible toilets and assistance points. Certainly, if UK airports were to adopt this sign for their special assistance counters and within accessible toilets and priority areas, it would help to alleviate some of the concerns raised about awareness and appropriateness of people with hidden disabilities, like dementia, making use of these facilities. The new 'any disability' symbol has been replicated with permission at Figure 15. The image is shown on its own and with the recommended accompanying wording as per the design guidelines (StudioLR, 2019b).



Figure 15 - Proposed new sign for people with any disability

(Images replicated with permission from StudioLR)

As noted in section 2.4, a further challenge with special assistance service provision has been attributed to the use of the PRM acronym to describe special assistance passengers due to its focus on passengers with reduced mobility. In an opinion piece Angrave (2017) stated that the continued use of PRM was hampering a cultural shift within aviation as to how passengers with additional needs are viewed and subsequently supported, suggesting that a move to PDN (people with different needs) or PID (people who interact differently) would be far more representative of this passenger group. Marchant (2021) agrees noting that the historical focus on PRM within aviation needs to change, with Heathrow Airport now changing their special assistance passenger acronym to PRS (passengers requiring support) to better reflect assistance passenger diversity. Programme theory one of the realist synthesis identified that one of the main mechanisms for change comes from action by sector pioneers, and it will be interesting to see whether other UK airports follow Heathrow's example by adopting the same acronym. However, given Angrave argued for a change to the PRM acronym in 2017 and ACI suggested a move away

from PRM to PWD (persons with disabilities) to better reflect disability legislation in their 2018 disability handbook (ACI, 2018; Angrave, 2017), it could be suggested that changing historical and ingrained thinking within aviation may take some time.

It is also noted that the Convention on International Civil Aviation, upon which the majority of international air travel standards and recommendation practices (SARPs) are based (International Civil Aviation Organisation [ICAO], 2021), may be hindering change to PRM terminology. Their definition of [a] person with disabilities begins with the wording ‘any person whose mobility is reduced due to...’ and then lists a range of disabilities including ‘intellectual disability’ (ICAO, 2017, p.1-4). This suggests that while a range of disabilities and health conditions are recognised in this SARP, reduced mobility is still the primary concern. Accordingly, a change in thinking at this strategic level may also be needed in order to elicit widespread changes to the potentially outdated PRM terminology. Certainly, obtaining such buy in from sector specific leadership organisations is also considered to be a key mechanism for change in programme theory one (see section 6.1) of the realist synthesis to ensure that change becomes a normal and accepted part of everyday business. This is in keeping with change management literature (Fleming, Fay & Robinson, 2012).

7.4 Problems with service delivery

The WHO reported that barriers within service delivery can include, amongst others, a lack of service coordination and inadequate training (WHO, 2011). Both people living with dementia and their travel companions reported barriers arising from these factors.

7.4.1 Lack of service coordination

Some participants' reported that service co-ordination was particularly poor between the airline and the departure airport. Despite explaining to the airline the assistance needed, for example non-wheelchair based support, the airport frequently offered the traditional wheelchair option on arrival or were unaware that the passengers had requested special assistance at all. This indicates both a lack of awareness of the rights of those travelling with a hidden disability (Council Regulation (EU) 2006/1107, 2006) and adequate training needed to enable those rights to be upheld. Some participants' reported that existing infrastructure, such as the design of airline booking websites, could be adding to the challenges around poor service co-ordination as the booking options still focus heavily on those with reduced mobility. This frequently resulted in travel companions having to book special assistance in a different way, such as by telephone. As noted in programme theory two, increased awareness of passenger rights among all staff is considered important in recognition of the legal responsibility that organisations have to not stigmatise or discriminate against their customers. Clearly, being unable to book special assistance online if someone has anything other than a physical disability is not in keeping with the requirements of equality legislation (Equality Act 2010).

A further area of poor service coordination that some participants reported was at the destination. Some participants felt that there was not enough information provided inflight around how to access special assistance on arrival and for flight connections. This caused apprehension, particularly for some travel companions who commented that they became anxious that the responsibility would again fall to them. The

continued challenges experienced in international airports suggest that, even though dementia friends is a global movement, much more needs to be done to raise awareness of passengers with dementia with airport staff around the world. Accordingly, links have been made by the researcher and research supervisors with interested parties around the world to form the International Dementia Air Travel Group (I-D-Air) with a view to improving air travel experiences for people with dementia. The group held its first presentation at the 34th Alzheimer's Disease International Conference (Howard *et al.*, 2020), with further awareness raising activities planned for the future. Atkinson and Bray (2016) suggest that an important aspect of any dementia friendly community is raising awareness of the challenges that people living with dementia face. Given the burden fragmented services also place on travel companions it is arguably equally important to include their experiences within any future training package. This would also be in keeping with the provisions of the Care Act 2014 which advocates for the carer's view to be taken into consideration in any given situation.

7.4.2 Inadequate training

The majority of participants reported experiences of poor communication from airport staff. Although some participants felt that communication improved inflight with the cabin crew being more skilled at dealing with passengers who were anxious or distressed, with communication around receiving special assistance on arrival (see section 7.4.1) and not always recognising that people with dementia might struggle to make decisions under pressure being the only issues reported in this regard. As identified in the realist synthesis, dementia friendly staff are a cornerstone of any dementia friendly setting. Key attributes include having an awareness of dementia,

being patient, understanding, empathetic and non-judgmental and focussing on what people with dementia can do rather than what they cannot (Crampton & Eley, 2013).

Kate Swaffer, a person living with dementia and a dementia activist, highlighted the importance of communication in an online webinar on dementia rights:

What use is it for me to go to a bank or supermarket if the staff can't communicate with me? Not to provide equitable access ... for everyone is like asking someone without legs to climb a flight of stairs.

(Swaffer, 2020b)

Swaffer's (2020) quote has been included here as it demonstrates with stark honesty a lack of parity that may be seen as unacceptable if it was experienced by someone living with a physical disability. The example outlined should act as a benchmark when considering whether a lack of access is unjust or undignified, in that we must ask ourselves what our reaction would be if a person with any other disability was unable to gain access to a particular service or activity and consider whether a person living with dementia is also entitled to experience and enjoy those same rights of access as laid down by legislation (Convention on the Rights of Persons with Disabilities, 2006).

Clearly, the ability to communicate with a person with a disability, including dementia, is an integral aspect of accessibility and the importance of communication in all its forms needs to be adequately reflected in staff training and competencies. Strategies to help staff members communicate with people living with dementia were

discussed at some length in programme theory five including the use of mnemonics such as the MESSAGE strategy (Smith *et al.*, 2011) to help guide communication practice. Emphasis should also be made on the importance of non-verbal communication, particularly facial expressions, as research suggests that people living with dementia understand this form of communication for far longer than the spoken word (Young & Manthorp, 2009).

One of the main areas identified in the realist synthesis for best practice dementia awareness and support training, was the involvement of people living with dementia to reduce fear of the unknown (MacPherson *et al.*, 2009) and challenge the stigma and prejudice surrounding the condition (Parveen *et al.*, 2018). The underlying theory of contact education was discussed as part of programme theory three (see section 6.2) and it is recommended that contact with a person living with dementia should be an integral part of any training package within the aviation sector in the future for the reasons specified.

7.4.2.1 Lack of understanding of the travel companion's role

Participants in both the living with dementia and the travel companions groups reported that they had experienced conflicts between security protocols and the need for the person living with dementia to receive additional support at certain points of the airport journey from their travel companion. These points tended to be those aspects of the airport with increased complexity such as negotiating automated systems, certain aspects of security, and at border and passport control (Edwards *et al.*, 2016). The main challenges at these points were the complete

separation of the person living with dementia from their travel companion or the staff on duty refusing to enable the travel companion to assist the person living with dementia.

Given that the interviews were conducted post the issuing of landmark guidance on supporting people with hidden disabilities within airports, this demonstrates that some aviation staff remain unaware that people with hidden disabilities should not be separated from the person they are travelling with (CAA, 2016a). It also demonstrates a lack of understanding of the role of the travel companion as an advocate for the person living with dementia, with some of the companions reporting that they are able to take complex instructions and relay them in a way that the person living with dementia understands. While some of the incidents of separation occurred when the participants were travelling without special assistance or any visible identifier such as the hidden disability lanyard, this was not the case in all incidents. Therefore, the need to keep the person living with dementia with their companion for safety, reassurance, and advocacy purposes, particularly at the key pressure points, (CAA, 2016a; CAA, 2018a), is deemed essential in any training package for the aviation sector.

7.4.2.2 Who should receive training within aviation?

The question of who should receive dementia awareness and support training within aviation was discussed at some length with the project's Reference Group (See Appendix A / RG13). The Reference Group are of the opinion that all customer facing staff should be trained to recognise and support someone living with dementia

wherever possible, and that they should have access to the Dementia Friends awareness programme (Alzheimer's Society, 2017) as an absolute minimum. This view was echoed in the interviews for this project. However, the findings of this research would suggest that a context specific airport training programme is essential for all staff likely to come into contact with a person with dementia (see section 6.4.1). One person who is not normally classed as being customer facing, but who has the final say on whether or not a person can travel on a flight is the pilot. Due to pilots having the power to enable or impede a person's ability to travel, a CAA representative indicated in a presentation to the project Reference Group that they are considering whether pilots should be included in any hidden disability training that is developed in the future as part of their new airline disability compliance scheme (Wicher, 2019).

7.5 Lack of accessibility

7.5.1 General environmental barriers

Orientation and wayfinding were reported as particular challenges within the airport environment, with participants living with dementia reporting that they found some of the airport signage difficult to see and follow. Particular concerns were raised around the high level positioning of some signs and difficulties finding facilities such as the toilets. Participants also reported that some toilets did not have clearly marked exits, which had resulted in some participants needing help to exit these facilities.

Interestingly, in a letter to The Lancet 16 dementia experts highlighted the need for improved toilet signage, including exit signage, as inaccessible facilities are linked to

social isolation and loneliness as people with dementia become increasingly afraid to leave home (Swansea University, 2017).

Some participants also noted that they found the use of directional arrows within signage ambiguous. Interestingly, a wayfinding checklist designed by the Aviation Cooperative Research Program of the American Transportation Research Board stipulates that directional arrows should be replaced with plain language wherever there is a risk of potential confusion such as where something is ‘upstairs’, ‘downstairs’, or ‘straight on’ (Transportation Research Board, 2019). The same document reports that improved signage can help older travellers and people living with a range of disabilities to negotiate airports more independently, stating that signs should be clear, well lit, non-reflective, mounted at eye level and preferably have words and pictures on them (Transportation Research Board, 2019). Whilst this document and associated wayfinding checklist is American in origin and language, research from the Airport Cooperative Research Program is driven by, and offers practical solutions to, real world aviation challenges (Transportation Research Board, 2021). This makes this document and its associated wayfinding checklist document recommended reading for any UK airport wishing to improve their environmental accessibility.

Some people living with dementia also reported airports could make better use of landmarks in their directional guidance as they could navigate using these more effectively than with spoken directions (see sections 4.1 and 4.3). This was supported by evidence gathered as part of the realist synthesis with the use of

landmarks at key decision-making points being considered a helpful navigation tool for a supportive physical environment (see Table 10 in section 6.5.5). Evidence suggests that landmarks are useful for people living with dementia as they provide visual cues that allow the person to navigate smaller sections of a route and, by travelling landmark to landmark, the person with dementia does not have to comprehend the complexity of a route in its entirety (Kleibusch, 2018). The Transportation Research Board (2019) also concurs with this recommendation stating that landmarks should be incorporated into airport design at key decision points, be visible from multiple viewpoints, but should not impede passenger flow. Examples of successful landmarks include paintings or plants (Plymouth Dementia Action Alliance, 2021).

Technological advances are also being made to assist wayfinding. For example, one UK airport has invested in a bespoke wayfinding mobile phone application, which helps to guide passengers through the airport using 2,000 navigation beacons which enable passengers to identify where they are in real time and to receive directions to where they need to be, alongside personalised gate information and flight updates (Gatwick Airport, 2018). However, it is unclear how helpful such applications would be to people with disabilities travelling alone, particularly people living with dementia, many of whom would find the divided attention aspect of walking while following a route map difficult (Atchison & Dirette, 2012).

Participants living with dementia also discussed the continued pressure of the airport journey. They experienced sensory overstimulation in terms of crowds, high levels

and different frequencies of noise, bright lights and scents and the physical pressure of standing for long periods of time while waiting and queueing. These environmental pressures exacerbated symptoms of dementia and led to an increase in anxious and repetitive behaviours, decreased confidence, word finding difficulty, fatigue, and impatience. This finding has parallels with the concept that people with dementia have a reduced stress threshold which can lead to increased anxiety and progressive functional incapacity as environmental stressors increase (Smith *et al.*, 2004). The effects of inadequate environmental design and the resultant sensory overstimulation was also discussed in the realist synthesis, with quiet and calm areas and quieter and less congested routes being seen as integral to accessibility (see Table 10 in section 6.5.5). One architect writing about dementia friendly airport design notes that while a person living with dementia needs the support of an enabling environment due to their reduced visuospatial capabilities, duty free shops are purposefully designed to cause disorientation and to hamper wayfinding in order to maximise the amount of time individuals spend in these retail areas (Jones, 2020).

The CAA has also recognised the impact of the airport environment on those with hidden disabilities, recommending that quiet routes and rooms be offered to passengers to negate some of these environmental stressors (CAA, 2016a).

However, the fact that the majority of the participants in this study indicated that they would benefit from such facilities, but were unaware that such facilities existed, let alone that they were entitled to access them, again indicates that more needs to be done to publicise the support that is available. This need to recognise and uphold the rights of people living with dementia was echoed by ADI (2020) when launching the World Alzheimer Report, particularly in terms of the importance of equality of access

to the built environment and the urgent action needed to move from rhetoric to reality on this subject. One of the key authors of the report, Charras (2020), argues that environmental barriers cause those living with dementia to withdraw from society much earlier than is necessary due to believing that they can no longer cope in social settings. However, Charras's (2020) assertion that inaccessible environments automatically reflect organisational and societal attitudes to those living with dementia is open to debate. As highlighted in programme theory two of the realist synthesis, a further, more pragmatic, explanation for the inaccessibility of environments and organisations' inaction to support those living with dementia may be that it has simply not occurred to them that there is a problem. Or that they are in a position to improve both access and quality of life for this group. However, a study of dementia friendly tourism did identify that some businesses actively chose not to cater for people with dementia as they were concerned that to do so may discourage other customers (Connell *et al.*, 2017).

7.6 Lack of consultation and involvement

The WHO (2011) identified that those living with disabilities were frequently excluded from contributing to discussions and decisions that directly affected their lives. The importance of placing those with lived experience at the centre of healthcare practice was highlighted in the NHS white paper which stated '[that there should be] no decision about me without me' (Department of Health, 2010a, p.3). While including people living with dementia is also considered to be integral to any dementia friendly project (Crampton & Eley, 2013). Consultation with the disability community through accessibility forums now forms part of the CAA's quality standards for airport

disability compliance under Council Regulation (EU) 2006/1107 (2006), with a lack of such a forum lowering an airport's overall disability compliance ranking (CAA, 2019b). It is interesting to note that, while it is not a requirement, the CAA 'strongly recommends' that passengers with disabilities or those that care for them should be integral to the make-up of such a disability forum and that forums should not consist purely of representatives from disability organisations (CAA, 2019b, p.11). This could be interpreted that the CAA is concerned that airports may not consult directly with people living with disabilities, but rely on professionals from the health, social care, education and voluntary sectors instead. The CAA's recommendation to include people with lived experience in disability forums is in keeping with upholding the rights of this group (Convention on the Rights of Persons with Disabilities, 2006).

As the CAA do not report on such matters in their annual reports, it is unclear whether or not the voices of people with lived experience of disability are actually being heard in the way the CAA intended. However, it is noted that some of the study participants reported that they had been involved with a one off visit to their local airport to offer general guidance on accessibility via an airport open day or walk through. However, they were unaware of the existence of a wider disability consultation group or forum at the airport. They were also unsure how much difference their contribution had made towards improved accessibility, as they had not received any form of post visit information from the airports involved. It is therefore recommended that airports should provide feedback on any recommendations made, or advice given, by disability groups.

7.7 Inadequate funding

7.7.1 Funding as both a barrier and opportunity

Perhaps unsurprisingly, one of the major barriers to improving access for people living with dementia identified within programme theory two of the realist synthesis was a lack of funding. However, programme theory two further identified that investing in support for people living with dementia provides a commercial opportunity for the reasons stated. The link between improved access and improved profitability was highlighted in a recent airport accessibility report, whereby it was noted that inaccessible airport environments result in reduced spend within the onsite food, beverage, and shopping facilities or complete avoidance of these commercial sites altogether (Revealing Reality, 2021). Thus programme theory two, can be utilised to draw attention to the benefits of investing in improved accessibility as commercial organisations are more likely to understand and take notice of cost/benefit discussions than those centred purely on consumer need. This will be discussed further in section 7.8.2.

7.7.2 Covid-19 and its impact on the aviation industry

At the time of writing this thesis, travel and border restrictions due to the Coronavirus pandemic were having a devastating effect on the global aviation industry, with one report estimating that the total job losses in the sector could exceed those seen in the demise of the UK coal industry in the 1980's (New Economics Foundation, 2020). Whilst it could be argued that improved accessibility is not a priority for the aviation industry given the challenges it currently faces, the decimation of air traveller numbers as a result of the pandemic may provide the ideal opportunity to highlight

the potential benefits of accessing a previously underexplored market segment. This is important given that a comparative analysis of data gathered in the first two quarters of 2020 demonstrated that, contrary to expectations, the numbers of air passengers requiring assistance maintained, and at points continued to grow, while traditional air passenger numbers declined overall (Ozion Airport, 2020). Whilst this data was only gathered from nine European Airports and may not be representative of all assistance travel, it does correlate with findings from the UK CAA that assistance traffic had demonstrated year on year growth prior to the Coronavirus outbreak in 2020 (CAA, 2019a). This trend could be attributed, at least in part, to greater awareness of the implementation of , which sought to both protect and highlight the rights of air passengers with disabilities. Noting this historical upward trend, Castiglioni (2020) argued that catering for passengers with disabilities has traditionally been seen as a duty rather than an opportunity within aviation, and investment in improved accessibility would help to maximise the potential of this consumer group as part of their coronavirus recovery plan. As highlighted in programme theory two, improvements for people with dementia would help a number of other passenger groups, further justifying any investment made.

7.8 Data and evidence

The WHO identified that a lack of evidence of disability issues can be a major barrier to understanding and action in any setting (WHO, 2011). As noted in chapter 2, the evidence-base for air passengers with dementia and those who travel with them is extremely limited. This research has made a unique contribution to knowledge in that it has identified the lived experiences of people with dementia and their companions

when travelling by air from the UK. The best practice elements of dementia awareness and support training outside of the field of healthcare have been identified using realist methodology, the resulting framework is shown in Figure 9 (see section 6.8) and may be utilised as a form of checklist when creating such training in the future. This research supports the findings of an Australian study (Edwards *et al.*, 2016), whereby many of the problems experienced by people living with dementia were landside rather than airside, with lack of awareness of the help available, sensory overload, and wayfinding and orientation difficulties all proving to be considerable barriers to participation.

A further study of air passengers within the UK was completed in 2020. The survey claims to be the largest of its kind within aviation capturing the views of 11,400 passengers, 150 airport staff and 60 stakeholder groups, however it should be noted that the majority of the data was captured through quantitative means, such as surveys, with just 12 qualitative in-depth interviews being conducted (Revealing Reality, 2021). This therefore limits the scope of lived experience and discussion of barriers to air travel outside of the data captured by the standardised survey questioning. It is also unknown how many people from each of the five categories of personal circumstances took part in the study. While the report does mention cognitive personal circumstances as one of the five categories of personal circumstances as previously noted, there is no specific mention of dementia within the report which is potentially a missed opportunity for raising awareness that people living with dementia still want to travel by air.

Whilst the target audience for Revealing Reality's (2021) report is unclear, it is also surprising that, while the report discusses air passengers' needs and expectations, it does not reinforce the importance and duty of upholding their rights to equality of access through applicable legislation (Convention on the Rights of Persons with Disabilities, 2006; Council Regulation (EU) 2006/1107, 2006; Equality Act 2010). However, the Revealing Reality (2021) report has added considerable value to the arguments around the diversity of special assistance passengers, and the need to move away from the traditional PRM terminology towards something more appropriate such as PRS. However, it is noted that this research was funded by Heathrow Airport, the key staff for whom are already familiar with some of the challenges for people with hidden disabilities due to their membership of the Prime Minister's Dementia Challenge Group for Air Transport. As the surveys and stakeholder interview questions for the Revealing Reality (2021) research have not been published along with the findings, caution needs to be expressed as to whether the questions may have been in any way leading due to the staff's existing knowledge of this topic.

7.8.2 Facilitating change within Occupational Therapy

While the WHO discuss the importance of creating evidence in order to facilitate change for people with disabilities (WHO, 2011), evidence creation on its own is unlikely to significantly change the status quo. Indeed, it has been suggested that only 14% of evidence-based interventions are translated into practice, with translation of that evidence taking anything up to 17 years (Nilsen & Birken, 2020). Whilst these statistics are startling, it is unclear how they have been derived.

Essentially, however, evidence needs to be used to make a case for change as per programme theory two of the realist synthesis (see section 6.2). This programme theory identified that greater understanding of contextual consumer challenges, alongside potential commercial and staff benefits, may lead to increased receptivity and uptake of training. It was further argued that this programme theory was underpinned by behavioural psychology and marketing and communication theory and could be better understood through the use of the Attention, Interest, Desire, Action or AIDA model (Tuan, 2015). A practical application of the AIDA model as it applies to the implementation of dementia awareness and support training within aviation is shown at Figure 16.

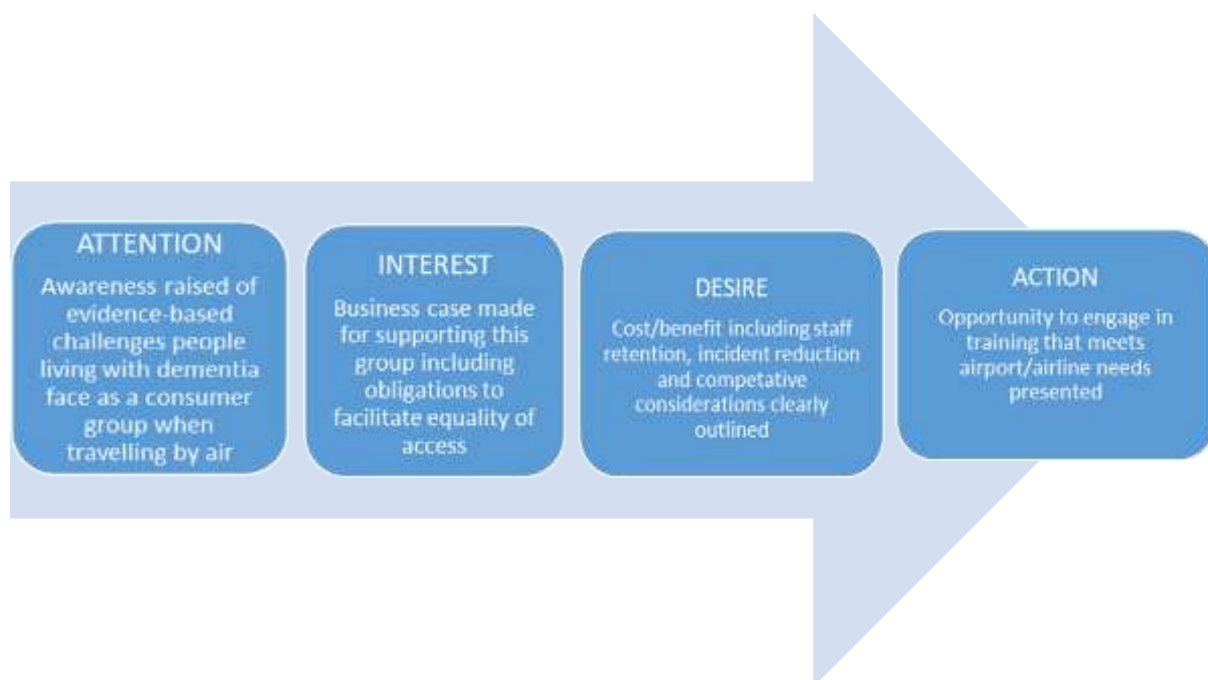


Figure 16 - Use of the AIDA model to facilitate training uptake in aviation

The need for a proactive, rather than a reactive, stance in highlighting occupational injustices is a key part of the call for the occupational therapy profession to become more politically active by working and advocating for people not just at an individual

level, but also at a societal level (Kirsh, 2015). Indeed, Pollard and Sakellariou (2014) assert that, as identifying, enabling, and advocating for people to overcome barriers to participation is integral to occupational therapy practice, occupational therapists are inherently political. However, it is unclear how politically active we are as a profession in reality.

Advocating for the needs and rights of people living with dementia has been core to my ethos throughout this doctoral study. From the rights-based approach used when requesting ethical clearance, to being an active member of a local airport's disability consultative committee and as a member of the Prime Minister's Dementia Challenge Group for Air Transport. This has enabled challenges and solutions derived from the research to be shared with key change makers such as airports, airlines, cabin crew and the UK CAA. The research has also been discussed with members of I-D-Air and added to a joint presentation of the group (Howard *et al.*, 2020). This recognises that individual airports and airlines can only do so much to facilitate change and that a cultural shift is needed to improve accessibility for people with hidden disabilities across the wider aviation industry (Revealing Reality, 2021), with occupational therapists arguably having a key role in facilitating that cultural shift.

7.9 The meaning of air travel and the dimensions of occupation

Whilst this chapter has focussed on the barriers to air travel, utilising the headings of the WHO's world report on disability (WHO, 2011), a further area for discussion

about the importance of air travel for people living with dementia was captured within the study – *the meaning of air travel*.

Both those living with dementia and their travel companions indicated that being able to travel was a meaningful occupation for them. The meanings ascribed by the participants are shown in Table 11. The meanings have been categorised into the accepted occupational science concepts of doing, being, and becoming proposed by Wilcock (1999) as a construct of the dimensions of occupation needed for health and wellbeing. Wilcock's work has been widened to include the dimension of belonging (Hammell, 2004) but all dimensions have been critiqued for lacking justification and evidence (Hitch, Pépin & Stagnitti, 2014). Also, a recent framework analysis of occupational therapy models has identified that the dimension of belonging tends to be seen as contextual, rather than a driving factor, in occupation (Hitch & Pepin, 2021). Therefore, the section on belonging has attempted to capture the participants' feelings and experiences in relation to this dimension of occupational engagement.

Doing	Continuing to engage and do everyday occupations provided those living with dementia with control over their condition, with the majority of participants wishing to engage in air travel for as long as possible post diagnosis. Some people living with dementia have developed established routines within the airport and aircraft environments as part of their adaptation techniques.
Being	For some participants engagement in air travel and being able to visit destinations overseas allowed them to be themselves without judgment, while for others it allowed them to relax away from everyday pressures of living with dementia at home. There was considerable emphasis throughout the study on the importance of how travel allowed those living with dementia to be their authentic selves. While some explained the sheer pleasure of being a traveller. Spending time in the sunshine, swimming in the sea, and the enjoyment of being in the moment.
Becoming	Those living with dementia are becoming more adept at understanding their rights and asking for, and expecting, these rights to be upheld. In doing so, they are moving away from disempowering societal expectations to a state of empowerment. Awareness of their rights allows people living with dementia and those who travel with them to continue to travel by air by asking for support as needed throughout the travel chain. There was also emphasis on the restorative nature of travel with people living with dementia reporting that their breaks away enabled them the time and space to rejuvenate.
Belonging	Travel by air allows people living with dementia and those who travel with them to participate in occupations in places, and with people, of significant meaning. While some people viewed returning to familiar destinations as a coping strategy, for others visiting familiar destinations and family and friends were integral to their self-concept and feelings of belonging. Fundamentally, those living with dementia saw continued participation in meaningful occupations like travel as being key to them belonging to, and being part of, general society rather than being seen as outsiders who have limited control over their own lives.

Table 11 - The meaning of travel for people living with dementia

Reporting the meanings ascribed to air travel within these dimensions, which are now widely accepted within occupational science and models of practice (Hitch & Pepin, 2021), is not without its challenges however. For example, it is unclear which

dimension one of the most meaningful aspects of travel as reported by some participants might be placed within. Travel companions reported that making, and reflecting on, memories was very important to them, particularly after the person with dementia could no longer remember their memories or had died (see section 5.2). While taking part in the interviews and reading their interview transcripts brought back important memories for some of the participants living with dementia and provided them with a lasting record of holidays that they could look back on. The difficulties encountered in trying to label occupations has been noted in the literature, in that some occupations are hard to quantify and can be described as meaning more than one thing to one person (Hammell, 2009).

Roberts and Bannigan (2018) recognised the limitations of utilising accepted occupational science dimensions when considering the meaning of occupations in general, proposing a new framework for how meaningful occupations, and the associated therapeutic value of those occupations, might be understood. The rationale for this framework was the lack of evidence for the traditional dimensions of occupation (Hitch, Pépin & Stagnitti, 2014). Consequently, Roberts and Bannigan (2018) completed a qualitative metasynthesis of 20 occupational science studies containing primary interview data on the meaning of occupation to add to the evidence base on this topic. Their resulting framework, using the headings of the four main themes of meaning identified, has been used in Figure 17 to outline the meaning of air travel by way of comparison to the traditionally accepted dimensions of occupation.

<p>Fulfilment</p> <ul style="list-style-type: none"> • Continuing to engage in the meaningful occupation of travel • Increased self-esteem from defying poor societal expectations • Learning new routines in order to remain engaged in travel 	<p>Identity</p> <ul style="list-style-type: none"> • Ability to be their true selves without judgment when on holiday • Increased sense of self through re-connection to people and places • Sense of achievement and self-esteem from maintenance of usual routines • Ability to make new personal and social travel memories • Asking for help may be a turning point in an individual's sense of self.
<p>Meaning of air travel for people living with dementia</p>	
<p>Restoration</p> <ul style="list-style-type: none"> • Opportunity to rest and relax away from everyday pressures • Pleasure derived from spending time in the sea and sunshine and from living in the moment • Rejuvenating effects of being on holiday – the feeling of travel being a tonic 	<p>Social, cultural, and intergenerational connection</p> <ul style="list-style-type: none"> • Facilitates connection to people and places of significant meaning • Travel companions can support people living with dementia to remain engaged • Provides a means of being part of, rather than separate from, society • Reminiscing about the experience reconnects people with important memories, people and places across time and space

Figure 17 - Dimensions of meaning associated with air travel (adapted from Roberts and Bannigan 2018)

Arguably, given the importance of both making and recollecting memories in the occupation of air travel, Roberts and Bannigan (2018) provide a clearer framework for capturing this information as demonstrated. It is also interesting to note that remembering personal experiences, and how this concept might link to the dimensions of occupation, has received very little attention in the occupational science literature, suggesting that further research is needed on this topic. The concept of participating in interviews being potentially beneficial to those living with dementia is also considered to be an important finding for future researchers when deciding whether or not to include people living with dementia within their studies (Cridland *et al.*, 2016). As, aside from a person with dementia's right to be supported to take part in research (National Dementia Action Alliance, 2020), remembering past-experiences may contribute to their sense of self, their self-esteem and their overall wellbeing. Accordingly, recommendations related to these two points will be made in the next chapter.

7.10 Chapter summary

This chapter has explored the main barriers to air travel for people living with dementia and those who travel with them utilising headings from the world disability report as they are embedded in disability and rights legislation and focus on increasing participation (WHO, 2011). As it has been noted that travel encompasses numerous points where barriers can occur, through the so-called travel chain, these barriers have also been depicted chronologically in Table 12 to demonstrate that barriers can occur both prior to and during travel. The next chapter, chapter 8, will provide a conclusion to this research and provide guidance on how some of the

barriers identified in this research and discussed in this chapter may be reduced for people living with dementia and their travel companions.

<p>↓ Pre travel</p> <ul style="list-style-type: none"> ○ Risk aversion and paternalistic attitudes may cause some people with dementia to cease travel earlier than needed ○ Difficulties obtaining travel insurance, potentially due to imprecise risk profiling of people living with dementia ○ General lack of awareness of the rights of, and what services are available to, passengers with a hidden disability like dementia. ○ Airline special assistance information and booking pages can compound confusion around eligibility by focussing heavily on those with a physical, rather than a hidden, disability
<p>↓ At the airport</p> <ul style="list-style-type: none"> ○ Prevalence of wheelchair symbolism at the special assistance counter and use of the 'PRM' acronym are perpetuating eligibility confusion and dissuading some people with hidden disabilities from asking for help ○ Sensory overload from noise, crowds, scents, and artificial lighting, with a lack of awareness of the availability of quiet routes and rooms ○ Lack of awareness of rights when unforeseen situations occur such as travel delays ○ Conflicts between security protocols and accessibility needs throughout the airport journey resulting in a) separation from travel companions at key pressure points and b) lack of recognition of the role of the travel companion as an expert communicator and advocate ○ Poor or ambiguous signage and lack of landmarks can affect wayfinding ○ Lack of communication skills to enable staff to adequately engage a person with dementia and/or recognise and assist with the challenges they face at key pressure points ○ Concern that use of assistance services and accessible toilets and seating will foster negative responses from other passengers due to generalised lack of public awareness of hidden disabilities
<p>↓ Boarding the aircraft</p> <ul style="list-style-type: none"> ○ Uncertainty over use of priority areas at the gate ○ Lack of awareness of entitlement to priority boarding ○ Concerns around lack of overhead luggage space if opting to board last
<p>↓ Inflight</p> <ul style="list-style-type: none"> ○ Concerns over being separated inflight ○ Dehydration risks due to fear of using on-board toilets ○ Difficulties with decision making under pressure e.g. drinks/meal choices. ○ Lack of awareness of what assistance can be offered by cabin crew
<p>↓ Arrival at destination</p> <ul style="list-style-type: none"> ○ Limited guidance on how to access special assistance on arrival or during connections causing continued apprehension ○ Language barriers may amplify difficulties with obtaining person-centred assistance in some destinations

Table 12 - Barriers throughout the air travel chain for people living with dementia and their companions

7.10 Reflexive Commentary

Writing this chapter has proved somewhat challenging as there are so many potential avenues that could be discussed both from the findings of the qualitative interviews and the realist synthesis. Clearly, the final subjects chosen for further exploration are open to potential influence from my own experiences and it is important to recognise and to highlight this. Whilst the discussion is embedded within the research findings and supported by legislation and evidence, some of the subjects chosen for further discussion have undoubtedly been influenced by my personal experiences, values, and beliefs about what might be considered important.

For example, my firm belief as an occupational therapist that people have the right to engage in occupations and to be their true selves, has undoubtedly influenced the rights-based framing of this chapter. As has my interest in human rights activism through my membership of a human rights Charity. The focus on contact education, and the belief that the inclusion of people living with dementia can reduce fear of the unknown and challenge stigma, is also closely aligned to my belief in the importance of inclusivity over marginalisation. This has direct links to my Nan's experience of increasingly becoming a passive observer in her own life following her dementia diagnosis. While the concept of balancing supporting a person living with dementia to continue to engage in meaningful occupation with the stressors that such support can bring to the carer, has an obvious link to my longstanding work with carers and my Mum's personal experiences of managing this balance when caring for my Nan.

Interestingly, these links were not immediately apparent when I originally wrote the chapter, only on writing this reflexive entry when I challenged myself by asking why I have focussed on the areas for discussion that I have. However, the fact that these issues have been highlighted by the primary and secondary research undertaken for this thesis demonstrates their value and importance for further discussion. This is particularly important given that many of the issues that were being discussed more than a decade ago, such as paternalistic attitudes and risk aversion, and a disproportionate focus on physical attributes of disability, are still contributing to reduced participation for people living with dementia today.

CHAPTER 8: CONCLUSION AND IMPLICATIONS FOR PRACTICE

“Why do we focus on a diagnosis of dementia as being the end of someone’s life, as opposed to them beginning to live their life differently?”¹⁴

(Reference Group Member - Liz Hitchins, 2019)

8.0 Introduction

The first two chapters of this thesis outlined the background to the study and provided an overview of the limited literature and knowledge on the topic of air travel for people living with dementia and their travel companions. At the end of the literature review within chapter 2 it was apparent that there was a knowledge gap in the literature on the barriers and facilitators to air travel experienced by people living with dementia and their travel companions within the UK. It was also apparent from the limited evidence available that staff within the aviation sector did not always know how to support people living with dementia and their travel companions when travelling by air. This lack of training and knowledge of dementia was further highlighted by a discussion of critical incidents in chapter one where the special assistance programme, and wider aviation representatives such as UK Border Force, had at times failed to recognise, support, and protect people living with dementia when travelling alone in the airport environment.

¹⁴ Quote used with permission

Chapter 3 outlined the methodology for the study which sought to both a) capture the lived experiences of people with dementia and their companions when travelling by air and b) explore best practice dementia awareness and support programmes outside of the field of healthcare. Chapters 4 and 5 outlined the lived experiences of air travel for people with dementia and their travel companions respectively from semi-structured interviews undertaken with these groups. While chapter 6 built a programme theory of best practice elements of dementia awareness and support training, culminating in a transferable realist refined programme theory at Figure 9 (see section 6.8). Chapter 7 discussed the findings from chapters four, five, and six. This chapter will provide conclusions for the research, including suggestions for how some of the main barriers to air travel, as identified in chapter seven, may be overcome.

A best practice-training framework will also be provided, highlighting some of the key mechanisms discovered as part of the realist synthesis in chapter six (see Table 15). This is followed by the implications for future practice, the impact of the study to date including an innovative method of disseminating some of the study's key findings, the limitations of the study, and areas for future research. The chapter will end with a final reflexive entry.

8.1 Contribution to knowledge

When this study began, it was apparent that there was limited evidence on the air travel experiences of people living with dementia and their companions, with the majority of evidence available being purely anecdotal (Warren *et al.*, 2016). It was

also the case that research which included the voices of people living with dementia was limited due to the perceived difficulties in obtaining ethical clearance to interview this group, with researchers relying heavily on the opinions and experiences of proxies (Risser *et al.*, 2015).

From the outset, it was my intention that this research should address these two gaps in knowledge of this subject. While there has been a study on air travel and people with dementia in Australia, this research represents the first known study within the UK to explore the phenomenon of air travel from the perspectives of people living with dementia and their companions in any depth. This exploration of the dual perspectives of the person with dementia and their companion allowed for a fuller investigation of the phenomenon of air travel from both points of view, and recognised that companions of people with dementia have expertise that complements the knowledge derived from those diagnosed with the condition. Findings have been shared with key policy makers, legislators and aviation representatives throughout the research journey through the Prime Minister's Dementia Challenge Group for Air Transport. Whilst the study was undertaken from the perspective of passengers and travel companions of people living with dementia within the UK, the learning derived extends beyond this context with key findings being shared with other researchers and interested parties through an International Dementia and Air Travel Research Group (I-D-Air) chaired by Mr Ian Sherriff, BEM.

Recommendations for addressing some of the barriers to air travel as identified and discussed in chapter 7 are outlined utilising headings in line with those of the WHO world report on disability for ease of reference (WHO, 2011). Recommendations

from participants on some of the factors that helped them to facilitate travel and lead to positive experiences will also be shared (see Table 13).

8.2 Recommendations for removing barriers to participation in air travel

8.2.1 Inadequate policies and standards within aviation

The difficulties encountered by people living with dementia and their companions in obtaining competitively priced travel insurance were discussed in section 7.1.1.

Whilst the work of the Insurance United Against Dementia task group is undoubtedly helping to support staff and customers affected by the disease (Alzheimer's Society, 2021b), the issue of imprecise risk profiling underpinning inflated premiums remains a concern. As this is outside the scope of this doctoral research study, *it is **recommended** as an area for further research.*

This study identified that the UK CAA as the National Enforcement Body for EU Regulation 1107/2006 has been active in improving the accessibility of air travel for people living with hidden disabilities including dementia (CAA, 2016a; CAA, 2018a; CAA, 2018b). However, those interviewed were largely unaware of these policies and the assistance services available to them including the availability of the hidden disability lanyard scheme (Gatwick Airport, 2016). The lack of awareness around the CAA's hidden disability policies extended to those participants within the study who would describe themselves as dementia activists, and for whom understanding and knowledge of anything that would support their rights is important and empowering.

*It is therefore **recommended** that in readiness for the recommencement of international air travel (see section 8.4.5) an article is co-written by the researcher and members of the project Reference Group on the rights of people living with dementia when travelling by air. As the intention of this article is to raise awareness of the help available to people with dementia and those who travel with them, publication needs to be sought in an accessible magazine such as 'Living with Dementia' published by the Alzheimer's Society. As the researcher also has contacts with members of the Three Nations Dementia Working Group, a joint article or webinar with this group would also be beneficial. As this research identified a number of hints and tips from people living with dementia and their companions (see Table 13), inclusion of these within such an article or webinar would also be highly beneficial for other travellers in a similar position. It is also **recommended** that the CAA should utilise the recommencement of international air travel as a catalyst to inform passengers of the special assistance that is available to people with a range of disabilities through social and other forms of media such as print and television news.*

Focus	Recommended strategies for air travellers with dementia
<p>From people living with dementia</p> <p>(see chapter 4)</p>	<ul style="list-style-type: none"> • <i>Air travel is possible, but it helps to plan and ask for help</i> • <i>Request assistance at the time of booking – you have the right to do this or ask a travel agent to help book assistance for you</i> • <i>Travel agents can also help with recommending hotels that are small and quiet and booking seats on the plane</i> • <i>Check the airport's website for what assistance facilities are available</i> • <i>You have the right to use assistance services at the airport like the hidden disability lanyard scheme, accessible toilets, priority seating and priority boarding</i> • <i>If you experience sensory overload take headphones and sunglasses to help block out the noise and light</i> • <i>Travel with a trusted companion</i> • <i>Allow plenty of time</i> • <i>Maintain a positive attitude</i> • <i>If you are travelling a long way to the airport consider staying at an airport hotel the night before travel</i> • <i>Minimise check-in luggage and take one item of hand luggage</i> • <i>Identify how many items you are carrying at the start of the journey – coat, scarf, bag, etc – and check the number of these items regularly</i> • <i>Adapt the way you travel – a single destination is better than a multi-centre trip</i> • <i>Travelling from small regional airports can be easier than some of the national airports</i> • <i>Returning to the same destination can help with recall and confidence</i>
<p>From travel companions of people with dementia</p> <p>(see chapter 5)</p>	<ul style="list-style-type: none"> • <i>Travelling from a local airport negates the need to stay overnight</i> • <i>Travelling from the same airport can help to create a familiar routine</i> • <i>Investigate airport facilities online or in person before you go or attend an airport familiarisation day</i> • <i>Plan your departure and arrival times to avoid busy periods/rush hour</i> • <i>Apply for a blue badge to reduce walking distance/time at the airport</i> • <i>Allow plenty of time</i> • <i>Consider travelling with other people for support</i> • <i>Have a plan for if you become separated</i> • <i>Pack essentials – tissues, moist wipes, spare items of clothing</i>

	<ul style="list-style-type: none"> • <i>Take a rucksack rather than a handbag as it frees up your hands</i> • <i>Upgrade your travel or consider an airport lounge</i> • <i>Prepare for security to reduce the risk of being stopped</i> • <i>Ask for help / request special assistance and ask for a hidden disability lanyard</i> • <i>With the right help you do not have to give up travelling too early</i>
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Table 13 - Hints and tips from people living with dementia and their companions derived from the interviews

The participants also suggested a number of innovations that airports could make in the future to improve the experience for people living with dementia and those who travel with them. Those suggestions are shown in Table 14.

Suggested innovations for airports
<ul style="list-style-type: none"> ✈ Fixed 'you are here' stands and maps ✈ A film of the airport journey that people with dementia can watch before travel ✈ An expansion of the lanyard scheme so that both the person with dementia and their companion can wear a lanyard to signify that they are together ✈ Greater information on the re-use of the lanyards for future travel in the same or a different airport ✈ A card that the person with dementia can carry in their passport so that anyone at border force can identify why the passenger may have difficulty explaining their future and past travel arrangements ✈ An accessibility guide detailing all the services that a passenger with assistance needs can expect at the airport they have chosen. The guide could appear on the airport's website and/or be automatically sent to the person requesting special assistance when their booking is made

Table 14 - Innovations for the future suggested by participants

As the WHO recommend that enforcement of policies can improve disability standards (WHO, 2011), *it is also **recommended** that the CAA considers the implementation of a visible system whereby airports need to display their annual disability compliance ranking at their assistance counter and online.* This ranking is awarded as a result of the CAA's annual review of each airports' compliance against the standards set down in Council Regulation (EU) 2006/1107 (2006) (CAA, 2020). While the airports' annual compliance ratings are available on the CAA website and issued as a media release, airports do not currently have to display them. It is considered that the compulsory public display of each airport's disability ranking

would both encourage the airports to maintain or improve their disability compliance standards and empower passengers to choose an airport and associated special assistance service best suited to their needs.

8.2.2 Negative attitudes to people living with dementia

This research identified that those in both participant groups felt that societal expectations of people living with dementia continues to be poor, dementia stereotypes, stigmatisation, paternalism, and risk aversion are still pervasive in many areas of society including the health and social care professions. Consequently, there are a number of actions that can be taken as a result of this study to contribute to the widespread efforts of changing societal attitudes to people living with dementia by improving understanding of people living with dementia's continued aspiration and right to travel by air. *An important **recommendation** is to continue this research in terms of the development of a context specific training package for use within aviation (see section 8.6).* Whilst this study has added to the evidence base of the meaning of travel for people with dementia it was not the primary focus of this study. *Therefore, further studies on the meaning of travel for people living with dementia would help to reinforce the fact that people living with dementia still wish to engage in meaningful leisure occupations post diagnosis to further challenge societal expectations of this group.* Given the occurrence of prescribed disengagement™ (Swaffer, 2015) within this research, *a study of health professionals' attitudes and expectations of people living with dementia post diagnosis would also be an interesting topic for further investigation.*

This research identified that travel companions were one of the main facilitators to travel for people living with dementia, with all participants interviewed in the living with dementia group travelling with another person. The limitations of this for this research will be discussed in section 8.4.2. However, *the main **recommendation** derived from this is that the role of companions as enablers and expert communicators needs to be more widely recognised within aviation.* This is due to participants living with dementia reporting that their companions were not being allowed to help them to negotiate some of the more complex areas of the travel chain, causing unnecessary confusion, stress and anxiety.

It was also noted that travelling with a person with dementia created stress and pressure on some companions. This was particularly prevalent in those companions who had travelled with people living with more advanced dementia who needed almost constant monitoring due to the fear of becoming separated from them. *It is therefore **recommended** that any guidance produced as a result of this research should recommend that companions take a version of The Herbert Protocol (West Yorkshire Police, 2020) on holiday with them just in case the person with dementia does go missing either at the airport or their destination and the local Police need to become involved.* The Herbert Protocol was created for people with dementia at risk of going missing and contains information that will help the Police to locate the person with dementia such as clothes worn and a recent photograph (West Yorkshire Police, 2020). *Further research into the benefit of assisted travel for people living with dementia and their companions is also **recommended**, both within the UK and abroad.* Improvements to, and an increase in, assisted travel options would give participants with dementia and their companions a further opportunity to

keep travelling when the companion can no longer manage to support the person living with dementia on their own.

8.2.3 Lack of provision of services within aviation

This research identified that there is a lack of knowledge and confusion around special assistance provision and eligibility. Participants felt this was compounded by airlines' propensity to focus on physical disabilities within their online special assistance booking services and airports' continued use of physical disability imagery in their special assistance signage. *It is therefore **recommended** that airlines are encouraged to improve the accessibility of booking special assistance through their website for people living with hidden disabilities and those who travel with them. The online booking should incorporate support options for people with a range of hidden disabilities, and not just focus on the support options available to those with physical disabilities.*

*It is also **recommended** that airports follow the example of Airports Council International in their capacity as the worldwide representative of airports, and individual airports such as London Heathrow, in moving away from the PRM acronym to better reflect the needs of the passengers it seeks to serve (ACI, 2018; Marchant, 2021).* Although it would be beneficial if a consensus could be reached on the new acronym to avoid further confusion, with ACI advocating a change to 'PWD or persons with disabilities' (ACI, 2018) and London Heathrow moving to 'PRS or people requiring support' (Marchant, 2021). Given this potential disparity, there is

clearly a role for the UK CAA, alongside UK aviation representatives, to *recommend a consensus change in terminology to better reflect passenger diversity and needs.*

*A further **recommended** change that all airports could make is to adopt the ‘for people with any disability’ symbol (StudioLR, 2019b) on their websites and at their special assistance desks, and on accessible facilities throughout the airport environment such as waiting areas, priority seating, and toilets (see Figure 15, section 7.3).* This change in signage would have the dual effect of increasing public awareness of hidden disabilities and also reduce the fear that some people with dementia have of making use of these facilities for fear of retribution from other passengers.

8.2.4 Problems with service delivery within aviation

This research identified a lack of service coordination between airlines and airports as a barrier to air travel for people living with dementia and their companions. Special assistance requests were frequently not shared or, when they were shared, the special assistance teams were unsure how to support someone living with dementia. *It is therefore **recommended** that the CAA consider implementing a quality check around communication of special assistance needs between airlines and airports as part of their airline disability compliance framework (Wicher, 2019).* However, the main **recommendation** under this category is for improved training within the airport environment. The findings from the qualitative interviews and the realist synthesis identified a number of areas for inclusion in any training package. As the realist refined programme theory (see Figure 9, section 6.8) covers pre and

post training activity, the key items recommended to be included in any future training package have been set out separately in Table 15.

Focus	Recommendations
Airport staff	<ul style="list-style-type: none"> • <i>Co-produce and present training with people with dementia to reduce fear and challenge stigma and preconceptions</i> • <i>Explore the rights of passengers with dementia to participate in air travel as set down by legislation and CAA policies</i> • <i>Walk any key routes with a person with dementia or companions to identify, discuss and resolve any problematic touchpoints</i> • <i>Emphasise how a staff member can ‘make or break’ a person living with dementia’s experience and the effect they can have on their emotional memory</i> • <i>Emphasise key attributes of dementia friendly staff including patience, understanding, empathy and being non-judgmental</i> • <i>Include communication strategies such as the MESSAGE strategy (Smith et al., 2011) and the FRIEDA principles (Butchard & Kinderman, 2019) to help staff engage with people living with dementia and understand their rights</i> • <i>Emphasise how separating a person living with dementia from their companion and the stressors from key pressure points such as security and border control can adversely affect their communication and functional ability</i> • <i>Emphasise the need for greater recognition of the travel companion’s role as an expert communicator</i> • <i>Include context specific interactive activities to facilitate peer and group learning</i> • <i>Include discussion on potential low cost solutions for changes that can be made within the setting and how this may help other customer groups</i> • <i>The need for airports and airlines to move away from the PRM acronym due to better represent passenger diversity</i> • <i>Recommend that ALL airport staff should have access to the Alzheimer’s Society Dementia Friends and Dementia Champions awareness programmes as a minimum</i>
Airline staff	<ul style="list-style-type: none"> • <i>Include applicable elements from airport staff section above</i> • <i>Include the pilot in any training as the key decision maker for whether or not a person with dementia is allowed to travel</i> • <i>Encourage cabin crew to discuss what they are and are not able to help with when settling priority passengers into the cabin</i> • <i>Encourage cabin crew to provide guidance on how to use toilet facilities on board and to reiterate that they can be unlocked from outside if needed</i>

	<ul style="list-style-type: none"> • <i>Encourage cabin crew to remind passengers of the dehydrating environment of the aircraft which may exacerbate a person living with dementia's cognitive ability</i> • <i>Ensure that cabin crew are aware of any passengers with dementia who may need additional time or support to make drink or food choices.</i> • <i>Encourage cabin crew to reassure special assistance passengers of the procedure for disembarkation including any connecting flights</i>
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Table 15 - Key elements derived from this training for context specific aviation research

8.2.5 Lack of accessibility

Physical barriers for people living with dementia identified within this study were orientation and wayfinding, the pressure of the airport journey in terms of sensory overstimulation and the physical and cognitive pressure of the prolonged periods of queuing and waiting. *It is therefore **recommended** that airports audit their environments utilising a wayfinding checklist such as that from the Transportation Research Board (2019) which has been specifically designed to assess the accessibility of an airport environment for older passengers and passengers with physical and hidden disabilities. Other **recommendations** include ensuring all toilet exit points are marked (Swansea University, 2017) and greater use of landmarks when giving verbal or written directions to people with dementia to help them find their way through the airport (Plymouth Dementia Action Alliance, 2021). The final **recommendation** is to ensure that passengers with dementia are given access to quiet routes and rooms to counter environmental stressors. It would also be beneficial for people living with dementia to be given access to other facilities that reduce pressure on them such as security slow lanes, preferably with seating areas for disrobing and robing.*

8.2.6 Consultation and involvement of people with lived experience

While the involvement of some participants living with dementia was highlighted in section 7.6, greater involvement of people with lived experience of dementia within airport accessibility forums is essential. *It is also **recommended** that, to reduce any propensity towards tokenism, the CAA considers including an expected number of people with disabilities to be recruited to any airport accessibility forum in the UK as a requirement within their regulations rather than as a suggestion. Where disability groups have completed assessments of airport environments in an advisory capacity, it is also **recommended** that it would be good practice for the airport(s) concerned to provide feedback to these groups with regard to any changes made as a result of their advice.* This is in recognition that those with dementia wish to utilise their lived experience to enact positive change for those with dementia in the future as a form of legacy (Johnston & Narayanasamy, 2016).

8.2.7 Overview of recommendations

As a number of recommendations have been made to address barriers across the travel chain, the main recommendations have been listed in Table 16 for ease of reference.

Barrier identified	Recommended Action
<ul style="list-style-type: none"> <i>Lack of awareness by passengers with dementia of their rights to access special assistance.</i> 	<ul style="list-style-type: none"> <i>Rights based dissemination campaign</i> <i>CAA media campaign highlighting support available to all passengers with hidden disabilities when travelling by air</i>
<ul style="list-style-type: none"> <i>Pressure on companions</i> 	<ul style="list-style-type: none"> <i>Request special assistance</i> <i>Complete and carry copies of relevant sections of the Herbert Protocol (West Yorkshire Police, 2020) when travelling</i>
<ul style="list-style-type: none"> <i>Focus on physical disability within special assistance services</i> 	<ul style="list-style-type: none"> <i>Redesign of airline special assistance booking pages, to include options for people with hidden disabilities to book special assistance online.</i> <i>Implementation of a sign/symbol denoting an airport's disability compliance ranking for display at the airport's special assistance counter</i> <i>Change of the PRM acronym to better reflect the diverse needs of passengers served</i> <i>Replacement of physical disability signage with more inclusive symbolism at special assistance counters and on accessible and priority facilities throughout the airport environment. For example, 'for people of any disability' signage (StudioLR, 2019b)</i>
<ul style="list-style-type: none"> <i>Lack of understanding of the needs of people living with dementia in the airport environment</i> 	<ul style="list-style-type: none"> <i>Trial of context specific training package based on the findings from this research including all recommendations in Table 15</i> <i>Improved communication between airline and airport assistance services for people with hidden disabilities</i>
<ul style="list-style-type: none"> <i>Lack of accessibility</i> 	<ul style="list-style-type: none"> <i>Airports to complete context specific accessibility checklist</i> <i>Increased use of exit signage within toilet facilities</i> <i>Improved communication of quiet routes, rooms and other facilities available to people with dementia such a security slow lanes with seating</i> <i>Greater use of landmarks within verbal and written communication to aid wayfinding</i>

<ul style="list-style-type: none"> • <i>Lack of consultation and involvement of people with dementia</i> 	<ul style="list-style-type: none"> • <i>Involve people living with dementia in airport accessibility forums and not just proxies</i> • <i>That the CAA considers it a statutory requirement within their disability compliance policies that a set number of people with lived experience of disabilities should be represented on airport disability forums (e.g. 1/3)</i> • <i>That feedback be given to dementia groups who provide accessibility advice to airports</i>
<ul style="list-style-type: none"> • <i>Lack of understanding of the needs of people living with dementia in flight</i> 	<ul style="list-style-type: none"> • <i>Trial of context specific training package based on the findings from this research including all recommendations in Table 15</i>

Table 16 - Recommended actions to address barriers in the air travel chain derived from this research

8.3 Dissemination of research findings

The findings of this research have been disseminated at a number of conferences nationally and internationally as noted in the conferences and publications at the start of this thesis. Findings have also been regularly disseminated to key change makers within aviation through the Prime Minister's Dementia Challenge Group for Air Transport, the International Dementia Air Travel Research Group (I-D-AIR), and with airports in the South West of England. It is planned that the dissemination of the research will continue through the publication of associated articles. I have also been invited to be a co-author on a book chapter on the concept of air travel and occupational justice aimed at occupational therapists that is currently in production. The use of cartoons as a novel dissemination tool of some of the key findings from this study is also planned as described in section 8.3.1.

8.3.1 Cartoons as discussion starters

During the background research for this study, I became aware of the work of the cartoonist Tony Husband. Husband's Father had dementia and his experiences were recorded in the book 'Take Care Son' (Husband, 2014). Due to his personal interest in dementia, Husband has been commissioned by a range of organisations to utilise his artistic skills to help to spread the message about what it is to like to live with dementia. Whilst it is recognised that the experiences of people with dementia differ from person to person (Social Care Institute for Excellence, 2020b), cartoons can provide an accessible means of ensuring that the voices of people with dementia are captured and shared with both the general public and those who have the ability to enact change (Beesley, Husband & McMillian, 2018). Paivio's seminal dual coding theory proposes that images can be highly beneficial in teaching environments, as verbal and visual information is stored separately within the human working memory increasing the likelihood of information retention and recall (Paivio, 1991). Cartoons have also been found to create a human connection between the character and learner and increase critical thinking and problem solving through discussion of the image content (Eker & Karadeniz, 2014).

Accordingly, with the help of a grant from the QR Strategic Priorities Fund at the University of Plymouth, Husband was commissioned to produce a series of 12 images from this research. As there were a number of potential scenarios that could be turned into images, an online meeting of the project Reference Group was held to discuss a number of quotes and to determine the final selection. During this meeting, a person living with dementia noted that it was important to not just focus on the negatives of a situation, but also on the positives so that anyone viewing the image

could both understand the difficulty and what could be done to help. An example of one of the 12 images is shown at Figure 18.



Figure 18 - Poor societal expectations of people with dementia

Image © Turner, K, Warren, A. and Sherriff, I., University of Plymouth

While a draft of a finalised poster board with the addition of further information is shown at Appendix T. The images will be utilised in a range of settings including airports, conferences, and teaching environments as a means of increasing discussion and awareness around this important subject. As the copyright now belongs to the University of Plymouth, the images will be used in a variety of ways including within online presentations and webinars. It is also planned that they will be printed out and displayed in a pop-up exhibition that can be taken to airports and dementia conferences to continue to raise awareness of people with dementia's need to engage in meaningful occupations like air travel.

8.4 Limitations of the study

8.4.1 Limited number of qualitative interviews

Whilst it is considered that the use of descriptive phenomenology aided one of the key requirements of the study, to hear the voices of people living with dementia and those who travel with them, it is recognised that a level of interpretation can never be completely avoided (Bryman, 2016). The focus on rich personal experience is also a potential limitation in itself. In total 10 people living with dementia and 10 travel companions were interviewed, so these findings cannot be deemed to be representative of a larger population. While the richness of the data is extremely useful in understanding complex social phenomena such as air travel, the lack of generalisability is a frequent critique of qualitative research in general (Denscombe, 2014). However, it is anticipated that the rich descriptions provided will allow readers, particularly those in the field of aviation, to make an informed judgement on the relevance and transferability of the findings to their own context and country.

8.4.2 Absence of data from lone travellers with dementia

It is also the case that no participants living with dementia were identified who travelled by air alone, with all participants in this group travelling with a companion. Therefore, the findings need to be viewed in the context that the reported barriers and facilitators to air travel for those living with dementia may have been different if they had been travelling by themselves. This is particularly important given that the majority of the more serious air travel incidents have occurred when the person with dementia was travelling alone (Edwards *et al.*, 2016; The Guardian, 2015; Washington Post, 2013). However, given participants' comments about their inability to obtain insurance unless they were able to confirm that they were travelling with another person, it is unclear how many people with dementia are still travelling by air by themselves. *It is therefore recommended that further research is conducted in this area in the future.*

This lack of lone traveller data also means that this study has gathered limited data to answer a frequently asked question for this passenger group: 'when should people living with dementia cease travelling by air?' Although, some of the travel companions of passengers with more advanced dementia reported that there came a point where the person with dementia could not, and indeed would not, follow the instructions of the cabin crew. This ability to follow instructions and safety protocol is a prerequisite for air travel, especially as all aircraft operators must be able to evacuate an aircraft at maximum passenger capacity within 90 seconds (European Regions Airline Association, 2018).

Accordingly, a key **recommendation** for anyone concerned about a person living with dementia's ability to follow inflight safety protocol would be to arrange an assessment visit to a replica aircraft cabin facility such as those available at Queen Elizabeth's Foundation for disabled people (2014) or the Virgin Airlines training centre (Gunner, 2019). Indeed, Virgin Airlines encourages familiarisation visits to its Gatwick training centre for passengers with hidden disabilities like dementia so that they can discuss and solve any challenges they think they may have once inflight (Gunner, 2019). The point at which a person with dementia should cease travelling by air due to safety concerns, is a further potential area for research.

8.4.3 Procedural nature of the photographic travel guide

A further challenge with the research method was the production of the photographic travel guide (Appendix C). While the guide did act as a visual prompt for key touchpoints along the air travel chain as intended (Allen *et al.*, 2017), the procedural nature of the visual guide may well explain why the final themes for both groups were very similar as it could have directed rather than guided the discussions. However, as van Manen (2017) points out, themes are not the final product of phenomenology and it is the rich descriptions that capture the essence of an experience. By following the process for descriptive phenomenology as presented in the seminal text by Colaizzi (1978), it is considered that the framework statements for both participant groups (see Sections 4.7 and 5.6) remained true to the essence of the lived experience of air travel as described to me.

8.4.4 Respondent validation with people living with dementia

One potential challenge with Colaizzi's method when working with people with dementia however is the respondent-validation element (Colaizzi, 1978). With the exception of one person living with dementia, all of the feedback to the interview transcriptions and framework statements came from the travel companions. However, when assessing the suggested changes made by companions to the people living with dementia's framework statement, I returned to the interview transcripts to identify if evidence for the suggested changes was present. Some of these changes were supported by the transcript data and consequently the changes were made. However, some suggested changes could not be supported in this way and were not included as it was considered that to do so would have taken away from the voices of those living with dementia. This potential for companions to speak for the people living with dementia was an important consideration within this study (see, for example, section 3.4.9), although its actual manifestation in reality was limited with the majority of the companions supporting participants living with dementia, demonstrating their propensity to be enabling, rather than disabling, in this regard. It is thought that one of the main reasons why companions speak for the person with dementia in this way is as a protection mechanism (Waite, Poland & Charlesworth, 2019). It is therefore considered that visiting people in their own homes, taking time to build rapport before the interviews began and explaining that there were no right or wrong answers, helped to put both the person with dementia and their companions at ease and prevented companions' highly protective nature from being triggered.

8.4.4 Realism as a new methodology

A further limitation to the study relates to the adoption of the realist synthesis methodology. This is a relatively new methodology for literature reviews and guidance on how it should be undertaken is variable and frequently conflicting. It is also the case that, while mechanisms and potential underlying transferable theories were discussed within chapter 6, another researcher may have reached different conclusions from the papers examined. However, I am confident that through the accepted realist process of inference to best explanation (Wong *et al.*, 2014), the realist synthesis has uncovered a number of areas that should be considered when designing any future dementia awareness and support training package for the reasons noted.

8.4.5 Timing of the research in light of the Covid-19 Pandemic

A final and important limitation is to note that data collection took place before Covid-19, a novel coronavirus disease first noted in the People's Republic of China in December 2019 (WHO, 2021). The virus rapidly spread to the rest of the world resulting in the WHO declaring it a public health emergency of international concern in January 2020 and a pandemic in March 2020 (WHO, 2021). Given the global threat from the virus, many Countries closed their borders to international travel, decimating the aviation industry as noted in section 7.7.2. At the time of writing (April 2021), international air travel for recreation purposes is still illegal within the UK and a date for the reopening of this sector is unknown. However, supporting all passenger groups who wish to travel by air will become a priority for the aviation industry when international borders do reopen and airports and airlines begin their

recovery (Castiglioni, 2020) highlighting the study's continued importance and relevance. *However, it is **recommended** that research on the experiences of air passengers with dementia is undertaken due to the widespread changes as a result of Covid-19. Particularly given the likelihood of the need to carry additional vaccination documentation and/or undergo testing, the need to wear a mask and the possibility of having to be quarantined on return to the UK.*

8.5 Implications for future practice in Occupational Therapy

It is now over 10 years since it was suggested that occupational therapists were ideally placed to identify barriers and solutions to participation within transport in general (Brown, 2009). This research has demonstrated that occupational therapists have the ability to utilise their skills in understanding and finding solutions for barriers within air transport. This is an area that remains open to further exploration across a range of transport options and for a range of conditions. Opportunities provided as a result of the Prime Minister's Dementia Challenge Group for Air Transport have also demonstrated the value of occupational therapists and occupational therapy students taking on the role of political activists in raising and providing potential solutions for issues of note. It is suggested that all therapists need to be political to a degree in order to facilitate change (Pollard & Sakellariou, 2014), with one author stating that activism is embedded in the very roots of our profession (Schwartz, 1992).

*It is therefore a **recommendation** of this research that occupational therapists and occupational therapy students become more politically active whatever the social or environmental change being sought.*

Arguably, occupational therapists also have a responsibility through their own actions to reduce the stigmatisation of people living with dementia. For example, by including people living with dementia within their research rather than being overly reliant on proxies and conducting and publishing research literature across and beyond the traditional dimensions of occupation. This will serve to emphasise that all people, including people living with dementia, should have the right to choose and access occupations that are meaningful to them and which improve their sense of self and personal wellbeing (Hammell, 2017).

Some dementia activists are also beginning to give in person talks about their experiences of living with dementia to students on occupational therapy degree programmes (see, for example, Oliver, 2016). This is encouraging, particularly given the importance of contact education in reducing stigmatisation of people living with dementia as identified in the realist synthesis (sections 6.3.1 and 6.3.4). However, increased use of contact education with people living with dementia within occupational therapy programmes would be highly beneficial and, to borrow the title of Keith Oliver's book, would ensure that occupational therapists of the future are prepared *and actively encouraged* to 'walk the walk and talk the talk' (Oliver, 2016).

The difficulty in defining occupational therapy was described in section 1.4.1. Within the profession, we invariably discuss our role as a variation of enabling people to do the things they want and need to do. However, the importance of recognising, upholding, and campaigning for occupational justice as an embodiment of a person's human rights was highlighted within this research (see, for example, section 7.0.1). It

is therefore recommended that occupational therapy as a profession should demonstrate the importance of this through greater recognition of a person's rights in our everyday practice. Whilst not specific to occupational therapy per se, the partnership between Queen Margaret University and Alzheimer Scotland to develop a rights-based practice module for allied health professionals who work with people with dementia demonstrates much needed innovation and leadership in this field (Maclean & Hunter, 2019). It is appreciated that not all practising occupational therapists are in a position to engage (or re-engage) with higher education, however. Consequently, a simple way all occupational therapists could begin to engage in everyday rights-based practice is to reframe their answer to the common question 'what is occupational therapy?' by stating that it is the practice of enabling a person to do the things they want, need, ***and have the right*** to do.

8.6 Areas for future research

Whilst this thesis includes a realist refined programme theory for what works in dementia awareness and support training outside of the field of healthcare, this programme theory has not been tested and evaluated. This provides an opportunity for the continuation of this research in terms of the designing and testing of a context specific training programme for the aviation industry to support people living with dementia and their travel companions when travelling by air. This would be particularly valuable given the enormous changes to the field of aviation as a result of the Covid-19 pandemic and the opportunities that this passenger group provides to the financial recovery of the aviation sector as previously noted.

The research also identified a number of other areas throughout the air travel chain where further research would be beneficial as detailed in Table 17.

Travel chain area	Recommended research area
Pre-travel	<ul style="list-style-type: none"> • <i>GP and health practitioner views on people living with dementia travelling by air post diagnosis and an exploration of the advice and support they give to their patients in this regard.</i>
Pre-travel	<ul style="list-style-type: none"> • <i>How the travel insurance industry categorises people with dementia in terms of risk profiling and the parity of insurance premiums with other health conditions</i>
Booking	<ul style="list-style-type: none"> • <i>Travel agents' knowledge of special assistance rights and services for customers with dementia</i> • <i>An exploration of the special assistance options and information available to passengers with hidden disabilities through airline and online travel booking sites</i>
Travel experience	<ul style="list-style-type: none"> • <i>The value of assisted travel to people living with dementia and their companions in the UK and overseas</i> • <i>Experiences of air travel by passengers with hidden disabilities, including dementia, post Covid-19</i>
Travel as an occupation	<ul style="list-style-type: none"> • <i>The importance of travel memories or remembering meaningful travel activities as a unique occupation.</i>
Occupational justice and human rights	<ul style="list-style-type: none"> • <i>How occupational therapists' and occupational therapy students' can utilise their core skills to enable wider participation for people with a range of health conditions within transport</i>

Table 17 - Recommended areas for future research

8.7 Final remarks

This thesis aimed to explore the phenomenon of air travel from the perspectives of people living with dementia and those who travel with them and to identify what works and why within best practice dementia awareness and support training outside

of the field of healthcare. The experiences of air travel were explored through in-depth semi-structured interviews. Both participant groups of people living with dementia and travel companions of people with dementia identified difficulties throughout the air travel chain, with the majority of the barriers identified as occurring pre-travel and at the airport rather than inflight. Hints and tips for improved air travel experiences were shared by both participant groups (see Table 13), together with suggested innovations for the future (see Table 14). While the findings from the realist synthesis have assisted in the creation of a checklist of key mechanisms that may be included in future training packages within aviation (see Figure 9, section 6.8).

As noted in section 8.3, the findings from the qualitative interviews have been shared with key change makers within aviation at regular intervals through the Prime Minister's Dementia Challenge Group for Air Transport. Pre Covid-19, the needs of air passengers living with dementia were beginning to be recognised within the UK aviation sector (CAA, 2016a; CAA, 2018a; CAA, 2018b). It is hoped that the recognition of this passenger group will continue as the sector begins to recover from the financial crisis as a result of the Covid-19 pandemic. It is also hoped that this study will add to the evidence for the occupational therapy profession and demonstrate the impact and benefits that occupational therapists can have alongside their traditional workplace settings within health and social care. This is in keeping with the occupational therapy profession's historical ambition to support those marginalised by society (Creek, 2020).

8.8 Reflexive commentary

During my doctoral studies, I have utilised elements of this research for a postgraduate workshop for occupational therapy students on the concept of occupational justice. Up until 2020, I asked the students to imagine how they might feel if they were deprived of the opportunity to engage in meaningful occupations. As I have never experienced occupational deprivation myself to any degree, I also had to imagine how it might feel when making this point. However, when I ran the workshop in 2021, we no longer had to imagine the feelings that enforced occupational deprivation might bring as our occupations, like everyone else's around the world, have been severely curtailed as a result of the Covid-19 pandemic. However, our occupational deprivation has been tempered by the promise that a return to a semblance of normality is not far away and our enforced occupational deprivation will be relatively short lived.

It occurs to me, however, that for people living with dementia their life as they know and experience it can end, or may certainly never be the same, from the day of their diagnosis due to the constraints placed upon them by a stigmatising and disabling social and physical environment. Research participant Lewis¹⁵ shared his experience of being advised by his neurologist that he should cancel his long haul holiday on the same day he was diagnosed with dementia and how devastated it made him feel. Tony Husband vividly brought Lewis's devastation to life, in one of the drawings commissioned as a dissemination and discussion tool for this research (see Figure 18). This should be compared with Figure 19 which depicts just one of the ways

¹⁵ Pseudonym

travel can be meaningful to people living with dementia as derived from this study – the sheer joy of being in the sunshine and swimming in the sea and the feeling of rejuvenation and personal freedom that comes from being in this setting.

One of the Reference Group members to this research described the power of these drawn images over verbal descriptions of the same scenarios that they had read some months previously. Whilst pictorial evidence may indeed be more powerful than verbal evidence, and research certainly suggests that it is encoded differently within our working memory (Paivio, 1991), I believe we all see and understand things differently due to our own experiences of the Covid-19 pandemic. I have previously said that I believe that occupational justice is inherently about upholding a person's human rights. However, I cannot guarantee that I would have chosen to focus on this as strongly within this thesis if Covid-19 had never occurred. If the pandemic has taught us anything, it has taught us how valuable our meaningful occupations are and how it feels to be denied access to them, even for a short time.

The realist synthesis identified that people with personal experience of dementia can be change makers. I would like to think that our personal experiences of occupational deprivation will also assist our occupational therapy practice in the future. For the next few years at least, Covid-19 will provide us with a connection with others that we can use to facilitate change for those for whom occupational deprivation is a regular occurrence. No-one has to imagine what it is like to experience occupational deprivation anymore, including those who are in a position to enact change. For people living with dementia that shared level of understanding

may be the catalyst needed to begin to address what has historically been an unjust and unwelcoming world, with occupational therapists continuing to strive to enable participation in those meaningful occupations that people living with dementia want, need, and **have the right**, to do.



Figure 19 - Travel as a tonic: the meaning of air travel for people living with dementia

Image © Turner, K., Warren, A. and Sherriff, I., University of Plymouth

APPENDIX A: Record of Reference Group meetings held during this research

Meeting Code	Held	Present ¹⁶	Meeting content and aims
RG1	July 2016	Carers/travel companions - 4 Community developer – 1 Healthcare professional/Occupational Therapist – 3 Person living with dementia - 1	<ul style="list-style-type: none"> ❖ Introduction to the group and purpose ❖ Update on debate held in House of Commons and circulation of Hansard (debate record) ❖ Group discussion and formulation of feedback on Civil Aviation Guidance Document (CAP1411) ❖ Discussion of doctoral research project and agreeing the reference group's role in supporting this research
RG2	January 2018	No record of attendance taken	<ul style="list-style-type: none"> ❖ To discuss and agree draft participant information sheet and consent form for qualitative interviews ❖ To discuss Civil Aviation Authority draft guidance for airlines on assisting people with hidden disabilities (CAP1603)

¹⁶ Note: Some participants in the Reference Group have multiple roles. For example, the Chair of the PM Group is also an Ambassador of the Alzheimer's Society, as well as being a dementia specialist. However, only the person's primary affiliation has been shown in the 'present' list to prevent misrepresentation of participant numbers.

RG3	April 2018	No record of attendance taken	<ul style="list-style-type: none"> ❖ Overview presentation of realist synthesis aims and objectives. ❖ Discussion on appropriateness of realist synthesis as a systematic research methodology. ❖ Discussion on appropriateness of proposed research question for realist synthesis. ❖ Workshop to discuss: Personal and professional experiences of what helps/hinders Dementia Training outside of the field of healthcare. ❖ Discussion on potential theories (ideas) arising from literature circulated prior to the meeting.
RG4	June 2018	<p>Aircrew and trainer – 1 Carers/travel companions - 2 Chair of Prime Minister's Group – 1 Dementia project lead (University of Plymouth) - 1 Healthcare professional/Occupational Therapist - 2</p> <p>Additional pre and post meeting input from: Airport representative – 1 Community developer – 1</p>	<ul style="list-style-type: none"> ❖ Discussion on final wording for realist synthesis research question following group feedback at the April meeting. ❖ Discussion and group feedback on proposed search strategy for realist synthesis. ❖ Feedback and discussion on experiential information gathered from April Workshop. ❖ Discussion on key paper from Connell et al., (2017) and the draft working theories derived from this. ❖ Discussion on next steps of realist synthesis.
RG5	August 2018	<p>Alzheimer's Society representative - 1 Carers/travel companions - 2 Community developers - 1 Healthcare professional/Occupational Therapist - 3</p> <p>Additional pre and post meeting input from: Airport representative – 1 Community developer – 1</p>	<ul style="list-style-type: none"> ❖ Recap of realist synthesis thinking/terminology. ❖ Discussion on resources circulated prior to the meeting with particular emphasis on the data extraction form designed by KT and comments/feedback on accuracy of data extraction technique. ❖ Flipchart exercise to explore: 'How, Why and If personal stories and experiences can assist the learning process'.

RG6	October 2018	<p>Aircrew and trainer – 1 Alzheimer's Society representative - 1 Carers/travel companions - 2 Chair of Prime Minister's Group – 1 Community developer – 1 Healthcare professional/Occupational Therapist – 3</p> <p>Additional pre and post meeting input from: Person living with dementia - 1</p>	<ul style="list-style-type: none"> ❖ Introduction of key dates/timeline document ❖ Creation of volunteer list for reviewing/overseeing papers/data sources during October/November ❖ Group exercise to review the initial working theories from Connell et al (2017) against the group's theories from their own practical experience in order to create one final working theory document
RG7	January 2019	<p>Aircrew and trainer – 1 Carers/travel companions - 2 Chair of Prime Minister's Group – 1 Dementia project lead (University of Plymouth) - 1 Healthcare professional/Occupational Therapist - 2</p>	<ul style="list-style-type: none"> ❖ Formulation of group response to Civil Aviation Authority ❖ Discussion of rights based air travel article by Rochford-Brennan and Jenkins (2019).
RG8	March 2019	<p>Aircrew and trainer – 1 Carers/travel companions - 2 Healthcare professional/Occupational Therapist - 1</p> <p>Additional post meeting input from: Person living with dementia - 1</p>	<ul style="list-style-type: none"> ❖ Feedback from local dementia user group meeting on dementia and air travel ❖ Consideration and prioritisation of draft theories
RG9	June 2019	<p>Aircrew and trainer – 1 Alzheimer's Society representative - 1 Carers/travel companions - 1 Healthcare professional/Occupational Therapist – 3</p>	<ul style="list-style-type: none"> ❖ To discuss qualitative interview findings from people living with dementia ❖ To discuss potential themes for findings from this group

RG10	August 2019	Aircrew and trainer – 1 Alzheimer's Society representative – 2 Carers/travel companions - 3 Chair of Prime Minister's Group – 1 Community developers – 2 Healthcare professional/Occupational Therapist - 3 Person living with dementia - 1	<ul style="list-style-type: none"> ❖ To discuss widening of hidden disabilities lanyard scheme and advantages/disadvantages of this ❖ Planning for Dementia Conference presentation and information stand by the group members
RG11	September 2019	Alzheimer's Society representative – 1 Carers/travel companions - 2 Chair of Prime Minister's Group – 1 Community developers – 2 Healthcare professional/Occupational Therapist - 2 Person living with dementia - 1	<ul style="list-style-type: none"> ❖ To receive report and photographic record of recent experience of special assistance at [airport name withheld] by [name withheld – companion of a person living with dementia] ❖ To discuss focus group input for upcoming hidden disability film ❖ Planning for Dementia Conference presentation and information stand by the group members ❖ To discuss interview findings from companions of people living with dementia ❖ To discuss potential themes for findings from this group ❖
RG12	November 2019	Alzheimer's Society representative – 1 Carers/travel companions - 1 Chair of Prime Minister's Group – 1 Civil Aviation Authority Representative – 1 Community developers – 2 Healthcare professional/Occupational Therapist - 3	<ul style="list-style-type: none"> ❖ To receive presentation from Civil Aviation Authority representative and input into their policy and enforcement framework research project. ❖ To consider research statements for the two participant groups (final stage of the qualitative research analysis process) ❖ To provide feedback to [airport name withheld] as requested on their special assistance service

RG13	June 2020 (virtual meeting due to Covid-19 pandemic)	Aircrew and trainer-1 Alzheimer's Society representative - 1 Carers/travel companions - 2 Chair of Prime Minister's Group - 1 Community developers - 2 Healthcare professional/Occupational Therapist - 2 Person living with dementia -1	<ul style="list-style-type: none"> ❖ Presentation and discussion on 7 programme theories derived from the realist synthesis. ❖ Changes to programme theory wording agreed in line with Reference Group feedback.
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APPENDIX B: Interview schedule person living with dementia

Introduction to the research and regaining of consent undertaken at the start of each interview.

1. Ice breaker:

- a. What do you enjoy most about flying?
Where do you tend to fly to?
Why is this?

2. Can you tell me about a recent experience where you travelled by plane?

- a. What kinds of things did you do to prepare for the trip?
 - i. For example
 - 1. Booking
 - 2. Registering for assistance.
 - a. Explain assistance if needed e.g. "buggy".
 - 3. Pre visit to airport.
- b. Did you have any problems at the airport?
 - i. (if needed) for example:
 - 1. checking in
 - 2. automated services such as check in/electronic passport gates
 - 3. security checks
 - 4. Using toilets
 - 5. Waiting times
 - 6. finding your boarding gate
 - a. How did you feel about this...?
- c. How did things go once you were on the plane? (prompts added as a result of pilot study)
 - i. Were you able to find your seat easily?
 - ii. Did you manage to stow your luggage in the overhead compartments or under the seat in front?
 - iii. Did the seat you were allocated provide you with enough personal space as to be comfortable?
 - iv. Were you able to move around the plane freely when you needed to?
- d. Did you need to ask the flight staff for anything while on board the aircraft?
 - i. (if yes) Were flight staff able to help with your request(s)?
 - ii. How did you feel about this...?

3. What do you think has been the most difficult aspect of air travel since you began to experience problems with your memory?

4. Can you describe anything you would do to make air travel go more smoothly?

5. Do you have any 'top tips' for other people with dementia who are planning to travel by air?

6. Is there anything that airlines or airports could do to help you to travel more comfortably?

7. Is there a point at which you think you will stop travelling by air?
 - a. Why is this do you think?
8. Are there any other comments relating to travelling by air that you would like to talk about?

Questions adapted *with permission* from: 'Infrequent Flyers' (Edwards *et al.*, 2016).

APPENDIX C: Photo prompt sheet of a typical journey through an airport



Participation in Air Travel for People Living with Dementia



**Airport
Car Park**



**Airport
Shuttle Bus
(Car park to
Terminal)**



Signage/Departures



Check in and Bag drop (usually staffed).

Self-check in machines

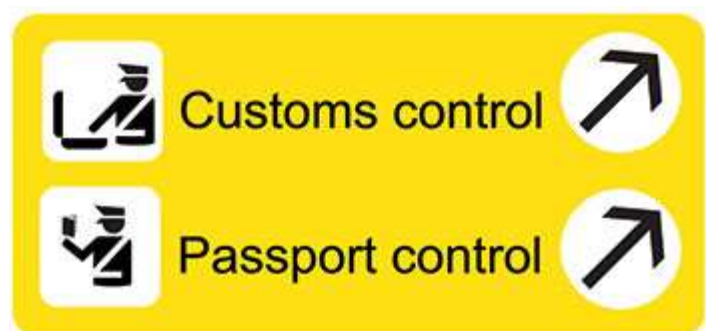


Toilets at airport



**Security channel /
searches / pat downs /
bag scanning /
searches.**

Customs and Border control



Duty free and other shops



Travel to Gate



Waiting area and Boarding Gates





Boarding the plane



**In Flight
experience**



**Aircraft
toilet**



**Exiting
the
plane**



**Border and
passport
controls on
arrival**

Baggage reclaim



Arrivals and onward travel



APPENDIX D: Research field note extract (George)

1. Describe the environment where the interview took place in as much detail as you can (e.g. time, space, lighting, sound)

Interview took place in George's living room. He sat in his own chair which was positioned so George could see me. It was quiet and calm. The windows were open. It was a very warm day. The room was flooded with natural daylight. There was no clock in the room. There was also a large china ornament [details withheld as potentially identifying] that I asked George and Millie about. George said that this was associated with an important memory from his childhood.

2. Describe the participant in as much detail as you can (e.g. appearance, body language, tone of voice, comfort level)

George sat back in his chair with a relaxed but closed posture to begin with (he had his arms firmly folded across his chest). He kept looking at Millie for reassurance/confirmation of what he was saying. Millie would provide reassurance, but not answer for him.

3. Describe the interview process (e.g. flow, depth of participant responses, rapport between interviewer and participant, change over the course of the interview).

To begin with George was hesitant and clipped in his responses, but gradually he opened up. By the time we switched the recorder off he was open and laughing.

4. Were there any unexpected interruptions that need to be explained? (e.g. loud noises, someone needing to take a phone call, the recorder being shut off for a period of time).

No, it was all quiet. A van drove up and down the road a few times which Millie commented on. Millie also left the room to fetch a book to show me. George seemed a little uncomfortable when she went out of his line of sight.

5. Think back over the interview. Were there any keywords or phrases used by the participant that struck you in some way? If so, list them here.

George kept talking about being calm and being Zen. I got the impression this was something he had been working on.

6. Summarise the key points from this interview in 2-3 paragraphs.

George does not like to be rushed or pushed. He likes order and calm. He wants to be unhurried. He loves holidays but dislikes flying. George looks to Millie for reassurance frequently.

Millie is very much an enabling person. For example, she would not answer for George but if he was struggling she would try to rephrase the question for him. There was clearly a lot of love in the room between them.

7. Consider your main interview question. In what ways does this interview help you respond to that question?

A barrier for George is the attitude of people around him. He likes calm and patience. He gets frustrated by people rushing him and his brain 'explodes'. Millie is a facilitator and he says he wouldn't fly without her.

8. Now think about the aims of your study. Describe how this interview connects to those aims.

This interview brings in a new concept of a partner's attitude being central to engagement. George would not travel without Millie. She is his rock but she enables him to do, rather than does for him.

9. Now turn your attention to your own experience of the interview itself. How did you respond throughout the session? Did you hear pretty much what you expected to hear? If so, explain. Did anything about the participant's experience surprise you or make you feel uncomfortable? If so, explain.

I was concerned about George's reaction to the question about stopping flying and what would be the trigger for this, but he answered honestly and openly 'I'm not there yet'. But he says the time for travelling on his own has passed. I was quite moved when he said he needed someone to hold his hand 'literally and metaphorically'.

APPENDIX E: Participant information sheet and consent form – participants living with dementia

Participant Information Sheet



Study Key Facts:

- This study is about experiences of air travel for people with dementia and their travel companions.
- It is being undertaken by Kate Turner a student at Plymouth University.
- Kate is an Occupational Therapist.
- Kate would like to learn more about your experiences of air travel since you began to experience difficulties with your memory.
- Taking part in the study is voluntary.
- You can withdraw from the study at any time up to the point of data analysis.
- Taking part will involve one interview with Kate of approx. 60 to 90 minutes.
- The interviews will be audio recorded.
- What you say will remain confidential.
- You could help people with dementia participating in air travel in the future.

Invitation to take part in the study:

You are invited to take part in a research study about air travel for people with dementia and their travelling companions. Taking part in this study is **entirely voluntary**. Please read this information sheet before deciding whether or not

you want to take part as it explains what is involved in the study. Please also speak with a family member or friend about this study if you wish to and ask me if anything is unclear or if you would like any further information before taking part.

Background to the study

My name is Kate Turner and I am a Student at Plymouth University. I am an Occupational Therapist. Occupational Therapists help people to participate, or continue to participate, in activities that are meaningful to them.



What is the study about?

This study will look at the experiences of air travel for people with dementia and anyone who usually travels with them. The study aims to understand how people with dementia can be supported to continue travelling by air in the future.

Why are you asking me?

I would like to talk to people who have been diagnosed with dementia about their experiences of travelling by air since their memory problems began. If you have travelled by air in the last three years, your experiences would be very helpful for the project.

Do I have to take part?

No - not at all – it is entirely up to you. If you do want to take part you will be given a form to sign to confirm you are happy for me to visit and interview you about your experiences of air travel. Even if you sign the form, you are still free to withdraw from the study at any time up to the point of data analysis without giving a reason. If you decide not to take part, or to withdraw from the study, please be assured this will have absolutely no impact on any service you currently receive.

What do I have to do if I decide to take part?

If you would like to take part in the study, I will visit you either at home or at a place local to you to interview you about your experiences of air travel. It is fine for someone else to be present when I visit if you feel more comfortable having a familiar face with you. I will ask you to tell me about your experiences of air travel and I will tape record what we say so that I can keep an accurate record of our discussion. The interview should last no more than an hour and a half. If at any point during the interview you feel that you would not like to continue then you will be free to stop.

Are there risks to my taking part?

There is a slight risk that talking about your air travel experiences may be upsetting for you. I will talk through any issues raised with you at the time of the interview and will provide a list of support groups to you just in case anything arises after our interview has taken place.

What are the benefits to my taking part?

Whilst taking part may not benefit you directly if you no longer undertake air travel, it is anticipated that the results of the study will benefit people with dementia who wish to travel by air in the future by highlighting to airports and airlines what they are doing well and how their services can be improved.

Will what I say be kept private?

Yes. All information will be kept confidential and will only be seen by members of the research team. All data will be kept in accordance with the Data Protection Act 1995 (and the General Data Protection Regulations 2016 which will repeal this Act in 2018). As this is a study of personal experiences, I would like to use an anonymous name when referring to your comments in any written or verbal reports in the future. You can choose the name yourself or we can choose one together when we meet.

Who is in charge of the research and who is funding it?

The research is part of a Doctoral Study funded by Plymouth University through their School of Health Professions. The day to day research will be undertaken by me, Kate Turner, a qualified Occupational Therapist. The study will be overseen by Dr Alison Warren, who is also a qualified Occupational Therapist and Lecturer in Higher Education. Alison has many years' experience of working with people with dementia in a range of settings.

What will happen to the results of the study?

As well as forming part of my Doctoral Thesis, the results will be published in journals and presented at various conferences and events. If you take part, an anonymous name will be used so you will not be able to be identified. Everyone taking part in the study will have the opportunity to receive a follow up telephone call from me to talk through the results of the study. An update report can also be provided in writing.

Has anyone reviewed the study?

This study has been checked and approved by Plymouth University's Ethics Committee for Health and Social Sciences. Their approval reference giving permission for the study to take place is: 17/18/899.

Who can I contact if I want more information or to take part?

Please contact me at the address and phone number below:

Kate Turner

MPhil/PhD Student, Occupational Therapy
Faculty of Health and Human Sciences
Plymouth University
Peninsula Allied Health Centre
Derriford Road
Plymouth
Devon, PL6 8BH

Email: Katherine.turner@plymouth.ac.uk

Tel: [Redacted as number belongs to Researcher personally]















If you wish to make a complaint regarding this study please contact:

Dr Alison Warren
Interim Academic Lead for Occupational Therapy
Programme Lead for MSc Advanced Professional Practice in Occupational
Therapy
Lecturer in Occupational Therapy
Faculty of Health & Human Sciences
Plymouth University
Derriford Rd
Plymouth
Devon, PL6 8BH

Email: Alison.warren@plymouth.ac.uk

Thank you for considering taking part in this research study.



Please confirm whether you agree or disagree with each comment below by ticking the relevant box:	Agree	Disagree
I have read and understood the Participant Information Sheet for 'Participation in Air Travel for People with Dementia' OR had it read and explained to me to enable me to understand it.		
I have been given the opportunity to ask questions about this study.		
I understand that taking part in this study is voluntary and that I do not have to take part.		
I give my permission for any interview I give as part of this study to be audio recorded.		
I understand that if any of my views are used or quoted in the future that an anonymous name will be used to protect my identity.		
I give my permission for my anonymised views and comments to be included in the researcher's PhD Thesis, in any Journal Publication, as part of a presentation at Conferences and Events or in any aviation guidance documents published as a result of this study.		
I understand that as the researcher (Kate Turner) is a student, the data gathered as a result of this study may also be heard and viewed by her supervisors who also agree to maintain my confidentiality.		

Participant (Please print)

Date

Signature

Researcher (Please print)

Date

Signature

APPENDIX F: Participant information sheet and consent form – travel companions

Participation in Air Travel for People with Dementia

Participant Information Sheet

(Travel Companion)



Invitation to take part in the study:

You are invited to take part in a research study about air travel for people with dementia and their travelling companions. Taking part in this study is **entirely voluntary**. Please read this information sheet before deciding whether or not you want to take part as it explains what is involved in the study. Please also ask me if anything is unclear or if you would like any further information before taking part.

Background to the study

My name is Kate Turner and I am a Student at Plymouth University. I am an Occupational Therapist. Occupational Therapists help people to participate, or continue to participate, in activities that are meaningful to them.



What is the study about?

This study will look at the experiences of air travel for people with dementia and anyone who usually travels with them. The study aims to understand how people with dementia can be supported to continue travelling by air in the future.

Why are you asking me?

This study is primarily seeking to gather the first hand air travel experiences of people with dementia since their memory problems began. However, it is recognised that the person they usually travel with will also have a wealth of knowledge about their air travel experience from a companion's perspective. If you have travelled by air with someone with dementia in the last three years, your experiences would be very helpful for the project. Your input would also be incredibly helpful if the person you normally travel with is no longer able to travel by air *for whatever reason*.

Do I have to take part?

No - not at all – it is entirely up to you. If you do want to take part you will be given a form to sign to confirm you are happy for me to visit and interview you about your experiences of air travel. Even if you sign the form, you are still free to withdraw from the study at any time up to the point of data analysis without giving a reason. If you decide not to take part, or to withdraw from the study, please be assured this will have absolutely no impact on any service you currently receive.

What do I have to do if I decide to take part?

If you would like to take part in the study, I will visit you either at home or at a place local to you to interview you about your experiences of air travel. I will ask you to tell me about your experiences of air travel as a companion of a person with dementia and I will tape record what we say so that I can keep an accurate record of our discussion. The interview should last no more than an hour and a half. If at any point during the interview you feel that you would not like to continue then you will be free to stop.

Are there risks to my taking part?

There is a slight risk that talking about your air travel experiences may be upsetting for you. I will talk through any issues raised with you at the time of the interview and will provide a list of support groups to you just in case anything arises after our interview has taken place.

What are the benefits to my taking part?

Whilst taking part may not benefit you directly if you no longer undertake air travel with someone with dementia, it is anticipated that the results of the study will benefit people with dementia and their companions in the future by highlighting to airports and airlines what they are doing well and how their services can be improved.

Will what I say be kept private?

Yes. All information will be kept confidential and will only be seen by members of the research team. All data will be kept in accordance with the Data Protection Act 1995 (and the General Data Protection Regulations 2016 which will repeal this Act in 2018). As this is a study of personal experiences, I would like to use an anonymous name when referring to your comments in any written or verbal reports in the future. You can choose the name yourself or we can choose one together when we meet.

Who is in charge of the research and who is funding it?

The research is part of a Doctoral Study funded by Plymouth University through their School of Health Professions. The day to day research will be undertaken by me, Kate Turner, a qualified Occupational Therapist. The study will be overseen by Dr Alison Warren, who is also a qualified Occupational Therapist and Lecturer in Higher Education. Alison has many years' experience of working with people with dementia in a range of settings.

What will happen to the results of the study?

As well as forming part of my Doctoral Thesis, the results will be published in journals and presented at various conferences and events. If you take part, an anonymous name will be used so you will not be able to be identified. Everyone taking part in the study will have the opportunity to receive a follow up telephone call from me to talk through the results of the study. An update report can also be provided in writing.

Has anyone reviewed the study?

This study has been checked and approved by Plymouth University's Ethics Committee for Health and Social Sciences. Their approval reference giving permission for the study to take place is: 17/18/899.

Who can I contact if I want more information or to take part?

Please contact me at the address and phone number below:

Kate Turner

MPhil/PhD Student, Occupational Therapy
Faculty of Health and Human Sciences
Plymouth University
Peninsula Allied Health Centre
Derriford Road
Plymouth
Devon, PL6 8BH

Email: Katherine.turner@plymouth.ac.uk

Tel: [Redacted as number belongs to Researcher personally]

If you wish to make a complaint regarding this study please contact:















Dr Alison Warren
Interim Academic Lead for Occupational Therapy
Programme Lead for MSc Advanced Professional Practice in Occupational Therapy
Lecturer in Occupational Therapy
Faculty of Health & Human Sciences
Plymouth University
Derriford Rd
Plymouth
Devon, PL6 8BH

Email: Alison.warren@plymouth.ac.uk

Thank you for considering taking part in this research study.

Participant Consent Form



Please confirm whether you agree or disagree with each comment below by ticking the relevant box:	Agree	Disagree
I have read and understood the Participant Information Sheet for 'Participation in Air Travel for People with Dementia'.		
I have been given the opportunity to ask questions about this study.		
I understand that taking part in this study is voluntary and that I do not have to take part.		
I give my permission for any interview I give as part of this study to be audio recorded.		
I understand that if any of my views are used or quoted in the future that an anonymous name will be used to protect my identity.		
I give my permission for my anonymised views and comments to be included in the researcher's PhD Thesis, in any Journal Publication, as part of a presentation at Conferences and Events or in any aviation guidance documents published as a result of this study.		
I understand that as the researcher (Kate Turner) is a student, the data gathered as a result of this study may also be heard and viewed by her supervisors who also agree to maintain my confidentiality.		

Participant (Please print)

Date

Signature

Researcher (Please print)

Date

Signature

APPENDIX G: Extract from interview transcript – Len

Len: but when they make changes is the problem you know? They made a big change about 12 months ago and it was... it was a nightmare. I was going round in circles but that's another thing yeah.

Kate: so what did they change?

Len: they changed the way walking into... into the erm... you know they make you go through the duty-free first don't they you know?

Kate: I know yeah

Len: You know that ridiculous thing which I hate. They changed that round, it was in a different area and set out different so I was getting confused.

Kate: yeah.

Len: So then I was thinking am I in [international airport] here or am I in [local airport]? What's going on you know? It takes... it's those changes sometimes kick in and then you get confused you know? The confusion starts which leads to anxiety, which leads to a b c d and e you know?

Kate: yeah

Len: So yeah...but I mean you get used to it, well I got used to it anyway. So now I know you know where to go so I don't get... so the confusion's gone out of that one til the next change comes in

Kate: yeah, yeah

Len: change is a big thing with people with dementia, we don't like it

Kate: no and is that because usually you're familiar with the environment and that helps you to get round?

Len: it is yeah, it is yeah, familiarity is the main cause of keeping on track during the day you know?

Kate: yeah

Len: because if you forget then it kicks in

Kate: yeah ok. So last time you went away was only a few weeks ago

Len: yeah

Kate: where did you go then? You said you went to [European Country] but whereabouts did you go?

Len: oh I went to [place name]

Kate: You went to [place name]?

Len: yeah

APPENDIX H: Extract of phenomenological reduction process

Original Transcript	Analysis Round 1	Analysis Round 2
<ol style="list-style-type: none"> 1. Well thank you again for having a chat with me and, as I say, I'm here to talk about your experiences of air travel 2. V: Yeah 3. K: Now I understand...have you been away this year? 4. V: Actually we've done a lot this year. We've done a lot of travelling 5. K: Have you? 6. V: Ploughing through what we called our bucket list (laughs) 7. K: OK 8. V: Since my diagnosis. So, yeah, we've had a lot of experience of travelling (1) 9. K: OK. So where have you been this year? 10. V: Oh, my word! (laughs) 11. G: We started last October 12. V: Yes. We started...where was the first place we went? 13. G: [Country name withheld] 14. V: We went to [Country name] 	<ol style="list-style-type: none"> 1. Victoria explains that, after her diagnosis, she and Gertie created a 'bucket list' of holidays that they wanted to go on and they have travelled extensively this year 	<p>1/2/3/4/5/104/ - Meaning of travel/post diagnosis actions/attitude</p> <p>After Victoria's diagnosis, she and Gertie created a bucket list of all the places they wanted to travel to. In the 12 months prior to the interview, they have seen [withheld], the [withheld], celebrated a special birthday in [withheld], visited [withheld] and made the 'supreme effort' to go and see family in [withheld] (line 55). Their remaining bucket list places are now UK based and they plan to drive as they want to take their two dogs with them.</p> <p>9/ - Requesting special assistance</p> <p>Victoria says they have learned from previous holidays and now request assistance, but acknowledges that Gertie makes all the arrangements for this (line 88).</p>

APPENDIX I: Feedback from Reference Group Workshop on 5/4/18 on what works and what does not work within dementia training

Area	What works from personal experiences of the Reference Group	What does not work from the personal experiences of the Reference Group	What does the evidence say?
Attitudes and knowledge (to training)	<p>Working together – sensitivity, encouragement, EI</p> <p>Positive attitude around dementia for culture change and to reduce stigma</p> <p>Awareness raising does work</p> <p>Re-educating people as to what's important</p>	<p>Fear</p> <p>Not interested in dementia</p> <p>Not their responsibility</p> <p>Too difficult</p> <p>Not rewarding</p> <p>Not a priority</p> <p>No consequences</p> <p>Organisations seeing training as a tick box</p> <p>Fear of 'getting it wrong' in the eyes of statutory authorities.</p>	<p>Businesses need to recognise that people with dementia need to remain active and involved¹.</p> <p>Figure 2 within this paper is very good in presenting an organisation's progress towards dementia friendly tourism¹</p>
Training (Who should be involved)	<p>Training is often approached in a "Top down" manner i.e. the presenter is the expert.</p> <p>Having the real experts speak about their experiences has been successful in my experience</p> <p>Understanding how people feel/their experiences</p> <p>Relatability – hearing from people with Dementia</p> <p>Sharing of knowledge and experience</p> <p>Communities sharing experience</p> <p>People with personal experience of Dementia</p>		<p>Having personal experience of dementia may help to increase awareness and take up of training within a business¹</p>

<p>Training (What should be included)</p>	<p>Discussion and conversation Understanding journeys are different Talking about progression Having a practical side to training Practical activities leads to understanding Understanding behaviours Knowing how to react [to behaviours] Clear communications Clear solutions/instructions – knowing what to say Immersive experiences – considering sensory impact and experiences e.g. ‘Dementia bus’ Increasing knowledge [of Dementia]</p>	<p>What does being trained in dementia mean? Training is often based on the medical model i.e. assessing /measuring deterioration and behaviour – not person centred or focused on positive outcomes</p>	<p>Recognise that it is important for customer facing staff to communicate and interact positively and with empathy towards people with dementia and their carers¹ Recognition that people with dementia may not admit to having dementia or be able to ask for help¹ Recognition that people with dementia are part of the visitor economy¹ There is a lack of understanding of the specific needs of people with dementia at all stages¹ There is a lack of awareness on how to get it right – each person with dementia has a different experience¹ Training needs to cover how to help people with dementia and their carers feel comfortable – need for individual personal attention – understanding that each person has a different dementia journey¹ Role-play and user friendly communication habits to be encouraged²</p>
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			<p>Staff satisfaction is increased when experiential, reflective and active learning is used – immersive training methods³</p> <p>There is a gap in knowledge across transport providers (p55)²</p> <p>Staff need to be aware of their role in customer facing services with people with dementia¹</p> <p>People can enable or impede travel – aircrew and ground staff are more likely to facilitate as it is linked to their role whereas security staff have a different focus to their role²</p> <p>Challenges happen at all points of the journey from the GP onwards²</p>
Training design and delivery considerations	<p>Informal and continuous</p> <p>Continuity of training</p> <p>Formal information sessions</p> <p>Memory matters produce very good information – booklets/large writing</p> <p>Multiple sessions</p> <p>Having a break</p> <p>Group learning is preferable</p>	<p>E-learning is less engaging. Don't know if the person is taking the training on board?</p> <p>Out of date information</p> <p>Just watching videos</p> <p>The Quality of presenter often influences learning outcomes</p> <p>Training via computer is difficult in airports as not everyone will have access or find time to undertake it.</p>	<p>Is dementia friends training enough?¹</p> <p>It is unclear what training is currently received within airports²</p> <p>Need to investigate any publications e.g. Gatwick²</p> <p>Other priorities impact on how staff interact within settings (e.g. terrorism and motivations for doing job²</p> <p>Sharing knowledge will make travel more accessible for people e.g. develop training programmes</p>

			<p>to think more holistically about people's needs²</p> <p>Enhanced training for all staff (p57)²</p> <p>Staff need to be better prepared to meet needs²</p> <p>Understanding that dementia training is challenging³</p> <p>E-learning is not an effective method³</p>
<p>Environment (wider effects of training)</p>	<p>Peer support</p> <p>Offer of support</p> <p>Person centred – emotionally supportive</p> <p>Respecting timing of training</p> <p>Technology</p> <p>Understanding competitive environment (e.g. lanyards)</p> <p>Having training at the appropriate time for the organisation (avoid busy times)</p>	<p>Losing valuable people</p> <p>Memory cafes? Creating inclusive rather than exclusive environments?</p> <p>Training not specific to organisation</p> <p>Training EVERYONE</p> <p>Training key people in airports such as front of house and security as a priority</p>	<p>Businesses can be more open in their presentations and marketing strategy¹.</p> <p>Dementia alliances where businesses are part of a dementia friendly community¹</p> <p>Businesses can be afraid of getting it wrong and look for sector leaders to provide guidance¹</p> <p>Seeing what other organisations are doing to promote dementia inclusivity can be a positive catalyst for change¹</p> <p>Training should promote accessibility and inclusivity¹</p> <p>Past experiences of training costs (e.g. implementation of the Disability Discrimination Act) can be off putting for organisations¹</p>

			<p>Organisations may be unaware that what will help people with dementia may be of benefit to other consumer groups¹</p> <p>None of the training models targeted all staff members who had contact with dementia patients on a frequent basis³</p>
Outcomes of training	<p>Personally and professionally rewarding</p> <p>Getting feedback after training</p>	<p>No measured change as a result of training</p> <p>Training does not change attitudes</p> <p>Poor knowledge translation - I do not see staff being able to translate their acquired knowledge into the care they provide</p> <p>No follow up</p> <p>Forgetting one off training</p>	<p>There is a lack of knowledge whether the training makes a sustainable impact over time³</p> <p>Does the training positively impact on the experience of the person?³</p>

Group 1 Group 2 Group 3 Group 4

Publications referred to in 'what does the evidence say section' – comments derived from April workshop

¹Connell, J., Page, S.J., Sherriff, I. and Hibbert, J. (2017) 'Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy' *Tourism Management*, 61, pp. 110-128.

²Grice, H. (2017) 'Research Dissertation', OCTP710. Plymouth University: unpublished dissertation.

³Scerri, A., Innes, A. and Scerri, C. (2017) 'Dementia training programmes for staff working in general hospital settings – a systematic review of the literature', *Aging and Mental Health*, 21(8), pp. 783-796.

APPENDIX J: Combined feedback from Reference Group and Key Paper

Attitudes and knowledge

- *Lack of knowledge of the dementia continuum, and people with dementia's continued wish to remain engaged in occupations of meaning, can lead to a negative view of dementia engagement in terms of perceived stigma by association and lack of understanding of this consumer group's needs.*
- Development of the workforce is required to improve communication skills, promote positive attitudes around including those with dementia and to reduce stigma surrounding the condition.
- Staff and organisations need to be aware that inclusivity for people with dementia is important and everyone's business. It is not a tick box exercise.
- *The sector needs to be aware that many measures to engage with, and reduce barriers for, people with dementia are simple and cost effective in order to reduce the apprehension resulting from the implementation of previous policies and legislative demands (for example the perceived cost and confusion surrounding the physical access requirements within the Disability Discrimination Act).*
- *Changes that will help a person with dementia will also help other consumers with a range of physical and hidden disabilities (e.g. improved toilet signage, implementation of a quiet room, etc).*
- Working together is to be encouraged in order to develop key traits (such as sensitivity, encouragement and emotional intelligence) and to foster cultural and organisational change.

Who should be involved

- *A member of staff who has a personal connection to someone living with dementia can positively affect the level of awareness and 'buy in' to dementia friendly initiatives within the setting.*
- Including those with personal experience of dementia within the training, either in person or through case studies, films or vignettes, is important as this can help to increase the relatability.
- *Engagement with dementia training is likely to be enhanced by increasing awareness of the potential commercial benefits to the organisation of engaging with this consumer group.*
- *Take up of good practice training and dementia friendly adaptations would be improved by high profile communication from a sector specific leadership body as many organisations are either unsure what to do to engage with people with dementia or are afraid of getting it wrong and need inspiration and guidance.*

What should be included

- Training needs to recognise and address that each person's journey with Dementia is different.
- Training should not be designed on the medical model and purely address deterioration and behaviour with little to no focus on positive outcomes or the needs of the individual.
- Training should encourage discussion and conversation.
- Training should have a practical element as practical activities and immersive experiences can lead to understanding.
- Communication skills and understanding how to react and respond to behaviours is important.

Delivery Methods

- Training should have an element of continuity to ensure information does not become out of date.
- Follow up training should include feedback of real case studies (good and bad) to help to make the training meaningful for those within the setting.
- Solitary learning methods (such as e-learning) or activities that do not require any level of audience participation (such as just watching videos) can be less engaging; there is also no way of knowing if the person undertaking the learning has truly understood the training materials and is able to relate the key messages to practice. Peer support and interaction is important.
- Training should be developed with the target audience in mind (e.g. Memory Matters materials have been found to be very effective for those living with dementia and the people who care for them due to their easy read, jargon free, design).
- The quality of the presenter is linked to learning outcomes. Reference group experience of having people with dementia and their carers as part of the presenting team has been extremely positive.
- *In order to meet the demands of staff turnover and to enable all staff to have regular updates in order to keep the training current and relevant, any training needs to be cost effective, comprehensive but concise and easily replicated in situ.*

Wider effects of training

There should be an opportunity for peer support on an ongoing basis.

Training should be designed with the realities of the context in mind e.g. the timing of the training and technology available.

Organisations need to understand that engaging in training and offering items such as lanyards can lead to a competitive advantage.

Engagement with dementia training is likely to be enhanced by increasing awareness of the potential commercial benefits to the organisation of engaging with this consumer group.

When considering training in an organisation it is important to consider training everyone, starting with key staff if the training needs to be 'phased in'.

Training should allow for the loss of key individuals and be replicable to allow for staff growth/turnover.

Training should focus on creating inclusive, rather than exclusive, environments (such as memory cafes).

Outcomes

- *Any training intervention should lead to a positive change in culture within the organisation.*
- Training should be personally and professionally rewarding.
- One off training can be easily forgotten if there is no follow up.
- Training needs to have an element of feedback/evaluation.
- Feedback from service users on the impact of the training is very important.
- Training needs to translate into practice (emphasizing the importance of tailoring training to a specific environment so that it makes sense, and can be implemented, in real terms).
- *Exemplars of sector specific dementia awareness and support training through the use of media activity and case studies can act as a competitive incentive for take up in similar settings.*

APPENDIX K: Example data extraction from realist synthesis background search stage

Reference	Our lived experience: Current evidence on Dementia Rights in the UK (2017) co-produced by: The Dementia Policy Think Tank, The DEEP Network and Innovations in Dementia CIC. Full document available at: https://dementiavoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717_1.pdf
Intervention	This is a 'state of the nation' type report on people with dementia's lived experiences, and the challenges they have faced, within various contexts.
Context	The report covers Stereotypes and Prejudices, Accessible Transport, Independent Living, Community Inclusion, Accessible Care and Work.
Audience	Anyone interested in, or who is committed to, upholding the rights of persons with disabilities as prescribed by the United Nations.
What works (and why)	Training should raise awareness of, and reduce stigma surrounding, hidden disabilities such as dementia. For example people living with dementia feel there is a strong stereotype of how a person with dementia is expected to look and report facing accusations that because they can speak at conferences, write blogs, go out on their own or live independently <i>that they can't really have dementia at all</i> (p 8,9,10,11). The use of empowering language is also important and outdated and negative language should be challenged (such as by using #dementiawords on social media). Having well trained, empathetic and informed staff can be of tremendous value to an organisation as such individuals can 'make or break' a person's day (p15). Access to transport in all its forms can help a person with dementia to maintain contact with their friends and family, remain independent with day to day tasks such as attending appointments or going to the shops, and helps to reduce loneliness and social isolation.
What doesn't (and why)	Statements like 'person centred care', 'living well with dementia' and 'dementia friendly communities' are widespread, but are considered to be meaningless if they do not also place an emphasis on Human Rights. Such as the right of those living with dementia to remain active participants in their communities and to maintain meaningful connections by accessing transport in all its forms. Such emphasis on upholding and protecting human rights is also contained within the Prime Minister's Dementia Challenge 2020. Training needs to be in-depth and context specific in order to make a real difference: <i>'it is no good giving them [the staff] a 45 minute dementia friends session and calling it training'</i> (p15). People's attitudes can be a significant barrier to participation, with some people automatically thinking a person with dementia won't be able to do something rather than helping them to think of ways in which they can remain actively involved. Assisted travel is also considered to not work for those with invisible disabilities and a middle ground is needed between travelling unaided and the full assisted travel service that is currently offered. <i>"Assistance travel does not work when you're not in a wheelchair"</i> (p22). Overly complex paperwork, information and websites (including booking tickets online) can be prohibitive to participation and make people with dementia feel 'confused, embarrassed or stupid' (p23).
Already present in Connell et al.	<ul style="list-style-type: none"> • Lack of knowledge of dementia can lead to a lack of understanding of this consumer group's needs. • Challenges within the physical environment (such as signage) also need to be addressed. Small changes can make a big difference to those living with dementia.

Adds to Connell et al.	<ul style="list-style-type: none"> • The need to emphasise within any training intervention the importance of upholding and protecting the human rights of those with dementia. Such as, for example, their human right (Under the UN Convention of Human Rights) to have equality of access to transport in all its forms. 'Dementia friendly' is a term at risk of becoming completely meaningless if it does not also focus on a rights based approach (p31). • Training should also challenge negative stereotypes of what a person living with dementia looks like and what their capabilities may be. This includes addressing the practice of ignoring the person with dementia and speaking to whoever may be with them. Such practice can lead to a person with dementia feeling dismissed, written off or made to feel as if they are being an inconvenience. • Training should highlight the fact that the learner could be the person who helps to maintain a person with dementia's independence or quality of life by helping to remove or reduce social or physical barriers to participation. They are literally the person who could 'make or break' someone's day. This includes moving away from a one size fits all approach to travel assistance. • Training should also seek to address the use of disempowering and outdated language such as 'sufferer' or 'victim' as those living with dementia report that [such hurtful] words are 'like prodding an open wound' (p13). • Training should also address how the physical environment can be as disabling as the social environment with a particular emphasis on complex paperwork, websites, booking systems (tickets and assistance) as well as signage in and around an environment.
Other Critique	<p>Grey literature. Opinion piece. However, realist synthesis would see this as a mine of information.</p>

APPENDIX L: Key legislative and political dates that have helped to shape the Context of Dementia Interventions

1979	The Alzheimer's Society is founded in the UK as a Registered Charity
1995	The Disability Discrimination Act
1997 (April)	Professor Tom Kitwood publishes his seminal text "Dementia Reconsidered: The Person Comes First (Rethinking Aging)"
1998	The Human Rights Act https://www.legislation.gov.uk/ukpga/1998/42/contents
2005	The Japanese Government launches the forerunner of the global 'Dementia Friends' initiative, a 10 year nationwide scheme to raise awareness of dementia and to create dementia friendly communities within Japan.
2005	The Mental Capacity Act https://www.legislation.gov.uk/ukpga/2005/9/contents
2006	United Nation Convention on the Rights of Persons with Disabilities https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
2006	Regulation (EC) No 1107/2006 of the European Parliament and of the Council of 5 July 2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32006R1107&from=EN
2009	UK Ratifies UN Convention on the Rights of Disabled People bringing it on to the UK Statute Books https://www.gov.uk/government/publications/un-convention-on-the-rights-of-persons-with-disabilities-initial-report-on-how-the-uk-is-implementing-it
2010	The Equality Act https://www.gov.uk/guidance/equality-act-2010-guidance (Replaces Disability Discrimination Act 1995)
2011	The Localism Act https://www.legislation.gov.uk/ukpga/2011/20/contents/enacted
2012	Prime Minister's Challenge on Dementia https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf
2013 (Feb)	Dementia Friends officially launches in the UK https://www.gov.uk/government/news/alzheimer-s-society-launches-dementia-friends-information-sessions

2014	The Care Act https://www.legislation.gov.uk/ukpga/2014/23/contents
2015 (Feb)	Alzheimer's Society UK reaches 1M Dementia Friends https://www.dementiafriends.org.uk/WEBNewsStory?storyId=a0B2000000cKwIREAS#.W3rST_IKjIU
2015 (Feb)	Prime Minister's Challenge on Dementia 2020 https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020
2018 (May)	The (EU) General Data Protection Regulations are brought onto the UK Statute books via The Data Protection Act 2018 https://www.legislation.gov.uk/ukpga/2018/12/contents
2018 (July)	Alzheimer's Society UK reaches 2.5M Dementia Friends https://www.dementiafriends.org.uk/WEBNewsStory?storyId=a0B0J00000rPGWsUAO#.W3rShPIKjIU
2019	Professor Dawn Brooker releases a revised version of Professor Tom Kitwood's seminal text ("Dementia Reconsidered, Revisited: The person still comes first") to explore his work 20 years on
2019	World Alzheimer Report: Attitudes to dementia published https://www.alz.co.uk/research/world-report-2019
2019 (Sept)	UK Travel Company Thomas Cook Retail Ltd and its subsidiary companies cease trading on 23 September triggering a major repatriation of holiday makers back to the UK by the CAA (CAA passenger experience staff working on accessible air travel projects are re-assigned)
2020	The Covid-19 pandemic spreads across the world. Borders close and airlines are grounded. The UK Government spends £75M repatriating UK Citizens from across the world https://www.parliament.uk/business/news/2020/april/foreign-office-gives-update-on-repatriation-of-uk-nationals-during-covid-19-pandemic/ New Economics Foundation warns that up to 124,000 aviation and aviation supply chain jobs at risk of being lost in the UK https://neweconomics.org/uploads/files/aviation-workers.pdf Alzheimer's Society warns of major redundancy programme affecting 20% (n=300) of its workforce https://www.thirdsector.co.uk/alzheimers-society-warns-300-job-losses/article/1690105

APPENDIX M: Draft Search Strategy

A search of the existing literature for dementia awareness and support training outside of healthcare will be undertaken. The search terms have been developed with the assistance of the project Reference Group and the final search strategy has been discussed with, and approved by, the Reference Group at the June 2018 meeting.

The search will be limited to the English language in order to gain an understanding of dementia awareness and support training primarily within the United Kingdom. In order to maximise the relevance of the search the date range will be set for a ten year period from 2008-2018.

Keywords to be used:

Dementia	(dementia OR hidden disabilit* OR cognitive disabilit* OR cognitive frail* OR memory OR young onset OR mild OR early OR mid OR late OR Vascular OR Picks OR PCA OR Lewy Bod* OR Cognitive impairment*)
‘Alternative’ terms that people may have used	(confus* OR old OR vague OR age* OR vacant OR disorientated or distant OR forgetful OR sufferer OR mental health OR mental illness)
Terms used by Air Crew in incident reporting	(Distress* OR Threat* OR Damage OR Assault OR Aggressi* OR Harrass* OR Rowd* OR Abus* OR Throw* OR Hit* OR Endanger* OR Disturb*)
Dementia Friendly Attitudes and Training	(tolerance OR understanding OR inclusive OR culture OR kind OR caring OR respect* OR aware* OR experience* OR train* OR educat* OR competen* OR skill* OR confident* OR capable OR best practice OR polic* OR procedure* OR standard* OR key performance indicator* OR famil* OR friend* OR neighbour* OR social capital OR press OR media OR terminology)
Dementia Friendly Settings outside of healthcare	(markets OR shops OR businesses OR banks OR barbers OR hairdressers OR opticians OR dentists OR public OR GP* OR librar* OR church* OR religion* OR faith* OR culture* OR architecture OR transport* OR travel OR train* OR rail* OR bus* OR taxi* OR air* OR tram OR destination* OR environment* OR town OR city OR village OR hotel* OR restaurant* OR attraction* OR Venue* OR heritage OR museum OR cinema OR passenger OR School* OR College* Or Universit*)

APPENDIX N: Revised and abridged Search Strategy following Information Specialist advice

((Dementia OR Alzheimer*)

AND

(Support OR Train* OR Education* OR learning OR Awareness)

AND

(Friend* OR inclusive OR Champion OR Communit* OR Environment*)

AND

(Communication OR Skills OR Activities))

Databases searched and results obtained

Business Source Complete	54
Emerald	501
Hospitality and Tourism Complete	4
PsycArticles	2,327
Web of Science	1,494
Medline	516
Psychinfo	1,128
Cinahl	1,043
TRID	3
Total	7,070

APPENDIX O: Inclusion and exclusion criteria for title and abstract screening

Inclusion	Exclusion
Dementia awareness projects	Dementia training for health professionals (including GP's, care staff and healthcare students)
Dementia 'Friendly' projects (unless based in healthcare settings)	Cognitive training
Dementia communication techniques/training (not within health or care but including communication training for carers to screen for communication methods/systems)	Activity training
Large Inclusive design/DF design projects (not home design). Care homes/hospitals included to identify inclusive public building design	Training for carers of people with dementia (except for relevant communication techniques). Most carer training is about coping with the stresses of caring.
Dementia Champions projects (unless based in healthcare settings)	Dementia training for palliative/end of life settings
	Training around assistive technology
	CBT and mindfulness training
	Reminiscence (unless training of individuals to facilitate occurs outside of care/healthcare settings)

APPENDIX P: Extract from realist synthesis worksheet of all papers rejected at full text stage

The full Excel spreadsheet for Appendix P is too large to replicate here, so only information from key columns will be included. However, for completeness, a list of all column headings for the full spreadsheet is shown below:

Column	Description
1	Paper number
2	Author
3	Title
4	Type of paper/study
5	Full text acquired?
6	Associated journal/source
7	Year of publication
8	Type of training
9	Context of training
10	Was the training evaluated? If so, how?
11	Relevance Does this paper add to/refute/refine theories under examination YES/NO?
12	If YES what are the main theories that the source adds to?
13	Rigour Is this paper considered rigorous enough for inclusion? Notes on sample size, data collection method and analysis and the claims made
14	Accept or reject?
15	Reason for acceptance or rejection
16	Other comments

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
1 ¹⁷	Phillipson, L.; Fleming, R.; Swaffer, K.; Steele, L.; Sheridan, L.; Burns, S.;	Creating a dementia enabling university using a Knowledge Translation approach: Innovative practice	2019	Education?	N/A	Unable to access via library or inter library loans system
2	Brenske, Shasta; Rudrud, Eric H.; Schulze, Kimberly A.; Rapp, John T.	Increasing activity attendance and engagement in individuals with dementia using descriptive prompts	2008	Within nursing care	N/A	Within healthcare
3	de Klerk-Rubin, Vicki;	Validation techniques for dementia care: The family guide to improving communication	2008	Family	N/A	More up to date version of text available and included

¹⁷ Note: As these are the rejected papers the paper numbers are non-sequential

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
4	Parker, Deborah; Mills, Sandra; Abbey, Jennifer	Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review	2008	Various (systematic review)	The paper was written in 2008 but is based on studies from 2000 to 2006 so the information is somewhat out of date. Also focusses heavily on the needs of the carer. For example, negative aspects of caring such as 'carer burden', depression, quality of life and subjective wellbeing. As such there is limited transferable knowledge to the review.	Does not add to theories under construction
5	Ryan, T.; Noble, R.; Thorpe, P.; Nolan, M.	Community Care - Out and about: a valued community respite service	2008	Within healthcare	N/A	Within healthcare
6	Codinhoto, Ricardo	The impacts of the built environment on health outcomes	2009	Healthcare environments mainly hospitals	N/A	Not training. Not dementia. Looking specifically at healthcare environments and their effect on health outcomes. For example, how poor ventilation design can cause MRSA & TB etc.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
7	Davis, S.; Byers, S.; Nay, R.; Koch, S.	Guiding design of dementia friendly environments in residential care settings: considering the living experiences	2009	Within healthcare	N/A	Within healthcare. Paper focusses on design of residential homes, particularly around bedroom design and end of life care.
8	Hobbs, L.	Communication and dementia: how can we help families?	2009	Care home/family members	Care home manager opinion. It is unclear whether the statements are evidence based. Following discussions with AW it is considered that other communication papers are more robust and can better provide evidence for the review.	This brief opinion piece paper does not appear to be evidence based but is based on a care home manager's professional experience. There are other studies that would add more to the review.
13	Silverstein, Nina M.; Sherman, Robin	Taking control of Alzheimer's disease: A training evaluation	2010 (covering a period of 2004-2008)	Training covered ways of taking control including making advanced care directives, finding out more about Alzheimer's Disease, etc.	73 participants including 33 people living with dementia and 40 carers. The sessions being evaluated pre-dated the timelines of this study (2004-2008).	The article does not discuss the training in any depth just outlines content. The training package is aimed at people living with dementia and their carers taking some level of control of the condition. Does not add to the theories under construction.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
14	Teitelman, J.; Raber, C.; Watts, J.	The power of the social environment in motivating persons with dementia to engage in occupation: qualitative findings	2010	Within assisted living	N/A	Within healthcare
15	Lindgren, H.; Soda, P.; Tortorella, F.	Knowledge Artefacts as Tools to Communicate and Develop Knowledge in Collaborative User-Driven Design	2012	Within healthcare	N/A	Within healthcare (diagnostics and care planning)
16	Marquardt, G.	Wayfinding for People With Dementia: A Review of the Role of Architectural Design	2011	Within healthcare	N/A	Within healthcare (nursing homes)
18	Mizuno, Yoko; Kumamoto, Keigo; Arai, Asuna; Arai, Yumiko	Mobility support for older people with dementia in Japan: Financial resources are an issue but not the deciding factor for municipalities	2011	Mobility support	N/A	Does not include staff training ideas or techniques
19	Pulman, A.; Galvin, K.; Hutchings, M.; Todres, L.; Quinney, A.; Ellis-Hill, C.; Atkins, P.; Greener, S.; Rospigliosi, A.	Using Lifeworld-led Multimedia to Enhance Learning	2012	Healthcare students	N/A	Within healthcare

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
21	Thinnes, Andrea; Padilla, René	Effect of Educational and Supportive Strategies on the Ability of Caregivers of People With Dementia to Maintain Participation in That Role	2011	Various - systematic review	The review includes 43 articles although there was no table within the article outlining what the articles were and whether or not the training strategies were from within or outside of healthcare.	Does not add to theories under construction to any degree.
23	Doeg, Rachael	Seeing dementia differently	2012	N/A	N/A	Unable to access full text through library or inter library loans service
24	Drossel, Claudia	Helping those who cannot help themselves: Enhancing collaborations in dementia care through individualized assessment and training	2012	American Student thesis	N/A	Unable to access full text through library, inter library loans service or British Library thesis repository.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
28	Ford, Claire	Enriching life with creative expression	2012	Art galleries and museums	Paper is based on an artist's experiences of working with art galleries and museums in the US as part of a Winston Churchill travelling fellowship grant. It provides a toolkit for galleries to engage people living with dementia within art workshops. It does not include staff training techniques that would be transferable to the review. Evidence for claims made is unclear.	Does not include staff training ideas or techniques.
29	Itoi, Waka; Kamei, Tomoko; Tadaka, Etsuko	The characteristics of the intergenerational program at the Intergenerational School in Cleveland in USA	2012	Intergenerational programme at a School in the USA	N/A	Non English language (Japanese)
30	Jankoski, Jo Ann; Frey, Sr Annette	Students Connecting with the Elderly: Validation as a Tool	2012	Within healthcare student training	N/A	Within healthcare

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
32	O'Donnell, Kelly S.	Global mental health: A resource primer for exploring the domain	2012	List of resources	N/A	Not dementia. Not training. Does not add to theories under construction.
35	Taylor, Kerry A.; Lindeman, Melissa A.; Stothers, Kylie; Piper, Karen; Kuipers, Pim	Intercultural communications in remote Aboriginal Australian communities: What works in dementia education and management?	2014	Awareness raising of dementia for aboriginal population	Qualitative evaluation in four aboriginal communities. 5 focus groups (n=26 people). Semi structured interviews with healthcare professionals and service co-ordinators (n=5). Observation of the resource being implemented. Limited generisability of the study findings. No pre-post testing of knowledge.	Within healthcare (predominantly). This paper is more about raising awareness of dementia amongst the aboriginal population, so that those affected by dementia can seek care as appropriate. Many of the focus group members and all of the interview participants were healthcare staff.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
38	Boyd, Kyle; Nugent, Chris; Donnelly, Mark; Bond, Raymond; Sterritt, Roy; Hartin, Phillip	An investigation into the usability of the STAR training and re-skilling website for carers of persons with dementia	2014	Formal carers in assisted living facilities	This paper concentrates on the usability of an online training package by using eye tracking software with 5 participants	This paper does not add to the theories under construction. Link to original training followed and STAR is defined as Staff Training in Assisted living Residences. Consequently within healthcare and outside of the scope of the review.
40	Paton, N.	Call for more businesses to support employees with dementia	Undated	Workforce	Brief web article highlighting the release of a separate document the link for which is broken	News bulletin highlighting an Alzheimer's paper which cannot now be accessed as presumably it has been superceded.
42	Butler, Mark	More than a badge	2015	Nursing	Short opinion piece	Within healthcare (Dementia specialist nurses).
43	Heimerl, Katharina; Plunger, Petra; Tatzer, Verena; Reitingner, Elisabeth	OA53 "dementia friendly pharmacies" a community based health promotion project	2015	Community Pharmacies	N/A	Abstract only - full papers on this project have already been included
44	Mayrhofer, A.; Goodman, C.; Holman, C.	Establishing a community of practice for dementia champions (innovative practice)	2015	Community of practice for dementia champions	N/A	Within healthcare

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
48	Robertson, Jacinta; Evans, David	Evaluation of a workplace engagement project for people with younger onset dementia	2015	Work buddies in a retail environment	Work buddies training is mentioned only briefly. Content of training is not discussed nor evaluated. Evaluation is purely from the perspective of participants.	Does not add to theories under construction.
49	Walters, Philip	Creative minds: developing supportive creative opportunities in our communities	2015	Community	N/A	Not training or dementia. Does not add to theories under construction.
50	Adefila, Arinola; Graham, Sean; Clouder, Lynn; Bluteau, Patricia; Ball, Steven	myShoes – the future of experiential dementia training?	2016	Virtual reality resource to emulate what living with dementia might be like.	VR technology was tested by 14 health professions students in the Faculty of Health at the University of Coventry to provide feedback on impact and to suggest ideas for further development.	Within Healthcare (students)

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
54	Fortune, Darla; McKeown, Janet	Sharing the Journey: Exploring a Social Leisure Program for Persons with Dementia and Their Spouses	2016	Peer support group	N/A	Does not include staff training ideas or techniques
56	Kenny, Jocelyne; Asquith, Ian; Guss, Reinhard; Field, Elizabeth; Slade, Lewis; Bone, Alex; ra; Oliver, Keith; Jones, Mark; Ryan, Chris; Brooks, Melvyn; Norris, Chris;	Facilitating an evolving service user involvement group for people with dementia: what can we learn?	2016	Service user involvement	N/A	Within healthcare
57	Mayrhofer, Andrea; Goodman, Claire; Smeeton, Nigel;	The role of Dementia Champion in dementia care: Its aspirations, development and training needs (innovative practice)	2016	Dementia Champions	N/A	Within healthcare
58	Connell, Joanne; Page, Stephen J.; Sheriff, Ian; Hibbert, Julia	Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy	2017	Dementia friendly tourism	N/A	Already included in first stage of review (background papers)

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
61	Munn, Flavia	Simple ideas that could help remove the stigma associated with Alzheimer's disease	2017	Dementia Friends within healthcare	N/A	Within healthcare (aimed at nurses)
63	Roderick, Leonie	Alzheimer's Society rebrands to ensure disease is seen 'as everyone's problem'	2017	N/A	N/A	Unable to access. Article available only to subscribers of marketing week. Not available online or in any other form.
64	Shaw, Courtney;	Emergency departments must be dementia friendly: Adapting the physical environment and introducing more skills-based training could improve patient outcomes	2017	Emergency departments	N/A	Within healthcare. Although, emergency departments are a grey area with regard to inclusion/exclusion. However, as this piece is very short and does not include or refer to any particular training, it has been rejected.
65	Sweeney, Dave; Rule, James;	Sport and Community Engagement in Ageing Health: Tackling isolation and scoring better outcomes. NHS Halton CCG and Widnes Vikings	2017	Community sport	Abstract only. No training information included	Does not add to theories under construction.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
71	Gerolimatos, Lindsay A.; Page, Kyle S.; Balestracci, Phyllis; Hinrichs, Kate L. M.	Interdisciplinary development and implementation of a dementia skills training program in a VA community living center: a pilot study	2018	Healthcare staff training	N/A	Within healthcare
72	Haapala, Irja; Biggs, Simon; Kurrle, Susan;	Social aspects of dementia and dementia practice	2018	Healthcare	This is a brief editorial which effectively acts as a signpost to a number of articles within a special issue of International Psychogeriatrics.	Does not add to the theories under construction. Articles signposted are within healthcare.
74	Marshall, F.; Basiri, A.; Riley, M.; Denning, T.; Gladman, J.; Griffiths, A.; Lewis, S.;	Scaling the Peaks Research Protocol: understanding the barriers and drivers to providing and using dementia-friendly community services in rural areas - a mixed methods study	2018	Dementia friendly services in rural areas	Protocol only	The protocol does not add anything to the review at this stage.
75	Matthijsse, Mathilde; van de Velde, Iris; de Klerk-Jolink, Nicolette; Timmermans, Olaf;	Exploring experiences and perspectives of people living with dementia and their informal carers and entrepreneurs on dementia friendly leisure activities	2018	Dementia friendly leisure	Conference abstract	No training information included. Does not add to theories under construction.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
80	Rhonda, Riachi	Person-centred communication in dementia care: a qualitative study of the use of the SPECAL® method by care workers in the UK	2018	Communication training for Social care workers	N/A	Within healthcare
81	Sheaff, Rod; Sherriff, Ian; Hennessy, Catherine Hagan	Evaluating a dementia learning community: exploratory study and research implication	2018	Care homes	N/A	Within healthcare (reducing unplanned hospital admissions).
82	Sousa, Lia; Sequeira, Carlos; Ferré-Grau, Carme;	Living together with dementia' - Conceptual validation of training programme for family caregivers: Innovative practice	2018	7 Week training programme for carers	N/A	Does not add to theories under construction. Contributors to the delphi study were practitioners from within healthcare.
84	Verkerk Maarten, J.;	A neurological and philosophical perspective on the design of environments and technology for older people with dementia	2018	Design model – not training	This is a theoretical model for the design of care home environments.	Does not add to the theories under construction.
85	Weigel, Kayla Marie;	Decreasing Dementia Caregiver Burden: A Quality Improvement Intervention	2018	Caregiver burden	Doctoral Thesis	Within healthcare

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
89	Casan, R. M.; Giner, P. J.; Herrero, C. I. P.;	Analysis of an inclusive leisure experience for older people suffering from Dementia and Alzheimer's Disease at the Museu Comarcal De L'Horta Sud (Torrent, Valencia)	2019	Inclusive leisure	N/A	Article unavailable in English
91	del Barrio, Elena; García, Alvaro; Tomasena, Ainara; Buiza, Cristina; Arriola, Enrique; Afagi, Afagi; Amilibia, Lide; Díaz-Veiga, Pura;	Friendly Basque Country: Actions for promote dementia friendly communities	2019	Age friendly businesses and communities	Conference abstract only	Unable to access full documents
92	Funnell, Liam	Dementia-friendly design of television news broadcasts	2019	Dementia friendly television	Does not include staff training ideas or techniques.	Does not add to theories under construction.
96	Masuda, Seiko; Murashima, Kotoka; Majima, Yukie; Nakamura, Yumiko;	Development of a Practical Course to Assist Elementary School Students in Acquiring the Ability to Support for Elderly People with Dementia	2019	School dementia awareness and support programme	N/A	Unable to access full text through library or inter library loans service. Similar article included.

Paper No.	Author	Title	Year of publication	Context	Rigour	Reason for rejection
98	Ovenden, I.; Denning, T.; Beer, C.;	"Here everyone is the same" - A qualitative evaluation of participating in a Boccia (indoor bowling) group: Innovative practice	2016	Community leisure (indoor bowling)	Does not include staff training ideas or techniques.	Does not add to theories under construction.
99	Parke, B.; Hunter, K. F.; Schulz, M. E.; Jouanne, L.;	Know me - A new person-centered approach for dementia-friendly emergency department care	2019	Dementia friendly emergency departments	N/A	Within healthcare. Also unable to access journal through library or inter library loans service.
101	Savundranayagam, Marie Y.; Basque, Shalane R.; Johnson, Karen;	Feasibility of a dementia-focused person-centered communication intervention for home care workers	2019	Communication for paid carers	N/A	Within healthcare

APPENDIX Q: NVIVO Codes for Realist synthesis

Original if/then statement	Ideas for resource	Ideas for reasoning	NVIVO codewords
A. IF staff are aware that people with dementia have a right to participation by law THEN this may help to embed the training within the setting. (There is potentially also something here about people living with dementia being more aware of their rights to participation and expecting these rights to be upheld).	1. Increased awareness of dementia legislation and rights to participation	2. Increased seriousness of staff to provide appropriate support – not wanting to break the law. 3. Increased expectation from those living with dementia that their needs will be met.	Disability legislation, rights and awareness
B. IF people do not have the right training or the right attitude THEN they can be a barrier to a person with dementia's engagement in an activity that is meaningful to them. Trainees need to know that they can literally make or break someone with dementia's day. (The Reference Group asked for this to be part of statement A but I have separated this back out for ease of capturing associated data).	4. Increased awareness of an individual's personal impact on someone living with dementia, potentially by including the concept of 'emotional memory'.	5. Increased seriousness of staff to provide appropriate support. 6. Potential for staff to be shamed into taking action. (Not wanting to be the person who upsets or discourages someone else). 7. Concerns over complaint culture.	Personal impact of staff member
C. IF staff lack knowledge of the dementia continuum, and people with dementia's continued wish to remain engaged in occupations of meaning, THEN this is likely to lead to a negative view of dementia, increased stigma and a lack of understanding of this group's needs. WHEREAS, workforce development to raise awareness of dementia and	8. Awareness raising initiatives such as Dementia Friends	9. More likely to understand a person with dementia and less likely to stigmatise. 10. Increased ability to recognise someone with dementia and increased confidence to provide appropriate assistance.	Dementia awareness

<p>improve communication skills is likely to lead to positive attitudes of people with dementia and to reduce stigma surrounding the condition.</p> <p>D. If the training includes the specific skills that can be affected in a person with dementia such as engaging with others and engaging with environments then the trainee is more likely to be able to recognise and assist a person with dementia</p>		<p>11. Decreased ability to put awareness into practice if awareness activity is not context specific - trainees may not easily be able to link awareness to their role.</p>	
<p>E. IF the commercial sector is aware that the measures needed to support people with dementia can be simple, cost effective and help others with hidden disabilities, as well as giving them a commercial advantage, THEN they are more likely to engage with workforce training and environmental adaptation.</p>	<p>12. Involvement of hidden disability groups to discuss shared challenges.</p>	<p>13. Increased understanding of commercial cost/benefit of assisting those with hidden disabilities.</p> <p>14. Increased understanding that changes may benefit more than those living with dementia making adjustments more attractive.</p> <p>15. Increased understanding that acting to support people with dementia may give the organisation an advantage over their competitors.</p>	<p>Commercial concerns</p>
<p>F. IF it is understood that the environment in all its forms can be a barrier to participation for a person with dementia THEN this should lead to improvements in signage and complex paperwork, websites and booking systems.</p>	<p>16. Site meetings and walkthroughs of problem areas to aid understanding of environmental barriers.</p>	<p>17. Ability to see the environment through the person with dementia's eyes leading to increased understanding and wish to change the environment.</p>	<p>Environmental barriers</p>

<p>G. IF people with personal experience of dementia are included within the training, either in person or through case studies, films or vignettes, THEN this can help to increase the relatability of the training. Such involvement of a person with dementia will also help to reduce stigma and address societal expectations as well as ensuring any intervention meets and reflects their needs, priorities and wishes.</p>	<p>18. Staff member with personal experience of dementia. 19. Involvement of a person living with dementia in person or through case studies, films and vignettes.</p>	<p>20. Increased relatability and likelihood of seeing the person behind the dementia. 21. Reduced stigmatisation of people living with dementia. 22. Increased social expectations of people living with dementia.</p>	<p>Personal experience</p>
<p>H. IF a specific body champions the training for the sector THEN this is likely to improve participation in training schemes and increase adaptations by providing leadership, inspiration and guidance. Sharing of project exemplars can also act as an incentive for take up in similar settings.</p>	<p>23. Leadership, inspiration, guidance and exemplars from sector leader/champion. 24. Awards/badges/logos and identifiers.</p>	<p>25. Incentive to take action either through fear of providing inadequate services (which may lead to repercussions e.g. 'name and shame' or simply wishing to remain competitive in the field by being a respected member of the sector. 26. Accreditations may encourage take up through wish to remain professional and to be seen in a good light by professional body, competitors and customers.</p>	<p>Sector specific leadership/support</p>

I. IF a member of staff has a personal connection to someone living with dementia THEN this can positively affect the level of awareness and buy in to dementia friendly initiatives within the setting	27. Employee or other staff member with personal experience of dementia.	28. Increased willingness to enact and facilitate change within the organisation. 29. An individual may be driven by personal experience and knowledge of difficulties encountered and want to change things for the better.	Dementia leaders (change agents)
J. IF peer support is offered on an ongoing basis alongside an in service expert THEN the training is likely to be more successful	30. Peer support initiatives 31. Peer discussion	32. Supportive atmosphere may foster a positive attitude to the training. 33. Increased relatability of the training to the setting and the role of the individual. 34. Staff may interpret inclusion of peers as a sign that the organisation is taking the training seriously which may in turn affect their motivation.	Peer support
K. IF training includes communication skills and how to react to behavioural changes especially in challenging situations (such as travel disruption) THEN the trainee is likely to be more confident in their role and find their role more personally and professionally rewarding.	35. Scenarios and communication techniques. 36. Role-play activities.	37. Increased confidence in dealing with complex situations. 38. Ability to cope may lead the individual to find their role more personally and professionally rewarding.	Communication skills

L. IF training has practical activities and immersive experiences THEN this is likely to lead to greater understanding of the needs of a person with dementia. Such training should not focus too heavily on solitary learning methods and should encourage discussion amongst the trainees.	39. Interactive learning experiences.	40. Increased understanding of how a person with dementia might feel in a given situation, encouraging the trainee to take action.	Practical activities/immersive experiences.
<p>M. If the training is designed with the target audience in mind then it is more likely to be successful as it will make the training more meaningful and transferable to practice as well as reducing the likelihood of potential barriers to participation.</p> <p>N. If training is cost effective and replicable in situ then it is more likely to withstand changes and demands in the setting such as staff turnover or business growth.</p>	<p>41. Bespoke training package applicable to the sector</p> <p>42. Cost effective and replicable training.</p>	<p>43. Training is more meaningful and transferable to practice.</p> <p>44. Reduced likelihood of barriers to participation.</p> <p>45. Increased likelihood that the training will be continued beyond a one off session as designed to withstand changes and demands in the setting such as staff turnover or business growth.</p>	Training design factors
O. If training is to make a real world difference then it needs to incorporate feedback and evaluation from service users.	<p>46. Outcomes monitoring</p> <p>47. Staff feedback.</p> <p>48. Willingness to adapt and change in light of feedback.</p>	<p>49. Increased understanding whether (or not) actions are making a difference.</p> <p>50. Increased understanding that service user and staff feedback is valued and utilised to further develop the training programme.</p>	Outcomes monitoring

APPENDIX R: Themes derived from the air travel experiences of participants with dementia

Theme	Associated meaning units from which theme has been derived
<i>Theme 1: Importance of a positive social environment</i>	<ul style="list-style-type: none"> • Companions as enablers • Attitudes of medical professionals • Pervading ignorance and stigma within wider society • Meaning of travel for people with dementia • The need for change in the travel insurance industry • Aviation staff as makers or breakers of the air travel experience • Understanding the physical effects of dementia on activity • Positive communication techniques • Companions as expert communicators
<i>Theme 2: Special assistance as both a barrier and facilitator</i>	<ul style="list-style-type: none"> • Lack of knowledge of services and facilities available • Dominance of the wheelchair symbol • Concern over asking for help • Assistance and the effect on independence • Difficulties getting to and finding special assistance • Lack of understanding of the needs of passengers with dementia • Poor experience as a permanent barrier • Lanyard scheme not well advertised • Benefits of wearing a lanyard • Lack of continuity of service • Lanyards as a potential for unintentional disclosure and labelling • Lack of recognition of lanyards outside of the United Kingdom • Assistance ideas for the future

Theme 3: Challenges within the general airport environment	<ul style="list-style-type: none"> • Structural changes and subsequent navigational difficulties • Challenges with directional and other signage • Sensory overload in Duty Free • Challenges of unusual flooring surfaces • Struggling to use automated systems • Challenges of finding and exiting toilets • Negotiating crowds • Running the gauntlet of security • Security as the <i>perfect storm</i> of environmental factors • Feeling lost and insecure without companions • Effect of shouted instructions • Pre-packing and searching as a security coping strategy
Theme 4: Subtle differences from the usual inflight experiences	<ul style="list-style-type: none"> • Value of priority boarding versus last on, last off • Choosing seats and fear of separation • Special assistance in flight • Aircraft toilets • Information overload • Disembarkation challenges
Theme 5: Recommended strategies for other air travellers with dementia	<ul style="list-style-type: none"> • Investigate help and facilities available • Importance of knowing your rights • Reducing sensory overload • Travel with a companion • Reducing anxiety levels • Take a manageable amount of luggage • Adapt the way you travel • Build new routines around air travel

APPENDIX S: Themes derived from the air travel experiences of travel companions

Theme	Associated meaning units from which theme has been derived
<i>Theme 1: Planning and preparing for travel</i>	<ul style="list-style-type: none"> • Finding a helpful travel agent • Perceptions around special assistance • Lack of information on help and support available • Challenges of booking special assistance online • Challenges of advertising special assistance • Enabling the person with dementia to travel • Concerns about travelling from family members • Difficulties of obtaining travel insurance • Difficulties of trying to pack ahead of time • Challenges of the unforeseen • Being aware of travel rights for diversion or delay • Making the most of travel opportunities • Tackling discrimination in general society • The importance of creating travel memories • Travelling to the person's capabilities
<i>Theme 2: Negotiating the airport environment</i>	<ul style="list-style-type: none"> • Travelling to the airport • Difficulties locating the assistance desk • One size fits all approach to assistance provision • Not understanding the needs of the companion • Benefits of the hidden disability lanyards • Assistance staff lacking knowledge of the lanyard scheme • Challenges of re-use of the hidden disability lanyards • Need for hidden disability lanyards and greater understanding of dementia overseas • Person with dementia not wanting to wear an identifier • Language barriers at special assistance

	<ul style="list-style-type: none"> • Communicating with airport staff • Companions as expert communicators • Making staff aware their support is needed • Challenges of automated systems • Challenges of unusual flooring surfaces • Signage difficulties • Physical effects of dementia in the airport environment • Lack of support from other passengers • Awareness of mirroring behaviours • Paying attention to non-verbal cues • Usefulness of airport lounges • Security as the main airport difficulty • Trying to help the person with dementia in security • Distress at being separated at security • Lack of understanding of dementia in security • Difficulties using airport and accessible toilets • Need for good toilet signage • Difficulties at the boarding gate • Collecting luggage from the carousel • Difficulties for a person with dementia when travelling alone
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Theme 3: Supporting the person with dementia in flight

- Advantages of pre-boarding
- Difficulties with boarding last
- Importance of sitting together
- Importance of choosing seats
- Providing assistance with seatbelts
- Difficulties using the aircraft toilets
- Risk of dehydration inflight
- Advantages of having an accessible toilet on-board
- Keeping the person with dementia occupied when travelling
- Experiences of the inflight meal service
- Positive experiences of cabin crew
- Guilt at asking for help from the cabin crew
- Lack of communication regarding onward assistance
- The need to brief cabin crew about passengers' needs

Theme 4: Sharing strategies for a positive flight experience

- Advantages of travelling from a local airport
- Importance of familiarity and routine
- Undertake a pre-visit to the airport
- Careful planning of flight times
- Apply for a Blue Badge
- Allow plenty of time to travel to the airport
- Benefits of travelling as a party
- Having a plan for if you get separated
- Prepare for travel
- Benefits of travelling business class
- Advantages of using airport lounges
- Prepare for security
- Importance of asking for help
- The need to request special assistance
- Do not give up travelling too early
- Training expectations
- Opening the door to inflight support
- Benefits of good airport design
- Innovations for the future

APPENDIX T: Draft of cartoon poster board

Preparing to travel – poor societal expectations of people living with dementia



People living with dementia may be advised to disengage from meaningful activities at the point of their diagnosis. Such paternalism and risk aversion within health and social care was recognised in a review of the Mental Capacity Act (House of Lords, 2014). However, with the appropriate support, it is possible for people to live well with dementia and to continue to engage in activities that are meaningful to them like air travel.

UK airports and airlines have a legal duty to support passengers with all forms of disability, including hidden disabilities like dementia, through their special assistance services. The UK Civil Aviation Authority reports that 4 million passengers were assisted at 31 UK airports during the 2019-20 financial year, up from 2.5 million in 2014 (Civil Aviation Authority, 2020).

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