Loughborough University

Improving Accessibility for People with Dementia: Web Content and Research

A Doctoral Thesis

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Abstract

The Internet can provide a means of communication, searching for information, support groups and entertainment, amongst other services, and as a technology, can help to promote independence for people with dementia. However, the effectiveness of this technology relies on the users' ability to use it. Web content, websites and online services need to be designed to meet the abilities and needs of people with dementia, and thus the difficulties that these users encounter must be explored and understood.

The primary aim of this thesis is to investigate web content accessibility for People with Dementia and develop recommendations for improving current guidelines based on accessibility needs. The secondary aim is to support people with dementia having a voice within research through development of accessible ethical processes.

Qualitative data were collected with a scoping study using questionnaires about everyday technology use (people with dementia and older adults without dementia); and in-depth interviews to explore difficulties and web accessibility issues. A document analysis was conducted on Web Content Accessibility Guidelines (ISO/IEC40500:2012) for inclusion of the needs of people with dementia followed by review of Web Usability Guidance (ISO9241-151:2008) to consider how gaps relating to the unmet accessibility needs for people with dementia could be met.

The scoping study found that both people with dementia and older adults without dementia use everyday ICT to access the Web. Both groups described difficulties with web interface interactions, which refined the research scope to web content accessibility.

The interview data with people with dementia (n=16) and older adults without dementia (n=9) were analysed using Grounded Theory techniques. It was found that both user groups experienced the same types of difficulties using the Web, but that dementia symptoms could exacerbate the difficulties from usability issues (older adults without dementia) into accessibility issues for people with dementia. Navigation was a key issue for both groups, with a range of web content design elements contributing to accessibility issues with navigation for people with dementia.

The document analysis found that the accessibility guidance did not address all the accessibility issues encountered by people with dementia. However, the usability guidance did address many of the accessibility issues for web content navigation experienced by people with dementia.

The research provides recommendations for improvements to web content accessibility guidelines including content from usability guidelines, and amendments to current guidelines and success criteria. A new ethical recruitment/consent process was developed and tested as part of the research process and is recommended for use in future research to support engagement of people with dementia.

Keywords: *accessibility, Web accessibility, accessibility guidelines, Human Factors, Inclusive Design, Human Computer Interaction, Design ethics, people with dementia, design for dementia.*

Acknowledgements

Undertaking this PhD has been quite a challenge, and it would not have been possible to do without the support, guidance and encouragement that I have received from many people. I would like to take this opportunity to express my gratitude to those that have supported me throughout this experience.

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Publications/Conference Proceedings

- ALLEN, R.S., COOK, S., HIGNETT, S. and JAIS, C., 2017. Involving people with dementia in participatory design: ethical processes and consent for dementia research. *Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association*, Volume 13, Issue 7, p.156-157.
- ALLEN, R., COOK, S., HIGNETT, S. and JAIS, C., 2016. *The Use of Everyday Technologies by People with Dementia*. Presented at 11th Dementia Congress UK (UKDC 2016), Brighton, UK, 1-3rd November.
- ALLEN, R., COOK, S. and HIGNETT, S., 2016. *How do People Living with Dementia Use Technology?* Presented at the Healthcare and Society: New Challenges, New Opportunities. International Conference on Healthcare Systems Ergonomics and Patient Safety (HEPS 2016), Toulouse, France, 5-7th October, pp. 410-413.

List of Acronyms/Abbreviations

AD	Alzheimer’s Disease
AT	Assistive Technology
ET	Everyday Technology
FTD	Frontotemporal Dementia
GT	Grounded Theory
ICT	Information Communication Technology
LBD	Lewy Body Dementia

Table of Contents

List of Figures

List of Tables

Chapter 1. Introduction

1.1 The Need to Design for Dementia

1.1.1 Prevalence

This research is positioned in the context of the global ageing population, in which dementia prevalence is predicted to increase (Prince *et al.*, 2016). Over 46.8 million people live with dementia across the world, and this number is forecast to increase to 131.5 million by 2050 (Prince *et al.*, 2016). In Europe, the number of people with dementia is expected to increase by 78% between 2015 and 2050, from 10.5 million to 18.66 million (Prince *et al.*, 2016), with over 2 million people with dementia living in the UK by 2051 (Alzheimer's Society, 2014).

1.1.2 Dementia

The word dementia is an umbrella term that describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These symptoms become severe enough to affect daily life, and people with dementia may also experience changes in their mood or behaviour (Alzheimer's Society, 2015).

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease, or a series of strokes, and the specific symptoms that are experienced depends on the parts of the brain that are damaged and the disease that is causing the dementia (Alzheimer's Society, 2015). The most common disease of the brain that causes dementia is Alzheimer's disease, accounting for 62% of dementia (Alzheimer's Society, 2014). The proportions of other subtypes of dementia are as follows:

Vascular dementia	17%
Mixed dementia	10%
Dementia with Lewy bodies	4%
Frontotemporal dementia	2%
Parkinson's dementia	2%
Other	3%

(Alzheimer's Society, 2014)

All types of dementia are progressive, meaning that the structure and chemistry of the brain become increasingly damaged over time. This means that the person’s ability to remember, understand, communicate and reason gradually declines (Alzheimer’s Society, 2016).

Dementia can present a variety of symptoms, depending on its type and stage of progression, and how quickly dementia progresses depends on the individual. However, the range of symptoms that dementia can present include behavioural and psychological symptoms such as aggression, apathy and irritability, and physical and cognitive symptoms (Alzheimer’s Disease International, 2016). Cognitive symptoms often begin with decline in memory, but can also include difficulties with communication, concentration, visuospatial skills, disorientation to time and place, and decreased judgement (Alzheimer’s Disease International, 2016). Physical symptoms can include a shuffling gait, or trembling of the limbs (Alzheimer’s Society, 2013).

The natural cognitive and functional decline of ageing is exacerbated by dementia, and impacts the independence of an individual. This can lead to needing to move to care facilities, if there is not adequate support to remain living at home. The risk of dementia increases with age, with 1 in 14 people over 65 years of age having dementia in the UK, and 1 in 6 people over the age of 80 years (Alzheimer’s Society, 2014). With an ageing global population, ensuring that there is adequate support for the increasing number of people living with dementia is vital, as dementia prevalence is predicted to increase further still.

1.1.3 Societal/Social Inclusion

The UK government launched a national challenge to fight dementia in March 2012, and have stated that by 2020, they want England to be ‘*the best country in the world … for people with dementia, their carers and families to live’* (Department of Health 2015. p3). As part of the national approach to the challenge of dementia, the Dementia Friends initiative was launched in May 2014, which aims to teach members of the public what it is like to live with dementia (Department of Health 2015, p17). This is one of many examples of how the UK is trying to improve understanding and compassion from everyone, as well as supporting research by scientists. Dementia Friends is part of the Dementia Friendly Communities programme, which facilitates the creation of dementia-friendly communities across the UK. This programme advocates that '*everyone, from governments and health boards to local services, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community'* (Alzheimer's Society, 2017a).

The acknowledgement that it is a shared responsibility to ensure that people with dementia - as individuals with a disability –are supported in their community, can be viewed as a manifestation of the social model of disability in practice. Whereas the preceding '*medical model'* of disability assumed that an individual with a disability must make adjustments to meet the norm, the '*social model'* attributes the disability not to the individual, but to a complex set of conditions, many created by social environment, which prevent the full integration of an individual into society (Johnston, 2003). The social model is concerned with how an individual's impairments affect their integration in society, rather than with the medical condition they have which causes their disability (Johnston, 2003). Therefore, within this model, society is responsible for adjusting the environment to allow individuals to participate fully; a stance shared with the principles of Human Factors and Inclusive Design.

The social model, first coined in the early 1980s initially captured ideas of the barriers encountered in society only by those with physical impairments (Milligan and Thomas, 2016). In the 1980s and 1990s, the case was won that people with sensory and learning impairments should also be included as people with disabilities within the social model, with the scope of individuals being widened in the 1990s and 2000s to include people with chronic illnesses and mental health problems (Milligan and Thomas, 2016). It is only recently that a small number of researchers have started to think about how the social model of disability might apply to people with dementia. Shakespeare et al. (2017) have called for further expansion of our ideas about social models to incorporate the experiences of people with dementia, with Milligan & Thomas (2016) supporting this need, as adopting the social model of disability in this context can encourage researchers to explore the everyday experiences and perspectives of people with dementia.

People with dementia are covered by the Equality Act (Equality and Human Rights Commission, 2010), in which a person is defined as having a disability if the person '*has a physical or mental impairment'* and '*the impairment has a substantial and long-term adverse effect [on the person's] ability to carry out normal day-to-day activities'* (Equality and Human Rights Commission 2010, p4). The Equality Act (ibid, 2010) exists to protect individuals with protected characteristics (age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, or sexual orientation) from direct and indirect discrimination in the workplace and wider society. The Act details how public spaces and services must provide equal access to all; this includes people with disabilities, which includes people with dementia. The Equality Act (Equality and Human Rights Commission, 2010) demonstrates that there is a legal requirement for society to become inclusive for people with dementia, in addition to the moral commitment depicted in the social model of disability.

The digital environment is part of the inclusive society that is the focus of enabling people with dementia (Section 1.3). Web content, websites and online services need to be designed to meet the abilities and needs of people with dementia, and thus the barriers that these users face must be explored and understood. Research needs to be conducted within the social model of disability, to ensure that the experiences and perspectives of people with dementia are understood and that emphasis is given to how the difficulties these users may encounter due to the effects of their impairments can be reduced through design. The social model of disability gave rise to the principles of inclusive design (Johnston 2003, p374). However, in some ways, the inclusive design approach involves reconciling the social model with the preceding medical model, as the designer must understand the relationships between health conditions and impairments, and between impairments and their impact on activity (Johnston 2003, p374). The principles of inclusive design must be understood to enable the consideration of the abilities and requirements of people with dementia when designing to include them in the growing digital environment, as part of our wider society.

1.2 Designing for People with Dementia: Inclusive Design

Inclusive design is '*a general approach to designing in which designers ensure that their products and services address the needs of the widest possible audience, irrespective of age or ability'* (Clarkson and Coleman, 2015). Inclusive design is defined as '*design of mainstream products and/or services that are accessible to, and usable by, people with the widest range of abilities within the widest range of situations without the need for special adaptation or design*' (British Standards Institute, 2005). Inclusive design is an integral part of the current trend toward better integration of older people and people with disabilities in the mainstream society (Clarkson and Coleman, 2015). The term '*inclusive design'* was first used in 1994 (Coleman, 1994) and has been increasingly applied since then (Clarkson and Coleman, 2015). However, cognitive user capabilities and needs remain poorly understood when compared to physical user needs that were researched initially within earlier design initiatives. Designing inclusively for people with dementia requires a better understanding of their needs, which stem from cognitive impairments.

1.3 Research Context

In the absence of a cure for dementia, innovative solutions need to be developed to help promote independence and quality of life (Cahill, Macijauskiene, *et al.*, 2007). Technology is frequently cited as a potential solution to supporting people with dementia to continue living independently, by providing monitoring capabilities, keeping people physically and cognitively active, and facilitating communication, amongst other potential (Newell and Gregor, 2002; Lazar, Thompson and Demiris, 2015).

Access to everyday technologies such as information communication technology (ICT) can provide a means of communication, searching for information, support groups and online gaming, amongst other services (Nygård and Starkhammar, 2007; Blaschke, Freddolino and Mullen, 2009). Such technologies can support maintained social interaction, connections to society and independence in sourcing information, as well as providing opportunities for cognitive engagement. Older adults – and therefore people with dementia – will be exposed to these technological interfaces through necessity as technology moves on and becomes impossible to avoid (Wallace *et al.*, 2010). Therefore, it is highly important that the experiences and perspectives of people with dementia are explored, to develop an understanding of their needs, and what can cause difficulty with access to, and use of everyday technologies. Access to technology is not merely a question of technology being available, it also needs to correspond to the users' needs if it is to enable them to participate fully in society (Nygård and Starkhammar, 2007). As technologies are being developed in a '*hyper-cognitive society'*, where assumptions about cognitive ability are implicit (Brittain *et al.*, 2010), there becomes an increasing risk of people with dementia being excluded from society; the demands of technologies may be beyond the capabilities of someone living with dementia.

Whilst the Equality Act (Equality and Human Rights Commission, 2010) does not explicitly state that websites must provide equal access for all, it is understood that online digital platforms are considered a '*service'* under the Act. The UK Government have expressed within their Digital Inclusion Strategy that:

> '*we must enable people in every part of society - irrespective of age, gender, physical ability, ethnicity, health conditions, or socio-economic status - to access the opportunities of the internet. If we don't do this, our citizens, businesses and public services cannot take full advantage of the transformational benefits of the digital revolution. And if we manage it, it will benefit society too.*' (Government Digital Service, 2014)

AgeUK's Digital Inclusion Review (Green and Rossall, 2013) states that websites must be designed to be accessible, usable and attractive to older adults, to promote better digital inclusion of this user group. ISO/IEC 40500:2012 (International Standards Organisation, 2012) is one standard that can be used to support accessibility to web content for older, and disabled users. Initially developed by the W3C, who are considered to be the global authority of web accessibility standards, the Web Content Accessibility Guidelines were published as a standard in 2012, and are now legally required to be adhered to by all government sites in the UK, and even more widely in other countries. Adherence to the guidelines in this standard is intended to facilitate equal access to web content for all, and reduce some of the barriers individuals with impairments may face – approached with the principles of the social model of disability.

Whilst research is published in the area of ICT for older adults, there is a lack of research specifically investigating the needs of people with dementia, particularly regarding the software interfaces of the Internet and websites. As a result, current guidance for web accessibility does not adequately address the cognitive limitations of people with dementia (Arch and Abou-Zhara, 2008), and thus web content designers do not have guidance to follow that will meet the complex needs of people with dementia.

This thesis aims to address these gaps in research, in relation to current ICT interfaces. The research presented in this thesis is limited to investigating people with dementia of older adult age (60+). It is acknowledged that Inclusive Design seeks to consider a broader range of users, and that some people with dementia are younger than 60 years. However, the age range included within this research represents the majority of people with dementia, and enabled the research findings to be considered within the context of published research on older adults without dementia and web accessibility. Furthermore, the cognitive impairments of younger people with dementia and older people with dementia, that are caused by dementia, are similar in nature, and thus focusing on those over 60 years does not neglect to consider people with dementia who are younger than the typical age of diagnosis.

1.4 Research Aims and Objectives

This research aims to explore issues affecting people with dementia when navigating web content, in order to contribute toward more inclusive Web Content Accessibility Guidance. It is proposed that the current guidance may be inadequate for the design of web content that is truly accessible for people with dementia.

In order to contribute to more inclusive web content accessibility guidance for people with dementia, the objectives of this research are:

1. To understand the context and current knowledge of technology accessibility for people with dementia using systematic reviews of literature;
2. To explore the methodologies appropriate for the inclusion of people with dementia within research in the field of Human-Computer Interaction (HCI);
3. To explore the (accessibility and usability) issues affecting people with dementia and older adults without dementia when using the Web;
4. To understand how cognitive impairments of dementia may impact web navigation;
5. To assess/evaluate current guidance for web content accessibility in order to determine where inclusivity for people with dementia may be improved.

1.5 Research Questions

In order to achieve the research aim, the following research questions have been identified:

- Which barriers to web accessibility do people with dementia encounter; and how do these compare to those encountered by older adults without dementia?
- How inclusive are current web content accessibility guidelines for supporting people with dementia to access and use web content?

1.6 Research Theme

This thesis presents the theme of **accessibility** for people with dementia. Within this theme, two areas are addressed: accessibility of web content for people with dementia, and accessibility of conducting research when including people with dementia in research.

Figure 1 shows the two areas which were addressed in parallel throughout this research, identifying which chapters contribute knowledge in each of the two areas of accessibility.

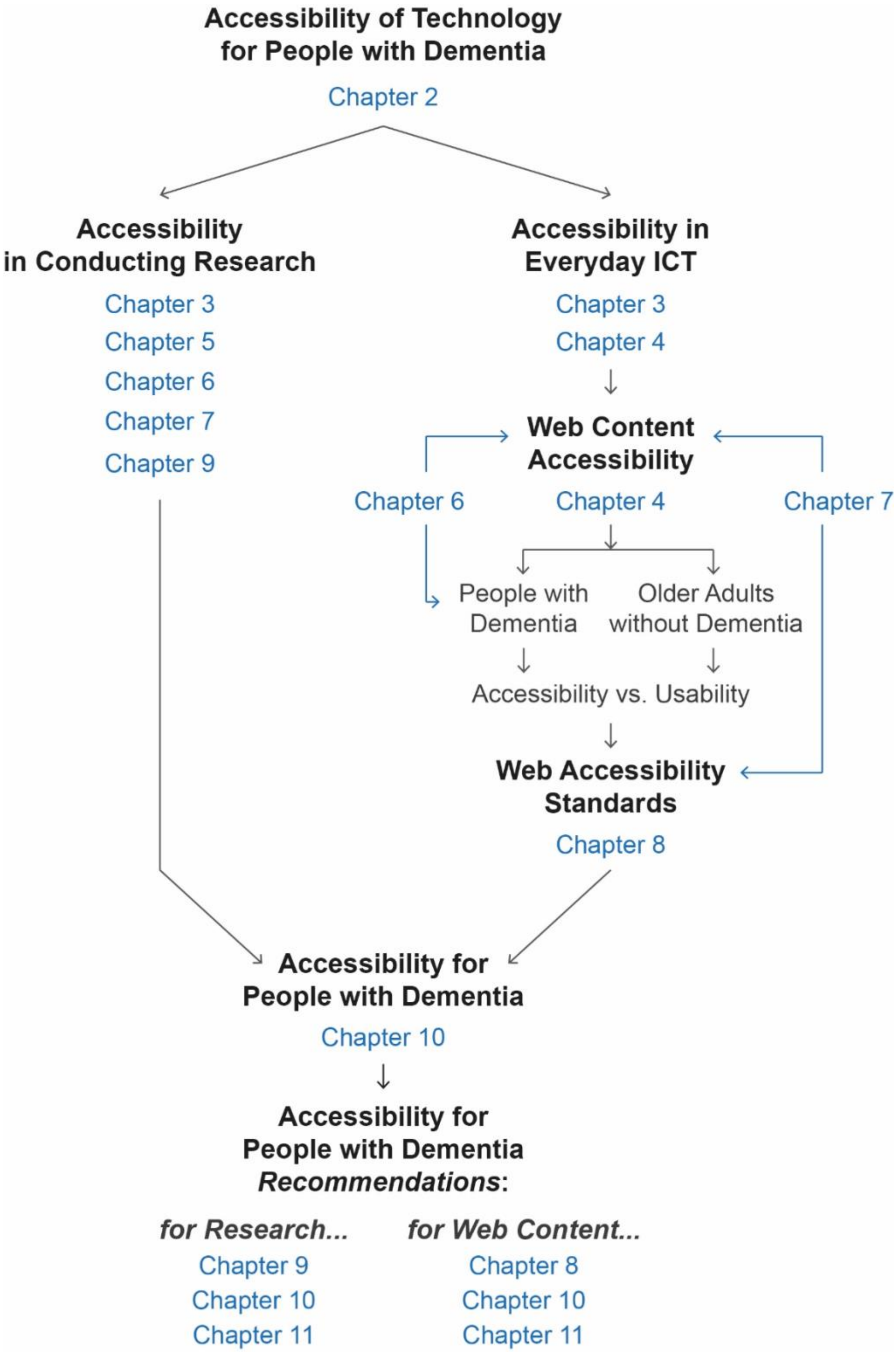


Figure 1 - Research Contributions to Thesis

1.7 Thesis Outline

This thesis presents information and data concerning web accessibility for people with dementia.

Chapter 2 reviews the literature relating to technology use and usability by people with dementia. This identified that everyday technology use by people with dementia is underexplored and that issues encountered using these technologies should be explored as they provide opportunity to support continued independence of people with dementia in a variety of ways.

Chapter 3 is presented in two parts, covering two topics addressed within a scoping study. Part A details how a study exploring everyday ICT use by people with dementia and older adults without dementia facilitated refinement of the research scope identified in Chapter 2. Part B presents research activities that contribute to practice knowledge for the inclusion of people with dementia in research, including the development of inclusive, accessible consent processes for people with dementia.

Chapter 4 presents a second systematic literature review exploring web interface accessibility and usability for people with dementia, including a summary of the available supporting guidance for accessible and usable interfaces. This chapter concludes that the dementia-specific requirements for web content accessibility need further investigation to enable them to be differentiated from the requirements of older adults without dementia. This differentiation is required before existing web content accessibility guidance can be assessed for its inclusivity of the needs of people with dementia specifically.

Chapter 5 details the research methodologies used to address the research aims and objectives. Constructivist Grounded Theory is identified as an appropriate methodology for research with people with dementia to develop an understanding of the topic. Interviews were selected, as they are the most accessible method for collecting data with people with dementia.

Chapter 6 presents the findings of the Web Use Experiences study with people with dementia and older adults without dementia. The chapter concludes that the types of difficulties faced by both user types are primarily navigation focused, and that whilst both user groups face similar types of issues, the symptoms that people with dementia live with may exacerbate the issues encountered by older adults without dementia from usability into accessibility issues, thus preventing their successful use of web content interfaces. A theoretical review of the cognitive abilities required for navigation is proposed, in addition to identifying how current accessibility guidance may be assessed for its inclusivity of the needs of people with dementia.

Chapter 7 presents the findings of the Web Accessibility for People with Dementia study. Specific navigation issues experienced by these users, in association with dementia related cognitive impairments that they have are identified. The extent to which people with dementia experience navigation as a usability or accessibility issue is explored, leading to an assessment of current web content accessibility guidelines to determine whether they address the accessibility issues experienced by people with dementia when navigating web content. Current guidance was not found to address the accessibility issues experienced by people with dementia.

Chapter 8 presents an analysis of web usability guidance, where guidelines that address the accessibility issues experienced by people with dementia are identified, and used to develop recommendations for improving the inclusivity of current web content accessibility guidelines with regard to the needs of people with dementia.

Chapter 9 discusses the knowledge developed throughout the research in this thesis, regarding the accessibility of research to enable the inclusion of people with dementia as participants. This chapter concludes with guidance developed based on the experiences of the researcher, detailing improved practice for creating accessible research that promotes the inclusion of people with dementia as participants.

Chapter 10 summarises the findings of the research and their contribution to knowledge. The main conclusions of the research and their implications within the wider literature are discussed, before the chapter concludes with a consideration of the lessons learned from including people with dementia within this research, and the benefits, challenges, and limitations of doing so.

Chapter 11 concludes this thesis connecting the research findings to the research aims and objectives. This chapter describes what are considered to be the main contributions of knowledge from this research, and identifies areas for future work.

Chapter 2. Literature Review (1)

2.1 Introduction

With the number of people with dementia in the UK forecast to increase to over 2 million by 2051, the need for society to support these people is of paramount importance (Alzheimer's Society, 2014). While research continues to work towards effective treatments, there is need for further research to improve the lives of people living with the symptoms (Alzheimer's Research UK, 2015).The focus on independent living is increasing (Department of Health, 2015), and technology has been cited as a solution to facilitate this independence, through assistive and everyday devices.

Whilst there is a vast array of potential technological interventions to support people with dementia to live independently, the effectiveness of technology relies on the users' ability to use it (Wallace *et al.*, 2010). It is therefore vital that people with dementia are supported in the uptake and use of technologies, to ensure they can overcome any challenges they may face in doing so as a result of their dementia symptoms.

Some obstacles to the uptake and use of technology by older adults have been identified as insufficient perceived need, interest and relevance, as well as design and interface issues, lack of training, and cost in relation to income (Arning and Ziefle, 2009; Rosenberg *et al.*, 2009; Astell *et al.*, 2010; Wallace *et al.*, 2010; Gell *et al.*, 2013; Agree, 2014). Many of these obstacles will be relevant for people with dementia, as they are in the majority of older adult age, but exploration of specific obstacles faced by people with dementia is sparse. Therefore, this literature review explores the obstacles faced by people with dementia in relation to technology use.

2.2 Aims and Objectives

Aims

- To explore the use of technology by people with dementia.
- To identify which types of technologies have been evaluated for use by people with dementia.

Objectives

- To list the obstacles faced by people with dementia when using technology.
- To examine and list the methods and perspectives sought when evaluating technology use by people with dementia.
- To appraise the methodological quality of the identified literature.

2.3 Search Strategy

Literature searches were conducted using the following databases: Medline, PubMed, Ergonomics Abstracts, Scopus, Web of Science, Science Direct and ASSIA. These databases were chosen as they covered a range of journals that relate to design and technology, as well as content focused on dementia. The specific search terms used were:

Dementia OR Alzheimer*
AND Technolog*
AND Assistive OR ICT OR comput* OR Internet OR tele*
AND Difficult* OR barrier* OR limitation* OR challeng* OR problem*

Additional search terms were identified from other relevant reviews (e.g. Topo 2009) and through initial scoping of the topic. A visual representation of the initial scoping conducted is shown in Figure 2.

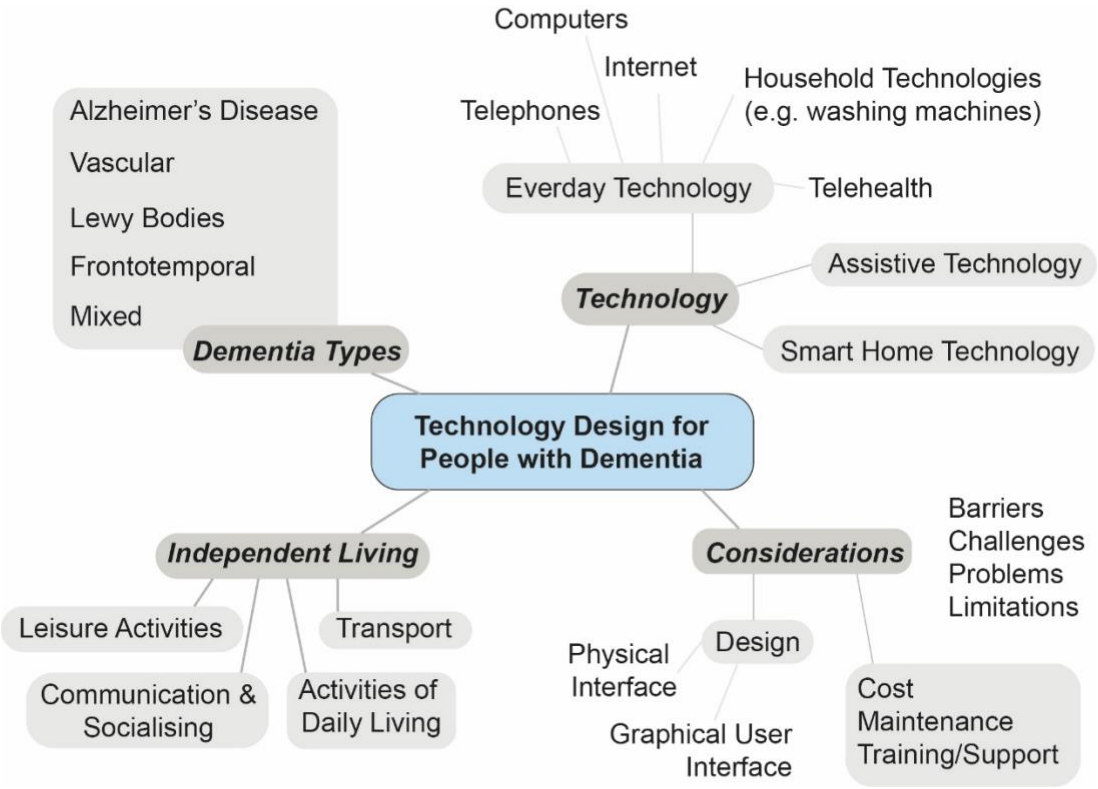


Figure 2. Initial Scoping of Topic

2.3.1 Screening and Selection of Papers

Titles and abstracts of the 1297 papers were found and screened. Papers were discarded if they looked at clinical interventions or diagnostic technologies, or did not address the other literature search objectives. Where the relevance could not be established from the titles and abstracts, full papers were retrieved and read. Duplicates of papers found on multiple databases were removed.

2.3.1.1 *Inclusion and Exclusion Criteria*

To be included, papers had to meet the following criteria:

- Focus on the evaluation of technology use from the perspective of people living with dementia (i.e. people with dementia or their carer)

OR

Focus on the evaluation of obstacles faced by people with dementia using technology measured by an alternative method (i.e. objective measures)

- Evaluate technology use by people with dementia specifically, not by older adults as a broader group.
- Be published within a journal or conference proceedings, in any year.

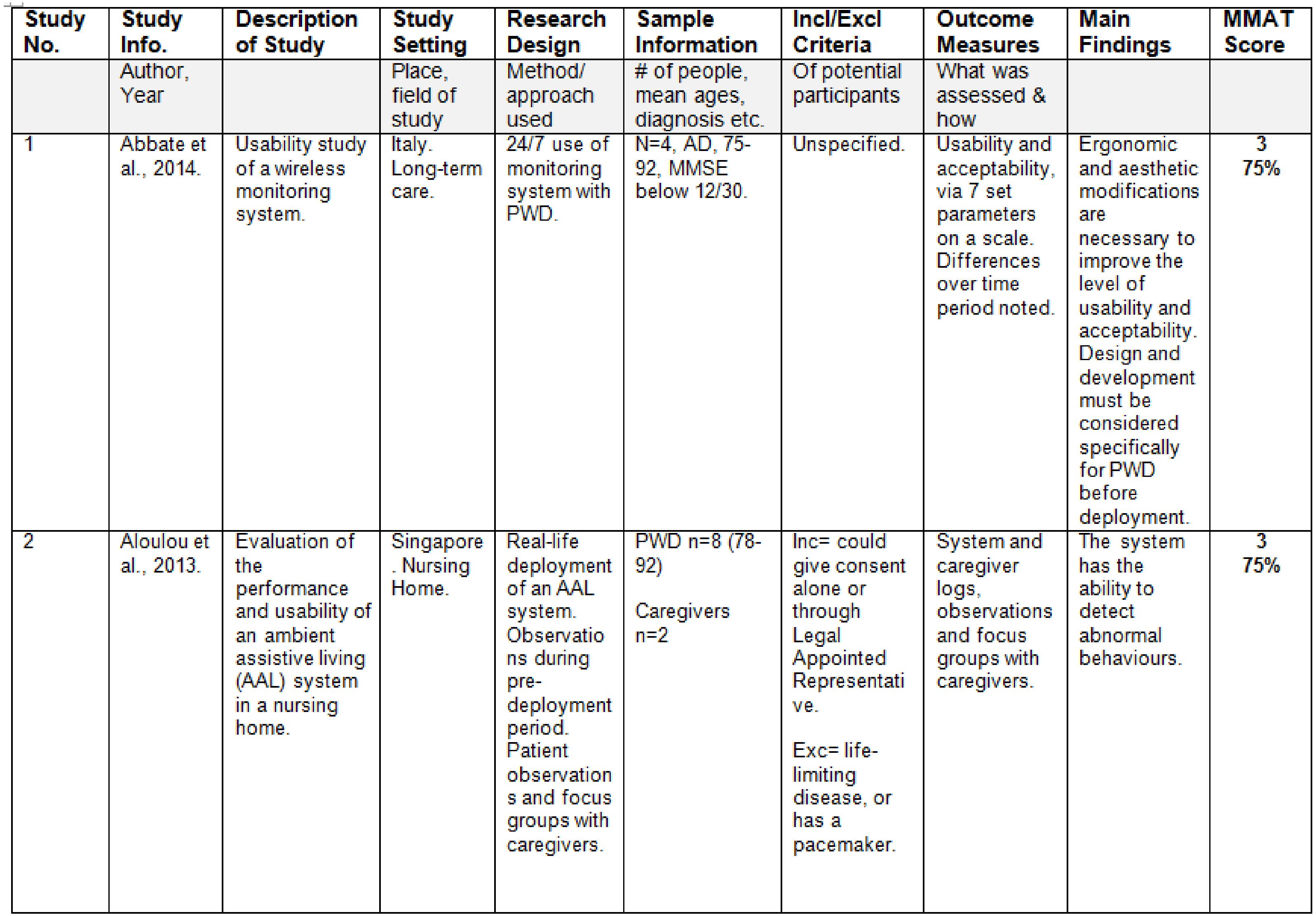
Papers were excluded if they:

- Did not meet the inclusion criteria
- Were professional opinion papers
- Were written in any language other than English.

2.3.2 Critical Appraisal

The mixed methods appraisal tool (MMAT; Pluye et al., 2009) was used to assess the methodological quality of the included papers. This tool included five different types of mixed methods components (Qualitative, Quantitative and Mixed Methods) and the quality criteria against which each type of study can be assessed.

Using the MMAT, included papers were given methodological quality scores of 0-4, depending on how many of the criteria they met. A score of 0 indicated that no criteria were met, and a score of 4 indicated that all criteria were met. Papers that score an MMAT score of 0 or 1 were discarded as the quality of the studies were deemed too poor for inclusion. A sample of the papers scored using the MMAT is shown in Figure 3, with the full dataset in Appendix A.



Study No.	Study Info.	Description of Study	Study Setting	Research Design	Sample Information	Incl/Excl Criteria	Outcome Measures	Main Findings	MMAT Score
	Author, Year		Place, field of study	Method/ approach used	# of people, mean ages, diagnosis etc.	Of potential participants	What was assessed & how		
1	Abbate et al., 2014.	Usability study of a wireless monitoring system.	Italy. Long-term care.	24/7 use of monitoring system with PWD.	N=4, AD, 75-92, MMSE below 12/30.	Unspecified.	Usability and acceptability, via 7 set parameters on a scale. Differences over time period noted.	Ergonomic and aesthetic modifications are necessary to improve the level of usability and acceptability. Design and development must be considered specifically for PWD before deployment.	3 75%
2	Aloulou et al., 2013.	Evaluation of the performance and usability of an ambient assistive living (AAL) system in a nursing home.	Singapore. Nursing Home.	Real-life deployment of an AAL system. Observations during pre-deployment period. Patient observations and focus groups with caregivers.	PWD n=8 (78-92) Caregivers n=2	Inc= could give consent alone or through Legal Appointed Representative. Exc= life-limiting disease, or has a pacemaker.	System and caregiver logs, observations and focus groups with caregivers.	The system has the ability to detect abnormal behaviours.	3 75%

Figure 3. Sample of MMAT Table

2.4 Results

Figure 4 shows the process followed for the literature search, in which 40 papers were identified for inclusion.

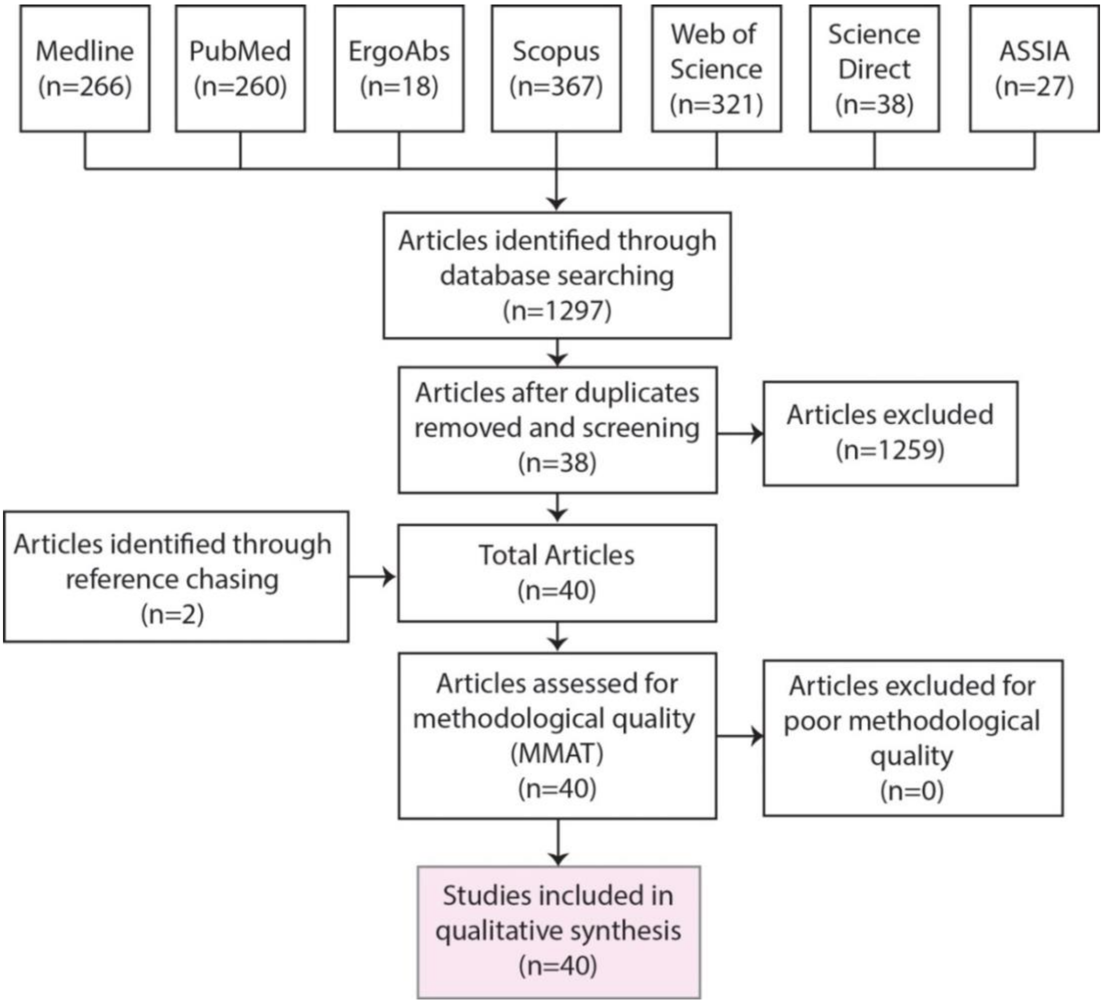


Figure 4. Literature Search and Selection Process

2.4.1 Characteristics of Included Studies

The sample sizes in the included studies varied from 2 - 180 participants, though the majority of the studies had low participant numbers. Not all studies involved people with dementia, but of those that did, over two thirds involved participants with varied types of dementia, whilst the others involved those with Alzheimer’s disease only. People with dementia of different stages of their dementia were involved in various studies, though only 3 involved those with late stage dementia.

Studies were largely conducted in Europe, with fewer studies being conducted in other locations across North America, Asia and Australia. The majority of studies were conducted within participants' homes, or communities, though a significant number were conducted within care facilities (e.g. day centres, nursing homes).

2.4.2 Main Findings

Included papers were coded thematically in QSR NVivo10, to identify key topics: types of technologies evaluated (Section 2.4.2.1); range of obstacles experienced (Figure 5); evaluation methods used (Section 2.4.2.3); and perspectives sought for evaluation (Section 2.4.2.4).

2.4.2.1 Types of Technology

As Topo (2009) stated, the technology types developed and evaluated within the included literature often focused on the safety and security of people with dementia. However, various developed assistive technologies (ATs), everyday technologies (ETs) and care-provision technologies have also been evaluated. Categories of technology types included safety technologies, assistive technologies, everyday technologies, rehabilitation technologies, and other technology types. Technologies were evaluated for various environments including at home, in care-residence and in memory-clinics.

2.4.2.1.1 Safety Technologies

Safety technologies are intended to monitor the location and safety of people with dementia. Passive technologies such as electronic tracking systems (Faucounau *et al.*, 2009), wearable monitoring systems (Abbate, Avvenuti and Light, 2014), passive positioning alarms (Olsson, Skovdahl and Engström, 2016), safety and monitoring technology (Riikonen, Mäkelä and Perälä, 2010) and lost-seeking devices (Chen and Leung, 2012), do not require direct input from people with dementia during use. These technologies primarily benefit caregivers, by reducing their care load, but also benefit people with dementia by increasing their level of independence.

2.4.2.1.2 Assistive Technology (AT)

An assistive technology is defined as '*any item, piece of equipment, product or system, whether acquired commercially, off-the-shelf, modified or customised, that is used to increase, maintain or improve functional capabilities of individuals with cognitive, physical or communication disabilities'* (US General Services Administration, 1998).

Arntzen et al. (2014), Lindqvist et al. (2013) and Boger et al. (2014) explored the successful incorporation of AT into the everyday life of young people with dementia, and people with dementia who have Alzheimer's Disease, whilst many studies have evaluated the use of AT devices developed for people with dementia specifically. The types of AT include prompting technologies (Labelle and Mihailidis, 2006; Bewernitz *et al.*, 2009; Nugent *et al.*, 2011; Boyd *et al.*, 2015), organising technologies (Cahill, Begley, *et al.*, 2007; Karlsson *et al.*, 2011; Rosenberg and Nygard, 2011; Imbeault *et al.*, 2014), simple devices such as a stove timer device (Starkhammar and Nygård, 2008), and complex technologies such as a telephone robot (Moyle *et al.*, 2014) and intelligent cognitive assistant (Wolters, Kelly and Kilgour, 2015). Some of these studies use every day Information Communication Technology (ICT) as the basis of the device (Cahill, Begley, *et al.*, 2007; Imbeault *et al.*, 2014), such as tablet computers, whereas other studies evaluate ETs for their intended primary use, such as remote controls.

2.4.2.1.3 Everyday Technologies (ETs)

Commercially available ETs have been evaluated for use by people with dementia (Malinowsky et al. 2010; Malinowsky et al. 2015; Nygård & Starkhammar 2007). These include simple technologies such as remote controls (Rosenberg *et al.*, 2009; Jentoft, Holthe and Arntzen, 2014), microwave ovens (Rosenberg et al. 2009; Rosenberg & Nygård 2014), and telephones (Topo, Jylha and Laine, 2002; Patomella *et al.*, 2011; Rosenberg and Nygård, 2014). More complex, modern technologies have also been evaluated; smart phones (Brankaert, Snaphaan and Den Ouden, 2014), computers and the Internet (Rosenberg *et al.*, 2009; Patomella *et al.*, 2011), and tablet computers (Ekström, Ferm and Samuelsson, 2015).

2.4.2.1.4 Rehabilitation and Care-Technologies

Some common ETs are used as the basis for technological solutions used in care and reminiscence therapies, and the potential for opportunities in dementia care was explored by Lazar et al. (2016). Technology has been used in cognitive training (González-Palau *et al.*, 2013; Zmily, Mowafi and Mashal, 2014), in communication within care (Olsson *et al.*, 2012), and to facilitate activities in the care environment such as art therapy (Leuty *et al.*, 2013) and music therapy (Topo *et al.*, 2004). These technologies have been used with individuals and groups of people with dementia with the support of a caregiver, mainly within care environments, as a form of rehabilitation.

2.4.2.1.5 Other Technologies

Two studies had different focuses for the technologies that they evaluated. An ambient assistive living system was one of these, which could be defined as a technological system with AT purposes, being used within a smart-home environment (Aloulou *et al.*, 2013). The other, focused on how eHealth could be accessed by people with dementia using the necessary technologies (Malinowsky, Nygård and Kottorp, 2014). This is another example of how ETs are core to enabling the independence of people with dementia to be maintained, within the growing domain of eHealth.

2.4.2.2 Obstacles

A range of obstacles to technology use by people with dementia were identified; awareness, cost and availability, need for carer input, attitudinal, design, need for habitual change and learning, and emotional reactions.

2.4.2.2.1 Awareness

Lack of awareness by both occupational therapists (OTs) and carers regarding AT devices that are available and how to access and use them were identified as an obstacle to the uptake of AT (Boger *et al.*, 2014). Riikonen et al. (2010) stated that to ensure healthcare professionals do not get lost in the ‘*technical jungle’* of AT, more information on available technologies and criteria for their use needs to be provided.

2.4.2.2.2 Cost & Availability

The cost of AT was reported by family caregivers and OTs as a factor contributing to the non-uptake of these types of technologies (Boger *et al.*, 2014). One OT in a study conducted by Boger et al. (2014) highlighted that high cost of AT is particularly problematic for seniors who may have limited finances; an opinion with which family caregivers concurred. Both direct and indirect costs of AT were highlighted as an obstacle to the uptake of the technologies (Gibson *et al.*, 2015). 'Do It Yourself' (DIY) assistive technologies based on commercially available devices were felt to be better value than formal purpose-specific AT devices by carers (Gibson *et al.*, 2015), in addition to being more readily available.

Availability of commercial devices that can be utilised as AT is a reason specified by caregivers for the non-uptake of formal AT devices (Gibson *et al.*, 2015). These readily available commercial devices were also considered to be more familiar to people with dementia and their caregivers (Gibson *et al.*, 2015); lack of familiarity was a design factor considered to be a potential obstacle to technology use. The availability of formal AT to people with dementia and their caregivers heavily depends on OTs and healthcare providers having an awareness of the potential AT devices (Riikonen, Mäkelä and Perälä, 2010), as discussed previously.

2.4.2.2.3 Need for Carer Input

A low degree of engagement and interest of the carer can result in unsuccessful incorporation of AT (Arntzen, Holthe and Jentoft, 2014), and needs to be considered when professionals evaluate the different AT devices (ibid.). Without sufficient interest in the AT device, carers may not fulfil their supportive role when people with dementia are using technology. Carers play a key role in facilitating the integration of AT into the usual routines of people with dementia by undertaking much of the everyday work required to ensure their habitual use (Gibson *et al.*, 2015). Carers often need to provide support when people with dementia use technology, as a prompt (Cahill, Begley, *et al.*, 2007), to guide people with dementia in how to learn and use the device (Faucounau *et al.*, 2009; Imbeault *et al.*, 2014; Gibson *et al.*, 2015), or to reassure people with dementia if they are unsure or anxious about the device (Gibson *et al.*, 2015).

It was also reported that carers' capability with using technological devices can enable or prevent successful incorporation of a new device (Brankaert, Snaphaan and Den Ouden, 2014); another factor that can determine the uptake and use of AT.

2.4.2.2.4 Attitudinal

The presence of a negative attitude toward AT was shown to create an obstacle to the uptake of technology. Sceptic people with dementia can be uncertain of the usefulness of an AT, or their own capability to manage it (Arntzen, Holthe and Jentoft, 2014). Doubt and distrust can also contribute to a negative attitude, resulting in unsuccessful implementation of AT (ibid.). These negative attitudes can create an obstacle to AT use if they are present in people with dementia themselves, or their carers; e.g. if a carer is of the belief that no technology can aid the people with dementia that they care for (Boger *et al.*, 2014).

Gibson et al. (2015) found that people with dementia often adopt an attitude that they will 'tolerate' a certain AT as an inconvenience within their homes if they felt that this would be of benefit to their carer. It is therefore vital that if a technology is to be successfully accepted by people with dementia, that they are perceived to be a better solution than their current coping strategy (Arntzen, Holthe and Jentoft, 2014). Without being perceived as needed, or useful, by both people with dementia and other stakeholders such as carers, the attitude toward the technology is likely to be an obstacle to its uptake or use (Boger *et al.*, 2014).

2.4.2.2.5 Design

The design of any technology has to meet the needs of its user, to facilitate successful incorporation. Some of the design features of technologies that have been shown to create obstacles to technology use, due to poor physical or cognitive incompatibility with people with dementia include; too many buttons, too many operations required, ambiguous visual prompts, and features being too small.

A technological product needs to meet both the needs and the desires of people with dementia. Ergonomic and aesthetic considerations are necessary to ensure a satisfactory level of accessibility, usability, and acceptability (Abbate, Avvenuti and Light, 2014). Technological devices may be problematic to handle because they have too many buttons, that are often too small, or because they require too many operations and procedures, resulting in excessive demands on the user (Faucounau *et al.*, 2009; Chen and Leung, 2012; Arntzen, Holthe and Jentoft, 2014; Boger *et al.*, 2014; Jentoft, Holthe and Arntzen, 2014; Gibson *et al.*, 2015). These are examples of how products may not meet the needs of people with dementia, for physical reasons or because they demand too much from a person living with cognitive impairment.

Visual prompts were often found to be ambiguous to people with dementia (Boyd *et al.*, 2015), poorly chosen language that is not meaningful may cause confusion (Brankaert, Snaphaan and Den Ouden, 2014; Boyd *et al.*, 2015), and text in a typeface that was too small, or audio at a volume that was too low were also found to be obstacles to successful technology use by people with dementia, who are predominantly older users (Cahill, et al. 2007; Imbeault et al. 2014; Topo et al. 2004). Comfort, battery life and aesthetical properties such as the colour of products were also identified as being important contributing factors to encouraging and enabling people with dementia to use technology (Faucounau *et al.*, 2009; Chen and Leung, 2012).

The obstacles that poor design can create to the uptake and use of technology by people with dementia include; the need for habitual change and learning, and emotional reactions.

2.4.2.2.6 Need for Habitual Change and Learning

People with dementia are more at ease with familiar objects, even when they are living with severely damaged conceptual knowledge (Cahill, et al. 2007). Unfamiliar designs have been seen to be a major deterrent for a person with dementia using a product, and these products require an adjustment to change, and new learning on the part of people with dementia. This is something that is difficult, given the varied and changing nature of dementia (Cahill, et al. 2007). It has also been shown that people with dementia find using technology more difficult than older adults without cognitive impairment and that they require more help to do so (González-Palau *et al.*, 2013). This is likely to be because episodic memory is one of the most common cognitive deficits in dementia, and this memory is indispensable for learning new concepts and applications (González-Palau *et al.*, 2013).

However, it has been stated that it is a common misconception that older adults are averse to change and are unwilling to use new technologies; they express a willingness to learn to use new devices (Faucounau *et al.*, 2009). Whilst this is not specifically about people with dementia, it is still potentially relevant as the majority of people with dementia are older users. González-Palau et al. (2013) suggest that despite the difficulties found in the learning abilities of people with dementia, their interest in new technology is preserved.

Familiarity of objects can reduce the need for habitual change and make it easier for people with dementia to adapt to new technologies. Arntzen et al. (2014) found that people with dementia continued to search for older and more familiar technology, despite new technology being easier and more manageable. This demonstrated that if a technology is internalised in the everyday practice of people with dementia, it can influence their ability to incorporate new AT. Essentially, new technologies must fit in with, or be easily incorporated into family life routines and the different users' habitual practices (Arntzen, Holthe and Jentoft, 2014). If products do not fit into habitual practices, prompts to use the technology may be required from carers (González-Palau *et al.*, 2013), resulting in more reliance on the carer.

The fit of a product's design into the habitual practice of a people with dementia can enable, or become an obstacle to its use, and this must be considered when developing technology for people with dementia.

2.4.2.2.7 Emotional Reactions

Technology design that does not meet the needs and desires of people with dementia may result in an emotional reaction that can impede the successful uptake or use of technology. For example, shortcomings in design resulting in complicated and non-user-friendly procedures were found to be contributory factors to negative emotions such as distress, fear and frustration (Arntzen, Holthe and Jentoft, 2014; Imbeault *et al.*, 2014; Gibson *et al.*, 2015). Technology behaving in an unexpected manner, being difficult to gain control over, or demanding too much of the people with dementia were all design obstacles that generated negative emotional attitudes toward technology (Riikonen, Mäkelä and Perälä, 2010; Arntzen, Holthe and Jentoft, 2014; Gibson *et al.*, 2015).

Technology that led to people with dementia feeling incompetent, as a result of being too complex or demanding for their abilities was also identified as being unlikely to be successfully incorporated (Arntzen, Holthe and Jentoft, 2014). It is vital that technology creates a feeling of expertise, as this prevents feelings of incompetency and failure (Arntzen, Holthe and Jentoft, 2014).

Another negative emotional reaction that poor design of technology can evoke in people with dementia is the feeling of stigmatisation. Technology that is not passive or discrete, and that forces people with dementia to engage with the fact that they have dementia can result in the non-use of a device (Gibson et al. 2015; Cahill et al. 2007). People with dementia were found to feel stigmatised as a result of feeling embarrassed about being tagged by safety technologies (Cahill et al. 2007), and being ‘labelled’ as a result of needing AT (Chen and Leung, 2012). Faucounau et al. (2009) found that to ensure successful incorporation of AT, devices must evoke autonomy and not be stigmatising.

2.4.2.3 Evaluation Methods

Interviews, focus groups, observations, questionnaires, and log data or error scores were used for technology evaluation in different combinations. Table 1 shows the studies using different method combinations, and their methodological quality.

MMAT scores for the reviewed studies indicate that employing qualitative methods should be encouraged when evaluating technologies for people with dementia. A combination of objective evaluation methods together with an interview is the most frequently used methodology, and should thus be considered as methodology for studies conducted on this topic.

Table 1. Methods Used in Studies

Method	Study Numbers	Low Quality*	Medium Quality*	High Quality*	Total Sources
Objective (Scoring, observations alone)	*4, 6, 14, 18, 30, 36, 40*	**2**	**5**		**7**
Objective with Focus Group	*2*		**1**		**1**
Objective with Questionnaire	*1, 7, 26*	**2**	**1**		**3**
Objective with Interview	*3, 10, 15, 16, 22, 25, 27, 31, 33, 35*	**3**	**5**	**2**	**10**
Focus Group	*39*		**1**		**1**
Questionnaire	*8, 9, 13, 20, 23, 24*	**2**	**2**	**2**	**6**
Questionnaire with Interview	*19, 37, 38*	**2**	**1**		**3**
Interview	*5, 11, 12, 17, 21,28, 29, 32, 34*	**1**	**7**	**1**	**9**

*Quality determined by MMAT Scores, as follows: Low Quality = Score of 2, Medium Quality = Score of 3, High Quality = Score of 4.

2.4.2.4 Perspectives Sought

The perspectives sought when identifying obstacles faced by people with dementia when using technology varied. Six studies collecting objective data such as observations, log-data, or scores for interaction types or numbers did not seek the perspective of people with dementia, nor people in their support network, such as carers or family members (Labelle and Mihailidis, 2006;

Bewernitz *et al.*, 2009; Patomella *et al.*, 2011; Tak, Beck and Hong, 2013; Imbeault *et al.*, 2014; Zmily, Mowafi and Mashal, 2014; Boyd *et al.*, 2015).

Eight studies collected data solely from people with dementia, 3 solely from carers or health professionals. Twenty-three studies collected data from combinations of these stakeholder groups. The studies collecting data from different stakeholder combinations is shown in Table 2.

Table 2. Perspectives Sought in Studies

Combination of Perspective	Study Numbers	Low Quality*	Medium Quality *	High Quality*	Total Sources
Person with Dementia	*1, 4, 22, 23, 24, 27, 29, 34*		**4**	**4**	**8**
Carer/Family	*9, 16, 28*	**3**			**3**
Person with dementia & Carer/Family	*2, 3, 7, 8, 10, 11, 12, 15, 17, 21, 25, 26, 32, 33, 35, 37, 38, 39*	**7**	**10**	**1**	**18**
Carer & Professional	*5, 20*		**2**		**2**
Person with Dementia & Professional	*13*			**1**	**1**
Person with Dementia & Carer & Professional	*19, 31*		**2**		**2**

2.5 Discussion

Table 3 summarises the number of sources relating to each obstacle type. The majority were design based, or triggered by the inappropriate design of technology. The included studies varied in methodological quality, indicating that some findings may be more reliable or valid than others.

Table 3. Studies Relating to Each Obstacle

Obstacle Type	Study Numbers	Low Quality*	Medium Quality*	High Quality*	Total Sources
Awareness	*5, 31*		2		2
Cost/Availability	*5, 12, 31*		3		3
Need for Carer Input	*3, 7, 8, 11, 12, 14*	2	3	1	6
Attitudinal	*3, 5*		1	1	2
Design	*1, 3, 5, 6, 7, 8, 9, 11, 12, 14, 15, 38*	4	7	1	12
Habitual Change & Learning Technology	*3, 8, 11, 13*	1	1	2	4
Emotional Reactions	*3, 8, 9, 11, 12, 14, 31*	2	4	1	7

*Quality determined by MMAT Scores, as follows: Low Quality = Score of 2, Medium Quality = Score of 3, High Quality = Score of 4.

2.5.1 Types of technology

Technology has been evaluated by people with dementia living in different environments, with different stages of dementia. Technology can support increased independence for everyday activities, both when living at home and within care environments. The majority of studies evaluated ATs, considering their potential to support people with dementia within smart-home environments, and the field of e-Health. These technologies are expected to empower people with dementia and relieve their carers, and increase the efficacy and efficiency of healthcare providers respectively (Aloulou *et al.*, 2013).

It is generally accepted that enabling people to perform activities that they were previously able to carry out is good for self-esteem (Boyd *et al.*, 2015). In addition, providing support for activities which involve several steps is considered to be important to the quality of life of people with dementia, and technology can be a means to the provision of this support (Orpwood *et al.*, 2007).

ICT has also been found to be a means to meeting some of the needs of people with dementia and their relatives (Olsson et al. 2012). Technologies used in the care of people with dementia are diverse and can be used from different perspectives, for instance, people with dementia, their carers, and/or healthcare staff. These technologies can serve several purposes too; e.g. to facilitate independent living, safety and security, and/or wellbeing and psychological support (Olsson, Skovdahl and Engström, 2016).

If people with dementia are provided with technologies that are less complex in design, or guided in how to use them, their lives could become more independent and they may be able to participate in society to a greater extent (Patomella *et al.*, 2011). This will become increasingly required, as society becomes increasingly technological in many respects.

2.5.2 Obstacles

A range of obstacles to successful technology uptake and use were identified, many of which correspond to those identified for older adults without dementia. Insufficient perceived need, interest and relevance, design and interface issues, lack of training, and cost (Arning and Ziefle, 2009; Rosenberg *et al.*, 2009; Astell *et al.*, 2010; Wallace *et al.*, 2010; Gell *et al.*, 2013; Agree, 2014), were all found to be relevant to people with dementia. Each obstacle is discussed in Sections 2.5.2.1 - 2.5.2.5, and Figure 5 shows a map of the identified obstacles and the relationships between them. Some obstacles were found to have an impact on the uptake of technologies alone, whilst others affected both the uptake and use of devices.

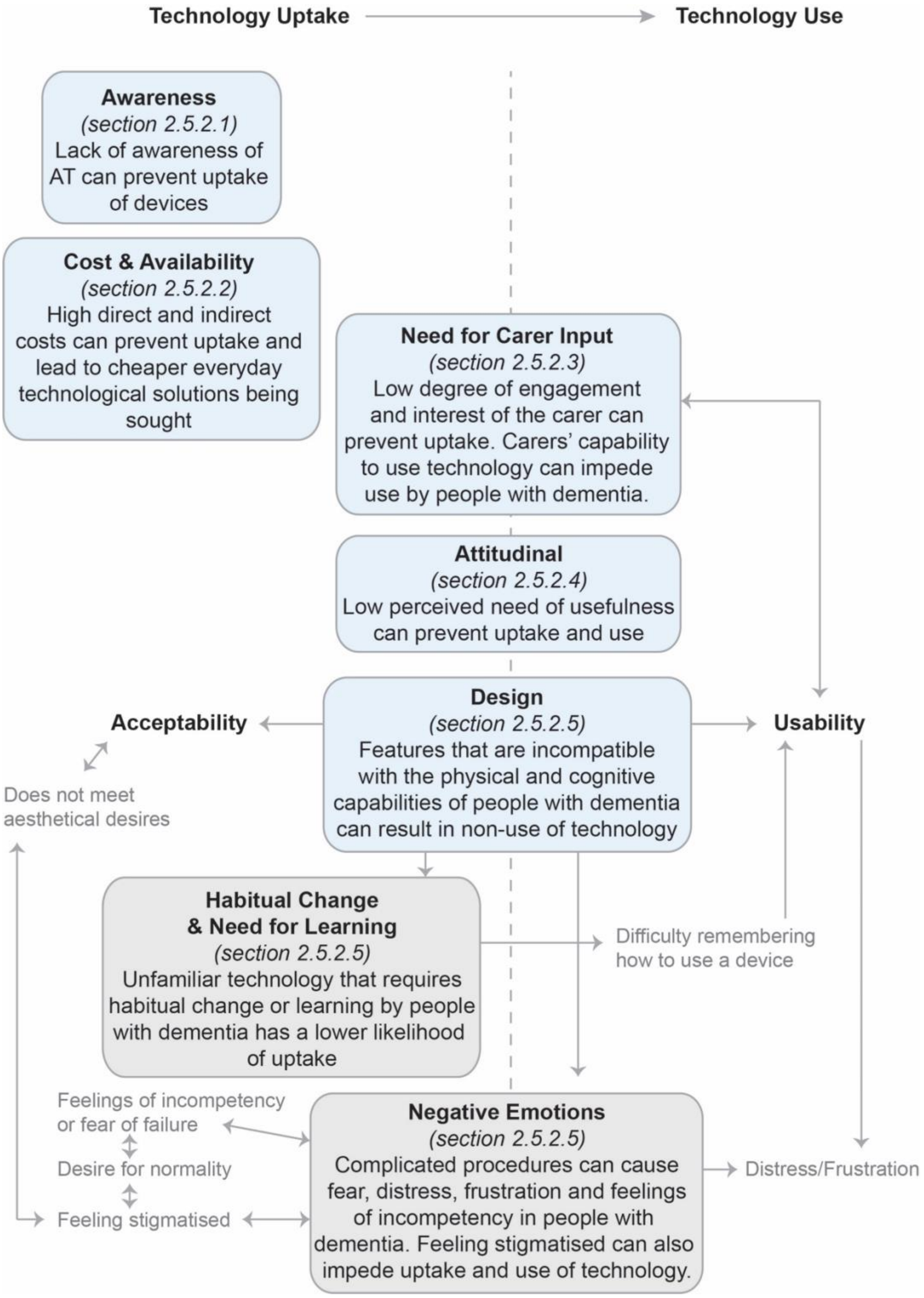


Figure 5 - Map of Technology Obstacles

2.5.2.1 Awareness

Whilst only identified as an obstacle to AT specifically, uptake can be hindered due to a lack of awareness of occupational therapists and carers, of suitable technologies that are available. This can cause difficulty in making an informed decision about which devices may be beneficial. This obstacle is an example of how successful uptake and use of technology is reliant on other stakeholders than people with dementia themselves; the roles of both carers and healthcare professionals need to be considered.

2.5.2.2 Cost & Availability

A second obstacle for uptake of ATs, is cost. High costs can inhibit the purchase of beneficial technologies, which can sometimes lead to cheaper alternatives being sought; often in the form of using everyday devices such as mobile phones and tablet computers (as AT in a 'DIY' manner). This obstacle exists within technology uptake, rather than technology use, and was identified mainly by stakeholders other than people with dementia themselves (Boger *et al.*, 2014; Gibson *et al.*, 2015).

2.5.2.3 Need for Carer Input

Caregivers can play a crucial role in the uptake of AT (Sections 2.5.2.1 and 2.5.2.2). Their role is vital for successful incorporation and use of these devices. Carers are often needed to provide support for technology use, guidance when learning new devices, and to provide reassurance to people with dementia who may be uncertain about technology. As a result, the capability of the carers to use technology can become an obstacle in itself (Brankaert, Snaphaan and Den Ouden, 2014).

The role of carers and the need for their input was only highlighted in relation to AT (Cahill, Begley, *et al.*, 2007; Arntzen, Holthe and Jentoft, 2014; Brankaert, Snaphaan and Den Ouden, 2014; Imbeault *et al.*, 2014; Gibson *et al.*, 2015) and safety technologies (Faucounau *et al.*, 2009). It is unknown to what extent these issues may affect the uptake and use of other technology types, such as more common everyday ICT.

2.5.2.4 Attitudinal

Negative attitudes of either people with dementia or carers can become an obstacle to both the uptake and use of AT (Arntzen, Holthe and Jentoft, 2014; Boger *et al.*, 2014). There was a lack of exploration concerning attitude as a potential obstacle to other types of technology, such as everyday devices being used for assistive purposes, as opposed to formal AT devices. Topo (2009) defined perceived need and usefulness as vital within all stakeholders if technology is to be incorporated and used in the lives of people with dementia. The technology must be perceived as a better solution than current coping solutions, and the technology’s design must be perceived as acceptable and usable for this to be the case (Arntzen, Holthe and Jentoft, 2014) (see Section 2.5.2.5).

2.5.2.5 Design

The design of technology can cause a range of obstacles to the uptake and use of a device. Ergonomic and aesthetic considerations are necessary to ensure a satisfactory level of accessibility, usability, and acceptability. Inappropriate or poorly fitting design can cause difficulty learning how to use a device, exceed user capabilities by placing physical and cognitive demands on the user, and induce negative emotions as a result. Many of the effects of poor design are linked to both technology uptake and usage (see Figure 5).

Most of the design related obstacles were identified by people with dementia, and it was suggested that these obstacles exist due to insufficient understanding of users’ needs during the design process (Faucounau *et al.*, 2009). Topo (2009) suggested that this could potentially be resolved by developing methods to increase user involvement in the design process. The need to include people with dementia in the design and evaluation processes, in addition to other stakeholders such as carers, was identified in numerous studies (Starkhammar and Nygård, 2008; Faucounau *et al.*, 2009; Olsson *et al.*, 2012; Lindqvist, Nygård and Borell, 2013; Brankaert, Snaphaan and Den Ouden, 2014; Jentoft, Holthe and Arntzen, 2014; Kerkhof, Rabiee and Willems, 2015; Wolters, Kelly and Kilgour, 2015; Olsson, Skovdahl and Engström, 2016). As the needs of people with dementia and their carers can differ, responding to the needs of people with dementia as defined by carers is insufficient (Kerkhof, Rabiee and Willems, 2015).

By implementing a user centred design model, which advocates involving users in the whole design process, a product should better match the user requirements and its practical use should be improved (Chen and Leung, 2012). However, complex considerations about the capabilities of people with dementia to partake in evaluation phases have been raised (Karlsson *et al.*, 2011) in addition to questions about capabilities for abstract reasoning about needs (Rosenberg and Nygard, 2011). Ensuring that all stakeholders can contribute is clearly important, though as discussed in Section 2.5.3, people with dementia have not always been equally involved in evaluating technological devices.

2.5.3 Obstacle Identification

Different obstacles were described, depending on the methods, and the stakeholders. Objective data collection methods (e.g. error scores or log data) only evaluated usability, rather than identifying and exploring specific obstacles to technology use – and it cannot begin to identify other obstacles; these require more subjective, qualitative methods. Focus groups, questionnaires, and interviews have been used to elicit subjective information from stakeholders. These are sometimes used as a way to explore the findings from quantitative data collection, particularly when evaluating usability. Three high quality studies (Nygård and Starkhammar, 2007; Arntzen, Holthe and Jentoft, 2014; Rosenberg and Nygård, 2014) involved interviews, which supports the use of this method within future studies when identifying obstacles.

The perspectives sought when evaluating obstacles faced appear to bias the obstacles identified. For example, as carers usually fulfil the role of identifying suitable technologies for people with dementia to use, if carers are not involved in the research, obstacles in the technology uptake phase are considerably less likely to be identified. Other obstacles are more likely to be identified by people with dementia only – such as the negative emotion of feeling stigmatised, or particular design issues associated with high cognitive demand. Another finding is that not *all* identified obstacles are directly associated with devices. Many obstacles, including the need for carer input, attitudinal obstacles, and awareness, are caused by more social factors.

As it is clear that the use of some technology by people with dementia is partially dependent on the role of other stakeholders, including carers, the importance of collecting data from the perspective of each stakeholder is highlighted. As mentioned in Section 2.5.2.5, carers and people with dementia do not always express unified opinions, so it is important that suitable methods are selected to elicit information from each stakeholder. However, examples from high quality studies (Nygård and Starkhammar, 2007; González-Palau *et al.*, 2013; Abbate, Avvenuti and Light, 2014; Arntzen, Holthe and Jentoft, 2014; Rosenberg and Nygård, 2014; Malinowsky *et al.*, 2015) all sought the perspective of people with dementia, so exploration of the involvement of people with dementia, carers and other stakeholders, and the selection or development of the most appropriate methods will be required in future research.

2.5.4 Obstacles and Technology Types

Not all obstacles have been identified for all technology types. Awareness, cost/availability, need for carer input, and attitudinal obstacles were solely identified with a focus on ATs. However, as the majority of studies were evaluating the use of ATs, it is not known whether these obstacles exist for other types of technologies. This is a gap in current knowledge.

Attitude as a potential obstacle could be of particular interest to explore, as older adults, and therefore people with dementia, are found to have varied interest in different technologies. eHealth technologies are one example where there is a greater perceived need and more positive attitude toward technology use (Arning and Ziefle, 2009), whereas tracking ATs give an example of negative attitude (Chen and Leung, 2012; Abbate, Avvenuti and Light, 2014).

2.6 Conclusions

The literature review highlighted the types of technology that have been evaluated for use by people with dementia, including the environments in which they are used, and the obstacles faced by people with dementia during these technology evaluations. The key points identified in response to the aims and objectives of this review are summarised below.

> ***Which obstacles do people with dementia face when using technology?***
>
> Obstacles included:
>
> - Awareness

- Cost/Availability
- Need for Carer Input
- Attitudinal
- Design.

These can create obstacles associated with need for habitual change and learning, and emotional reactions to technologies. The identified obstacles are found to affect both technology uptake and technology use, with different obstacles often identified by different stakeholders. Some obstacles are social challenges faced by people with dementia and other stakeholders (e.g. carers), and some are caused directly by technological devices. Some are affected by both social and technological factors, and many are linked (see Figure 5).

Which technologies have been evaluated for use by people with dementia?

Most obstacles were identified solely in the evaluation of ATs. Therefore, it is unclear whether these obstacles are present for other technology types, such as everyday ICT that has the potential to support the independence of people with dementia in a range of ways, including communication, leisure activities and accessing online services.

How is technology use by people with dementia evaluated?

A range of qualitative and quantitative methods have been used, both as single and mixed methods. These included error scores, observations, interviews, focus groups and questionnaires. Qualitative methods enabled the perspective of people with dementia to be explored. A mixture of perspectives was sought, including those of people with dementia, carers, and health professionals.

Methodological Quality

This review aimed to appraise the literature on its methodological quality. Assessment of the studies using the MMAT (Pluye *et al.*,

2009) found that 70% of the studies were rated as medium or high quality. This shows that the literature was relatively strong in terms of methodological quality, and thus conclusions can be drawn with confidence.

The literature review has highlighted two gaps in knowledge that need to be more extensively addressed through research:

1. Everyday ICT use by people with dementia needs to be investigated, to establish which obstacles are encountered, and whether these vary from obstacles faced by older adults without dementia. This knowledge could contribute to more inclusively designed devices that are accessible, usable and acceptable to people with dementia.
2. Further research is required to increase the involvement of people with dementia in technology-focused research.

These two areas will be addressed in Chapter 3, Parts A and B respectively, where the scope of this thesis will be refined and improved practice for the inclusion and involvement of people with dementia as participants will be addressed.

Chapter 3. Study 1- Everyday ICT Use and Accessibility in Research

3.1 Introduction

This chapter details research activities forming a scoping study conducted in response to the findings of the first literature review (Chapter 2); everyday ICT use by people with dementia needs exploration, and that people with dementia need to be supported for inclusion within research to ensure that their experiences and needs are accurately identified.

The chapter will be presented in two parts:

- Part A will detail the preliminary topical insights gathered through an interview-style study, which enabled the accessibility and feasibility of the topic for investigation with people with dementia to be assessed, and to further refine the scope of the research questions.
- Part B will present the development of dementia-inclusive informed consent processes and appropriate data collection methods, developed to ensure that the research within this thesis is accessible to people with dementia as participants, and that their voices could be heard.

3.2 Part A: Everyday ICT Use Study

Everyday ICT has potential to be used by people with dementia in many ways to support continued independence. The need to investigate their use by people with dementia was identified in the first literature review (Chapter 2), to establish any differences in experience of people with dementia and older adults without dementia. A small interview-style scoping study was conducted to establish whether investigating such technologies with people with dementia was feasible, and to further refine the scope of this research. This study facilitated the gathering of preliminary insights about everyday ICT use, whilst testing the accessibility of the topic of research for further investigation. The findings of this chapter section informed the second literature review (Chapter 4), where the research scope is further refined and research questions are defined.

3.2.1 Aim & Objective

The aim of the research presented in this part of this chapter was to assess the feasibility of the identified research scope when working with this population. To achieve this aim, a small interview-style study was conducted with the following objectives:

- To gather preliminary data relating to everyday ICT use by people with dementia and older adults without dementia.
- To identify specific areas of research interest within the scope being assessed for suitability within this study.

3.2.2 Method

The most frequently used methods for eliciting information from people with dementia are interview, focus groups, and ethnographic observation. Guidance suggests that semi-structured interviews are the most successful approach (Gillies, 2000; Reid, Ryan and Enderby, 2001; Harris, 2004; Gibson *et al.*, 2007; Hellstrom *et al.*, 2007; Orpwood *et al.*, 2007; Roger, 2008; Wherton and Monk, 2008; Lawrence *et al.*, 2010; Miranda-Castillo *et al.*, 2010; Brorsson *et al.*, 2011; Pesonen, Remes and Isola, 2011; Gill, White and Cameron, 2011; Moyle *et al.*, 2011). As this study did not aim to collect in-depth data, the method selected was a questionnaire (Section 3.2.2.1).

However, to ensure that the data collection process was appropriate for people with dementia, the questionnaire was conducted in a style similar to that of a semi-structured interview. The focus of the questionnaire was which everyday ICT that provide access to information people with dementia and older adults without dementia use, and for which purpose. People with dementia were supported throughout the completion of the questionnaire, with a researcher scribing their responses, so that writing skills were not required of participants. The use of a physical questionnaire was a visual prompt to people with dementia, intended to support participants' focus, as it was designed to include images that depicted the topic of the questions.

As data was required from both people with dementia and older adults without dementia (for which caregivers often fit the criteria) to enable comparisons in experience and ICT use to be made between types of user, it was felt that approaching people with dementia and carer dyads was appropriate for this study. Recruiting dyads also provided an opportunity to observe the dynamics between these stakeholders during the research process (Section 3.3.6.3.4).

3.2.2.1 Questionnaire

The questionnaire used within this scoping study focused on which everyday ICT devices people with dementia and older adults without dementia use, and for which purpose (Appendix B). The questionnaire focused on the most common everyday ICT devices used in domestic environments; landline and mobile telephones, and tablet, desktop and laptop computers. People with dementia and their carers, as older adults without dementia, were asked to detail which of the devices they used, and then explain what they used them for, as individual users. The questionnaire sought to identify ICT devices used by the two user types, and differences and similarities in the purposes for which the devices were used. This enabled the accessibility and suitability of the proposed research scope to be assessed, by determining whether people with dementia use ICT and are both willing and capable to discuss this.

The method chosen was intended for low participant numbers, as reflection on the accessibility and suitability of the proposed research scope was being sought with more importance than being able to statistically analyse large numbers of data.

3.2.2.2 Ethics

The ethical considerations and practice followed within the studies of this research is detailed in Part B of this chapter (Section 3.3).

3.2.2.3 Procedure

The study was conducted in person, within the environment of a community dementia-support group meeting. Members of the group were invited to participate, and individuals that expressed an interest in participating were provided with a participant information and consent form. Participants were supported to complete the questionnaire – conducted in an interview style – by scribing the participants' responses. Completion of the questionnaire took between 5-15 minutes.

3.2.3 Results and Analysis

Fifteen participants completed the questionnaire. The number of carers and number of people with dementia are shown (with their gender) in Table 4. The numbers of each participant type are not equal, as Carer- person with dementia dyads could not always be recruited.

Table 4. Participant Information

-	Male	Female	**Total**
Carer	2	7	**9**
Person with dementia	4	2	**6**
Total	**6**	**9**	**-**

The answers that both people with dementia and carers gave during the questionnaire, in relation to which ICT they use and for what purpose, are shown by device type in Table 5. With exception of laptop computer use, carers reported a greater range of uses for each device than people with dementia. The reason for this is unknown, though it may be due to the greater number of participants that were carers.

The uses of technology fit with the proposed uses of technology identified in the literature review. Communication was the primary use of these devices, between family and friends, and healthcare or care support services. Other uses included recreational activities such as playing games and Internet browsing, banking and shopping online, and using a mobile phone as a form of safety technology by utilising the ‘find-a-friend’ location service on an iPhone.

Landline telephones and mobile telephones were the most frequently used devices amongst both people with dementia and carers, with lower numbers of participants reporting using computer devices. The numbers of carers and people with dementia that use each device type are shown in Table 5.

These results provide evidence that the research area of comparing everyday ICT use by people with dementia and older adults without dementia is appropriate and feasible to address with the intended participant types.

Both people with dementia and older adults without dementia were found to use the Web for a variety of purposes, and whilst it was not the aim of the study, many participants voluntarily expressed difficulties that they encountered when using this technology. This would suggest that the challenges faced by people with dementia and older adults without dementia could be explored through discussion with users, to investigate further the difficulties they encounter with the use of web interface technologies specifically.

Table 5. Scoping Study ICT Use Results

Technology Type	Carers	Common uses of Carer & People with Dementia as individuals	People with dementia
Landline Phone	**7**	**-**	**5**
	Calling carer support Seeking hospital advice Telephone purchases	Calling friends Making appointments (doctor/dentist/hospital) Emergency calls	Receiving calls only Making calls (other)
Mobile Phone	**9**	**-**	**5**
	Follow up doctors' appointments Calling taxis Making medical appointments Find-a-friend function to locate people with dementia	Emergency calls Taking photographs Texting friends/family Doctor appointments (confirmation/reminder) Calling friends/family	Receiving calls only
Desktop Computer	**4**	**-**	**1**
	Ancestry searches Dementia research Photo storage Banking Games Online banking/shopping Spreadsheets Writing letters Browsing Emails		Skype/video calls
Laptop Computer	**3**	**-**	**3**
	Skype/video calls Games	Browsing	Writing letters Printing documents Buying vouchers PowerPoint Ancestry searches Emailing Spreadsheets (of medication)
Tablet Computer	**5**	**-**	**3**
	Photographs Contacting family Checking weather Arrange travel Banking Online bookings of holiday/tickets	Browsing Downloading books Reading news	Games Watching media Emailing

3.2.4 Discussion

The small study conducted with both older adults with and without dementia has enabled the research scope defined following the literature review (Chapter 2) to be assessed for its appropriateness, and feasibility for investigation within the defined user populations. Participants from both user populations were found to use everyday ICT to access the Web. Some participants described difficulties that they faced when using the Web – in reference to interface interactions - and expressed their resultant frustrations. Whilst these difficulties were not explored further at this point, as it was out of the scope of the study aim, it does indicate that the defined research scope is appropriate and addresses issues experienced by both people with dementia and older adults without dementia living in the community when using ICT. The feasibility of exploring these issues can also be reflected upon here, as whilst the participant numbers were low, it was found that both user populations seem willing and confident to discuss the issues that they experience. Despite having recruited people with dementia for this scoping study, it was noted, that due to the variance in dementia symptoms and stages of dementia of attendees at such dementia support groups, identifying and recruiting suitable participants for a larger study may be challenging.

Before commencing research with people with dementia and older adults without dementia into their experiences of accessing and using web content, a further literature review is required, to establish current knowledge on the topic of Web and software interface accessibility specifically for people with dementia. Scoping literature on interfaces including those of non-web software will enable the amount of research conducted in the area of interface design to be established more broadly in the context of people with dementia. As some overlap would be expected between experiences of using different user interfaces, this will enable a more complete understanding of current relevant knowledge to be obtained. This review will enable gaps in knowledge to be identified within a more refined scope and contribute to understanding the differences in experiences of people with dementia and older adults without dementia when using ICT.

3.3 Part B: Access to Research for People with Dementia

The development of dementia-inclusive consent documentation is detailed in this part of this chapter, and is discussed in context of the legal frameworks for mental capacity. The consent and recruitment processes developed for use within the studies of this thesis are presented for participants with and without dementia, and the role of carers of people with dementia during the research process is described. The content of this chapter section contributes to the methodology developed for use within the further studies in this thesis (Chapter 5).

3.3.1 Aim & Objectives

The aim of this part of this chapter is to understand how to ethically and inclusively involve people with dementia as participants in Human Factors design research within this PhD.

Objectives:

- To explore known issues of conducting research involving people with dementia, including obtaining ethical clearance and informed consent.
- To further understanding of appropriate research practice and methods when involving people with dementia.

3.3.2 Background

3.3.2.1 Vulnerability of People with Dementia

Informed consent is a requirement for all research involving human participants (Slaughter *et al.*, 2007). People with dementia are considered a vulnerable population, as they may have compromised decision-making ability, which can affect their capacity to consent, and can put them at risk of being exploited (Cubit, 2010). However, there is an ever increasing need to include people with dementia in research, to ensure that their subjective experiences of living with dementia are elicited and understood. From a humanistic perspective, and within user-centred design practice, people with dementia should have a voice in matters of concern to them; assuming this population are unable to participate not only reinforces negative stereotypes of incapacity, but denies them the opportunity to make a meaningful contribution to research (Slaughter *et al.*, 2007). The challenge is to encourage dementia research whilst protecting the rights and interests of participants with dementia (Slaughter *et al.*, 2007), and ensuring valid data collection.

3.3.2.2 Exclusion of People with Dementia from Research

People with dementia remain one of the most excluded groups in western society, living with two powerful stigmas: ageing, and increasing cognitive impairment (Hellstrom *et al.*, 2007). Reflecting this exclusion in society, this population are often excluded from participating in research, despite the importance of addressing the needs of people with dementia and older adults in future designs, as dementia prevalence increases and the global demographic continues to age. Ethical difficulties are often cited as a reason for the exclusion of people with dementia (Hellstrom *et al.*, 2007); obtaining informed consent is a common challenge for researchers seeking to recruit people with dementia. The opportunities available to people with dementia have been limited by researchers' perception of assumed inability and incompetence, rendering their contributions as invalid, or at best, unreliable (Bamford and Bruce, 2000; Gillies, 2000; Lloyd, Gatherer and Kalsy, 2006).

Proxy accounts, such as those of family carers, are often used in place of those of people with dementia, as their involvement does not pose such ethical difficulties concerning informed consent for participation. However, there is evidence that the views of proxies and people with dementia do not always concur (Reid, Ryan and Enderby, 2001; Beattie *et al.*, 2004; Dröes *et al.*, 2006; Steeman *et al.*, 2007; Gill, White and Cameron, 2011). As a result of these disparities between the views of proxies and those of people with dementia themselves, there is growing critique on the reliance on proxy accounts (Hellstrom *et al.*, 2007). It is therefore of paramount importance that people with dementia are supported to be involved in research and to express their own views and experiences as stakeholders.

People with dementia are insightful about their needs and capable of expressing them (Beattie *et al.*, 2004; Moyle, 2010; Gill, White and Cameron, 2011), and thus every effort should be made to promote and support their inclusion in research. To enable the inclusion of this population within this research, the challenges of obtaining informed consent were explored and addressed, to facilitate ethical recruitment of people with dementia to the studies of this thesis who would be able to contribute valid data to the research.

3.3.3 Informed Consent & Dementia

Informed consent has two main aims; firstly, to acknowledge and promote participants' autonomy; and secondly, to protect them from potential harm (Jefford and Moore, 2008). Consent is an important issue in any research, but obtaining informed consent for participation is a major issue at the heart of involving people with dementia in research, and has stimulated extensive debate (Dewing, 2007; Hellstrom *et al.*, 2007). As dementia progresses, there is a decline in a person's ability to comprehend and appreciate the consequences of involvement in research. Due to this vulnerability of this population, additional measures are required to protect people with dementia (Slaughter *et al.*, 2007). Consent can only be considered 'informed' when the person has the cognitive capacity to understand the information provided, and to appreciate the consequences of consenting to participate (Cubit, 2010). People with dementia have a greater capacity to understand when the focus is on feelings and experiences rather than on the recollection or manipulation of facts (Hellstrom *et al.*, 2007). However, ethics committees can feel that obtaining informed consent from people with dementia is practically too difficult and that the risks involved in doing so are too great (Dewing, 2007). For this reason, researchers are often required to sacrifice the valuable participation by people with dementia when it comes to consent, to satisfy the demands of research ethics committees (Grout, 2004).

For any research wanting to recruit participants who have a condition such as dementia - which could reduce their capacity to consent - research must be conducted with regard to the Mental Capacity Act (HM Government, 2005), and consent must be sought following the statutory guidance in the Act's Code of Practice (Department of Constitutional Affairs, 2007).

3.3.3.1 Mental Capacity Act 2005

The Mental Capacity Act 2005 (HM Government, 2005), introduced in England and Wales in 2007, provides the legal framework to define the measures that need to be taken to support people to make their own decisions and to protect those who may lack the capacity to do so. The Act applies to any intrusive research within England and Wales, in addition to all health and social care practices, and is not limited to research undertaken within NHS organisations or other public bodies.

The Act is underpinned by five statutory principles that are rooted in common law, ethical guidelines and best practice, and are compliant with the relevant sections of the Human Rights Act (Department of Constitutional Affairs, 2007). These principles are listed here, together with relevant information to the research being discussed; other guidance is available within the Code of Practice, but is applicable only to clinical environments.

Principle 1: A person must be assumed to have capacity unless it is established that they lack capacity.

It is important to note that just because someone has a condition that may result in them lacking capacity to consent, a person’s diagnosis or behaviour should not lead to presumption that capacity is absent. This is applicable to people with dementia; a diagnosis of dementia does not result in the absence of capacity, but does necessitate an assessment of capacity to ensure that participants are recruited in accordance to the ethical approval granted for the research.

Principle 2: A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

The kind of support people might need to help them make a decision varies, but may include ‘*providing information in a more accessible form’* (Department of Constitutional Affairs 2007, p 22).

Principle 3: A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

Capacity is determined by the process by which a decision is reached, not the decision itself. This acknowledges that individuals have their own values, beliefs, preferences and attitudes.

Principle 4: An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Principle 5: Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Principles 4 and 5 were not applicable to this research.

Principles 1, 2 and 3 were those relevant to this research, as they are key to the best practice of obtaining informed consent from those who have the capacity to consent, and to the involvement of people with dementia as valuable and necessary participants. The process of consent was explored and developed in relation to Principle 2 of the Mental Capacity Act (discussed in Section 3.3.4). People with dementia who did not have the mental capacity to understand information, make decisions or to consent were considered out of the scope of the study, as participants would be required to engage in conversation and to understand information provided to them to attempt the task that formed part of the interview. Principles 4 and 5 are applicable only to decision making involving people who lack the capacity to consent, and it is acknowledged here that if this study had recruited people lacking this capacity, additional ethical approval would have been needed from an appropriate body. This research recruited only participants with the capacity to consent, and thus ethical approval for this research was sought and granted from the Loughborough University Ethics Approvals (Human Participants) Sub-Committee. This approval was granted with the understanding and agreement that each potential participant with dementia, who may therefore lack capacity to consent, would be subject to the Mental Capacity Act two-stage test of capacity, as in accordance with the Act's Code of Practice. The procedure implemented within this research to assess the capacity of participants with dementia is discussed in Section 3.3.4.4.1.

3.3.4 Dementia – Inclusive Consent

The second principle of the Mental Capacity Act 2005 (HM Government, 2005) highlights the requirement to maximise the ability of a person to make decisions and maintain their autonomy. Chapter 3 of the Code of Practice for the Mental Capacity Act (Department of Constitutional Affairs, 2007) emphasises the importance of the way that information is presented to help people make their own decisions. The Health Research Authority (HRA; 2017) state that participant information sheets are often too long and complex, and whilst they may cover every detail of a study, and thereby protect researchers and sponsors against litigation, they do not necessarily facilitate the true understanding and consent of potential participants. The HRA therefore recommend a proportionate approach to seeking consent, so that potential participants are not overwhelmed by inaccessible information sheets, but instead are provided with '*succinct, relevant, truthful information in a user-friendly manner that better promotes their autonomy'* (2017. p.5).

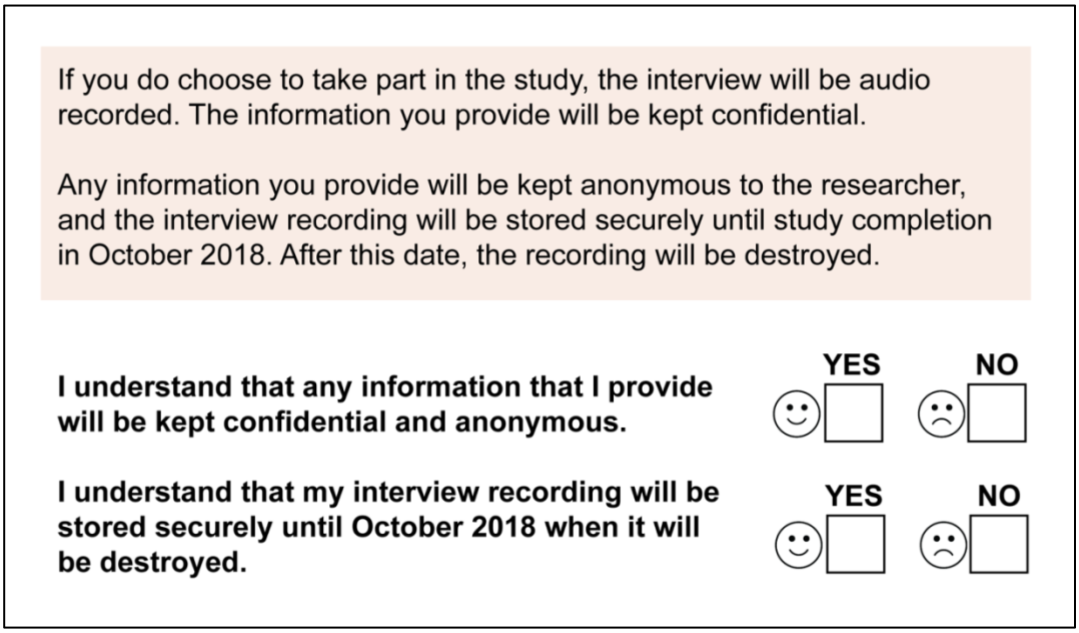
The author acknowledged that the abilities of potential participants must be deliberated to enable the process of obtaining informed consent to be adapted to facilitate the consideration of taking part in research. This was considered when developing written consent documentation for the research into which people with dementia were to be recruited. The standard University participant information and consent document templates were considered to be inaccessible to people with dementia when they were evaluated against available guidance on 'dementia-friendly' written information, published by the Dementia Engagement and Empowerment Project (DEEP; 2013). It was apparent that a more accessible presentation of participant information and consent information was required for the recruitment of people with dementia.

Within dementia research, alternative methods of obtaining informed consent, aside from the written form have been used with people with dementia. Verbal consent, in combination with behavioural consent have been sought in a number of studies (Bamford and Bruce, 2000; Gillies, 2000; Beattie *et al.*, 2004). Providing verbal consent is considered to be less of a potential anxiety trigger for people with dementia, as it does not rely on the ability to write, or to read written words, which can be abilities affected by dementia in some individuals. In addition, verbal consent does not bear similarities to the formality of medical forms that written consent can (McKillop and Wilkinson, 2004). However, written consent may be required to satisfy ethics committees for some research, and has been successfully sought in studies involving people with dementia (e.g. Beattie et al. 2004; Roger 2008). A decision was made to develop a dementia-inclusive written informed consent process, which would fully satisfy the Ethics committee, and could be used as a memory aid for people with dementia with short-term memory impairment during the consent process and participant involvement. In addition, the participants that were being sought for the research were web users, which would suggest that they retained some ability to read written information, and thus written information could be accessible to these individuals. Dementia-inclusive informed consent documentation was developed, with the expectation that the document design would support people with dementia to make an informed decision with regard to consenting to participation.

3.3.4.1 Development of Dementia-Inclusive Consent Documentation

Existing guidance in literature regarding '*dementia-friendly'* written information was sparse, with the guidelines published by DEEP (2013) the most pertinent source of guidance, as they were developed by people with dementia themselves. These guidelines, and advice on obtaining consent from people with dementia published by Alzheimer Europe (2012), had great significance in the document design. In light of the information gathered from the little research in this area, a combined participant information and consent form was developed to facilitate understanding of the research for people with dementia.

Whereas convention is to provide all pertinent information in a participant information sheet to be read by a participant before providing an informed consent form to be completed, the dementia-inclusive form was designed in chunks, where each section of participant information is followed by a statement of understanding and agreement to which the participant can consent. This structure was intended to reduce the reliance on memory, and thus aid people with dementia to consent in an informed manner, even if they lived with the common dementia symptom of reduced memory capability. This structure was entirely different from the conventional presentation of a participant information sheet and a consent form, which are provided as separate documents. It was felt that presenting the informed consent documentation in the conventional format could result in people with dementia facing difficulty with retaining all of the study information to which they were consenting, before giving their consent; if the participant did not retain all that they were consenting to, pseudo-consent could be obtained from these participants. To ensure that truly informed consent was obtained, the combined structure of presentation was implemented in the dementia-inclusive document design. A sample extract of this consent documentation structure can be seen in Figure 6.



If you do choose to take part in the study, the interview will be audio recorded. The information you provide will be kept confidential.

Any information you provide will be kept anonymous to the researcher, and the interview recording will be stored securely until study completion in October 2018. After this date, the recording will be destroyed.

	YES	NO
I understand that any information that I provide will be kept confidential and anonymous.	☺ ☐	☹ ☐
I understand that my interview recording will be stored securely until October 2018 when it will be destroyed.	☺ ☐	☹ ☐

Figure 6. Sample extract of the dementia-inclusive document

The document design also incorporates elements specified within available guidelines for accessible written information for people with dementia, which are summarised in Table 6.

In addition, symbols were included within the document to aid comprehension of agreement or disagreement to the included statements. Visual aids to support textual information were used in the consent process used with participants with Huntington's Disease, described by Wilson, Pollock, and Aubeeluck (2010), and using more than one form of communication is commonly recommended when working with people with dementia.

Table 6. Guidelines used to inform consent document design

Incorporated Design Element	Informative Guidelines
Present information logically, one piece at a time, paying attention to the amount of information being given by presenting in manageable chunks.	(Alzheimer Europe, 2012; DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Write concisely, using simple language and short sentences.	(Wilson, Pollock and Aubeeluck, 2010; DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Use large type (14pt minimum)	(Wilson, Pollock and Aubeeluck, 2010; DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Use colour to distinguish between different sections of information.	(DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Use bold text to separate/highlight sections of important text.	(Wilson, Pollock and Aubeeluck, 2010; DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Use sans-serif font – Arial recommended.	(DEEP: The Dementia Engagement and Empowerment Project, 2013c)
Ensure withdrawal statement is positioned close to the statement of consent.	(Alzheimer Europe, 2012)

3.3.4.2 Assessment of Dementia-Inclusive Consent Documentation

In comparison to the standard informed consent documentation templates used by Loughborough University, the re-designed documentation is both shorter in length, and more compliant with the available guidelines that detail how written information can be designed to be more accessible to people with dementia. A comparison of compliance to these guidelines for the standard and re-designed documentation has been summarised in Table 7, where compliance is rated as low, medium or high.

Table 7. Comparison of original and re-designed documents: Compliance to Guidelines

Guideline	Standard University Document Template Compliance	Dementia-Inclusive Re-designed Document Compliance
Logical presentation of information	Medium	High
Information presented in manageable chunks	Low	High
Simple language used	Medium	High
Short sentences used	Medium	High
Large type (minimum 14pt)	Low	High
Colour used to distinguish between different sections of information	Low	High
Bold text used to highlight sections of important text	Medium	High
Sans-serif font used (Arial recommended)	High	High
Withdrawal statement close to statement of consent	Low	High

3.3.4.3 Ethics Committee Approval and Support

The inclusive document design was approved by Loughborough University Ethics (Human Participants) Sub-Committee for this research when recruiting people with dementia. The Committee supported the adaptation of information materials for people with dementia, as they acknowledged that this can make research more accessible for this participant group. Whilst the author had intended the consent document to be used for all participants, as a document designed to be inclusive of the needs of people with dementia, but not for use solely with this population, the University specified that the re-designed document would only be approved for use with people with dementia. The justification given for the stance of the committee was that whilst there was reason to adapt the format to make the information accessible to people with dementia, this was not necessary for older adults without dementia, and thus the standard structure of participant information and consent forms must be used for participants without dementia. The consent form used for people with dementia and the documents provided to participants without dementia within this study were designed in the same way as those used in Studies 2 and 3 (seen in Appendix C and Appendix D respectively). The documents used for participants without dementia were designed aesthetically in a similar way to the form for people with dementia, as larger font, type of font and the use of colour can benefit all older people (Ellis and Kurniawan, 2000; Zaphiris, Kurniawan and Ghiawadwala, 2007; Liu *et al.*, 2014).

The document re-design is considered to support people with dementia to make informed decisions regarding their participation in the research, in accordance with Principle 2 of the Mental Capacity Act 2005. However, the utilisation of more accessible consent documentation does not mean that all people with dementia will have the capacity to consent. Therefore, approval for using the re-designed document was granted with the understanding and agreement that each potential participant with dementia, who may therefore lack capacity to consent, would be subject to the Mental Capacity Act two-stage test of capacity, as in accordance with the Act’s Code of Practice.

3.3.4.4 Written Consent within Consent Process

3.3.4.4.1 Mental Capacity Assessment

A person’s capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made, and not their ability to make decisions in general (Department of Constitutional Affairs, 2007). Mental capacity is the ability to make a decision, including everyday decisions such as when to get up, as well as more serious decisions such as whether to have surgery. The assessment of someone’s capacity to make a decision for themselves (i.e. give consent to participate) should use the two-stage test of capacity, as described in the Mental Capacity Act Code of Practice (Department of Constitutional Affairs, 2007):

Stage 1: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?

This first stage requires that the person has an impairment of the mind or brain; if the person does not have such an impairment or disturbance, they will not lack capacity under the Act. Dementia is listed as an example of an impairment of the mind or brain.

Stage 2: Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

A person is considered to lack capacity to make a decision if their impairment affects their ability to make the specific decision when they need to. A person is considered by the Act as unable to make a decision if they cannot:

1. Understand information about the decision to be made (the Act calls this ‘relevant information’)
2. Retain that information in their mind
3. Use or weigh up that information as part of the decision-making process, or
4. Communicate their decision (by any means)

(Department of Constitutional Affairs 2007, p45)

The first three points should be applied together, and if a person cannot do any of these three things, they should be treated as unable to make the decision. The fourth point only applies in situations where people cannot communicate their decision in any way.

Prior to seeking consent, potential participants were deemed to have demonstrated some capacity to make decisions for themselves by the way in which recruitment was managed. The research was introduced (via oral presentation and distribution of advertisement posters) to groups of people, explaining the purpose of the research, and what participation would involve, and recruitment only occurred when individuals expressed an interest to participate themselves. The requirement for individuals to express this interest – as opposed to being asked about participation on an individual basis – showed that they had understood the information given about the research, retained that information and used it to decide they would like to participate, and communicated this to the researcher.

In accordance with the Act’s Code of Practice, the official assessment of capacity was conducted at the time at which consent was being sought for participation, which was immediately before the interview commenced. All people with dementia were provided with the dementia-inclusive consent document, and given adequate time to read this document, and discuss the information with their carer if they desired. Opportunity was given for participants to ask questions about the study and their involvement, to further ensure that they understood the relevant information to the decision, and that the presentation of information had been appropriate for their capabilities. To ascertain whether the participant had the capacity to retain the relevant information, and if they had used the information appropriately to make their decision, following completion of the consent form, participants were asked to summarise their understanding of what the interview would involve. Participants were also asked to confirm their understanding about withdrawal from the study. In accordance with the Act’s Code of Practice, if a person was unable to retain the information for this period of time, this was not assumed to indicate a lack of capacity. Participants could use the consent form as a prompt if required, to enable them to recall specific information (e.g. deadline dates for withdrawal from the study). Upon an accurate confirmation of the study information and understanding of the participants’ involvement, the researcher was assured that the participant had the capacity to make the decision to consent, this was recorded on the notes for the data collection with that participant, and thus data collection could commence.

3.3.4.4.2 Ongoing Consent

Initial written consent to participation from people with dementia was facilitated using the dementia-inclusive consent document. However, it was acknowledged that written consent could only be considered merely a part of the complete consent process that runs throughout the whole of the involvement of an individual in a study, to reflect the fluctuations experienced in capacity and symptoms by people with dementia. Dewing (2007) described that during the consent process, initial consent should be '*revisited and re-established on every occasion or even within the same occasion'*, to monitor ongoing consent. This research only involved each participant on one occasion, and thus ongoing consent was only required throughout each interview. If at any point during data collection a participant appeared to be anxious, or disengaging with the interview process, the researcher asked whether they wanted to continue their participation. The role of the carer during data collection contributed to monitoring the comfort of people with dementia, as they had more knowledge of and greater ability to recognise signs that the individual was uncomfortable or becoming anxious. The carer was instructed prior to the interview commencing that they too may ask the people with dementia if they needed a break from the interview, or if they would like to terminate data collection. The decision to request that carers took on this role was taken as it was felt to serve as an additional assurance of the ethical involvement of people with dementia; a person with dementia may feel more comfortable expressing a wish to terminate their participation with somebody they are more familiar with.

3.3.5 Recruitment Processes

Participants for the studies in this thesis were recruited from two populations; older adults with dementia, and older adults without dementia, to enable comparisons to be drawn between the two user types.

Recruitment was initially conducted using a purposeful sampling strategy, using the inclusion/exclusion criteria specified in Table 8.

Much research has listed Mini-Mental State Examination (MMSE) cut-off scores for the recruitment of people with dementia to studies, to determine the severity of dementia with which a person is living and define the user group for the study. However, as acknowledged by Savitch and Zaphiris (2007), cognitive impairment is a complex phenomenon and some cognitive functions are more essential to certain activities than others; the authors advocate a flexible process for selecting people for inclusion. Using an arbitrary cut-off score on the MMSE test has been proven not to be useful as a screening instrument for '*interviewability*' (determining people who are interviewable on the subject) as it can exclude people who retain the capability of being interviewed (Mozley *et al.*, 1999). Hellstrom et al. (2007) also acknowledged that MMSE and similar cognitive tests cannot give an indication of the abilities of a people with dementia to discuss their life, their experiences or needs. This further strengthens the argument against using cognitive test scores as inclusion criteria for participant recruitment.

Peterson et al. (2009) successfully conducted a study recruiting people with dementia without citing MMSE cut-off scores as inclusion criteria, instead specifying that older adults with dementia who live in their own dwelling in the community would be included. This more flexible approach to recruiting people who acknowledge that they have a dementia diagnosis was implemented within the inclusion criteria for this research.

Table 8. Inclusion and Exclusion Criteria for Participant Recruitment

Inclusion Criteria	Exclusion Criteria
People with Dementia	
• Diagnosis of dementia • Age 65+ • Actively use computer technologies independently (minimum of once a month) • Living in the community, not in a residential care environment • English Speaking	• Non-user of technology • Sight or hearing impairment that cannot be compensated for with an aid
Older Adults without Dementia	
• Age 65+ • Actively use computer technologies independently (minimum of once a month) • Living in the community, not in a residential care environment • English Speaking	• Non-user of technology • Sight or hearing impairment that cannot be compensated for with an aid

Note: For the final study, the age inclusion criterion was changed to 60+, to reflect the defined age of 'older adult' by the World Wide Web Consortium (W3C).

Research participants were recruited via existing dementia support groups and charities, enabling people to volunteer to participate, rather than being pre-selected by a gatekeeper such as a clinician in an NHS environment, or manager within a residential care facility. Both people with and without dementia were recruited via these groups. Where possible, the researcher attended the group meeting, to introduce the research and speak with potential participants about the study. For this reason, the researcher sought Disclosure and Barring Service (DBS) clearance as an additional assurance to group coordinators of the safety of their group members in the presence of the researcher. In other cases, a recruitment poster was provided in either a physical or digital format to group members, distributed in person by the group coordinator or within a newsletter. This poster was designed in the same way as those used for Studies 2 and 3, as shown in Appendix E.

Access to ten groups was granted for the researcher to recruit participants from, with suitable participants being recruited from four of these. Some cases of snowball sampling were applied throughout recruitment, as community group members informed other individuals about the study, and these people contacted the researcher regarding participation.

An additional route of recruitment was followed, where recruitment posters were shared on Twitter, a social media platform used by many people with dementia. These advertisements were also sent directly to people with dementia who advocate for dementia research on Twitter, which led to individuals contacting the researcher regarding participation, and further recruitment.

3.3.5.1 Role of Carers in the Recruitment of People with Dementia

The role carers within research involving people with dementia in research has been debated (see Section 3.3.2.2 and Chapter 5, section 5.3.1.3.4). Much of this discussion is focused on the phases of data collection and where subjective accounts are sourced from. However, carers can influence the recruitment of people with dementia as research participants too, before data collection commences. This influence has been identified at two points: accessing people with dementia D for recruitment, and during the process of obtaining consent.

3.3.5.1.1 Carer Roles in Gatekeeping

Gatekeeping is a term referring to the action of '*the person involved in the process to allow or deny another [the researcher] access to someone or something*' (Gray 2013, p73). Access to potential participants can either be as members of an organisation, or individuals under another person's care. Gatekeepers have the responsibility of ensuring that people within their organisation, or who are under their care, remain protected and safeguarded, remaining free from coercion or exploitation at all times (McFadyen and Rankin, 2016).

Gatekeepers have more commonly been used formally within studies recruiting people with dementia who may lack capacity, living within residential care or clinical settings. For example, Astell et al. (2016) used care service staff within the recruitment process as gatekeepers, by identifying potential participants and providing them with information sheets. This PhD research recruited only people living in the community, and thus not under the institutional care of a residential home. This study took a stance in line with the views of Dewing (2007) that it is not always necessary to secure permission from a gatekeeper before approaching a person with dementia. This stance was taken as people with dementia lacking capacity to make their own decisions were not being sought for recruitment. In addition, when recruiting people with dementia living in the community, there are issues regarding the role of gatekeepers, as some may have a pessimistic view of the capability of a person with dementia to contribute to an interview (Beattie *et al.*, 2004) and thus people with dementia may be excluded from research. This study aimed to include all people with dementia (with capacity to consent) who expressed an interest in participating. Obtaining permission or invites to attend community support groups from organisers, to enable the research to be discussed with group members is acknowledged as a form of gatekeeping, but on a group basis, rather than gatekeeping for an individual.

Whilst this study did not use formal gatekeepers to access people with dementia, it acknowledged that both people with dementia and their informal carers have previously expressed a desire for the involvement of carers within this recruitment process in other studies. Therefore, the research was designed to enable this, where justifiable on both ethical and legal terms. The involvement of a carer, as a person deemed meaningful to a person with dementia, can provide reassurance and feelings of safety to participants (Dewing, 2007). The protective nature of the role of a carer was highlighted in a study by Keady (1999) where carers wanted to be present during the consent and interviewing process. Carers can clearly provide support to people with dementia throughout their recruitment to, and involvement in research, and on ethical terms, their involvement is encouraged for the protection of the participant with dementia. Carers as gatekeepers have a valid protective role when supporting people with dementia into research (Pratt, 2002). For this reason, this research facilitated this by recruiting a person with dementia, with the understanding that their carer may be present throughout the duration of their participation. However, whilst carers as gatekeepers can be particularly influential and support people with dementia to make their own decisions (Hellstrom *et al.*, 2007), there are legal implications regarding the involvement of other people, when obtaining consent from people with dementia. For this reason, the role of the carer in the specific process of obtaining consent from people with dementia has been considered in detail, and in relation to the Mental Capacity Act Code of Practice.

3.3.5.1.2 Carer Role in the Consent Process

Whilst carers can support someone to make a decision for themselves, their role in the process of gaining consent from the person that they care for cannot be extended to making a decision on their behalf. Ultimately, the person with dementia must have the capacity to make a decision to consent for themselves, and thus the carer can only provide support in terms of communication with this individual. General guidance for communication in the Mental Capacity Act Code of Practice includes advice on asking carers on the best form of communication to use with the individual being assessed for capacity (Department of Constitutional Affairs 2007, p.32). Whilst people with dementia were expected to be able to understand the informed consent documentation, as it was designed to be accessible to this population according to available guidance, if a person with dementia required additional help from their carer to understand the information, this was permitted in accordance with the guidance for the Mental Capacity Act's Code of Practice. The carer was not permitted to assist in completing the consent form, nor responding in the assessment process of capacity, as this would not result in consent being given independently by the person with dementia.

As discussed in Section 3.3.4.4.2, the carer fulfilled a role concerning ongoing consent throughout interviews with people with dementia, by monitoring for non-verbal and behavioural signs of distress, anxiety or fatigue. It was requested of carers in their explicit role that they would make it known if they felt that the person with dementia was no longer comfortable with participation, to address the possibility that a person with dementia may feel obliged to continue otherwise. If this occurred, the researcher would ask the participant whether they would like to take a break from the interview, to continue with the discussion, or to terminate their participation.

3.3.5.2 Recruitment of Participants without Dementia

Older adults without dementia were recruited through community groups, in the same way as people with dementia. The consent process implemented with these participants was not required to be conducted with regard to the Mental Capacity Act, as they did not have a condition that would indicate they may lack mental capacity to make a decision. Therefore, a participant information sheet and consent form, designed to the standard Loughborough University template, were provided to each participant without dementia. These documents can be seen in Appendix C

3.3.6 Implementing Dementia-Inclusive Practices

The developed dementia-inclusive consent document design was trialled within the scoping study detailed in Part A of this chapter. This enabled reflection on its implementation in addition to reflection on the methods and research practices used when including people with dementia as participants.

3.3.6.1 Procedure

Following each questionnaire, a method reflection form was completed by the researcher, to capture insights about any successes or challenges identified within both the design of the study documentation, or the dynamics observed when involving dyads of participants. A copy of this reflection form is shown in Appendix F. These reflections were included within the results produced through using a reflective practice model, as discussed in Section 3.3.6.3.

3.3.6.2 Method

The content of the method reflection forms that were completed after each questionnaire was processed using Reflective Practice.

Reflective practice is an intentional activity with the focus on improving and changing practice, which has most often been used in nursing and teaching (Driscoll and Teh, 2001). Reflective practice goes beyond contemplating an experience or event, as using a model can lead to new ways of thinking or behaving in practice, whereas contemplation is not always purposeful

(Andrews et al. 1998). Reflective practice can generate practice-based knowledge, as it is based on real practice. Jarvis (1992) advocates the need for reflective practice since nurses deal with people who because of their individual nature, require them to be responsive and reflective instead of simply carrying out the routine task of everyday nursing practice. This need to adapt practice to meet the diverse needs of individuals can be translated into conducting research with people with dementia. Thus, different aspects of the research process and the methods used with people with dementia were analysed using a model of reflective practice; the What? Model of Structured Reflection (Driscoll 2000, cited in Driscoll & Teh 2001). Figure 7 shows the used model, based on that developed by Driscoll (2000, cited in Driscoll & Teh 2001) which contains three elements of reflection.

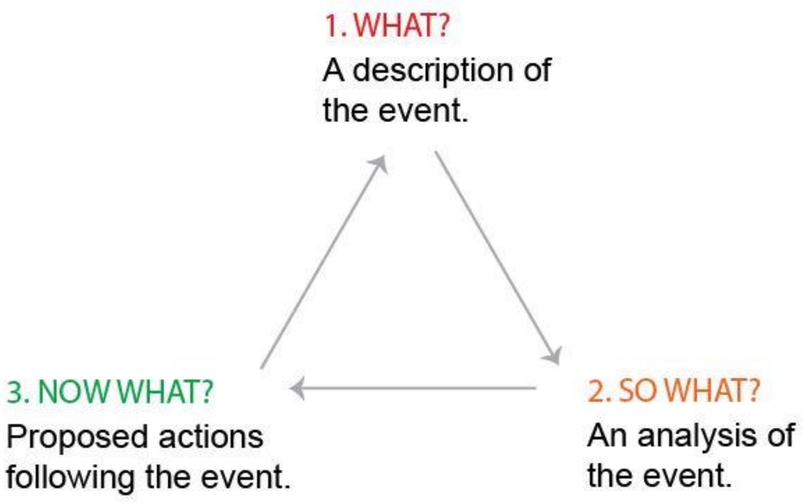
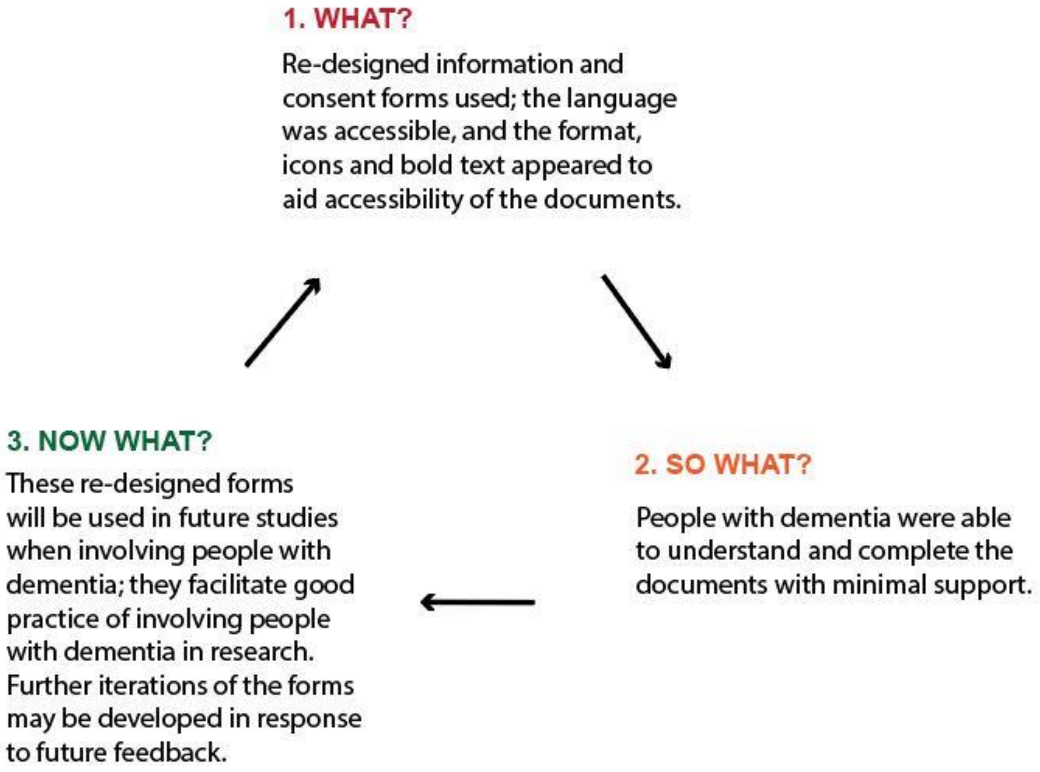


Figure 7. The 'What?' Model of Structured Reflection

3.3.6.3 Results

Figures 8 – 11 display the key issues highlighted within the method reflection forms that were analysed using the reflective model. The resultant outcomes, and how these will be incorporated into the methodology of this thesis are discussed.

3.3.6.3.1 Dementia-Inclusive Consent Document Design



1. WHAT?

Re-designed information and consent forms used; the language was accessible, and the format, icons and bold text appeared to aid accessibility of the documents.

2. SO WHAT?

People with dementia were able to understand and complete the documents with minimal support.

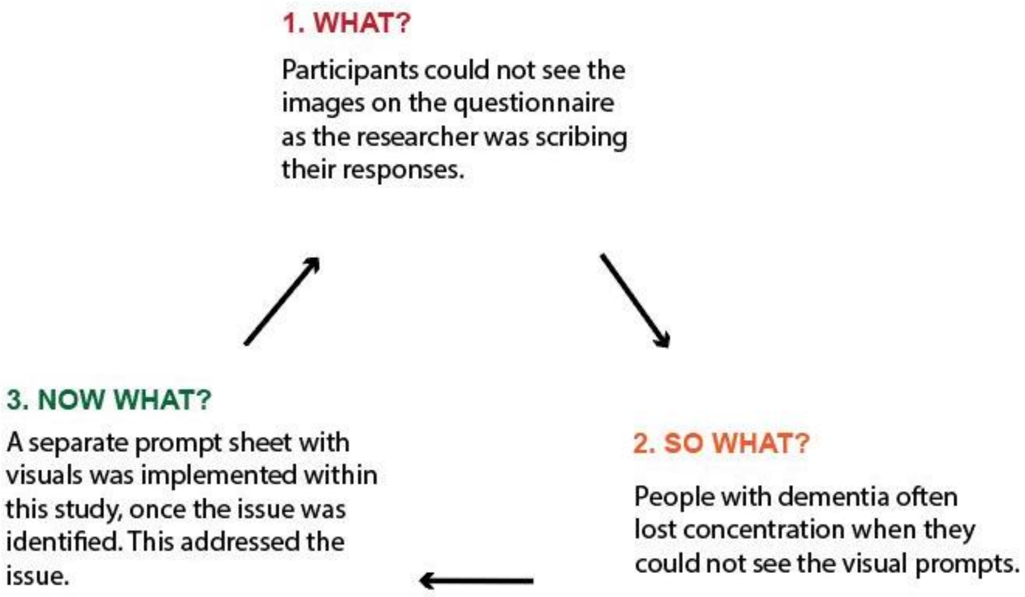
3. NOW WHAT?

These re-designed forms will be used in future studies when involving people with dementia; they facilitate good practice of involving people with dementia in research. Further iterations of the forms may be developed in response to future feedback.

Figure 8. Reflection on Dementia-Inclusive Consent form

The use of the dementia-inclusive document discussed in Section 3.3.4.1 was reflected upon (see Figure 8). The design proved to be accessible to people with dementia, and therefore this was considered a successful element of this study. The outcome of this reflection was that the dementia-inclusive consent document design should be implemented within the studies of this thesis where people with dementia are recruited.

3.3.6.3.2 Questionnaire Procedure



1. WHAT?

Participants could not see the images on the questionnaire as the researcher was scribing their responses.

2. SO WHAT?

People with dementia often lost concentration when they could not see the visual prompts.

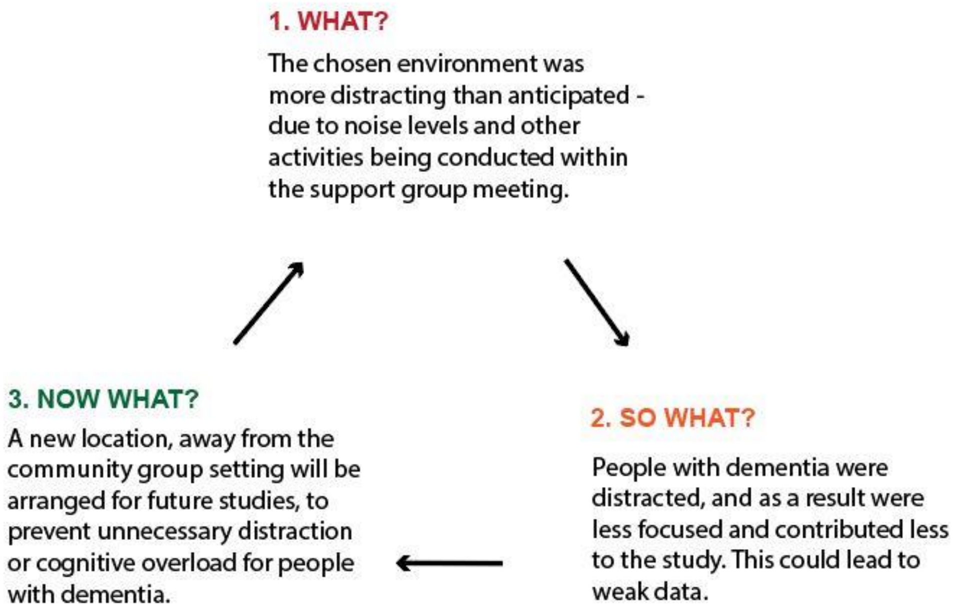
3. NOW WHAT?

A separate prompt sheet with visuals was implemented within this study, once the issue was identified. This addressed the issue.

Figure 9. Reflection on Questionnaire Procedure

The practice of scribing for participants led to reduced vision of the visual prompts included on the questionnaire for participants during the study, as the images were shown on the same sheet being used by the researcher. For people with dementia, this led to loss of concentration, thus potentially reducing the quality of data collected. A separate visual prompt sheet was produced part way through the study, which addressed the issue successfully during the remaining questionnaires. It is considered that where possible, data should be collected in audio format only, to create a more natural interaction and thus reduce potential for distraction.

3.3.6.3.3 Study Setting



1. WHAT?

The chosen environment was more distracting than anticipated - due to noise levels and other activities being conducted within the support group meeting.

2. SO WHAT?

People with dementia were distracted, and as a result were less focused and contributed less to the study. This could lead to weak data.

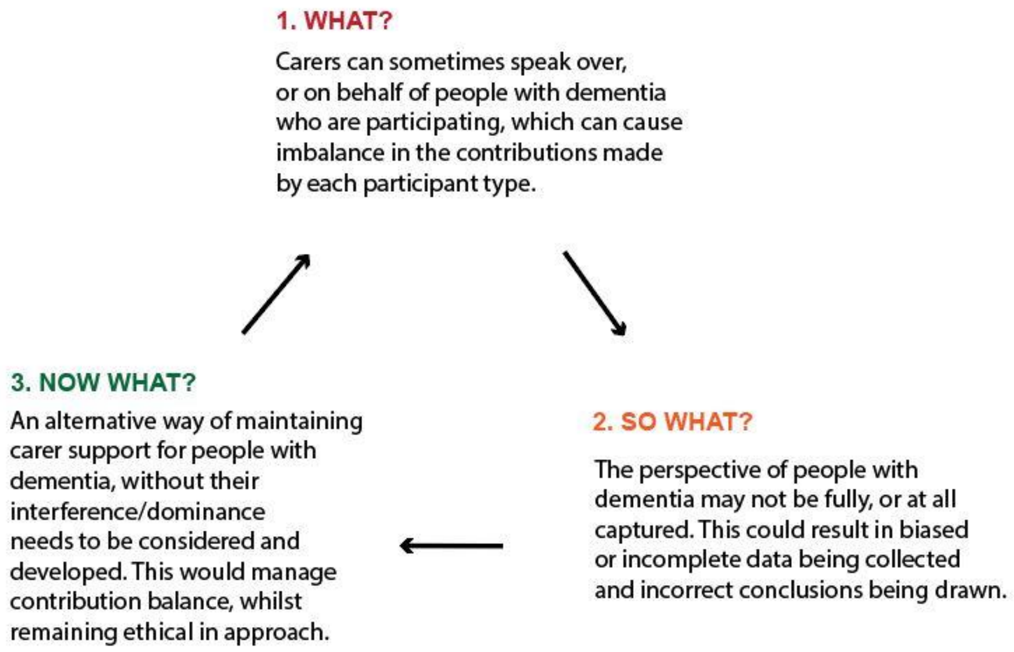
3. NOW WHAT?

A new location, away from the community group setting will be arranged for future studies, to prevent unnecessary distraction or cognitive overload for people with dementia.

Figure 10. Reflection on Study Setting

Whilst the location was selected due to its familiarity to people with dementia, its suitability was challenged since participants were distracted more frequently than anticipated, by other activities and constant noise within the support group environment. This resulted in people with dementia having difficulty discussing the questionnaire topics, and may have resulted in incomplete data being collected. To address this in future studies, a quieter environment will be selected to reduce the potential for distraction.

3.3.6.3.4 Person with Dementia and Carer Dynamics


1. WHAT?

Carers can sometimes speak over, or on behalf of people with dementia who are participating, which can cause imbalance in the contributions made by each participant type.

2. SO WHAT?

The perspective of people with dementia may not be fully, or at all captured. This could result in biased or incomplete data being collected and incorrect conclusions being drawn.

3. NOW WHAT?

An alternative way of maintaining carer support for people with dementia, without their interference/dominance needs to be considered and developed. This would manage contribution balance, whilst remaining ethical in approach.

Figure 11. Reflection on People with Dementia and Carer Dynamics

The dynamics within people with dementia-carer dyads varied, with some contributing more equally than others. It became apparent that an alternative approach to collecting data from both stakeholders may be required, to reduce the impact that unequal contribution may be having on the perspectives being captured. However, other factors still need to be considered, such as the carer remaining present to support people with dementia when required. This requirement will be addressed during the development of the methodology for the studies in this thesis.

3.3.7 Discussion

A dementia-inclusive informed consent document has been developed for use within an ethical consent process, to address the aim of Part B of this chapter. The document promotes inclusivity of people with dementia as an often neglected population within research, and facilitates the recruitment of people with dementia as participants within relevant legal frameworks. Assessment of this inclusively designed document has provided evidence to support a case for its implementation within research involving people with dementia, as a contribution to improved practice, via both comparisons to available guidance, and trialled use with people with dementia.

Reflections on appropriate research methods and approaches for improved practice when researching with people with dementia as participants have also been presented. The reflective practice on method implementation within this small scoping study will inform the methodology used within the further studies of this thesis (Chapter 5). In particular, the study setting will be changed, with further consideration for the needs of people with dementia, to avoid unnecessary distractions, and data will be collected via audio recording for the same reason. Both of these decisions, made as a result of reflection on this study, will enable better practice for the involvement of people with dementia, and optimise the opportunity for more complete data to be collected from participants. A further finding from the study reflective practice, where the complexities of the dynamics between people with dementia and their carer are identified, has demonstrated that this issue will need to be explored when defining research methods and addressed in future studies. To prevent unbalanced contributions of people with dementia and carers, and thus potentially resulting in the perspective of people with dementia being lost, the dynamics between participants with regard to data contribution must be managed in a more structured way. This management of the carer’s contributions must be balanced with maintaining the important role that they fulfil ethically, in ensuring the wellbeing and comfort of people with dementia throughout their involvement.

This chapter has enabled known issues of conducting research involving people with dementia to be explored, and has furthered the author’s understanding of appropriate research practices for use when researching with this population. Whilst the reflective practice has brought some challenges and further considerations to light, further reflection will be conducted throughout the studies of this thesis to capture and address any further challenges that arise. Additional reflection, conducted by the author, but also contributed to by research participants will enable guidance on improved practice approaches when involving people with dementia to be provided within this thesis.

3.4 Limitations

The study reported enabled two aims of this chapter to be addressed; the assessment of the appropriateness and feasibility of the defined research scope, and to further knowledge on research processes and methods to be used when involving people with dementia as participants. However, there are some limitations. The study only involved 15 participants, with only 6 people with dementia. It is therefore acknowledged that due to the diversity of people with dementia, the sample is not fully representative of the diverse population of people with dementia living in the community. Although the results should therefore be viewed with caution, this was seen as an acceptable sample considering the aim of this study; the focus of the study was to assess the appropriateness and feasibility of the research scope defined, and to facilitate the assessment of the research methods and approaches implemented, rather than to enable finalised recommendations to be made or conclusions to be drawn about the role of technology within the lives of people with dementia and older adults without demenita. The study successfully provided insights that will contribute to the developed methodology and scope of the further studies in this thesis.

3.5 Conclusions

The results of this chapter support the following conclusions:

- Dementia-inclusive informed consent documentation can be implemented to enable the ethical involvement of people with dementia as participants.
- People with dementia and older adults without dementia are found to use the Web for a range of purposes, but both encounter difficulties in doing so. This supports the appropriateness of the more refined research scope for this thesis – web accessibility for people with dementia. A further literature review is required to establish current knowledge on this topic.

- Careful consideration for the research approach and methods used when involving people with dementia is needed. The study setting, procedures followed during data collection, and the management of the dynamics between a person with dementia and their carer need particular consideration, to ensure the perspective of the person with dementia is actually elicited without distractions. A structured role to address the person with dementia and carer dynamic is required to manage this complexity in further studies.

The overall aims of the chapter have been met: an appropriate dementia-inclusive informed consent document has been developed to enable the involvement of people with dementia in studies, and the study has enabled the suitability of the research scope and details of the research methods to be assessed. The issues identified with regard to improved practice in research when involving people with dementia, such as the management of the Person with Dementia-Carer dynamic and contributions, will be addressed in Chapter 5.

The findings within this chapter necessitate a better understanding of practice within research involving people with dementia, and contributes an accessible and inclusive method of obtaining informed consent from people with dementia that meets both legal framework requirements and the requirements of ethical committees. The knowledge gathered within this chapter will contribute to the development of an appropriate and inclusive methodology for the further studies in this thesis, as detailed in Chapter 5, and contribute to the guidance for accessible research for involving people with dementia presented in Chapter 9.

Chapter 4. Literature Review (2)

4.1 Introduction

People with dementia and older adults without dementia use the Web for a variety of purposes (Chapter 3). Both populations face difficulties using the Web, but the differences in difficulties faced by older adults without dementia and people with dementia when using technology remain underexplored.

Much research has been conducted regarding the accessibility and usability of hardware components and output devices for older adults, including web interface interactions; computer mouse, keyboards, keypads, and touchscreens. The conclusion is that touchscreens are the most accessible and usable technology for the general older adult population, as they offer a direct input-display relationship, allow good hand-eye coordination, and are easy to learn (Caprani et al. 2012; Taveira & Choi 2009). Touchscreens remove the need for peripheral, often unfamiliar input devices, such as the mouse or keyboard (Holzinger 2003), and have been found to improve performance time (Rau & Hsu 2005) whilst reducing anxiety in older adults without dementia, more than other computer types do (Umemuro 2004). It has been argued that touch-based user interfaces can be successfully adopted by older adults, regardless of their physical or cognitive weaknesses (Häikiö et al. 2007).

People with dementia are also reported to be more capable of using touchscreens than other devices, with adequate support and encouragement (Alm, Astell, Gowans, Dye, Ellis, Vaughan & A. Newell 2007; Alm et al. 2004), and they have been deemed to be user-friendly by people with dementia (Astell et al., 2010; Leuty, et al. 2013; Nijhof et al. 2013; Upton et al. 2011). This is encouraging, as in an increasingly digital world, people with dementia may encounter touchscreens in a variety of situations; public environments, domestic environments, healthcare environments, and communication and social devices, amongst others (Caprani et al. 2012).

Whilst the physical accessibility of devices has been addressed to some extent for both older adults without cognitive impairment and people with dementia, few attempts have been made to design suitable user-software interfaces for people with dementia (Wallace et al. 2010). The accessibility of application programmes, web content and software for people with dementia have not been extensively researched. Indeed, in studies which report new digital technologies for people with dementia, there is rarely a clear rationale for how and why an interface has been chosen, or if the design has been based on evidence of best practice for people with dementia (Cudd et al. 2013). Specific design features of interfaces for people with dementia are rarely described, and there are no guidelines for 'dementia-friendly' user interface design features.

A literature review recommended more research and investigation in specific areas of web content access by older adults, including those with cognitive impairments (W3C 2008). Arch & Abou-Zhara (2008) concur that cognitive issues remain a central issue that needs to be researched and understood to design appropriate requirements. This opinion is shared amongst web developers, who find cognitive disabilities to be the least understood and least discussed disabilities (WebAim 2013).

By not considering the interaction needs of people with dementia, interface designers may be isolating this user group, and negating the potential effectiveness of technologies (Ancient & Good 2014). This could lead to prospective, or existing users disregarding a technology which could enhance their quality of life, provide access to a service, or increase their safety, which would enable them to remain independent in a community for an extended period of time (Ancient & Good, 2011; Brorsson et al. 2011).

In a world where computing is increasingly ubiquitous, it is important that all users can access the interfaces. For people with dementia to be included within user interfaces, designers must be informed about their specific needs. This systematic literature review aims to establish what is currently known about web content and software interface accessibility for people with dementia, and whether evaluation studies of interfaces offer insight for the needs of people with dementia.

Note: From this point on, 'interfaces' will refer to both those encountered within software programmes and those used to access web content, but it should be clarified that physical interfaces are not included within this term.

4.2 Aims and Objectives

Aims:

- To identify and examine current knowledge about interface accessibility for people with dementia, including specific guidelines
- To establish what is known about interface accessibility for people with dementia
- To identify the methods used for interface accessibility evaluations for people with dementia

Objectives:

- To identify existing guidelines for interface accessibility for people with dementia
- To examine methods used for interface accessibility evaluations for people with dementia
- To appraise the methodological quality of the identified literature

4.3 Search Strategy

Literature searches were conducted using the following databases: ACM Digital Library, Ergonomics Abstracts, Scopus, and Web of Science. These databases were selected as they cover a range of journals that relate to computers and technology, as well as content focused on dementia. The search terms used were:

	Dementia OR Alzheimer*
AND	web* OR app* OR Internet* OR interface* OR HCI OR software* OR "Human Computer Interaction"
AND	accessib* OR usab*

These terms were identified through initial scoping of the topic. A visualisation of this scoping is shown in Figure 12.

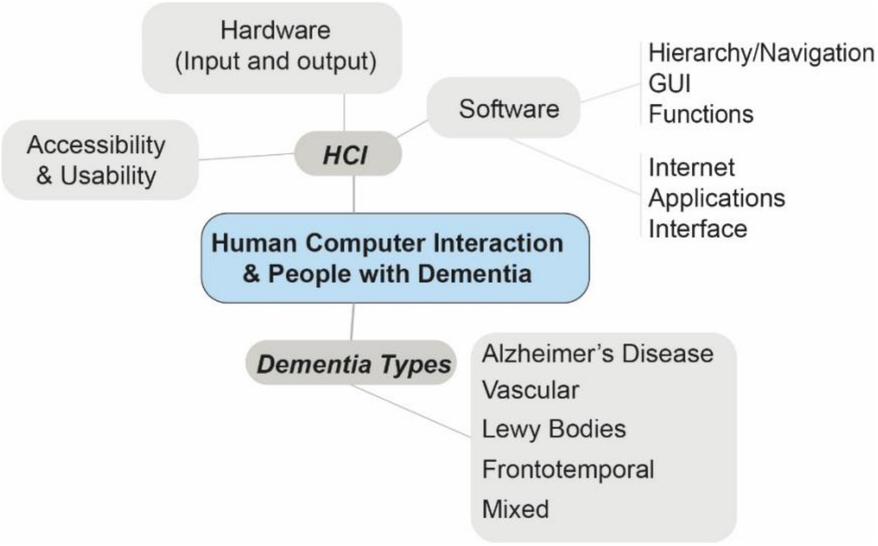


Figure 12 - Initial Scoping

4.3.1 Screening and Selection of Papers

Titles and abstracts of the 1079 papers were screened. Papers were discarded if they evaluated dementia diagnostic software, or did not meet the inclusion/exclusion criteria. Where the relevance could not be established from the titles and abstracts, full papers were retrieved and read. Duplicates of papers were removed.

4.3.1.1 Inclusion and Exclusion Criteria

To be included, the papers had to meet the following criteria:

- Be published within a journal or conference proceedings, in any year
- Focus on people with dementia specifically, not other cognitive impairments
- Focus on interface use by people with dementia, not by their carers or for dementia diagnostic purposes

Papers were excluded if they:

- Did not meet the inclusion criteria

- Were professional opinion papers
- Were written in any language other than English

4.3.2 Critical Appraisal

The mixed methods appraisal tool (MMAT; Pluye et al., 2009) was used to assess the methodological quality of the included papers. This tool included five different types of mixed methods components (Qualitative, Quantitative and Mixed Methods) and the quality criteria against which each type of study can be assessed.

Using the MMAT, included papers were given methodological quality scores of 0-4, depending on how many criteria were met. A score of 0 indicated that no criteria were met, and a score of 4 indicated that all criteria were met. Further information about MMAT is shown in Appendix G. Papers with an MMAT score of 0 or 1 were discarded as the quality of the study was deemed too poor for inclusion. Figure 13 shows the process followed for the literature search. A sample of the results for scoring papers using the MMAT is shown in Figure 14, and the full data table found in Appendix H.

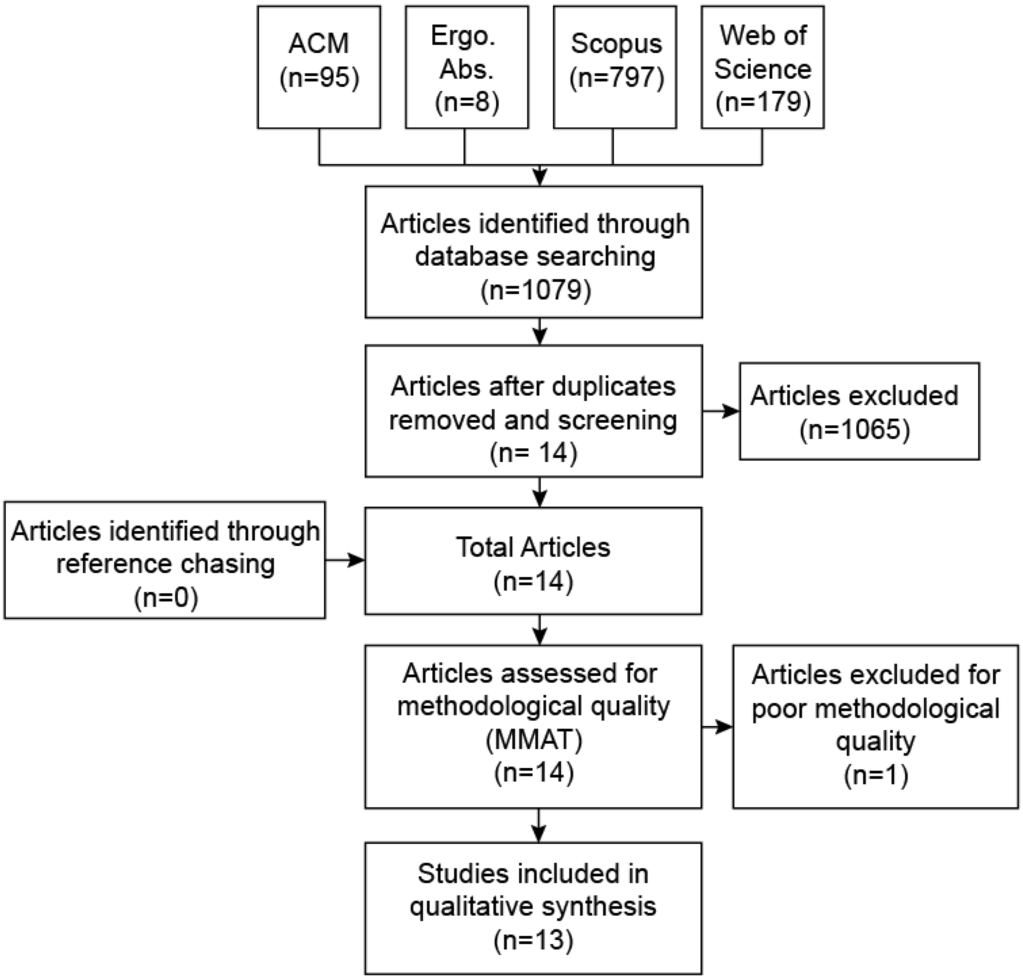


Figure 13. Literature Search Process

Study #	Study Info	Description of Study	Study Setting	Research Design	Sample Information	Inc/Excl Criteria	Outcome Measures	Main Findings	MMAT Score
	Author, Year		Place, Field of Study	Method/Approach Used	# of people, mean ages, etc.	Of potential participants	What was assessed and how		
1	Alm et al., 2007	Interactive entertainment system use by PWD.	Scotland	Questionnaire for professionals, post VR environment. Interview for PWD post VR experience.	Environment :13 Professionals 5 PWD (2M, 3F) Activities: 6 PWD (2M, 4F)	N/A	Interview and questionnaire; data of experience of VR environment and activities	VR can provide a safe way to occupy PWD	2 50%
2	Astell et al., 2016	Effect of familiarity of games on the enjoyment of PWD	UK & Canada	2 games played and compared using a quantitative questionnaire	30 PWD (25F, 5M, 78-100yrs) MoCA scores 8-21	N/A	Questionnaires: enjoyment and learning patterns	Familiarity is not enough as a sole property to ensure that apps are dementia-friendly	3 75%

Figure 14. Sample of MMAT Scoring Table

4.4 Results

Quality scores for individual papers varied, and no papers were scored as high quality (see Appendix H). The sample sizes in the included studies ranged from 3 to 30 participants, though the majority had very low participant numbers. Studies were mainly conducted in Europe, with a few from Asia and North America. The majority of studies evaluated software applications, with a few focusing on the accessibility or usability of websites.

The results are categorised as icons, visual features and labelling, and layout and navigation.

4.4.1 Icons, Visual Features and Labelling

4.4.1.1 Location and Size

The location of features on a screen, including icons, has the potential to cause distraction to people with dementia, and should be considered (Boyd *et al.*, 2014). Sarne-Fleischmann et al. (2011) supported this opinion, and established the need for icons to be isolated to avoid confusion between two separate features.

The size of icons and other visual features is also important to people with dementia, as there can be difficulties with bounded icons and ‘clickable’ boundaries (Sarne-Fleischmann *et al.*, 2011). Sizing of arrows and visual prompts were discussed by Alm et al. (2007), but no specific guidance was provided.

4.4.1.2 Colour

Colours have significance in the accessibility and usability of interfaces for people with dementia. Calming colour schemes for backgrounds (Sarne-Fleischmann *et al.*, 2011; Hattink *et al.*, 2016) and contrasting colours have been found to facilitate optimal usability (Hattink *et al.*, 2016). However, colour can also hinder interface use by people with dementia. Bold colours can cause distraction if they are used on a feature not intended to attract attention (Sarne-Fleischmann *et al.*, 2011). In addition, the placement of colour throughout interface screens can play a role in usability for people with dementia, as using the same colour to highlight features with different functions can cause confusion (Boman et al. 2014).

4.4.1.3 Language and Labelling

Using labels to accompany visual features such as icons can assist people with dementia to navigate an interface. However, the language used for such labels can either help or hinder usability, depending on the words and phrases selected. Language should be simplified (Boyd *et al.*, 2014) and avoid abstract or metaphorical language (Freeman *et al.*, 2005). People with dementia can have differing understanding of terminology, as seen when selecting appropriate menu labels for a website providing information on dementia (Savitch and Zaphiris, 2005) and can struggle to interpret labels if phrased as a question (Savitch and Zaphiris, 2006). Labels may be required to clarify the meaning of non-intuitive icons, but the potential distraction must be considered (Sarne-Fleischmann *et al.*, 2011).

4.4.1.4 Prompts, Cues and Reminders

Prominent visual prompts, such as on-screen button flashing and occasional text messages were found to work very well (Alm et al. 2007), and when combined with verbal cues, can help recognition memory for people with dementia (Freeman et al. 2005). Alm et al. (2007) found that spoken prompts do not work well for people with dementia, yet Boman et al. (2014) found a preference for voice messages over text messages amongst the same user group.

Freeman et al. (2005) found that the use of icons as a visual prompt may help or hinder interface usability, due to the difficulties that people with dementia can experience with shifting attention. No unified conclusion was reached regarding the use of prompts for facilitating interface use by people with dementia. However, Alm et al. (2007) found that an absence of prompts hindered successful use of software by people with dementia, and the use of a physical reminder in an ongoing conversation - in the form of a tethered handset - was found to facilitate successful use of a video-calling interface (Boyd *et al.*, 2014).

Boman et al. (2014) concluded that using both visual and audio feedback could be useful as a cue to people with dementia to show that they had interacted with an element of the interface.

4.4.2 Interface Layout and Navigation

4.4.2.1 Simplicity and Cognitive Load

A simple interface, with minimal available options, use of simple language and icons, minimum number of steps to achieve a goal, and minimal distracting elements have been found to aid usability for people with dementia (Freeman *et al.*, 2005; Sarne-Fleischmann *et al.*, 2011; Boman *et al.*, 2014; Astell *et al.*, 2016; Hattink *et al.*, 2016). Animations and competing stimuli should be avoided to reduce the likelihood of distraction (Sarne-Fleischmann *et al.*, 2011). By providing a simple interface, the cognitive load created by the presentation is kept to a minimum, thus allowing cognitive effort to be spent on the primary function of using the software. Whilst familiarity of interfaces may not guarantee usability (Astell *et al.*, 2016), familiar features have been found to support usability by reducing the complexity of interpretation by people with dementia (Boyd *et al.*, 2014). Boman et al. (2014) state that it should be possible to adjust interfaces to each individual’s needs and wishes, to simplify and keep their cognitive load to a minimum.

4.4.2.2 Navigation of Layout and Interface Hierarchy

People with dementia have been found to prefer ‘traditional’ interface layouts, where the title is at the top (De Sant’Anna *et al.*, 2010) and the main menu is on the left-hand side (Savitch and Zaphiris, 2005). Rich media (Flash) was preferred by people with dementia to text-only, or frame-set layouts (Savitch and Zaphiris, 2006). Keeping pages structurally similar is also beneficial for learnings of an interface (Freeman *et al.*, 2005). Sarne-Fleischmann et al. (2011) found a simple three level hierarchy which can be navigated bi-directionally to be successful for people with dementia. However, Savitch & Zaphiris (2005) found that a long list of menu items was preferred to grouping information into abstract categories – potentially due to the mixed feelings regarding terminology (see Section 4.4.1.3).

One element of interface navigation that seemed to strongly affect the usability of software was the requirement to scroll through screens (Savitch *et al.*, 2006). This would support the conclusion that web content should be minimal and simple, to reduce the need for scrolling. Freeman et al. (2005) provided a recommendation to remove the need to scroll (Section 4.4.4).

4.4.3 Evaluation Methods

Interviews, observations, focus groups, surveys, talk-aloud protocol, usability tests, card sorting and quantitative measures such as timings and error counts were used within the included studies (Table 9).

Table 9. Study Methods and MMAT Scores

Method	Studies	Low Quality*	Medium Quality*	Total Sources
Usability Tests	Fleischmann et al., 2011	1		1
Talk Aloud	Savitch & Zaphiris, 2005		1	1
Talk Aloud & Interview	Alm et al., 2007	1		1
Card Sorting	Savitch & Zaphiris, 2006		1	1
Focus Group	Savitch et al., 2006		1	1
Focus Group & Observations	Mayer & Zach, 2013	1		1
Interview	Span et al., 2015	1		1
Interview & Observation & Quantitative	Astell et al., 2016		1	1
Interview & Observation	Boman et al., 2014		1	2
	Boyd et al., 2014	1		
Interview, Observation, Survey & Quantitative	Hattink et al., 2016	1		1

Quantitative & Observation	Freeman et al., 2005		1	1
Quantitative & Interview	De Sant'Anna et al., 2010	1		1

4.4.4 Guidelines

No papers referred to existing guidelines for interface accessibility for people with dementia. Some studies provided suggestions for HCI accessibility and usability as an output of their research, and these are detailed in Table 10.

Table 10. HCI Recommendations from Studies

Guideline/Recommendation	Study Source
Rearrange information so that it comes in blocks of one screen's worth, to keep contents menu and title page constantly visible.	Freeman *et al.*, (2005)
• **Clearly identify clickable targets** • **Break information into short sections** • **Minimize complex steps**	Hattink *et al.*, (2016)
• **Familiarity; design components based around meaningful items** • **Minimize complexity and choice, emphasise clarity and simplicity** • **Acceptance; non-stigmatising, reliable interface with quick response times** • **Supportive feedback; reassure users using all senses (vision, hearing, touch)** • **Learnability and clear instructions; clear affordances to help users to know implicitly what to do** • **Visual design; bright colours and high contrast, & use pictograms and metaphors to help understand unfamiliar interactions and interfaces**	Mayer and Zach, (2013)
• **Use a classic presentation** • **Tasks should not require speed** • **Mouse position arrow should be larger** • **Stable patterns throughout software**	De Sant'Anna *et al.*, (2010)

Simplified menus and larger, simplified text	Savitch and Zaphiris, (2005)
Navigation systems are important for people with dementia – a flat structure could be advisable but needs further investigation **Traditional HCI methodologies need to be adapted when designing for people with dementia**	Savitch and Zaphiris, (2006)

The only recommendation provided by more than one study (Savitch and Zaphiris, 2005; Mayer and Zach, 2013), is to keep interfaces simple in terms of their presentation and content. All of the recommendations are quite generalised, and it is unclear whether they are features needed specifically for people with dementia, or are more widely applicable to older adults without cognitive impairment.

4.5 Discussion

4.5.1 Current Knowledge

4.5.1.1 Software Features

A range of features that can form the interface of software applications or websites have been evaluated for people with dementia. These include the size and location of icons and visual features, the use of calming colour schemes and contrasting colours, and the importance of simple language for interface features. Visual and audio prompts have both been supported or rejected by different studies, for either helping or hindering the usability of interfaces by people with dementia, with no conclusive recommendation for the use of such features.

Due to the scarcity of studies that explore interface accessibility or usability by people with dementia, no conclusive knowledge can be reached as the studies hold opposing findings. The only conclusion supported by multiple studies is that using calming colour schemes and contrasting colours is important to facilitate optimal usability of interfaces for people with dementia (Sarne-Fleischmann *et al.*, 2011; Hattink *et al.*, 2016). However, this suggestion is countered by guidance provided by Mayer and Zach (2013) (see Table 10) who recommend the implementation of bright colours to aid comprehension of unfamiliar interfaces.

Minimal assessment of features found widely within interfaces has been conducted. The reported evaluations only explore the accessibility or usability of particular applications designed for people with dementia specifically, and do not gather data on the perception of people with dementia and their experiences of using software interfaces in everyday life. This could mean that the studies were unaware of interface features that help or hinder interface use in other web content or that software has not been explicitly evaluated.

4.5.1.2 Hierarchy and Navigation of Layout

It can be concluded that providing a simple interface, with minimal options, use of simple language and icons, minimum number of steps to achieve a goal, and minimal distracting elements can aid interface usability for people with dementia (Freeman *et al.*, 2005; Sarne-Fleischmann *et al.*, 2011; Boman *et al.*, 2014; Astell *et al.*, 2016; Hattink *et al.*, 2016). Provision of a simple interface layout reduces the cognitive load, allowing effort to be spent on achieving primary goals of the interface. It has also been suggested that using familiar features can reduce cognitive load by reducing the complexity of interpretation (Boyd *et al.*, 2014). The potential to adjust interfaces to individual needs and wishes has also been recommended to reduce cognitive load (Boman *et al.*, 2014).

As found by Boyd et al. (2014), familiarity of 'traditional layouts' has been identified as a preference amongst people with dementia for interfaces (Savitch and Zaphiris, 2005; De Sant'Anna *et al.*, 2010). Rich media (Flash) layouts (Savitch and Zaphiris, 2006), three level hierarchies (Sarne-Fleischmann *et al.*, 2011) and long lists of menu items (Savitch and Zaphiris, 2005) have all been identified as beneficial for people with dementia. However, no guidelines for the most appropriate interface for people with dementia, that are based on evidence from multiple sources have been published.

One element of navigation that is to be avoided, is the need to scroll through content (Freeman *et al.*, 2005; Savitch *et al.*, 2006). Freeman et al. (2005) highlighted that ‘losing’ the contents menu as a result of scrolling could be a key issue, as it can negatively impact successful navigation.

Due to the low participant numbers of all the reviewed studies, and the diversity of needs of people with dementia, any conclusions remain in need of further exploration.

4.5.1.3 Evaluation of Interfaces

No definite conclusion can be drawn with respect to the best methods for interface evaluation by people with dementia. The few available studies used a range and combination of qualitative and quantitative methods. However, those using methods to elicit both objective and subjective data scored higher in the MMAT. All studies used some qualitative data collection, giving people with dementia the opportunity for input, rather than being a subject of quantitative research. Savitch & Zaphiris (2006) identified that common HCI methods need to be adapted for use with people with dementia. Thus, identifying a successful combination of methods to evaluate interfaces for people with dementia will be important within studies.

4.5.1.4 Guidelines

There are no identified guidelines for designing interfaces for people with dementia within published literature, and very few recommendations have been provided from the studies (see Section 4.4.4). Many of the guidelines are broad, and lack both applied examples of best practice and specific guidance for older adults with cognitive impairment. Guidelines developed by people with dementia themselves were identified during this literature search (DEEP: The Dementia Engagement and Empowerment Project, 2013b), and whilst these did not meet the inclusion criteria for this review, their content was assessed and was found to be similar to recommendations provided by the reviewed studies.

Ancient & Good (2011;2014) explored the development of guidelines for interface design for people with dementia, yet no guidelines have been published to date. They go on to consider the overlap in needs of people with dementia and older adults without dementia (Ancient and Good, 2013). Impairments of older adults without dementia may be accentuated by dementia, and this will require guidelines to inform design. This issue identifies an opportunity regarding the interface design requirements specific to people with dementia.

4.5.1.5 Interface Design Requirements Specific to People with Dementia

Ancient & Good (2011) began to map where people with dementia may require a different interface design to older adults with no impairment. They considered a range of dementia-related symptoms (motor, cognitive, and visual), and compared these to known needs of older adults with no impairment for interface design. For example:

‘Older, inexperienced computer users will often struggle with new jargon. This will often be accentuated for people with dementia who will sometimes have problems finding the correct word’ (Ancient and Good, 2013).

This example suggests that the avoidance of jargon is more important for people with dementia than older adults with no impairment. Empirical studies to compare interface use by people with dementia and older adults with no impairment could provide an opportunity to give insight into the differences in difficulties experienced by the two user groups. This could be compared to existing guidelines for older adults with no impairment, to establish the additional difficulties that people with dementia specifically may have.

An exploratory study is needed to assess the differences found in difficulties faced with interface features, such as navigation systems (Freeman *et al.*, 2005; Savitch and Zaphiris, 2006). This would address one of two factors that Ancient & Good (2014) considered for dementia-friendly interfaces – personalisation (usability and accessibility). The exploratory study should also consider more subjective factors – user acceptance (user experience and technology adoption) (Ancient and Good, 2014), to establish whether people with dementia have different requirements to older adults with no impairments. These two factors, personalisation, and user acceptance, reflect the types of obstacles identified for assistive technologies in Chapter 2, as technical and social obstacles.

4.6 Conclusions

The literature review has summarised current knowledge of dementia-friendly interface design, and which features can help or hinder interface accessibility and usability. The absence of guidelines for dementia-friendly interface design was highlighted, with opportunities for further research identified. The key points for each finding are summarised below, corresponding to the research aims and objectives for this review (Section 4.2).

What is known about interface accessibility for People with Dementia?

Minimal evidence-based knowledge is available about interface accessibility and usability for people with dementia. People with dementia may require an alternative hierarchy, forms of navigation and layout within interfaces, with a simple design to facilitate optimal usability by reducing cognitive load. However, in contrast, some authors state that familiar/traditional interface layouts may be preferred by people with dementia. Thus it is inconclusive which forms of navigational structure should be recommended for people with dementia. There is strong evidence to support that interface design should create minimal cognitive load for people with dementia. What is not clear is how this differs from guidelines for older adults without specific cognitive impairment.

How is interface accessibility evaluated for People with Dementia?

Little is known about best practice for interface evaluation with people with dementia, other than HCI methods may need adapting for these users. Qualitative methods were widely used, with some combining these with quantitative methods. Each type of method elicited different data, and it is proposed that qualitative methods are required to understand the perspective of people with dementia.

Do any guidelines exist for interface accessibility for People with Dementia?

No guidelines were identified for designing dementia-friendly interfaces. Some studies made recommendations for features of interface design that may improve usability for people with dementia. However, these are based on minimal evidence and authors recommended further research was needed to provide evidence for these suggestions. It is also not clear from the guidance whether these are all usability issues, or whether some are accessibility issues for people with dementia.

Methodological Quality

Literature was not particularly strong in terms of methodological quality. 54% rated as low quality, and 46% as medium quality. The number of studies suggests that this area is underexplored, and that the methods used for this area of research are yet to be fully developed.

This literature review has established that the requirements for interfaces to be accessible to and usable by people with dementia are poorly understood, with little clarification of the differences between the recommendations given for these users, and those for older adults without dementia. Further research is required to identify the requirements specific to people with dementia. Once these requirements are identified, existing web content accessibility guidance can be assessed for its inclusivity of the needs of people with dementia.

This gap in knowledge defines the scope of further studies in this thesis (Chapters 6 and 7), where web content accessibility requirements for people with dementia are explored. The next chapter defines the methodology used for the studies in this thesis, with consideration for ensuring accessibility in research when exploring web accessibility requirements with people with dementia and older adults without dementia.

Chapter 5. Methodology

5.1 Introduction

This chapter presents the philosophical positioning of this thesis, exploring the potential methods that could be used to address the research aims, before detailing the selected methods of data collection and analysis that were used. Rationale is provided for the selected methods, with reference to related literature and findings from the study presented in Chapter 3.

The purpose of this thesis is to explore the experiences of accessing and using web content by people with dementia from the perspective of the user, and to identify web accessibility issues these users may encounter. To achieve an understanding of the experience of people with dementia specifically, both people with dementia and older adults without dementia were included in this research. This chapter considers both the types of participants recruited in the studies, and the field of Human-Computer Interaction (HCI) in which the research is positioned. These considerations enabled the most appropriate methods to be selected that would best address the research questions.

5.1.1 Research Questions

1. Which barriers to web accessibility do people with dementia encounter; and how do these compare to those encountered by older adults without dementia?

2. How inclusive are current Web Content Accessibility Guidelines for supporting people with dementia to access and use web content?

5.2 Philosophical Underpinning

5.2.1 Research Approaches and Paradigms

Traditionally, quantitative and qualitative approaches have been considered the alternatives when conducting social research (Robson, 2011). Quantitative research can be defined as research that explains phenomena using numerical data which are analysed using mathematically-based methods, especially statistics (Yilmaz, 2013). It is a type of empirical research that searches for causal explanations by testing a hypothesis. Quantitative research is sometimes considered to be limited by researchers working within the alternative approach – qualitative research – because it neglects the participants' perspectives within the context of their lives (Holloway and Wheeler, 2002). Qualitative research is used to explore the behaviours, perspectives, feelings and experiences of people, and is based on the premise that individuals are best placed to describe situations and feelings in their own words (Holloway and Wheeler, 2002). Qualitative studies are concerned with process, context, interpretation, meaning or understanding through inductive reasoning. They aim to understand and describe the phenomenon in question by capturing and communicating participants' experiences in their own words, usually via observation and interview (Yilmaz, 2013).

Quantitative and qualitative research differ in terms of their epistemological, theoretical and methodological underpinnings (Yilmaz, 2013), and thus are consistent with positivist and constructivist research paradigms respectively. Each paradigm presents different options for undertaking research. Table 11 summarises the main differences between these two paradigms.

As the aim of the studies was to understand participants' experiences from their perspective, a qualitative research approach was implemented, and was conducted within the constructivist paradigm on which the qualitative tradition is based (Slevitch, 2011). The epistemology for this research is consistent with the constructivist paradigm, whereby truth and knowledge are constructed by individuals through their interactions with, and experiences within the world (Gray, 2009). Individuals construct their own meanings to the phenomenon in question, rather than discovering a meaning.

The main alternative epistemological stance, consistent with the positivist paradigm, was considered unsuitable for this research, as it believes that the social world is independent of the researcher. In addition, positivism believes that the methods of the natural sciences are appropriate for the study of social phenomena because human behaviour operates on a set of laws that can only be discovered through empirical inquiry (Snape and Spencer, 2003).

The research sought to learn from older adults with and without dementia, and relied on the views and experiences that these user groups held, to increase knowledge and enable an evaluation of web content accessibility guidelines. With the relativist ontological belief that multiple realities exist to be explored, and a subjectivist epistemology, the philosophical position of this research was consistent with the constructivist paradigm.

Table 11. Differences between Positivist and Constructivist Paradigms, adapted from Slevitch (2011)

	Quantitative Approach	Qualitative Approach
Paradigm	Positivist	Constructivist *(Interpretivist)*
Ontology (views on reality)	Single, objective and independent reality exists and it can only be known or described as it really is.	Existence of multiple social realities that are mind-dependent and bound to people's points of views, values and purposes.
Epistemology (views on knowledge)	*Objectivist* ▪ Knowledge summarised in the form of generalisations ▪ Truth is a correspondence among the data and the existing reality, whereby the investigator cannot influence it ▪ Validity corresponds to how reflective of reality and generalizable results are	*Subjectivist* ▪ Reality is only knowable through socially constructed meanings of people ▪ Truth is a socially constructed agreement between investigator and participant ▪ Validity refers to credibility, description with which one agrees.
Methodology	*Experimental* ▪ Objective study to allow for generalised predictions ▪ Large sample sizes	*Hermeneutical/dialectical* ▪ Subjective study to understand phenomena from participants' viewpoint ▪ Smaller sample sizes
Method	Empirical examination/measurement, hypothesis testing, structured protocols, randomization, etc.	Case studies, narrative research, interviews, focus groups, observations, field notes, recordings, etc.

5.2.2 Theoretical Perspective

The most fitting theoretical perspective for this research, following constructivism is interpretivism. An interpretivist approach is the most commonly applied within qualitative HCI research (Blandford, Furniss, and Makri 2016, p.63). Interpretivists rely on the judgements individuals make to a given experience or situation, which for this research was the experience of accessing and using web content. As with constructivism, interpretivism rejects positivism and its demand for empirical inquiry and the measurement of scientific laws solely through observation. In accordance to researching with an interpretivist perspective, a range of approaches can be taken, and in turn, certain research methodologies. The potential approaches commonly known as available for interpretivist research are detailed in Table 12, adapted from Gray (2009).

Elements of both symbolic interactionism and phenomenological research were considered to be appropriate interpretative approaches for potential use within this research. Both approaches draw on subjective experiences and allow for the intricacies of individual experience to be understood. This is applicable to dementia, as the perceptions of the individual are often different than what may be perceived by individuals without dementia (Peterson *et al.*, 2009).

Grounded theory (GT), as a methodology, emerged from the sociological symbolic interaction tradition (Chenitz and Swanson, 1986, cited in Annells 1996). Thompson (1990, cited in Annells 1996) argued that symbolic interactionism and GT have long been informed by hermeneutical philosophy. Thus, as a methodology with roots in two interpretative research approaches, GT was selected as the most appropriate methodology for this research.

Table 12. Interpretivist Approaches

Interpretivist Approaches	Essential Elements of Approach	Associated Methodologies
Symbolic Interactionism	Human interaction through meaning-making and interpretation Meanings arise though interactions with the social world Experiences can alter existing meanings Change in perception of individual changes the meaning of objects, and hence changes individual behaviour.	Ethnography Observations Grounded Theory
Phenomenological Research	Experiences of people's social reality will enable researcher to understand their social reality Draws on subjective experience Eliminates bias through eliminating preconceptions	Interviews In-depth studies Small samples Qualitative methods
Realism	Scientific position in which research such as culture, and organisation exist independent of the researcher Systematic analysis Belief that there are phenomenon that exist but cannot be observed	
Hermeneutics	Social reality is socially constructed but cannot be understood through observation Interpretation is more important than explanation/description	
Naturalistic Inquiry	There are multiple constructed realities Inquiry is value bound to the researcher Inquiry is not generalizable, but specific to a case	Interviewing Observations Document and Content Analysis

5.2.3 Research Methodology

GT offers a way of attending to details in qualitative material to enable the systematic development of theories about the phenomena being studied (Lawrence and Tar, 2013). It is an inductive, theory discovery method that allows the researcher to develop a theoretical account of the general features of a topic while simultaneously grounding the account in empirical data

(Martin and Turned, 1986; Glaser and Strauss, cited in Lawrence and Tar 2013). As a methodology, GT makes its greatest contribution in areas in which little research has been done (Lawrence and Tar, 2013). GT is unlike most other research methodologies in that it merges the processes of data collection and analysis (Willig 2008, p.72). GT is most often derived from data sources of a qualitative (interpretative) nature (Birks and Mills 2011, p.6) and is compatible with a wide range of data collection methods, including semi-structured interview, participant observation, and focus groups.

A number of versions of GT have emerged since its original development, including the 'classic' (Glasserian) version, Strauss and Corbin's more structured approach, and Charmaz's constructivist version. GT was originally developed to allow new, conceptualised theories to emerge from data, as a reaction against the pervasiveness of quantitative, empirical, hypothesis-testing, and the associated application of existing theories to new data. Whilst all versions of GT arose from the same roots and sharing a number of methodological techniques, the versions of grounded theory can be differentiated by contrasting philosophical frameworks and conflicting methodological directives (Kenny and Fourie, 2015). The three traditions are distinguished by three key areas: Firstly, their opposing philosophical positions; secondly, their coding procedures; and thirdly, the difference in their use of literature (ibid). It is the first area - the opposing philosophical underpinning -that guided the selection of the most appropriate version for use within this research. Table 13 displays the ontological and epistemological stances of three versions that were available as the methodology for this research (Charmaz, 2000).

Table 13. Ontological and Epistemological Positions of Grounded Theory Versions

Grounded Theory Version	Ontological Position	Epistemological Position
Classic (Glaserian)	Realism	Objectivist
Straussian	Realism	Objectivist
Constructivist	Relativist	Subjectivist

Charmaz (2000) argued that both Classic and Straussian versions of GT are undergirded with positivist assumptions, and that both endorse a positivist epistemology. Charmaz (2000) refashioned the methodology into the Constructivist version, by reclaiming the potent tools of the methodology from their positivist origins to forge a more flexible, intuitive, and open-ended methodology which fits a constructivist paradigm. The fit of this to the paradigm in which this research was conducted was the primary reason for the implementation of Constructivist GT throughout this research and the rejection of other versions of the methodology.

A central tenet of Constructivist GT is to give a voice to participants, whilst acknowledging the influence that the researchers' own assumptions and expectations can have on the generated theory. This reflexivity works in accordance with Charmaz's argument that categories and theories do not '*emerge'* from the data – as implied by other versions of grounded theory that fit with a positivist paradigm – but are 'constructed by the researcher as they interact with the data' (Willig, 2008). It is acknowledged within Constructivist GT that the researcher's decisions shape the research process, and thus the findings. As a result, the theory produced constitutes one specific reading of the data, as opposed to discovering the only truth about the data. For this research, which was exploratory in nature, Constructivist GT fitted with the researcher's personal stance and the overall ontological and epistemological positioning of the research. Therefore, the coding procedures and use of literature within the research were conducted in accordance with Constructivist GT methods, which are discussed further in Section 5.3.2.

5.2.3.1 Grounded Theory in Dementia Research

GT has been used successfully in a number of dementia research studies (Beattie et al. 2004; Brittain et al. 2010; Brorsson et al. 2011; Dröes et al. 2006; Harris 2004; Lawrence et al. 2010; Pesonen, Remes, and Isola 2011; Steeman et al. 2007; Wherton and Monk 2008). This supported the selection of this methodology.

People with dementia have been found to be able to actively participate in qualitative studies, responding to open-ended questions in a meaningful way (Moore and Hollett, 2003). GT has been viewed as a way to make the most of available data, which often when obtained from people with dementia, may seem rather thin on first impression, as by adopting the perspective that as analysis is interpretive, the researcher creates meaning in the interaction (Moore and Hollett, 2003).

5.2.3.2 Grounded Theory in HCI Research

GT has grown as an appropriate analysis methodology within the field of HCI (Adams, Lunt, and Cairns 2008; Blandford, Furniss, and Makri 2016; Lazar, Feng, and Hochheiser 2010b). It can provide a structured and focused approach to qualitative HCI research, and has the potential to provide theories to explain realities (Adams, Lunt and Cairns, 2008). It can facilitate insight into the complex nature of phenomena, including people's values, understandings and experiences with technology (Adams, Lunt and Cairns, 2008; Furniss, Curzon and Blandford, 2011). Within HCI, GT has wide applicability and has been used to investigate a range of phenomena (Furniss, Curzon and Blandford, 2011).

HCI research into technology use by older adults has reported the use of GT as a methodology (Dickinson and Hill, 2007; Lindley, Harper and Sellen, 2009; Sayago and Blat, 2009; Grindrod, Li and Gates, 2014), supporting the appropriateness of its use within this research. In addition, whilst computer usage of users with impairments has not been explored in as much depth as with the general population of users (Lazar, Feng, and Hochheiser 2010, p.215), GT has been reported as a methodology used in studies reporting HCI research involving participants with impairments including visual impairment, mobility impairment and hearing loss (Tilley *et al.*, 2006; Shinohara and Wobbrock, 2011; Tomlinson, 2016). This, paired with evidence of GT being used to analyse research in other fields with people with dementia, supported the use of grounded theory as the methodology for this study.

5.2.4 Philosophical Stance

The philosophical research perspective shown in Figure 15 is taken within this research.

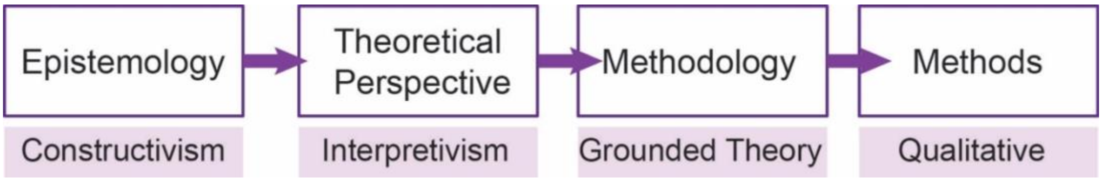


Figure 15. Philosophical Research Perspective, adapted from Gray (2009)

The methods used within this research, and the justification for their selection, are discussed in the Section 5.3.

5.3 Research Methods

5.3.1 Data Collection

The data collection methods used were informed by the exploratory nature of the research questions, the selection of GT as the research methodology, the field (HCI) in which the research was based, and the considerations associated with involving people with dementia.

GT is compatible with a wide range of techniques that gather qualitative data, including interviews, observations, focus groups and even the use of diaries (Willig, 2008). In addition, existing texts and documents can also be subjected to GT analysis (Willig, 2008). Whilst any of these techniques may generate data to be analysed using GT methods, the selection of appropriate methods for this study was guided by the suitability of qualitative methods when involving people with dementia.

5.3.1.1 Data Collection Methods – People with Dementia

The most frequently used methods for eliciting qualitative data from people with dementia are interview, focus groups, and observation. All of these methods have been successfully implemented in published studies involving people with dementia, yet each method has limitations and can present difficulties within data collection. The strengths and limitations of each method for general use, and specifically with people with dementia, are summarised in the following sub-sections.

5.3.1.1.1 Interviews

Individual interviews are the most widely used qualitative method of data collection. They provide an opportunity for detailed investigation of people's personal perspectives, for in-depth understanding of the personal context within which the research phenomenon is located, and for detailed subject coverage (Lewis 2003, p.59). Interviews vary in structure, from fully structured, to more open-ended, unstructured styles (Lazar, Feng and Hochheiser, 2010c). Interviews are considered to reflect the natural occurrence of conversation, particularly when they are minimally structured.

Interviews have successfully been used with people with dementia, and have enabled researchers to develop an understanding of their lives. Interviews can be tailored to individuals and provide opportunity to conduct data collection in an individualistic manner, reflecting the nature of dementia itself. When interviewing people with dementia, it is particularly important to consider the research environment, interview timing, and ethical aspects such as the presence of a carer to support interviewees (Clarke and Keady, 2002), as identified in Chapter 3.

5.3.1.1.2 Focus Groups

Focus groups involve several participants discussing the research topic as a group. Data are generated by interaction between participants. Participants present their own views and experiences, but also hear from other people (Finch and Lewis, 2003). This provides an '*opportunity for reflection and refinement which can deepen participants' insights into their own circumstances, attitudes and behaviours'* (Ritchie 2003, p.37).

Focus groups have potential advantages when involving people with dementia. They allow for increased control over level of participation, feelings of support and empowerment from other group members, and facilitate memories being triggered by the contributions of others (Bamford and Bruce, 2002). Limitations when involving people with dementia include lack of respect being shown between participants, parallel conversations being held instead of group discussion, and participants offering idealised, rather than realistic accounts (Bamford and Bruce, 2002). People with dementia also have an increased tendency to acquiesce, which can result in inaccurate accounts being given within a group setting (Bamford and Bruce, 2002). Focus groups can provide rich data on the lives and experiences of people with dementia, but do not facilitate the understanding of detailed individual accounts. A further limitation is that they do not provide as much opportunity to conduct the data collection in a style most suited to the individual (e.g. some people may require longer pauses in questioning to enable them to verbalise their thoughts).

5.3.1.1.3 Observations

Observation offers the opportunity to record and analyse behaviour and interactions as they occur naturally. Observation is a direct method: '*you do not ask people about their views, feelings or attitudes; you watch what they do and listen to what they say'* (Robson 2011, p.316).

Observation is well suited to research involving people with more advanced dementia who may be living with significantly limited communication abilities (Clarke and Keady, 2002). However, there are significant ethical considerations when conducting observations (Cook, 2002), in addition to being extremely time consuming. One further limitation of observation is that used as the sole method of data collection in research, it does not facilitate the exploration of subjective meaning or experience of participants. For this reason, observation is often used as supplementary method to other methods, such as interviews.

5.3.1.2 Selected Data Collection Method – Interview

As this research was focussed on exploring and understanding the experiences of individuals with and without dementia in relation to web content accessibility, the most appropriate method for data collection was deemed to be individual interview. It was important to uncover the perspective of each individual, from their subjective experience, and neither focus groups nor observations facilitated this when used as methods alone. As described previously, interview also enables a more individualistic approach, which is reflective of the individualistic experiences people have with dementia and its symptoms. Observation was used to complement the interviews, to address the potential disconnect that can exist when implementing interview as the sole method in an HCI study, as described by Lazar et al. (2010c) and recommended by Blandford, Furniss, and Makri (2016, p.36). Whilst researching with people with dementia, who may have reduced insight into their own behaviour, observations enabled some of the participants’ unreported behaviours and interactions to be included as data, and enabled observed behaviours to be further questioned, or to be used as prompts, in following interview questions.

In HCI research, interview and observation are considered appropriate methods, and are commonly used as complementary techniques (Blandford, Furniss, and Makri 2016, p.40). Interviews are best suited for understanding people’s perceptions of and experiences with technology, whilst observations provide an opportunity to witness what people actually do, as people’s ability to self-report facts is often limited (Blandford, Furniss, and Makri 2016, p.40).

Interview was used as the primary data collection method, with observation built into the participant studies as a secondary method to aid understanding of the relationship between what users say and what they do.

There are further specific issues that must be considered when conducting interviews with people with dementia, detailed in Section 5.3.1.3.

5.3.1.3 Interviewing People with Dementia

There are four key areas to consider regarding the approach used when interviewing people with dementia: the structure of the interview, communication strategies, the research environment, and the involvement of carers when interviewing a person with dementia. Each of these considerations are discussed in turn.

5.3.1.3.1 Structure of Interview

Interviews are the most common method of collecting data from people with dementia in qualitative studies, even though participation is challenging when cognitive and verbal functions are affected (Pesonen, Remes and Isola, 2011). There is debate in literature regarding the appropriate level of structure to use, in relation to the capabilities and tendencies that people with dementia have. Dementia is often characterised by vague and empty speech, dwindling vocabulary, and disordered speech patterns. These characteristics could compromise the ability to respond fully, or with fluency to open questions (Clarke and Keady, 2002; Lloyd, Gatherer and Kalsy, 2006). It is for this reason that Booth and Booth (1996) advocated direct questioning as an appropriate style when interviewing people with dementia. However, Lloyd, Gatherer, and Kalsy (2006) highlighted that people with dementia have a tendency toward acquiescence when asked direct questions, which could result in the data collected being strongly influenced by the phrasing or content of the questions used.

Semi-structured interview, which employs a combination of both broad, open-ended questions and more focused questions within their schedule have been successfully used with people with dementia in a number of published studies (e.g. Beattie et al. 2004; Nygård 2008). A structure implemented by Pesonen, Remes, and Isola (2011) whereby the interview became increasingly more focused and direct, was successful in yielding rich data from people with dementia. A similar style has also been successfully employed by other researchers (Hellstrom *et al.*, 2007; Brorsson *et al.*, 2011). At the outset of the interview structure, the researcher asks a few broad questions, to introduce the topic area and to build rapport. As data collection progresses, the themes guiding the interview become more focused and this is reflected in the questions being asked (Pesonen, Remes and Isola, 2011).

Structuring an interview in stages of this nature is reflected in general interview conduct guidance, and guidance for HCI research specifically, where the questions become more probing and complex. The stages advised by Lazar et al. (2010b) and Arthur and Nazroo (2003, p.112) are summarised in Figure 16, and these stages were built into the interview schedule developed for this research (see Section 5.3.1.5). Acknowledging that it may be more appropriate to follow the participant’s lead than impose a structure on a conversation with people with dementia (Savitch and Zaphiris 2007, p.241), the structure was intended to be flexible. Therefore, it was expected that to ensure the natural flow of conversation with participants, that alteration of the sequence or phrasing of questions may occur.

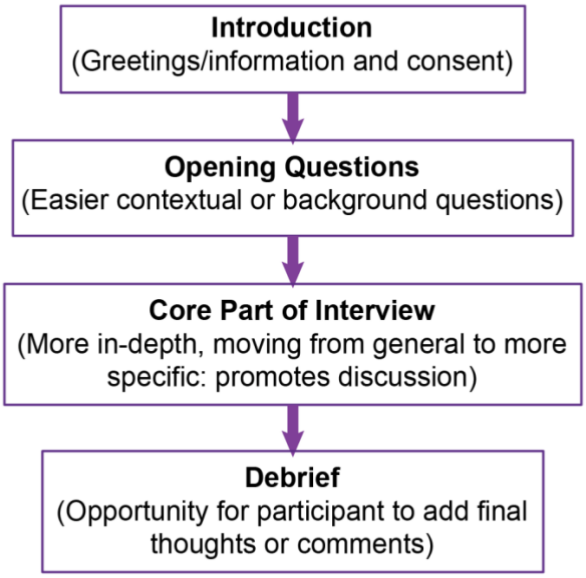


Figure 16. Interview Stages

5.3.1.3.2 Communication Strategies

Within any study involving people with dementia, researchers must be knowledgeable of potential communication challenges that can be faced by these participants. The complexity of the questions needs to be set by the researcher to a level that the person finds comprehensible (Dewing, 2002), and this can be done using the strategies advised by Beuscher and Grando (2011), Pesonen, Remes, and Isola (2011) and Lloyd, Gatherer, and Kalsy (2006), as detailed in Table 14.

Table 14. Strategies for Communication with People with Dementia

Effects of Dementia	Strategy	Reference
Attention and Concentration Lapses	Conduct interview in a less distracting place. Redirect Conversation.	(Beuscher and Grando, 2011)
Decreased Abstract Thinking and Communication Difficulties	Restructure questions to concrete topics. Use participant's wording. Allow ample time for responses. Offer reassurance if participants feel uncomfortable.	(Beuscher and Grando, 2011)

Memory Loss	Use reminiscence	(Beuscher and Grando, 2011)
Fatigue and Anxiety	Monitor for signs and offer to stop the interview.	(Beuscher and Grando, 2011)
	Allow the participant to decide the duration and pace of the interview.	(Clarke and Keady, 2002)
	Allow participants to be accompanied by a carer, according to their wishes.	(Pesonen, Remes and Isola, 2011)
Individual Experience of Symptoms	Speaking with participants prior to the interview to establish rapport and gauge the participant's expressive skills so that questions can be adapted accordingly.	(Lloyd, Gatherer and Kalsy, 2006)

These strategies have been employed by previous research involving people with dementia conducted by the author, which developed the author's knowledge on how to communicate with this participant type. In addition, the author had completed training within the Dementia Friends initiative managed by the Alzheimer's Society, both as a Dementia Friend, and a Dementia Friends Champion. This provided further opportunity to build knowledge about the best ways to communicate with people with dementia, and to support them in conversation.

Monthly attendance at the Hardy Group – a community dementia support group in Derby, UK – enabled the author to strengthen her communication abilities with people with dementia, and increased her confidence in doing so. Being embedded within this group, attended by people with dementia and their carers, provided opportunity to develop stronger communication skills with people with dementia both as individuals, and as a partner with their carer.

The individualistic nature of people with dementia, and thus their communication abilities, must be acknowledged when conducting qualitative research. It was therefore expected that the phrasing of interview questions, the pace at which the interview could be conducted and the contributions made by each individual participant may vary considerably. Speaking with participants prior to the interview to establish rapport, and to gauge the participant’s expressive skills, where possible, enabled questions to be adapted accordingly to suit the individual’s capabilities, as recommended by Lloyd, Gatherer, and Kalsy (2006). Where this was not possible prior to the interview being conducted, additional time was spent during the introduction phase of the interview to enable the researcher to establish an appropriate level of conversation. Hubbard, Downs, and Tester (2003) highlighted that not all challenges can be anticipated, and thus researchers need to resolve challenges within the fieldwork setting, and reflect continuously upon fieldwork practice. Reflective Practice was used to capture these elements of the data collection process, which enabled the researcher to explore strategies which were beneficial to participants, whilst enhancing the quality of data collected. Reflective Practice has been described by Pratt (2002) as an effective tool to find ways to interview people with dementia, as it provides opportunity to be critical about which methods facilitate being flexible with the individualistic nature of dementia. The use of Reflective Practice within this research is discussed further in Section 5.3.2.2.2.

5.3.1.3.3 Research Environment

Whilst true with any participant type, the impact of the research environment on both the participant’s comfort and the data collected is of particular importance when involving people with dementia, as identified within both literature and within Chapter 3. Not only are people with dementia often particularly prone to concentration lapses, and therefore benefit from research being conducted in less distracting environments, but the environment can affect people with dementia in other ways too.

In their influential paper, Cotrell and Schulz (1993) stated their belief that people with dementia may feel less threatened if research is conducted in their own home. The use of preference territory that is most familiar to people with dementia is important for both the point of data collection and the point of recruitment to a study (Clarke and Keady, 2002). Using preference territories, which is expected to be the individual’s own home, places the interviewee at an advantage. Whilst this was implemented as the research environment for data collection, the recruitment phase of the study was held within community support groups, as these provided an environment in which researchers could access potential participants, whilst the participants remained at an advantage of the environment being familiar to them.

Participant’s feelings of control over the research process can be enhanced by allowing the timing of the interview to be set by people with dementia (Cotrell and Schulz, 1993). Timing, in terms of the time that interviews are scheduled to begin, was led by people with dementia, to not only ensure that it was of optimal convenience to them, but also to acknowledge that people with dementia can often have certain times of day at which they feel most comfortable. For the same reason, participants were contacted on the day of the interview, to confirm that the scheduled time was still suited to them and how they may be feeling.

The duration and pacing of an interview should also be guided by the interviewee, to avoid tiredness and anxiety (Clarke and Keady, 2002). For people with dementia, it is reasonable to assume that interview duration would be shorter than for someone without cognitive impairment. Interviews with people with dementia within other studies have been restricted to 45 minutes (Keady, 1999), whilst other researchers have interviewed younger people with dementia for an average of two hours (Robinson *et al.*, 1997) and older people with dementia for over two hours (Pesonen, Remes and Isola, 2011). This research viewed the event of participant involvement as far more than the period that the Dictaphone is switched on, and thus restricted the interview duration itself to 45 minutes, whilst scheduling with participants an additional 15 minutes for their involvement, to allow for introductions and informed consent to be obtained, as expected within the introduction phase of the interview structure.

The research environment context of the interviews was designed to maximise the security and comfort of the interviewee. The location and the timing of the interview were suited to the individual participant, which was considered crucial as the research involved people with dementia, which can affect individuals so differently.

5.3.1.3.4 Involvement and Role of Carer

There is discussion in literature regarding the presence of carers during interviews with people with dementia, and the roles that they may have in this situation. The carer's perspective is a valuable source of information (Cotrell and Schulz, 1993), as they can have some potential insight into the person with dementia's experience (Pratt, 2002). However, accounts from carers are their subjective experience and interpretation of a situation (Hendriks, Slegers and Duysburgh, 2015), hence the growing critique of the reliance on proxy accounts (Hellstrom *et al.*, 2007) as they do not always concur with the accounts of people with dementia themselves. Joint interviews with a person with dementia and their carer can foster a sense of protection for people with dementia (Pesonen, Remes and Isola, 2011). Therefore, joint interviews have been preferred by people with dementia (Pesonen, Remes and Isola, 2011) and they have been found to ask for support from carers during interviews (Mason and Wilkinson, 2002). However, there have been situations where conversation has been imbalanced in joint interviews, with carers contributing more, and thus can interfere with individuals' voices being heard (Pesonen, Remes and Isola, 2011). This was identified in the study in Chapter 3 as an issue to be addressed.

It is clear that even when the perspective of people with dementia themselves is what is sought by the researcher, for some individuals the presence of a carer is crucial for the comfort of the interviewee. The challenge is to ensure that the person with dementia's voice is heard, whilst still providing an opportunity for carers to give their invaluable insight, and fulfil their natural role of protecting and reassuring the individuals that they care for. Mason and Wilkinson (2002) reported the role of carers within their study was to clarify points that the respondent had difficulty expressing, or providing additional information, though this was not an explicit role from the outset of the study, and only occurred when the interviewee requested the support of their carer. The research in this thesis aimed to define a role for carers which would enable them to contribute valuable information, whilst ensuring that interviewees' perspectives were given priority, to ensure that their voice was heard.

The primary role of the carer within this research was defined to enable them to support the interviewee emotionally, whilst requesting that they did not interject their opinions during data collection, to ensure that the person with dementia’s voice was heard. An opportunity for carers to note down thoughts they had, together with additional information they felt should be shared with the researcher was provided, so that these could be discussed with the researcher and interviewee once the interview schedule had been completed. A further role given to the carer throughout the interview process was to provide feedback on the methods and approaches used throughout the research study. Carers were invited to comment on the appropriateness of the consent process and documentation, the language used throughout the interview, the communication strategies used, and the overall inclusion of the people with dementia within the study. They were also asked to give suggestions for how the study’s inclusion of people with dementia could be improved upon. This defined role was discussed with representatives of people with dementia, and carers, from the community support group which the author had attended prior to any data collection commencing. Both participant types felt this respected the autonomy of people with dementia by enabling their voice to be heard, whilst empowering the carer to contribute additional information, and allowing them to fulfil their natural protective role. The role of the carer is defined within the carer’s consent documentation, and data collection document, which was provided to carers once their consent documentation completed (see Appendix I). The data collected from carers in this way was included within the Reflective Practice used throughout the study (see Section 5.3.2.2.2).

5.3.1.4 Participant Recruitment

The recruitment process for participants in this study was complex, due to the recruitment of people with dementia, considered to be a vulnerable user group. Issues concerning obtaining informed consent from participants, and working with regard to the Mental Capacity Act determined which people with dementia could be recruited. The development of an ethical recruitment process to facilitate the inclusion of people with dementia in this research is described in Chapter 3. Inclusion criteria for these participants and the older adults without dementia are also detailed in this chapter, together with information regarding the ethical approval granted for this research.

5.3.1.5 Developing and Piloting of Interview Schedules

An initial interview schedule was developed by the author, to reflect the gaps in knowledge that were aiming to be addressed; attitudes and experience of using web content, with a focus on how design can affect this. Consideration was given to the use of appropriate dementia-friendly (simple) language, and the order in which questions were asked to avoid participants' answers being influenced. The timing of the interview was piloted with 2 individuals without dementia, before a person with dementia and their carer were recruited to pilot and evaluate the interview schedule. Both of these individuals had experience with communicating effectively with people with dementia and gathering feedback from this user group. The interview schedule was piloted, and both participants gave suggestions for improvements to the interview schedule and related interview materials. Improvements included changes to the phrasing of the questions, and the introduction of visual prompts to facilitate better discussion regarding web design elements.

The amended interview schedule was used within the Web Use Experiences study (Chapter 6). A conversational and informal approach was taken toward the interviews to keep the participants relaxed, and thus the phrasing and order in which some questions were asked did vary between participants.

The interview schedule evolved further as the study progressed – to reflect the development of the grounded theory – as expected within a methodology that integrates data collection and analysis processes. The schedule also developed in response to participant and carer feedback on the research process, demonstrating the effectiveness and use of Reflective Practice.

5.3.2 Data Analysis

The steps taken in the GT analysis process of the collected data were as follows:

- Interview recordings transcribed

- Initial coding of transcripts using QSR Nvivo 10 - to code data in grounded themes and establish which were frequently identified
- Focused coding of transcripts using QSR Nvivo 10 - to establish which codes best explain the phenomenon
- Development of theoretical categories – by identifying relationships between focused codes and enable a grounded theory to be constructed.

Each of these steps is described in more detail in this section.

All interview audio recordings were transcribed verbatim by the researcher. The transcripts were analysed using Constructivist GT coding procedures, as proposed by Charmaz (2008). The coding procedure framework used in constructivist grounded theory is more flexible than other GT variants. Constructivist coding procedures are more interpretative, intuitive and impressionistic than Classic or Straussian GT, and they function in an adaptable manner which endorses '*imaginative engagement with data'* (Kenny and Fourie, 2015). The fluid framework proposed by Charmaz (2008) and implemented within this research consists of two stages to coding: initial, or open coding, and refocused coding. Initial coding is conducted by coding line by line, or paragraph by paragraph, to establish which initial codes are most frequent or significant. Initial codes are provisional, comparative and grounded in the data (Charmaz, 2006). Data collection continues concurrently with initial coding to progressively explore and fill out these codes. Focused coding commences once some strong analytic directions have been established from the initial coding. Focused coding means using the most significant or frequent codes to sift through large amounts of data, and scrutinising these codes to evaluate which ones best explain or interpret the phenomenon (Charmaz, 2008). Focused codes are tested against large batches of data, to decide which codes to raise to theoretical categories, where they are subject to further analytic treatment by specifying relationships between focused codes and are used to form the theory generated from the research. The coding procedures used within the Constructivist GT analysis used in this research are depicted in Figure 17.

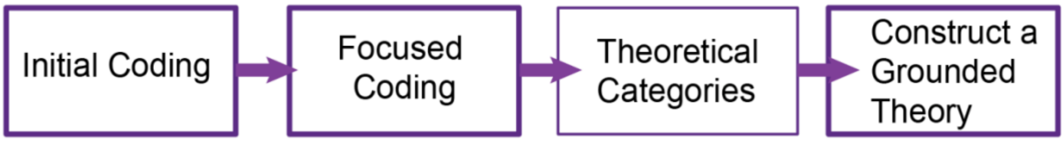


Figure 17. Constructivist Grounded Theory Coding Procedures

Whilst the reliability of the coding process used would have been most strengthened by a second researcher conducting the same analysis process to enable coding comparisons, this was not achievable within the resources of this PhD. However, to ensure the codes used to analyse the data were reliable, the researcher did follow the coding procedures twice for each interview transcript, to ensure that no data had been incorrectly coded due to misinterpretation during the initial coding stages.

5.3.2.1 Grounded Theory Analysis Techniques

Constructivist coding procedures are punctuated by many generic GT techniques, including memo-writing, constant comparisons, theoretical sampling, and saturation (Charmaz, 2008). The way in which each of these techniques was implemented within the analysis of this research is summarised.

5.3.2.1.1 Memo-Writing

Informal analytic notes - referred to as memos – chart, record, and detail analytic phases of the analysis process (Charmaz, 2006). Memos were written throughout the initial coding phase, where they were used to record what was happening in the data, how connections could be made between initial codes, and where areas lacking in data needed to be explored further. Memos were written throughout the research process, as codes moved toward theoretical categories, and served as a trail describing how categories emerged and changed as data collection and analysis progressed. Raw data was brought into memos, where it could demonstrate comparisons between data and data, or codes and codes, to provide sufficient empirical evidence to support the claims being made within that memo. The memos created throughout the research process formed a written record of the theory development, and provide information about the research process itself, as well as the substantive findings of the study. As guided by Willig (2008), all memos were dated and stated which sections of the data they were inspired by, to enable them to be viewed as a record of both the theory development and the iterative research process.

5.3.2.1.2 Constant Comparisons

Constant comparative analysis ensures that the coding process maintains momentum by moving between the identification of similarities and differences between emerging categories (Willig, 2008). This constant comparison facilitates the breakdown of categories into smaller units of meaning (Willig, 2008) ensuring that the full complexity and diversity of the data is recognised. This method of analysis generates successively more abstract concepts and theories (Charmaz, 2006) and was conducted at each stage of analytic development. Comparisons were made between data and data, data with categories, and categories with categories.

The constant comparative method of GT analysis did not end with the completion of data analysis. Literature from the review conducted served as a valuable source of comparison and analysis, as recommended by Charmaz (2006). Through comparing other evidence and ideas with the developed theory of this research, it was possible to identify where this theory fits, and where it challenges existing ideas in the field.

5.3.2.1.3 Theoretical Sampling

This type of GT sampling focuses on the researcher elaborating and refining the properties of the developing categories or theory. The researcher seeks people, events, or information to illuminate and define the boundaries and relevance of the categories that have been developed yet remain incomplete ideas (Charmaz, 2006). Theoretical sampling is conducted until no new properties of a category emerge. It is important to distinguish theoretical sampling from sampling until no new data emerge, as this is a common mistake made by qualitative researchers (Charmaz, 2006). Theoretical sampling is not employed to identify reoccurring patterns or themes in the studied world, but to examine tentative ideas about data through further empirical inquiry. Theoretical sampling is strategic, specific, and systematic, and follows directly from memo-writing (Charmaz, 2006). As theoretical sampling is dependent on having previously identified categories, it is significantly different from the initial sampling strategy which will have been designed according to inclusion criteria for people, cases or situations before entering the field.

Theoretical sampling was used to investigate preliminary categories, with the aim of completing these with theoretical sufficiency.

5.3.2.1.4 Theoretical Saturation – Theoretical Sufficiency

GT saturation is not the same as witnessing repetition of the same patterns. Theoretical saturation of categories in GT occurs when fresh data being gathered no longer reveals new theoretical insights, nor reveals new properties of the core categories (Charmaz, 2006). However, theoretical saturation functions as a goal rather than a reality (Willig, 2008). The reason for theoretical saturation not being wholly achievable is that modification of categories, or altered perspectives are always possible. For this reason, we can never know everything as there is never one complete truth. Dey (1999) proposed a preferred term that reflects this imprecision of the usage of the term ‘saturation’; ‘theoretical sufficiency’. Theoretical sufficiency is used to indicate the adequacy of data and fullness of coding within a grounded theory study, without implying that no further insights could emerge upon further investigation. Thus, a GT declaring theoretical sufficiency, rather than theoretical saturation acknowledges that a singular ‘truth’ is unobtainable and that GT is always provisional. This research sought to reach a point of theoretical sufficiency within the theory developed, and acknowledged that whilst desirable, true theoretical saturation is unobtainable in reality. The initial and focused coding conducted on the data from older adults without dementia and people with dementia established a core theme throughout all participants, with associated factors being strongly identified throughout interview transcripts. The researcher acknowledges that there may be additional factors associated with the core identified theme which could be revealed if much greater numbers of participants were included, but that the data collected provided sufficient evidence to support the developed theory relating to the difficulties faced by people with dementia and older adults without dementia when using web interfaces.

5.3.2.1.5 Use of Literature

Within most versions of GT, researchers are encouraged to conduct literature review after developing an independent analysis, to avoid seeing the world through the lens of extant ideas. However, Constructivist GT is consistent with Constructivist philosophy, which insists that research does not occur in a vacuum, but is influenced and often informed by the context in which the research is conducted (Kenny and Fourie, 2015). Charmaz (2006) echoed Strauss and Corbin's endorsement of using literature at each stage of the research process, but promoted a more specific use of literature – that a literature review chapter should be compiled, in addition to literature being interspersed throughout the entire thesis. Charmaz advised that this literature review chapter should be written after data analysis, to guard against the researcher becoming immersed in literature to the extent of losing one's creativity.

Whilst an initial literature review had been conducted prior to data collection, further comprehensive literature searching and review was suspended until data analysis had been completed. The exception to this was the use of literature during constant comparison. This balanced use of literature throughout the analysis enabled the resultant theory to be compared and situated within current ideas and theories within the field, whilst maintaining a space for the researcher to work creatively with the theory, without being influenced by pre-existing theories or beliefs derived from literature.

5.3.2.2 Quality of Research Methods – Reflexivity and Reflectivity

The reliability of qualitative data has been questioned by quantitative researchers, as it is based on immediate interactions that lone, possibly biased, observers have recorded (Charmaz, 2006). Constructivist GT is removed from its objectivist foundations where the researcher discovered the emerging theory, and brings the grounded theorist into the research process.

Therefore, the researcher in this research stood *within* the research process, allowing for interpretive possibilities within data analysis. As a result, researchers are obligated to be reflexive about what they bring to the scene, what they see, and how they see it (Charmaz, 2006). It is through reflexivity that HCI researchers are able to interpret, understand and improve their research (Adams, Lunt, and Cairns 2008, p.155). Reflexivity is important when striving for objectivity and neutrality (Snape and Spencer, 2003) and can play a role in the reliability of research, when practiced at various points throughout data collection and analysis (Lewis and Ritchie 2003, p.271). Researcher reflexivity has also become emphasised when assessing the validity of research (Creswell 2007; Denzin and Lincoln 2000, p.1021). The following sections detail where the researcher has implemented reflexive and reflective practices throughout this thesis and how these have been implemented to ensure that good quality research was conducted.

5.3.2.2.1 Reflexivity in Data Collection

Caution must be taken not to force data into preconceived categories, as when irrelevant, or forced questions are asked, they can shape the data collection and the subsequent analysis suffers (Charmaz, 2006). This necessitates researchers to be reflexive about the nature of their questions and whether they work for the specific participants and the GT developed following analysis. Memos were written throughout analysis to monitor the suitability of the questions asked of the participants, which could inform the next set of data collection where improvement was required.

An additional reflective exercise was conducted following each interview, to enable the researcher to record any additional information that could have influenced data collection with the participant. Fieldwork notes were written immediately following the conclusion of an interview, to capture information that would not be recorded within interview transcripts. These reflections, termed '*self-reflections'* by Marshall and Rossman (2011, p.97) contained notes on what worked, and what did not work so well, during data collection. This assisted in maintaining the research instrument (interview schedule) and ensuring it was both suitably designed for the participants involved, and captured the desired data.

5.3.2.2.2 Reflectivity for Methodological Knowledge

An additional reflective exercise was conducted, to enable new methodological knowledge to be contributed, with regard to the involvement of people with dementia in research. Aldridge (2015, p.138) highlighted this as an important role of reflexivity when working with vulnerable participants, and emphasised that researchers should contribute new methodological knowledge as well as new insights about researcher roles and relationships. In the same way that self-reflections were collected for data collection suitability, notes were made following each interview, to capture the successes and limitations of these methods for participants. The researcher made notes on the suitability of the informed consent process, the interview technique and process, and the dynamics observed between people with dementia and their carer as they fulfilled their assigned roles during data collection. In addition, carers and participants were invited to comment on the research process, and its suitability for them as participants. Issues that became apparent through this reflective exercise that needed to be addressed to ensure good quality research was being conducted, were evaluated using a model of Reflective Practice; the What? Model of Structured Reflection (Driscoll, 2000, cited in Driscoll and Teh 2001): see Figure 18.

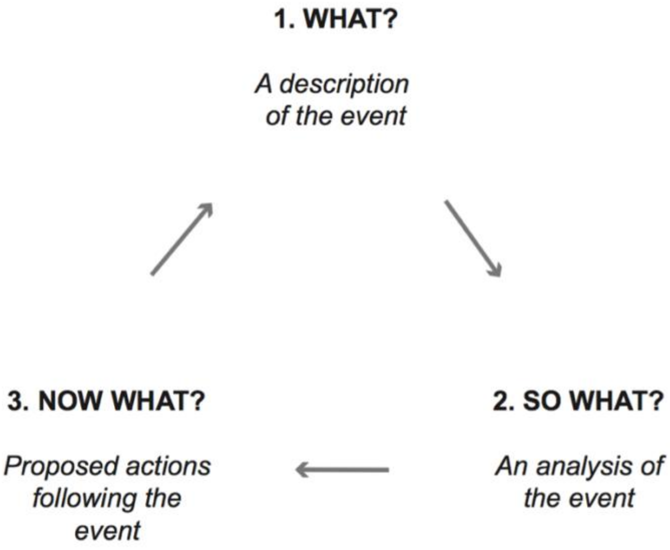


Figure 18. The 'What?' Model of Structured Reflection

As described in Chapter 3 Reflective Practice is an intentional activity with the focus on improving and changing practice (Driscoll and Teh, 2001). It can lead to new ways of thinking or behaving in practice (Andrews, Gidman and Humphreys, 1998). Reflective Practice was selected as an appropriate tool for reflectivity in this research as it is effective for reflection upon tasks involving people with an individual nature, such as people with dementia, and adapt practice to meet their diverse needs.

Lewis and Ritchie (2003) promote the reflection on the suitability of methods to enable participants to fully express their views, as it can be a way to internally check the validity of research.

5.3.2.2.3 Reflexivity in Data Analysis

Reflexivity is a core element of Constructivist GT, as the researcher has a role in the interpretation of data and the construction of the developed theory. All researchers shape the emergent writing, and thus need to accept this interpretation and be open about it within writings (Creswell, 2007). To monitor where the researcher has influenced the emergent interpretation and resultant theory, a number of reflexive activities were conducted throughout data analysis. Memos were written to capture the changes and developments in the researcher's attitudes and opinions on the research topic throughout the analysis. This enabled the account of the approaches and procedures that led to sets of conclusions to be developed in a way that remained transparent regarding the influence that the researcher's opinions had in this interpretation and analysis. Reflexivity during data analysis contributed to the detailed documentation of the research process. The provision of such documentation has been encouraged in literature, to ensure that research is of good quality (Henwood and Pidgeon, 1992), with enhanced reliability (Lewis and Ritchie, 2003).

5.3.2.3 Additional Validity Evaluation

Further aspects of the analysis procedures of GT that enhance the internal validity of the research are the use of constant comparison, and ensuring increased theoretical sensitivity as a further comparison. Constant comparison analysis is used as a check that the developed theory fits the raw data, and thus strengthens the internal validity of the analysis. The use of literature throughout analysis, and as a specific literature review, increases the theoretical sensitivity by using previous research comparisons. These are two of the seven rules specified by Henwood and Pidgeon (1992) that can ensure a high standard of analysis, in addition to reporting in detail the context in which research was conducted, and the procedures followed throughout the process, including the elements of reflexivity and reflectivity which have been described.

External validity is commonly evaluated using two methods: triangulation, and member checking (Lewis and Ritchie, 2003). However, as argued by Angen (2000) assessing validity through specific methodological criteria supports the positivist assumption that an external reality exists, untainted by the subjective involvement of the researcher. This assumption suggests that research results can be judged for their truth-value, which contradicts the interpretive perspective which is grounded in the belief that no objective truth or reality exists (Cohen and Crabtree, 2006).

‘Triangulation is a means of checking the integrity of the inferences one draws. It can involve the use of multiple data sources, multiple investigators, multiple theoretical perspectives, and/or multiple methods’ (Schwandt, 2007). In the case of this research, a combination of data sources and perspectives have been used to check the integrity of the research findings. The primary data source was interview with people with dementia, but both observations and the opportunity for carers to give their perspective were included within the research method, to gather all versions of the ‘truth’, allowing for conclusions to be drawn from the multiple relevant perspectives. Literature has been used to compare the research findings with those of previous studies, in addition to exploring the theoretical explanations behind the developed theory, therefore providing another data source from which to derive other perspectives.

Member checking is the process of returning analyses to participants for the confirmation of their accuracy and ‘truth’ (Angen, 2000). The method is used *‘to validate, verify, or assess the trustworthiness of results’* (Birt et al. 2016, p.1802). This method was not used within this research, for reasons beyond its positivist assumptions regarding the existence of objective reality. Extensive ethical attention was given to the protection of participants (particularly those with dementia) during both recruitment and data collection, yet similar attention is rarely afforded to the use of member checking in research (Birt *et al.*, 2016). This research acknowledged that participants with dementia may not be in the best position to check and confirm the data, as they may forget what they had said (Cohen and Crabtree, 2006). In addition, as highlighted by Birt et al. (2016, p.1805) *‘participants can be in a different phase of their life or illness when they receive the document*’ and this can lead to issues such as distress for participants or their family, due to being faced with the difference in the participants’ abilities over time. For people with dementia, it cannot be known how their condition may have progressed during the period in which analysis is conducted, and thus presenting these participants with their initial contributions, whether that be via a verbatim transcript, or resultant analysed themes, may no longer resonate their ‘truth’ to them, or could potentially cause distress through highlighting how their dementia has progressed. On these ethical grounds, it was decided that member checking would not be a suitable measure of validity for the analysis in this research, as participants’ needs needed to be put foremost in the research process. Informal member checking throughout each interview was conducted, by clarifying the meanings of participant’s statements in discussion. Whilst this does not contribute to the validity of the analysed data and resultant theory, it provided assurance that the researcher’s initial understanding of participants’ meanings used to develop the theory were correct.

5.3.2.4 Tool

The qualitative data analysis was conducted with the aid of computer-assisted qualitative design analysis software (CAQDAS). The transcribed interviews were uploaded to QSR Nvivo 10 software, which allowed the text to be coded, themed and retrieved efficiently; the same process was followed when drawing comparisons with literature. The analysis software also supported the visualisation of the analysis and resultant grounded theory of the research.

5.4 Chapter Summary

This chapter has introduced the theoretical perspective which underpins this thesis: Constructivist Grounded Theory. Justification for this decision, with reference to the selection of this version of the methodology has been presented. The methods, procedures and development of materials for data collection and data analysis have been described, with particular consideration for their use with people with dementia, and the field of HCI in which this thesis is being conducted. This has helped to ensure that the data collection methods and analysis techniques implemented in the studies conducted are appropriate to the aim and context of this research. Reflexivity and reflectivity practices for implementation during the data collection and analysis of the studies within this thesis have also been detailed, which contribute to ensuring good quality qualitative research by providing reliability and objectivity.

Chapter 6. Study 2- Web Use Experiences

6.1 Introduction

As identified in Chapter 4, there is a gap in knowledge regarding the difference in web content accessibility needs for people with dementia and older adults without dementia. This study explores the experiences of people with dementia and older adults without dementia using the Internet to access web content. Data were collected with interviews to explore participants' experiences of, and attitudes about using the Internet, and the difficulties experienced when using web interfaces. This chapter is presented in two parts: the first reports the results about experience and attitudes, and the second presents the difficulties faced. Differences and similarities identified between people with dementia and older adults without dementia are discussed in both parts.

The results address the first research question, by exploring and comparing the experiences of people with dementia and older adults without dementia when using the Internet. In addition, reflective practice throughout contributes knowledge on improved practice for the inclusion of people with dementia as participants in research.

6.2 Aims and Objectives

The aim was to identify which difficulties people with dementia experience when using the Internet, and to explore how these differ from the difficulties experienced by older adults without dementia.

Objectives:

- To investigate the attitudes of people with dementia and older adults without dementia toward using the Internet
- To identify the difficulties experienced by people with dementia and older adults without dementia when using the Internet
- To describe the similarities and differences between the experiences of people with dementia and older adults without dementia

6.3 Study Method and Process

Data were collected in two parts:

1) Interview questions
2) A web interface use task with observation and feedback

Both parts were conducted in one session, at the participant’s home.

For participants with dementia, there was also an opportunity for the participant and their carer to provide feedback about additional considerations for their web use, and opinions on the data collection procedure suitability for use with people with dementia. Each part of the data collection process is described with further information on the selection of the methods in Chapter 5 (Section 5.3.1).

6.3.1 Part 1: Interview

The interview schedule (Table 15) included:

- Contextual questions
- General questions about Internet use experiences
- Specific questions focused on the design of web interfaces.

The phase of the questions in the interview stages is described in Chapter 5 (Section 5.3.1.3.1). The full interview schedule including prepared prompts and rationale for the question being included is provided in Appendix J. As described in Chapter 5, whilst the interviews followed a high level structure, they were conducted in an informal, conversational manner and thus, the phrasing and order of the questions sometimes varied.

Table 15 - Interview Schedule Questions

Question	Question Phase
What do you usually do on the Internet?	Opening Questions *(Contextual, background and general questions leading to the core interview questions)*
How long have you used a computer for? And the Internet?	
[For people with dementia Only] Have you used the Internet differently since being diagnosed with dementia? If yes, how has this changed?	
Do you usually use the Internet independently? *[how has this changed?]*	
Do you enjoy using the Internet? *[how has this*	

changed?]	
Are you confident when using the Internet to do something new? If no, ask why. *[how has this changed?]*	
Do you find the Internet easy to use? *[how has this changed?]*	
What do you think makes websites easy to use? (In terms of design)	Core Questions *(Moving from the general questions to more specific)*
What do you think makes websites difficult to use? (in terms of design)	
Do you find it easy to navigate/find your way around websites to find what you want to?	
Is there anything else you would like to add to what you have told me about how you experience using the Internet?	Debrief Question

6.3.2 Part 2: Web Interface Task and Evaluations

Each participant was asked to complete a short task on a public access website, prior to giving their feedback on the design and experience of using that interface.

The guidance was:

- Using this website (www.nhs.uk/pages/home.aspx), please could you find information on where and when you would get the flu vaccination if you are over 65?

Following completion – or abandonment – of the task, each participant was asked:

- How do you feel about the design of that website?
- Which design features helped you to complete the task?
- Which design features made it more difficult to complete the task?
- What could be changed about the design to make the website easier to use?

- On a scale of 1 to 5, with 5 being the easiest to navigate, how would you rate this website? *[a visual scale aid presented to participant]*

Including a specific task enabled observations of real interface use, and an opportunity for participants to express their opinions on specific design features that they may have encountered when using the Internet. Observations on participants' actions when completing the task were noted on an observation sheet (see Appendix K) to aid understanding of the issues participants went on to discuss; if a participant was observed to have difficulty interacting with a specific element of a website, this was then used as a discussion point in the interview following the task.

To minimise the risk of participants feeling tested or becoming anxious, other web interface evaluations were conducted using static copies of the following web pages, where participants were asked to give their opinions on their design:

- www.thetrainline.com
- www.ageuk.org.uk
- www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia
- www.boots.com/health-pharmacy

6.3.3 Carer Feedback

When involving people with dementia, carers were invited to contribute to the study in two ways:

1) To contribute any additional information about the participant's Internet use that they felt had not been established during the interview itself and to discuss this with the researcher and participant.
2) To discuss their thoughts on the process followed during data collection, including how dementia-friendly the method was.

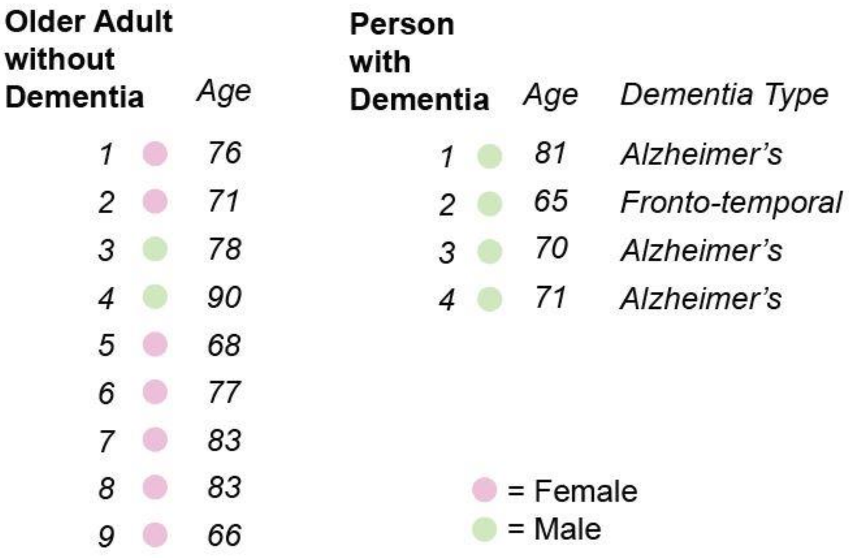
This section enabled participant and carer realities to be established in relation to changes in web use, in addition to supporting the ethical approach through reflective practice. The development to the study method in response to carer feedback and researcher reflective practice is addressed in section 6.4.3.

6.3.4 Changes in the Study Process Order

Initially, the section elements of the data collection were conducted with the interview questions asked before the task element (PWD1,2,3 and OAwoD 1-6). This was intended to provide time for the participant to feel comfortable with both the researcher and the study, and minimise the likelihood that the task element would cause anxiety or feelings of being tested. However, it was considered that rearranging the order of the study elements may address some of the hesitation of participants in knowing how to engage with design-focused questions. Therefore, the task was introduced to OAwoD7 between the opening interview questions and the core interview questions. This change in order appeared to better engage the participant with the design-specific core interview questions and thus was implemented in the data collection with the remaining 3 participants (PWD4, OAwoD 8&9).

6.3.5 Participant Sample

Thirteen people participated in this study. Nine of these participants were older adults without dementia and 4 were people with dementia, with ages ranging 65-90 years (Figure 19).



Older Adult without Dementia		*Age*
1	🟣	*76*
2	🟣	*71*
3	🟢	*78*
4	🟢	*90*
5	🟣	*68*
6	🟣	*77*
7	🟣	*83*
8	🟣	*83*
9	🟣	*66*

Person with Dementia		*Age*	*Dementia Type*
1	🟢	*81*	*Alzheimer's*
2	🟢	*65*	*Fronto-temporal*
3	🟢	*70*	*Alzheimer's*
4	🟢	*71*	*Alzheimer's*

🟣 = Female
🟢 = Male

Figure 19 - Participant Information

6.4 Results and Discussion

Data were analysed using grounded theory techniques, as described in Chapter 5 (Section 5.3.2.1). The themes and concepts developed as a result of this analysis are presented in the following sections.

The study results are grouped into three areas:

1. Experience of, and attitudes toward web use (Section 6.4.1)
2. Difficulties faced with web use (Section 6.4.2), and
3. Participant and carer feedback on the study procedure (Section 6.4.3).

Findings highlighted the limiting effect of negative web use experiences on future web use, the key issue of navigational difficulties for both people with dementia and older adults without dementia (and the factors that contribute to these difficulties) and positive feedback on the study procedures; in particular, the dementia-inclusive consent documents.

6.4.1 Internet Use: Experience and Attitudes

There were two key themes related to attitudes toward Internet use. The first theme presents the relationship between web uses and the attitudes of users, and includes sub-themes of convenience, enjoyment, and fear/concern. The second theme highlights the impact that experiencing difficulties can have on the broader attitude of users toward Internet use, and includes sub-themes of feelings of frustration, being overwhelmed/anxious, and tendencies to self-blame when faced with difficulties.

6.4.1.1 Attitudes, Experiences and Web Uses

Participants detailed a range of positive and negative attitudes toward the Internet, which have an impact on their range of activities using the Web (Figure 20).

People with dementia and older adults without dementia expressed positive attitudes regarding the convenience and enjoyment that using the Internet can bring, amongst negative attitudes stemming from fear and concern over the use of the Web.

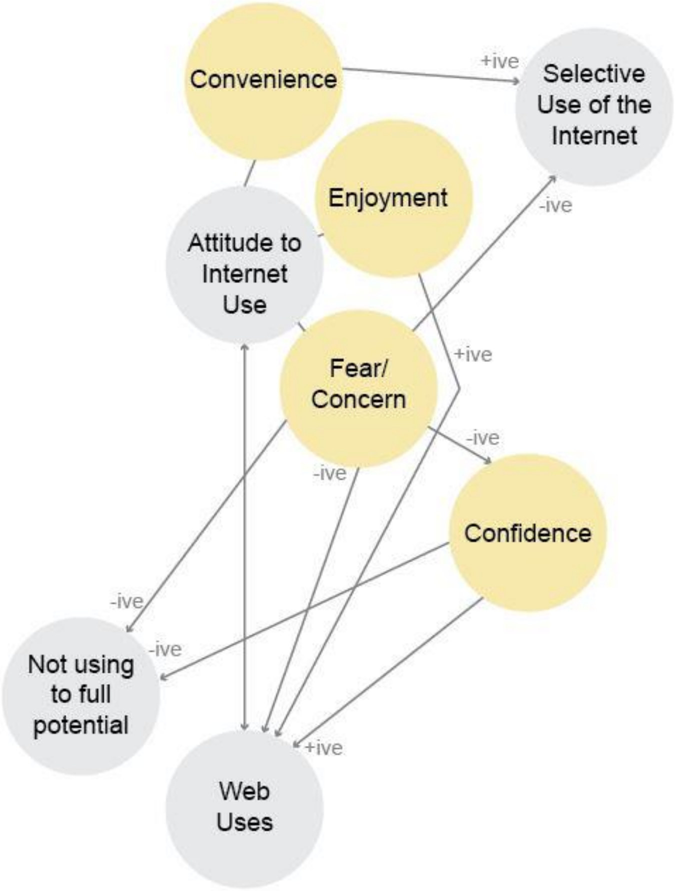


Figure 20 - Attitude and Web Uses

Older adults without dementia felt positively that the Internet can be a convenience to them, as it enables them to save time by completing tasks online that they would otherwise have to travel elsewhere to do; e.g. supermarket shopping, booking flights.

> *OAwoD 2: When the family came, even for Christmas he'd just stay in his room, so it was a time thing and I couldn't spend the two hours it would take doing the weekly shop, so I just went online and I've done it ever since. But now, I rely on that – you know it frees up the time to do what I want to do.*

> *OAwoD 6: I mean no; I find this is good. I found it so liberating. From the start, [daughter] said 'come over, Mum. You can fly over' and for a start I thought 'oh my goodness, how do I do all this' you know, and she would book the flights and I'd feel like such a*

> *nuisance and say 'can you book the flight please', but the first time I did it I thought 'YES!' [laughs]*

The convenience and availability of these online services is a motivation for using the Internet for these users. The convenience of online shopping was also referred to by a person with dementia, as he could no longer shop independently in physical shops due to his dementia:

> *PWD4: I'm a bit wary online, because I don't like giving bank details. But I must admit these days, I do give them online – just because I can't get the stuff now in [city], so yeah –.*

Enjoyment was another positive experience that promoted further web use and encouraged users to visit websites for extended periods of time, for leisure. When asked whether they enjoyed using the Internet, participants responded positively:

> *OAwoD4: Oh yes, often if I'm bored for a while, I get it and just go through different things I've been thinking about.*

> *OAwoD7: Yes, I do actually – if I can get on it. [laughs] I Google. If I find something to Google, and sort of one thing leads to another, I could sit on it for four hours and completely lose myself. Just going from one thing to another on Google.*

> *PWD2: Yeah, I love it – I don't know how we ever managed without it really!*

Older adults without dementia and people with dementia expressed enjoyment, suggesting that visiting websites is a choice, rather than always a necessity as many services move to be digital and online. Enjoyment, in addition to convenience, has a positive effect on the use of the Internet by users, as it promotes further use of the Internet for additional purposes, and fosters further positive experiences, thus providing an opportunity for leisure activities and entertainment.

A negative attitude taken by participants when considering using a new website, were coded as fear/concern. Participants expressed that they can feel fearful or concerned about using new websites as they are unsure how ‘safe’ they are, regarding for example, data protection, scams and viruses, or how to identify an ‘unsafe’ website.

> *OAwoD3: I mean the thing I most – I fear the websites, you know, of what it could do to you and your data, it’s unfathomable really!*

> *PWD1: I’m a bit wary because you hear such a lot about the, urm, the you know, the people getting onto the internet and you know, ur, and using it for illegal purposes.*

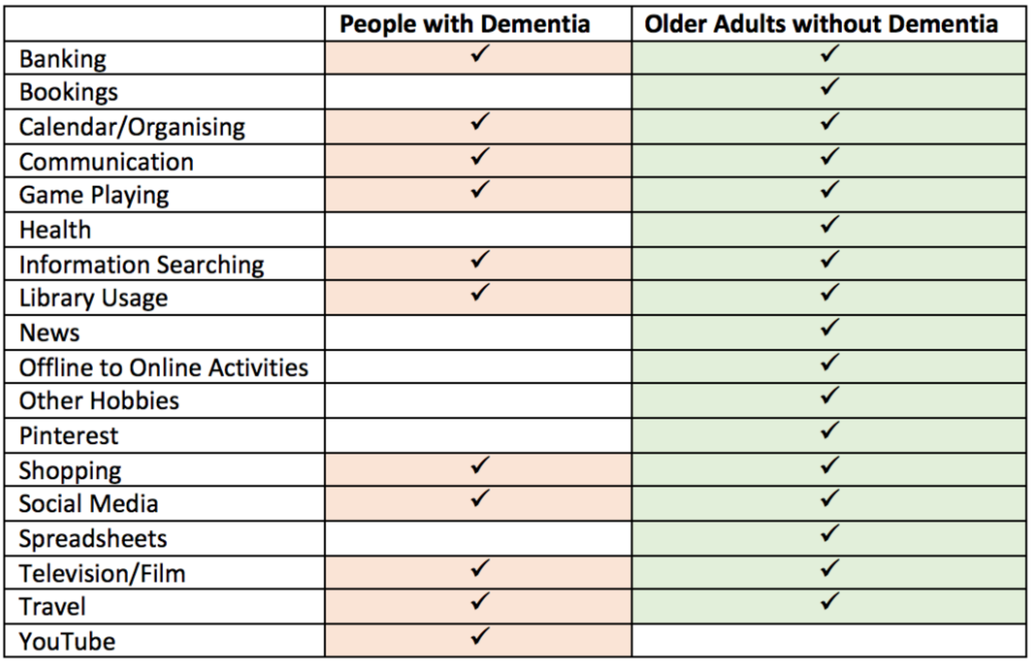
This cause of concern can prevent the use of the Internet to its full potential, and create a barrier to other potential online engagement. Concern was also expressed when using a new site:

> *OAwoD6: I mean for at the start I was really frightened of it, ur, I still am to a degree, because it’s as you can press something so easily and suddenly up something comes, and sometimes the problem is how do I get back? How do I get out of it? And if there isn’t an arrow at the top, going left, then I’m thinking ‘well what do I press now then?*

OAwoD1 expressed that if another person had recommended a site with an assurance that it could be trusted then this would overcome her fear of new sites. The role of other people is discussed further in Section 6.4.1.2. PWD4 expressed that the need to use online services - as his dementia symptoms prevented his continued use of offline services – had driven him to using his bank details online, despite his concern over safety. This effect of dementia symptoms changing Internet use was not further elaborated, but does highlight that users can continue using websites, yet be experiencing emotions such as fear, which can impact broader user experience.

The attitudes and experiences of both people with dementia and older adults without dementia with regard to Internet use influence the extent to which individuals continue to use the Web. The different uses of the Web were collated from the interviews (Table 16) with people with dementia using the Internet for 11 different activities/purposes.

Table 16 - Web uses for People with Dementia and older adults without dementia



	People with Dementia	Older Adults without Dementia
Banking	✓	✓
Bookings		✓
Calendar/Organising	✓	✓
Communication	✓	✓
Game Playing	✓	✓
Health		✓
Information Searching	✓	✓
Library Usage	✓	✓
News		✓
Offline to Online Activities		✓
Other Hobbies		✓
Pinterest		✓
Shopping	✓	✓
Social Media	✓	✓
Spreadsheets		✓
Television/Film	✓	✓
Travel	✓	✓
YouTube	✓	

The extended use by older adults without dementia compared with people with dementia could be a limitation of the participant group. However, it could also be related to a reduced perceived need as life becomes more challenging for people with dementia. Another possibility for the smaller range of activities could be more negative emotions as a result of difficulties with website use.

6.4.1.2 Attitudes and Difficulties with Web Use

Two emotions that were repeatedly mentioned were frustration and feeling overwhelmed/anxious. The attitude taken when faced with difficulties was self-blame, with references to the impact of ageing and dementia symptoms. The relationships between these emotions and attitudes, and the other themes are summarised in Figure 21, which shows that facing difficulties with website use has a negative impact, and can prevent the Web being used to its full potential. The role of other people assisting users to improve their confidence or overcome a difficulty using a website is highlighted.

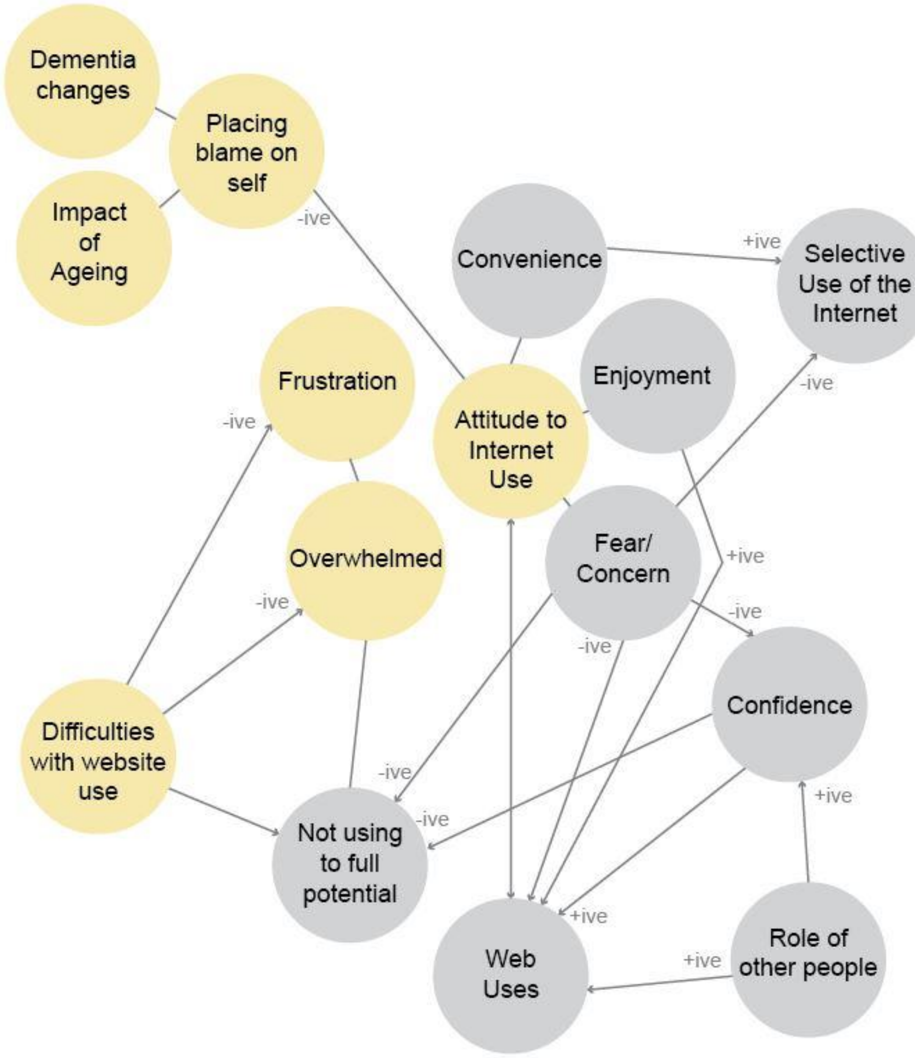


Figure 21 - Attitudes and Difficulties with Web Use

Participants expressed frustration when a website did not work as they expected, or if they became stuck/lost within a site. This can lead to task abandonment as well as experience of negative emotions both at the time, and for future Internet use.

> *PWD1: I think the big, my big problem is that it's, I get frustrated if it doesn't do exactly as I think it will.*
> *Interviewer: Right, so what do you do if that happens, do you stop completely?*
> *PWD1: Yeah, I tend to [laughs], switch off and walk away!*

However, both older adults without dementia and people with dementia expressed that they would first try to persevere when faced with difficulties on websites, and attempt to overcome their frustration in order to ‘succeed’ at whatever goal they were trying to accomplish.

In addition to the negative emotion of frustration, older adults without dementia referred to becoming overwhelmed by complex sites and becoming anxious if they are not able to use a site to the extent, or as successfully as, they believe they should be able to:

> *OAwoD6: I always think I’m not very clever, so I get anxious because I’m not getting there quickly.*

Whilst no participants with dementia mentioned feeling overwhelmed or anxious in relation to facing difficulties on websites, they described having “too much” on a website and this suggests being overwhelmed (section 6.4.2.3).

Where difficulties were faced when using the Web, older adults without dementia believed that they demonstrated inability with Internet use due to age -

> *OAwoD2: it’s just new technology is very difficult for someone of my age.*
>
> *OAwoD5: Oh dear, that is not user friendly, particularly to over 65s. It would be fine with youngsters who are used to navigate.*

; lack of training –

> *OAwoD5: At our age, if you’re new to computing, you’re thrown in at the deep end unless you go on a course.*

; or low intelligence –

> *OAwoD6: I thought it was confusing, but you see, I’m fully aware that I have a very slow brain. I felt so foolish.*
>
> *PWD4: It was okay, if I was with it, it may be me being thick.*

No participants with dementia referred to the effect of age, but did refer to their condition and how that may have impacted their ability to use the Web.

None of these examples of self-blame discussed that something could be done to support the use of websites, or to overcome their current difficulties.

PWD1 commented that his use of websites has changed post-dementia diagnosis, whilst discussing how he finds auto-suggestions from search bars useful. This could be due to changes in concentration levels, as he also commented that this can impact how much he can read.

> *PWD1: Now dementia, I, it's, I'm not completely struck with dementia, but obviously I'm beginning to do things a bit differently.*

A strategy for managing memory issues with Internet use (remembering where something was seen on a site) for PWD4 was to write things down - this was also alluded to by OAwoD5, who relied on writing instructions to complete a task online within a banking site.

PWD3 experienced a change in Internet use since living with dementia, from using it for functional purposes to using it primarily for leisure/entertainment (this difference was made apparent by the carer in this dyad, as the person with dementia had reported no change in use from his perspective/reality).

> *Carer PWD3: And he used it for all sorts of things, like booking tickets for concerts, Internet banking, but I've found him now not using it more to do these things, it's more watching things on YouTube –*

Although few references were made to changes in web use ability by people with dementia, dementia may exacerbate difficulties encountered by older adults without dementia, and thus change the way in which an individual uses the Internet; there is evidence that people with dementia may not be particularly aware of their changed abilities as their dementia progresses.

6.4.1.3 Attitude: With and Without Dementia

All participants shared many attitudes toward Internet use, and were aware of much of the functionality that the Internet offered them in terms of online services and web content. Both user groups mentioned that web functions can foster enjoyment, in addition to a convenient alternative to offline activities, both of which are key motivations for Internet use. However, both user groups highlighted that facing difficulties using websites can prevent them from utilising the Internet to its full potential, by reducing their enjoyment or stopping them from succeeding in completing an online goal. These difficulties and ‘negative’ emotions were identified in Chapter 2 where barriers to technology adoption and use for assistive technologies were mapped out (Figure 5).

The impact that negative experiences, and perceived difficulties with use can have on technology uptake or continued use of technologies fit with the Technology Acceptance Model (TAM). TAM is one of the most popular research models used to predict use and acceptance of information systems and technology by individuals (Surendran, 2012). Perceived ease of use is one of the most important determinants of actual system use, together with perceived usefulness, and can be influenced by external variables such as skills and facilitating conditions. These factors directly affect a user’s attitude toward using a technology and thus impact their intention to use the technology and the resultant actual use of the system. This study found that the attitudes users developed as a result of their perceived ease of use of web interfaces did impact their resultant system use, as perceived difficulties led to reduced engagement with the Web.

The shared attitudes toward the Internet, both in terms of its importance and convenience to users' lives, and in terms of how it can induce positive and negative emotions in an individual utilising a website, suggest that a dementia diagnosis does not necessarily present additional or vastly different attitudes or emotional experiences in comparison to older adults without dementia. Older adults without dementia are found to encounter barriers including frustration (Castilla *et al.*, 2016), mistrust (Castilla *et al.*, 2016; Hargittai and Dobransky, 2017), fear (Lynch, Schwerha and Johanson, 2013; Castilla *et al.*, 2016), confusion (Chadwick-Dias, Mcnulty and Tullis, 2003; Rodrigues, de Mattos Fortes and Freire, 2016; Hargittai and Dobransky, 2017) and a sense of being overwhelmed (Redish and Chisnell, 2004; Rodrigues, de Mattos Fortes and Freire, 2016; Hargittai and Dobransky, 2017). However, what may occur is that heightened difficulties experienced by people with dementia, due to their symptoms exacerbating difficulties with web use, could result in greater user experience impacts (most likely negatively, in terms of frustration/fear/feeling overwhelmed or anxious) - this is unclear from the data collected in this study, but is explored in the next study (Chapter 7). If this is a present factor within technology use for people with dementia, when viewed within the TAM, actual system use may become more infrequent or reduced as a result of lower perceived ease of use or more negative attitude toward using technologies developed as a result of these negative user experiences. This would then suggest that living with a dementia diagnosis could impact technology use, even when living with the earlier stage symptoms such as those participants of this study live with.

It is apparent that people with dementia may not have the necessary insight to provide information on how their Internet use has truly changed outside of their reality, since their dementia diagnosis. Whilst the perspective of the person with dementia's reality is of importance, as this can provide insight into the attitudes of people with dementia in their current reality toward the Internet, being able to put this in context of their lives prior to dementia diagnosis does usually require some input from their carer.

6.4.2 Website Use: Difficulties Faced

The range of difficulties that participants referenced when asked about using websites are displayed in Figure 22, with those referenced by people with dementia marked in purple.

Navigation is a key accessibility issue for both people with dementia and older adults without dementia, and is therefore considered in more detail. Navigation is also one of the most prominent issues for older adults without dementia identified in literature, characterised by problems searching for information and getting lost whilst doing so (Laberge and Scialfa, 2005; Haesner *et al.*, 2015). The literature supports that navigation is a core issue for older adults, and thus further justifies its exploration as a difficulty in web accessibility and usability for people with dementia.

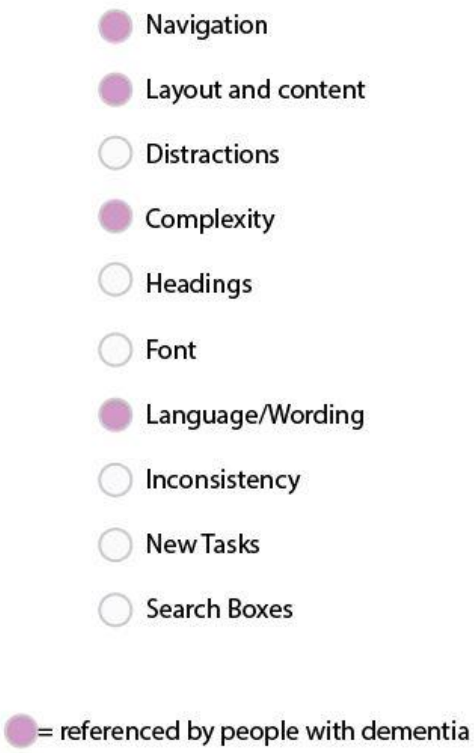


Figure 22 - Difficulties with Website Use: All Participants

People with dementia referred to considerably fewer difficulties than older adults without dementia. This could be due to how they experience fewer difficulties due to the types of web content that they use, or could reflect that they are less insightful about their Internet usage.

These difficulties were identified within data from interview questions prior to the introduction of ‘navigation difficulties’ and thus were not influenced or biased. These results supported the selected direction of the remaining interview schedule which focused primarily on navigation of websites. It was acknowledged that some difficulties could influence, or be influenced by the ability to navigate a website. For this reason, all elements of design that were mentioned as difficulties were analysed with regard to navigation; these design elements are shown in Figure 23, where those mentioned by people with dementia are depicted in purple.

● Layout and content
● Headings
● Inconsistency
○ Distractions
● Language/Wording
○ Complexity
○ Search Boxes
○ Font
○ Search Strategy
○ New Tasks
● Colour
○ Icons
○ Images/Pictures

●= referenced by people with dementia

Figure 23 – Design Elements Affecting Navigation: All Participants

People with dementia referenced one design element that they felt affected their navigation around websites that older adults without dementia did not refer to: colour.

Each of the design elements related to the ability to navigate web content, in an enabling or limiting way, are discussed within the four concepts:

- Unknown Structure (section 6.4.2.1)
- Distraction (section 6.4.2.2)
- Too Much/Too Many (section 6.4.2.3)
- Search Strategy Preference (section 6.4.2.4).

Other design elements that were found to contribute to navigational difficulty or success to a lesser extent are discussed in Section 6.4.2.5.

The results within each navigational difficulty concept are discussed in relation to literature in Section 6.4.2.6.

6.4.2.1 Unknown Structure

Participants encountered difficulty with navigation if they were faced with new tasks on sites not previously visited, or if the content or layout had changed throughout a previously visited website; or even on a single page of such a site, as this presented the issue of inconsistency.

Having options to choose from along the side of a page to navigate the site structure, or chunking information into smaller sections of content were said to support navigation, but participants repeatedly mentioned that "*getting back*" was a key issue for them. Due to this, participants often returned to the beginning of a task, sometimes by returning to a search engine rather than moving back through the pages of the site they had visited. This could result in tasks taking more time, participants experiencing frustration, and ultimately result in task, or site, abandonment. People with dementia also expressed difficulty with inconsistency in the layout of websites and throughout pages of a website, as they can become a difficulty for users who cannot understand (or perhaps, learn) how to navigate around a different design or structure. PWD1, when discussing using his banking website said:

> *PWD1: I can get onto it. But the, the big snag is, they keep changing the format, and I get lost.*

This issue was heavily emphasised by PWD1, but was also referred to by OAwoD3, 8 & 9. An example of how these inconsistencies can cause navigation difficulties was described:

> *OAwoD3: I think what I have found is that if you use it twice, it doesn't always appear to take you through the same route.*
> *Interviewer: Right, and how does that make it to use?*
> *OAwoD3: It makes it tricky to backtrack*

Participants expressed reduced confidence when needing to navigate a new interface, due to previous experiences of becoming lost, for example:

> *Interviewer: And what if you were going to use a new website, would you feel confident using that?*
> *OAwoD6: No, not really if it was something new.*
> *Interviewer: And why is that?*

> *OAwoD6: Well, like that fitness pal, I wasn't finding my way around that very well.*

Both people with dementia and older adults without dementia expressed navigational difficulty when encountering new, or 'unknown structures', due to unexpected or inconsistent layout and content.

6.4.2.2 Distraction

Distractions in various forms can impede navigation, both temporarily, which can result in longer task completion times, and more permanently, if a participant is distracted to the extent that the focus of the task is lost/forgotten, and thus the task gets abandoned. Images and moving, or flashing, content such as videos or adverts were specified by older adults without dementia and people with dementia as being particularly distracting:

> *OAwoD2: Yes, I mean I find this quite confusing, I find I get drawn into the pictures rather than into what I'm actually looking for. I get distracted by the pictures.*

> *OAwoD2: … there's so much going on and it's whizzing past your eyes very quickly, that you forget what you were looking for in the first place.*

Distraction was also observed in 2 people with dementia, where static content besides the main focus of the page caught their attention, and resulted in navigation to irrelevant site areas during the assigned task, resulting in the task goal being forgotten. Unrelated content that does not aid the understanding of the main focus of a page can be of particular distraction. For example, images mislead participants to think a page was not relevant, as they were a distraction from focusing on the desired content. Therefore, participants discounted relevant pages and this prevented successful navigation:

> *OAwoD4: Yes, but when I saw this [picture] I thought it was just for children and clicked off it.*

The results demonstrated that both people with dementia and older adults without dementia can become distracted by both dynamic and static content, particularly where the layout resulted in distracting content being located near the area of focus of the main page content.

6.4.2.3 Too Much/Too Many

Websites that require users to select from ‘too many’ options, or locate web content within a page with ‘too much’ content can be difficult to navigate. Headings, menu options, and general quantity of content presented can all be contributing features to this navigational difficulty.

Participants identified difficulties with complex structures of sites containing ‘too much’ content, and ‘too many’ options to choose from, or decisions to make to navigate the structure. These difficulties resulted in participants not being able to uncover information that was “buried” in the site or having difficulty knowing where to go next:

> *OAwoD3: I guess the issues were knowing where to get to where you need to go next, or where to find the next level of information that it was I wanted?*
> *Interviewer: And why was that? Could you pinpoint what the problem was?*
> *OAwoD3: I think that the information you wanted was buried in so much other information that it tended to get lost in the wood.*

> *OAwoD5: I looked at something the night before last – and it was so complicated. It wasn’t easy to focus for what I was looking for; it was all over the place.*

> *OAwoD5: For me they’re giving me too many options. For if I say I want just one of those, I’ve got to read through all three to find out what they’re offering me and find out which is the nearest.*

Having “too much” content on a webpage, or “too many” options to choose from or decisions to make on any one page can contribute to this issue, and can cause difficulties for users with reduced concentration:

> *OAwoD5: The elements are too much words, too much to read. If I wanted to find out further, I could carry on further, but I was only*

> *asking it a very simple question – where to get my flu jab, and it gave me much more information than I needed.*

> *PWD3: Yes, it's not easy to find what I wanted.*
> *Interviewer: And what was the reason for that?*
> *PWD3: Urm, such a variety of information on there*
> *Interviewer: And do you mean by that the amount of information on there, or the amount of different types of information?*
> *PWD3: Lots of categories I suppose, yes.*

There were conflicting opinions regarding preferences for having a deep or shallow site structure; PWD4 expressed that he felt frustrated if there were "too many" levels to navigate through, whilst OAwoD3 & 6 expressed they would rather have many levels to navigate through, with fewer options to choose from on each level. This raises questions regarding whether there is an optimal site structure that can support successful navigation for users with and without dementia, and whether this is reflected within current Web content accessibility guidance, ISO/IEC40500:2012.

Having many options to choose from, and thus requiring good memory and decision making abilities can present difficulties navigating a site structure for both people with dementia and older adults without dementia. Similarly, having vast amounts of content within a complex page or site can present navigational difficulty, due to the need to determine relevant content without becoming distracted or fatigued. The key finding within the results for this navigational difficulty concept is that both people with dementia and older adults without dementia require simplicity to support successful web content navigation.

6.4.2.4 Search Strategy Preference

Participants employed different strategies when searching for information within a web page or site, with some preferring to follow menu hierarchies, and others opting to use a search box. However, older adults without dementia and people with dementia expressed positive opinions of using a search engine such as Google to locate a particular item of information that they may be searching for, rather than identifying an appropriate site and searching within that using headings or search-boxes; they would use key words from that site and search with them using Google:

> *OAwoD7: …if I couldn't find what I wanted, then I would break it down and I would go back to Google and put it in broken down again.*

> *PWD1: Well, what I do is go onto Google and type it in, and it generally comes up and gives you a list of what you need.*

It would appear that both groups saw limitations to the in-site navigation options, such as difficulties with language used for headings, and viewed search engines as an alternative search strategy. Websites need to provide appropriate features that support and enable users to navigate within the site itself; this raises questions regarding how these features could be improved to facilitate this, and how current guidance (ISO/IEC40500:2012) may address this issue.

Frustration was expressed by OAwoD4, in relation to search boxes not always knowing what he was searching for:

> *OAwoD4: I mean sometimes it don't have a clue what I'm talking about, but I'll just keep going until something comes up which is in line and then I know what to go for.*

Observations suggest that some of the difficulties this participant was facing was due to inaccurate input by the user (e.g. spelling error), though this highlights that the search box functionality does not allow for such circumstances, or have the capability to support the user to succeed.

Another frustration expressed by OAwoD9 was that search boxes can return only slightly relevant, or part-matched results to what she had inputted:

> *OAwoD9: it would be nicer if you could – if you search on NHS, it brings up 2, 167, all with this one word in it, or this bit of one word, like most of them do. You know, that's what gets me about Google and things like that. I want to find out about the flu jab, not a word with F L U in it or J A B in it, I want to find – is this? … Search boxes – yes I like search boxes, however I like the*

> *information to come up that I'm searching for. Not something that I'm not searching for.*

Whilst older adults without dementia expressed quite negative thoughts about the weaknesses of search boxes, 3 of the 4 participants with dementia expressed a preference for using the search boxes rather than navigating through hierarchical heading structures:

> *PWD2: I think the search thing is wonderful on the Internet. Urm, yeah, I'd nearly always go to the search thing. In fact, as soon as I saw the search bar, I didn't even see this bit here that says vaccinations – there's a whole bar about vaccinations –.*

> *PWD3: [the search bar] appeals as it strikes me as being straight forward. I mean it's wide open to you know, to put some sort of subject I'm interested in.*

People with dementia could not explicitly explain their reasoning for this preference when asked, but it can be contemplated that this could be due to the reduced concentration and comprehension required to input into a search box rather than browse and navigate through levels of headings to locate the information that they are searching for. The effects that dementia may have on the ability of a person with dementia to navigate web content using either strategy require further exploration.

6.4.2.5 Navigational Difficulties: Other Design Elements

Other design elements that can support or hinder successful navigation to a lesser extent than the four developed navigational difficulty concepts include: headings, language/wording, font, colour, and icons.

Headings used within a website can aid navigation between pages, and within a single page when used as sub-headings. Sub-headings, when used to separate blocks of text can facilitate more efficient and successful navigation, particularly where an alternative font, size and colour are used to distinguish these headings from the main text:

> *OAwoD4: Well, I might flick through it and see if there were details [sub-headings] on there that referred to me. Are you with me?*

> *Interviewer: Yes –*
> *OAwoD4: So I'd have seen this bit [coloured sub-heading] and thought that's not me, and carried on until I got to the older adult bit.*

> *PWD4: Urm, I think the headings stood out, like the flu jab, and having different colours for headings. And you can easily scroll down it and find the next headings to the one to you want.*

Colour as an aid to navigation was mentioned by both older adults without dementia and people with dementia:

> *OAwoD5: I think the headings stood out, like the flu jab, and having different colours for headings. And you can easily scroll down it and find the next heading to the one you want.*

The size of text used in both headings and content can affect navigation:

> *OAwoD8: The things, the little bits at the top, the 'contact' and that could be a little bit bigger- because the picture stands out, probably to the detriment to the smaller things which you want I think for this, perhaps a smaller picture would have been better … and things like that [headings and text-based content] to be a little bigger.*

Another example of font-size presenting an issue was observed when the size of the typeface used for breadcrumbs was too small, meaning that OAwoD8 was unaware of their presence, and thus did not utilise the feature. OAwoD2 also referred to the typeface being very important, specifying that Arial was the font that she found simplest and most straight forward to understand.

Participants also highlighted the importance of suitable language being used within headings as unclear or ambiguous language/terminology could cause difficulties:

> *OAwoD1: So, this is here. It's about dementia, 'what is dementia' so I know I can click onto any of those and I know what I'm going to get. Sometimes you click and then think, that's not what I wanted – it didn't seem to sound like that.*

OAwoD1 said that they would explore different heading options to try and find an appropriate one, whilst OAwoD9 said that unclear terminology would result in them beginning their search from the beginning again, to see if they had missed an appropriate option. This could not only extend the time to complete a task, but could increase frustration and thus the likelihood for site abandonment.

Icons may also cause navigational difficulty. For example, icons within the browser menu were not understood by OAwoD5 & OAwoD8, which reduced the navigation options within the browser, and other icons were not always understood by participants:

> *OAwoD8: Icons are fine, if they tell you what they are first – because not everyone knows what they all are.*

There was mixed knowledge about the meaning of commonly used icons. For example, social media links were not always understood, but the shopping basket icon was identified successfully. Unlabelled or unrecognisable icons may cause difficulty, as they may not communicate what the web content designer intended.

These elements will be considered for accessibility and usability of web content in Chapter 7.

6.4.2.6 Navigation Difficulty Concepts

Focused coding was used to develop the four concepts to represent the prominent types of navigation difficulties discussed in the previous sub-sections. Each navigation difficulty concept from the results is shown in Figure 24 and will be discussed with reference to literature.

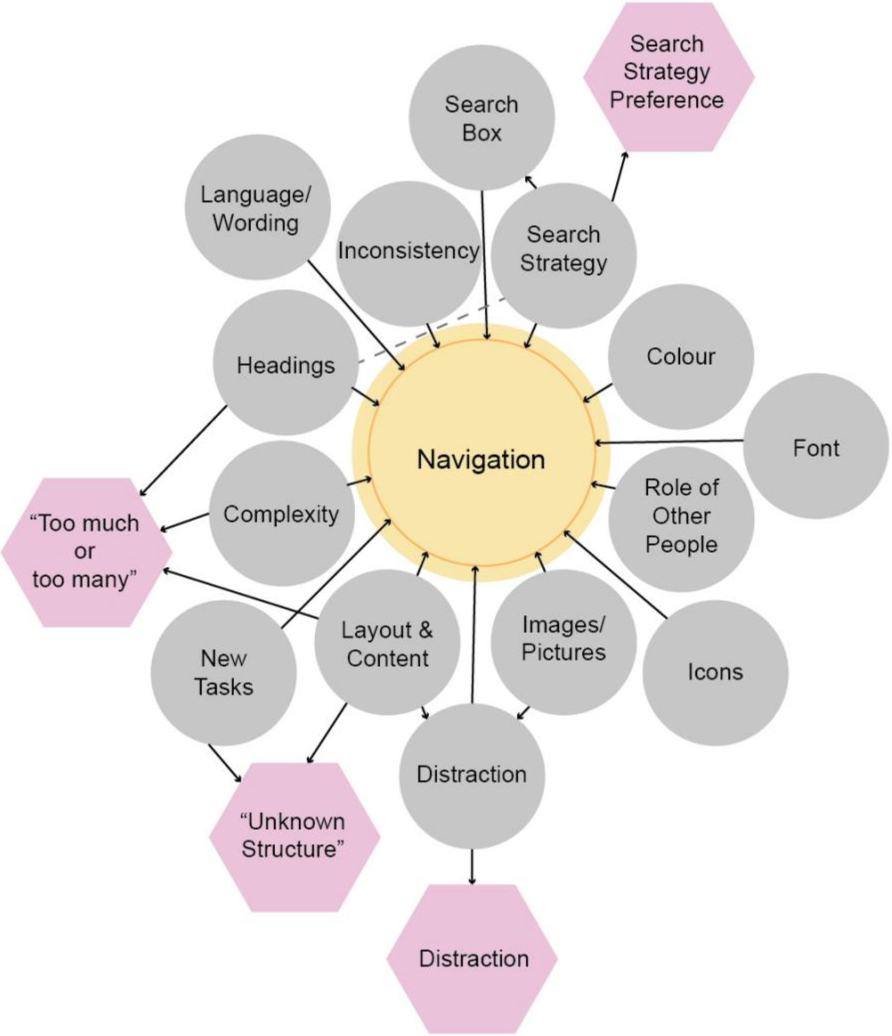


Figure 24 - Navigational Difficulties Concepts

6.4.2.6.1 "Unknown Structure"

Web-users can get lost within web content if they are unsure how to navigate the structure or hierarchical levels of a website (Wagner, Hassanein and Head, 2014). Attempting new tasks on new sites can cause additional difficulties, as users may be faced with a new structure or layout which is dissimilar to other sites they have previously used and are confident navigating; inconsistency between web pages and sites can exacerbate this issue. Participants expressed great reliance on browser 'back' buttons to try and locate themselves within a website again, suggesting that they did not understand the underlying structure of websites or how they may be able to navigate them.

This has been reported for older adults becoming confused about their location within the context of a site structure (Chadwick-Dias, Mcnulty and Tullis, 2003; Wagner, Hassanein and Head, 2014; Castilla *et al.*, 2016). Less familiar, non-linear navigation structures can reduce comprehension of older users, and being faced with re-structured or changed layouts/structures can result in information overload (Arch, 2009) and navigational issues leading to potential abandonment (Burmeister, 2010). Negative user experience can be caused by these difficulties.

Similar issues relating to unknown structures were identified in Chapter 4. People with dementia were reported to experience difficulty if pages in a website were not structured similarly (Freeman *et al.*, 2005; De Sant'Anna *et al.*, 2010). Providing clear affordances to help people with dementia know implicitly what to do was recommended by Mayer & Zach (2013). Hierarchical structures that allow bi-directional navigation recommended by Sarne-Fleischmann et al. (2011) to support people with dementia navigating 'back' as participants in this study expressed difficulty in doing within web interfaces.

6.4.2.6.2 "Distraction"

Distractions can interrupt web navigation by temporarily distracting the user, causing the activity to take longer, or losing focus of the end goal. This can impede usability and accessibility of web content respectively. Elements that were specified by participants included: moving content including adverts and moving images, and static content including images, and other content on the same page that draws undue attention, due to positioning, or use of colour.

Distractions due to adverts and moving content are recognised issues for older adults (Redish and Chisnell, 2004; Arch, 2009; Rodrigues, de Mattos Fortes and Freire, 2016). In addition, being faced with lots of choices can cause distraction as users may be attracted to irrelevant content (Redish and Chisnell, 2004; Rodrigues, de Mattos Fortes and Freire, 2016) and the requirement to scroll endlessly, or to open new windows can also cause distractions (Rodrigues, de Mattos Fortes and Freire, 2016). Redish and Chisnell (2004, p28) also highlighted that users may 'forget what they meant to do' if they are distracted, and may then face difficulty in getting back to the point they digressed from.

Many features have been found to be distracting to people with dementia (as reported in Chapter 4): the placement of icons (Sarne-Fleischmann *et al.*, 2011; Boyd *et al.*, 2014), bold colours, animations, or other competing stimuli (Sarne-Fleischmann *et al.*, 2011). These elements are similar to those identified by both people with dementia and older adults without dementia within this study, highlighting another similarity in the experiences of older users with and without dementia.

6.4.2.6.3 "Too Much/Too Many"

Demand on users to choose from 'too many' options, or focusing on an element on a page that has 'too much' other content on it can impede successful navigation of web content. Features that participants mentioned in relation to the concept of 'too much or too many' included: headings, content, and options presented to the user.

Information overload on a webpage, in the form of 'too much' information or clutter (Redish and Chisnell, 2004; Laberge and Scialfa, 2005; Arch, 2009; Romano Bergstrom, Olmsted-Hawala and Jans, 2013; Rodrigues, de Mattos Fortes and Freire, 2016) or too many choices to make (Redish and Chisnell, 2004; Chevalier, Dommes and Martins, 2012), can result in reduced navigational performance by older adults, due to difficulties in understanding, distraction or feeling overwhelmed.

Many studies report that efforts to reduce cognitive load for people with dementia should be made, by providing minimal options within a web page and menus within web interfaces, and requiring minimal numbers of steps to achieve a goal (Freeman *et al.*, 2005; Savitch and Zaphiris, 2005; Sarne-Fleischmann *et al.*, 2011; Mayer and Zach, 2013; Boman *et al.*, 2014; Astell *et al.*, 2016; Hattink *et al.*, 2016). The findings of this study, also highlighted that demanding too much of users cognitively can result in accessibility or usability issues.

6.4.2.6.4 “Search Strategy Preferences”

Some web-users have a distinct preference for the strategy they employ when navigating web content, both through singular pages and a site of multiple pages. People with dementia in particular are drawn to using search boxes where they are available. Difficulties with navigation arise if the features that facilitate these strategies do not function correctly, or in the way that the user would expect them to.

Whilst Coyne and Nielsen (2002, cited in Redish and Chisnell 2004) found that using a search function within a website gave older adults a sense of control, no other references to user search strategy preferences have been found in literature. Redish and Chisnell (2004) highlighted that the use of headings can make content more skimmable, and reduce working memory demands, which in turn supports more successful navigation, yet the focus in literature is on how site structure can support searching and navigation for users. Linear navigation is optimal for older adults (Castilla *et al.*, 2016), with shallow, or ‘flat’ structures being preferred (Burmeister, 2010) as deeper hierarchical structures can result in older adults getting disorientated or lost (Redish and Chisnell, 2004). Whilst this preference was not found in this study, it could be related to the search strategy preferences, as difficulties with the depth of site structures may result in some users adapting their strategy to locate information within a site.

6.4.2.7 Navigation Difficulties: Causes of Ageing and Dementia

Understanding the underlying causes of difficulties faced by web users can enable the issues to be addressed when developing guidance. For this reason, the changes in abilities due to natural ageing, and those due to dementia are discussed in sections 6.4.2.7.1 and 6.4.2.7.2 respectively.

6.4.2.7.1 Ageing Changes

There are functional requirements arising from ageing-related sensory and physical impairments, such as deterioration of vision requiring larger text, that need to be addressed to enable basic access to web content for older adults. Romano Bergstrom, Olmsted-Hawala, and Bergstrom (2016) also identified that older adults may not seek information in the peripheral of a page, as they experience reduced useful field of vision, and thus may not see it. However, other ageing-related impairments may impact web accessibility or usability, and result in older adults experiencing significantly more usability issues than younger adults (Chadwick-Dias, Mcnulty and Tullis, 2003) and thus having poorer search performance too, when websites present poor ergonomic design (Chevalier, Dommes and Martins, 2012). These other impairments are cognitive in nature, and cognitive load has been described as the most significant obstacle for older adults (Castilla *et al.*, 2016).

Cognitive skills that decline with the ageing process include processing speed, working memory and spatial perception (Redish and Chisnell, 2004; Burmeister, 2010; de Lara *et al.*, 2010; Chevalier, Dommes and Martins, 2012; Lynch, Schwerha and Johanson, 2013; Wagner, Hassanein and Head, 2014). Working memory *'involves the active manipulation, storage and updating of information to perform a given task'* (Salthouse 1990, 1994, cited in Laberge and Scialfa 2005). Navigation of planning and executing routes through sites on the Web appear to place significant demands on this type of memory (Laberge and Scialfa, 2005). Decision making and problem-solving also form part of navigation and also require working memory (Charness 1985, cited in Laberge and Scialfa 2005). Spatial ability refers to 'the capacity to acquire, manipulate and use information presented in two- and three-dimensional space' (Laberge and Scialfa, 2005). These abilities help people navigate virtual environments by enabling the creation of cognitive maps, or mental models (Laberge and Scialfa, 2005). Reduced attention span is also observed in older adults (Redish and Chisnell, 2004; Wagner, Hassanein and Head, 2014), which explains why older adults may be prone to distraction by design elements of a web page. The reduced skills in these cognitive functions are considered to be the cause of many of the navigational difficulties that older adults encounter and cause usability issues for them. Guidance for accessible and usable web interfaces for older adults often relates to reducing cognitive load, or demand on these impaired cognitive functions. For example, a flat site structure may reduce cognitive load (Burmeister, 2010), using headings can lower demands on working memory as well as assisting visual searching (Redish and Chisnell, 2004) and minimising the amount of choices to be made by reducing website complexity can minimise spatial, processing and working memory demands for older adults (Laberge and Scialfa, 2005; Chevalier, Dommes and Martins, 2012).

It is evident that ageing-related cognitive decline and impairment can negatively impact the ability of older adults to use a website; designs that do not cater for older users can reduce the level of usability for this user group (Johnson and Kent, 2007). Lynch, Schwerha, and Johanson (2013) highlighted within their analysis of the impact of ageing-related impairments on web accessibility and usability that whilst cognitive function decline is typical among older populations, even more severe memory-related problems can occur as a result of dementia.

6.4.2.7.2 Dementia Changes

Whilst the initial analysis of this study data would suggest the types of difficulties encountered by both user types are the same, there remains a question regarding the impact that cognitive impairments experienced by people with dementia may have on their ability to use websites, and how symptoms may exacerbate the difficulties encountered by older adults without dementia.

A narrative literature review explored which cognitive abilities are required for successful navigation, and compared the effects that natural ageing changes and pathological changes of dementia can have on these abilities (see Appendix L). Seven abilities were identified as contributing to spatial navigation ability within web content:

- Memory
- Cognitive Map Formation
- Attention/Concentration
- Perception
- Situational Awareness
- Reading/Comprehension, and
- Reasoning/Decision Making.

The relationships between these abilities are depicted in Figure 25, showing how decline in some abilities would directly cause a decline in other abilities – for example, impaired memory would result in reduced abilities with cognitive map formation.

Older adults without dementia were reported to experience a decline in five of the seven identified abilities due to natural ageing changes: Memory, Cognitive Map Formation, Attention/Concentration, Perception, and Situational Awareness (Figure 25).

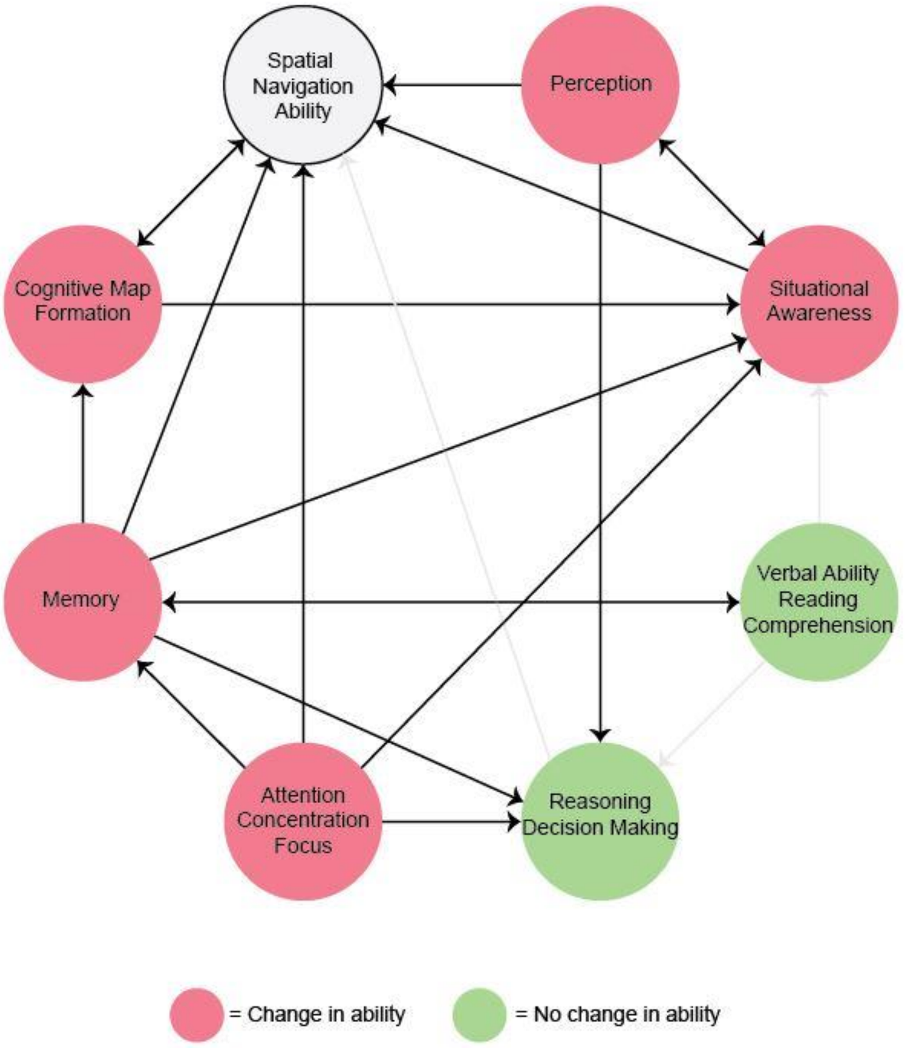


Figure 25 - Changes in Abilities for Older Adults without Dementia

People with dementia are reported to experience a decline in all seven of the abilities that affect spatial navigation, and to a greater extent than older adults without dementia in five abilities: Memory, Attention/Concentration, Perception, Reading/Comprehension, and Reasoning/Decision Making. No literature was found on the level of impairment for Cognitive Map Formation or Situational Awareness.

It can be concluded that people with dementia as a broad group of web users would be expected to experience greater difficulties with web navigation.

6.4.2.7.3 Additional Difficulties due to Dementia Changes

All four concepts are expected to be experienced to a greater extent by people with dementia. Figure 26 shows the relationships between navigational difficulty concepts and cognitive abilities; the abilities experienced with greater impairment by people with dementia than older adults without dementia are depicted in red.

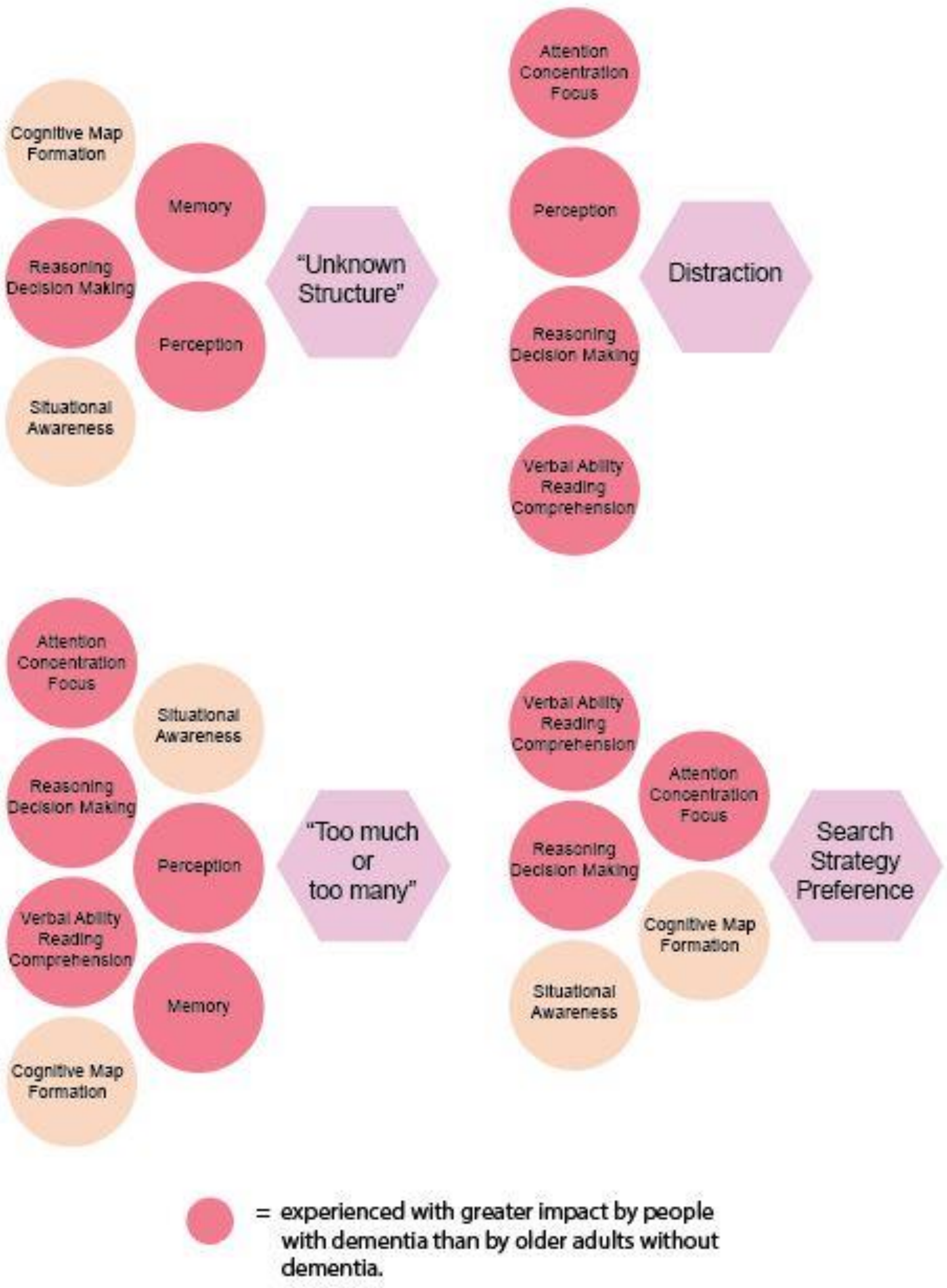


Figure 26 - Cognitive Abilities by Navigational Difficulty Concept

Whilst dementia may not cause different types of web use difficulties, the extent to which these are experienced may be worse for people with dementia. Usability issues for older adults without dementia may potentially become a more significant accessibility barrier which prevents use of web content by people with dementia, as they may not have the cognitive resources to overcome these barriers. Quesenbery (2009) inferred that cognitive disabilities can amplify mild usability annoyances experienced by users with full cognitive function into absolute barriers; it is this that needs to be contemplated with regard to the accessibility and usability of Web content for people with dementia, and whether established accessibility standards meet the nuanced requirements of people with dementia.

The relationship between accessibility and usability, with regard to current standards for their implementation in Web content needs to be considered before specific accessibility issues can be identified for people with dementia. Accessibility, usability, and their respective standards for web content are discussed in Chapter 7 (Section 7.2).

6.4.3 Participant and Carer Feedback on Process

Feedback given from participants and carers on the methods and process of this study is detailed in Table 17. Key developments for the study design included the direct use of participants' own terminology use to ensure understanding of field-specific terminology, and the provision of a written appointment for the interview time, with a future recommendation to use the dementia-inclusive consent documentation for carers and older adults without dementia too.

The inclusion of participant and carer reflection on the method and approach taken to the inclusion of people with dementia in research enabled direct reflective practice to be conducted by the researcher. As a result, improvements have been made to the practice of data collection with people with dementia as the study has progressed, with additional knowledge being gathered for future studies involving people with dementia (see Chapter 9). This element of the research method and process has supported the ethical and inclusive approach intended for this study.

Table 17 - Participant Feedback on Process and Resultant Changes to Method

Participant	Comment/Feedback	Reflective Change to Practice

PWD1/ CPWD1	Positive feedback received regarding researcher’s ability to respond to participant anxiety. Also positive feedback from person with dementia about the courtesy call given as it aided as a reminder.	No change required. Researcher continued to make courtesy calls ahead of arrival.
PWD2/ CPWD2	Carer highlighted that some participants may not understand field-specific terminology, such as ‘navigate’. Person with dementia expressed annoyance as he believed the researcher arrived early, despite the researcher arriving on time. This confusion was resolved by the participant checking the email the researcher had sent when scheduling the interview, which enabled the interview to proceed,	Researcher noted down during the interview the terminology the participant was using to reference the Internet/websites/navigation etc. and used these same terms in the phrasing of questions to ensure that the participant understood what was being asked. Researcher ensured that a written scheduling of interview time was provided to participants (via email or letter) to avoid potential confusion with future participants.
PWD3/ CPWD3	Carer gave positive feedback on researcher’s sensitivity to participant’s apparent distress and spoke well with the participant with dementia.	No change required.
PWD4/ CPWD4	Carer and Person with dementia commented positively about the location of the interview, highlighting that the requirement of travelling to an alternative location would have caused anxiety, and that if other people were present, the participant would have felt judged by others for his answers or abilities. Carer gave positive feedback on how dementia-friendly the consent form was that the person with dementia used, but expressed that	No change required. In future studies involving people with dementia, further requests to use the

	she too would have liked to have been provided the same form, as this does not ‘single out’ the person with dementia. Once aware of the difference in document being provided, the person with dementia expressed that he felt it was inappropriate and discouraging to be given a different form to his partner.	same format for consent documentation may be sent to the University ethics committee, on the grounds of equal access to, and treatment in research.

6.5 Limitations

The findings of this study must be interpreted within the context of the small participant sample; depth of investigation was achieved with the few people with dementia recruited, rather than a broad exploration which may be achieved with greater participant numbers.

The researcher presence has been accounted for during analysis, as it is likely to have influenced the participants’ experience during the web use task. Participant and carer feedback provided insight into the effects of this.

Additionally, due to the coding process used, whereby just one researcher coded the data, and a second researcher did not also conduct this process to enable comparison of coding, the reliability of the analysis approach is a limitation of the study.

6.6 Conclusions

This chapter has compared the experiences of older adults without dementia and people with dementia using web interfaces, to provide insights into attitudes and difficulties:

- Difficulties experienced by both older adults without dementia and people with dementia when using web content can negatively affect user attitudes, user experience and future engagement with the Web.
- Navigation is a key issue for both older adults without dementia and people with dementia, with a range of web content design elements contributing to these difficulties. Four concepts of navigational difficulty types were developed:

    - Unknown Structures
    - Distractions
    - “Too much” or “Too many”, and
    - Search Strategy Preferences.
- The types of issues encountered by people with dementia appear to be the same as those experienced by older adults without dementia. What remains unclear is the extent to which these difficulties may impact web accessibility for people with dementia. It is proposed that the increased impairments of cognitive abilities required for navigation experienced by people with dementia may exacerbate the usability issues experienced by older adults without dementia into accessibility issues for people with dementia. Therefore, the relationship between usability and accessibility must be explored to establish the impact that difficulties have on web use for people with dementia, and how this is reflected in accessibility and usability guidance.

Chapter 7 will investigate which navigational difficulties are encountered as accessibility issues by people with dementia, and thus should be addressed within web accessibility guidance (ISO/IEC40500:2012).

Chapter 7. Study 3- Web Accessibility for People with Dementia: Difficulties and Standards

7.1 Introduction

This chapter presents a study to address and further explore the conclusions of Study 2 (Section 6.6): it was found that people with dementia experience the same difficulties in using the Web as older adults without dementia, but proposed that people with dementia may experience these issues as greater obstacles to web use as their decline in cognitive abilities exacerbate the difficulties. The results of Study 2 were explored to determine whether these were experienced as accessibility or usability issues for people with dementia in Section 7.4.

The distinctions and similarities of, and relationship between usability and accessibility are explored in Section 7.2. This informed the study interview schedule and provided a framework of relevant standards and guidance with which study data were analysed.

This chapter addresses the second research question, by analysing current web content accessibility guidance, using the data from Study 3, to determine where current guidance needs improvements to inclusively address the needs of people with dementia with a range of cognitive impairments (section 7.5).

7.2 Accessibility and Usability

Relevant guidance within current standards for web content accessibility and usability were assessed for inclusivity of the needs of people with dementia.

7.2.1 Definitions, Overlap and Distinctions

Accessibility, at the most basic level, is *'…about people being able to access and use a product; the fundamental point is to be able to use a product at all'* (Henry, 2002). Henry, Abou-Zahra, and White (2016) state that accessibility includes:

- Requirements that are technical and relate to the underlying code rather than to the visual appearance.
- Requirements that relate to user interaction and visual design – these are classed as accessibility requirements because they can be significant barriers to people with impairments.

Usability, means *'…designing a user interface that is effective, efficient, and satisfying*' (Henry, 2002). In the context of usability, accessibility means designing an interface to be usable for more people in more situations – including those with disabilities. However, not as concerned with ensuring satisfaction of users, accessibility is more concerned with ensuring that interfaces are perceivable, operable and understandable (Henry, 2002).

It is difficult to distinguish between accessibility and usability, as many design aspects that are good for general usability are also required for accessibility. In essence, '*what is nice to have for some people is required by other people to be able to use [the product]*' (Henry, 2002). For example, consistent navigation is good for usability, but particularly important for accessibility. An inconsistent navigation style throughout a website may be a minor inconvenience for those with full sight who can scan a page to find an item location, but may pose accessibility barriers for users reliant on screen reading technology, or even for those without working memory to cope with these inconsistencies.

Despite the overlap, it is highlighted by Henry (2002), that when defining accessibility standards and guidelines, it can be essential to consider the distinction between accessibility and usability. The following definitions show the distinction between a usability problem and an accessibility problem:

- **Usability** problems impact all users equally, regardless of ability. That is, a person with a disability is not disadvantaged to a greater extent by usability issues than a person without a disability.
- **Accessibility** problems decrease access to a product by people with disabilities. When a person with a disability is at a disadvantage relative to a person without a disability *that* is an accessibility issue.

(Henry, 2002)

7.2.2 Ensuring Accessibility and Usability

If accessibility is approached by web designers as a checklist of meeting standards, '*the focus is only on the technical aspects of accessibility, and the human interaction aspect is often lost'* (Henry, Abou-Zahra and White, 2016). The Web Accessibility Initiative of the W3C recommended that accessibility standards are used alongside usability processes that involve real people, to ensure that web design is technically and functionally usable by people with disabilities (Henry, Abou-Zahra and White, 2016); this is referred to as **usable accessibility**. However, usability processes alone cannot address all accessibility issues, so accessibility guidelines, standards and techniques are used to ensure that the wide range of issues are adequately covered. For this reason, it is imperative that accessibility standards consider aspects of usability which may present as accessibility barriers to some users; this is particularly true for more complex user groups, such as people with dementia, who may not typically be included within usability processes, due to ethical complications.

Accessibility for users with cognitive disabilities can be a far greater challenge than other disabilities (Mariger, 2006). There is still much to be understood about the accessibility requirements of users with cognitive impairment, if appropriate guidelines are to be developed (Arch and Abou-Zhara 2008). Section 7.2.3 discusses current accessibility and usability standards, to highlight where the accessibility requirements of people with dementia may be both directly and indirectly addressed.

7.2.3 Standards

7.2.3.1 Accessibility Standards: ISO/IEC 40500:2012

ISO/IEC 40500:2012, '*Information technology- W3C Web Content Accessibility Guidelines (WCAG) 2.0'* (International Standards Organisation, 2012), - *from here on referred to as 'ISO/IEC 40500:2012*' - is a standard for increased accessibility to web content for people with disabilities. Originally developed by the World Wide Web Consortium (W3C), the twelve guidelines address the challenges that people with disabilities may face – including vision impairments, deafness and hearing loss, learning disabilities, cognitive limitations, and physical movement limitations. It is widely used internationally, with many governments and organisations adopting it as a legal requirement for web content of certain types (e.g. the UK requires all governmental sites to be compliant to the standard – to AA conformance level).

The guidelines in the standard are organised under four principles (perceivable, operable, understandable, and robust), and each has testable success criteria (61 total). Each criteria has an assigned 'conformance level', which reflects the impact on accessibility and accommodates different situations that may require or allow greater levels of accessibility than others (W3C, 2016b). The conformance levels are A, AA and AAA, which reflect minimum level of accessibility (A), an enhanced level of accessibility (AA) and additional enhancements for accessibility (AAA). The W3C also developed techniques for the guidelines that support web content authors to meet the guidelines and success criteria.

The W3C (2008) state that although the guidelines cover a wide range of issues, they are '*not able to address the needs of people with all types, degrees and combinations of disability'*, and acknowledged that even with AAA conformance, content will not be accessible to all individuals, particularly in cognitive areas. This suggests that the accessibility requirements of people with dementia may not be fully addressed in these guidelines. The acknowledged limitations, or gaps, in these guidelines regarding cognitive accessibility could be because the distinction between usability and accessibility is particularly difficult to define for cognitive (and language) disabilities (Henry, 2002). This is further blurred by the fact that functionality for people with disabilities generally benefit people without disabilities in terms of usability (ibid, 2002). For this reason, usability standards are discussed in Section 7.2.3.2 to identify where such potential cognitive accessibility requirements may be reflected within other standards.

7.2.3.2 Usability Standards: ISO 9241-151:2008

ISO 9241-151:2008, 'Ergonomics of human-system interaction – Part 151: Guidance on World Wide Web user interfaces' (British Standards Institute, 2008a) - *from here on referred to as 'ISO 9241-151:2008*' -provides guidance on the human-centred design of web user interfaces with the aim of increasing usability. The recommendations focus on aspects of the design of web user interfaces: high-level design strategy; content design; navigation and search; and content presentation. Some guidance is recognised as being important for accessibility of web interfaces, but this standard does not aim to cover accessibility in a comprehensive manner.

Each recommendation of ISO 9241-151:2008 is intended to be evaluated for its applicability, and to be implemented if deemed applicable. In relation to the difficulties encountered by people with dementia and older adults without dementia, where navigation was identified as a key barrier to successful use of web interfaces, the '*navigation and search*' section of this standard may be of particular relevance. Whilst these guidelines were developed for usability, some of the guidelines are important for accessibility. The same may apply for other usability-related guidelines. For example, Schniederman's 8 Golden Rules of Interface Design which are primarily concerned with issues of usability (Shneiderman *et al.*, 2016), yet rules such as '*reduce short-term memory load'* may be relevant to accessibility for people with dementia.

7.2.4 Difficulties of People with Dementia – Relevant Standards

Guidelines within accessibility and usability standards for web content design were mapped onto the four navigational difficulty concepts developed in Study 2 (discussed in Section 6.4.2.6). Accessibility guidance in ISO/IEC40500:2012 (International Standards Organisation, 2012) and usability guidance in ISO9241-151:2008 (British Standards Institute, 2008a) were assessed for relevance to each concept.

Table 18 shows which concepts, related difficulties, and cognitive abilities are referenced by guidelines within each standard.

Table 18 - Relevant guidelines within Accessibility and Usability Standards

		ISO/IEC40500: 2012	**ISO9241-151:2008**
Unknown Structure	Cognitive Map Formation	2.4.8; 3.2.1; 3.2.2; 3.2.3; 3.2.4	8.2.2; 8.3.8; 8.4.2; 8.4.5; 8.4.6; 8.4.8; 8.4.10; 8.4.12; 9.3.2; 9.3.3
	Reasoning/Decision Making	2.4.6	8.3.8; 8.4.6
	Situational Awareness	2.4.8; 3.2.1; 3.2.2; 3.2.3	8.2.2; 8.3.5; 8.3.6; 8.3.8; 8.4.2; 8.4.6; 8.4.11; 8.4.12
	Memory	2.4.6	
	Perception	3.2.2	8.3.8
	Layout and Content	2.4.8	8.2.2; 8.3.8; 8.4.2; 8.4.6
	Inconsistency	3.2.3; 3.2.4;	8.4.5; 9.3.2; 9.3.3

	Search Box		
Distraction	Attention/Concentration/Focus	2.2.4	7.2.3.1; 7.2.3.3; 8.3.10; 8.3.11
	Perception		7.2.3.1; 7.2.3.3
	Reasoning/Decision Making		
	Verbal Ability/Reading/Comprehension		7.2.3.1
	Images/Pictures		7.2.3.1
	Layout and Content		
	Colour		
	Icons		
	Language/Wording		
“ Too much or too many”	Attention/Concentration/Focus	2.4.1	9.6.3
	Reasoning/Decision Making	2.4.2	8.2.5; 8.3.3; 8.3.8; 9.6.3
	Verbal Ability/Reading/Comprehension	2.4.1; 2.4.2	8.2.5; 8.4.14; 9.3.6; 9.3.17; 9.4.15; 9.6.3
	Cognitive Map Formation	2.4.10	8.2.5; 8.3.8; 8.4.2
	Situational Awareness	2.4.10	8.3.8; 8.4.2
	Perception		8.3.3; 8.3.8
	Memory	2.4.2	8.3.3
	Layout and Content	2.4.1	8.3.8; 8.4.14; 9.3.6; 9.3.17; 9.4.15
	Headings	2.4.2; 2.4.10	8.2.5; 8.3.3; 8.3.8; 8.4.2
	Complexity		8.2.5; 8.3.3; 8.4.2; 9.6.3
	Colour		
	Images/Pictures		
	Icons		

When comparing the volume of relevant guidelines for navigational difficulties, considerably more references are made within usability guidance (ISO 9241-151:2008) than within accessibility guidance (ISO/IEC 40500:2012). This suggests that usability guidance holds potential to address the issues faced by people with dementia when using the web content, and thus could form the basis for recommendations for improvements to the inclusivity of accessibility guidance, if these difficulties are experienced as accessibility issues by people with dementia.

One navigational difficulty concept is addressed by ISO/IEC 40500:2012 already – Search Strategy Preference. Guideline 2.4.5 states:

> *Multiple Ways: More than one way is available to locate a Web page within a set of Web pages except where the Web Page is the result of, or a step in, a process (Level AA).*

There is a need to identify which issues within each of the remaining navigational difficulty concepts are experienced by people with dementia as accessibility issues and thus need to be addressed within accessibility guidance. This is explored and reported in Section 7.3.

7.3 Interview Study

7.3.1 Aims and Objectives

This study aimed to explore which difficulties faced by people with dementia when using web content are experienced as accessibility issues and/or usability issues, and to assess the inclusivity of ISO/IEC 40500:2012 in relation to the accessibility requirements of people with dementia.

Objectives

- To list further difficulties encountered by people with dementia when using the Web, identified through interview
- To identify which difficulties faced by people with dementia cause accessibility issues for people with dementia
- To assess current guidelines within web accessibility standard ISO/IEC 40500:2012 for its inclusivity of people with dementia's accessibility requirements.

7.3.2 Study Method and Process

Data were collected with an interview (Section 7.3.3), formed of questions to be answered purely verbally, and questions which were accompanied with rating scales to aid the participant to answer the related question (Section 7.3.3.1). Interviews were conducted in one session, at the participants' homes. As in Study 2, there was an opportunity following the interviews, for people with dementia and their carers to give feedback on the study procedure with regard to its suitability for use with people with dementia (Section 7.3.3.2).

7.3.3 Interview

As in Study 2, whilst the interviews followed some high level structure, they were conducted in an informal, conversational manner and thus, the phrasing and order of the questions sometimes varied. Interviews began with contextual questions related to both Internet use and dementia diagnosis and symptoms, before continuing to core questions regarding web navigation and the extent to which a range of difficulties affected web navigation (Table 19). The phase of the questions in the interview stages is described in Chapter 5 (Section 5.3.1.3.1). The full interview schedule including prepared prompts and rationale for the question being included is provided in Appendix M.

As identified in Section 7.2.4, ISO/IEC 40500:2012 addresses the difficulty concept 'Search Strategy Preference'. For this reason, this concept was excluded from this study, enabling the focus to remain on those difficulties faced that are not fully addressed in current accessibility guidance.

Table 19 - Interview Questions Schedule

Question	**Question Phase**
What do you usually do on the Internet?	**Opening Questions** *(Contextual, background and general questions leading to the core interview questions)*
Have you used the Internet differently since being diagnosed with dementia? If yes, how has this changed?	
It is important for us to understand as much as we can about your experience of using the Internet as someone with a dementia diagnosis – would you be able to tell us which type of dementia you have been diagnosed with? [and when?]	
Could you tell us about any symptoms of dementia that you experience? - Could you tell us whether any of them change the way you use the Internet?	
There are some abilities in particular which dementia is known to change over time, which we are particularly interested in. Could you please show us on this scale, how much each of	

these abilities have changed for you?	
Now I’d like to ask more about your use of the Internet. Do you usually use the Internet independently? - *How has this changed?*	
Could you indicate on this scale how confident you are when using the Internet to do something new? [ask Why] - *How has this changed?*	
Could you indicate on this scale how easy you find the Internet to use? - *How has this changed?* - *Which difficulties have you experienced?*	
Could you indicate on this scale how easy you find it to navigate around websites to find what you want to? *[how has this changed? Which difficulties have you encountered?]*	**Core Questions** *(Moving from the general question to more specific)*
Other people have told me about some specific issues they have experienced which made navigating Websites difficult for them. Could you please tell me which of these you too have experienced, and how much of a problem they have caused for you, by placing them on this scale?	
Is there anything else you would like to add to what you have told me about how you experience using the Internet?	**Debrief Question**

7.3.3.1 Rating Scales

Participants were asked to answer some questions using rating scales (Figure 27, with all scales included in Appendix M).

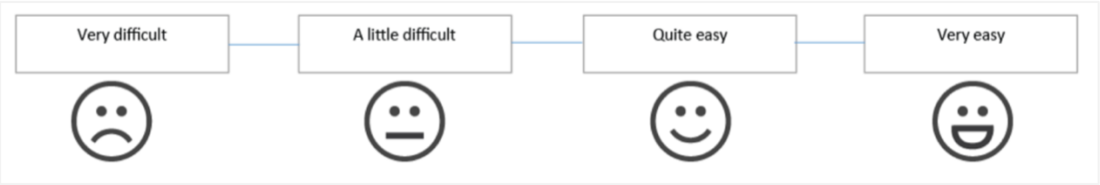


Figure 27 - Example of Rating Scale

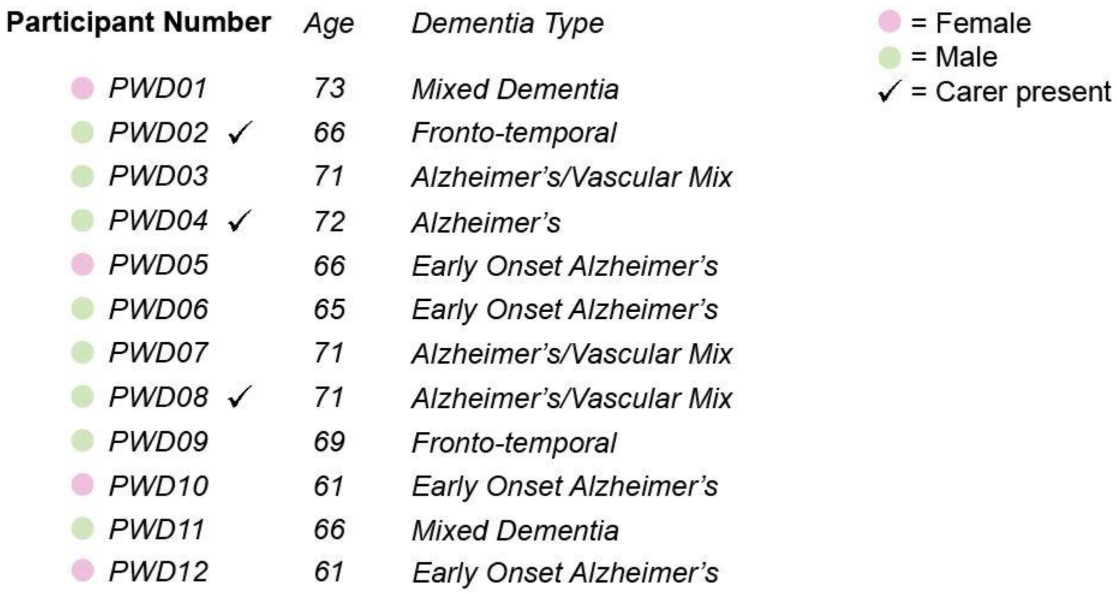
The scales were designed similarly to the consent form, where text was presented with icons to aid comprehension and simplify the questioning process; particularly for the scale on which participants placed a high number of difficulty cards. This only required the rating scale options to be explained once, saving time and cognitive effort for the participant.

7.3.3.2 Participant and Carer Feedback

Following the completion of the interviews participants (and their carers) were invited to give feedback on the study. This feedback was considered using reflective practice, and enabled the study procedure to be developed to be as dementia-inclusive as possible (section 7.4.5).

7.3.4 Participant Sample

Twelve people with dementia participated, with three accompanied by carers. Participant ages ranged from 61 to 72 years, and varied in both gender and dementia diagnosis (Figure 28).



Participant Number	*Age*	*Dementia Type*
🟣 *PWD01*	*73*	*Mixed Dementia*
🟢 *PWD02* ✓	*66*	*Fronto-temporal*
🟢 *PWD03*	*71*	*Alzheimer's/Vascular Mix*
🟢 *PWD04* ✓	*72*	*Alzheimer's*
🟣 *PWD05*	*66*	*Early Onset Alzheimer's*
🟢 *PWD06*	*65*	*Early Onset Alzheimer's*
🟢 *PWD07*	*71*	*Alzheimer's/Vascular Mix*
🟢 *PWD08* ✓	*71*	*Alzheimer's/Vascular Mix*
🟢 *PWD09*	*69*	*Fronto-temporal*
🟣 *PWD10*	*61*	*Early Onset Alzheimer's*
🟢 *PWD11*	*66*	*Mixed Dementia*
🟣 *PWD12*	*61*	*Early Onset Alzheimer's*

🟣 = Female
🟢 = Male
✓ = Carer present

Figure 28 - Participant Details

7.4 Results and Discussion

Data were analysed using GT techniques (as described in Section 5.3.2.1). The results are grouped into three themes:

- Difficulties (Section 7.4.1)
- Accessibility issues (Section 7.4.3)

- Key accessibility issues to be addressed in standards (Section 7.4.4)

Findings highlighted navigation as the key difficulty type for people with dementia, with specific difficulties reflecting those encompassed by the concepts developed in Chapter 6 (Section 6.4.2.6), supporting the conclusions of Study 2. Findings also included additional difficulties faced by people with dementia in relation to the concept of distraction. These were included when findings were prioritised to develop a list of navigational difficulties that need to be addressed for people with dementia, and considered when analysing the inclusivity of the needs of people with dementia within ISO/IEC 40500:2012 (Section 7.5).

7.4.1 Difficulties Faced

People with dementia were asked to identify difficulties that they face when using the Internet, prior to the focus of navigation being introduced. The difficulties identified fitted within the concepts developed in Study 2.

'Too much/too many':

> *PWD01: Too much choice is not a good thing … I can't go to the shops because I'm overwhelmed by the variety and the choice, it's too much, so the same with websites, they have to be limited in the choice that I've got.*

> *PWD02: Yeah, when all the information piles up like this – keeping on top of all the written info and things is getting a bit more difficult … it's just too much information to take in.*

> *PWD06: it's getting more difficult now because I think they're making web pages more difficult now because they're trying to put so much extra into them which complicates it. I just want what I want, I want to go in and think 'that's what I want' and that doesn't work!*

> *PWD04: I forget, urm, how to do things easily these days. It's more of a problem now trying to remember things, passwords and what to do … yeah I can never remember passwords now.*

Difficulties related to the **'unknown structure'** concept:

> *PWD10: Especially when they change. "Our new and improved website…" is an absolute nightmare! You know, because I've just got used to your old, wonderful website!*

> *PWD04: I'm thinking where, how do I get back? Don't I? Or if that's the back arrow, yeah and I didn't have to think about that before … that's the problem, I'm actually having to think about it, about where things are now, and it starts me panicking I suppose.*

PWD10 commented on how the difficulties with using the Web occurred once the website had been identified, suggesting that web content design is important:

> *PWD10: I'm very confident to start with and it depends how good, what I'm trying to find, how good they've designed their website … I can find them no problem. But then it's, you know, what you're met with that makes or breaks whether you can continue or not.*

Table 20 shows the ratings given by participants for the Ease of Internet Use and the Ease of Navigating Web content, which supported navigation as the key issue of web accessibility for people with dementia.

Table 20 - Internet Use and Web Navigation Ratings

Participant	**Ease of Internet Use Rating**	**Ease of Web Navigation Rating**
PWD01	Very Easy	Varied
PWD02	Quite Easy	A Little Difficult
PWD03	Quite Easy	A Little Difficult
PWD04	Quite Easy	Varied
PWD05	Quite Easy	Quite Easy
PWD06	A little difficult	Varied
PWD07	Quite Easy	Quite Easy
PWD08	Quite Easy	Unassigned
PWD09	Very Easy	Quite Easy

PWD10	Very Easy	Varied
PWD11	Very Easy	Varied
PWD12	Quite Easy	Varied

Three participants gave a poorer rating for ease of navigation than ease of Internet use, with six noting that ease of navigation could not be rated easily due to the variance in ease of navigation due to web design:

> *PWD06: Well, as I said, there's some very easy to navigate you know, which just have a little arrow which takes you to the next page of what you want and there are some which are not so easy, which I mean the online banking used to be easy but it's become very complicated for me now…*
> *PWD12: It's tricky [to answer] because if it's a site you use daily, like I go on Amazon probably every day to look for something, that would be like very easy, but if I went on a new site, like if someone recommended a site to me and then I go on it, that would be very difficult, yeah.*

Participants expressed an awareness of the link between their dementia progression and ability to use the Internet, and thus the difficulties they encounter using web content:

> *PWD06: Oh yeah, I mean I would have done that in my sleep, I mean I've noticed it's got every few months it gets less and less easy to use, you know, it just gets more complicated –*

> *PWD12: Oh, definitely I'm slower and I can get confused, but I try and most sites are okay, but you do get the odd site that is not very user friendly and you have trouble trying to find anything -*

These results support the conclusions of Study 2; navigation is the key issue for people with dementia using the Internet.

7.4.2 Accessibility or Usability?

Participants categorised difficulties they encounter when accessing and using web content on a scale which reflected the differences between accessibility and usability within current relevant guidance and standards (see Appendix

N). The terms accessibility and usability were not directly used with participants, but these concepts underpinned the options on the scale provided to participants for categorisation of difficulties (see Figure 29).

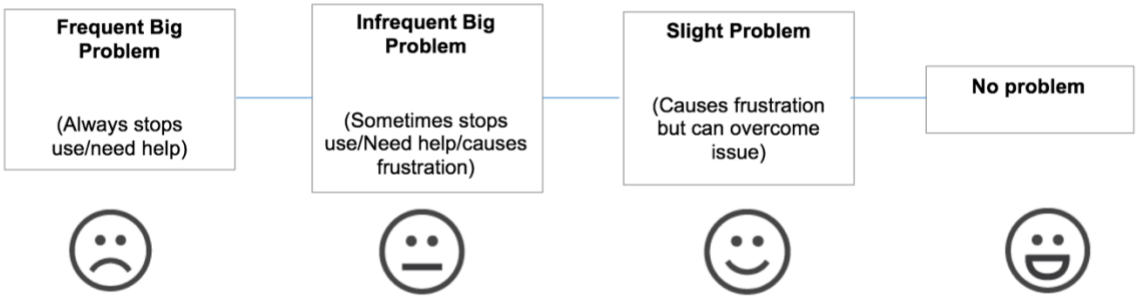


Figure 29 - Categorisation Scale for Web Use Difficulties

People with dementia with poorer ratings of Ease of Web Navigation categorised a higher number of difficulties as being accessibility issues, with people with dementiawho rated Ease of Web Navigation more positively identifying fewer accessibility issues, some usability issues and categorising many difficulty cards as ‘no problem’ (see Table 21).

Table 21 - Issues by Ease of Web Navigation Ratings

Ease of Web Navigation Rating	Accessibility	Usability	No Problem
Very difficult	0	0	0
A little difficult	**17**	11	10
Quite easy	8	**11**	**38**
Very easy	0	0	0
Varied	**92**	19	9

Participants giving a ‘varied’ response to the Ease of Web Navigation question categorised more difficulties as being accessibility than usability issues (Table 21). This suggests that those participants may have encountered a wide range of difficulties navigating Web content, but rated the Ease of Web Navigation as varied as they have also used websites with well designed content.

A further finding was between participants' self-reported level of cognitive impairments, and the number of accessibility issues that they encounter that affect their navigation of web content. People with dementia reporting minor, moderate or major impairments to fewer of the navigational abilities required for successful navigation categorised fewer difficulties as being accessibility issues. In contrast, people with dementia reporting changes to more of the abilities required for successful navigation, categorised more of the difficulties as accessibility issues. This suggests that people with dementia experience increasing accessibility issues as cognitive abilities decline. The importance of this finding is that participants had encountered a great number of accessibility issues, despite being in the early stages of dementia, and so require support to use web content independently; this needs to be reflected in web accessibility guidance.

Additions were made to the difficulty cards, where people with dementia expressed difficulties they had encountered that were not represented within the original card set. These included:

- Distraction by flashing content
- Distraction by pop-up windows
- Distraction by unexpected sounds, and
- Distraction by automatic re-directing.

The additional cards were included for categorisation as the study continued. Figure 30 shows the full range of difficulty cards that were used within this study. Difficulty cards depicted in grey were informed by both data from Study 2 and literature, those depicted in pink by literature alone, and those in blue were added during this study to represent the new data.

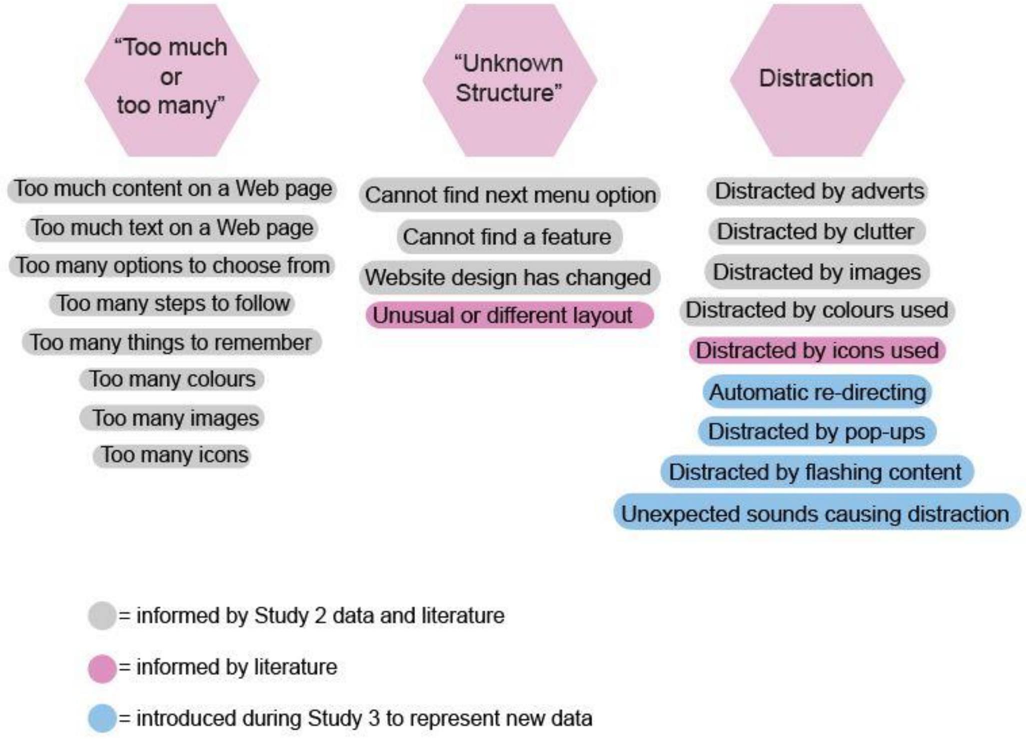


Figure 30 - Difficulty cards used within this study

Difficulty cards were often categorised as accessibility issues by people with dementia, evidenced by 123 counts of being categorised as accessibility issues (68 Frequent, 55 Infrequent). Forty-five counts of usability issues were categorised by people with dementia, with 71 counts of difficulty cards being categorised as 'no problem' by participants. Reflecting the individual nature of dementia, web users, and personalities of the participants, there was variance in the categorisation each difficulty card was given by each participant. However, commonalities across participants are present within the data.

The majority of the difficulty cards under each navigational difficulty concept were mostly categorised as accessibility issues by the participants in this sample. Difficulty cards mostly categorised as 'no problem' by participants included:

- distraction by colours
- distraction by icons
- distraction by images

- too many colours, and
- too many images.

Those difficulties categorised as ‘no problem’ were categorised as such by participants reporting less impairment of the related abilities to those difficulties, including visual perception, and the ability to concentrate and focus. Whilst some of the difficulties primarily categorised as ‘no problem’ can be explained by assessing the level of reported impairment of related abilities, there is an element of personal preference which would account for some of these specific difficulties. Examples of this would be the difficulty cards ‘too many images’ and ‘distracted by images’. Participants made comments to demonstrate the role that personal preferences can play in whether an element of web content design creates an accessibility or usability issue:

> *PWD04: They’re okay, I was just thinking then, it does distract me sometimes, rather than concentrating on what I’ve gone in for, I tend to look, because I like looking at – I was keen, well I still am keen on photography, so I like looking at pictures.*

> *PWD08: Yes, well I’m interested in pictures myself, so I suppose it’s logical that I should be okay with it.*

Difficulty cards categorised as ‘no problem’ by the majority were all categorised as accessibility issues by at least two other people with dementia. This could be due to the individual nature of the presentation of dementia symptoms, as those people with dementia who categorised these difficulties as accessibility issues had reported themselves to have impairments in the abilities linked with those specific difficulties. For example, the difficulty card ‘distracted by icons’ had been linked with the cognitive ability ‘concentration/focus/attention’. Participants who categorised this particular difficulty as an accessibility issue (PWD02, PWD06) had also reported having significant/major changes in their ability to concentrate/focus.

As the majority of difficulty cards were categorised primarily by people with dementia as accessibility issues, this supports the need for these difficulties to be considered for inclusion within accessibility guidance. The following sections provide supporting data for each of the difficulties categorised primarily as accessibility issues by participants; the difficulties are discussed within their respective navigational difficulty concepts (Sections 7.4.3.1, 7.4.3.2, & 7.4.3.3).

7.4.3 Accessibility Issues

The difficulties presenting as accessibility issues for the people with dementia in the participant sample are grouped into navigational difficulty concepts (Sections 7.4.3.1 - 7.4.3.3).

7.4.3.1 'Distraction' Difficulties

Difficulties related to distraction all have potential to cause people with dementia to forget their goal, or their become confused about their position within a navigational route or process. Navigational difficulties related to the concept of 'distraction' included:

- Automatic re-directing
- Distraction by adverts
- Distraction by flashing content
- Distraction by clutter
- Distraction by pop-up windows, and
- Distraction by unexpected sounds.

Automatic re-directing from one web page to another can create difficulties as it can distract users and interfere with their understanding of their position within a website, and thus prevent successful navigation to web content:

> *PWD01: What I find really bad is that you happen to – when you're using your finger as the cursor and you just happen to hesitate somewhere, hover over something and it takes you there and you don't want to go there! … It's infuriating, as then you can't find your way back sometimes.*

Adverts can cause distraction, particularly if they include moving content or automatically play audio:

> *PWD01: The ones that sort of jump around all the time, or they start their videos, that’s the worse one, you just happen to touch it and it starts its wretched video and you think ‘oh for goodness sake’!*

As with moving content of some adverts, any content that moves, or ‘flashes’ can cause distraction from the intended interaction:

> *PWD01: …flashing lights are a disaster, whatever the cause of them, which is why the moving adverts are no good. Flashing lights is like at Christmas, flashing lights, anyone with dementia hates them.*

> *PWD10: Again it’s just the visual image … it’s the static-ness, if things are moving then your brain gets jumbled.*

Clutter, in the form of unrelated text or image based content surrounding the main content focus, can also cause distraction:

> *PWD11: Oh God, yes. Especially newspapers, oh you know how they do it … you get all these things down the right saying, well the Daily Mail is usually about some sort of celebrity, in the [local newspaper] it’s everything you should know about reclaiming housing benefit or something.*

Pop-up windows can cause distraction by attracting attention, but users are also aware that if they interact with such windows, their expected navigational route may be changed and cause further difficulties:

> *PWD10: Oh, yeah I don’t like pop-ups because then I don’t know what to do with them, yeah, urm, and I often worry if I click on something that it is going to take me to somewhere else, so I prefer pop-ups not to appear. Unless it’s giving me information. I like the little ‘I’ information next to something where you can just hover over something and it’ll come up with a little box telling you what it means, that’s good, but not a pop-up window.*

Unexpected sounds, whether they be within adverts, upon the arrival of a pop-up window, or other automatically playing content on a web page, can cause distraction:

> *PWD11: Oh I have, I always have it on silent … because for me, noise is the one thing that's been affected for me. Noise.*

All of the difficulties related to the navigational concept of distraction would be expected to worsen for people with dementia with impaired focus/concentration/attention, and can contribute to both temporary and complete navigational failure. Once a person with dementia has become distracted, they may not be able to remember the route they had followed, and may even be so distracted that they forget their intended web use goal.

7.4.3.2 'Too Much/Too Many' Difficulties

Having 'too much' content, or 'too many' options to choose from, or decisions to make, creates demands of a range of cognitive abilities. This can overwhelm people with dementia, and may impede their ability to understand a navigational structure, or to remember their location. These difficulties included:

- Too many icons
- Too many options to choose from
- Too many steps to follow
- Too many things to remember
- Too much content, and
- Too much text.

Too many icons can cause an issue not only with the amount of content needing to be absorbed by people with dementia, but unfamiliar icons can demand additional comprehension and understanding which can complicate navigation if interacting with them is required:

> *PWD06: Yeah, yes they put too many things, too many things trying to get you to go to another part and you click the wrong part and you end up around the world somewhere!*

> *PWD10: Yes, having too much of anything is difficult, simple websites are the best ones.*

Having too many options to choose from can cause people with dementia to become overwhelmed and thus unable to make a decision. This can affect navigational success when such decisions between many options are required in order to proceed to the next navigational step:

> *PWD01: It has to be two, or three possibly, but not more than that.*

> *PWD04: I like things simple now, I can't cope with a lot.*

Too many steps to follow can cause people with dementia to feel overwhelmed and demand too much of their memory and attention. Following 'too many' steps could result in people with dementia feeling lost within a navigational structure of a website:

> *PWD05: Yeah, where you're going through a website and having to go here, there and everywhere! Yeah I get cross with that and go [calls husband's name], 'help!'*

Requiring people with dementia to remember information in order to access or navigate web content is problematic for people with dementia, who express particular difficulty with passwords, reflecting how impaired memory can directly affect web accessibility:

> *PWD02: That's probably got worse quite recently. Urm, we've got permanent issues with passwords, we've got them all written down but we forget to update that –*

> *PWD10: Yeah, oh passwords are a nightmare! … I changed my iPad recently and of course most of my passwords disappeared – And I was like 'Oh my God, what do I do?', so so many I had to say 'no, forgotten password, forgotten password, forgotten username, forgotten password' and anything that I had to remember was just gone.*

As with clutter causing a distraction (section 7.4.3.1), having too much content on a web page can cause distraction from the intended task and potentially cause people with dementia difficulty in returning to their original navigational route to accessing the desired information:

> *PWD01: If there's too much of anything, it's a disaster … it needs to be simple.*

> *PWD06: Urm, yeah you want to go in and find what you want, if you've got too much there it just distracts and takes you away from your train of thought of what you want and then you're, you might start, see something else on there, and then you've forgotten what you went on there for in the first place.*

Participants also highlighted the additional consideration of content presentation, including font size, when the quantity of content is increased, which can cause additional accessibility issues:

> *PWD11: Yeah, that's definitely a problem because if there's too much content it's almost certainly going to be in small writing as well, and you just, it's like being confronted with a page of printed text without paragraphs, you just give up, yeah.*

People with dementia express difficulty in navigating to desired web content if they are required to read 'too much' text in order to do so:

> *PWD03: If there's too much and they want you to read it all, yes.*

> *PWD06: Yeah, urm, it depends on the font as well. Sometimes it's too small so even with your glasses you're like this [squinting] so you'll have to make it big on the screen and then you'll have to touch something that'll take you out of the website and you just think 'oh no'.*

> *PWD12: If you go onto a page that's just full of text and paragraphs of text, that can be quite confusing and tiring, whereas if it's broken up with other bits it does help.*

All of the difficulties related to the navigational concept of 'too much/too many' would be expected to worsen for people with dementiawith reduced focus/attention/concentration, reduced reasoning/decision making abilities, as well as impaired short-term/working memory. These difficulties can contribute to distraction, in addition to feelings of becoming overwhelmed or indecision. Having ‘too much/too many’ of any web content element can result in a website becoming too complex for people with dementia to navigate successfully.

7.4.3.3 ‘Unknown Structure’ Difficulties

Difficulties in understanding new structures of unfamiliar websites can cause significant navigational difficulties for people with dementia. This suggests that people with dementia may rely on their expectations of web structures and the general cognitive map of web layouts they may have built from previous web use. This applies to specific details of new structures, such as the placement of expected features, and to overall layout of navigational structures. Navigational difficulties related to the concept of ‘unknown structure’, that were experienced by people with dementia as accessibility issues included:

- Cannot find a feature
- Unusual or different layout
- Website design changed since previous visit, and
- Cannot find the next menu option.

People with dementia, as with many user types, have expectations on where certain features will be on a website that will enable them to navigate content, such as search boxes. Not being able to locate an expected feature in its expected location can cause navigational difficulties:

> *PWD06: Yeah because they sometimes put it in stupid little places, or have a little ‘press x’ and you can’t find them [about search boxes]*

> *PWD10: Urm, so I’d simply abandon that site and go on another one!*

In the same way that needing to locate a feature in an unexpected location can cause difficulty, if the layout of a web page or website is unfamiliar, or different to the traditional website layout, people with dementia are required to learn how to interact with and navigate around a new structure, which can be problematic:

> *PWD03: Yeah that'd be a, a big, yeah, it can throw you off and think 'oh I can't be bothered', I've adopted that policy now … I'll just come out of it.*
> *PWD04: If it's urm, I wouldn't even, even it was there I probably wouldn't see it if you know what I mean, because I'm not used to it … if it's not where you think it would be, yeah.*

> *PWD11: Absolutely, yes. I mean I looked at one yesterday and I can't remember what it was for now but it was just big pictures. No text, other than the title of the place it was, or I can't actually remember what it was for, but you had to click on them to go further. Stupid.*

As with the difficulties in navigating an unusual website layout, if a familiar website changes its layout or structure, people with dementia can experience this as though needing to learn how to use a new website, which can be a navigational issue:

> *PWD01: Yes that happened with Barclays and it was horrendous. They completely changed everything so I stopped using them and they contacted me and asked why I wasn't using them, so I told them it was impossible to use –*

> *PWD10:. "Our new and improved website…" is an absolute nightmare! You know, because I've just got used to your old, wonderful website!*

When following menu hierarchies to navigate a website, difficulties with identifying the most appropriate menu option to select can cause issues with navigation. The difficulty occurs when users try to return to their previous position, having selected an inappropriate menu option, which can confuse their understanding of their current position in the whole website structure:

> *PWD03: Yeah, you think you've found the right thing, but then clearly you haven't and then so sometimes you go back and it takes you out of the site altogether….*

> *PWD12: … you have trouble trying to find anything in the menu that relates to what you're looking for, so you have to try and think outside the box and think 'what would they call it?'*

The difficulties related to the navigational concepts of ‘unknown structure’ would be expected to worsen for people with dementia with reduced perception, and impaired short-term/working memory. These difficulties are particularly evident in web content design that deviates from traditional layouts, or when people with dementia are required to interact with web content, layouts, or navigational structures that are new to them – or even appear new to them if previous visits have been forgotten. These difficulties can result in total navigational failure if people with dementia are unable to understand or learn the structure of a website.

7.4.3.4 Accessibility Issues: The Literature

Many of the accessibility issues identified by people with dementia are also recognised as difficulties within literature (Chapter 4). Whilst it is not always clarified in literature whether these difficulties are presented as usability or accessibility issues, the study data supports that such difficulties can become accessibility barriers in terms of web navigation. Difficulties found to be accessibility issues within this study that are recognised in literature include:

- Distracted by flashing content (Sarne-Fleischmann *et al.*, 2011)
- Distracted by clutter (Freeman *et al.*, 2005; Sarne-Fleischmann *et al.*, 2011; Hattink *et al.*, 2016)
- Too many icons (Freeman *et al.*, 2005)
- Too many options to choose from (Freeman *et al.*, 2005; Sarne-Fleischmann *et al.*, 2011)
- Too many steps to follow (Boman *et al.*, 2014; Hattink *et al.*, 2016)
- Too much content (Freeman *et al.*, 2005; Hattink *et al.*, 2016)
- Unusual or different layout (Freeman *et al.*, 2005; Savitch and Zaphiris, 2005; De Sant’Anna *et al.*, 2010)
- Cannot find next menu option (Savitch and Zaphiris, 2005).

The following accessibility issues identified by participants are not found to be referenced within relevant literature:

- Automatic re-directing

- Distraction by adverts
- Distraction by pop-ups
- Distraction by unexpected sounds
- Too many things to remember
- Too much text
- Cannot find a feature
- Website design changed since previous visit.

Data analysis highlighted that some of the difficulties that were not found in literature to frequently cause accessibility issues for people with dementia (Table 22). This knowledge can contribute to assessing which difficulties need to be addressed within web accessibility guidance to support web use by people with dementia (Section 7.4.4).

7.4.4 Accessibility Issues to be Addressed

The majority of difficulties were categorised primarily as accessibility issues by the participant sample, and so this indicates a range need consideration in terms of Accessibility Guidance. Due to the individual nature of dementia, there is variation amongst the categorisation given for each difficulty and thus determining which issues most need to be addressed within Accessibility Guidance must be based on where the majority of the participant sample categorised difficulties to be Accessibility issues. However, it is acknowledged here that the participant sample does not represent *all* people with dementia. Therefore, the research activities from this point on are reflective of the participant sample only, and a larger scale study following the same process would be required to better represent people with dementia more broadly.

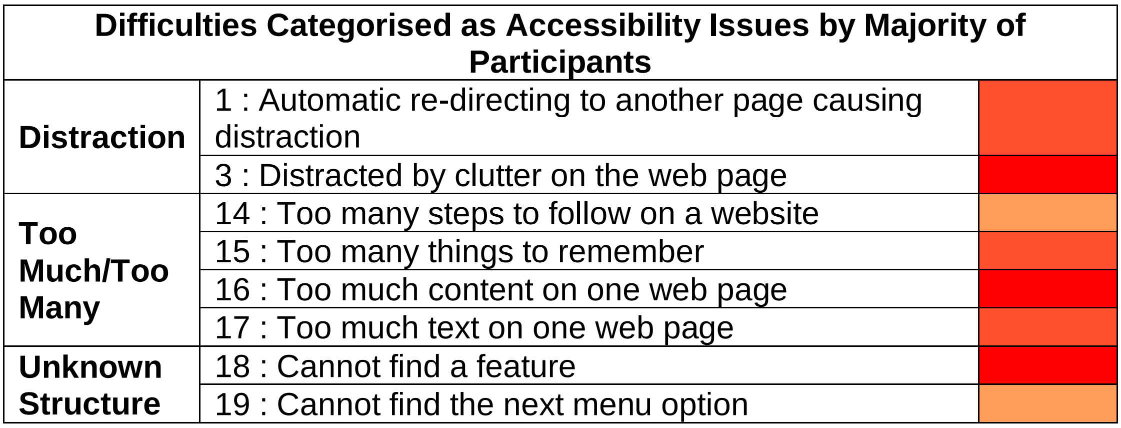
Table 22 indicates which difficulties were categorised by the majority of participants to be Accessibility issues, and thus will be included in the assessment of Web Content Accessibility Guidance in ISO/IEC 40500:2012 (International Standards Organisation, 2012).

The difficulties that will be considered within the Accessibility Guideline assessment (section 7.5) are summarised in Table 23.

Table 22 - Difficulties categorised as accessibility issues

	Categorised as Accessibility Issue
1 : Automatic re-directing to another page causing distraction	🟧
2 : Distracted by adverts	🟨
3 : Distracted by clutter on the web page	🟥
4 : Distracted by colours used on a web page	🟩
5 : Distracted by flashing content	🟨
6 : Distracted by icons on the Web page	🟩
7 : Distracted by images	🟩
8 : Distracted by pop-up windows	🟨
9 : Unexpected sounds causing distraction	🟩
10 : Too many colours	🟩
11 : Too many icons	🟨
12 : Too many images	🟩
13 : Too many options to choose from	🟨
14 : Too many steps to follow on a website	🟧
15 : Too many things to remember	🟧
16 : Too much content on one web page	🟥
17 : Too much text on one web page	🟧
18 : Cannot find a feature	🟥
19 : Cannot find the next menu option	🟧
20 : Unusual or different layout	🟨
21 : Website design has changed since previous visit	🟨

Table 23 - Difficulties to be considered in Guidance assessment



Difficulties Categorised as Accessibility Issues by Majority of Participants		
Distraction	1 : Automatic re-directing to another page causing distraction	🟧
	3 : Distracted by clutter on the web page	🟥
Too Much/Too Many	14 : Too many steps to follow on a website	🟧
	15 : Too many things to remember	🟧
	16 : Too much content on one web page	🟥
	17 : Too much text on one web page	🟧
Unknown Structure	18 : Cannot find a feature	🟥
	19 : Cannot find the next menu option	🟧

7.4.5 Feedback on Process (Carer and People with Dementia)

Participant and carer feedback on this study is tabulated in Appendix O. In response to feedback from PWD1, some alterations were made to the consent form, including pre-populating date fields, to support individuals with memory impairment. Positive feedback was received regarding this altered aspect from following participants (PWD7; PWD8). PWD8 and his carer also recommended providing the same consent document style to both participants and carers, as this would not only treat all participants equally, but be easier to use for people with and without dementia alike. This is a recommendation for future research involving people with dementia and carers (Chapter 9, Section 9.2.2).

Positive feedback was received on the use of rating scale activities to gather data. It was felt that these activities helped to focus people with dementia, in addition to providing opportunity to read the information as well as listening to it (PWD2; PWD6; PWD10; PWD12). Other participants also commented that these interactive elements helped by providing breaks from interviewing, which could potentially be too intense if data collection was solely verbal (PWD11; PWD12).

The approach taken by, and the nature of the researcher was also commented on positively by people with dementia and carers alike (PWD2; PWD3; PWD8; CPWD8); participants fed back that the nature of the researcher fostered a comfortable environment which enabled open discussion around interview topics. This contributed to feedback about positive experiences of involvement in this research (PWD3; PWD5; PWD6; PWD10; PWD11; PWD12).

Guidance based on the lessons learned through reflective practice on this participant feedback, in addition to researcher observations is detailed and discussed further in Chapter 9.

7.5 Accessibility Issues: Standards Analysis

Web Content Accessibility Guidelines standard, ISO/IEC40500:2012 (International Standards Organisation, 2012), was analysed to establish whether its current form addresses the eight specific difficulties identified as key accessibility issues by people with dementia (Table 23). It was concluded that the standard only addresses one of the 8 issues proposed as important for inclusion within web content accessibility guidance, 'Cannot find a feature' and 4 of the remaining 7 issues are partially addressed (

Table 24) :

- Automatic re-directing
- Too many steps to follow
- Too much content
- Too much text.

Table 24 – ISO/IEC40500:2012 Success Criteria that address accessibility issues

Accessibility Issue	Relevant Success Criteria in ISO/IEC40500:2012
Automatic re-directing Hovering over text (often in a menu) without clicking, or the selection of a menu link resulting in user being moved to	3.2.1 On Focus: When any component receives focus, it does not initiate a change of context (level A)

another Web page or opening another window, causes distraction, and thus has potential to cause disorientation.	3.2.5 Change on Request: Changes of context are initiated only by user request or a mechanism is available to turn off such changes (level AAA)
Too many steps to follow Processes of navigation to reach user's desired Web content that require many steps to be followed can prevent successful navigation. Aspects of difficulty of this manner include: 1. too many levels of menu options to choose from (difficulty in decision making/concentration/memory), and 2. too many steps required to reach information/content can cause problems with remembering the route back to a previously seen page.	2.4.8 Location: Information about the user's location within a set of Web pages is available (level AAA) [relates to point 2]
Too much content Web pages that contain large quantities of content and appear 'busy' can cause distraction, and a feeling of being overwhelmed. Locating desired content within a dense Web page requires skills of reasoning/decision making/concentration. This is related to 'distracted by clutter', and can result in users forgetting their intended task goal and/or becoming disoriented. Content that is not structured with navigational cues such as sub-headings require users to sift through information; an ability often impaired by dementia.	2.4.2 Page Titled: Web pages have titles that describe topic or purpose (level A) 2.4.6 Headings and Labels: Headings and labels describe topic or purpose (level AA) 2.4.10 Section Headings: Section headings are used to organise the content (level AAA)
Too much text Web content comprised of lengthy blocks of text-based content can cause inaccessibility as it requires attention/memory/reading/comprehension. Content that is split with comprehension-aiding image based content, or white spaces is more accessible as text is presented in smaller, more manageable chunks.	2.4.2 Page Titled: Web pages have titles that describe topic or purpose (level A) 2.4.6 Headings and Labels: Headings and labels describe topic or purpose (level AA) 2.4.10 Section Headings: Section headings are used to organise the content (level AAA)
Cannot find a feature If commonly found features of a website	3.2.3 Consistent Navigation: Navigational mechanisms that are repeated on multiple Web

are not located in commonly expected positions on screen (e.g. search box in top right corner; home button top left corner), this can cause inaccessibility due to users lacking abilities of perception and impaired situational awareness. Confusion and disorientation caused by this can prevent successful navigation.	pages within a set of Web pages occur in the same relative order each time they are repeated, unless a change is initiated by the user (level AA) 3.2.4 Consistent Identification: Components that have the same functionality within a set of Web pages are identified consistently (level AA)

Conforming to success criteria (SC) 3.2.1 and 3.2.5 ensures predictable functionality and gives users full control of changes to context, which partially addresses the issue of ‘automatic re-directing’. SC 3.2.5 is currently included at AAA conformance level, but for people with dementia, it is a key feature for accessibility, and it should be listed as important for these users with cognitive impairment. Additional guidance referring to the opening of new windows is required.

SC 2.4.8 addresses only part of the issue ‘too many steps to follow’ – remembering steps taken through web content to enable return to a previous page. SC 2.4.8 is listed at AAA conformance level – it is not applicable to all websites. Therefore, this should be listed as important for people with dementia specifically, to support the standard’s guidelines. Additional guidance is required to address the other part of the issue, regarding the number of steps required in a navigation task.

Conforming to SC 2.4.2 and 2.4.6 will provide structure and aid people with dementia to identify desired content without processing all other content on a page; helping people with dementia to manage websites with ‘too much content’. SC 2.4.10 cannot be included at AA conformance level as it is not always applicable, so this should be in a supporting list to the standard, as important for people with dementia, as it can aid navigation through web content. Additional guidance is required to reflect the overall need for reduced content on websites to support successful navigation for people with dementia.

SC related to ‘too much content’ also address part of the issue of ‘too much text’. Whilst these SC partially address the issue, further guidance on other presentation techniques of text-based web content is required.

SC 3.2.3 and 3.2.4 address the issue of ‘cannot find a feature’. If these success criteria are conformed to throughout a website, this accessibility issue should not be experienced by people with dementia.

The three remaining issues proposed for inclusion are not addressed within the standard:

- Distracted by clutter
- Too many things to remember
- Cannot find the next menu option.

This analysis shows that ISO/IEC40500:2012 does not completely address the accessibility issues identified by people with dementia, despite SC fully addressing one, and partially addressing four of the issues. Further guidance needs to be included to better address the accessibility requirements of people with dementia.

A further analysis of usability standard guidelines for web content will be conducted to establish whether guidance in other standards address any of the issues not currently addressed at all, or in full by ISO/IEC40500:2012. This analysis is presented in Chapter 8, where recommendations for improvements to the standard’s guidelines will be given that better address the accessibility issues identified by people with dementia.

7.6 Limitations

Whilst the number of participants in this study is greater than many related studies published within this field which often recruited between 1 and 10 people with dementia (Section 4.4), numbers were small and the findings must be interpreted in this context. In addition, the participant sample does not equally represent all types of dementia. However, as reported in Savitch and Zaphiris (2007), research of this nature presumes that the similarities are more important than the differences in symptoms.

As in Study 2 (Chapter 6) the reliability of the analysis approach is a limitation of the study, due to the coding process used, whereby just one researcher coded the data, and a second researcher did not also conduct this process to enable comparison of coding.

7.7 Conclusions

This chapter explores the difficulties faced by people with dementia when using web interfaces, and identifies which difficulties are commonly present as accessibility issues for people with dementia. The findings were used within an analysis of the current Web Content Accessibility Guidelines standard to establish the extent that the accessibility issues of people with dementia are addressed. The results support the following conclusions:

- Many navigational difficulties caused by web content design were found to be experienced as accessibility issues by people with dementia, with different diagnoses and symptoms. Other difficulties were more commonly experienced as usability issues by people with dementia and did not present accessibility barriers.
- Four of the eight key identified accessibility issues are partially addressed within the current Web Content Accessibility Guidelines standard (ISO/IEC40500:2012):
    - Automatic re-directing
    - Too many steps to follow
    - Too much content
    - Too much text
- One of the eight key identified accessibility issues is fully addressed within the current Web Content Accessibility Guidelines Standard (ISO/IEC40500:2012):
    - Cannot find a feature.
- Three of the eight key identified accessibility issues are not addressed within the current Web Content Accessibility Guidelines standard (ISO/IEC40500:2012):
    - Distracted by clutter
    - Too many things to remember

    - Cannot find the next menu option.
- Additional guidance is required within the standard (ISO/IEC40500:2012) to ensure the accessibility issues experienced by people with dementia when navigating web interfaces are fully addressed. Such guidance may be present within usability standards related to web content design, and thus these standards must be analysed for relevant content (Chapter 8).

Chapter 8. Standards Analysis: How can usability guidance contribute to improved Accessibility guidelines?

8.1 Introduction

This chapter details the analysis of software interface usability standards, to identify guidance which may address the accessibility issues experienced by people with dementia that are not currently addressed within ISO/IEC40500:2012; '*Information Technology- W3C Web Content Accessibility Guidelines (WCAG) 2.0'* (as identified in Chapter 7, Section 7.5). Relevant guidance identified within analysed standards are detailed (Section 8.3.1) and these are used to form recommendations on how these may contribute to improved inclusivity of the accessibility needs of people with dementia within ISO/IEC40500:2012 (Sections 8.3.2 & 8.4).

8.2 Selection of Standards for Analysis

ISO9241, is a multi-part series of standards that cover usability considerations related to visual display terminals and human-system interaction, and is commonly referenced within literature as the key document to reference for usability. The ISO9241 series consists of many parts covering both the hardware and software-ergonomics aspects of human-system interaction, under the general titles of '*Ergonomics requirements for office work with visual display terminals (VDTs)*' and '*Ergonomics of human-system interaction'*. The principles, recommendations and requirements given in the software-ergonomics standards help prevent users from experiencing usability problems. In addition, their application is reported to contribute to increased levels of accessibility when used within a human-centred design approach (British Standards Institute, 2018, p.5).

Part 151 of the ISO9241 series, 'Guidance on World Wide Web User Interfaces' (British Standards Institute, 2008a) was analysed first, as it focuses specifically on the interface evaluated within this research. After this analysis, the following documents listed as normative references, that are indispensable for the application of ISO9241-151:2008 were analysed, together with their superseding documents (*Note: for clarity, references are not included here, but a referenced list of included standards can be found in Appendix P)*:

- **Part 11: Usability: Definitions and concepts** (ISO9241-11:2018)
- **Part 12: Presentation of information**; *Superseded by:*
    - **Part 112: Principles for the presentation of information** (ISO9241-112:2017)
    - **Part 125: Guidance on the visual presentation of information** (ISO9241-125:2017)
- **Part 13: User guidance** (ISO9241-13:1998)
- **Part 14: Menu dialogues** (ISO9241-14:2000)
- **Part 15: Command dialogues** (ISO9241-15:1998)
- **Part 16: Direct manipulation dialogues** (ISO9241-16:1999)
- **Part 17: Form-filling dialogues**; *Superseded by:*
    - **Part 143: Forms** (ISO9241-143:2012)
- **Part 20: Accessibility guidelines for information/communication technology (ICT) equipment and services** (ISO9241-20:2008)
- **Part 110: Dialogue principles** (ISO9241-110:2006)

- **Part 303: Requirements for electronic visual displays** (ISO9241-303:2011)
- **ISO13407:1999 – Human centred design processes for interactive systems**; *Superseded by:*
    - **Part 210: Human-centred design for interactive systems** (ISO9241-210:2010)
- **ISO14915: Software ergonomics for multimedia user interfaces**
    - Part 1: Design Principles and frameworks (ISO14915-1:2002)
    - Part 2: Multimedia navigation and control (ISO14915-2:2003)
    - Part 3: Media selection and combination (ISO14915-3:2002)
- **WCAG 1.0** (Web Content Accessibility Guidelines, version 1.0)
- **WCAG 2.0** (Web Content Accessibility Guidelines, version 2.0)

Updated guidelines within the W3C (World Wide Web Consortium) recommendation for **WCAG 2.1** were also analysed (W3C, 2018c) to assess whether recent developments on guidelines which will be incorporated into future versions of ISO/IEC40500 address any of the issues experienced by people with dementia.

Two additional documents were included within this analysis, as they were identified to be relevant, and to potentially hold guidance which could address the accessibility issues at the core of this analysis:

- **ISO9241 'Part 171: Guidance on software accessibility'** was included as it contains accessibility guidance for software more broadly, beyond the scope of web content.
- **BS ISO/IEC 29138-1: 2018, 'Information Technology – User Interface – Part 1: User accessibility needs'** was included. This standard identifies a set of user accessibility needs that can be used to understand and improve the accessibility of ICT systems for diverse users in diverse contexts of use.

Whilst these additional documents focus on accessibility, rather than usability, they were included as they held accessibility focused guidance beyond that contained within ISO/IEC40500:2012.

8.3 Standards Analysis and Recommendations

8.3.1 Initial Analysis

Each of the standards listed in Section 8.2 were analysed for guidance that potentially related to any of the accessibility issues needing to be addressed in ISO/IEC40500 to better reflect the accessibility needs of people with dementia, as identified in Chapter 7 (Section 7.4.4):

- Automatic re-directing
- Distracted by clutter
- Too many steps to follow
- Too many things to remember
- Too much content
- Too much text
- Cannot find the next menu option.

Guidelines that potentially addressed these accessibility needs were not identified in every analysed standard. Those standards that were not found to contain any potentially relevant guidelines were screened out of the analysis process at this stage. Analysed documents containing duplicate guidelines (e.g. WCAG 1.0 and WCAG 2.0, as these formed the content of the more recent ISO/IEC40500:2012) were also screened out at this stage.

Table 25 presents a roadmap to all of the potentially relevant guidelines identified within the standards analysis, together with guidance previously identified from ISO/IEC40500:2012 (Chapter 7, Section 7.5). Listed by accessibility issue, Table 25 shows that the analysed standards contain numerous guidelines that potentially address the accessibility issues experienced by people with dementia that are not currently fully addressed in ISO/IEC40500:2012.

All identified guidelines are discussed in detail, in Sections 8.3.2 - 8.3.2.7, where recommendations drawn from these guidelines are detailed.

Table 25 – Roadmap of Potential Relevant Guidelines Identified in Standards Analysis

		Automatic re-directing	Distracted by clutter	Too many steps to follow	Too many things to remember	Too much content	Too much text	Cannot find the next menu option
	Chapter Section:	8.3.2.1	8.3.2.2	8.3.2.3	8.3.2.4	8.3.2.5	8.3.2.6	8.3.2.7
Standard Analysed								
ISO 9241	Part 151:2008	8.3.11		8.2.2 8.2.5		8.4.14	8.4.14 9.6.2 9.6.3	8.3.3 8.3.4
	Part 14:2000							
	Part 112:2017		6.2.2.1 6.5.2.2 6.5.2.3				6.4.5.1 6.4.5.2	6.4.3.4
	Part 125:2017		5.1.4					
	Part 20:2009				7.6.2			
	Part 110:2006					4.3.2		
	Part 171:2008			8.4.2				
	ISO29138-1:2018	6.5.21	6.5.27	6.6.20		6.5.29		6.6.8
	ISO /IEC40500:2012	3.2.1 3.2.5		2.4.8		2.4.2 2.4.6 2.4.10	2.4.2 2.4.6 2.4.10	

Note: This table is intended to provide a roadmap to the potential relevant guidelines identified only. For further detail, refer to the chapter sections indicated, where the relevancy of each guideline is discussed.

8.3.2 Detailed Analysis

Each of the potentially relevant guidelines identified within the initial analysis was considered for inclusion within ISO/IEC 40500 improvement recommendations. The relevance of the guideline in terms of how directly it addresses the accessibility need was assessed, and this consideration is shown within the rationale for the inclusion/exclusion of each guideline, reported in Tables 28 - 32. The included guidelines were used to form recommendations for improving the inclusivity of ISO/IEC 40500 with regard to the accessibility needs of people with dementia. The detailed analyses for each accessibility need are discussed in Sections 8.3.2.1 - 8.3.2.7.

8.3.2.1 Automatic re-directing

Guidelines identified to address the issue of '*automatic re-directing'* within the analysed standards are presented in Table 26, where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO/IEC 40500:2012 is provided.

Table 26 - Guidelines that address 'Automatic Re-direction' issue

<table>
<tr><td colspan="3">Automatic re-directing:
Hovering over text (often in a menu) without clicking, or the selection of a menu link resulting in user being moved to another Web page or opening another window, causes distraction, and thus has potential to cause disorientation.</td></tr>
<tr><th>Guideline</th><th>Include?</th><th>Rationale for Inclusion/Exclusion</th></tr>
<tr><td>BS EN ISO9241-151:2008
8.3.11. Avoiding opening unnecessary windows.</td><td>✓</td><td>Specifically addresses the issue with regard to new windows being opened.</td></tr>
<tr><td>BS ISO/IEC 29138-1: 2018
6.5.21. To locate and identify all actionable components without activating them.</td><td>✗</td><td>Specifies that all interactive components should be available to locate and identify without activation. This user need reflects Success Criterion 3.2.1 (ISO40500) and does not offer additional guidance.</td></tr>
<tr><td>ISO/IEC40500:2012
3.2.1. On Focus: When any component receives focus, it does not initiate a change of context (level A).</td><td>✗</td><td>Partially addresses the issue by protecting the user from accidentally activating controls when exploring the website interface. Already included within ISO40500.</td></tr>
</table>

3.2.5. Change on Request: Changes of context are initiated only by user request or a mechanism is available to turn off such changes (level AAA).	✓	Prevents confusion about automatic-redirection by informing users about imminent change of context, and could prevent disorientation.

To improve ISO/IEC40500 by addressing the issue of '*automatic re-directing'*, it is recommended that:

- Guideline 8.3.11 (ISO9241-151) should be included, to address the effect that opening new windows can have on accessibility for people with dementia. This may be within Success Criterion 3.2.5, or as an Advisory Technique for Guideline 3.2 *'Make Web pages appear and operate in predictable ways'*, where it is not success criteria specific.
- The conformance level of Success Criterion 3.2.5 (ISO/IEC40500) should be changed from AAA to AA, to reflect the importance of user awareness and control over change of contexts for people with dementia.

These recommendations relate to the WCAG principle, '*Understandable'*.

8.3.2.2 Distracted by clutter

Guidelines identified to address the issue of '*distracted by clutter'* within the analysed standards are presented in Table 27, where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO/IEC40500 is provided.

Table 27 - Guidelines that address 'Distraction by Clutter' issue

Distracted by clutter:

Content that is not the main focus of a page, and does not aid understanding of the main content focus can cause distraction and result in difficulty remembering the task being done, or disorientation. Such clutter includes advertisements between main content and on the periphery of the page, and links to other non-related pages and sites.

Guideline	**Include?**	**Rationale for Inclusion/Exclusion**
BS EN ISO 9241-112: 2017 **6.2.2.1.** Presented task-relevant information should be clearly distinct from any background or changing information that is added to the presentation for non-task-relevant purposes (e.g. to "enhance" the artistic nature of the presentation). **6.5.2.2.** Presentation should avoid excess information (e.g. excessive wordiness, unnecessary visual attributes, unnecessary background music, unnecessary tactile stimulations). **6.5.2.3.** Additional information that does not support the user's tasks should be avoided.	✓ ✓ ✓	Ensures task-relevant information is distinct from background; this would help to address the distractions that content on the periphery of a page can cause. Ensures only information that supports the user's task is presented, by reducing the volume and density of text- and non-text information. This reduces the likelihood of user distraction as a result of clutter. *As above.*
BS EN ISO 9241-125: 2017 **5.1.4.** *Density of displayed information* The density of displayed information should be such that the information is not perceived as being "cluttered" by the user and does not lead to a degradation of task performance.	✓	*As above.* The content of this guideline supports the essence of Guideline 6.5.2.3 (ISO9241-112).
BS ISO/IEC 29138-1: 2018 **6.5.27.** To avoid distractions that prevent focusing on a task.	✗	Specifies that distractions that prevent focusing on task should be avoided. This user need reflects Guideline 6.5.2.3 (ISO9241-112) and does not offer additional guidance.

To improve ISO/IEC40500 by addressing the issue of '*distracted by clutter*', it is recommended that:

- Guideline 5.1.4 (ISO9241-125) and Guidelines 6.2.2.1, 6.5.2.2, and 6.5.2.3 (ISO9241-112) should be combined to form a new success criterion under Guideline 1.4 of ISO40500, '*Make it easier for users to see and hear content including separating foreground from background'*. This success criterion should ensure that clutter does not prevent users focusing on the main content/task, perhaps by providing a way for selecting their area of focus, or to hide other content which they perceive as clutter. As the essence of this new success criterion is the comprehension of content, it is also recommended that the phrasing of Guideline 1.4 should be amended to reflect this; '*Make it easier for users to see, hear, **and comprehend** content, including separating foreground from background*'.

This recommendation related to the WCAG principle '*Perceivable'*.

8.3.2.3 Too many steps to follow

Guidelines identified to address the issue of '*too many steps to follow'* within the analysed standards are presented in Table 28 where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO/IEC40500 is provided.

Table 28 - Guidelines that address 'Too Many Steps to Follow' issue

Too many steps to follow: Processes of navigation to reach user's desired Web content that require many steps to be followed can prevent successful navigation. The two points of difficulty within this issue are: 1. too many levels of menu options to choose from (difficulty in decision making/concentration/memory), 2. too many steps required to reach information/content can cause problems with remembering the route back to a previously seen page.		
Guideline	**Include?**	**Rationale for Inclusion/Exclusion**
BS EN ISO 9241-151:2008 **8.2.2.** Showing users where they are.	✗	*Relates to Point 2 of this issue*: supports users to identify their current position within a website. This guideline advises the same as Success Criterion 2.4.8 (ISO40500) and thus is not included.
8.2.5. Minimizing navigation effort.	✓	*Relates to Point 1 of this issue*: minimizes navigation effort by optimizing the number of steps required for any task. This could support people with

		dementia that struggle with decision making, memory and concentration.
BS EN ISO 9241-171:2008 **8.4.2.** Optimize the number of steps required for any task.	✓	*Relates to Point 1 of this issue*: optimizes the number of steps required for any task. *As above.*
BS ISO/IEC 29138-1: 2018 **6.6.20.** To have the steps for completing tasks optimized to match an individual's needs and clearly explained.	✗	*Relates to Point 1 of this issue*: specifies that steps for completing a task should match users' needs. This user need reflects Guidelines 8.2.5 (ISO9241-151) and 8.4.2 (ISO9241-171) and does not offer additional guidance.
ISO/IEC40500:2012 **2.4.8.** Location: Information about the user's location within a set of Web pages is available (Level AAA).	✓	*Relates to Point 2 of this issue*: supports users in identifying their current position within a site, and thus could help users identify a route back to a previously seen page. This could support people with dementia within memory impairment.

To improve ISO/IEC40500 by addressing the issue of *'too many steps to follow'*, it is recommended that:

- Guidelines 8.2.5 (ISO9241-151) and 8.4.2 (ISO9241-171) should be combined to address Point 1 within this accessibility issue, by supporting optimisation of the number of steps required to complete a task by minimising navigation effort. These guidelines should be combined to form a new success criterion under Guideline 2.4 of ISO/IEC40500, '*Navigable: Provide ways to help users navigate, find content and determine where they are'*. This success criterion should enable more users to navigate menu levels, and stages within a task on a website, by balancing the number of steps required for efficient navigation, with the provision of sufficient explanation of any steps taken.
- The conformance level of Success Criterion 2.4.8 (ISO/IEC40500) should be changed from AAA to AA, to reflect the importance of supporting users to find their way 'back' through a website's pages. This would address Point 2 of this accessibility issue.

These recommendations relate to the WCAG principle, '*Operable'*.

8.3.2.4 Too many things to remember

The sole guideline identified to address the issue of '*too many things to remember*' within the analysed standards is presented in Table 29 where the rationale for its inclusion within the recommendations for improving ISO/IEC40500 is provided.

Table 29 - Guidelines that address 'Too Many Things to Remember' issue

Too many things to remember: Web content that can only be accessed following input of passwords or user names that must be remembered from previous visits can cause inaccessibility due to the reliance on memory.		
Guideline	**Include?**	**Rationale for Inclusion/Exclusion**
BS EN ISO 9241-20:2009 **7.6.2.** Avoiding unnecessarily high cognitive demands.	✓	Provides an example of how ICT services can avoid unnecessarily high cognitive demands with reference to remembering passwords, and could be transferred to remembering other data such as user names.

To improve ISO/IEC40500 by addressing the issue of *'too many things to remember*', it is recommended that:

- Guideline 7.6.2 (ISO9241-20) should contribute toward the development of a new success criterion, under the principle '*Operable*'. The success criterion should reduce the need for users to remember passwords/user names where possible, and where required (e.g. for user data protection), provide alternative means of access such as biometric measures (where technology supports this), or an alternative way of confirming identity, such as a phone service. The content of this proposed success criterion does not clearly fit within any current ISO/IEC40500 guidelines, and thus may need to be included as a new guideline.

This recommendation related to the WCAG principle, '*Operable'*.

8.3.2.5 Too much content

Guidelines identified to address the issue of *'too much content'* within the analysed standards are presented in Table 30 where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO/IEC40500 is provided.

Table 30 - Guidelines that address ' Too Much Content' issue

Too much content: Web pages that contain large quantities of content and appear 'busy' can cause distraction, and a feeling of being overwhelmed. Locating desired content within a dense Web page requires skills of reasoning/decision making/concentration. This is related to 'distracted by clutter', and can result in users forgetting their intended task goal and/or becoming disoriented. Content that is not structured with navigational cues such as sub-headings require users to sift through information; an ability often impaired by dementia.		
Guideline	**Include?**	**Rationale for Inclusion/Exclusion**
BS EN ISO 9241-151:2008 **8.4.14.** Sub-dividing long pages.	✗	Structures content to enable users to sift through content by dividing content into labelled sections. Not included, as covered by Success Criterion 2.4.10 (ISO/IEC40500).
ISO 9241-110:2006 **4.3.2.** The dialogue should avoid presenting the user with information not needed for the successful completion of relevant tasks.	✓	Prevents users having to locate desired content amongst task-irrelevant surrounding content, thus reducing mental workload.
BS ISO/IEC 29138-1: 2018 **6.5.29.** To have only the content necessary for the current task presented.	✗	States that task-irrelevant content should not be presented. This user need reflects the content of Success Criterion 4.3.2 (ISO/IEC40500).

ISO/IEC 40500:2012 **2.4.2.** Page Titled: Web pages have titles that describe topic or purpose (Level A).	✗	Aids users to identify desired content without processing all content on a page. Already included in ISO40500.
2.4.6. Headings and labels: Headings and labels describe topic or purpose (Level AA).	✗	*As above.* Already included in ISO40500.
2.4.10. Section Headings: Section headings are used to organize the content (Level AAA).	✓	Supports users to identify most relevant content sections amongst surrounding related content.

To improve ISO/IEC40500 by addressing the issue of '*too much content'*, it is recommended that:

- Guideline 4.3.2 (ISO9241-110) should be developed as a success criterion, within ISO/IEC40500 Guideline 2.4 '*Navigable: Provide ways to help users navigate, find content, and determine where they are*'. The criterion should prevent users from being faced with unnecessary content, which would help people with dementia living with impairments to concentration, reasoning, decision making and memory.
- The conformance level of Success Criterion 2.4.10 (ISO/IEC40500) should be changed from AAA to AA, as continued structuring of content within a web page can assist with locating desired content within surrounding related content, by supporting sifting of information.

These recommendations relate to the WCAG principle, '*Operable'*.

8.3.2.6 Too much text

Guidelines identified to address the issue of '*too much text'* within the analysed standards are presented in Table 31 where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO/IEC40500 is provided.

Table 31 - Guidelines that address 'Too Much Text' issue

Too much text: Web content comprised of lengthy blocks of text-based content can cause inaccessibility as it requires attention/memory/reading/comprehension. Content that is split with comprehension-aiding image based content, or white spaces is more accessible as text is presented in smaller, more manageable chunks. [Related to 'Too much content'].		
Guideline	**Include?**	**Rationale for Inclusion/Exclusion**
BS EN ISO 9241-151:2008 **8.4.14.** Sub-dividing long pages.	✗	Dividing content into labelled sections structures text-based content to support sifting of information. Not included as addressed in Success Criterion 2.4.10 (ISO/IEC40500).
9.6.2. Supporting text skimming.	✓	Improves opportunity for text-skimming, particularly through the use of bulleted lists, and short phrases and sentences that reduce the length of blocks of text.
9.6.3. Writing Style.	✓	Supports navigation and comprehension of text (as in Guideline 9.6.2) and promotes key point summaries of text-based content before elaborating in longer blocks of text.
ISO 9241-112:2017 **6.4.5.1.** Where large volumes of textual content are presented, the purpose of the content should be made clear before presenting the details of the content.	✓	Promotes summarizing purpose of text, before presenting details of content (as in Guideline 9.6.3, ISO9241-151).
6.4.5.2. Short sentences should be used, where possible.	✓	Supports text-skimming (as in Guideline 9.6.3, ISO9241-151) by presenting text in more manageable chunks.

ISO/IEC40500:2012 **2.4.2.** Page Titled: Web pages have titles that describe topic or purpose (Level A).	✗	Aids users to identify desired content without processing all content on a page. Already included in ISO/IEC40500.
2.4.6. Headings and Labels: Headings and labels describe topic or purpose (Level AA).	✗	*As above.* Already included in ISO/IEC40500.
2.4.10. Section Headings: Section headings are used to organize the content (Level AAA).	✓	Supports users to identify most relevant text amongst surrounding related content.

To improve ISO/IEC40500 by addressing the issue of '*too much text*', it is recommended that:

- Guideline 9.6.2 (ISO9241-151) and Guideline 6.4.5.2 (ISO9241-112) should be combined in the development of a new success criterion under ISO/IEC40500 Guideline 3.1 '*Readable: Make text content readable and understandable*'. This success criterion should support text skimming, through the encouraged use of short sentences and phrases, and other means that reduce the length of blocks of text, such as bulleted lists.
- Guideline 9.6.3 (ISO9241-151) and Guideline 6.4.5.1 (ISO9241-112) should be combined in the development of a new success criterion under ISO/IEC40500 Guideline 2.4 '*Navigable: Provide ways to help users navigate, find content, and determine where they are*'. This success criterion should support users to identify relevant blocks of text, through means of a summary presented as a manageable chunk before longer text-based content is presented, and thus reduce the need for users to skim longer blocks of text to navigate to desired content.
- The conformance level of Success Criterion 2.4.10 (ISO/IEC40500) should be changed from AAA to AA, as continued structuring of text-

based content can assist with locating desired content within surrounding related content, by supporting sifting of text.

These recommendations relate to the WCAG principles ‘*Understandable’* and ‘*Operable’*, respectively.

8.3.2.7 Cannot find the next menu option

Guidelines identified to address the issue of ‘*cannot find the next menu option*’ within the analysed standards are presented in Table 32 where the rationale for the inclusion/exclusion of each guideline within the recommendations for improving ISO40500 is provided.

Table 32 - Guidelines that address 'Cannot Find the Next Menu Option' issue

<table>
<tr><td colspan="3">Cannot find the next menu option:
If menu headings are not grouped into clearly defined meanings or concepts that represent their contained content, users cannot easily navigate the menu and associated Web pages. Categorising content into concepts that are abstract in any way can require users to employ abilities of reasoning/decision making/reading/comprehension, which can be problematic for people with dementia. If the number of menu options is too great, this issue is exacerbated as attention and memory are required to a greater extent.</td></tr>
<tr><th>Guideline</th><th>Include?</th><th>Rationale for Inclusion/Exclusion</th></tr>
<tr><td>BS EN ISO 9241-151:2008
8.3.3. Breadth versus depth of the navigation structure.
8.3.4. Organising the navigation in a meaningful manner.</td><td>✓
✓</td><td>Addresses the need for logical grouping and labelling of menu links, and the management of the number of links. [Related to ISO9241-14: Guidelines 5.1.1, 5.1.2. & 5.1.3.].
Addresses the need for navigation structures to be organized on meaningful and relevant concepts for the user.</td></tr>
<tr><td>BS EN ISO9241-14:2000
5.1.1. Conventional categories.
5.1.2. Logical categories.
5.1.3. Arbitrary grouping.</td><td>✓
✓
✓</td><td>These guidelines provide support on how menu links can be organized, depending on their content, to make them most usable in terms of navigating to the most relevant link. This supports comprehension of link names, and decision making between available links.
These guidelines also reference how the numbers of menu links within a navigation structure should be managed.</td></tr>
</table>

BS EN ISO 9241-112:2017 **6.4.3.4.** Presented information should be unambiguous.	✓	Addresses the need for Web content to be unambiguous, which is applicable to menu links, as comprehension of this content is essential for successful Web content navigation.
BS ISO/IEC 29138-1: 2018 **6.6.8.** To have presented information as easy to understand as possible.	✗	Reflects the need for unambiguous information, which can aid comprehension and thus enable navigation. Does not offer additional guidance beyond Guideline 6.4.3.4. (ISO9241-112).

To improve ISO/IEC40500 by addressing the issue of *'cannot find the next menu option*', it is recommended that:

- Guidelines 8.3.3. and 8.3.4 (ISO9241-151) should be used with related guidelines 5.1.1, 5.1.2, and 5.1.3 (ISO9241-14) to develop a success criterion reflecting the importance of logical and meaningful grouping within navigational structures for people with dementia. This criterion should demand consideration for the number of links used in a menu, and should be positioned under ISO/IEC40500 Guideline 2.4 '*Navigable: Provide ways to help users navigate, find content, and determine where they are'.*
- Guideline 6.4.3.4 (ISO9241-112) should be incorporated into a new success criterion under ISO/IEC40500 Guideline 3.1 '*Readable: Make text content readable and understandable',* to encourage menu links within navigational structures to be unambiguous and avoid abstract terms that can be problematic for people with dementia.

These recommendations relate to the WCAG principles '*Operable'* and '*Understandable*', respectively.

8.4 Recommendations: Context and Development

Recommendations for improving the inclusivity of ISO/IEC40500:2012 (Web Content Accessibility Guidelines) to meet the needs of people with dementia, by including relevant guidelines from usability standards have been detailed in Sections 8.3.2.1 - 8.3.2.7.

Of the 25 documents included within the analysis, guidelines from only 9 were identified, and considered within the detailed analysis (Table 25). The following types of recommendations for improvement to ISO/IEC 40500 have been made as a result of the analysis:

- 7 New Success Criteria
- 1 New Guideline
- 4 Changes to conformance level of existing ISO40500 Success Criteria (AAA to AA level)
- 1 Change of Guideline name
- 1 Amendment to an existing Success Criterion

A summary set of guidelines included within the recommendations, based on this analysis is provided in Table 33, together with current ISO/IEC40500 success criteria that are identified as being important for meeting the accessibility needs of people with dementia, and included within proposed ISO/IEC40500 improvements.

Recommendations regarding how existing ISO/IEC40500 success criteria may meet the accessibility needs of people with dementia have been included as these criteria currently exist at AAA conformance level only, and thus are not required to be met by websites adhering to the standard by law. It is proposed that these particular criteria are of such importance for the inclusivity of the needs of people with dementia, that they should be promoted to AA conformance level. However, in recognition that many AAA conformance level guidelines cannot be included at AA conformance level as they are not applicable to all web content, an alternative proposition is that such criteria should be highlighted as important for people with dementia (or users with cognitive limitations) and potentially included within a specific accessibility guidance list for this user group. This approach to proposing changes to conformance level of existing success criteria in response to newly identified user needs is that taken by the W3C in their current research into web accessibility for users with cognitive impairment (W3C, 2018a); this supports the possibility that the conformance level of success criteria can be changed to reflect new knowledge of the cognitive accessibility. Changes in success criteria conformance level in response to new knowledge within the field of cognitive impairment were also made in the development of the current guidelines (W3C, 2007).

The recommendations for including guidelines from usability guidance are given in the knowledge that for inclusion within ISO/IEC40500, they would need to have testable success criteria developed, so that web content could be checked for conformance. Developing these guidelines to this stage is not within the scope of this research, and the recommendations are given as the basis for development within future work.

The W3C, the community that developed the guidelines and success criteria within ISO/IEC 40500:2012 (previously ‘WCAG 2.0’) are currently researching the state of web accessibility for users with cognitive impairment, and have published their ongoing work as working draft documents. Within the ‘*Cognitive Accessibility Roadmap and Gap Analysis’* working draft published by the W3C (W3C, 2018a), the following stages are included for developing new guidelines and success criteria:

1. User Research: to identify user needs/challenges that are not fully included within WCAG 2.0;
2. Compile list of authoring techniques to meet identified user needs;
3. Create testable success criteria for each identified user need.

The research in this thesis has identified user needs/challenges that are not fully included within ISO/IEC40500:2012, and analysed accessibility and usability standards to identify guidelines that address these. When considered against the stages followed by the W3C in their related work, this research contributes knowledge within the first stage, ‘User Research’. Therefore, the recommendations given for each of the user needs identified within this thesis should be developed within future work, by following the next two stages, where authoring techniques that meet these user needs are compiled, and testable success criteria are developed for these.

The guidelines identified within usability standards to address the identified user needs should be used as the basis for the developed success criteria and their associated authoring techniques, as it is these guidelines that currently address the issues faced by people with dementia. These existing usability guidelines need to be formatted to fit with the structured guidance levels of ISO/IEC40500 to give web developers/designers sufficient detail on how to address these issues as accessibility needs.

Table 33 - Guidelines included within recommendations for improvements to ISO40500

		Automatic re-directing	Distracted by clutter	Too many steps to follow	Too many things to remember	Too much content	Too much text	Cannot find the next menu option
	Chapter Section:	8.3.2.1	8.3.2.2	8.3.2.3	8.3.2.4	8.3.2.5	8.3.2.6	8.3.2.7
Standard Analysed								
ISO 9241	Part 151:2008	8.3.11.		8.2.5.			9.6.2. 9.6.3.	8.3.3. 8.3.4.
	Part 14:2000							5.1.1. 5.1.2. 5.1.3.
	Part 112:2017		6.2.2.1. 6.5.2.2. 6.5.2.3.				6.4.5.1 6.4.5.2	6.4.3.4.
	Part 125:2017		5.1.4.					
	Part 20:2009				7.6.2.			
	Part 110:2006					4.3.2.		
	Part 171:2008			8.4.2.				
	ISO/IEC 40500:2012	3.2.5.		2.4.8.		2.4.10.	2.4.10.	

Note: This table summarises the guidelines proposed for inclusion within ISO/IEC40500 to improve the inclusivity of the needs of people with dementia*. See referenced chapter sections for rationales and recommendations for their inclusion.*

8.5 Limitations

As acknowledged in Section 8.4, the W3C are currently working on improvements to the Web Content Accessibility Guidelines which are the basis of ISO/IEC40500, towards a publication of updated guidelines. Whilst the W3C recommendation for WCAG 2.1 was analysed for relevant guidelines within this chapter, further improvements currently being developed by the W3C cannot be accessed at present beyond the latest working draft (November 2018); further improvements developed by the W3C may better reflect and address the needs of people with dementia. The analysis in this chapter was limited to the available publications to date.

8.6 Conclusions

This chapter analysed existing usability standards to identify guidance that addresses the accessibility issues experienced by people with dementia that are not currently addressed within ISO/IEC40500:2012, '*Information technology- W3C Web Content Accessibility Guidelines (WCAG) 2.0'*. The findings were used to develop recommendations for improving the inclusivity of ISO/IEC40500 by addressing the accessibility needs of people with dementia. The results of the analysis and resultant recommendations support the following conclusions:

- Usability standards contain guidelines that address accessibility issues experienced by people with dementia when accessing and using web content.
- Usability guidelines could be used as the basis for the development of new, and amended, success criteria and guidelines within ISO/IEC40500 which would address the accessibility needs of people with dementia.
- The recommendations given in this chapter (Sections 8.3.2.1 - 8.3.2.7) should be further developed in the following two stages, in adherence with the format of the ongoing work by the W3C who seek to develop more inclusive guidelines:
    - Authoring techniques to be compiled for each identified user need.

  - Testable success criteria to be created for each identified user need (based on the usability guideline influenced recommendations given in this chapter).

Chapter 9. Accessibility in Research: Involving People with Dementia as Participants

9.1 Introduction

People with dementia are often excluded from participating in research, with ethical difficulties and assumed inability often being cited as reasons for this (Lloyd, Gatherer and Kalsy, 2006; Hellstrom *et al.*, 2007). However, people with dementia are capable of expressing their needs, when their inclusion in research is supported (Moyle, 2010; Gill, White and Cameron, 2011). Reflective Practice has been described as an effective tool to develop ways to interview people with dementia, as it provides an opportunity to identify which methods facilitate the flexibility required when working with the individualistic nature of dementia (Pratt, 2002), and as a result works to assist in reducing the barriers to the inclusion of people with dementia in research.

This chapter discusses the success and outcomes of the Reflective Practice conducted throughout this research (Section 9.2), which contribute knowledge on improved practice for involving people with dementia in research. There are many stages within research for which the needs of people with dementia as participants must be addressed, if their involvement is to be fully supported. Therefore, a list of guidance covering the following aspects of research will be provided (Section 9.3), to contribute to improved practice for involvement of people with dementia in future research:

- Recruitment
- Consent processes and documents
- Data collection - Interviews
- Research procedures.

The guidance provided within this chapter builds on the existing guidance in literature, which was used to develop the initial methods and procedures of this research, as detailed in Chapter 5 (Section 5.3.1.3).

In accordance with the writing style of reflective practice, this chapter will be written using the first person, to convey my personal experience of researching with people with dementia.

9.2 Reflective Practice: Outcomes and Discussion

The reflective practice conducted in each of the studies enabled improvements to be made to study methods and procedures as the research progressed. The method of reflective practice used is described in Chapter 5 (Section 5.3.2.2.1). The issues identified through reflective practice, how these issues were addressed within this research, and how remaining issues may be resolved in future research involving people with dementia are summarised in Sections 9.2.1-9.2.5. Each of the adjustments made to the study methods and procedures was implemented to improve the accessibility of research for people with dementia as participants. The lessons learnt from this reflective practice contributed to the ‘Improved Practice’ guidance presented in Section 9.3.

9.2.1 Recruitment

Considering ethics during recruitment is important, as people with dementia should be making their own decision regarding their involvement, and thus recruitment approaches must not make potential participants feel pressured or coerced into participation. Gatekeepers can play a role in the ethical recruitment of people with dementia (Chapter 3, Section 3.3.5.1) by ensuring they remain protected and free from coercion or exploitation (McFadyen and Rankin, 2016). Carers can fill the role of gatekeeper when supporting people with dementia into research (Pratt, 2002), particularly when approaching people with dementia living in communities, rather than institutions, and those with the capacity to consent, as they can support those under their care to make their own decisions and thus ensure their recruitment is ethical.

Recruitment for my research began by establishing links with a dementia support group (The Hardy Group, in Derby, UK), and liaising with the leader of this group who agreed to let me have exposure to this group, by attending their monthly meetings. The leader of this group advocated the involvement of the group members in my research, and introduced me to the group, prior to the talk I gave to the members on my research. Regular attendance at this dementia support group enabled me to become embedded within a community, providing the opportunity for group members to become familiar and comfortable with both myself, and the studies. Group members approached me to register their interest in participating, often after having built rapport during previous conversations. Reflecting on this, in comparison to the recruitment achievements in groups where my regular attendance to build rapport had not been possible, this knowledge is important for improved practice of recruiting people with dementia to research; to be most successful, researchers should allow sufficient time to build rapport with group leaders, and potential participants before recruitment commences. Having rapport with researchers can enable potential participants to feel more at ease with the recruitment process and thus make this first stage of a research study more accessible to people with dementia who may be experiencing difficulties engaging with new people due to their dementia. In addition, for people with dementia, the knowledge that a leader of a group that they attend is an advocate of the research can give reassurance that their involvement will be a positive experience and something within their capabilities.

Despite the positive impact that building rapport had on the recruitment of people with dementia from support groups, it was apparent upon reflection that additional recruitment strategies should be used in the future, to engage with optimal numbers of people with dementia, as the recruitment of sufficient numbers is a significant challenge to research with people with dementia. Other strategies that would be recommended for future recruitment would be extended attendance at additional dementia-focused groups, engagement with recruitment platforms such as Join Dementia Research, and further applications for research partnership with the Alzheimer's Society *(Note: this study was not considered by the society as a suitable match to their research themes at the time of recruitment).*

9.2.2 Consent Processes and Documents

Consent that is considered 'informed', and thus ethical, can only be obtained when the person has the cognitive capacity to understand the provided information, and to appreciate the consequences of consenting to participation (Cubit, 2010). As a result, obtaining informed consent is a challenge when involving people with dementia in research (Dewing, 2007; Hellstrom *et al.*, 2007) and additional measures are required for their protection (Slaughter *et al.*, 2007). For example, any research involving people with dementia must be conducted with regard to the Mental Capacity Act (HM Government, 2005), including taking all practicable steps to help an individual to make a decision independently (discussed in Chapter 3, Section 3.3.3).

Reflections on the implementation of the dementia-inclusive consent documentation and process designed for this research demonstrated their success (Chapter 3, Section 3.3.6.3.1). Feedback provided by both people with dementia and their carers in the second and third studies also supported their use, as they were described as being simple to understand and complete. Specific comments from participants focused on the short length of the document, the helpful icons used to aid text comprehension, and the clear wording. This feedback demonstrates that dementia-inclusive designs of consent documents and processes can improve the accessibility of research for people with dementia, and enable independent decision making. One recommendation, based on reflections conducted during Study 3, is that the date field on consent documents should be pre-populated, to reduce the reliance on memory of people with dementia, and the potential anxiety associated with this. This recommendation was adhered to for participants in Study 3 and was found to assist people with dementia; this was also supported by participant feedback.

Carer feedback in the second and third studies included suggestions to use the dementia-inclusive consent documents for all participants, including people with dementia and carers. It was suggested that this would reduce the likelihood of people with dementia feeling the stigma of using different documents, whilst also making the consent process more usable for all participants and carers. Carer feedback supported the stance that designing consent documents and processes to be accessible to people with dementia also results in better usability for older adults too; designing for people with dementia can result in better design for all. The restrictions of Loughborough University Ethics Committee for using alternative consent document formats prevented the use of the dementia-inclusive design of consent documentation within this research for older adults without dementia and carers. However, this would be recommended for future studies, as it would promote a more inclusive approach to research, if all participants are treated equally in every possible aspect of a study.

9.2.3 Data Collection - Interviews

Individual interviews are the most commonly used qualitative data collection method with people with dementia, despite the complexities of working with individuals whose cognitive and verbal functions are impaired (Pesonen, Remes and Isola, 2011) as the method can be tailored to individuals. When interviewing people with dementia, it is important to consider the interview structure – including the phrasing and language used in questions – and interview timings (Clarke and Keady, 2002). Ensuring the interview method considers the needs and abilities of the people with dementia is important for ethical, successful data collection.

Reflections on the feedback from a carer in Study 2, regarding a participant's confusion over the terminology used within interview questions, led to an improvement in methodology. The carer of PWD2 in this study noted that words such as 'navigation' may not be self-explanatory to some web users, and that some might refer to this using alternative phrasing such as '*moving around*'. For this reason, I took note of the language used by participants in all following interviews, to enable their own language to be used within the interview questions, which was found to help the flow of conversation, and appeared to assist with question comprehension.

The visual aids, in the form of rating scales, used within Study 3 received positive feedback from both people with dementia and their carers. The use of visual aids was found to provide focus for people with dementia, and help to maintain concentration throughout the interview. In addition, visual cues provided a cue or reminder for participants whose memory impairments prevented them from retaining the question they had been asked whilst they considered their answer. Their success has led to the recommendation that visual aids should be used wherever possible, to support the interview questions that are asked verbally.

Reflection on my notes from interviews in Studies 2 and 3, revealed that short breaks from engagement within the interview period provided people with dementia with the opportunity for rest. These short breaks were enabled by my need to rearrange interview materials, such as the rating scales, or by making notes on the previously given response from the participant. These short breaks were observed to allow participants a moment of rest before returning to focus on the interview, and I felt this was beneficial to the prevention of participant fatigue as a result of being interviewed.

9.2.4 Research Procedures

When involving people with dementia in research, it is important to consider all aspects of a study, including the research environment, and ethical aspects, such as the presence of a carer to support participants (Clarke and Keady, 2002). Each element of research can affect participants’ comfort, which is of primary importance, and as a result can impact the quality of data collected. Prioritising the experience of people with dementia as participants contributes to ethical research, and thus all research procedures should be developed with consideration for this at all stages of research involving people with dementia.

Reflections on the differences between Study 1, and Studies 2 and 3, regarding the location of data collection highlighted the importance of ensuring interviews are conducted at a familiar, comfortable location for people with dementia. Allowing people with dementia to participate within their own home for Studies 2 and 3, at a time convenient to them, with another person of their choosing present, reduced their anxiety and gave participants more control over their involvement. This was a positive reflection, when compared to that conducted in Study 1 where it was found data collection within a busy group environment led to unwanted distractions (Chapter 3, Section 3.3.6.3.3). For this reason, it is recommended that data collection environments are led by people with dementia where possible in future research where the environment does not need to be in a specific location.

One participant in Study 2 expressed annoyance when he believed I had arrived earlier than agreed, until he checked the written confirmation of the interview time. Written confirmation was provided to each participant, for their reference, and reflections on this instance provided additional reasoning to include this within the improved practice guidance for research procedures when involving people with dementia in research.

Multiple participants expressed appreciation of the courtesy call given on the day of their involvement, to check that the appointment was still convenient to them with relation to both their plans and experienced dementia symptoms that day. As this procedure in research was found to be helpful to people with dementia, this too is included within the improved practice guidance.

Reflections that were conducted in Study 1 highlighted the imbalance in contributions that can be experienced between people with dementia and their carers when a carer is present (Chapter 3, Section 3.3.6.3.4). A specific role for carers in this instance was developed in response to this reflection (Chapter 5, Section 5.3.1.3.4), and implemented in Studies 2 and 3. This role was found to address the imbalance difficulties, as it provided carers with a focus, enabling them to participate and contribute to the research within pre-determined boundaries which had been discussed and agreed. The alternative to this would be to interview people with dementia without a carer present, or to interview the carer separately, but this would not meet the ethical need to ensure the wellbeing of people with dementia is prioritised, by allowing them to have a carer present during their participation. The development of a specific role for carers during the participation of people with dementia is recommended for future research, to ensure both the wellbeing of people with dementia as participants, and a way to ensure their voice is heard in each interview, whilst still providing a space to hear the voice of carers, to capture their opinions and thoughts.

9.2.5 Reflective Practice: A tool in dementia research

Reflective Practice was reflected upon as a tool, to assess the benefits it offers to the conduct of research involving people with dementia. Reflective Practice was found to provide a structured opportunity to reflect on issues arising during the studies, and to formulate improvements to the methodology and research approach taken to address these issues. Including a structured approach to reflecting on both the research methodology and my own conduct resulted in many improvements to both aspects of this research as the studies progressed, as detailed in the previous sections. Hubbards, Downs & Tester (2003) and Pratt (2002) recommended the use of Reflective Practice within research involving people with dementia, and I strongly support this recommendation. It is proposed that conducting Reflective Practice should be encouraged within any studies where participants are particularly individualistic, whether that be cognitively, physically or otherwise, as this tool enables a platform for consideration where researchers can assess how ‘standard/conventional’ research methods and approaches work for more nuanced participant types.

It is particularly important to reflect on how each element of research design may work with the individual nature of dementia, considering the vast range of symptoms that differing dementia diagnoses can present. This is fitting with the commonly referenced Professor Tom Kitwood quote *‘When you’ve met one person with dementia, you’ve met one person with dementia’* (SCIE, 2015). In essence, it is important to remember that the methodology used in a study may need to be adjusted to meet the individual capabilities of participants, depending on their experience of dementia and its symptoms, as no two people with dementia will be the same. This is reflected in particular aspects of the developed guidance, such as using participants’ own language within the interview questions asked of them, to aid their individual comprehension. Reflecting on the successes and limitations of the implemented methods with each participant gives a researcher an opportunity to assess how these may be improved for the subsequent participants.

The benefits of Reflective Practice were observed, as participants were increasingly engaged with the study as the method and approach were further refined with each reflection. Looking critically at the aspects of the research that supported people with dementia well, and those that required improvement, both during and after each interview, enabled improvements to be made as the study progressed. These improvements could then be trialled and reflected upon too, before being included within the guidance developed for future research involving people with dementia. Reflective Practice within future research engaging people with dementia as participants would be expected to facilitate further exploration of Improved Practice for research methods when involving people with dementia, and to generate additional guidance for future researchers as a result.

9.3 Guidance for Involving People with Dementia in research

The following guidance for the involvement of people with dementia in research (see Table 34) was developed from the knowledge obtained through the initial discussions with the group leader of the dementia support group and his partner with dementia when discussing and developing appropriate research approaches, my observations and reflective practice conducted throughout the studies, and the feedback provided by people with dementia and their carers on the study procedures. The guidance listed supports many of the guidelines provided in literature, with additional considerations based on the experiences of this research; related literature and study reflections are referenced alongside each point of guidance. The guidance covers four key areas to be considered in research:

- Recruitment
- Consent processes and documents
- Data collection - Interviews
- Research procedures.

It is proposed that this guidance could be used to inform accessible, dementia-inclusive research, and that this guidance should be built upon in future studies where Reflective Practice is used to develop further practice guidance.

Table 34 – Guidance for studies involving people with dementia as participants

	Guidance	**Study Reflections & Supporting References**
Recruitment	***Establish links with group leaders*** to provide the opportunity for them to become an advocate of the research and introduce you to potential participants within community/support groups.	• Studies 1, 2 & 3
	Build rapport with potential participants to provide opportunity for them to feel comfortable with the researchers and to ask questions about the study.	• Studies 1, 2 & 3 • Lloyd, Gatherer and Kalsy (2006)
	Consider possible routes for recruitment to enable optimum engagement with people with dementia (e.g. existing support groups, Join Dementia Research, Alzheimer's Society partnerships, etc.)	• Studies 2 & 3
	Allow sufficient time prior to the study commencing to build rapport with potential participants, and to apply for recruitment opportunities (e.g. Join Dementia Research).	• Studies 2 & 3
Consent Processes and Documents	***Design consent documentation to be accessible to people with dementia:*** combine participant information and consent forms in a chunked format; use simple language; use symbols to aid comprehension; use recommended fonts in large sizes; ensure good contrast throughout document; use white space to make reading easier. Pre-populate fields such as 'date' to support people with dementia with memory impairment. Where possible, use this documentation design for people with dementia and their carers to practice inclusive research design. Accessible, inclusive consent processes enable optimum recruitment of people with dementia.	• Studies 1, 2 & 3 • *See Chapter 3 for detail on dementia-inclusive document design.*

	Conduct consent processes with regard to the Mental Capacity Act, and follow the two-stage test for capacity described in the Act's Code of Practice. This ensures ethical practice that adheres to legal requirements in the UK.	• Studies 1, 2 & 3 • HM Government (2005); Department of Constitutional Affairs (2007)
	Consider the first consent sought (written or verbal) as the beginning of an ongoing consent process. Monitor for behavioural signs of fatigue/anxiety which may alter the consent of people with dementia; if signs are observed, ask for continued consent verbally.	• Studies 1, 2 & 3 • Dewing (2007); Beuscher and Grando (2011)
Data Collection - Interviews	***Implement a schedule which becomes more focused and direct as data collection progresses.*** This helps build rapport, provides an opportunity to gauge participants' expressive skills, and keeps people with dementia focused. Ensure this schedule is flexible enough to allow natural conversation flow.	• Studies 2 & 3 • Hellstrom *et al.* (2007); Brorsson *et al.* (2011); Pesonen, Remes and Isola (2011)
	Use participants' natural language and wording within interviews to aid their comprehension of questions and prevent confusion over terminologies.	• Studies 2 & 3 • Beuscher and Grando (2011)
	Use visual aids when asking questions, such as rating scales, as a reminder that can support people with dementia to focus on, and remember, the question being asked.	• Studies 2 & 3 • DEEP: The Dementia Engagement and Empowerment Project (2013a)
	Consider the length of the interview and whether building in breaks may be appropriate to allow people with dementia rest time, to avoid fatigue.	• Studies 2 & 3 • DEEP: The Dementia Engagement and Empowerment Project (2013a)

Research Procedures	***Conduct research in a comfortable environment*** for people with dementia, such as their own home, to reduce anxiety. Allowing people with dementia to select the environment gives participants more control over their participation.	• Studies 1, 2 & 3 • Clarke and Keady (2002)
	Provide confirmation of appointment time: 1. Provide written confirmation when interview is scheduled 2. Provide courtesy call on the day of appointment to confirm it is still convenient. This confirmation supports people with dementia with memory impairment, and ensures that previously made commitments are still suitable for people with dementia on the day, which may not always be the case due to the fluctuations in dementia symptoms.	• Studies 2 & 3
	Allow people with dementia to be accompanied by a carer according to their wishes. This may prevent anxiety for people with dementia by enabling them to feel supported and at ease.	• Studies 1, 2 & 3 • Clarke and Keady (2002); Pesonen, Remes and Isola (2011)
	Where carers are present during data collection, ensure they are given sufficient guidance on the expectations of their contributions by detailing a role for them. This will help to manage potential interruptions to the interview as a result of carers wanting to help and contribute, which can impact data collected from people with dementia. Ensure carer roles still enable their perspective to be captured whilst they continue to fulfil the natural carers role for the people with dementia.	• Studies 1, 2 & 3 • Mason and Wilkinson (2002)
	Researchers should routinely conduct Reflective Practice on their study method and personal researcher skills to enable practice guidance for research involving people with dementia to be developed further.	• Studies 1, 2 & 3 • Pratt (2002); Hubbard, Downs and Tester (2003)

	Following completion of a study, researchers should provide feedback to participants in a dementia-inclusive format. This step is important for confirming the value of the contributions made by people with dementia, and is ethical practice to provide feedback where desired/requested by participants.	• *See Appendix Q for feedback sheet given to people with dementia, designed to be dementia-inclusive, which was accompanied by a cover letter.*

The guidance provided in Table 34 is intended to guide accessible, dementia-inclusive research, and is thought to be particularly useful for research which utilises interviews as a data collection method. In acknowledgement that each person with dementia has individual capabilities and needs, I recognise that this guidance is by no means exhaustive, but that it forms the basis for improved practice in interview studies involving people with dementia, onto which future researchers can contribute further knowledge and guidance, based on their experiences of researching with people with dementia. Similarly, I recommend that Reflective Practice should be used by researchers implementing other methods with people with dementia, to develop accompanying guidance for other suitable methods for researching with people with dementia.

9.3.1 Guidance for Selecting Researchers to Conduct Research involving People with Dementia

An additional reflection on the research I conducted centred upon the required skills and qualities of the researcher conducting studies involving people with dementia. Many participants commented throughout the research that my personal manner and behaviours had enabled them to engage with the research, and to enjoy their experience of participation. I therefore believe that the researcher responsible for interactions with participants with dementia should have the qualities detailed in Table 35. These qualities reflect my own skills and attributes, and I believe increase the likelihood of a successful study, where insightful data can be collected through ethical research procedures. Therefore, my final recommendation for improved practice of research involving people with dementia, is to select a researcher with the desired skills and qualities to conduct the research, to maximise both the potential of data collection, and the experience of the people with dementia involved in the project.

Table 35 - Researcher Skills and Qualities

Researcher Skill/Quality	Reason for importance
Skilled in communication with people with dementia and related communication impairments. Achieved through: prior experience; dementia awareness training.	Understanding the potential communication difficulties encountered with people with dementia, and knowledge on how to communicate despite these impairments not only enables data to be collected, but puts people with dementia at ease.
Friendly and approachable manner, with a natural ability to reassure people with dementia and to put people at ease in unfamiliar situations.	It is essential that people with dementia feel comfortable with the researcher, as they are likely to become anxious if they feel the researcher is judging them or their abilities.
Ability to adapt and be flexible within research procedures.	People with dementia can sometimes struggle with interpreting particular questions, or focusing on activities within a study. It is therefore important for a researcher to be able to adapt research to meet the abilities of an individual and work flexibly to allow for this.
Possess a genuine interest in the experiences of people with dementia, paired with a genuine belief in the capability of people with dementia to make valuable contributions to knowledge.	People with dementia express their appreciation of researchers who want to hear, and value, their experiences/opinions. It is therefore essential that researchers genuinely value the contributions of people with dementia as participants.

9.4 Conclusions

This chapter has detailed outcomes of the reflective practice conducted throughout the three studies of this research, and identified how these reflections were used to improve study methods. These reflections have been used to develop improved practice knowledge for research involving people with dementia, and these have been presented in the form of a table of guidance (Table 34). Conducting reflective practice throughout this research has led to the following conclusions:

- The guidance developed for the improved practice of involving people with dementia as participants (Section 9.3) can be used as the basis of developing accessible, dementia-inclusive study design, which will enable people with dementia to access and participate in research.
- Reflective practice as a tool can contribute to improved practice when involving people with dementia in research, and its use is recommended for other researchers. This could further develop the guidance in this chapter (Section 9.3), when used to reflect upon studies involving other people with dementia, both in interview-based studies and those utilising other methods.
- People with dementia can be supported as research participants, when research methods and procedures are designed inclusively, to meet their accessibility needs.

This chapter has presented development of improved practice within research involving people with dementia, and contributes knowledge and guidance for accessible and inclusive research methods and procedures.

Chapter 10. Discussion

10.1 Overview

Web accessibility for people with dementia was investigated throughout this research, in order to inform guideline improvement recommendations for Web Content Accessibility Standards that address the needs of people living with cognitive changes caused by dementia. To develop these recommendations, the research has comprised:

1) a review of the literature

2) the development of accessible research methods for people with dementia

3) the use of interviews to understand the experiences and needs of people with dementia when using the Web, and

4) an assessment of the inclusivity of current Web Accessibility Standards to establish where improvements are required.

The results of each individual study are discussed in Chapters 3,6 and 7. This chapter integrates the findings to consider the four main areas for further discussion:

- The experiences and needs of people with dementia and older adults without dementia as users of technology and the Web (Section 10.2.1)
- The inclusivity of the needs of people with dementia within Web Content Accessibility Guidance (Section 10.2.2).
- The potential benefits of improving the inclusivity of Web accessibility standards (Section 10.3)
- The lessons learnt from including people with dementia as research participants; the challenges, limitations and development of improved practice guidelines (Section 10.4)

10.2 Main Findings

As the results of the individual studies have already been discussed (Chapters 3, 6 and 7), this section integrates and discusses the main findings.

10.2.1 The experiences and needs of people with dementia as users of technology and the Web

The experiences and needs of people with dementia as users of technology - including the Web - were explored using literature and empirical studies throughout Chapters 2, 3, 4, 6, 7 and 8. The types of technology that are used by people with dementia have been explored (Section 10.2.1.1), difficulties encountered by these users when using technology have been identified and assessed (Section 10.2.1.2), Web accessibility issues for this user group have been identified (Section 10.2.1.3) and then considered in context of the overall present and future experience of using the Web for people with dementia (Section 10.2.1.4).

10.2.1.1 Technology and Web use

Literature in the first review (Chapter 2) showed that people with dementia use a range of technologies for different reasons, ranging from purpose-specific safety technologies such as electronic tracking systems (Faucounau *et al.*, 2009) and assistive technologies such as prompting technologies (Labelle and Mihailidis, 2006; Bewernitz *et al.*, 2009; Nugent *et al.*, 2011; Boyd *et al.*, 2015), to using commonplace ICT such as smartphones (Brankaert, Snaphaan and Den Ouden, 2014), computers and the Internet (Rosenberg *et al.*, 2009; Patomella *et al.*, 2011), and tablet computers (Ekström, Ferm and Samuelsson, 2015). Most of the previous research focused on the use of safety and assistive technologies, with fewer studies evaluating everyday technologies, and technologies for rehabilitation and care.

The scoping study (Chapter 3, Section 3.2) sought to contribute additional knowledge of the use of commonplace ICT by people with dementia, as previous literature on the use of those types of technology by community-dwelling people with dementia was sparse. Results from Chapter 3 showed that community-dwelling people with dementia used all of the everyday ICT devices included within the questionnaire; landline and mobile phones, and desktop, laptop and tablet computers. When compared with older adults without dementia, people with dementia were found to use ICT for a less varied range of purposes, yet both user types were found to use these technologies primarily for communication between family and friends, and healthcare or care support services, fitting with the uses identified in Chapter 2. Other use included recreational activities such as playing games and Internet browsing, banking and shopping online, and using a mobile phone as a form of safety technology by utilising the ‘find-a-friend’ location service on an iPhone. Chapter 3 highlighted that both people with dementia and older adults without dementia use the Web via a range of ICT devices, for a range of purposes, including shopping, banking, information seeking and game playing. These purposes go beyond those identified in Chapter 2 (e.g. finances, transport planning). Chapters 6 and 7 also demonstrated that people with dementia use the Web for a range of purposes, including communication, shopping, banking, information searching and entertainment (Table 5).

10.2.1.2 Difficulties experienced with using technology and the Web

As discussed in Chapter 2 people with dementia experience difficulties with a range of technologies, from barriers preventing technology uptake, to accessibility and usability issues with the use of specific interfaces (Figure 5). Results from Chapter 3 showed that both people with dementia and older adults without dementia face difficulties using everyday technologies, often when interacting with the Web, and other software interfaces. Chapter 4 revealed the need for more research with regard to the use of web interfaces by people with dementia, to enable appropriate requirements to be designed (Arch and Abou-Zhara, 2008; W3C, 2008a). The review identified a range of interface elements that can present difficulties for people with dementia accessing and using the Web; icons, visual features and labelling, and layout and navigation. Chapter 4 concluded that minimal evidence-based knowledge is available about software interface accessibility and usability for people with dementia specifically, as no distinction was drawn about the user needs specific to people with dementia beyond those shared with older adults without dementia, nor classification of those needs as accessibility or usability requirements. These findings support the question raised by Haesner *et al.*, (2015), about whether there is a general difference in website usage between older adults with and without cognitive impairments, as recently published data shows age-related differences in ability to use websites successfully, but does not consider older adults with cognitive impairments.

Chapter 6 sought further knowledge on user needs specific to people with dementia, by comparing the experiences of people with dementia with older adults without dementia when using the Web, and the difficulties they experienced when doing so. Results from this study showed that people with dementia and older adults without dementia experience similar types of difficulties, with navigation problems being the core issue for both user types. Four navigational difficulty categories were developed to reflect the issues faced by both people with dementia and older adults without dementia; Unknown Structures, Distraction, Search Strategy Preference, and ‘Too Much or Too Many’. Each of these categories was linked to a number of specific design features that contributed to navigational difficulty. Each feature was explored to establish why they caused difficulty.

The impact that both physiological natural ageing, and pathological dementia changes have on cognitive abilities required for successful navigation were considered in relation to the difficulties encountered by people with dementia and older adults without dementia (Chapter 6, Section 6.4.2.7). The impairments in cognitive abilities caused by ageing and dementia were considered to explain how both user groups may experience similar difficulties with navigating web content, but to differing extents; people with dementia often experience a decline in all seven abilities required for navigation, whereas older adults without dementia experience a decline in just five, and to a lesser degree (underlined in the list below):

- Memory
- Cognitive map formation
- Attention/Concentration
- Perception
- Situational Awareness
- Verbal ability/Reading/Comprehension
- Reasoning/Decision making

Chapter 6 concluded that navigational difficulties encountered by older adults without dementia as usability issues are likely to be experienced by people with dementia as accessibility issues, reflecting their exacerbated impairments to cognitive abilities as a result of dementia. This supports the stance of Quesenbery (2009) who inferred that cognitive impairments can amplify mild usability annoyances experienced by users with full cognitive function into absolute barriers.

Chapter 7 enabled this conclusion to be tested, and for difficulties that present as accessibility issues for people with dementia to be identified (discussed in Section 10.2.1.3).

10.2.1.3 Web accessibility issues experienced by people with dementia

Chapter 4 identified elements of web content that have been found to cause difficulty for people with dementia as web users, but whether these difficulties were usability or accessibility issues was undetermined. The overlap and commonality in difficulties encountered by people with dementia and by older adults without dementia was identified in the second literature review (Chapter 4) and in the study presented in Chapter 6. This overlap was considered to be due to the commonly shared older age of participants, and thus the shared cognitive impairments due to ageing. In addition, whilst dementia can cause further impairments to abilities required for navigation beyond those impaired naturally by age, dementia also *exacerbates* the abilities impaired by age, so those ability impairments are shared, but to differing extents.

Difficulties identified in Chapters 6 and 7 were categorised by participants (people with dementia) into accessibility and usability issues (Section 7.4.3). Of the sixteen difficulties categorised as accessibility issues, eight had previously been identified in literature (Chapter 7, Section 7.4.3.4), but had not previously been directly classified as issues of accessibility. The remaining eight accessibility issues identified in Chapter 7 had not been identified within reviewed literature as being difficulties for people with dementia, and thus contribute to knowledge on the topic of web content accessibility issues for people with dementia.

Results of Chapter 7 also supported the theoretically anticipated relationship between self-reported level of cognitive impairment, and the web accessibility issues experienced by people with dementia (Section 7.4.2). People with dementia reporting minor, moderate or major impairments to the abilities required for successful navigation categorised more of the difficulties they encountered as accessibility issues, providing evidence that people with dementia experience more accessibility issues as their cognitive abilities decline, even when in the early stages of dementia.

Eight difficulties categorised as accessibility issues by the majority of participants in Chapter 7 were considered to be key issues that should be addressed within accessibility guidance if they are to be inclusive of the needs of people with dementia:

- Automatic re-directing
- Distracted by clutter
- Too many steps to follow
- Too many things to remember
- Too much content
- Too much text
- Cannot find a feature
- Cannot find the next menu option.

Current Web Content Accessibility Guidance (ISO/IEC40500:2012) was assessed for whether it addressed these accessibility issues, to establish how inclusive current guidance is of the needs of people with dementia, and thus addressing the second research question of this thesis (see Section 10.2.2).

10.2.1.4 Impacts of difficulties using the Web

The effects of facing difficulties using the Web were explored with people with dementia and older adults without dementia in Chapters 6 and 7, contributing to the understanding of the broader impact of such issues. Negative emotions were often cited as a response to experiencing difficulties when using the Web, including frustration and feeling overwhelmed, with participants often placing blame on themselves, rather than the technology interface. Experiencing these emotions and the negative impact these can have on the confidence and attitude toward web use, was shown to have an influence on future web use of both people with dementia and older adults without dementia, as shown in Figure 21. Exploring the surrounding issues of attitude toward Web use in relation to difficulties faced revealed that difficulties can negatively impact web use by both people with dementia and older adults without dementia, even when a difficulty is not an accessibility barrier to them. This is because encountering difficulties can reduce confidence in users and result in reduced engagement with the Web and the services it provides access to. These additional barriers to technology use, caused by difficulties with web content design fit with those difficulties identified for technology more broadly in literature (Chapter 2).

As discussed in Chapter 6, these findings fit with the Technology Acceptance Model (TAM), where perceived ease of use can directly affect the resultant intention and actual use of a technological system. These findings also fit with the Senior Technology Acceptance Model (STAM) (Chen and Chan, 2014 as cited in Shore *et al.*, 2018) shown in Figure 31, and offer considerations on how this model may be extended to include senior users with dementia.

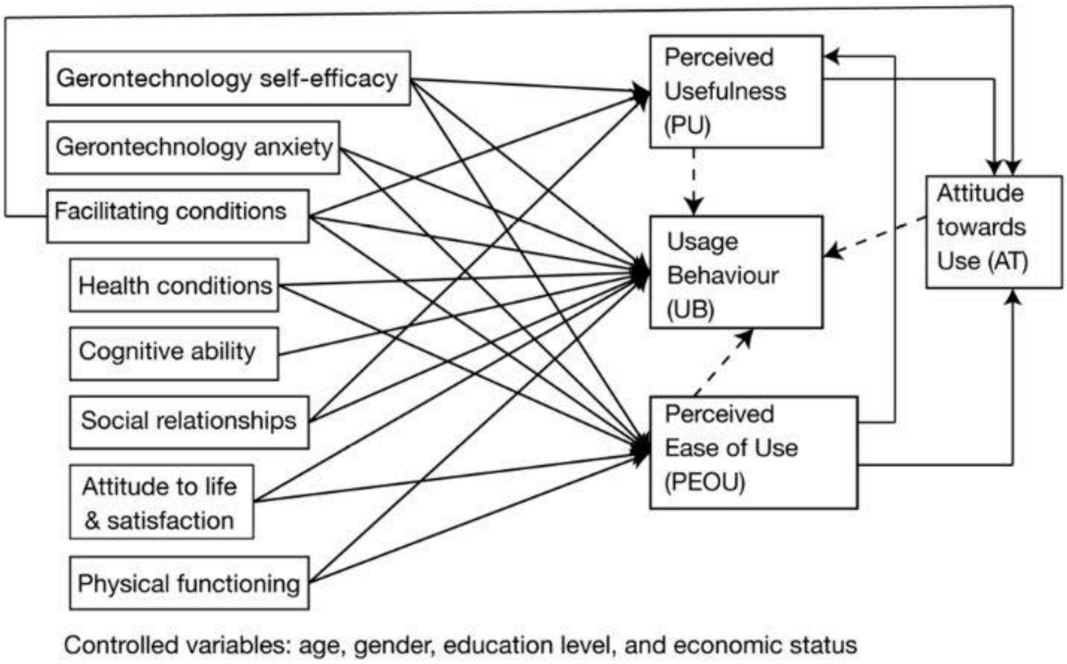


Figure 31 – Senior Technology Acceptance Model (STAM) (Chen and Chan, 2014, as cited in Shore *et al.*, 2018)

As within STAM, the web usage behaviours of people with dementia were found in Chapter 6 to be directly affected by facilitating conditions (i.e. Accessibility), health conditions, cognitive ability, and self-efficacy. Similarly, facilitating conditions were found to affect attitude towards use, and as a result, usage behaviour. The fit between STAM and the findings of this research once again demonstrates the overlap between the experiences of people with dementia and older adults without dementia as users of technology. An additional link between elements of STAM that was found in this research was that between cognitive ability and perceived usefulness of technology; the usefulness of technology was found by people with dementia to change as their cognitive abilities became impaired. For some people with dementia, the perceived usefulness of the Web increased as their cognitive abilities declined, as online services could replace non-digital services which were no longer usable by these individuals (e.g. online shopping in place of visiting a physical shop). For other people with dementia, the Web was perceived as less useful as their cognitive abilities declined, as they no longer required access to a number of services which were managed by their carers, such as banking, or travel bookings. The level of perceived use may be affected by both personal motivations, and/or the level of impairment an individual is living with. A further link was suggested by the findings, between level of cognitive ability and attitude towards use; people with dementia expressed that their decline in cognitive ability negatively changed their attitude towards web use, as they experienced greater difficulties in using the Web. These additional links between existing elements of STAM, show that whilst similar to the experiences of older adults without dementia, the experiences of people with dementia could be more complex and thus their needs must be considered if they are to be supported to both accept and use the Web.

10.2.2 The inclusivity of the needs of people with dementia within Web Content Accessibility Guidance – ISO/IEC40500:2012

An initial analysis of the Web Content Accessibility Guidelines standard (ISO/IEC40500:2012), was conducted in the knowledge that in its current form the standard claims to address [most of] the accessibility needs of older adults as a broader user group, yet acknowledges that there are gaps reflecting the lack of knowledge about accessibility requirements for users with cognitive impairments (W3C 2008). This analysis showed that of the eight key accessibility issues identified by people with dementia in Chapters 6 and 7, one is *fully* addressed by the standard in its current form:

- Cannot find a feature

; Four are *partially* addressed:

- Automatic re-directing
- Too many steps to follow
- Too much content
- Too much text

; and three are *not addressed at all*:

- Distracted by clutter
- Too many things to remember
- Cannot find the next menu option.

The analysis highlighted where gaps are in the standard for web users with dementia, and addressed the second research question of this thesis;

How inclusive are current Web content accessibility guidelines for supporting people with dementia to access and use Web content?

ISO/IEC40500:2012 does not adequately address the accessibility requirements of people with dementia in its current form, and requires improvement. These results further demonstrated the recognised gap in knowledge and guidance (Arch and Abou-Zhara, 2008; W3C, 2008a; WebAim, 2013).

Whilst some of the accessibility issues identified by people with dementia in Chapter 7 were not addressed within ISO/IEC40500:2012, analysis of other guidance showed that they were reflected in usability guidelines (Table 25). Many usability guidelines were found to directly address the needs of people with dementia, and thus it was proposed that such guidelines should be used as the basis of improvements to ISO/IEC40500 (Table 33). Such improvements, in the form of amended or new success criteria, new guidelines, or changes of conformance level of existing success criteria, are recommended for development using the improvement framework used by the World Wide Web Consortium (W3C) (Chapter 8, Section 8.4).

The recommendations described in Chapter 8 to improve the inclusivity of the needs of people with dementia within ISO/IEC40500, only represent *some* of the accessibility needs of people with dementia, as the studies were conducted with small participant numbers, and focused on issues identified by the majority of participants only, with a focus on navigational difficulties. As a result, the recommendations do not address all the issues identified in Chapter 7, nor all the issues found in the literature (Chapter 4) and further research is required to establish which other issues commonly cause accessibility difficulties for people with dementia. It is suggested that the approach taken in this research could be applied in a larger scale study involving more participants.

It is expected that in a larger scale study, that some of the other issues listed in Chapter 7 that were not experienced by the majority of the participant sample (e.g. ‘too many options to choose from’, ‘distracted by pop ups’, ‘distracted by flashing content’), may be commonly experienced by people with dementia, and thus need to be addressed in ISO/IEC40500. There are also a range of difficulties identified within the literature that are not currently addressed within ISO/IEC40500:2012, but were not identified by the participants in this sample; these may also be identified within a larger and more varied participant sample.

Improving the inclusivity of web content accessibility guidelines for people with dementia contributes knowledge on how these users can be supported to access and use the Web, thus enabling them to continue benefiting from digital services and information, and extending their ability to use the Web independently. However, the benefits of improving accessibility guidelines for people with dementia can be extrapolated to other web users with cognitive impairments, contributing further to an inclusive design approach to web accessibility (see Section 10.3).

10.3 Potential Benefits of Improving the Inclusivity of Web Accessibility Standards

Improving the inclusivity of Web Accessibility Standards by addressing the needs associated with the cognitive impairments of people with dementia, could support web designers to develop content that is accessible to people with dementia. The benefits of this extend beyond individual websites that meet the improved standard guidelines being more accessible to this user group. Other resultant benefits include the possibility of a more inclusive digital society, maintained independence of people with dementia, and improved web accessibility for other user groups who share impairment types with people with dementia – these broader issues are discussed respectively in sections 10.3.1, 10.3.2, & 10.3.3.

10.3.1 Inclusive Digital Society

Society has created an information and technology rich environment in which individuals have to perform daily activities in new ways and where the possibility of avoiding technology is limited (Emiliani, 2006 as cited in Nygård, 2008). As a result of this environment, technology that is inaccessible to certain users can lead to their exclusion from this digital society. This can result in exclusion from the range of services, information and activities to which the Web can provide access, and in turn can contribute to social isolation, and reduce independence (autonomy) for these users. Current Web Accessibility Guidelines do not fully consider people with dementia (Chapters 7 and 8), and thus web content designed to meet these guidelines may digitally exclude people with dementia. Improvements to these guidelines, to reflect the accessibility issues and needs of people with dementia would enhance the inclusivity of web content designed to meet the standard, and thus contribute to a more inclusive digital society in which people with dementia can continue to participate and benefit. Friedman and Bryen (2007) stated that the identification and implementation of web accessibility guidelines are a crucial step in achieving web accessibility to combat the digital divide experienced by people with cognitive disabilities.

Design guidelines represent an approach to achieving equity, in line with the principles of inclusive design. However, it is acknowledged that following guidelines alone cannot provide full accessibility, and that usability testing and involvement throughout the design process together with guideline application are recommended where feasible to achieve optimal accessibility (Rømen and Svanæs, 2012; Henry, Abou-Zahra and White, 2016; W3C, 2018b). A significant benefit of improving the inclusivity of web accessibility guidelines to reflect the needs of people with dementia is that when it is not feasible to recruit people with dementia for usability processes, the accessibility guidelines will help to ensure that a wide range of issues are adequately covered for this user type (W3C, 2016a).

Rosenberg and Nygård, (2014) found that it is important to support the continued use of everyday technology as long as it is valued and relevant to people with dementia. Improving the inclusivity of Web Accessibility guidelines would contribute to ensuring that the use of web content can be continued by people with dementia as their cognitive abilities decline, and as a result, enable them to use the Web as the major medium it is for information, communication and commerce. People with dementia may benefit from having improved access to a range of services they already do, or would like to use, including Internet banking and online shopping, (French, 2016; SCIE, 2017c; Lindqvist *et al.*, 2018), entertainment (SCIE, 2017a) and communication services (French, 2016; SCIE, 2017b). Accessibility of web content providing these opportunities to people with dementia, could not only enable them to contribute online and fulfil a role in the digital society, but also provide opportunities for social interaction, which could help to address the common isolation, loneliness and exclusion that people with dementia often face.

A third of people with dementia surveyed by the Alzheimer's Society (2017) reported feeling lonely, and research has shown that for older adults without dementia, Internet use can counter social exclusion and reduce loneliness (Age UK, 2015; French, 2016; Griffiths, 2017; O'Rourke, Collins and Sidani, 2018). If people with dementia were to be able to access web content as well as older adults without dementia, they too may benefit from web use countering their social exclusion, and in turn experience less loneliness. This would contribute to tackling loneliness and social isolation, which are known to be higher risks for people with dementia than older adults without dementia (Alzheimer's Society, 2018b) and contribute toward enabling people with dementia to live longer and more happily.

10.3.2 Maintained Independence

The provision of a more inclusive digital society would enable people with dementia to independently conduct several activities online for an extended period of time, despite their cognitive abilities declining, and thus continue to fulfil an independent role in society. Maintained independence often makes people with dementia feel happier (Alzheimer's Society, 2019) as ability to live independently is something that dementia affects over time as cognitive abilities decline. Rosenberg *et al.*, (2009) reported that vocational and social activities are usually the first to be affected by dementia, followed by instrumental activities of daily living (IADLs) such as managing finances, shopping, and transport, whilst personal activities of daily living (ADLs), such as feeding, last longer. The Web can offer support to people with dementia to continue with vocational and social activities, and some IADLs, providing the opportunity to retain independence as their cognitive abilities decline in the early-mid stages of dementia.

Accessible web content can not only support people with dementia to continue to use the Web as they previously had, but has the potential to enable people with dementia to continue to engage with everyday activities that they may otherwise have lost the ability to do. An example of accessible web content facilitating independence of an individual is for those who may no longer be able to navigate the physical world independently to go shopping, due to cognitive impairments affecting disorientation; people with dementia could replace the physical shopping task with completing shopping online, if the web content within the service was designed to be accessible to them.

Accessible web content and services can serve as a strategy to increase or maintain independence in people with dementia, and as a result, can also lower the level of stress experienced by their caregiver, as it reduces the tasks with which people with dementia needs support and assistance (Alzheimer Society of Canada, 2019). Minimising the demands on the time and energy of unpaid carers (usually spouses or adult children) is important, as the demands of caring for people with dementia can affect their own health, employment and well-being, which as consequences, all generate their own costs (Prince *et al.*, 2014). Enabling the independence of people with dementia to conduct everyday tasks online can help to lessen the demands on the time and energy of unpaid carers, and thus prevent the associated costs of these demands.

IADLs that are required for successful independent living, (e.g. shopping, making appointments, and managing finances) are often mentioned as tasks that can be supported with accessible ICT, as they are thought to be vulnerable to cognitive decline (Nygård, 2003 as cited in Fang *et al.*, 2015). However, as Keates, Kozloski and Varker (2009) describe, there are other areas of life endeavour that accessible web content may be able to support the independence of people with dementia, beyond extended ADLs (e.g. transport/travel, self-organisation, commerce/shopping); socialising, and entertainment. Maintaining independence in any activities of living, even for a short period of time before worsened cognitive impairment prevents this, can contribute to a happier, better quality of life for people with dementia, and reduced demands on caregivers. Accessible web content within service provisions can contribute toward this if content is designed to meet identified accessibility needs of people with dementia, and these are most likely to be met if they are reflected within the de facto guidance for Web Accessibility worldwide: ISO/IEC40500:2012.

10.3.3 Inclusive Design – Other Users

Designing web content to be inclusive of the needs of people with dementia will not only benefit people with dementia, as the well known principle in Accessibility is that *'improved access for one user group can carry across to improved access for everyone'* (Yaneva, 2016).This may be particularly true for user groups who share similar impairments and needs.

Different people with cognitive disabilities may have problems in the following areas:

- Memory
- Executive Functions
- Reasoning
- Attention
- Language
- Understanding Figurative Language
- Literacy
- Other perception, including motor perception
- Knowledge
- Behavioural

People with dementia are one group of people who have limitations in these areas, which can impact their ability to navigate and use web content, and these limitations may be shared with other groups, such as those with Autism Spectrum Disorder (ASD), Attention Deficit Disorder, or Down Syndrome, as well as those living with age-related impairments (W3C, 2015). For this reason, improving the inclusivity of Web Accessibility guidance to reflect the requirements of people with dementia could also address the same issues for other web users with similar cognitive impairments. The contribution of knowledge on the requirements of people with dementia may contribute towards better accessibility for other user groups for whom there has been minimal research, and thus ISO/IEC40500:2012 does not address their needs completely; e.g. ASD (Britto and Pizzolato, 2016; Raymaker *et al.*, 2019), and Down Syndrome (Alonso-Virgos *et al.*, 2018; Alonso-Virgós *et al.*, 2018), though this is suggested in acknowledgement that further research is needed to assess the commonalities and differences in requirements between users with differing cognitive impairments (Eraslan *et al.*, 2018).

As a result of accessibility guidelines that are more inclusive of the needs of people with dementia, web designers will have a tool available to assist them in designing accessible web content for a broader range of web users with diverse needs; designing accessibility for people with dementia will also be designing for other web users with similar cognitive impairments and accessibility requirements.

In addition to helping web users that fall under the umbrella term of ‘cognitive disabilities’, it would be expected that improvements to ISO/IEC40500 to reflect the needs of people with dementia would improve the accessibility and usability of web content for older adults without dementia also, as they were found to experience the same types of difficulties during web use (Study 2, Chapter 6). This improvement for older adults without dementia could enhance their web use experiences, as it is found that web designers do not currently always consider them as a user group (Gilbertson, 2014). Fang *et al.*, (2015) identified that people with Mild Cognitive Impairment (MCI) often have needs and impairments that fit between those of older adults without dementia and people with dementia. Therefore, it would be expected that improvements to ISO/IEC40500 for people with dementia would also benefit those with MCI.

It is not only web users with physiological or pathological cognitive impairment that may benefit from the improved guidelines reflecting the needs of people with dementia – users without diagnosis, or with temporary circumstantial impairments (e.g. distracted by environmental noise, or working with divided attention) are also likely to benefit. Abascal and Nicolle (2001) suggested that guidelines presented for inclusive design for HCI will contribute to a more inclusive design philosophy leading to more usable systems for all, and this principle would apply to guidance developed for web design for people with dementia. Accessible web content is an example of an innovation originally intended for people with disabilities, but that provides benefits to all people (W3C, 2019), much like other innovations in the physical society such as curb cuts (Abascal and Nicolle, 2001; Friedman and Bryen, 2007).

Whilst many guidelines intended for users with a certain impairment inadvertently benefit other users too, some guidelines contain contradictions when aiming to design web content for a range of users with conflicting requirements. An example of such a guideline is contained in the recommendations provided in Chapter 8 for accessibility for people with dementia (see Table 27). Guideline 6.5.2.2. '*Presentation should avoid excess information'*, when developed to meet the accessibility needs of people with dementia, by ensuring a simple layout and simple content within a web page, may result in other users – those who benefit from additional surrounding information – experiencing a reduced quality of user experience. From a designer's perspective, visual attributes can enhance users' experience of web content, by providing both aesthetic and contextual information – for example, an image in the background of related text. However, from the perspective of a user who is prone to distraction arising from this unnecessary information, such a feature can pose an accessibility issue. This is where web designers need to balance user needs, and work to prioritise design decisions or to provide options. In the example given, it has been recommended that the area of desired focus can be selected by the user, to hide the excess information. This will allow the content to remain accessible to people with dementia, whilst still providing opportunity for additional user experience features for users without impairment. It is important that accessibility needs are considered with primary importance, whilst acknowledging that other aspects of web design, such as visual content contributing to user experience, will also need to be considered and balanced within web content, to ensure it is truly inclusively designed. This inclusive approach should extend beyond the Web, and other interfaces that display information electronically (e.g. household appliance interfaces, touch screen ticket booking machines, self-checkouts) may also benefit from the knowledge developed on the accessibility needs of people with dementia, and resultant guidance.

10.4 Lessons learnt from including people with dementia as participants

Involving people with dementia as research participants is of paramount importance if their real experiences and needs are to be captured, but their involvement is complex in terms of creating research methods and processes that are accessible to them (Wilkinson, 2002; Hubbard, Downs and Tester, 2003; Hellstrom *et al.*, 2007).

Accessibility was considered throughout the research in this thesis, in terms of the methods and research processes of the studies conducted and their accessibility for participants. This consideration not only ensured that people with dementia could participate in the studies of this thesis, but also addressed the issues of consent and appropriate methods cited as barriers to the inclusion of people with dementia in research within the literature (Chapters 2, 3 and 5).

Chapter 3 (Section 3.3) detailed the development of ethical consent processes and documentation, designed to be accessible for people with dementia within non-medical research, as called for in literature (Brooks, Savitch and Gridley, 2017). Without this development, the inclusion of people with dementia as participants would not have been ethical, as conventional consent documentation formats and processes were found to be inaccessible for people with dementia (Chapter 3, Table 7). Reflective practice was used throughout the studies in Chapters 3, 6 and 7 together with participant feedback on the study processes, to capture weaknesses and successes in the applied methods and approaches used when researching with people with dementia. This culminated in a set of improved practice guidelines for the inclusion of people with dementia as research participants being developed (Chapter 9), which, together with existing guidance on the inclusion of people with dementia within research, are intended to inform and support researchers of future studies to include people with dementia in an ethical and effective way.

The following sub-sections (10.4.1, 10.4.2, & 10.4.3) discuss the value that directly involving people with dementia as participants can give to research, the challenges and limitations of their inclusion, and the resultant guidance that has been given as a result of including people with dementia in the studies of this thesis (Chapter 9).

10.4.1 Value of Including people with dementia as Participants

Including people with dementia as participants in research, and eliciting their opinions through qualitative methods, rather than their involvement being merely as a subject for observation, provides the opportunity to explore and understand their experiences. In this research, this meant that not only were the web content design features that caused problems for people with dementia identified, but the reasoning behind these difficulties could be explored with the users themselves, rather than making assumptions based purely on theory or intuition. Understanding the full experience of a person with dementia, enabled the causes and consequences of design accessibility issues to be explored, and insights from their own perspective to be included. Without the inclusion of people with dementia as participants, it is likely that some accessibility issues would have been identified, but the reasoning behind the problem would not have been fully understood, or could only have been assumed based on theoretical explanations; involving people with dementia provides the *why*, behind the *what* that is happening when they are interacting with the Web.

As mentioned in the literature, whilst the perspective of a carer is a valuable source of information, their accounts are their subjective experience and interpretation of a situation (Hendriks, Slegers and Duysburgh, 2015) and do not always concur with the accounts of people with dementia themselves (Hellstrom *et al.*, 2007). The inclusion of people with dementia highlighted this point within this research, and further evidenced the value that recruiting people with dementia as participants can provide. The carer of PWD02 had been unaware of some of the issues encountered by the people with dementia, and thus without exploring the topic with the people with dementia themselves, these accessibility issues would not have been identified – valuable data would not have been captured.

An additional value of including people with dementia, is the fulfilment and purpose their inclusion brings to the participants themselves. Many of the people with dementia involved in this research commented on how they had enjoyed taking part in the studies, and were pleased to be able to contribute to research which may in the future benefit others living with dementia. This supports the citations of those benefits reported in the literature (Hellstrom *et al.*, 2007; Slaughter *et al.*, 2007). This research also saw another previously noted benefit to people with dementia as a result of their involvement in research – the value of having their opinions and experiences heard and valued by an external interested party (Barnett, 2000; Clarke and Keady, 2002; Dewing, 2002; Hellstrom *et al.*, 2007). Many people with dementia expressed their appreciation that someone wanted to hear their experiences, rather than making assumptions of their needs; suggesting prior experience of not seeing their personal experiences reflected in the output of dementia research, or in the discussion of the needs of people with dementia.

Including people with dementia as participants within well considered and designed research can not only provide valuable insights into the ‘real’ experience of dementia, but can also provide a range of benefits for all concerned. The value that involving people with dementia offers is of paramount importance for encouraging other researchers to include them as participants, yet the challenges and limitations of doing so (see Section 10.4.2) must be considered and overcome to ensure the optimum value is gained by all parties when people with dementia contribute as participants.

10.4.2 Challenges and Limitations

The challenges and limitations of involving people with dementia as participants have been referenced throughout this thesis, with particular focus on:

- Recruitment (Chapters 3 and 5)

- Ethical consent processes (Chapters 3, 6 and 7)
- Data collection – interview methods (Chapters 5, 6 and 7)
- Research procedures (Chapters 3, 5, 6 and 7)

Whilst some of the challenges faced are frequently cited in literature (e.g. access to participants via gatekeepers, capacity for consent, and selecting research methods suited to the varied abilities of people with dementia), two key additional challenges were faced in this research which have been discussed less within published literature:

- Recruitment of an appropriate and representative participant sample
- Management of the contributions of carers

Whilst 99.2% of adults aged 16-44 in the UK are recent Internet users, only 46.8% of those aged 75+, and 83.2% of those aged 65-74 are (Office for National Statistics, 2019), showing that age often plays a role in web use. people with dementia recruited to this research fitted within the older adult demographic (60+), and as a demographic themselves, people with dementia often find using everyday technologies and the Internet more difficult as their dementia progresses (Malinowsky *et al.*, 2010; DEEP: The Dementia Engagement and Empowerment Project, 2013b), which presents a challenge when recruiting people with dementia to discuss such a topic as web accessibility, as the specific inclusion criteria often exclude many people with dementia to whom researchers have ethical access. In addition to this, many of the attendees of the community based dementia support groups that can be used as a route for recruitment live with symptoms that have progressed beyond independent living and the ability to communicate through speech effectively, thus also excluding these individuals from recruitment. As a result of the reduced number of potential participants due to these exclusions, the research in this thesis was challenged to recruit large numbers of participants that fully represented people with dementia as a broader group.

The recommendation given in response to this challenge of recruitment is to consider all possible routes for recruitment to enable optimum engagement with people with dementia, and to obtain an appropriate sample. Cridland *et al.*, (2016) discuss obtaining a representative group via routes of dementia research centres, community centres, and global advocacy groups, and this is considered the most appropriate approach for future research following on from the studies in this thesis, as the small sample size is a limitation of this research. However, as Newell & Gregor (2002, p.5) stated, '*when the user group includes older and disabled people, the range of functionality and characteristics of users can be so great that it is practically impossible to produce a small, representative sample of the user group'*. In addition, Savitch and Zaphiris, (2007, p.239) stated that, '*the lack of a truly representative user group should not stop designers and researchers seeking the views of people with dementia.* It is therefore believed that it is better to capture the views of people with dementia, despite smaller participant samples which may not represent the whole user group, than to exclude the needs of a user group on this basis, which would knowingly result in design exclusion. Therefore, whilst every effort should be made to recruit a representative sample following the advice of Cridland *et al.*, (2016), research with any group of people with dementia, despite their level of diversity, is valuable to improving understanding of design for this group.

This research was also challenged with managing the contributions of both people with dementia and carers during data collection for which they were both present, to ensure that both perspectives were gathered, without loss of any contributions from people with dementia due to carers 'taking over' or speaking on behalf of the person they care for (Chapter 3, Section 3.3.6.3.4). Recognising the importance of the contributions of both people with dementia and carers, and providing opportunity for these to be shared, whilst ensuring the voice of the person with dementia is heard is often a challenge, as carers can naturally begin to speak on behalf of people with dementia in daily life. It is suggested that carers could be interviewed separately, but there are ethical complexities in managing this:

1) People with dementia should be allowed to have a carer present during their own participation for support and assurance, but this may lead to the voice of people with dementia being interrupted if the carer is unclear on when their contribution is required.

2) People with dementia may not want their experiences discussed without their presence, and so ethically, the carer may only be able to contribute alongside the person with dementia for whom they care.

Ensuring the voice of people with dementia is not lost due to carer contributions was managed through the development of a specific role for carers (Chapter 5, Section 5.3.1.3.4) which was found to manage contributions well. However, a limitation associated with this, was that not all people with dementia chose to have a carer present during their participation, so carers' views were not always captured for comparison, and the evaluation of the carers' role was somewhat limited. However, the use of a specific role to direct carers in their contributions is included within the guidelines for improved practice presented in Chapter 9, as the evaluation of its use was found to be promising as an effective tool.

10.4.3 Improved Practice Guidelines

Guidelines for Improved Practice when including people with dementia as participants in research were developed and presented in Chapter 9 (Table 34).They covered the following aspects of research:

- Recruitment
- Consent processes and documents
- Data collection – interviews
- Research procedures

This set of guidelines was derived from the researcher's reflective practice of the involvement of people with dementia in this research, and participant feedback on the study procedures, and built on existing guidance in literature. New guidance, building on existing guidelines in literature included practical steps to ensure successful research procedures, such as the timings of research phases and the management of carer contributions. Guidance on how to design consent documentation for people with dementia contributes a new area of guidance beyond published guidelines, and the presentation of guidance to support the inclusion of people with dementia, provides a collective list format of guidelines not currently found in literature. The development of these guidelines highlighted the complexities of involving people with dementia in research, and the range of additional considerations needed to ethically and successfully facilitate their inclusion.

These guidelines are intended for use as the basis of developing accessible, dementia-inclusive study design, which will enable people with dementia to access and participate in research. However, the guidelines are not intended to be an exhaustive list of practice techniques, as it is acknowledged that like the commonly referenced Professor Tom Kitwood phrase says, '*once you've met one person with dementia, you've met one person with dementia'* (SCIE, 2015). Further experiences of involving people with dementia with different dementia diagnoses and impairments would therefore be expected to produce additional, nuanced guidelines, reflecting the individual nature of people with dementia and their experiences of living with their set of symptoms.

Chapter 11. Conclusions

11.1 Introduction

This chapter connects the overall findings to the research aims and objectives, to conclude this thesis. The chapter describes what are considered the key contributions of this research. The last section of the chapter proposes areas for future work.

11.2 Returning to the Aims and Objectives

The research in this thesis was conducted in response to the lack of research into everyday technology accessibility and lack of guidelines for web accessibility for people with dementia, identified in Chapter 1. This research aims to contribute knowledge on accessibility for people with dementia within two areas. Firstly, web content accessibility for people with dementia, and secondly, accessibility within research to support the inclusion of people with dementia as participants. The specific aims of this thesis have been, 1) to explore issues affecting people with dementia when navigating web content; and 2) to contribute toward more inclusive web content accessibility guidance.

These aims have been achieved through addressing the objectives of this research (detailed in Chapter 1, Section 1.4). The following sub-sections describe the research activities that enabled the objectives to be addressed. Each sub-section summarises the main findings and conclusions from these activities.

11.2.1 Objective 1

> *To understand the context and current knowledge of technology accessibility for people with dementia using systematic reviews of literature.*

This objective was achieved through two systematic literature reviews (Chapters 2 and 4) which enabled an understanding of the broader context of technology use by people with dementia, in addition to the identification of current knowledge of accessibility issues faced by people with dementia with both software interfaces (including the Web) (Chapter 4) and technology more generally. This knowledge provided direction for the empirical studies, which included the exploration and identification of technology use by people with dementia compared to older adults without dementia (Chapter 3), and accessibility issues faced by people with dementia when using the Web (Chapters 6 and 7) as well as the evaluation of inclusivity of the needs of people with dementia within accessibility guidance (Chapter 8). The empirical studies, with the main conclusions drawn from their results are detailed under objectives 3, 4 and 5. The main conclusions from the literature reviews relating to this objective were:

- Technology use by people with dementia has primarily been evaluated for assistive technologies; there is need to evaluate everyday ICT use by people with dementia.
- People with dementia face a range of obstacles which can affect both technology uptake and technology use, including: lack of awareness; high cost or poor availability; need for carer input; attitudinal; and design.
- Minimal evidence-based knowledge is available about software interface accessibility and usability for people with dementia.
- No conclusive guidelines were identified for designing dementia-inclusive interfaces, and within the recommendations found, little clarification of the differences between these, and recommendations given for older adults without dementia was provided, meaning that the accessibility requirements specific to people with dementia cannot be identified.

11.2.2 Objective 2

> *To explore the methodologies appropriate for the inclusion of people with dementia within research in the field of Human-Computer Interaction (HCI).*

To achieve this objective, literature was used as the basis for developing methodologies and research processes for including people with dementia within this research situated within the field of HCI. Key areas for consideration were identified: recruitment procedures; ethical consent processes; data collection methods; and research procedures.

The development and implementation of the methodologies and processes used were reflected upon throughout the empirical studies (Chapters 3, 6 and 7) using Reflective Practice as a tool. As a result, guidelines for the improved practice for developing research that is accessible and supportive of the inclusion of people with dementia as research participants were developed (Chapter 9). The main conclusions drawn from these activities were:

- The inclusion of people with dementia as participants in research can be supported when all aspects of research are considered with regard to their capabilities and potential impairments.
- Consent documents and processes can be developed to be dementia-inclusive, within the framework of the Mental Capacity Act.
- The role of carers and gatekeepers within recruitment, consent, and data collection phases need to be managed with regard to balancing ethical requirements and research needs. Development of a specific role for carers was found to address this need.
- Conventional HCI research methods need to be tailored to meet the need and capabilities of people with dementia, and may need adjusting to enable people with dementia with specific impairments to participate.
- Reflective Practice as a tool enables research methodologies to evolve and develop into their most appropriate form as a study progresses, and can contribute to further guidance on the inclusion of people with dementia in research.

11.2.3 Objective 3

To explore the (accessibility and usability) issues affecting people with dementia and older adults without dementia when using the Web.

To achieve this objective, two empirical studies were conducted (Chapters 6 and 7), to contribute toward the gap in knowledge within the area of web accessibility for people with dementia identified in the literature (Chapter 4). The first of these two studies focussed on understanding the experiences of people with dementia and older adults without dementia when using the Web, including identifying the purposes for which they used the Web, their attitude toward web use, and difficulties they encounter whilst interacting with web interfaces (Chapter 6). This study enabled comparison between the two user groups' experiences. The following are the main findings from this study:

- Navigation is a key issue for both people with dementia and older adults without dementia, with a range of design elements of web content contributing to these difficulties. Four concepts of navigational difficulty types were developed, which encapsulate the issues; Unknown structures; Distractions; “Too Much” or “Too Many”; and Search Strategy Preferences.

- Difficulties experiences by both people with dementia and older adults without dementia when using the Web can negatively affect user attitudes, user experience and future engagement with the Web.
- The types of issues encountered by people with dementia appeared to be the same as those experienced by older adults without dementia, but the extent to which these difficulties may impact web accessibility for people with dementia remained unclear. It was considered that the cognitive impairments of people with dementia may exacerbate the issues experienced by older adults without dementia (usability) into accessibility issues.

A narrative literature review was used to theoretically explore and seek to explain how the differences in cognitive ability impairments between people with dementia and older adults without dementia may relate to the extent to which difficulties experienced with web use present as either usability or accessibility issues. This is further explained within Objective 4.

The second of the studies addressing this objective focussed on the difficulties faced by people with dementia, with the aim of establishing which difficulties they face present as accessibility issues and thus should be considered within relevant accessibility guidance (Chapter 7). The following are the main results of this study:

- Many navigational difficulties caused by web content design were found to be experienced as accessibility issues by people with dementia, with different diagnoses and symptoms. Other difficulties were more commonly presented as usability issues, and did not present people with dementia with accessibility issues.
- Eight key accessibility issues were identified as important for inclusion within relevant web content accessibility guidelines:
    a. Automatic re-directing
    b. Too many steps to follow

    c. Too much content
    d. Too much text
    e. Cannot find a feature
    f. Distracted by clutter
    g. Too many things to remember
    h. Cannot find the next menu option.

- Of the 8 identified accessibility issues, 1 was found to be fully addressed by current guidance (ISO/IEC40500:2012) (*e*), 4 to be partially addressed (*a, b, c and d*), and 3 to be unaddressed (*f, g, and h*). This is further elaborated within Objective 5, but overall this study confirmed the necessity for improvements to the inclusivity of web content accessibility guidelines to reflect the experiences and needs of people with dementia.

11.2.4 Objective 4

To understand how cognitive impairments of dementia may impact Web navigation.

An important part of this research aimed to identify and distinguish accessibility issues and needs of people with dementia that differ from those of older adults without dementia, as existing literature did not often provide this differentiation (Chapter 4). Theoretically understanding how cognitive impairments of dementia may impact the ability to navigate web content when compared to the cognitive impairments associated with the natural ageing process, contributed to this differentiation. A narrative literature review established that whilst older adults without dementia experience impairment to 5 of the 7 abilities required for navigation due to natural ageing, people with dementia experience impairment to all 7, and to a greater extent that older adults without dementia in 5 of these; memory; attention/concentration; perception; reading/comprehension; and reasoning/decision making (Chapter 6). Part of the empirical study presented in Chapter 7 also contributed towards understanding how the impairments of dementia may impact web navigation, by considering the relationship between the impairments experienced by each participant with the accessibility issues they faced. The following conclusions can be drawn from the research activities associated with this objective:

- Of the seven cognitive abilities required for successful navigation of web content, older adults without dementia experience impairment to five. People with dementia experience impairment to all seven required cognitive abilities, and to a greater extent than older adults without dementia. It would therefore be expected that whilst people with dementia may face many similar navigational difficulties to older adults without dementia, they will do so to a greater extent. In turn, this may exacerbate usability issues (older adults without dementia) into accessibility issues, and thus have a greater impact on successful web navigation for people with dementia.
- The more of the abilities required for successful navigation that are impaired by dementia, the more accessibility issues people with dementia face. Therefore, the further dementia has progressed in an individual, the more difficult web navigation will become.

11.2.5 Objective 5

> *To assess/evaluate current guidance for web content accessibility in order to determine where inclusivity for people with dementia may be improved.*

An assessment of current web content accessibility guidance, in ISO/IEC40500:2012 '*Web Content Accessibility Guidelines (WCAG 2.0)'*, was conducted in Chapter 7, to determine how inclusive it was of the accessibility needs of people with dementia identified within this study. This assessment concluded that the standard's guidelines, in their current form, do not address all the accessibility issues faced by people with dementia.

An additional analysis was conducted, to explore how the inclusivity for people with dementia within ISO/IEC40500 could be improved. This analysis (Chapter 8) assessed usability guidelines, to determine whether they contained guidance that addresses the accessibility issues identified by people with dementia in Study 3 (Chapter 7). Guidelines were identified to address the accessibility issues of people with dementia, and these were used as the basis for recommendations for improving the inclusivity of ISO/IEC40500 to reflect the needs of people with dementia.

The analyses conducted in relation to this objective led to the following conclusions:

- ISO/IEC40500:2012 ‘Web Content Accessibility Guidelines (WCAG 2.0)’ does not comprise guidelines that address all the issues faced by people with dementia, and thus cannot be considered inclusive of their needs in its current state.
- Improvements to reflect accessibility needs identified by people with dementia are required to ensure the web accessibility standard is inclusive of these web users.
- Usability guidelines are found to address many of the accessibility issues experienced by people with dementia, and thus are recommended for inclusion within accessibility guideline improvements.

11.3 Contributions to Knowledge

This research has provided contributions to knowledge in Human Factors, Human Computer Interaction, and Inclusive Design domains. These contributions are outlined in Sections 11.3.1 - 11.3.4 . The last section (11.3.5) lists the dissemination of this research so far.

11.3.1 Web Use by People with Dementia

As discussed in the literature review (Chapter 4). much of the research on technology use by people with dementia has focussed on assistive technologies, designed specifically for people with dementia as users. Fewer studies have investigated everyday ICT (including the Web) use by people with dementia. This research contributes to understanding the ways in which people with dementia use the Web, and highlights its potential for enabling these users to engage in activities of daily living and leisure, which in turn could contribute to maintained independence of people with dementia as their dementia progresses.

This research has also demonstrated that people with dementia have an interest in, and motivation for, using the Web, contributing toward the current argument that technology has huge potential to support people with dementia in a range of ways and thus further research into this area is both justified and necessary.

11.3.2 Comparison of Web Use Experiences between older adults without dementia and People with Dementia

As identified in the literature review (Chapter 4), much of the research on web use by people with dementia, and the needs of this user group for this activity, do not differentiate between older adults *with* and *without* dementia. This research has employed literature review and empirical study (interviews) to explore the differences and similarities between the two groups, enabling comparison between people with dementia and older adults without dementia.

This comparison has highlighted that the experiences of both user types are similar in terms of the types of issues they face, but different in the extent to which such issues affect their experience of web use; older adults without dementia may face usability issues that affect user experience, but people with dementia may face accessibility issues as their dementia symptoms exacerbate the difficulties they encounter. This finding contributes to addressing the gap in research regarding the differences between how people with dementia and older adults without dementia experience using the Web. In addition, this contributes towards the inclusive design literature, by showing that designing for people with dementia is likely to benefit older adults without dementia too.

11.3.3 Web Accessibility Requirements of People with Dementia

As identified by the authors of the WCAG 2.0 guidelines, accessibility requirements of users with cognitive impairments (including people with dementia) are poorly understood, and thus are not represented well within guidelines for web content accessibility (Arch and Abou-Zhara, 2008).The literature review findings concurred, showing that minimal research has been conducted into identifying the accessibility requirements of people with dementia as web users (Chapter 4). Results of Study 3 (Chapter 7) confirmed that the accessibility issues identified by people with dementia are not addressed within the current guidelines within ISO/IEC40500:2012, and that improvements are required.

The results of this research contribute toward knowledge on the accessibility issues faced by people with dementia, and thus their requirements for web content accessibility, in addition to offering recommendations for how the inclusivity of web content accessibility guidelines could be improved to reflect the requirements of this user group (Chapter 8). These contributions to knowledge can be extended beyond consideration within design for people with dementia; as discussed in Chapter 10, the benefits to people with dementia as a result of improved web accessibility guidelines are likely to be shared with other web users with shared cognitive impairments, such as those with Autism, Mild Cognitive Impairment, and older users with impairments caused by natural ageing. A further extension of these contributions, is that this knowledge may also have bearing on other non-web HCI interactions, such as interface design of self-checkouts. Thus this knowledge contribution may support people with dementia, and users who share their impairments, in other interactions beyond Web use.

11.3.4 Development of Dementia-Inclusive Research Processes

Dementia-inclusive research processes have emerged from this research. The development of dementia-inclusive consent documentation and process facilitated the inclusion of people with dementia as research participants, and was found to be more accessible than conventional consent documents and processes. Reflective Practice used throughout the empirical studies of this thesis has culminated in guidance for improved practice for the inclusion of people with dementia in research, including guidance on the four key areas for consideration when developing dementia-inclusive, ethical studies; Recruitment; Consent Processes and Documents; Data Collection – Interviews; and Research Procedures.

As discussed in Chapter 10 (Section 10.4.3) the improved practice guidance developed throughout this thesis provides guidelines on which future research can be based, to practically contribute toward dementia-inclusive research processes, which facilitate and encourage the involvement of people with dementia as active participants. This contributes to the discussion of how to ethically involve people with dementia, as a vulnerable group, within research, to ensure their voice is heard.

11.3.5 Research Dissemination

As a result of the research conducted in this thesis, the following dissemination has been achieved so far:

- ALLEN, R.S., COOK, S., HIGNETT, S. and JAIS, C., 2017. Involving people with dementia in participatory design: ethical processes and consent for dementia research. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, Volume 13, Issue 7, p.156-157.
- ALLEN, R., COOK, S., HIGNETT, S. and JAIS, C., 2016. *The Use of Everyday Technologies by People with Dementia*. Presented at 11th Dementia Congress UK (UKDC 2016), Brighton, UK, 1-3rd November.
- ALLEN, R., COOK, S. and HIGNETT, S., 2016. *How do People Living with Dementia Use Technology?* Presented at the Healthcare and Society: New Challenges, New Opportunities. International Conference on Healthcare Systems Ergonomics and Patient Safety (HEPS 2016), Toulouse, France, 5-7th October, pp. 410-413.

11.4 Future Work

This research has highlighted a number of potential areas for future research that have come out of this thesis. These areas are outlined in the following subsections.

11.4.1 Furthering knowledge of navigational accessibility issues

This research has contributed to knowledge on accessibility issues faced by people with dementia when navigating web content. However, as stated in Chapter 7, the participant sample size was small, and thus not representative of *all* people with dementia; larger numbers would be likely to identify a broader range of accessibility issues, as would a more varied sample of different dementia diagnoses. Therefore, more research is needed to identify further navigational accessibility issues faced by people with dementia. This could be done by following the steps taken in this research, in a larger scale study which recruited participants with a wider range of dementia diagnoses.

11.4.2 Furthering knowledge of other accessibility issues

The knowledge of accessibility issues faced by people with dementia developed in this thesis has focussed on navigational difficulties. However, other types of accessibility issues experienced by people with dementia have not been explored, and this is an opportunity for future research. Chapter 6 identified difficulties experienced by people with dementia that may be found to present as accessibility issues, such as the font type used within text-based web content, and the complexity of language being problematic for comprehension; these could be explored further. In addition, within a larger, more varied sample (as described in Section 11.4.1) more issues are likely to be identified for further consideration. It is important that as many accessibility issues as possible are addressed within guidance, if people with dementia are truly able to access and use web content in an inclusive way.

11.4.3 Development of improvements to ISO/IEC 40500

As detailed in Chapter 8, the recommended improvements to ISO/IEC40500 need development into usable guidance. This development should follow the stages used by the W3C (as described in Chapter 8, Section 8.4). It is also recommended that these guidelines should be empirically tested with people with dementia, to ensure the guidance is valid and does address their accessibility needs sufficiently, as this is part of guideline development that is often found to be neglected (Zaphiris, Kurniawan and Ghiawadwala, 2007; Rømen and Svanæs, 2012).

Following improvements to the web accessibility guidelines, it is important that these become more widely used by web content designers if these improvements are to help people with dementia use web content in practice. One observation made throughout this research was the inaccessibility of the guidelines themselves. Therefore, it is recommended that within future research, the presentation and format of these guidelines is reconsidered, to make their use by web content designers easier and thus increase the likelihood of their use as standard practice.

11.4.3.1 Users with cognitive impairments

This research explored the accessibility needs of people with dementia, to identify where guidance could be improved to address the issues they face. However, it was identified in the literature that current guidance does not reflect the needs of users with cognitive impairments more broadly, either. Therefore, it is recommended that the process used in Chapters 7 and 8 could be used with other user groups (e.g. people with Autism) to identify their accessibility needs. As explored in Chapter 10 (Section 10.3.3), it is expected that some of these needs would overlap with those of people with dementia as some of their impairments may overlap, but that additional needs may exist due to the differences in their cognitive impairments.

11.4.4 Further development of Improved Practice guidelines

This research used Reflective Practice to build on existing guidance for including people with dementia as research participants, to develop a table of improved practice guidelines. It is recommended that the same tool should be used within future research involving people with dementia, to contribute to and further develop these guidelines. Practice guidelines are believed to be useful to support researchers to ethically and successfully include people with dementia in research, which in turn provides opportunity for their voices to be heard, their experiences to be understood, and thus, more likely that their needs will be met and designed for inclusively.

It is recommended that within future work, these guidelines could be formatted into a booklet for researchers seeking to engage people with dementia within their research. Not only would this provide researchers with a starting point for good practice of involving people with dementia, but it presents an opportunity to highlight the importance of web content accessibility guidelines for people with dementia too. Reference to the web content accessibility guidelines should be made within the guidance for improved research practice with people with dementia booklet. This would be of particular use when researchers plan to use online platforms for recruiting people with dementia to their studies. In addition, this would provide an additional opportunity to share web content accessibility guidelines within both academic and professional research communities, and as with the improved practice guidance, would encourage consideration of people with dementia throughout all aspects of research.

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Appendices

Appendix A. Full MMAT Table (Literature Review 1)

Study No.	Study Info.	Description of Study	Study Setting	Research Design	Sample Information	Incl/Excl Criteria	Outcome Measures	Main Findings	MMAT Score
	Author, Year		Place, field of study	Method/ approach used	# of people, mean ages, diagnosis etc.	Of potential participants	What was assessed & how		
1	Abbate et al., 2014.	Usability study of a wireless monitoring system.	Italy. Long-term care.	24/7 use of monitoring system with PWD.	N=4, AD, 75-92, MMSE below 12/30.	Unspecified.	Usability and acceptability, via 7 set parameters on a scale. Differences over time period noted.	Ergonomic and aesthetic modifications are necessary to improve the level of usability and acceptability. Design and development must be considered specifically for PWD before deployment.	**3** **75%**

2	Aloulou et al., 2013.	Evaluation of the performance and usability of an ambient assistive living (AAL) system in a nursing home.	Singapore. Nursing Home.	Real-life deployment of an AAL system. Observations during pre-deployment period. Patient observations and focus groups with caregivers.	PWD n=8 (78-92) Caregivers n=2	Inc= could give consent alone or through Legal Appointed Representative. Exc= life-limiting disease, or has a pacemaker.	System and caregiver logs, observations and focus groups with caregivers.	The system has the ability to detect abnormal behaviours.	**3** **75%**
3	Arntzen et al., 2014	Exploration of what characterises AT being beneficial to YPD in everyday life.	Norway, Domestic settings.	Longitudinal qualitative study. In-depth interviews and observations. Repeated every 3rd month for up to 12 months.	12 YPD (8 female, 4 male, 52-65) and 14 family carers (19-89). Mild-mod dementia (AD, FTD, D)	Inc: below 66yrs, diagnosed within 12 months, have a family carer.	Reflections of participant experiences. Phenomenological hermeneutical method of structuring and analysing data.	AT has to: Address practical, emotional & relational challenges, be better than established strategies, generate positive emotions, be reliable & trustworthy, be user-friendly, adaptable & manageable, interest & engage the carer.	**4** **100%**

4	Bewerntiz et al., 2009	Exploratory: feasibility of machine-based prompting to assist PWD.	Florida, US. Domestic (2) and day centre (9).	Quantitative descriptive. Evaluation of 3 self-care tasks using prompt counts and response counts.	11 PWD (7 female, 4 male) with mod dementia, community dwelling.	Inc: MMSE scores of 12-20.	Counts of number and types of cues, coded with responses gained. Observers comments included. Frequency counts by task and participant. Means calculated to seek trends.	Largely able to complete tasks with cognitive assistance. Need for this assistance is highly individual. Some preference shown for male synthesized voice cues. Suitability of visual cues still uncertain.	**3** **75%**
5	Boger et al., 2014.	Exploration of which ATs are in use, factors that affect use and gaps in support from multiple stakeholders.	Canada. Community settings.	Mixed Methods. Descriptive statistics of guided interviews, with qualitative data giving insights into quantitative findings.	Family Caregivers n=3 Occupational Therapists n=10 All female.	Inc= FC: live with PWD, report PWD as dependent for 2+ ADLs, fluent in English. OT:3months+ work with PWD, possess knowledge & familiarity of AT and have previously recommended or prescribed AT to PWD.	Interview data – Qualitative & Quantitative.	Common enablers (familiarity, ease of use, low cost, etc.) and barriers (no perceived usefulness or need etc.) of AT are identified. Many of these support previous studies by other authors. The comprehensive data could be used by many different stakeholders to target AT development, procurement, education & policy.	**75%** **(3)**

6	Boyd et al., 2015	Exploratory study of prompting formats for PWD.	Bath, UK. Homes of PWD	Quantitative Descriptive. Touch-screen computer trials scored to establish prompt type effectiveness.	9 pairs (1 PWD with 1 Carer). PWD: 4 female, 5 male, 73-86years, with mild-mod dementia of different types.	Inc: Functioning at the planned or exploratory levels in daily living and leisure activities according to the Pool Activity Level (PAL) instrument.	Scoring system to evaluate quantitatively the prompt formats and their effectiveness.	Text and audio prompts are clear and effective. Picture and video prompts require too much interpretation and can therefore be distracting. Different steps/tasks lend themselves to different prompt types. Meaningful language is key.	**3** **75%**
7	Brankaert et al., 2014	Evaluation of a smartphone interface for PWD.	The Netherlands. Homes of PWD.	Bi-daily questionnaire issues to evaluate experience and perspective of PWD and caregivers.	N=9 pairs	Unspecified.	Questionnaire findings and objective data about smartphone use.	Everybody tried actively to use the device, but only a few maintained using it. Barriers to successful use included design inconsistencies and insufficient battery provision.	**2** **50%**

8	Cahill et al., 2007.	Trial of AT in the homes of PWD, assessing their use and usefulness.	Ireland. PWD homes.	Exploratory descriptive design. Mixed methods used on questionnaire completion.	N=34. (PWD 7M/13F) + caregivers.	Inc= mid-mod dementia, 50+, MMSE min. 12/30, good general health, primary caregiver willing to participate. Exc= major psychiatric disorder, involved in other medical trials.	Semi-structured questionnaire. Descriptive statistical analysis & thematic analysis conducted.	Most devices needed a carer present to remind the PWD to use them, but in general were considered useful by PWD.	**50% (2)**
9	Chen & Leung, 2012	Exploration of the needs of PWD in the lost seeking devices and the problems they encountered.	Taiwan. Domestic environment.	Quantitative Descriptive. Interview (status quo analysis) and questionnaire survey. Analysed using descriptive statistics.	37 caregivers (20 female, 17 male. 28 – 86 years).	Inc: must care for a PWD above mild level and who has experienced disorientation.	Survey responses analysed with descriptive statistics (SPSS).	3 problems identified: poor information transmission, low user acceptance and individual material security anxiety.	**2 50%**

10	Ekström et al., 2015	Exploration of the possibilities and pitfalls of using personalised communication apps on tablet computers to support communication for PWD.	Sweden, Center for Dementia Research at Linköping University. Participants' home.	Quantitative descriptive, of studies with a qualitative methodological basis. Calculations performed to compare contexts in a valid way.	1 pair: Female with AD and her partner (M).	N/A	Comparison of two data sets; with and without the use of tablet. Communication timings and types compared between sets.	Increased communication when using AAC. Positive experience of using technology as an aid, but support was needed in every video session for the PWD to use the tablet computer.	**2** **50%**
11	Faucounau et al., 2009.	Exploration of the needs & perceptions of wandering PWD and their carers towards existing tracking devices, and their acceptability and usability; A Case Study.	France, Participants' home.	Qualitative; Interview.	1 PWD (M, 84, moderate AD, MMSE 12/30 score). 1 Carer (F, 68).	N/A	Participant experience and reflections discussed in an interview.	PWD: Feedback given about aesthetics being unsatisfactory. Carer: Malfunction and usage difficulties reported. Involving end-users in co-design of new tech is necessary for building tailored devices.	**3** **75%**

12	Gibson et al., 2015	Qualitative Study of everyday AT use by PWD and their familiies.	Newcastle, UK. Participants' homes, workplace and a dementia café.	Semi-structured interviews. Thematic analysis and constant comparative method.	N= 39. 13 PWD, 49-91 26 carers, 49-82	Inc: PWD: formal dementia diagnosis, capacity to give formal consent, live independently. Carers: currently or have experience of caring for PWD.	Interview transcripts analysed thematically using constant comparison method.	Private AT provision supplementing state provision of AT, is a key feature of mainstreaming AT services. Determining how everyday tech can be used in conjunction with AT within effective models of AT provision is a subject for future research.	**3** **75%**
13	González-Palau et al., 2013.	An examination of usability aspects of a cognitive and physical training platform, comparing these in healthy elderly, those with MCI and others with dementia.	Spain. Memory clinics or participants' living institution.	Training of platform, usability assessment using questionnaire. Comparisons drawn between cohort groups.	N= 180. 33 Mild dementia, 52 Mild Cognitive impairment, 95 older adults with no cognitive impairment diagnosed.	Inc= 60+ years, fluent in Spanish, not enrolled in other research. Exc= advanced dementia or other relevant psychiatric or neurological diagnosis.	Usability measures assessed by questionnaire of perception of the LLC platform.	PWD expressed more difficulties in learning how to use the system (41%). High scores found in all questionnaire sections, indicating good usability and satisfaction. Importance of evaluating immediate issues of design and acceptance by users is highlighted	**4** **100%**

14	Imbeault et al., 2014.	Evaluation of electronic organiser use by PWD (AD). Based on observation.	Canada, in 'real life' situ and laboratory.	3- step learning process, and errorless learning method. Pre- and post-intervention comparison.	N = 2 71, M 80, M with an MMSE score of 25/30.	Inc = AD diagnosis, aware of memory problems, motivated to participate. Exc= history of central nervous system deficit, significant medical condition or psychiatric diagnosis, history of substance abuse or sensory impairment.	Performance assessed on 4-point scale, with pre- and post-intervention scores compared. Visual graphical representation provided of learning curves found.	Positive effects found in relation to memory deficit issues from organiser use. These remained over time, despite disease progression. PWD (AD) can learn to use new technologies to compensate for memory deficit, which opens new opportunities for rehabilitation.	**3** **75%**
15	Jentoft et al., 2014	Exploration of the impact of AT on the lives of YPWD – a simple remote control.	Norway. Participants' homes.	Longitudinal qualitative study, using in-depth interview and observation. Situated learning approach used in analysis.	N = 8. 52-65yrs, 5Fem/3Male, MMSE scores: 16-28, mild-moderate dementia.	Inc= below 65 years, diagnosed in the last 12 months, family member willing to participate and willing to explore tech device in home.	Interview data on experience of introduced AT in everyday life analysed using phenomenological hermeneutical method, with thematic coding.	The remote successfully solved the challenges faced by YPWD with operating TVs, thus reducing stress for them and caregivers. A simple AT can have a large impact on the everyday life of YPWD. Support from caregivers and professionals is important for the	**3** **75%**

								learning process.	
16	Karlsson et al., 2011	Exploration of the complex issues involved with the use of a new user-driven digital assistive device by PWD	Sweden. Participants' homes.	Qualitative case study. Unstructured observations and interviews with PWD. Carer interviews. Content analysis in qualitative method.	N= 2, mild dementia. 1M, 80, MMSE: 22 1F, 60, MMSE: 17	Inc= mild dementia, MMSE score 17-25/30, living in own home.	Reflections of experiences and opinions within interviews and observations analysed by all researchers to establish key findings.	Even if PWD are incorporated in the development of the device, it is a process to integrate it into daily life. Self-image is important to tech acceptance and supporting the right level of needs throughout the process can help device integration.	**2 50%**

17	Kerkhof et al., 2015	Development process of using a memory aid to structure and support daily activities for PWD.	The Netherlands, small-scale group accommodation.	Qualitative methods. Individual interviews with PWD, focus groups with carers & staff. Analysed using Ritchie & Spencer's Framework.	PWD n=6 Carers n=5 Staff n=6	Unspecified.	Interviews and focus groups taped and transcribed. Analysed using Ritchie & Spencer's Framework.	Installation errors, limited ease of use and a lack of knowledge regarding the function and use of the memory aid were issues that prevented a successful implementation.	**3** **75%**
18	Labelle and Mihailidis, 2006.	Evaluation of an automated prompting system to facilitate hand washing in PWD.	Canada. Long-term care unit.	Single-subject research design of 4 phases to test intervention. Wizard of Oz method used.	N = 8. 7M, 1F, 78-88. 4 severe dementia, 4 moderate dementia.	Inc= dementia diagnosis, mod-severe, MMSE less than 19/30, requires hand washing assistance, responds to verbal cues, has consent from primary decision maker. Exc= admission in past 6 mths, other sensory deficits, history of physical aggression.	Scoring of interaction frequency required and steps completed without input from caregivers.	Able to complete more steps with fewer caregiver interactions. Audio-visual prompts reduced interactions required.	**3** **75%**

19	Lazar et al., 2016.	Feasibility study: Evaluation of a multifunctional technology system in a memory care unit (MCU).	USA. MCU.	Mixed Methods: Quant; evaluation of cognition, depression, QoL & resource utilisation. Qual; semi-structured interviews.	PWD in MCU: n=5, 4F/1M, Mean age 87.8 (mild-severe) Family members: n=4, 3F/1M, Mean age 64.3 Staff: n=7, 5F/2M, Mean age 31.7	Inc= PWD; 50+, English speaking. Fam; 18+, visit MCU monthly, English speaking. Staff; 18+, interact directly with PWD. Exc= PWD; legally blind. Fam & Staff; legally blind or significant hearing impairment.	Descriptive statistics on questionnaire data. Inductive and deductive thematic analysis on interview transcripts.	Benefits for PWD; enjoyment, interactions, connections with others and mental stimulation. Challenges included technical and usability issues.	**75% (3)**
20	Leuty et al., 2013.	Usability evaluation of ePAD, an AT used to engage PWD in creative occupations.	Canada, Care Therapy Facility.	Pragmatic mixed methods, with Qual. data being used to clarify Quant. results. Pilot test of a prototype.	PWD n=6, mean age 89.2, mean MMSE 16.5. Therapist n=6	Inc= PWD; 65yrs+, MMSE 10-24/30 (mild-mod), participating in art therapy program. Therapist; 2yrs+ experience of PWD in art therapy.	Comments on questionnaire analysed using direct content, using codes created from quant. data. Descriptive statistics provided for Likert scale questions.	ePAD found to be engaging by all participants, but prompts were not found to be effective.	**3 75%**

21	Lindqvist et al., 2013.	Exploration of how people with early Alzheimer's Disease became users of AT, and what the use of AT came to mean to them and their significant others.	Sweden. Home visits.	PWD provided with AT for 6 months. Semi-structured interviews conducted during the intervention period and constant comparative approach used for analysis.	N=10 5F/5M, 63-79, MMSE scores 15-28/30.	Inc= diagnosed with AD, interested in AT, min. MMSE score of 18/30.	Interview transcripts.	PWD perceived time and effort saved, worries and stress decreased, sense of safety increased. Could perform valued activities to a greater extent than before.	**3** **75%**
22	Malinowsky et al., 2010.	A comparison of ability to use everyday tech – PWD, MCI and OA.	Sweden. Participants' homes or communities.	Mixed methods. Observations with a scoring system and interviews.	PWD n=38 MCI n=34 OA n=45	All 55yrs+ MMSE (min): PWD 18/30 MCI 25/30 OA 27/30	Measurement of everyday technology assessment (META) used in observations. Computer measurement model used to generate ability measures for comparisons.	Management of everyday technology significantly more challenging for PWD and MCI than OA. PWD faced most challenges. This indicates potential exclusion of everyday activity participation and loss of independence risk.	**75%** **(3)**

23	Malinowsky et al., 2015.	Investigation of stability & change in perceived relevance and difficulty of everyday technology (ET), between OA with and without cognitive impairment.	Sweden.	Everyday Technology Use Questionnaire (ETUQ) Comparison of three sub-groups over two time periods.	ETUQ1: N=157 ETUQ2: N=118 Subgroups: Older Adults “ with MCI “ with dementia.	Inc= 55yrs+, use ETs, be motivated to participate. Exc= other diagnosis that could cause cognitive deficit or non-corrected sensory impairment.	ETUQ data analysed using Rasch rating scale model. Statistical outputs compared between time frames for each sub-group.	70% of ET considered to be equally or more relevant in ETUQ2. PWD have shown increased perceived relevance of ET. Many ETs perceived as easier to use – potentially due to increased habitual use.	**4** **100%**
24	Malinowsky et al., 2014.	Evaluation of potential use of e-health services for OA with and without cognitive impairment.	Sweden.	ETUQ delivered as an interview. Examined perceived access to and difficulty in use of 7 ET important for eHealth services. Comparison of 3 sub-groups.	PWD n=37 (Alzheimer’s) MCI n=37 OA n=44	Inc= AD diagnosis Exc= other diagnosis that could cause cognitive impairment (stroke, depression).	6 step rank scale in ETUQ, each eHealth tech received measure of perceived difficulty and each participant measure of perceived difficulty in ET use.	Perceived access to tech for PWD 30-97%. PWD lowest potential to access eHealth services. Cannot assume OA with cognitive impairment would be non-users of eHealth services.	**3** **75%**

25	Moyle et al., 2014.	Feasibility study of a telepresence robot.	Australia. Long-term care facility.	Mixed methods; semi-structured interviews, call records and video observational data.	PWD n=5, mild-moderate, 4F/1M, 79-89, Family members n=6 Staff n=7	Inc= dementia diagnosis, in long-term care, no significant hearing loss.	Key Focus areas: acceptability, implementation, practicality, integration, efficacy and adaptation. Interview data thematically analysed. Facial emotional response, engagement & visual cues.	Participants perceived this novel approach as a feasible option. Participants were also found to enjoy the experience, despite some technical difficulties being encountered.	**3** **75%**
26	Nugent et al., 2011.	Evaluation of video reminding technology for PWD.	Northern Ireland.	Usability data over 5 weeks, with qualitative pre- and post-evaluation questionnaire.	PWD n=4 (3F/1M, avg. 70 years) Carers n=4, (2F/2M, 45-77).	Inc= mild dementia, living alone, MMSE min. 18/30.	Questionnaire responses and prompt acknowledgement counts.	Most prompts acknowledged by PWD, but carers were found to play a significant role in the success of the solution. 14 days settling period was found to be average.	**2** **50%**

27	Nygård & Starkhammar, 2007.	Exploratory study to identify and characterise difficulties with and hindrances to using everyday technology.	Sweden. Participants' homes.	Open-ended interviews & observations. Ethnographically inspired. Data analysed using constant comparative approach.	PWD n=8, 5F/3M, 57-82, 7AD/1VD, MMSE scores 19-28/30	Inc= dementia diagnosis (pref. AD), mild-mod, living alone.	Data analysed using constant comparative approach, grouped into categories of problems.	Difficulties in 4 domains: encompassing conditions that interfere with the use of tech, deficiencies in knowledge and in the communication between users and their technology, and limitations in the use of instructions.	**4** **100%**
28	Olsson et al., 2012	Relatives' reflections on using ICT in dementia care.	Sweden.	Interview study, with purposive sample. Qualitative content analysis used to identify categories and themes.	14 spouses of PWD. 62-89, 8F/6M.	Inc= relative of PWD, having knowledge of or previously used ICT in dementia care, able to communicate in Swedish.	Data analysed inductively using manifest and latent qual. content analysis. Answers about perceptions & experience of ICT in care analysed.	3 categories. ICT- a support in daily life, ICT- internal & external conditions, ICT- to use or not to use. A theme was revealed throughout; shifting between different perspectives: my, your, and our needs for safety and security.	**2** **50%**

29	Olsson et al., 2016.	Description of a passive positioning alarm among PWD.	Sweden. Participants' homes.	Repeated informal interview study.	11PWD (mild AD). 5F/6M, 62-72, Average MMSE score: 25/30.	Inc= have mild AD, need/desire to be alone outdoors, able to participate in conversation.	Transcripts analysed using qual. content analysis, deductively. Coded into perceived advantages & concerns.	Participants perceived safety and security for both themselves & carers. Concerns about cost, usability and early introduction to the device expressed.	**3** **75%**
30	Patomella et al., 2011.	Exploration of what makes an ET easy or difficult to use for OAs with or without cognitive impairment.	Sweden. Participants' homes or nearby community.	Observation of PWD managing 27 ETs. Regression analysis used and predefined assumptions investigated.	116 OAs, 55-92. PWD: 38 MCI: 33 OA: 45	Inc= 55yrs+, active users of ET, sensory impairments must be corrected. MMSE min. scores: PWD17/30 MCI 24/30 OA 27/30	Management of Everyday Technology Assessment (META) used before statistical analysis conducted.	Less frequently used ET and those with more complex designs were more difficult to handle. ICT needs to be designed to be more user-friendly and less complex. Age & gender did not affect difficulty of use levels.	**3** **75%**

31 *Reference Chased*	*Riikonen et al., 2010.*	*Evaluation of effectiveness of safety & monitoring technologies for PWD.*	*Finland. Participant homes.*	*Interviews and observations throughout technology intervention period.*	*PWD (AD) n=25, 54-90, 5M/20F.* *Family Caregivers n=25, (5 65+)*	*Inc= AD, living at home, patients of South Ostrobothnia Health District*	*Interview data from PWD and family members.*	*Installed technology increased 'home time' by an average of 8 months, resulting in a postponement of need of institutionalised care. Therefore, technology is cost-effective.*	***3*** ***75%***
32	Rosenberg et al., 2009.	Perceived difficulty in ET use by older adults with and without cognitive deficits.	Sweden.	Structured interviews with everyday technology use questionnaire (ETUQ).	OA: n=93, 37M/56F, MMSE 24-30/30 MCI: n=30, 13M/17F, MMSE 20-30/30 PWD: n=34, 16M/18F, MMSE 16-29/30. All 55yrs+	Inc= living in own home. Exc= Vision impairment	Statistical analysis on ETUQ scores between 3 groups.	PWD lowest perceived relevance of ETs. PWD highest perceived difficulty in using ETs.	**3** **75%**

33	Rosenberg & Nygård, 2011.	Exploration of the actions and driving forces of those involved in the process of bringing AT into the lives of PWD.	Sweden. Participants' homes.	Grounded theory principles applied to a complementary case study approach. Observations and in-depth interviews.	3 PWD (2F/1M, 79-91) with significant others.	Inc= 55+, mid-mod diagnosis, live in own home.	Interview data analysed within 1 core category and 3 sub-categories.	Conflict between actors found. Difference in: choice of problem, choice of AT solution, role of AT and its adjustment and placement. The one who had decision power greatly influenced the process.	**3** **75%**
34	Rosenberg & Nygård, 2014.	Study of PWD and people with MCI – learning and using technology in intertwined process.	Sweden.	Interviews whilst using own technology, with META observation instrument being used.	PWD (AD) n=10 MCI n=10 56-87yrs.	Inc= 55+, user of ETs, willing to participate. MMSE scores: PWD: 17-30/30 MCI: 24-30/30	Grounded theory analysis into four categories.	A variety of management strategies used. Importance of supporting continued use of ET highlighted. 3 Categories: significance of others, communicating with ET and management strategies. These are intertwined in the process of using ETs.	**4** **100%**

35	Starkhammar & Nygard, 2008.	Experiences of using a timer device for a stove: people with memory impairment and their families.	Sweden.	Interviews & observations, analysed using grounded theory.	N=14, PWD (AD) n=3.	Inc= 65+, with memory impairment or caring for someone with memory impairment.	Qualitative findings from interviews.	Users explored and learnt how the device worked. Most felt increased sense of safety, but unforeseen difficulties were also encountered.	**2** **50%**
36	Tak et al., 2013.	Feasibility study; providing computer activities for PWD in nursing homes.	USA. Nursing homes.	Resident completed computer activity program (CAP) & 462 observational logs of CAP sessions were analysed.	PWD n=14. 61-102, 4 severe, 10 mild-mod.	Inc= 65+, dementia diagnosis, MMSE: 4-27/30, no change in psychoactive meds in past 30 days, 2+ weeks residency in the nursing home.	Monitoring log for each CAP session – time, engagement levels, assistance needed, reactions and barriers to engagement. Content analysis conducted.	PWD (mild-mod) preferred cognitively challenging games, PWD (severe) enjoyed watching slideshows with music. Some interface complexity and visual challenges were reported.	**2** **50%**

37	Topo et al., 2002	Exploration of telephone use by PWD and an evaluation of an easy to use phone.	Finland.	2 month test of phone. 4 interviews and a questionnaire.	PWD n=6, plus their spouses. 55-90, M.	Unspecified.	Interview notes and questionnaire responses.	Most problems experienced by PWD using telephones did not disappear when using the new phone design.	**2** **50%**
38 *Reference Chased*	Topo et al., 2004	Assessment of a music-based multimedia program for People with Dementia	Finland, Ireland, Norway, UK. Day care units.	Questionnaires, interviews,	PWD N=28 With 5 drop outs. Age 60-89. M=8, F=15.	Inc = sight and hearing good enough to use the technology.	Questionnaire responses and Interview data used for statistical analysis.	Multimedia products can be used in dementia care, if support is available and the design of the product takes into account the user requirements of PWD.	**2** **50%**

39	Wolters et al., 2015	Designing a spoken dialogue interface to an intelligent cognitive assistant (ICA) for PWD.	UK.	Focus Groups, transcribed and analysed thematically.	PWD n=6, OA=4, Carers n=1, Other n=1.	Unspecified.	Thematic analysis in Nvivo of focus group transcripts.	Voice and interaction style should be based on preference of users, not their carer. ICA should be able to adapt to cognitive decline.	**3** **75%**
40	Zmily et al., 2014.	Usability study – Spaced retrieval exercise using mobile devices for AD rehab – an integrated App.	Jordan. Residential Care Facility.	User test of 2 interface designs (one text-based, one graphics-based) on a tablet device.	PWD n=10, early AD, 6M/4F, Avg. age 75.	Unspecified.	Comparison of average correct answer scores for each interface. Statistically analysed.	Better performance, less workload, and better response time for graphics-based task compared to text-based task. PWD (early AD) could use mobile devices without prior experience, though initial settling was required before PWD felt comfortable with the technology.	**2** **50%**

Appendix B. Scoping Study Questionnaire

ID:____

Research Study:
Technology use of people living with memory loss or dementia

If you are living with memory loss or dementia, please complete this questionnaire about how you use technology.

Please indicate which products you use, by ticking the box next to each one that you use. If you do use any of them, please explain what you use them for.

Please tick to show which of these products you use.	✔	What do you use these products for?	
A home telephone 	☐	e.g. You may use a home telephone to call friends or family, or to book appointments... Carer	PWD
A mobile telephone 	☐		
A desktop computer 	☐		

Please tick to show which of these products you use.	✔	What do you use these products for?	
		Carer	PWD
A laptop computer 			
Tablet computer (e.g. iPad) 			

Thank you for your help.

If you would be happy to tell me more about how you use these products, please provide your name and contact details below.

Name ____

Contact Telephone Number ____________________________

Contact Email Address ______________________________

Alternative Method of Contact _________________________

____

____

Appendix C. Consent Documentation for People with Dementia

Hardy group

Loughborough University

Internet accessibility for people living with and without dementia

Adult Participant Information and Consent Form

This interview study is being conducted as part of Ruby Allen's PhD research at Loughborough University. This research is supervised by Sharon Cook and Professor Sue Hignett.

Please read and complete this form, by ticking whether you agree or disagree with the statements made, before taking part in the interview.

The purpose of this interview study is to explore how people with and without dementia experience using the Internet. Any differences in experience will be used to inform better web-design guidelines that will support the needs of people with dementia.

The interview will last up to 45 minutes. You will also be asked to complete a short task on a website, using a computer provided by the researcher.

If you have any questions about this study, please ask the researcher.

	YES	NO
The purpose and details of this interview study have been explained to me.	☺ ☐	☹ ☐
I have had the opportunity to ask questions about taking part in this study.	☺ ☐	☹ ☐

If you do choose to take part in the study, the interview will be audio recorded. The information you provide will be kept confidential.

Any information you provide will be kept anonymous to the researcher, and the interview recording will be stored securely until study completion in October 2018. After this date, the recording will be destroyed.

	YES	NO
I understand that any information that I provide will be kept confidential and anonymous.	☺ ☐	☹ ☐
I understand that my interview recording will be stored securely until October 2018 when it will be destroyed.	☺ ☐	☹ ☐

Completing this interview is voluntary, and you do not have to take part in this study. You can stop taking part at any stage, for any reason, and will not be asked to explain your reasons for not taking part.

You may withdraw your data from the study up to two weeks after the interview. After this time period, it will not be possible to withdraw your individual data from the research.

I understand that I do not have to take part in this study, and may stop taking part at any stage without having to explain my reasons for stopping. YES ☺ ☐ NO ☹ ☐

I understand that I have up to two weeks after the interview to withdraw my data if I wish to. YES ☺ ☐ NO ☹ ☐

I agree to take part in this study. YES ☺ ☐ NO ☹ ☐

Name ______________________________

Signature ______________________________

Date ______________________________

If you have any questions about this form, or this study, please contact the researcher or project supervisors using the contact details provided on the additional sheet.

Researcher's Signature ______________________

I have some more questions; who should I contact?

If you have any questions about this study, please contact **Ruby Allen**, the Main Investigator of this research:

Telephone: 01509 223 586 Email: R.S.Allen@lboro.ac.uk

Postal Address:
2.24 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

Alternatively, you may contact either of the project supervisors:

Sharon Cook
Telephone: 01509 226 927 Email: S.E.Cook@lboro.ac.uk

1.18 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

Sue Hignett
Telephone: 01509 223 003 Email: S.M.Hignett@lboro.ac.uk

2.10 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact Ms Jackie Green, the Secretary for the University's Ethics Approvals (Human Participants)
Sub-Committee:

Ms J Green, Research Office, Hazlerigg Building, Loughborough University, Epinal Way, Loughborough, LE11 3TU. Tel: 01509 222423. Email: J.A.Green@lboro.ac.uk

The University also has a policy relating to Research Misconduct and Whistle Blowing which is available online at http://www.lboro.ac.uk/committees/ethics-approvals-human-participants/additionalinformation/codesofpractice/ .

Appendix D. Consent Documentation for Older Adults without Dementia

Internet Accessibility for People with and without Dementia

Adult Participant Information Sheet

What is the purpose of the study?

The purpose of this interview study is to explore how older people with and without dementia experience using the Internet. Any differences in experience will be used to inform better web-design guidelines that will support the needs of people with dementia.

Who is doing this research and why?

This study is being conducted by Ruby Allen, a research student from Loughborough University, as a part of a PhD project. The research is supervised by Sharon Cook and Professor Sue Hignett.

Are there any exclusion criteria?

To participate in this study, you will need to:

- Be over 65 years of age, and
- Use a computer at least once a month.

If you do not meet these criteria, unfortunately you will not be able to participate in this study.

What will I be asked to do?

You will be asked to participate in an interview about your experiences of using the Internet. This interview will last no longer than 45 minutes. As part of this interview, you will also be asked to complete a short task on a website, using a computer provided by the researcher.

Once I take part, can I change my mind?

Yes. After you have read this information and asked any questions you may have we will ask you to complete an Informed Consent Form, however if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing.

However, once the results of the study are aggregated (two weeks after your participation) it will not be possible to withdraw your individual data from the research.

Will I be required to attend any sessions and where will these be?

You will be required to participate in one interview session. The researcher will travel to you, to conduct the interview in your home at a time convenient for you.

How long will it take?

The total time that your participation will take is no longer than 1 hour.

Is there anything I need to bring with me?

Participants do not need to provide any equipment for this study. The researcher will provide a computer device for you to use for the task completion part of this study.

What personal information will be required from me?

Your name and age will be required during your participation. If you wish to be contacted with the results of the study, you will also be asked to provide contact details to enable the researcher to contact you in the future.

Are there any risks in participating?

There are no anticipated risks in participating in this research.

Will my taking part in this study be kept confidential?

Any information you provide during your participation in this study will be kept confidential. All information you provide will be anonymised for data storage and analysis. The audio recording of your interview will be stored securely until study completion in October 2018. After this date, the recording will be destroyed.

Giving permission for the study to be photographed is optional. If you do give permission, these photographs may be used in publications of the research.

What will happen to the results of the study?

Following analysis of the data collected from interviews, the results of the study will be included within conference/journal papers, and within Ruby Allen’s PhD thesis. Where participants indicate an interest in receiving a summary of the study results, a summary document will be provided to participants upon study completion (*expected October 2018*).

I have some more questions; who should I contact?

If you have any questions about this study, please contact **Ruby Allen**, the Main Investigator of this research:

Telephone: 01509 223 586 Email: R.S.Allen@lboro.ac.uk

Postal Address:
2.24 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

Alternatively, you may contact either of the project supervisors:

Sharon Cook
Telephone: 01509 226 927 Email: S.E.Cook@lboro.ac.uk

1.18 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

Sue Hignett
Telephone: 01509 223 003 Email: S.M.Hignett@lboro.ac.uk

2.10 Loughborough Design School, Loughborough University, Leicestershire,
LE11 3TU.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact Ms Jackie Green, the Secretary for the University's Ethics Approvals (Human Participants)
Sub-Committee:

Ms J Green, Research Office, Hazlerigg Building, Loughborough University, Epinal Way, Loughborough, LE11 3TU. Tel: 01509 222423. Email: J.A.Green@lboro.ac.uk

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Loughborough University

Internet Accessibility for People with and without Dementia

INFORMED CONSENT FORM
(to be completed after Participant Information Sheet has been read)

Taking Part	***Please initial box***
The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethics Approvals (Human Participants) Sub-Committee.	☐
I have read and understood the information sheet and this consent form.	☐
I have had an opportunity to ask questions about my participation.	☐
I understand that I am under no obligation to take part in the study, have the right to withdraw from this study at any stage for any reason, and will not be required to explain my reasons for withdrawing.	☐
I agree to take part in this study. Taking part in the project will include being interviewed and audio recorded.	☐
Use of Information	
I understand that all the personal information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others or for audit by regulatory authorities.	☐

I understand that anonymised quotes may be used in publications, reports, web pages, and other research outputs. ☐

I agree for the data I provide to be securely archived anonymously at the end of the project. ☐

(Optional)
I give permission for the interview to be photographed, and for these photographs to be used in publications of the study. ☐

___________________	_________________	____________
Name of participant [printed]	Signature	Date
___________________	_________________	____________
Researcher	Signature	Date

Participant ID: _______

Appendix E. Recruitment Poster

Do you have dementia, or care for someone who does?

Would you like to tell us about your experiences of using the Internet?

Researchers at Loughborough University are looking for participants for a study, to explore how older adults with and without dementia experience using the Internet.

The study will include an interview and completing a short task on a website.

The interview will last 45 minutes, and the researcher will travel to you.

A computer will be provided for your use during the study.

To participate, you must:

- Be 65+ years of age
- Use a computer at least once a month

If you are interested in knowing more about this study, please contact:

Ruby Allen
email: R.S.Allen@lboro.ac.uk
phone: 01509 223 586

LDS 2.24 Loughborough Design School,
Loughborough University, LE11 3TU.

Appendix F. Reflection Form

Reflection Form

Any key observations made during contact with participants, when completing the consent forms and the questionnaires should be noted in this form.

Consent Form	
Language	
Format	
Questions Asked by Participant	
Support Required for Completion	
Other	

Questionnaire	
Language	
Format	
Questions Asked by Participant	
Dynamics between carer and PWD: Contributions made by each.	
Other	

Other comments on Method/Process (including potential improvements)

Appendix G. MMAT Information

Types of mixed methods study components or primary studies	**Methodological quality criteria (see tutorial for definitions and examples)**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	• Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

Appendix H. Full MMAT Table (Literature Review 2)

Study #	Study Info	Description of Study	Study Setting	Research Design	Sample Information	Inc/Excl Criteria	Outcome Measures	Main Findings	MMAT Score
	Author, Year		Place, Field of Study	Method/Approach Used	# of people, mean ages, etc.	Of potential participants	What was assessed and how		
1	Alm et al., 2007	Interactive entertainment system use by PWD.	Scotland	Questionnaire for professionals post VR environment. Interview for PWD post VR experience.	Environment:13 Professionals 5 PWD (2M, 3F) Activities: 6 PWD (2M, 4F)	N/A	Interview and questionnaire; data of experience of VR environment and activities	VR can provide a safe way to occupy PWD	2 50%
2	Astell et al., 2016	Effect of familiarity of games on the enjoyment of PWD	UK & Canada	2 games played and compared using a quantitative questionnaire	30 PWD (25F, 5M, 78-100yrs) MoCA scores 8-21	N/A	Questionnaires: enjoyment and learning patterns	Familiarity is not enough as a sole property to ensure that apps are dementia-friendly	3 75%

3	Boman et al., 2014	Usability of a videophone mock up for PWD	Sweden	Interviews and observations at home. Test of mock up in a laboratory	4 PWD & significant others. (2M, 2F, 66-74)	Inc= have dementia and able to participate in interviews and observations.	Experience of testing the mock up (interview). Analysed using content analysis.	PWD enjoyed using the mock up but some design features need to be addressed to overcome difficulties	3 75%
4	Boyd et al., 2014	Development & testing of a video-link for PWD	UK	Home testing of products and follow up interviews	10 PWD and carer dyads	N/A	Interviews of product testing experience	A usable video link was developed in response to difficulties encountered by PWD	2 50%
5	Fleischmann et al., 2011	Development and evaluation of personalised reminiscence for PWD	Israel	Usability tests each lasting 45 minutes	3 PWD (AD). 2M, 1F.	N/A	Usability testing with post-interview of experience and	Aspects of interface design can hinder usability for PWD; positioning	2 50%

		(AD)					opinions.	of infor, colours, icons used, etc.	
6	Freeman et al., 2005	Improving website accessibility for PWD (early)	UK	Participants testing websites, with Quant and Qual. analysis in counterbalanced order	5 PWD (m, 57-72)	Inc= dementia diagnosis. MMSE 18+	Behavioural observation and quant. self-reported measure of satisfaction. Thematic analysis of field notes	Clear recommendations for website improvements following identification of issues encountered on both sites	3 75%
7	Hattink et al, 2016	Usability and usefulness of an online portal for PWD and carers	Netherlands	Descriptive = observations, online survey, semi-structured interviews	6 PWD 6 Carers 6 Professionals	N/A	Interview, obs and survey. Based on SUS and User Satisfaction Ease of Use.	PWD found using the portal more difficult than other participants	2 50%

8	Mayer & Zach, 2013	Participatory design of an assistive tool for PWD	Germany	Prototype evaluation. Initial familiarisation with evaluation of static interface design.	4 MCI 1 PWD	N/A	Interviews and observations of interaction with the prototype.	Guidelines for how to design for PWD proposed.	2 50%
9	Sant'Anna et al., 2010	Computer accessibility for people with mild-moderate AD	France	Comparison of PWD and OA (NI) in use of keyboard, mouse pad and screen. Interviews.	10 OA (NI) 8 PWD 62-83yrs	Excl= Parkinsons, or MMSE less than 21.	Quant. analyses. Qual = degree of participation, engagement and enjoyment	PWD faced more difficulties than OA (NI). Guidelines recommended.	2 50%
10	Savitch et al., 2006	Involving PWD in the development of a discussion forum online	London	Focus groups – split by PC familiarity	7 PWD (2F, 5M, 57-82)	N/A	Focus group opinions themed into results	Text only interfaces are not appropriate for PWD	3 75%

11	Savitch & Zaphiris, 2005	Accessibility of web-based information for PWD	London	Analysis of 4 Alzheimer's Association websites using cooperative evaluation method	5 PWD (3M, 2F), 55-72yrs	N/A	Cooperative evaluation method – comparison of sites and evaluation against web design criteria for older users	It may be possible to elicit some info about what makes a site easy to use for PWD – more research needed	3 75%
12	Savitch & Zaphiris, 2006	Accessible websites for PWD; investigation into information architecture	London	Card sorting methodology to discover navigation design needs	10 PWD (8M, 2F). Comparison group of 8 information workers	N/A	Card sorting ability and selection. Analysed with IBM's EZ Sort software	HCI Methodology needs to be adapted when designing for PWD; menu hierarchies and navigation systems may not be suitable	3 75%

13	Span et al., 2015	Evaluation of an interactive web tool	Netherlands	Structured interviews, observations and participant logs	4 PWD 12 informal caregivers 3 care managers	Inc= mild-mod dementia, availability of 2 caregivers, willingness to use web tool.	Interviews and observations.	Usable web tool, but the interface needed further refinement for PWD	2 50%

Appendix I. Carer Consent and Data Collection Documents

Internet Accessibility for People with and without Dementia

Carer Participant Information Sheet

What is the purpose of the study?

The purpose of this interview study is to explore how older people with and without dementia experience using the Internet. Any differences in experience will be used to inform better web-design guidelines that will support the needs of people with dementia.

Who is doing this research and why?

This study is being conducted by Ruby Allen, a research student from Loughborough University, as a part of a PhD project. The research is supervised by Sharon Cook and Professor Sue Hignett.

What is my role, as a carer, in this study?

Your role as a carer present during data collection is to ensure the comfort of the person that you care for throughout the study. You will also have the opportunity to express your views on the study at the end of the interview being conducted.

What will I be asked to do?

You will be asked to monitor the comfort of the person for whom you care, during the interview being conducted. This may include notifying the researcher during the interview if you feel that the person may need a break from the study, or if you feel that the interviewee may be getting distressed.

You will also be provided with a feedback sheet to note down any thoughts you have on the study content or process, which can be discussed with the researcher at the end of the interview.

Once I take part, can I change my mind?

Yes. After you have read this information and asked any questions you may have we will ask you to complete an Informed Consent Form, however if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing.

However, once the results of the study are aggregated (two weeks after your participation) it will not be possible to withdraw your individual data from the research.

Will I be required to attend any sessions and where will these be?

You will be required to attend one interview session, to accompany the person that you care for during their participation. The researcher will travel to the participant’s home, to conduct the interview at a time convenient for you.

How long will it take?

The total time that your participation will take is no longer than 1 hour.

Is there anything I need to bring with me?

You do not need to provide anything for this study.

What personal information will be required from me?

Your name will be required during the consent process for this study. If you wish to be contacted with the results of the study, you will also be asked to provide contact details to enable the researcher to contact you in the future.

Are there any risks in participating?

There are no anticipated risks in participating in this research.

Will my taking part in this study be kept confidential?

Any information you provide during your participation in this study will be kept confidential. All information you provide will be anonymised for data storage and analysis. The audio recording of the interview will be stored securely until study completion in October 2018. After this date, the recording will be destroyed.

Giving permission for the study to be photographed is optional. If you do give permission, these photographs may be used in publications of the research.

What will happen to the results of the study?

Following analysis of the data collected from interviews, the results of the study will be included within conference/journal papers, and within Ruby Allen’s PhD thesis. Where participants indicate an interest in receiving a summary of the study results, a summary document will be provided to participants upon study completion (*expected October 2018*).

I have some more questions; who should I contact?

If you have any questions about this study, please contact **Ruby Allen**, the Main Investigator of this research:

Telephone: 01509 223 586 Email: R.S.Allen@lboro.ac.uk

Postal Address:
2.24 Loughborough Design School, Loughborough University, Leicestershire, LE11 3TU.

Alternatively, you may contact either of the project supervisors:

Sharon Cook
Telephone: 01509 226 927 Email: S.E.Cook@lboro.ac.uk

1.18 Loughborough Design School, Loughborough University, Leicestershire, LE11 3TU.

Sue Hignett
Telephone: 01509 223 003 Email: S.M.Hignett@lboro.ac.uk

2.10 Loughborough Design School, Loughborough University, Leicestershire, LE11 3TU.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact Ms Jackie Green, the Secretary for the University's Ethics Approvals (Human Participants)
Sub-Committee:

Ms J Green, Research Office, Hazlerigg Building, Loughborough University, Epinal Way, Loughborough, LE11 3TU. Tel: 01509 222423. Email: J.A.Green@lboro.ac.uk

The University also has a policy relating to Research Misconduct and Whistle Blowing which is available online at http://www.lboro.ac.uk/committees/ethics-approvals-human-participants/additionalinformation/codesofpractice/ .

Loughborough University

Internet Accessibility for People with and without Dementia

INFORMED CONSENT FORM
(to be completed after Participant Information Sheet has been read)

Taking Part	***Please initial box***
The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethics Approvals (Human Participants) Sub-Committee.	☐
I have read and understood the information sheet and this consent form.	☐
I have had an opportunity to ask questions about my participation.	☐
I understand that I am under no obligation to take part in the study, have the right to withdraw from this study at any stage for any reason, and will not be required to explain my reasons for withdrawing.	☐
I agree to take part in this study. Taking part in the project will include being present during interview, which will be audio recorded.	☐
Use of Information	
I understand that all the personal information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others or for audit by regulatory authorities.	☐

I understand that anonymised quotes may be used in publications, reports, web pages, and other research outputs. ☐

I agree for the data I provide to be securely archived anonymously at the end of the project. ☐

(Optional)
I give permission for the interview to be photographed, and for these photographs to be used in publications of the study. ☐

___________________ ________________ ___________
Name of participant [printed] Signature Date

___________________ ________________ ___________
Researcher Signature Date

Participant ID: _________

Loughborough University

Internet Accessibility for People with and without Dementia

Carer Participation

As a carer of an interviewee with dementia, we would greatly value your contribution to the study in the following three ways:

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1. **Help in ensuring the comfort and wellbeing of the person you care for.**

   This is of primary importance to us and so we would be grateful if you could let us know if:

- The interviewee is becoming anxious or distressed,
- The interviewee is becoming tired,
- The interviewee may benefit from a break from the study.

---

2. **Help in providing context to what has been discussed.**

   It is an important part of the study that the interviewee responds with their thoughts and opinions with no influence from other people. For this reason, we request that you do not interrupt or contribute verbally to the interview, but instead note down any points which you think are important to raise with us later.

3. **Help in designing the study process.**

   If you have any thoughts on the approach taken for this study (including the language used, and the structure of the interview), or suggestions on how this may be designed to be more dementia-friendly, please tell us below:

Which elements of the study worked well?

What could be improved, to make the study more dementia-friendly?

Thank you for your participation and assistance in this research.

Participant ID: ________

Appendix J. Study 2 Interview Schedule

Question	**Prompts**	**Rationale**
What do you usually do on the Internet?	- Do you contact family or friends? - Do you look up information? - Do you do shopping or book tickets?	Gather background on Internet use. Establish participants’ vocabulary when referring to web content.
How long have you used a computer for? The Internet for?		
[For People With Dementia only] Have you used the Internet differently since being diagnosed with dementia? [if Yes, Ask why they think this has changed]	- Do you still use the Internet for the same things as you did before you were diagnosed with dementia?	To establish whether dementia limits the potential use of software or alters the perceived need for Internet use.
Do you usually use the Internet independently? *[how has this changed?]*	- Do you always use the Internet alone, or with family/friends?	To establish whether web content interfaces are usually accessed independently.
Do you enjoy using the Internet? *[how has this changed?]*	- Do you find the Internet fun to use?	To gather attitude about using web content and establish whether it is a positive or negative experience.
Are you confident when using the Internet to do something new? [If no, ask Why] *[how has this changed?]*	- Do you ever try browsing new websites, or downloading new apps?	To determine whether participants feel they can use interfaces without being taught by someone else – i.e. can they be independent users.

Do you find the Internet easy to use? *[how has this changed?]*	- Do you ever find it difficult to know how to use a website? - Do you ever get frustrated?	To establish whether accessing and using web content is a positive or negative experience.

Web Content Use Task

I have a website I'd like you to use… www.nhs.uk/pages/home.aspx Could you find the information on this website about where and when to get the flu vaccination?		To observe navigation strategies and to identify the range of difficulties encountered by PWD and OAwoD when trying to navigate a site for information.
How do you feel about the design of that website?		
Which design features helped you complete the task?		
Which design features made it more difficult to complete the task?		
What could be changed about the design to make the website easier to use?		
AAA Level Features: - *Location of user in pages?* - *Link purpose?* - *Section headings to organise content?*	Could/did [insert level AAA feature] help you to navigate the website?	
On a scale of 1 to 5, with 5 being the easiest to		

navigate, how would you rate this website? *[Use visual aid]*		

What do you think makes websites easy to use? (in terms of their design)	- Which parts of the design help you to know how to use it?	To ascertain which design elements help a user to access or use web content.
What do you think makes websites difficult to use? (in terms of their design)	- Are you ever unsure how to use a website? - Do you ever get confused when using a website?	To ascertain which design elements can hinder a user's access to, or use of web content.
Do you find it easy to navigate around websites to find what you want to?	- Do you always find what you're looking for? - Do you ever get lost in a website?	To establish whether PWD and OAwoD feel differently about web content navigation.

Is there anything else you would like to add to what you've told me about how you experience using the Internet?

Would you like to receive a summary of the study findings upon study completion? *If yes – request contact details.*

Appendix K. Observation Form

ID: _______

Task Observation Form

Feature	Problem	Next Step Taken

Appendix L. Narrative Review of Cognitive Changes (Dementia and Natural Ageing)

Introduction

This literature review aimed to establish which cognitive abilities are required for successful navigation of websites, and to compare how these abilities are affected by both natural physiological ageing changes (older adults without dementia) and pathological changes of dementia (people with dementia). The results of this review will be used to explain, using theory, how the differences in impairment to these cognitive abilities may affect the level of navigational difficulties (usability/accessibility) experienced by older adults without dementia and people with dementia as web users.

The following objectives will be met to achieve the aim of this narrative review:

- Identify the cognitive abilities required for successful navigation within digital spaces (i.e. Websites)
- Identify how both natural ageing, and dementia change the abilities needed for successful navigation.
- Compare the impact of ageing and dementia on each of the abilities required for successful navigation.

Spatial Ability

Spatial navigation is a complex function that includes cognitive and perceptual processes – it refers to the ability to orient and to find the correct way within an environment (Rusconi *et al.*, 2015). Spatial ability is an important determinant of navigational performance (Burgess, Maguire and O’Keefe, 2002; Juvina and van Oostendorp, 2006; Marangunic and Granic, 2009), with high abilities resulting in more efficient and accurate navigational success (Ahmed and Blustein, 2006). Spatial ability is considered important for navigating not only the real world, but also in abstract information spaces, such as websites (Neerincx, Lindenberg and Pemberton, 2001; Herder and Juvina, 2004; Rotondi *et al.*, 2007; Marangunic and Granic, 2009; Wolbers and Hegarty, 2010), as there are clear parallels between navigation in physical space and electronic space (Mcdonald and Spencer, 2000).

Spatial navigation is particularly complex, as it is a '*multi-sensory process in which information needs to be integrated and manipulated over time and space' through the involvement of basic perceptual and memory related processes* (Wolbers and Hegarty, 2010). However, Kritchevsky (cited in Ahmed and Blustein 2005) specified that there are five broad categories of spatial functions; perception, memory, attention, mental operations, and construction. These are considered acceptable attributes within the community of psychology (Ahmed and Blustein, 2006) and contribute to the level of spatial ability that an individual has. These five spatial functions, all together, contain nine basic spatial skills, each of which can be impaired if an individual experiences damage to associated areas of the brain, and each of which individuals can display weaknesses or strengths in: these skills can be tested via a battery of cognitive function tests. Whilst each of these functions contribute to the overall spatial ability of an individual, and thus impact their spatial navigational ability, other cognitive abilities by similar names (e.g. memory) perform independently from the functions for spatial cognition.

Seven cognitive abilities were found to be commonly linked to navigational (spatial) ability for navigating the Web, and these are discussed in turn within this review:

- Memory
- Cognitive Map Formation
- Attention/Concentration
- Perception
- Situational Awareness
- Reading/Comprehension
- Reasoning/Decision Making

Physiological Ageing Changes

The decline of cognitive capacities is a normal part of human ageing and studies show that spatial abilities decline with age (Haesner et al. 2015; Gazova et al. 2012; Neerincx et al. 2001; Pak et al. 2008; Zakzanis et al. 2009; Gazova et al. 2013). In particular, allocentric impairment is observed in the elderly (Gazova et al. 2012) and it is plausible that these deficiencies in spatial processing are manifestations of age-related changes in the hippocampal and other neural circuiting (Moffat, 2009). In contrast, egocentric spatial abilities and navigation are not found to be as much of a pronounced impairment in older adults with the normal cognition of physiological ageing (Gazova et al. 2012). The decline in spatial ability is shown to be apparent in adults above 60 years, and the deficiency is increasingly evident after 70 years of age (Gazova *et al.*, 2013).

Pathological Dementia Changes

In the early stages of Alzheimer's disease (AD), people lose spatial and topographical orientation (Hettinga et al. 2009; Nedelska et al. 2012; Possin 2010; Verghese et al. 2017; Vlcek & Laczo 2014; Gazova et al. 2013; Morganti et al. 2013; Tu et al. 2017; Burgess et al. 2002). People with AD are frequently impaired in spatial ability, but people with Lewy body dementia (LBD) are usually more impaired in the early stages (Possin, 2010). In contrast, those with Frontotemporal dementia (FTD) may be relatively spared (Possin, 2010; Cerman *et al.*, 2016; Tu *et al.*, 2017). The subtle declines experienced by cognitively normal older adults are even more pronounced and have a greater impact on function in people with most types of neurodegenerative disease (Possin 2010; Vlcek & Laczo 2014).

Spatial memory is particularly poor for people with AD, with attention deficits believed to be the reason for this (Kessels, van Doormaal and Janzen, 2011). Spatial learning has also been found to be impaired in people with early stage AD, when compared to cognitively normal older adults (Gazova *et al.*, 2013).

Memory

Working memory, or short-term memory, is a cognitive function considered likely to play an important role in the use of websites, due to the types of tasks in which it is involved (Rotondi *et al.*, 2007). Working memory, which includes the visuospatial sketchpad, is involved in retaining and recalling information, essential for executing sequential tasks, making category assignments and recognitions, interpreting abstract concepts, and the creation of mental models (Rotondi *et al.*, 2007). It can be easy for a user to become lost in the Web, if they become unable to figure out where they are, how they got there, or where they want to be – all of which is dependent on the cognitive function of memory. The task of remembering one's position within a website and the comprehension of information on Web pages need to be conducted concurrently (Sharit *et al.*, 2009), which places great demand on an individual's working memory. As with spatial abilities, working memory capacity can be used to predict navigational performance: low working memory capacity is associated with increased probability of user perceived disorientation (Juvina and van Oostendorp, 2006).

Physiological Ageing Changes

Decline in working memory function is a normal part of physiological ageing (Juvina and van Oostendorp, 2006; Chevalier and Dommes, 2007; Moffat, 2009; Etcheverry, Terrier and Marquié, 2011; Gazova, Vlcek, *et al.*, 2012; Haesner *et al.*, 2015). Whilst other memory capabilities, such as those of semantic memory, can remain stable or even improve with age (Moffat 2009; Gazova et al. 2012), working memory can begin to show deficiencies making day to day tasks more challenging for older adults. This natural decline in working memory capacity and function can weaken their ability to process and manage information – particularly when task complexity is increased – with tasks such as reading and problem solving being affected (Chevalier and Dommes, 2007; Haesner *et al.*, 2015).

Pathological Dementia Changes

Memory loss is the most commonly known symptom of dementia (Burgess, Maguire and O'Keefe, 2002; Hettinga *et al.*, 2009), with impairment in episodic memory traditionally considered to be the first sign of AD (Serino *et al.*, 2015). People with AD also have difficulty learning new information and retaining it for more than a few minutes – an impairment caused by reduced working memory – an impairment experienced early in the course of the disease, together with executive dysfunction and attention deficits (Gazova et al. 2012). People with FTD exhibit variation in memory function, and thus memory capability cannot be used to diagnose this dementia type, unlike with AD (Tu *et al.*, 2017). People with LBD have greater impairment of working memory than people with AD, and an equally affected semantic memory, yet episodic memory is worse in AD (Calderon *et al.*, 2001).

Mental Model/Cognitive Map Formation

When acquired from navigation as a form of primary learning, spatial knowledge can be used to create cognitive maps (Wolbers and Hegarty, 2010). A cognitive map, or ‘mental model’ is ‘*a cognitive representation or schema of the organisation of information in a website that is the result of an iterative process that reflects a user’s cumulative understanding of a site and is updated as learning occurs’* (Dalal et al. 2000, cited in Rotondi et al. 2007). The creation and reference to cognitive maps of websites is of particular importance when navigating sites with deep hierarchical structures – a need that is reduced for the navigation of flat hierarchies (Rotondi *et al.*, 2007). The creation of cognitive maps is dependent on working memory ability, the visual-spatial sketchpad, and spatial abilities (Ahmed and Blustein, 2005; Rotondi *et al.*, 2007; Brouwers, 2013), and can influence the usability of a website considerably.

Physiological Ageing Changes

Older adults have been found to be slower and weaker at developing mental models, or cognitive maps, than younger adults by comparison (Neerincx, Lindenberg and Pemberton, 2001; Iaria *et al.*, 2009; Bennett and Giudice, 2017); a result of reduced spatial abilities and working memory capacity and capability. Some older adults retain the ability to form an accurate mental model, but face difficulties with utilising it when referring back to it with their working memory (Gilbert and Rogers, 1999). Even for those older adults who retain the ability to learn spatial information and form cognitive maps, there is evidence to suggest that these maps may exhibit greater decay over time as compared to younger adults (Bennett and Giudice, 2017), which results in navigational difficulties once previously formed maps become problematic to retrieve and access.

Pathological Dementia Changes

A preference for egocentric navigation in people with early-stage AD has been identified by Laczó et al. (2016), as they are specifically impaired in allocentric cues for navigation (Morganti, Stefanini and Riva, 2013; Serino *et al.*, 2015). However, egocentric navigation impairment has been found to be profound in people with AD too (Vlček, 2011). People with AD demonstrate a specific impairment in storing allocentric representations and using these for navigation (Serino *et al.*, 2015). In the task of Web navigation, users are required to use allocentric navigational strategies, which is a challenge for those who experience impairment with this. With reduced spatial abilities and memory as a result of dementia, the ability to develop cognitive maps will be impaired – perhaps beyond the difficulties experienced by cognitively normal older adults.

Attention/Concentration/Focus/Task-Set Switching

The ability to focus and concentrate selective attention – also referred to as '*task-set switching'* – has a positive effect on navigation (Small *et al.*, 2005). This ability has been found to be a strong predictor of search performance when navigating the Web (Sharit et al. 2004, cited in Sharit et al. 2009). Sustained attention and the ability to ignore distractions can impact Web use success (Rotondi *et al.*, 2007), as the need for frequent task-set switching can be a major mental load factor (Neerincx, Lindenberg and Pemberton, 2001).

Physiological Ageing Changes

Attention is another recognised cognitive function that declines in ability as part of the normal physiological ageing process (Haesner et al. 2015; Gazova et al. 2012; Moffat 2009; Neerincx et al. 2001; Bolstad 2001; Chevalier & Dommes 2007). There is a strong association between the ability to attend to, and concentrate on information, and working memory capacity. Older adults may be less able to suppress irrelevant information or distractions as they age, which can overload the working memory and thus interfere with the task being performed (Chevalier and Dommes, 2007). These effects have been observed in language comprehension and reasoning (Chevalier and Dommes, 2007). As a task become more complex, these difficulties become more pronounced (Bolstad, 2001). Furthermore, working memory can be overloaded by the need to switch attention between different information, which causes difficulty for older adults who have less capacity to switch between tasks (Neerincx, Lindenberg and Pemberton, 2001).

Pathological Dementia Changes

Research suggests that older adults with cognitive impairments experience diminished task performance in divided attention scenarios (Hettinga *et al.*, 2009). Reduced attention can negatively impact other cognitive abilities for people with dementia, such as working memory, and spatial memory (Kessels, van Doormaal and Janzen, 2011) and thus cognitive map formation. Attention impairments are experienced early in the course of AD (Gazova et al. 2012) and is a pronounced impairment for people with LBD (Calderon *et al.*, 2001; Possin, 2010).

Perception

Perception is one of the cognitive processes involved when navigating the Web (van Oostendorp and Aggarwal, 2015; Karanam, Oostendorp and Fu, 2016). As the use of the senses to acquire information or knowledge, perception of information guides an individual’s decisions and actions, and shapes beliefs of reality. For navigation, the required perceptual ability is primarily visual perception. Processes such as detection of borders or movement, and the detection of basic features such as colour, orientation and shape are required to enable basic perception of Web content, without which, a user may not be able to access or use a Web page or site.

Physiological Ageing Changes

Perceptual speed is known to decline with age (Bolstad, 2001; Haesner *et al.*, 2015). As a cognitive function, perception is required for an individual to attend to information, together with the physical ability to visually perceive information (Bolstad, 2001). Perception is a key function for adequate situational awareness, and thus poor perceptual speed can negatively impact an older adult's situational awareness; if an individual is unable to accurately perceive what is important in their surroundings, they will exhibit poor situational awareness at the initial perception level.

Pathological Dementia Changes

AD can impair visual processing functions, including motion perception, perceptual discrimination, and recognition of faces, objects and colours (Possin, 2010). Contrast sensitivity deficits are also found in people with AD (Possin, 2010), which can present challenges with tasks such as word reading and image discrimination. Visual acuity is relatively spared (Possin, 2010) but optic flow perception deficits are profound in AD (Vlcek 2011). Visual perception changes can be used to predict navigational performance of people with AD (Vlcek 2011), which is particularly relevant for the navigation of new environments, where perceptual abilities are more important than memory.

Different types of dementia can damage the visual perception system in different ways (Alzheimer's Society, 2018a) but can result in difficulties with detecting movement, changes to the visual field, and being less sensitive to contrast differences, amongst others. People with LBD have substantially greater impairment of perception than people with AD (Calderon *et al.*, 2001; Possin, 2010). Combined with memory deficits, visual perception impairment can result in spatial disorientation for people with dementia.

Situational Awareness

Situational awareness is a user's knowledge of their surroundings at a particular moment (Small *et al.*, 2005). The knowledge of situational awareness can be described in three levels: the perception of the environmental elements in relation to time and space, the comprehension of their meaning, and the projection of their status in the near future (Endsley 1995, cited in Neerincx et al. 2001). Poor situational awareness at the perception level can result in users struggling with navigation and becoming lost. Errors at the level of comprehension can result from poorly perceived data, and prevent users from achieving their navigational goals. For successful situational awareness, strategies are required that ‘encapsulate data’ to prevent users experiencing information overload (Small *et al.*, 2005). In addition, a fully developed mental model is required for adequate performance at the projection level (Neerincx, Lindenberg and Pemberton, 2001) and thus a poor understanding of the Web can contribute to difficulties with this level of this cognitive skill.

Physiological Ageing Changes

Older adults have lower situational awareness when compared to both younger and middle-aged adults (Bolstad, 2001; Caserta and Abrams, 2007). This ability is related to other cognitive abilities that are also affected by age – reduced attention, reduced working memory capacity, and slower perceptual speeds. In addition, older adults report physical abilities – vision and useful field of view – which can impair their situational awareness (Bolstad, 2001). It is believed that situational awareness is most reduced for older adults in the initial level of perception (Bolstad, 2001), which is potentially as a result of reduced perceptual speed through ageing.

Pathological Dementia Changes

Whilst no literature has been identified that directly assesses the impact that dementia symptoms have on situational awareness, the reduced cognitive abilities that people with dementia experience (e.g. reduced perception, poor attention and declining working memory) would have an impact on this ability. Caserta & Abrams (2007) identified that reduced cognitive abilities such as these would make a situational awareness dependent task more difficult for older adults with age-related declines in cognitive function, and as people with dementia experience exacerbated declines, it would seem reasonable to consider that people with dementia would face further difficulties with situational awareness.

Verbal Ability/Reading/Comprehension

Measures of verbal ability are found to be a strong predictor of performance when seeking information online (Sharit *et al.*, 2009) and the cognitive processes of reading and comprehension are required when navigating the Web (van Oostendorp and Aggarwal, 2015; Karanam, Oostendorp and Fu, 2016). During the process of Web navigation, users have to comprehend and understand visible hyperlinks on the page they are currently on, but also relate these to their previously chosen hyperlinks (van Oostendorp and Aggarwal, 2015). Without the ability to read or comprehend text, navigation can become particularly problematic as websites are hyperlink based, and thus without the ability to read and comprehend these, a user could quickly become very disoriented within the Web.

Physiological Ageing Changes

Whilst natural ageing has widespread effects on cognition with declines exhibited in many abilities, language comprehension is preserved (Samu *et al.*, 2017). Comprehension is varied in all adults, even from a younger age, but remains at an adequate level throughout ageing (Beni *et al.*, 2003). Vocabulary can even improve throughout ageing (Samu *et al.*, 2017) and can even be used with reading knowledge and experience to compensate for other abilities that decline with age, such as working memory (Beni *et al.*, 2003).

Pathological Dementia Changes

Semantic dementia, a variant of FTD, can result in a progressive loss of knowledge about words and objects, subtle language deficits, or less of semantic information about visual information(Garrard and Hodges, 2000; Possin, 2010; Bott *et al.*, 2014). For people with AD, language often is not affected until later on in their disease progression (Gazova, Vlcek, et al. 2012) but for these people, it has been suggested that they may have difficulty not only with single-word comprehension, but also in differentiating between items within the same semantic category (Martin and Fedio, 1983). Whilst language deficits are not one of the commonly considered impairments of any dementia type, declines in comprehension or knowledge of words could cause a considerable difficulty when navigating a Web formed of hyperlinks.

Reasoning/Decision Making/Problem Solving

Reasoning, as a cognitive ability, is a predictor of performance when navigating to find information on the Web, even for simple problems (Sharit *et al.*, 2009). As an action of thinking about something in a logical way, in order to form a conclusion or judgement, or making a decision, reasoning is essential for a user to navigate through successive pages, or sections of pages on the Web. Reasoning is essential for an individual to have the ability to make decisions, whereby a user must identify and choose between alternative options and for a person to solve problems. All of these are abilities required for successful navigation of the Web (van Oostendorp and Aggarwal, 2015; Karanam, Oostendorp and Fu, 2016), as they result in the ability to problem-solve; something which enables a Web user to achieve their goal. Inductive and deductive reasoning can both by used when navigating the Web, both within its structure and its content, but the abilities to perceive, comprehend and remember the options available are prerequisites for reasoning and decision making within Web navigation. These actions of thinking – reasoning, decision making and problem solving – are a group of essential cognitive abilities if a user is to navigate with purpose and success through websites and Web content.

Physiological Ageing Changes

Older adults are not reported to experience significant deficiencies in the abilities to make decisions or solve problems specifically. However, other changes they experience as a result of ageing, such as reduced attention, have been observed to be associated with reasoning (Chevalier and Dommes, 2007). Being easily distracted and having reduced working memory could result in slower decision making or problem solving for older adults but this has not been evidenced in literature as other changes in cognitive abilities due to ageing have.

Pathological Dementia Changes

Deficits in problem solving by people with AD are documented and are considered to exist due to reduced ability to distinguish relevant from irrelevant information, and reduced ability to structure a decision plan (Vlček and Laczó, 2014). Judgement and executive functions decline with AD progression (Possin, 2010; Vlček, 2011), and whilst they may not impact navigational abilities in the early stages, they can cause considerable challenges later on for people with AD.

As perception, comprehension and memory are prerequisite abilities for reasoning and decision making, people with dementia experiencing profound difficulties with these may then also struggle with any of these actions of thinking.

Summary

The literature has identified the effects of natural ageing on the cognitive abilities required for successful navigation, as contributors to overall spatial ability. The literature has also identified the comparative changes to these abilities, caused by dementia, for most of the abilities. Dementia is found to present worsened cognitive impairment than that caused by natural ageing alone for many of the abilities required for spatial navigation, as detailed in the following table:

Cognitive Ability	Changes through Ageing?	Changes through Dementia?
Spatial	Yes	Worse
Memory	Yes (Working memory)	Worse (+Episodic, +Semantic)
Cog. Map Formation	Yes (Slower)	*Unknown* (Presumed Worse)
Attention/Focus	Yes	Worse (LBD, AD)
Perception	Yes (Slower)	Worse (LBD, AD) (Discrimination, movement, contrast)
Situational Awareness	Yes	*Unknown* (Presumed Worse)
Reading/Comprehension	No	Yes (FTD)
Reasoning/Decisions…	No (Possibly reasoning)	Yes (due to worse perception, comprehension, memory)

Dementia is known to present more impairment to five of the seven abilities required for successful web navigation when compared to natural ageing changes:

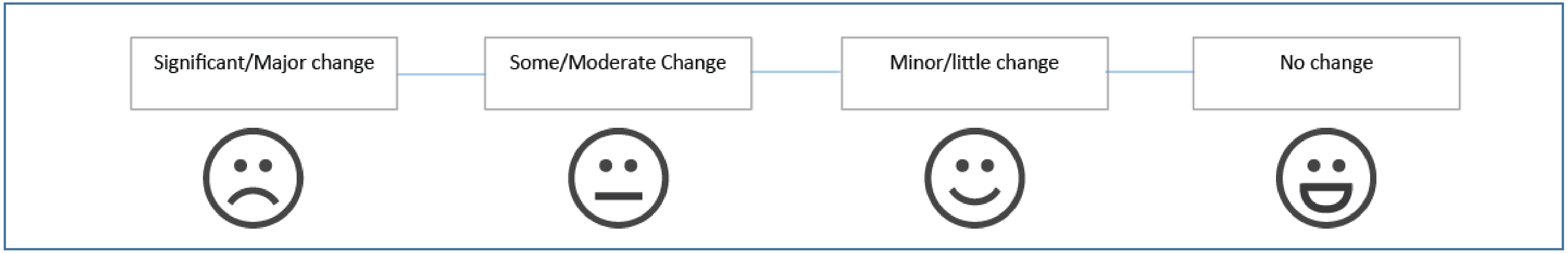
- Memory
- Attention/Focus
- Perception
- Reading/Comprehension
- Reasoning/Decision Making

Spatial ability, overall, is known to be more challenging for people with dementia than for older adults without dementia, and presumed worsening of the other two abilities (Situational Awareness and Cognitive Map Formation) can be drawn from the links between abilities identified in the literature. It would therefore, be reasonable to conclude that people with dementia will face similar navigational difficulties to older adults without dementia much of the time, but that these difficulties will be more challenging for people with dementia due to their exacerbated impairments to the required cognitive abilities.

Appendix M. Study 3 Interview Schedule

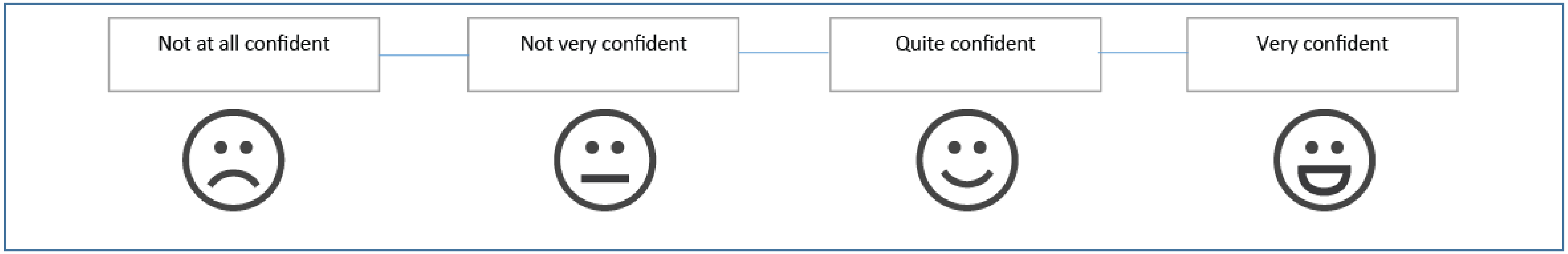
Question	Prompts	Rationale
What do you usually do on the Internet?	- Do you contact family or friends? - Do you look up information? - Do you do shopping or book tickets?	Gather background on Internet use. Establish participants’ vocabulary when referring to web content.
Have you used the Internet differently since being diagnosed with dementia? [if Yes, Ask why they think this has changed]	- Do you still use the Internet for the same things as you did before you were diagnosed with dementia?	To establish whether dementia limits the potential use of software or alters the perceived need for Internet use.
It’s important for us to understand as much as we can about your experience of using the Internet as someone with a dementia diagnosis – would you be able to tell us which type of dementia you have been diagnosed with? [and when?]	N/A	To gather information about the specific dementia diagnosis for each participant. Establish which symptoms may be experienced by this participant before specifically asking about their symptoms (based on current knowledge from literature and training of dementia types and related symptoms), which will enhance the understanding of the participants’ responses.
Could you tell us about any symptoms of dementia that you experience? *[note any which map onto navigation cognitive ability cards]* Could you tell us whether any of them change the way you use the Internet?	- Memory? - Decision making? - Navigation? - Concentration? - Learning capability?	To gather information about the specific symptoms that people with dementia experience, and how they find these can change their Internet use (e.g. memory impairment can make Web navigation more challenging). This will enable existing guidance for Web design to be analysed in terms of the impact on Internet use that symptoms have for people with dementia.

There are some abilities in particular which dementia is known to change over time, which we are particularly interested in. Could you please show us on this scale, how much each of these abilities have changed for you?	*Show cards for navigation cognitive abilities. Can be discussed with carer.*	To gather information on the extent the participant has experienced changes to relevant cognitive abilities, which will provide context for difficulties they may encounter with Web navigation.

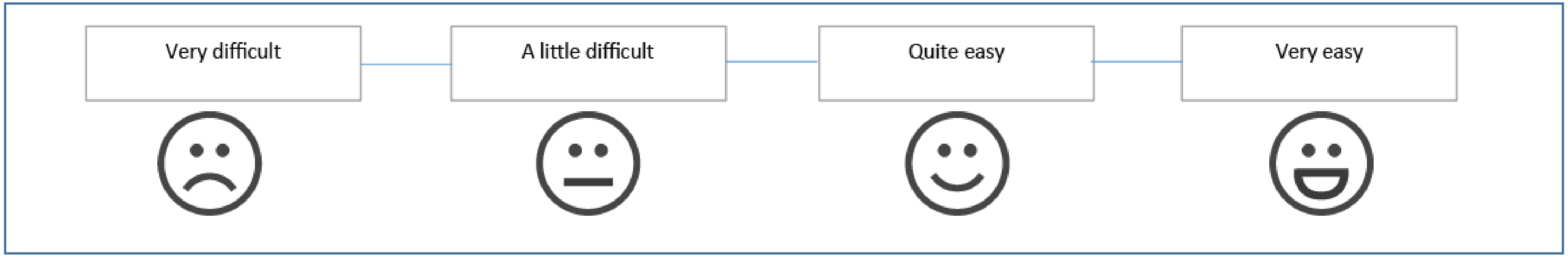


Now I'd like to ask more about your use of the Internet. Do you usually use the Internet independently? *[how has this changed?]*	- Do you always use the Internet alone, or with family/friends?	To establish whether web content interfaces are usually accessed independently. [Context]

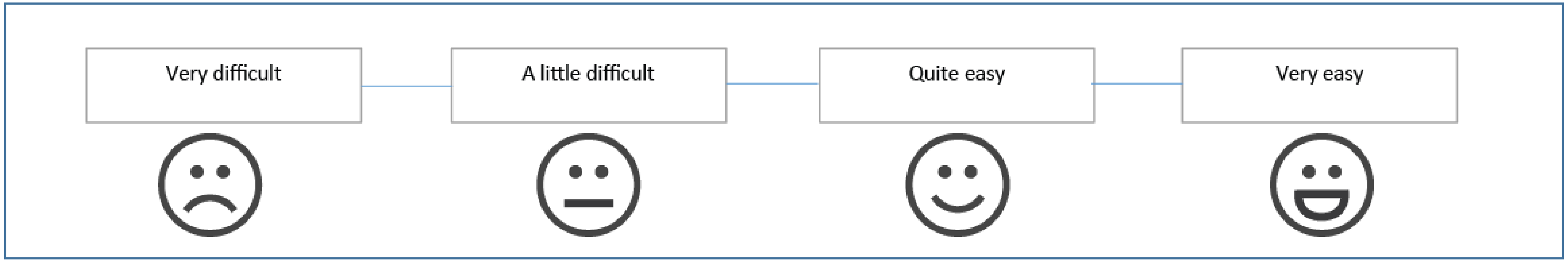
Could you indicate on this scale how confident you are when using the Internet to do something new? [ask Why] *[how has this changed?]*	- Do you ever try browsing new websites, or downloading new apps?	To determine whether participants feel they can use interfaces without being taught by someone else – i.e. can they be independent users. [Context]



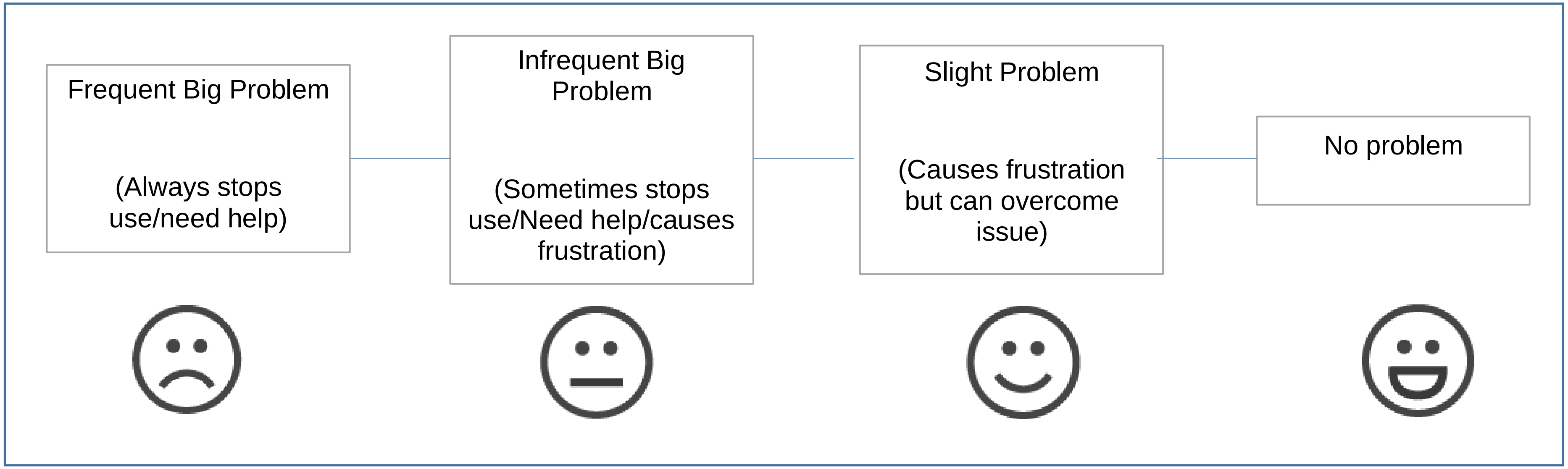
Could you indicate on this scale how easy you find the Internet to use? *[how has this changed? Which difficulties have you experienced?]*	- Do you ever find it difficult to know how to use a website? - Do you ever get frustrated?	To establish whether accessing and using web content is a positive or negative experience. [Context]. This question will potentially identify specific design-based issues encountered by the participant.



Could you indicate on this scale how easy you find it to navigate around websites to find what you want to? *(be aware of references to concepts)* *[how has this changed? Which difficulties have you encountered?]*	- Do you always find what you're looking for? - Do you ever get lost in a website?	To establish how PWD experience web content navigation. [Context]. This question will potentially identify specific design-based issues encountered by the participant.



Other people have told me about some specific issues they have experienced which made navigating Websites difficult for them. Could you please tell me which of these you too have experienced, and how much of a problem they have caused for you, by placing them on this scale? *[include named issues from previous question where applicable]*	*Use navigational difficulty cards*	To confirm which specific design features can impact navigational success for PWD, and to establish which of these may create accessibility barriers and which may be more common usability issues.



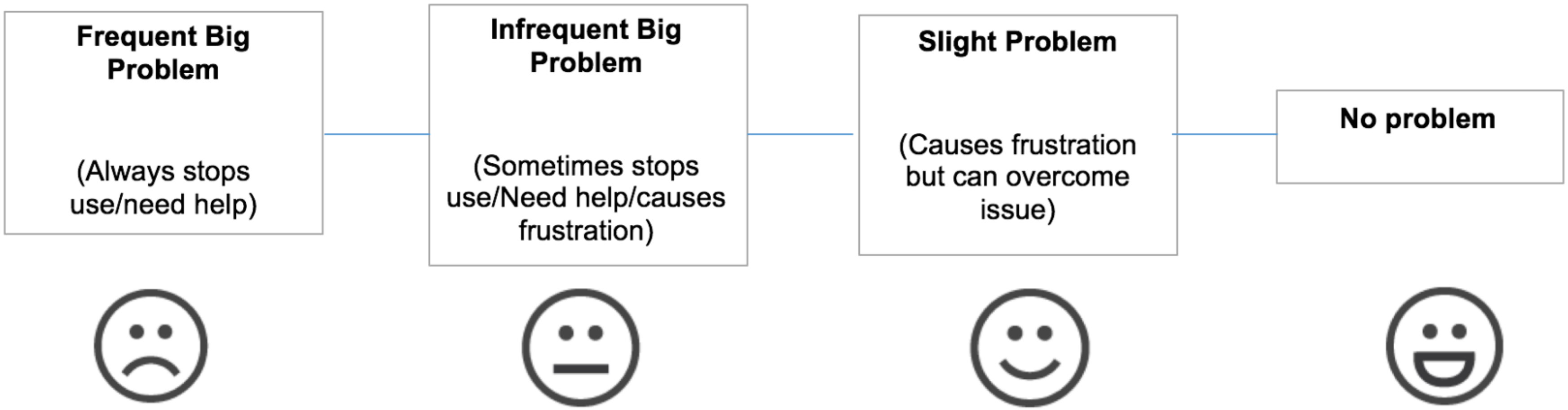
Self-Selected Demonstration [Optional **–** in case participants usually rely on bookmarking**]**

Would you like to show me a website that you often use, and show me what you find good and bad about its design? *[place any identified problems on the previous scale]* *(If participant cannot think of one, suggest NHS website as an example)*	- What do you think is good about the website design? - What do you think is difficult to use about the website design?	To provide opportunity for participants to give examples of design issues they experience/to show ways that they can be supported to navigate a Website.

Is there anything else you would like to add to what you've told me about how you experience using the Internet?

Would you like to receive a summary of the study findings upon study completion? *If yes – request contact details.*

Appendix N. Accessibility/Usability Rating Scale



Frequent Big Problem

(Always stops use/need help)

Infrequent Big Problem

(Sometimes stops use/Need help/causes frustration)

Slight Problem

(Causes frustration but can overcome issue)

No problem

Appendix O. Participant Feedback: Study 3

Participant	Comment/Feedback	Reflective Change to Practice
PWD1	Positive feedback on the use of chunked format, bold text, and white space within the dementia-inclusive consent documents.	No change required.
	Expressed frustration that she could not remember the date.	Pre-populated date fields were used in following interviews.
	Positive feedback on the nature of researcher and the approach taken throughout the study.	No change required.
PWD2/ CPWD2	Positive comment on the use of rating scales as an activity, rather than purely interview questions, as it provided a focus and prompted discussion.	No change required.
	Carer expressed differing opinions to person with dementia; both individuals requested to complete the rating scales for comparison of perspectives.	Researcher may introduce discussion between people with dementia and carer about differing perspectives if this occurs, once person with dementia has completed rating scales.
	Positive feedback on researcher's approach putting participant at ease, which enabled discussions which carer and medical professionals had previously been unable to achieve with people with dementia.	No change required.
PWD 3	Positive feedback on the use of rating scales, as the answer can be compared to previous answers given, for context, in addition to providing a visual focus which aided attention.	No change required.
	Request to provide additional information in response to interview topic via email, if additional information was remembered.	Researcher to allow additional information to be sent via email if participant requests this.
	Positive feedback on the approachable and interested manner of researcher.	No change required.

PWD4/ CPWD4	Positive feedback on the use of rating scales/cards, as they provided a focus and encouraged engagement more than interview questions alone. Person with dementia commented that the visual reminder helped him to stay focused on the question.	No change required.
	Positive feedback on consent form from person with dementia – commented that longer text passages would have lost his concentration.	No change required.
PWD5	Positive feedback on use of rating scales, as they provided an interactive element. Also commented that having the option to read the cards as well as hear them aloud was useful for comprehension.	No change required.
	Positive feedback on consent documents: simple wording, with helpful icons.	No change required.
PWD6	Commented favorably on the use of rating scales as they provided a focus when answering questions.	No change required.
PWD7	Commented on appreciation of receiving a courtesy reminder call on the morning of the interview.	No change required.
	Positive feedback on use of rating scales as they provided a focus and made it clear what was being asked.	No change required.
	Positive comment on pre-populated date section as he could not remember the date.	No change required.
PWD8/ CPWD8	Positive feedback on dementia-inclusive form from carer, though she felt that carers too should receive a more usable form.	No change required, but requests to ethics board for use of dementia-inclusive consent document design to be used with all older adults.
PWD9	Positive feedback on the timing of	No change required.

	the interview.	
PWD10	Suggestion made that consent form should be sent to participant ahead of the interview, to read all information in their own time. Positive comment on use of bold text and font within rating scales.	Offer consent form to future participants prior to conducting interview. No change required.
PWD11	Positive comment on dementia-inclusive documents being helpful for those with memory impairment, and particular comment on pre-populated date fields. Commented positively on the break the paperwork filing provided between tasks as a rest break.	No change required. No change required.
PWD12	Commented positively on the use of rating scale activities, as they provided structure for conversation and breaks between activities as paperwork was filed away.	No change required.

Appendix P. Analysed Standards List

***BS EN ISO 9241 Parts**:*

- **Part 11: Usability: Definitions and concepts** (British Standards Institute, 2018a)
- **Part 12: Presentation of information** ; *Superseded by:*
  - **Part 112: Principles for the presentation of information** (British Standards Institute, 2017a)
  - **Part 125: Guidance on the visual presentation of information** (British Standards Institute, 2017b)
- **Part 13: User guidance** (British Standards Institute, 1998a) (ISO9241-13:1998)
- **Part 14: Menu dialogues** (British Standards Institute, 2000)
- **Part 15: Command dialogues** (British Standards Institute, 1998b)
- **Part 16: Direct manipulation dialogues** (British Standards Institute, 1999)
- **Part 17: Form-filling dialogues**; *Superseded by:*
  - **Part 143: Forms** (British Standards Institute, 2012)
- **Part 20: Accessibility guidelines for information/communication technology (ICT) equipment and services** (British Standards Institute, 2009)
- **Part 110: Dialogue principles** (British Standards Institute, 2006)
- **Part 303: Requirements for electronic visual displays** (British Standards Institute, 2011)

- **ISO13407:1999 – Human centred design processes for interactive systems**; *Superseded by:*
  - **Part 210: Human-centred design for interactive systems** (British Standards Institute, 2010)
- **ISO14915: Software ergonomics for multimedia user interfaces**
  - Part 1: Design Principles and frameworks (British Standards Institute, 2002a)
  - Part 2: Multimedia navigation and control (British Standards Institute, 2003)
  - Part 3: Media selection and combination (British Standards Institute, 2002b)
- **WCAG 1.0** (W3C, 1999)
- **WCAG 2.0** (W3C, 2008b)
- **ISO9241 ‘Part 171: Guidance on software accessibility’** (British Standards Institute, 2008b).
- **BS ISO/IEC 29138-1: 2018, ‘Information Technology – User Interface – Part 1: User accessibility needs’** (British Standards Institute, 2018b)**.**

Appendix Q. Dementia-Inclusive Study Findings Feedback

We spoke to 16 older people with dementia, and 9 older people without dementia.

All participants told us they find the Internet useful and enjoy using particular websites.

People with dementia told us they use the Internet for many things. Including:

- communication
- entertainment
- banking
- ticket booking.

The main problem participants told us they had experienced was navigation.

This problem caused frustration for many people, and often stopped them from finding what they wanted to on the Internet.

We found 8 problems that people with dementia and people without dementia said they experienced frequently when trying to navigate around the Internet:

- Being automatically re-directed to another page without clicking on anything.
- Having too much content on a page, making it difficult to find desired information.
- Being distracted by 'clutter' on a website around the important information.
- Having too much text on a page, making it difficult to find the desired information.
- Having too many steps to follow when completing a task on a website.
- Not being able to find a particular feature on a website. E.g. the search box.
- Having too many things to remember, when using a website. E.g. passwords.
- Not being able to find the correct option within a website menu.

People with dementia found these problems more difficult to overcome than people without dementia. These problems often caused people with dementia to stop using a website.

Website designers follow guidelines for making websites accessible and easy-to-use. We assessed these guidelines to see whether they include guidance on the problems faced by people with dementia.

Most of the 8 problems experienced by people with dementia were not included in current guidelines for web designers.

We have made recommendations on how these guidelines can be improved so that website designers can better understand the needs of people with dementia and design websites that are accessible and easier-to-use.