A Qualitative Study of Internet Use Comparing the Experiences of People with Physical Disabilities and Early Onset Dementia

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Abstract

People living with Early Onset Dementia and/or physical disabilities face distinct challenges in accessing increasingly digitised services and information. Relatively little is known about how either of these groups access and use the internet on a day-to-day basis, or their plans to negotiate changes in access.

Early Onset Dementia, also called young onset or working age dementia, refers to a diagnosis of dementia given before the age of 65. People in this group usually have considerably different lifestyles and responsibilities compared to people who are diagnosed in their 80s. For example, people with Early Onset Dementia are likely to have more experience of computers and working online. Even so, they and their families may have difficulties in accessing appropriate information and services.

Another sizeable group for whom assistive online access may be highly relevant is people living with physical disabilities. People in this group may be dependent on assistive technologies and interventions to access technology and the internet. However, despite the difficulties that both of these groups are likely to face, relatively little research has been done about any of their day-to-day activities'.

This thesis collects and compares the experiences of two groups of participants through both the literature and qualitative research: Group 1, people living with physical disabilities; and Group 2, people living with Early Onset Dementia and their family members. A comprehensive literature search was conducted into internet use and service access by members of these two groups, and data were collected in semi-structured interviews and online questionnaires.

Group 1 comprised of 15 interviews with people living with physical disabilities across Nottinghamshire who were recruited with the assistance of Nottinghamshire County Council (NCC). In addition to the

interviews, 29 online questionnaires were completed by people with physical disabilities living across the UK. The data were analysed using an iterative coding approach to draw out the main themes and inform the approach used with Group 2.

Group 2 also used an online questionnaire, which had 19 participants, and semi-structured interviews to collect data. The interviews used a number of different online recruitment methods to recruit 10 people living with Early Onset Dementia and eight family members from across England. The data were also analysed using an iterative coding approach, followed by thematic analysis informed by the analysis and results of Group 1. These themes were then compared to posts from the Alzheimer's Society Talking Point forum by using word frequency analysis and word searches within the dataset.

The experiences of the two groups were then compared to draw out the similarities and differences between the two, with the main combined themes centring on online access, support, online information, and digital legacies. All these themes indicated similarities in how people with Early Onset Dementia, their family members, and people living with physical disabilities use the internet and online resources to find information and support.

There were also differences between the groups, especially between the group of people diagnosed with Early Onset Dementia and people with physical disabilities. The former group had far more limited involvement in searching for health-related information than the people with physical disabilities, or indeed their family members

The themes also highlight the need for further research on both of these groups regarding the appropriateness of a 'digital first' approach to local authority services and the nature of support needed by these groups to retain online independence. As online access is not yet universal, it is premature for local authorities to plan a programme of digitisation and assume that service users will be in a position to cope with this change. These themes also underline the need for more up-to-date and

appropriate post-diagnostic information, and guidance on which sites or services are safe or trustworthy.

Significantly, the findings also draw attention to the need to prompt conversations about changing access needs and the nature of digital legacy, both between family members and between service users and professionals. This includes not just what people think a digital legacy is, but also plans they may want to put in place for online accounts and digital assets, and when this should occur.

Further research is needed with larger cohorts of both people with Early Onset Dementia and people with physical disabilities who are active online to understand the changing patterns of internet use and dependence. This will help to ensure that people with Early Onset Dementia or physical disabilities can receive appropriate and accessible online services and support.

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Table of Contents

Chapter 1 Introduction 1
1.1 Early Onset Dementia 1
1.2 Physical disabilities 3
1.3 Online services 5
1.4 Research questions 7
1.5 Thesis outline 8
Chapter 2 Literature 10
2.1 Overview 10
2.2 Method 10
2.3 Early Onset Dementia 11
2.3.1 Results 13
2.3.2 Personal experience of EOD 15
2.3.3 Family experience of EOD 17
2.3.4 Service use 19
2.3.5 Social media and internet use 21
2.4 Physical disability literature 22
2.4.1 Results 24
2.4.2 Internet use 26
2.4.3 Support 29
2.4.4 Accessibility 32
2.5 Context literature 34
2.5.1 Health information seeking 34
2.5.2 Change over time 36
2.5.3 Smart devices and the Internet of Things 38
2.5.4 Digital legacy 40
2.6 Summary 41

Chapter 3 Research Design 43
3.1 Overview 43
3.2 Group 1: People with physical disabilities..... 45
3.2.1 Interview design 45
3.2.2 Interview recruitment..... 46
3.2.3 Questionnaire design 47
3.2.4 Questionnaire distribution 48
3.2.5 Participants 49
3.2.6 Analysis 50
3.3 Group 2: People with Early Onset Dementia and their families 51
3.3.1 Interview design 52
3.3.2 Interview recruitment..... 53
3.3.3 Questionnaire design 54
3.3.4 Questionnaire distribution 55
3.3.5 Participants 57
3.3.6 Analysis 57
3.3.7 Talking Point forum data 59
3.4 Ethical considerations 62
3.4.1 Ethics approvals 63
3.4.2 Capacity concerns 64
3.4.3 Confidentiality 65
3.4.4 Research and distress 67
3.4.5 Researcher safety..... 68
3.4.6 Data management 68
3.5 Reflections..... 69
3.6 Summary 73

Chapter 4 Group 1: Internet use amongst people living with physical disabilities in Nottinghamshire 74
4.1 Participants 75
4.2 Findings 77
4.2.1 Online activity 78
4.2.2 Social support 89
4.2.3 Accessibility 93
4.3 Discussion 101
Chapter 5 Group 2: Internet use by people living with Early Onset Dementia and their families 104
5.1 Participants 105
5.2 Findings 107
5.2.1 Change in use 108
5.2.2 Post diagnostic support 116
5.2.3 Accessibility – access issues and solutions 124
5.3 Discussion 131
Chapter 6 Discussion 134
6.1 Summary of findings 134
6.2 Themes 135
6.2.1 General internet use 136
6.2.2 Access 137
6.2.3 Information 140
6.2.4 Support 142
6.2.5 Legacy 145
6.3 Comparison 146
6.3.1 Similarities 146
6.3.2 Differences 148
6.3.3 Broader comparisons 149

Chapter 7 Conclusions 152
7.1 Return to research questions 152
7.2 Future directions 159
7.3 Summary of contributions 160
7.4 Implications 161
7.4.1 Future research 162
7.4.2 Policy implications 163
7.4.3 Technology implications 164
7.5 Final conclusions 165
Chapter 8 : References 167
Chapter 9 : Appendices 188
9.1 Group 1 questionnaire information and consent 188
9.2 Group 1 questionnaire outline 190
9.3 Group 1 interview ethics 193
9.3.1 School of Computer Science ethics form 193
9.3.2 Nottinghamshire County Council Privacy Impact Assessment forms 205
9.4 Group 1 Information Sheet 226
9.5 Group 1 example transcript 228
9.6 Group 2 questionnaire information and consent page 235
9.7 Group 2 questionnaire outline 237
9.8 Group 2 interview ethics and protocol 247
9.8.1 School of Medicine outcome 247
9.8.2 School of Medicine Protocol 248
9.9 Group 2 Information Sheet 269
9.10 Group 2 example transcript excerpt 273

Table of Figures

Figure 2-1 PRISMA chart for Early Onset Dementia Literature Search 14
Figure 2-2 PRISMA chart for physical disability literature search 25
Figure 3 -1 Overview of research design 44
Figure 3 -2 Group 1 Interview recruitment 47
Figure 3 -3 Group 1 Questionnaire distribution 49
Figure 3-4 Group 2 Interview recruitment 54
Figure 3-5 Group 2 Questionnaire distribution 57

Table of Tables

Table 4-1 Group 1 Questionnaire respondents 76
Table 4-2 Group 1 Interview participant demographics 77
Table 5-1 Group 2 Questionnaire respondents 106
Table 5-2 Group 2 Interview participants 106

Chapter 1 Introduction

This chapter will introduce the key topics for this thesis and provide the outline for the remaining chapters.

1.1 Early Onset Dementia

There are currently an estimated 850,000 people living with dementia in the UK. Of this group, approximately 43,000 people are diagnosed before the age of 65, and are classed as living with Early Onset Dementia (Adams, 2014; Alzheimer's Association, 2019; Young Dementia UK, 2019). This is also referred to as 'young onset' or 'working age' dementia in the literature, and has been called 'pre-senile dementia' in older bodies of research.

It is likely that the number of people living with Early Onset Dementia (EOD) in this group is higher than the estimate above, as the current epidemiology works on a diagnostic rate of approximately 5% of the total population with dementia being under 65; however, Young Dementia UK estimates the actual percentage as between 6-9% (Young Dementia UK, 2019). Although this represents a relatively small group within the population of the UK, there has still been comparatively little research conducted into the needs of this group - particularly the influence of the internet and technology on daily life.

For the purposes of this PhD, I will be following the convention of referring to all diagnoses of dementia given before the age of 65 as Early Onset Dementia. This includes people diagnosed before the age of 45 who may also be classed as having Young Onset Dementia, and navigates past the problematic terms of 'Working Age' and 'Presenile' dementia, which were based on a retirement age of 65 that is no longer relevant for the majority of this demographic in the UK.

Dementia is usually described as ‘a clinical syndrome that encompasses difficulties in memory, language, and behaviour that leads to impairments in activities of daily living’ (Robinson et al., 2015), with a number of subtypes which can affect people in different ways and at different stages of their life. While Alzheimer’s disease is by far the most common diagnosis received by people diagnosed with dementia over the age of 65, it is much less common in those diagnosed when younger. A 2003 study by Harvey et al. estimated that Alzheimer’s disease makes up 80% of dementia cases in the over 65 population, compared to 34% of cases in the under 65 population (Harvey et al., 2003). This is a contrast to the historical consideration of Alzheimer’s disease as a ‘pre-senile dementia’: the first recognised patient was 51 when first seen by Dr Alzheimer, having had symptoms for several years before (Stelzmann et al., 1995).

Most care for people diagnosed with dementia is provided in the community and by family members. Diagnosis has a wide reaching and potentially disabling impact on a large number of people outside of a clinical setting. It is often the family members and friends of people diagnosed who can assess the efficacy of new medication and interventions, as well as assessing the progression of the disease and the capabilities of the individual. It is also the family and friends who may initially notice that something is wrong and prompt medical intervention to discover what the problem is, and in the long term, seek a diagnosis.

Owing to the differences in the presentation of younger onset dementias and a failure to take note of the slowly presenting symptoms in younger people (Iliffe et al., 2009, 2006; Rossor et al., 2010), the diagnostic process for Early Onset Dementia can take an average of 4.4 years to receive a diagnosis, compared to 2.8 years for late onset dementias (van Vliet et al., 2013). However, the length of time taken for this process can promote stress and tension within families, as well as an extreme emotional response from the person waiting for the diagnosis. The time waiting for a diagnosis can be a

period of great uncertainty which has significant impact on people's work (and employment status in some cases); finances, as people search for support; and family and social life, as dynamics within the family change and responsibilities shift.

For dementia, both early and late onset, an early diagnosis can be crucial to the preservation of lifestyle and memories through the use of medications and other interventions which allow normality to continue for as long as possible. Medically, moves can be made to slow the loss of memory through medication and symptom management (Luscombe et al., 1998; Robinson et al., 2015). On a social front, moves can be made to prepare for future care planning, such as the preserving of memories through photo albums and memory books, like those described by Oliver James in *'Contented Dementia'* (James, 2009). Although this aforementioned book deals primarily with people diagnosed at a late stage and encountered in hospital wards, these themes are also relevant for younger people living with dementia, and could potentially extend to the addition of online photo collections and social media accounts which can similarly curate a collection of memories.

This thesis will look at the experiences of people living with Early Onset Dementia and their family members to try to understand the broad impact of dementia on internet use, and the practical challenges of ongoing technology use and online account access.

1.2 Physical disabilities

As a contrast to the smaller number of people with dementia, there are an estimated 13.9 million people in the UK living with disabilities (of whom 6.8 million have physical disabilities) with a wide range of conditions and severity represented within this number (Burke, 2018; Scope, 2019). Of this group, 52% reported having a disability which caused mobility issues, and 27% dexterity issues (Burke, 2018). While

the difference in group size perhaps does not lend itself to a direct comparison, it is important to remember the umbrella term “disability” actually comprises a spectrum of conditions and degrees of severity.

People with different long-term conditions may have distinct needs, and many individual conditions are also supported by specific charities providing support and information; for example, a multiple sclerosis charity supports a separate user group to a cerebral palsy charity. These groups, albeit generally larger than the number of people living with Early Onset Dementia, face distinct challenges in terms of accessing support and information online and are similarly under-represented in research on daily technology use.

It is also important to consider that dementia is now increasingly considered as a disability, and therefore people with dementia may also be included in the figures for associated dexterity problems in the figures on disability in the UK. The move to include dementia as disability is relatively recent, and is linked to the assessment and receipt of benefits. This is particularly significant for people living with Early Onset Dementia who struggle to access government support at present.

As government services are placed under increasing financial pressure to cut costs and meet targets, more services are being moved to online platforms with fewer person-to-person interactions. There is potential for this to improve access to services, as some can be accessed remotely, and accounts and information can be accessed 24/7 at the service user’s convenience. Based on these changes, it was anticipated that there would also be many shared challenges in navigating online information and accessing appropriate support for people’s conditions.

1.3 Online services

For groups with more specific information and service access needs, such as people living with Early Onset Dementia (EOD) or complex physical disabilities, there is an increasing need to stay active on the internet and retain good online access in the home. There has been little research on this to date, especially with people living with EOD, so we cannot know how well placed they are to deal with these challenges or what steps they have taken to resolve them. A specific concern for people living with EOD is that there has also been little research done into how appropriate the online information is, its relevance to themselves as a younger person, and the commitments that it may entail.

The internet is not only significant for information and service access: its growth has increased its importance as a social and commercial tool in daily life. Internet connectivity worldwide reached 55% in 2018 (Miniwatts Marketing Group, 2019), with 90% of adults in the UK being classed as ‘recent’ internet users by the Office of National Statistics (Prescott, 2018); ‘recent’ in this instance refers to people who had used the internet within the last three months.

This high level of use is reflected in the number of people engaging with popular commercial and social enterprises online. Commercially, online-only retailer Amazon shipped approximately 1,660,000 parcels per day globally in 2016 (Favors, 2017; Statista, 2019a), and in 2018 was the fifth largest retailer in the UK (Stevens, 2018). Socially, involvement online is no smaller in scale: Facebook, the social network with the largest share of the UK market (Statista, 2018), had an estimated 39.2 million users in the UK. Approximately 44% of the UK internet active population log on to Facebook at least once a day (Statista, 2019b). The trend of social network use is particularly relevant to this thesis, as both Facebook and Twitter are sources of information and support for groups of people with different physical

disabilities and for people with Early Onset Dementia (Craig and Strivens, 2016; Hemsley et al., 2015).

Local government social services are being moved increasingly online to reduce costs while also potentially improving out of hours access to information and advice. As these services are being developed, new challenges are presented to both the designers of the services and the users needing to access them in a time of increasing digital division through age and access to Information Technology (IT). These services are designed with the aim of creating a central access hub for all information (financial, social, or medical) needed by service users which can be accessed around the clock. This hub could act as a repository of information or as a signpost to other sources of information, whether from other branches of the same service or branching out to more appropriate organisations.

Access to such services is vital for people with physical disabilities to live their lives to their full potential. However, there has been little research into people's preferences for what type of information is provided online or how they access it, and indeed to what extent the existing information is being accessed. Crucially, the research that has been done in this area has been predominantly focused on online interventions and information provision and support for carers, rather than the affected person themselves. Research into this area is increasingly relevant as more information and service referrals are moved online.

The main sources of information about these services, and often medical conditions, are provided through a combination of national organisations (such as condition-specific charities) and local services like Connected Nottinghamshire (Connected Nottinghamshire, 2017). This is increasingly the case for services provided by local authorities or the NHS. The creation of these online information hubs is taking centre stage in resource planning and information sharing as local and regional governments redesign services for an online environment.

They link branches of the government together, such as social care and financial advice for care plans, alongside sources from charities and accessible travel sites to try and present all the information that could be needed from one point of access. Information banks can be reached outside of business hours and can link to a wider number of services than may have been possible if an individual was interacting with only one of the many agencies in the area.

This thesis will consider how people living with Early Onset Dementia and their families are using the internet to seek out support and information, and how this compares to people living with physical disabilities. The layout for this discussion is presented in section 1.5, which outlines the main topic of each chapter of this thesis.

1.4 Research questions

The research conducted for this thesis addresses five research questions. The core area of interest for these questions was created at the outset of the PhD: how are these groups using the internet, and is it for information and support purposes? Over the course of the PhD this initial question evolved into specifics on information, service access, and digital legacy. Some were then split into sub-questions to allow for direct comparisons of the responses of each group. The final research questions used to discuss the comparative experiences of people living with Early Onset Dementia and people with physical disabilities are as follows:

1. A) How are people with Early Onset Dementia and their families using the internet to find information and services?

   B) How are people living with physical disabilities using the internet to find information and services?

2. A) What role does online information play in the understanding of the diagnosis of Early Onset Dementia for both the individual and their family?

   B) What role does online information play in the understanding of their diagnosis for the person living with physical disabilities?

3. A) How valuable is online support and information for the individual diagnosed with Early Onset Dementia and their family?

   B) How valuable is online support and information for the individual living with physical disabilities?

4. Do people with Early Onset Dementia have a plan for the maintenance of their digital legacy or management of digital assets?

5. Are there similarities or differences in the online practices between people living with Early Onset Dementia and adults living with physical disabilities?

1.5 Thesis outline

The remainder of the thesis is organised as follows:

- Chapter 2 presents the literature regarding internet use amongst people with Early Onset Dementia and people with physical disabilities, and provides additional contextual literature for topics which emerge in the findings across chapters 4, 5, and 6.
- Chapter 3 discusses the comparative study, including the five data collection activities across the two groups (i.e. people with

physical disabilities and people with Early Onset Dementia and their family members). This chapter covers the description of the methods and the rationale, implications, and limitations of this choice.

- Chapter 4 describes the results of the research with people living with physical disabilities in Nottinghamshire and how they are engaging with the internet and Information Technology (IT) in their daily lives.
- Chapter 5 presents the results of the research with people living with Early Onset Dementia and their family members, and how they are using the internet and IT.
- Chapter 6 brings together the discussion across both groups, compares the findings between the two, and draws out implications for further research.
- Chapter 7 draws together the findings, discusses them in relation to the research questions, and presents the final conclusions of this PhD thesis.

Chapter 2 Literature

2.1 Overview

This chapter presents the relevant literature on internet use and support for people living with Early Onset Dementia and physical disabilities. This chapter also provides context for the research conducted and the themes which emerged in the data collected with the two comparator groups, including changes in online activity over time and health seeking behaviours. Contextual literature will draw in research from other disciplines in order to create an overview important for topics arising in chapters 4 and 5, which present the findings from each group.

The chapter begins with a systematic review of literature on Early Onset Dementia and physical disabilities. Following this, section 2.5 presents further context literature for the wider thesis. For each of these reviews there was some difficulty in identifying sufficient literature due to the limited amount of research done with people with Early Onset Dementia and the non-condition-specific nature of the physical disability group.

2.2 Method

This section describes the method used to conduct the reviews of Early Onset Dementia and physical disability literature. Search terms and results will be discussed separately in their respective sections.

Initial search terms were identified from the research questions set out in the introduction. These were then expanded in order to capture the relevant literature. This was done through the use of thesaurus and free text searches on the databases themselves, to give expanded sets of terms to be included for each word and avoid the need to

truncate search terms. This process also provided insight into synonyms that might not be captured. “Social media”, for example, would not capture references to individual sites such as Facebook, Twitter, or Instagram on EBSCO hosted databases but would do so on Proquest, meaning that site names needed to be included in the search terms for efficacy.

The search results were then downloaded from the databases and collated in Endnote to remove duplicate records. The records were then uploaded onto Rayyan (Ouzzani et al., 2016), a free online service designed to support the screening of papers for systematic reviews. The Rayyan system also provides a second opportunity to remove duplicates which may have been missed in the automated Endnote search.

Articles were initially screened for relevance based on title and abstract. Additional papers identified through other projects and PhD work, such as module essays and some related papers in Google Scholar, were also added in at this stage for review. The included papers were then re-screened for relevance in Rayyan based on the full article text for inclusion or exclusion in the review. Specific inclusion and exclusion criteria are given in each sub-section. During the final screening, themes within the papers were identified to shape the presentation of the findings of the literature review.

2.3 Early Onset Dementia

This section will present the literature related to people living with Early Onset Dementia (EOD) and their families, their experiences after diagnosis, and the role technology and the internet play in this period. Search terms were identified as described in section 2.2.

As indicated in the introduction, families were included as part of Group 2 in order to give a broader understanding of the day-to-day

challenges of continued technology and internet use faced by people living with EOD. For the same reason, families were included in the literature search to widen the scope of the search and provide more personal accounts of challenges faced outside of service design and institutional perspectives.

Searches were carried out on PsychInfo, CINAHL, MEDLINE, International Bibliography of the Social Sciences (IBSS), Scopus and Web of Science. Additional literature was identified through reference list searches and previously identified literature for other assignments and projects conducted during the course of the PhD (largely from Google Scholar). The search query for this section of literature was as follows:

1# “dementia” AND “early onset” OR “young onset” OR “working age” OR “presenile”
2# (“online support” groups OR services) OR (“social support” groups OR services) OR social AND media
3# identity AND online OR (social AND media OR facebook OR twitter OR Instagram OR snapchat OR tumblr OR social AND networking) OR information
4# 1 AND 2
5# 3 AND 4

Once duplicates were removed, the results of these searches were then screened as described in section 2.2 according to the following inclusion and exclusion criteria:

Inclusion	Exclusion
Related to experiences of people with Early Onset Dementia	Not related to Early Onset Dementia
Internet Use and dementia	Wrong topic
Technology use and dementia	Focus on Biomedical intervention/assessment
Social support	Focus on Genetic testing/genome sequencing
Information seeking	Focus on late onset dementia or age associated memory problems
Related to family members' experiences with Early Onset Dementia perspective	Published in a language other than English

2.3.1 Results

The search strategy from the previous section produced the following initial results, separated by database:

Database	Paper count
CINAHL	20
IBSS	148
MEDLINE	3
PsychInfo	24
Scopus	3
Web of Science	25

In addition to the 223 results found in the database searches, 255 records found through other projects and Google Scholar were included in the results to be reviewed. In total, 57 duplicate records were removed as reflected in the PRISMA chart on the next page:

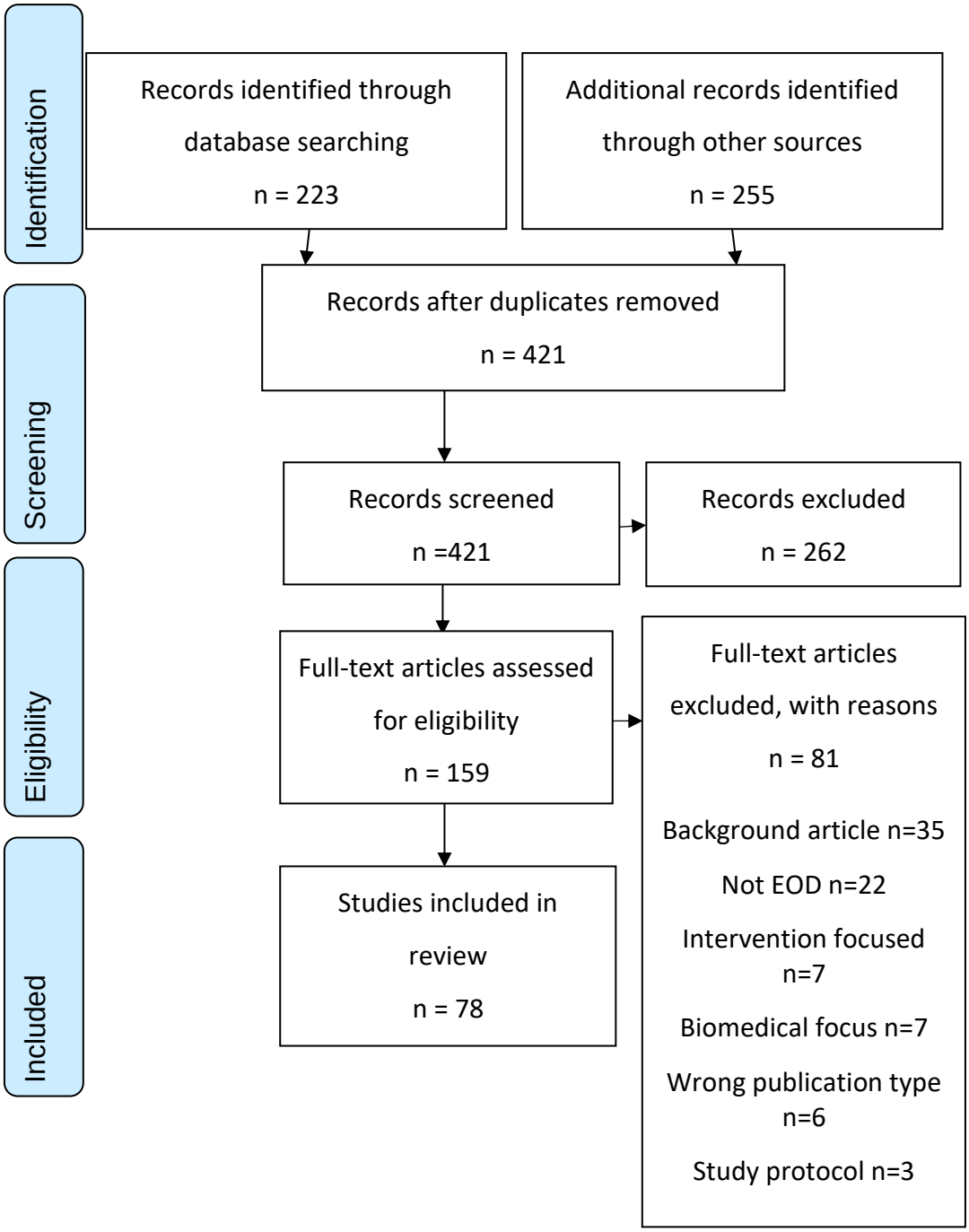


Figure 2-1 PRISMA chart for Early Onset Dementia Literature Search

Tags were assigned to each article during the full text screening to assist with sorting by theme for analysis. The included papers were then read again, and closely related tags combined to give the main inductive themes: the personal experience of Early Onset dementia, the family experiences of Early Onset Dementia, service use, and information and technology use. The included literature is presented below, considering each of these themes in turn.

2.3.2 Personal experience of EOD

Of the themes represented in these findings, this was the smallest group of literature, although arguably the most important. In 1993 Cotrell and Schulz wrote that the views of the person living with dementia are neglected in dementia research (Cotrell and Schulz, 1993). While much has changed since this was written, the views of younger people living with dementia still appear to be underrepresented in the literature collected for this search. The bulk of the research focuses on other family members (which are discussed in the next section) or the differing care needs compared to people living with late onset dementia.

Literature in this section deals with the personal experiences of living with Early Onset Dementia using both autobiographical and academic perspectives. Both Wendy Mitchell and Kate Swaffer have written autobiographies about their own experiences of living with EOD. These autobiographies offer a deeply personal view of diagnosis and living with EOD while also making moves to encourage broader conversation and awareness around the topic: they provide insight into the individual, not just the impact of diagnosis (Mitchell, 2018; Swaffer, 2015).

Academic literature has focused on the impact of a diagnosis of EOD on selfhood and identity. Harris and Keady focused on the transitional phases of diagnosis and how identity can change or be lost as an

individual's dementia progresses (Harris and Keady, 2009). Specific areas of this have been further researched by other authors. Öhman et al. (2001) and Ritchie et al. (2018) both focused on the impact of changes in the workplace or loss of vocation, and the negative impact this can have on an individual's sense of well-being and identity. Both groups emphasised changes that could be made in the workplace, both practically to support the individual, and policies to support implementing these practical changes in all workplaces to enable people living with dementia to stay in work longer. Velayudhan et al. (2018) discussed the impact of driving cessation after a diagnosis of EOD and the reasons associated with this. This loss of independence could be further compounded by a loss of agency and increased dependency in family settings (Harris, 2004), or the loss of voice in medical settings and decision making (Pipon-Young et al., 2012).

This loss of voice and agency can also contribute to difficulties in accessing effective and appropriate medical and social support. It can also be exacerbated by inconsistent and lengthy pathways to diagnosis which restrict access to appropriate care (Williams et al., 2001). Both Williams et al. and Roach et al. (2008) point to the need for greater provision for specialist services for people living with Early Onset Dementia to provide diagnoses and support to improve the experience of living with EOD. Beattie et al. (2004) conflicts with the findings of Pipon-Young et al. (2012) by finding that people with EOD can articulate what they want and need from dementia services, even when specialised services are not in place, rather than expecting that their views will be lost when asked.

It is clear from the literature focusing on the personal experience of the person with EOD that there are significant challenges in attaining a diagnosis and in daily life afterwards. The literature also shows that these challenges are not insurmountable. Greenwood and Smith (2016), Swaffer (2015), and Mitchell (2018) all show that a diagnosis is not a sign that 'people's lives are over'. With access to appropriate

support, some of the negative impacts on their social and personal lives could be mitigated.

2.3.3 Family experience of EOD

This section looks at the larger body of literature related to the family, rather than personal, experience of a diagnosis of EOD, with 31 papers on family members' experience of EOD to 14 papers focusing on the person diagnosed identified in the searches. It spans the impact of EOD on caregivers (van Vliet et al., 2010), their children (Ozawa, 2014), additional support needs (Ducharme et al., 2014), and how all of this can combine to change the understanding of the 'family' as responsibilities shift and change (Mackie et al., 2012; Roach et al., 2014a). Though the notion of 'shared experiences' in this area has been highlighted as problematic by Hoppe (2018), other research in this area has been increasingly aimed at the 'lived experience' (Spreadbury and Kipps, 2017) or 'family narrative' (Roach et al., 2014b) of dementia for both the individual with EOD and their family.

Linked to improving the understanding of the impact on family members, there has been a growing body of work in recent years that focuses on the experiences of children who have a parent living with EOD. Barca et al. (2014) and Johannessen et al. (2015) focused exclusively on the experiences of adult children (aged 18+), the impact on their personal development, and the lack of support from parents and outside agencies. Aslett et al. further expanded on the need for supporting the adult children of people with EOD through the potential role shift from child to caregiver and personal worries about their own risks of developing dementia (Aslett et al., 2017).

Sikes and Hall (2018) also contribute to the literature on this age group by focusing on the difficulties in forming normal familial relationships when the individual in question is not prepared for the fundamental changes in a parental figure caused by a dementia. These authors

also focused on the difficulties faced by children and young people in conveying their own emotions and experiences in the face of a parent being diagnosed with dementia, particularly when they were negative or traumatic (Hall and Sikes, 2018, 2017). They also focus on the grief and difficulty faced by this group when their experiences move against the traditional narrative of a person with dementia remaining the 'same' as the dementia progresses (Sikes and Hall, 2018), and how the emotional response to the diagnosis requires different support to other ill health causes (Sikes and Hall, 2017a).

There has been some research done into the needs of children and young people with a parent diagnosed with EOD with service development in mind. Milenaar et al., (2014) feeding back from the NeedYD study, highlighted the need for more accessible information and a family-centred approach to ensure children affected are provided with the support they need to understand the course of EOD. While Zeher (2013) focused on existing actions that have assisted children in coping with a parent's diagnosis of EOD, Svanberg et al. (2010) and Rosenthal and Greer (2011) both highlighted the need for family centred interventions and information to better meet the needs of children affected by EOD and improve their existing coping mechanisms.

The literature also clearly illustrates the challenges for partners and spouses as they fall into informal caregiving roles. This has a significant impact on them, as they deal with increased fear and likelihood of depression (Kaiser and Panegyres, 2007) in addition to existing obligations such as childcare and work that a caregiver for a person with Late Onset Dementia (LOD) may not have (van Vliet et al., 2010). Arai et al. (2007) made this comparison more explicitly by comparing challenges faced by caregivers of people with EOD and LOD, finding that caregivers of people with EOD required additional services due to the different presentation of behavioural symptoms.

These findings highlight the need for appropriate services for people with EOD in order to improve the family experience of moving through the diagnostic process (van Vliet et al., 2011) to post diagnostic support and services (Ducharme et al., 2014). Though research present in the literature shows that moves are being made to improve this (Boots et al., 2014), it still seems that there is limited uptake of available services by caregivers of people with EOD (Brodaty et al., 2005; Cations et al., 2017) for reasons outlined in the 1990s; lack of appropriate information (Husband and Shah, 1999) and appropriate services (Sperlinger and Furst, 1994). Svanberg et al. (2011a) highlighted a number of negative outcomes for both the person living with EOD and their family again in 2011, including a lack of appropriate support and services. Literature related to services and challenges in access is discussed in the next section.

2.3.4 Service use

This section continues the discussion around service and support use by people living with EOD and their families. Barber and Cooper (2011) describe the difference in experiences of services between older and younger people with dementia, and highlight the need for services to reflect the different needs of people living with EOD. As highlighted by Barber and Cooper and at the end of the previous section on the family experience of EOD, research has indicated that there has been a lack of age appropriate services since the mid-1990s (Delany and Rosenvinge, 1995; Sperlinger and Furst, 1994). This is not limited to post diagnosis support, which is the focus of both Delany and Rosenvinge, and Sperlinger and Furst, but also applies to the need for services which lead to a timely diagnosis (Bentham and La Fontaine, 2005) and continuity of care through the diagnostic pathway (Williams et al., 2001). The need for timely diagnosis and post diagnostic support has again been recently highlighted by Carter et al. (2018) and Mayrhofer et al. (2018a), both of whom further identified

that the lack of evidence around best practice and service design is hampering the commissioning and roll-out of services and care.

Building on the arguments of Beattie et al. (2004) on the importance of involving people living with dementia in developing services, Mayrhofer et al. (2018) also found that co-design is crucial in addressing what people with EOD and their families prioritise and in designing appropriate and successful services. Appropriateness of services is a consideration in whether or not people living with EOD and their families access the services in their area and their satisfaction with them (Luscombe et al., 1998). Services where people with dementia have been involved in the design have been shown to be successful, such as the Forget-me-nots social group (Parkes and Ward, 2014), or online support groups in which the individual with dementia can share their own story and control the narrative of their experiences whilst accessing relevant support (Craig and Strivens, 2016; Rodriquez, 2013). There are however issues with co-designed studies, as shown by Baker and Irving (2016), who highlighted the need for continued collaboration for the success of such projects; however, this is not always possible across geographic boundaries and budgets.

The literature on service use is not limited to those available to people living with EOD, but also the services available to caregivers and family members. Roach et al. (2012) highlighted the importance of acknowledging the family unit and proving support to family members as part of delivering effective support for people with EOD. Research on support for family members of people with EOD highlights numerous unmet needs, particularly in practical areas such as finances (Ducharme et al., 2014) and emotional support (Rosness et al., 2008). Access to this support is often restricted by lack of awareness of the services and the stigma of dementia diagnosis (Brodaty et al., 2005). In order to mitigate this stigma and be more convenient for time-pressed family caregivers, some support takes advantage of systems, considered novel at the time, to try and

improve accessibility for a larger number of people. This has evolved from a telemedicine support service in the 1990s (Harvey et al., 1998) to a wide range of internet-based support interventions for family caregivers (Boots et al., 2014), including the Alzheimer's Society Talking Point forums which were used for data collection for this thesis. This use of the internet for support and services will be explored further in the next section.

2.3.5 Social media and internet use

This section looks at the use of social media by people living with Early Onset Dementia, and the use of the internet and technology for information not related to the services Robillard et al. (2013) and Craig and Strivens (2016) have written about – i.e. the use of social media for sharing information and accessing social support on Facebook and Twitter. Both Facebook and Twitter allow the person diagnosed and their family members to connect with peers in the community and share information without geographic limitations. These social connections can also be used to supplement gaps in information by sharing information specific to the diagnosis or making difficult-to-find information sources more accessible; both of these issues were found to be problems across several European countries by Jones et al. (2018). Forums have also been used by people living with dementia and their families. Indeed, Rodriquez (2013) is the sole example from this search, and argues that the forums represent an important opportunity not only to share information but to take control of an individual's life narrative and regain some sense of independence post diagnosis.

While these studies show a benefit to continuing to access social media and use the internet, there are ethical challenges associated with this. Batchelor et al. (2012) highlight the ethical and legal complications associated with changing capacity when posting on

social media and sharing sensitive information such as location online. Linked with the ethical issues of social media use are the ethical issues of preventing their use when they form part of an identity and can be used as a tool for reminiscence and connection (Baldwin, 2005), or beneficially to potentially reduce feelings of isolation (Craig and Strivens, 2016).

2.4 Physical disability literature

The section deals with the literature on people with physical disabilities and their use of the internet and technology. Search terms were identified as described in section 2.2.

Literature searches were carried out on the Web of Science, Scopus, MEDLINE, CINAHL, PsychInfo and the Social Service Abstract databases, with additional literature being identified through reference list searches on Google Scholar. The searches were conducted in the same manner in each database, with slight variations in how the searches were combined owing to the different hosting platforms. The search query used was as follows:

1# physical AND disability OR disabilities OR disabled
2# (“online support” groups OR services) OR (“social support” groups OR services) OR (social AND media)
3# identity AND online OR (social And media OR facebook OR twitter OR Instagram OR snapchat OR tumblr OR social AND networking)
4# 1 AND 2
5# 3 AND 4

Once duplications were removed, the results of these searches were then screened as described in section 2.2 according to the following inclusion and exclusion criteria:

Inclusion criteria:	**Exclusion criteria:**
• Directly related to the experiences of people with physical disability	• Not related to physical disabilities
• Related to internet or technology use	• Focus on older people and frailty as an age-related disability
• Considers social support	• Does not include the perspective of the person with disability, e.g. articles about parents of children with disabilities
• Information seeking and sharing	• Intervention focused; efficacy of, not perspective of user
• Use of assistive technologies	• Design of assistive technologies
	• Duplicate record
	• Full text unavailable to read
	• Dementia focus
	• Published in a language other than English

2.4.1 Results

This search produced the following initial results from the previously mentioned databases:

Database	Paper Count
CINAHL	361
MEDLINE	70
PsychInfo	714
Scopus	4
Social Science Abstracts	4759
Web of Science	1480

The Social Science Abstracts database was used instead of the IBSS database for this search with the aim of finding more relevant results in the search. Of the 148 papers found in the Early Onset Dementia literature search, none were relevant for the review.

In addition to the papers from the databases, other relevant papers from reference lists and previous work were included in the results.

Records tagged as dementia-focused were excluded from the literature on physical disabilities and were included in the records screened for the previous Early Onset Dementia section of this chapter.

82 articles were excluded from the main review but provided additional context on how assistive technologies have changed in their design and uptake over time. These papers are discussed further in section 2.5.2 on change over time. In this review the ‘wrong publication type’ tag was used for a book review, notably because the book itself did not appear in the search results.

The PRISMA chart on the following page summarises the records considered:

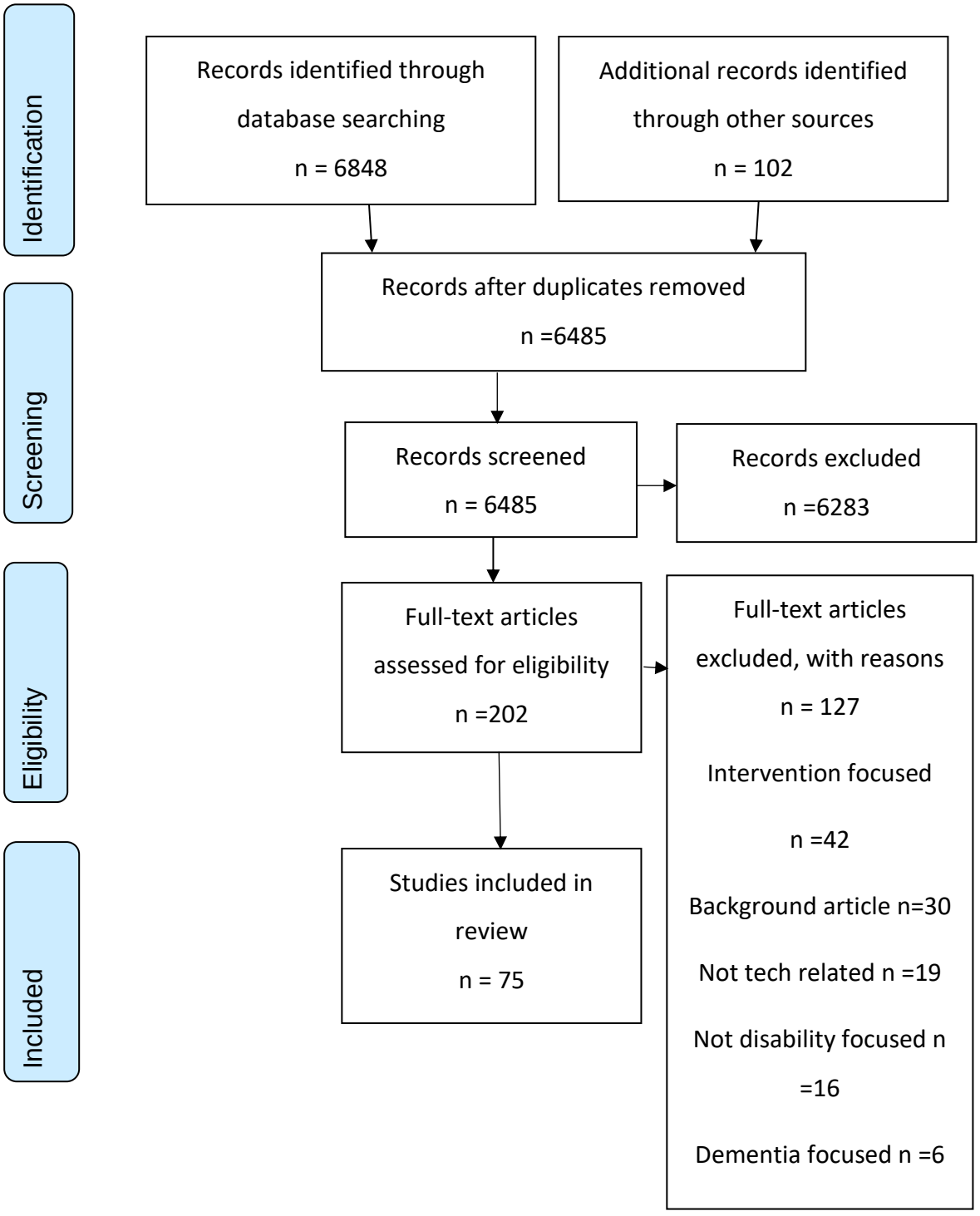


Figure 2-2 PRISMA chart for physical disability literature search

As stated in section 2.2, tags were assigned to each article during the screening process to assist with sorting by theme for analysis. The included papers were then read again, and closely related tags combined to give the main themes of internet use, support, and accessibility. This was done independently of the identification of themes within the EOD literature, with each set of themes being created inductively based on the tags produced during full text review. The included literature is presented below, considering each of these themes in turn.

2.4.2 Internet use

This section provides some context for general internet use amongst people with physical disabilities and the wide range of roles it plays in daily life. Note that there is a significant overlap between the themes. This is perhaps most significant with regards to the literature on social media and disabilities, which intersects with support, accessibility, and identity literature. The former two will be discussed in their own sections, and identity will be dealt with in this section.

The ability to access the internet is something which is often taken for granted in both the technology we use and the commissioning of government services and information channels which rely heavily on its access. However, it is an area where there is not equality of access or skills, some of which will be discussed in the later section on accessibility. Though the percentages have increased, there is still a disparity between the proportions of disabled and non-disabled people who are active on the internet, at 78% and 95% respectively (Prescott, 2019). This disparity is significantly smaller in the 16-24 age group (98% to 99% respectively), than in the over 75s (41% to 54%), reflecting general trends in internet use across age demographics. This trend is also evident in Duplaga, (2017) which showed disparity of use over

age demographics and education in Poland. There is however still more disparity in the numbers of younger people with physical disabilities active on social media, despite the potentially positive associations of doing so (Asbjørnslett et al., 2015). Some reasons for this are discussed in the accessibility section of this chapter.

Inclusion online was a common topic within this theme, whether in equity of access in school and education (Hemmingsson et al., 2015; Wrzesińska et al., 2016) or in inclusion and engagement with social groups leading to a greater independence and quality of life (Drainoni et al., 2004; Grimaldi and Goette, 1999; Soderstrom and Ytterhus, n.d.). The use of social media and presentation of identity online is linked to the potential of developing friendships and intimate relationships online (Seymour and Lupton, 2004).

Giddens (2013) discusses the body as a 'construct' that can be shaped by individuals according to setting and circumstance. This is an idea which is particularly relevant to studies on social media (and internet use more generally) amongst people with physical disabilities who can take advantage of the affordances allowed in this area more than the general population, such as potential for anonymity, identity construction, and atemporal methods of communication though messaging services. Furr et al. (2016) focused on the reasons people with disabilities may or may not disclose their disability online, and the impact this can have on the forming of friendships and relationships away from the 'ongoing' negative stereotypes present in face-to-face interactions. Hill (2017) and Cole et al. (2011) also go on to discuss the importance of taking control of personal representation online, and how the disclosing of a disability, or not, can be an empowering act in defining identity and individuality. Bowker et al. (2002a). further expanded on whether or not this is always a positive decision, and explored the implications of disclosing, or not, a status of disability and the impact it could have on the relationships formed in online spaces This dilemma around disclosure and formation of online identities has also been linked to online dating, and has similar implications for

understanding the role a disability plays in self-presentation when disclosure is less immediate (Saltes, 2013). Mazur et al. (2017)added to this discussion by looking at how the selection of dating sites can play into this presentation and how site use can be different between disabled and non-disabled users.

Away from dating sites, social media and online gaming are common areas of internet use for people with physical disabilities (not dissimilar to able-bodied internet use) but this was not well documented in the literature found in this search. The terms focused more on social media and information seeking than online gaming habits, which have been explored in more detail by authors such as Tom Boellstorff (2015) and Bonnie Nardi (2010). General internet use is one of the areas with the biggest intersections with the other two themes in this review (support and accessibility) but this section will focus on literature related to identity and connection making in digital spaces. While there can be elements of fear associated with the open disclosure of a disability in online spaces (Furr et al., 2016), there are some groups for whom this is a benefit and creates a sense of community, such as Paralympians who are able to connect with each other and advocate for their sports through social media spaces (Bundon and Hurd Clarke, 2015). It can also create a sense of community across geographic distance (Gale and Bolzan, 2016) or amongst additionally marginalised groups, such as queer or trans disabled people who are potentially better able to create and manage their identities in these spaces (Miller, 2017).

Taking advantages of the affordances of online communication and social media is an area which is frequently covered in disability and internet use literature. It can span from the topics already covered in this section to assisting with tourism (Anuar et al., 2017) and communicating in times after natural disasters (Kent and Ellis, 2015). These affordances are something that will be discussed in more detail in the ‘Health information seeking’ and ‘Change over time’ sections within the context literature section of this chapter, as they are also relevant to people with Early Onset Dementia and their families’ use

of the internet and technologies. The next theme discussed in this chapter, support, will also touch on these affordances and how they are used to find and develop social support and information sharing networks amongst people with physical disabilities.

2.4.3 Support

This section will discuss the literature related to social and online support networks utilised by people with physical disabilities.

As with all the sections of this literature review, there was some crossover in the tagging of papers and questions as to which section they best fit. The literature discussed in this section had the primary tag of ‘support’, with other secondary tags including ‘social media’ and ‘accessibility’. Papers tagged as ‘change over time’ will also be discussed further in the change over time section of this chapter.

One of the key issues in the development and utilisation of support is how well the intended audience can access it. Hammel (2003) highlights the importance of health care providers listening to the needs of their users on the appropriateness of technological interventions; what may be of benefit to one individual may be a significant barrier to another. Further discussion on the means and ability to access support and online information is in the next section on accessibility.

A significant area of focus in this literature is the role of social media as a support mechanism for people living with physical disabilities. This covers a range of ages, from young people using social media to enhance social interactions and the development of broader social skills (Martínez, 2015) to adults who use it for support and to change the narrative around disabilities in professional settings on LinkedIn (Baker et al., 2013). Ersoy and Guneyli (2016) focus on the use of social networking as a tool for learning, as well as social support and community amongst adults with physical disabilities living in Turkish

Cyprus. Bay (2018) also focuses on the experiences of adults living with a physical disability, specifically ALS, in using the internet and computer mediated communication to maintain contact and enhance social participation, creating a sense of community after diagnosis.

As a contrast to the focus on adults with physical disabilities, both Raghavendra et al. (2013) and Caron et al. (2016) focus on the experiences of young people with physical disabilities on social networking sites, and their importance in supporting communication with peers without the potential constraints of face-to-face interaction. Raghavendra et al. (2016a, 2016b, 2012). have also focused on the importance of supporting training for young people in accessing social networking and sites like their peers, and how this can impact the reasons behind differences in use and access

This is one of the areas of research which shows a marked change over time as technologies and social networking sites have grown. This will be discussed further in the ‘change over time’ section later in this chapter, as interactions move away from the condition-specific support groups and message boards discussed by Braithwaite et al. (1999), Finn (1999), and Tichon et al. (2003), in the early 2000s to social networking sites and virtual worlds and communities (Boellstorff, 2015; Drainoni et al., 2004; Lupton and Seymour, 2000).

That is not to say that support forums are no longer in use; they do indeed still play a role in computer mediated support. This is in part linked to the negotiation of identity and the removal of stigma discussed in the previous section of this chapter; Obst and Stafurik (2010) discuss the positive impact of disability-specific websites on community development and personal wellbeing in a liminal space that allows all users to act as ‘able bodied’. This growth of community around a shared disability or diagnosis is also explored by Phillips and Rees (2018) with people living with an invisible disability, in this case Multiple Chemical Sensitivity (MCS). This is a group which is not always recognised medically, and the authors are able to explore how

online forums are used to share information and support, connect with peers, and play a role in the construction of identity both for the group and individuals with MCS. Crafton (2011)also discusses the sharing of information and treatments, this time linked to chronic pain, through specific online support groups.

As part of the changing methods of support, from support forums to social networking sites, another area apparent in support for people with physical disabilities online is virtual worlds. The specific site of focus across all research in this is Second Life, a site which allows users to customise both avatars and environments extensively, and has been well researched as a site of numerous different community groups (Boellstorff, 2015). This platform can be used for a variety of purposes, from community building and exploration (Tzemopoulos et al., 2014) to sharing information and social support enabled by the supported augmented communication methods (Best and Butler, 2013). Developing beyond community and peer-to-peer support, the choice of users to disclose a disability or not allows the platform to be used as mechanism for social advocacy and activism amongst the wider user base of the world (Bloustien and Wood, 2016). By exploring representation and advocacy online, there is potential for this to extend into offline actions.

Though not the focus of this review, it is important to recall that not all support networks are digital: offline support networks play a significant role in the lives of all individuals. While online support can supplement offline, it cannot fully replicate the benefits of a supportive offline network (Cummings et al., 2002), and indeed can offer additional difficulties researchers cannot always mitigate, such as cyber-bullying (Alhaboby et al., 2017). Almeida Hol et al. (2015) focus on the significance of this offline social support of family members and friends in enabling people with disabilities in Paraiba to engage with wider social networks. This is particularly important to consider alongside issues of access and digital inclusion or division (Duplaga, 2017), which will be discussed in the next section.

Though there was sufficient literature to identify this as a theme, the majority of support seeking literature found in this search was related to support sought by parents and teachers of children with both physical and mental developmental disabilities such as (Browne and Millar, 2016; Segui and Garcia, 2012; Zuurmond et al., 2019). This was excluded in the initial screening phase as being not from the perspective of the person with a disability, or child-focused if the research was conducted in an educational setting.

2.4.4 Accessibility

As alluded to in earlier sections, the issues around accessibility and inclusion are crucial to the design and use of internet and computer-mediated services by people living with physical disabilities. A number of different approaches have been taken to understanding the 'digital divide', such as highlighting the implications for health service practitioners in technology roll out (Watling and Crawford, 2010), examining the factors influencing the existence of such a gap (Vicente and López, 2010), and further looking at issues of inclusion in the research agenda (Jaeger, 2012, 2006).

While van Deursen et al. (2014) have found that people living with disabilities in Holland are more likely to be active online on a day-to-day basis, this is something that is reflected in the wider literature from around the globe. The challenges of access faced by people living with disabilities have evolved since Kaplan (1997) wrote about the sources of information on assistive technology in 1997, but even with the near ubiquity of mobile phones and internet-connected devices, there are still issues of inequality of access for people living with disabilities (Pal and Lakshmanan, 2015). Alper (2017) and Helkala (2012) highlight a number of issues that lead to inequalities in access and use of internet services, such as the authentication processes of social media or

government websites, or the physical cost of accessible devices or adaptions for existing systems.

The changing formats of social media are also causing fluctuating levels of engagements amongst users with different disabilities. While it can enable some people living with disabilities to support accessible tourism (Altinay et al., 2016), connect more with peers (Raghavendra et al., 2018), and have a positive impact on reducing social isolation (McMillen and Alter, 2017), Loureiro et al. (2015, 2014). found the accessibility of social networking sites to be limited in 2015 This trend appears to have continued as the format of social media sites can be a particular challenge for people who are visually impaired as image posts become more dominant and accessibility options lag behind (Liu and Chen, 2017; Morris et al., 2016). Fuglerud et al. (2012) had previously explored the use of social media by people with visual impairments in Norway and had highlighted accessibility issues around image posts, leaving users with limited functionality on the sites.

Some of these accessibility issues can be mitigated through the use of assisted and augmented communication technologies. Comfort and ability to use relevant technologies has a significant influence on the online activities of people living with physical disabilities (Bache and Derwent, 2008; Mann et al., 2005). The use of these technologies can be empowering (Buchholz et al., 2018; Buehler and Pelka, 2014), and can encourage greater levels of engagement than face-to-face interactions due to the greater control over perception and self-identity (Caron and Light, 2017; Hynan et al., 2014).

This control over identity links back to the previous sections on internet use and support, the need for further exploration of disability discourse online, and the safety aspects of disclosing a disability to both researchers and the online community at large (Alhaboby et al., 2017; Bowker and Tuffin, 2003, 2002b).

2.5 Context literature

This section covers literature that was excluded from the specific reviews above, but that nonetheless provides important context to the use of the internet and technology in healthcare and the broader themes influencing this thesis. Additional literature was found by searching for related papers to those that had been excluded from both the Early Onset Dementia and physical disability literature searches. This section will start by looking at literature on health information seeking and online interventions before moving on to how technology use for health in general has changed over time, smart homes and the Internet of Things (IoT), and concluding with a section on digital legacy.

2.5.1 Health information seeking

This section covers health information seeking literature in general and draws on work from a number of different disciplines and medical conditions. It will therefore be less focused on information seeking related to Early Onset Dementia or physical disabilities, and more on trends from this large area of research. By focusing on the trends rather than specifically on physical disabilities or dementia, it is hoped that it can better reflect changes over time and the impact of increasingly aware consumers on how they access and use healthcare (Cline and Haynes, 2001).

Health information seeking behaviours online is perhaps one of the best areas in which to observe changes in internet use and health engagement over time. Not only has the near ubiquity of the internet and internet connected devices enabled more people to connect and seek out information independently, but it is also allowing people to take more control of the direction of their medical treatment (Lambert and Loiselle, 2007). This change is observable from Beisecker &

Beisecker (1990), in 1990, when patients sought out information from doctors and medical professionals when in face-to-face meetings, but would not have sought out information independently beforehand to 2004 when 4.5% of internet searches were related to health information seeking (Morahan-Martin, 2004).

Of this 4.5% of searches, not all were conducted on an individual's personal health, and there is a body of literature which focuses on health searches for other family members. For example, although these do not relate to the findings presented in this thesis, there is a portion of literature related to disability and internet use which focuses on parental internet searches for information on a child's diagnosis or disability (Alsem et al., 2017; Khoo et al., 2008). Khoo et al. (2008) focus on whether parents feel that information found online can be considered trustworthy, as well as its impact on the value of traditional face-to-face information sharing between parents and doctors.

While the increase of health information seeking online is potentially helping to reduce health inequalities in some areas of the global population (Brodie et al., 2000), it does not have a universally positive effect. As discussed later in this thesis, the move to locate information online creates a problem for people with limited access to technology and the internet, such as older people or people with complex health needs (Ennis et al., 2012; van Deursen and van Dijk, 2014). Hale et al. (2010) also discuss this disparity in terms of an urban rural divide in internet use. This disparity is a theme which presents later on in this thesis, as the difference in access to services and information is exacerbated by whether or not group participants live in an urban or rural setting. It is also likely that the findings from Hale et al. have shifted slightly due to international moves to increase broadband coverage in rural and low income communities (Ginossar and Nelson, 2010), and a focus on technology for older people in an attempt to minimise the effects of a 'digital divide' in service and information access (Jeffrey, 2010).

The trustworthiness of online information is an area of concern amongst health professionals and researchers, who have sought to understand how patients assess the trustworthiness and validity of information they find online (Miller and Bell, 2012). While Cline et al. (2001) argue that this is a benefit to public health, with more people informed about their health and choices, it can also lead to a loss of trust in medical professionals. Patients who are dissatisfied with their care are more likely to rate information on the internet highly (Tustin, 2010), while also not seeking an unbiased or credible source for the information, rarely moving beyond the first page of search results (Morahan-Martin, 2004). This is one of the driving factors behind interventions designed to inform and encourage help seeking (Hurt et al., 2016), reduce depression (Boeschoten et al., 2012) or anxiety (Yuen et al., 2013), and potentially assist in self-management (Rod, 2016). Online interventions are not directed solely at people living with physical or mental health conditions, but also their carers or family members. There are several studies focusing on the use of online interventions for carers of people with dementia, both to improve quality of life (Torp et al., 2013) and encourage engagement with information and peers online (Powell et al., 2008).

The face of health information seeking research is changing as health records become increasingly connected and in the control of the individual as the consumer of healthcare. Some of this is reflected further in the next section on ‘change over time’, which discusses how the use of the internet for healthcare research and peer support has changed over time with the growth of social networks and the increasing ubiquity of smart devices.

2.5.2 Change over time

This section will look at how the internet has been used for health and information connectivity as technology and connectivity have improved

over time. The literature in this section was found during the searches for Early Onset Dementia and physical disability literature and tagged as ‘change over time’ during the screening process. It was also supplemented through Google Scholar searches to confirm the timeline for internet use and spread.

Since the World Wide Web became widespread in the 1990s (Coffman and Odlyzko, 2002), its use and accessibility have increased exponentially from local servers and email lists to continuous connectivity and the rise of social media sites through the early 2000s. Though IT solutions for people living with dementia and their carers are a more recent development, since the 1980s a number of different resources and sites have been developed for people living with a broad spectrum of physical disabilities. The precursor to internet, or at least prior to the early 2000s, interventions were predominantly based around text-telephone technology, something that has been used by deaf people since the 1960s and continues to be used alongside other contemporary means such as social media or other virtual platforms (Roos and Wengelin, 2016). What is a distinct change from text-telephone technology towards 1980s interventions is that each intervention becomes specific to a particular diagnosis, potentially acting as a way of connecting with peers with the same diagnosis, but dividing those who are unable to interact on the same platforms.

Distinct platforms do however have the benefit of making it easy for people to find support around a common issue. For example, DEAFNET was software similar to USENET, but it aimed to give additional useful business and links to deaf people, their friends and family (Middleton, 1983). A crucial issue with DEAFNET, and USENET as a larger system, was that it was not nationwide or cross-compatible with other local computer-based communication networks. As connectivity improved towards the world wide web, or the internet as it is more commonly known now, these networks of communication and support could spread wider and connect a larger audience through online groups and forums hosted on a number of platforms. Both Finn

(1999) and Braithwaite et al. (1999) explored online self-help groups in 1999 and found that they were able to offer some of the same emotional support as face-to-face groups without the need to share physical space. Tichon and Shapiro (2003) followed this up further in 2003 by looking at the importance of self-disclosure in online support groups in order to develop effective online relationships. Websites of this nature allow people to discuss the nature of disability, and in the case of Hall (2018), their relationship with desire and sexuality in a "safe" environment. Studies of websites also expanded to include those hosting virtual worlds such as "Second Life", which present different opportunities for self-expression, and self-disclosure than other online platforms.

The discussion of self-disclosure on social media is also set against the rising focus on web accessibility (Ellcessor, 2010), an area which has remained a topic of research as the face of the internet has evolved. This has been of particular focus in relation to the changes in social media sites, such as Twitter, which have become increasingly image focused and have not kept up with the accessibility needs of blind or partially sighted users (Morris et al., 2016). Twitter has also been the focus of how augmentative and alternative communication can be utilised online effectively for greater social inclusion (Hemsley et al., 2018). These alternative communication technologies encourage the potential for greater independence (Agree, 2014), and through smartphones and other "smart" devices, offer the potential for more rapid innovations and connectivity in existing healthcare devices (Ng et al., 2017). This use of smart devices and integration with the Internet of Things will be discussed further in the next section.

2.5.3 Smart devices and the Internet of Things

This section gives an overview of the current state of smart devices and the Internet of Things (IoT) in health and medical fields. This

search was conducted separately to the main Early Onset Dementia and physical disability literature searches in order to supplement the topics already discussed in the previous section on change over time.

A summary on the history of the IoT cites the first use of the phrase the ‘Internet of Things’ as a presentation in 1999 on the use of Radio Frequency Identification (RFID) to link the Proctor and Gamble supply chain to the internet (Braun, 2019). The author of the presentation, Kevin Ashton, has since written that the way the IoT is now understood - as a network of internet-connected objects (Fortino and Trunfio, 2014) - is not necessarily as he had intended as it overlooks the limitations of human-centric data (Ashton, 2009).

However, the breadth of the IoT and types of connected devices has increased rapidly since Ashton’s article was published in 2009. The IoT has spread beyond connected packaging to systems which allow real-time tracking of cars in ridesharing apps like Uber and Lyft, and to smart devices which allow multiple levels of connectivity. ‘Smart’ objects are autonomous objects with networking capabilities (Fortino and Trunfio, 2014) which connect more readily to the internet. These objects have come a long way from the unaffordable LG smart fridge, which cost more than $20,000 at launch in 2000, to smartphones that are used by approximately 78% of the UK population (O’Dea, 2019).

Smart objects are increasing in prevalence in the UK, with around a quarter of the UK population owning one or more smart home devices in 2018 (Feldman, 2018). The most common are smart speakers. These can then be integrated into a local IoT environment (Risteska Stojkoska and Trivodaliev, 2017) and controlled by a home assistant, such as a Google home hub or Alexa device. Smart home setups can assist in accessibility for people with disabilities or dementia (Dewsbury and Edge, 2001). While these devices have not always been met with confidence and acceptance in a ‘smart home’ setup (Demiris et al., 2004), their acceptability and use is continuing to grow in the UK as illustrated above.

2.5.4 Digital legacy

With more of people's lives being curated online, from photos to family contact information, there is an increasing concern about what happens to these accounts and the data stored on them once the account owner has died (Edwards and Harbinja, 2013). This is a relatively new area of research, with the bulk of work being done in the last seven years. It focuses on older adults or is part of an end of life plan for terminal patients, similar to a traditional will. Organisations such as the Digital Legacy Association have helped to push forward the conversation amongst groups working in end of life care, but it is not something which is well known about or considered by the general public - or indeed the participants in the study presented in this thesis.

Both the Digital Legacy Association, and Carroll and Romano in the 2010 book 'Your Digital Afterlife', aim to provide practical guidance on how to manage the legacy of social media accounts and other online logins after death and how to make your wishes known to your family, as well as suggesting methods for passing on and carrying out these wishes securely (Carroll and Romano, 2010).

In academic literature the focus has mainly been from the Human Computer Interaction (HCI) community, focusing on the practicalities of using legacy management software and settings. These have focused particularly on the practicalities of existing software, such as Google's inactive account setting, and the legality of bequeathing digital assets. Most famously in the latter case is the often cited but inaccurate claim that Bruce Willis sued Apple over ownership of iTunes downloads (Hickman, 2012; Raymundo, 2012). Although he did not sue Apple, it did bring the legal issues of passing on digital libraries into the public consciousness in a way it had not been previously. Researchers such as Lillian Edwards have explored the legal issues associated with the transfer of digital assets, and if the existing solutions to this issue resolve or exacerbate them (Edwards and Harbinja, 2013). Whilst Edwards focuses on the legality of a

number of technical solutions, Prates et al. (2015)and Maciel et al. (2015) focus explicitly on the options available in a Google inactive account, which arguably has a smaller scope of responsibility than a solution like ‘LegacyLocker’.

Other researchers have looked at the value of this data and at individuals’ understanding of legacy management. Gulotta et al. (2013) looked at how parents understood the future of their digital information and found that the technology available did not fit their participants’ plans for how they wanted to treat their data. Similarly, other research conducted with older adults is showing that the current offerings for legacy storage and curation do not fit with their existing plans or understanding of a digital legacy. These studies highlight a need for a discussion earlier in time for people already active online, and a greater level of personalisation and training to be available for older adults who have digital assets to manage and bequeath (Manchester and Facer, 2015; Thomas and Briggs, 2014).

While this research provides a base, it also highlights a need for the conversation on digital legacy planning to be prompted with individuals using the technology and resources available to them at the time. It is also likely that this conversation would need to be prompted earlier with people with dementia, and particularly with younger diagnosed people. They are likely to have a larger digital presence and a greater need to have appropriate plans in place for future management of accounts and passwords sooner than otherwise anticipated due to loss of capacity or ability.

2.6 Summary

This chapter has described the methods used in the literature searches for this study. It has also described the literature related to the two participant groups, and additional literature that gives context to the growth of the Internet of Things and the importance of digital

legacy management. The next chapter will set out the methods used for data collection during this PhD study.

Chapter 3 Research Design

3.1 Overview

This study uses a mixed methods approach. The data from each group were collected using an online questionnaire and a semi-structured interview. Although the initial approach for each was similar, there were some differences in the recruitment strategies between the two participant groups that will be discussed later in this chapter.

In addition to the questionnaires and interviews, the data for Group 2 (people with Early Onset Dementia (EOD) and their families) were supplemented by working with the Alzheimer's Society to access online forum data on relevant threads. This was done with the aim of assessing the validity of themes drawn out of interviews and questionnaires completed by people living with EOD, their friends, or their family members.

Figure 3.1 gives an overview of the research method, outlining the path from data collection through to final analysis. These stages are described in more detail in the subsequent sections of this chapter, starting with the methods used for recruitment and data collection with Group 1 in 3.2 (people with physical disabilities) and continuing through the analysis approach. Following on from this section, 3.3 describes the recruitment, data collection, and analysis methods used for Group 2.

After discussing the methods, section 3.4 covers the ethical issues that arose during the planning and data collection stages across both groups, and the actions that were taken to address them.

This chapter concludes with a reflective section on the challenges faced during the planning and conducting of research. The reflection section allows for a discussion of the original research plan from the start of the PhD and the choices that were made as time progressed, forming the final research project presented in this thesis.

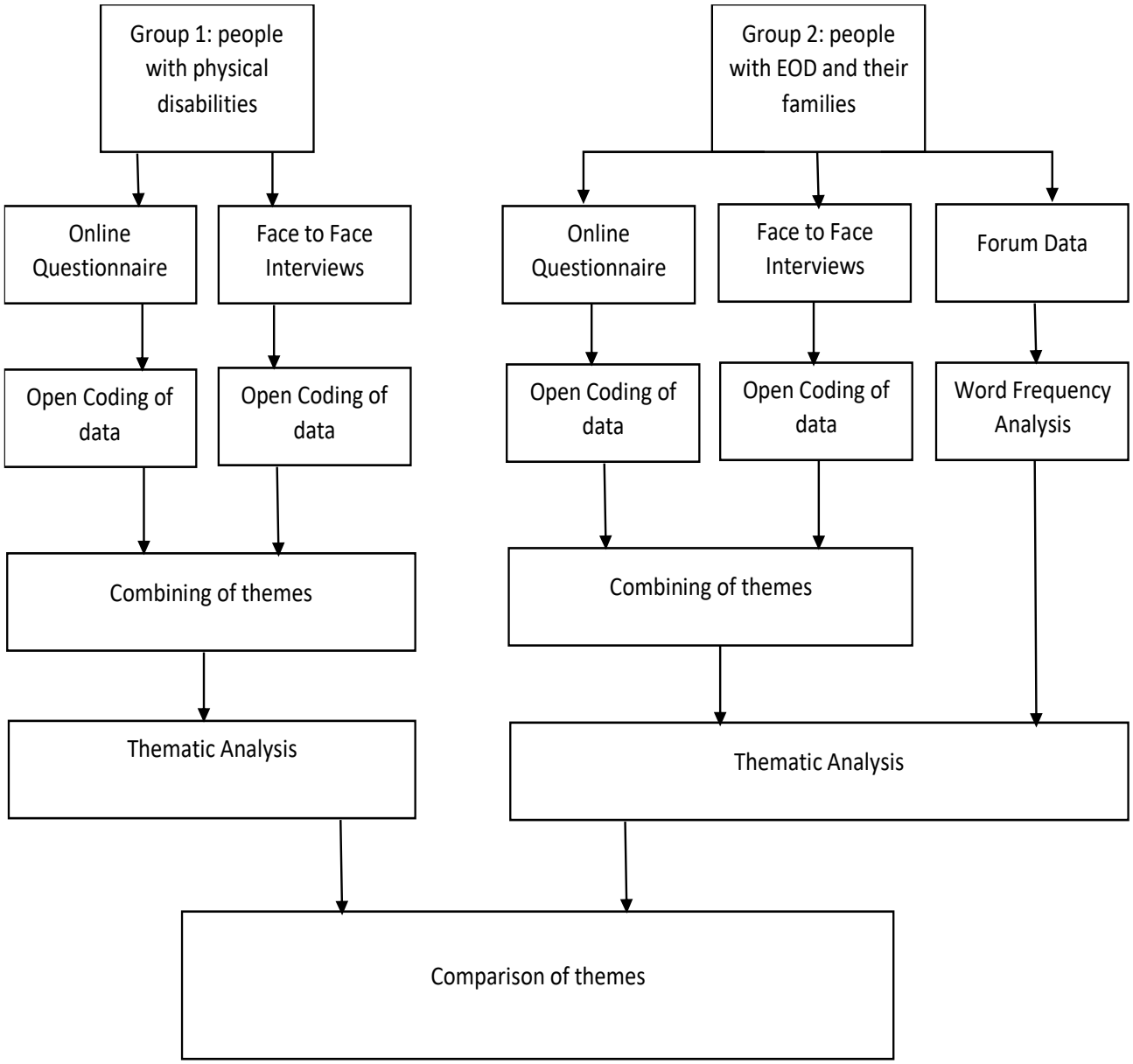


Figure 3 -1 Overview of research design

3.2 Group 1: People with physical disabilities

While the initial focus of this work was on people with Early Onset Dementia, adults with physical disabilities were selected as a participant group who might have comparable problems of access and potentially deteriorating access to IT and the Internet. Specifying people under 70 also meant that it would be adults in the same age range as those who would be affected by Early Onset Dementia, and therefore likely to have similar experiences of the expansion of social media and smartphones. Data collection with this group comprised of face-to-face interviews and online questionnaires. This section will discuss each of the data collection methods in turn, followed by a subsection on the analysis methods used for this group's data.

3.2.1 Interview design

This initial interview schedule was designed to answer some basic questions about internet use amongst people living with physical disabilities, ways a physical disability could influence use and access, or how it can cause a change in use or access over time.

The interview was semi-structured in order to accommodate different circumstances and to allow for greater follow up on relevant emerging topics with each participant. The schedule also included a section of questions about accessing local government services and information. This was included to answer Nottinghamshire County Council's (NCC) questions around the use and uptake of a new website that had been launched during the time this project was moving through the NCC internal ethics process. The inclusion criteria for the interviews were as follows:

- Aged between 18 - 70
- Living with physical disability
- Not listed as having cognitive impairment by NCC
- Living in own home or with family members
- In receipt of services from NCC Adult Social Services department

3.2.2 Interview recruitment

The interviews were conducted as part of a feedback gathering exercise for NCC and were undertaken in partnership with the Adult Social Services department. Therefore, recruitment was also carried out in partnership with the department. In order to ensure confidentiality of potential participants, NCC would send out a recruitment letter with my contact information in, allowing potential participants to contact me, but I would have no information about them unless they did so.

After a discussion about inclusion criteria with my contact in NCC, I wrote a recruitment letter to be sent out to people meeting the inclusion criteria mentioned in the section above. NCC posted 1500 letters to people in receipt of their services across the county. However, an unknown number of letters were sent to people living in care homes and assisted living facilities. Obviously, these individuals did not meet the inclusion criterion of living in their own home or with family. A large number of initial responses were received from potential participants with a wide range of ages, living situations, medical conditions, and access to the internet or IT.

In total, 18 participants were recruited using opportunistic sampling, with 16 interviews conducted as two participants dropped out due to ill health. A further participant was excluded after the interviews had been conducted due to issues with recording; see figure 3.2.

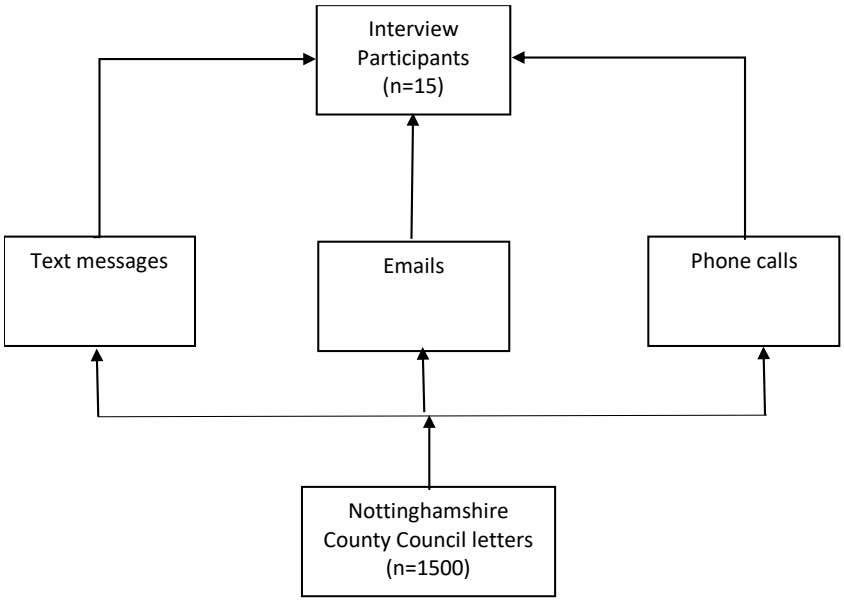


Figure 3 -2 Group 1 Interview recruitment

3.2.3 Questionnaire design

The process of moving the application to carry out interviews through NCC internal ethics approval was slow, which led to increasing concerns over the time it would take before data collection would start. In order to alleviate the risk of no data being collected due to interviews not progressing through ethics or time running out on being able to conduct them, I decided to launch an online questionnaire so that data collection could start with this participant group.

The questionnaire was designed to mirror the semi-structured interview schedule by using a mix of multiple-choice and free text responses for each question. A copy of the questionnaire is included as Appendix 9.2 to illustrate the balance between the two responses. It was intended that including the free text options would replicate the space for elaboration allowed in an interview, while the multiple-choice questions would capture other areas that might be listed (such as the devices used to access the internet, or activities online). The online questionnaire also allowed me to ask for more demographic information, which could then be used to more directly compare to

responses from Group 2 (people living with Early Onset Dementia and their family members). In addition to mirroring the questions in the interview schedule, launching an online questionnaire also enabled me to widen the geographic range of responses from Nottinghamshire only to UK wide. The inclusion criteria for the questionnaire were as follows:

- Aged over 18
- UK resident
- Living with physical disability
- No cognitive impairment
- Presumed able to provide consent
- Living in own home or with family members

In the interview study, capacity to consent could be more directly assessed by the interviewer. For the questionnaires, it was assumed participants were truthful about meeting the inclusion criteria, although any responses that appeared particularly confused or irrelevant to the question would have been excluded.

3.2.4 Questionnaire distribution

Distribution for the questionnaire was carried out entirely online through social media sharing, a participant recruitment website, and word of mouth in research and social networks. The questionnaire was hosted on Bristol Online Surveys (now Online Surveys) which provided a link that could then be shared across other websites. One of the main ways of sharing the link, as well as an information sheet that was viewable before clicking on the BOS link, was by creating a Call for Participants (CfP) page. CfP hosts a number of academic and industry studies that are actively recruiting participants, and allows access to a database of potential participants who are automatically sent information about new studies if they have opted in to contact when completing another study. The CfP site also has social media channels

that promote active studies on their Twitter and Facebook pages to increase the number of networks the page is visible in.

The CfP was also shared by myself and others in my personal network on Twitter, Facebook, and on Reddit. Targeted hashtags were used in an attempt to raise the impact and views of the tweets. After some discussions, several relevant charities and publications also shared the questionnaire link on their main social media pages. This included Scope, who shared the CfP link on their Twitter page, and allowed me to post in their support forums to reach out to more people that way. The figure below illustrates the distribution strategy of this questionnaire. In total, the front page of the questionnaire on BOS received 442 views, and 29 complete responses were recorded.

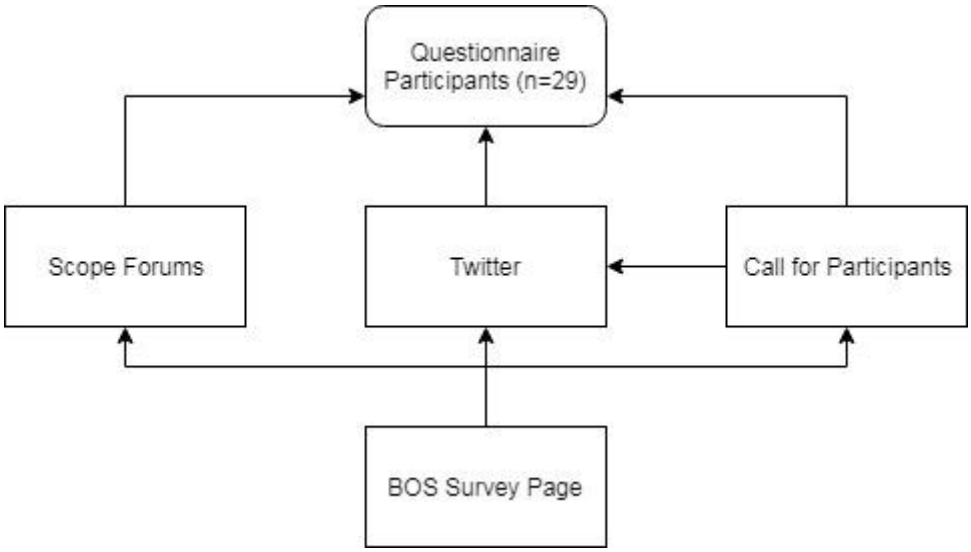


Figure 3 -3 Group 1 Questionnaire distribution

3.2.5 Participants

Henceforward, participants of this group of people living with physical disabilities will be labelled as IP1-1 to IP1-15 to indicate their participation as an interview participant, or QR1-1 to QR1-29 to indicate them as a questionnaire respondent. Interview participants were renumbered sequentially during analysis after two participants dropped out of the study, and one was excluded due to issues with the

audio recording. Demographic information about the participants is included at the start of Chapter 4.

3.2.6 Analysis

In this section the interview and questionnaire data are going to be discussed jointly for the purposes of analysis due to the high levels of interaction between the two. The main reason the two sets were not combined was the difference in depth of data between them: not all questionnaire respondents filled in the free text responses in detail, and although the interview schedule and questionnaire were the same, the data from each did not map closely enough onto each other to be one set. While they were not one data set, they were analysed using the same methods, and in particular the questionnaire data were used to provide a wider national context to a county-based interview group.

Interviews were transcribed, two by myself, and the remaining by a transcription company contracted to the University of Nottingham. Once the transcriptions were received, they were printed out for the first round of analysis to be carried out on paper. The analysis used on these data was an iterative thematic method starting with open coding of the data, moving through a combining stage, and finally an overall thematic analysis once themes have been established (Saldana, 2009). This method is inspired by a grounded theory approach to coding (Charmaz, 2014; Corbin and Strauss, 1990), but did not seek to develop theories as the analysis progressed.

This first round comprised of open coding which involved highlighting everything of interest in the participant responses (Saldana, 2009). After this was completed on all 14 transcripts, a second iterative round of coding was carried out that started to group the first codes together; for example, the first round codes ‘Facebook’, ‘Twitter’, and ‘Instagram’ were combined in the second round into the code ‘Social media’.

Once the second round codes were established, these were compared for similarities and then combined into three main themes which will be used to frame the findings chapter (Chapter 4). Another round of coding using these themes was carried out both on paper and in NVivo in order to ensure no participant responses had been missed. This round of coding was also iterative, and based on the main themes identified, some of the second round codes became more nuanced. The 'Social media' code, for example, was split at this stage into those which fell into general online activity and those that were based around using social media to access social support.

Open coding was also carried out on the free text responses on the online questionnaire, and then compared to the second round themes from the interviews. The responses were then added into the data for each of the three main themes, and contributed to the write up in the findings chapter. Participants from the questionnaires are identified as such using the labelling system described in the previous section.

Chapter 4 was then written based on the combined coding and analysis of the hard copies of interview and questionnaire data.

3.3 Group 2: People with Early Onset Dementia and their families

Research with this group comprised face-to-face interviews and an online questionnaire, supplemented with forum data from the Alzheimer's Society. This section will discuss each of the data collection methods, followed by a subsection on the analysis methods used for this group's data. I will also discuss the collection of data from the Alzheimer's Society Talking Point forum and its eventual use in the analysis of emergent themes from interview and questionnaire data.

3.3.1 Interview design

Following on from the Group 1 interviews, some changes were made to the interview schedule so that it would better reflect the experiences of people living with EOD or their family members. The revised schedule focused more on changes over time and the management and access of online accounts. The decision to include family members if they wished to participate was made early in the research planning process to try and capture the changes in use following a diagnosis of EOD, and the shifting responsibilities for online account and service management. The schedule was also extended further than that of Group 1 to include questions on digital legacy and future wishes for the management of social media accounts, an area of interest that had arisen between the data collection periods for Group 1 and Group 2 following several discussions with colleagues in the university and at the Digital Legacy Association. To this end, Research Question 4 will only deal with the findings from Group 2.

The interviews remained semi-structured in order to accommodate for different personal circumstances, and to allow for greater follow up of relevant topics and themes that emerge during the interview. It also allowed time for demonstrations or to be shown aspects of IT or internet use - something which had occurred more than once during the interviews with Group 1 participants, and had not been accounted for in the predicted length of interview or the schedule when planning. The inclusion criteria for the interviews were as follows:

- Index participants will have been diagnosed with a dementia before the age of 65
- Have been diagnosed for less than 5 years
- Have capacity to consent
- Be living at home with family at outset of study (can be spouse/parents/children)
- Live within 50 miles of Nottingham (later changed to 75 miles)
- Family members also willing to consent and participate; children under 18 must be willing to provide assent to take part
- Adequate verbal communication skills and hearing
- Participants are English speaking

3.3.2 Interview recruitment

Recruitment for this participant group was less straightforward than originally anticipated, as recruitment through the Working Age Dementia clinic in Nottinghamshire became impossible (see section 3.4.1). Consequently, I had to move to alternative methods of recruiting participants rather than seeking them as NHS patients. This involved creating a Call for Participants (CfP) page for recruitment and sharing the link over social media. I shared the link personally with contacts I had made in the peer support community amongst people living with EOD and their family members online, but also reached out to relevant charities and publications with a social media presence to get the recruitment link shared on their pages too. The recruitment call was also shared in the DEEP newsletter in both email and paper format.

This method had limited success, and only one index participant was recruited using the aforementioned methods. This participant and their partner (IP2-1 and IP2-1P) were recruited through the DEEP newsletter, and before the study design was revised for a second time. Subsequently they were the only participants to be interviewed twice.

The remaining participants were recruited after registering with Join Dementia Research (JDR) and accessing their resources to reach a wider audience, who had already expressed an interest in being

contacted to take part in research. Recruitment through JDR was therefore more targeted and allowed me to search for potential participants using my inclusion criteria within a 50-mile radius of Nottingham. This area was later extended to 75 miles to include Birmingham, Salford, and Bradford. The JDR platform also allowed me to screen out individuals who did not fit the inclusion criteria and contact others using their preferred methods. In total, 72 potential index participants were contacted and ten recruited. With family members included, the interviews had a total of 17 participants.

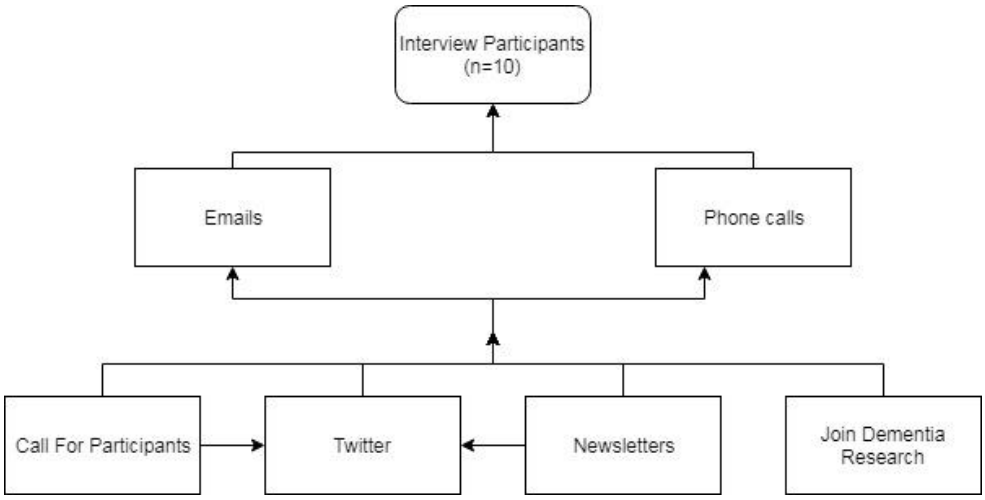


Figure 3-4 Group 2 Interview recruitment

3.3.3 Questionnaire design

The questions set were based around the interview schedule, with the design of the questionnaire incorporating three different strands of questions. This approach allowed me to create a strand of questions targeted for people living with EOD, their family members or carers, and friends of people living with EOD within the same questionnaire and from the same sharing link.

This questionnaire was designed similarly to the one used for Group 1, with free text options for appropriate questions aiming to replicate the free responses from a semi structured interview. It also expanded on some of the questions from the first group and responded to some

of the feedback left by participants, such as a greater number of options in some multiple choice answers, e.g. how the internet is accessed and what it is typically used for. The recruitment criteria were also expanded as was appropriate for the potential audience being recruited from, and were as follows:

- Aged 18 or over
- UK resident
- Diagnosed with dementia before age 65
- OR family member or friend of someone diagnosed with dementia before age 65
- OR care for someone diagnosed with dementia before age 65
- Presumed able to consent

As with the Group 1 questionnaire, capacity to consent was presumed in the absence of a way to assess it directly. No explicit exclusion criteria were set for this questionnaire.

It was again inferred in the giving of consent that the participant truthfully met the inclusion criteria, although there was no way of confirming this. If any responses were particularly confused, or it seemed particularly evident that the participant had not understood the questions, then that response would be excluded. However, in the event, this was not the case for any of the responses received.

3.3.4 Questionnaire distribution

As with the questionnaire for Group 1, this questionnaire was distributed online and through word of mouth. I created a CfP page to share over social media, and spoke about it at the groups I attended to try and recruit participants. It is not known whether any of the participants were present at these groups, but they were not successful in recruiting people living with EOD for interviews.

Similarly to Group 1, CfP posted about the study over their social media channels to improve visibility as I continued to share over my

networks, focusing particularly on Twitter. This was in part due to the more public nature of Twitter over Facebook, but also down to the seemingly very active community of people living with EOD or family members of people with EOD who post regularly about their experiences of EOD and services in their area. Some members of this group are also active in a weekly #Alzchat discussion with health care practitioners, researchers, and peers. Twitter also has the additional benefit of being able to make posts easily visible through the use of active hashtags. This was a slight change from the online distribution of the questionnaire for Group 1, which was shared by charities over their social media, and therefore extended the impact beyond what I would have been able to achieve on my own. This questionnaire was not shared by charities online, and so was more reliant on my own network and highlighting the best hashtags, including #researcher, #phdresearch, #earlyonsetdementia, #dementia, #youngdementia, #youngdementiauk, and #dementiaresearch. I also reached out to a number of influential accounts to try and spread the reach of the questionnaire, and also potentially recruit the account owners to either the questionnaire or interviews.

The questionnaire was also registered on JDR, where it would show as an available study to members who met the inclusion criteria. It is not known how many page views or responses were recorded from each of the distribution methods. The figure below illustrates the distribution method for this group.

In total, the BOS landing page received 437 views, and 21 complete responses were recorded.

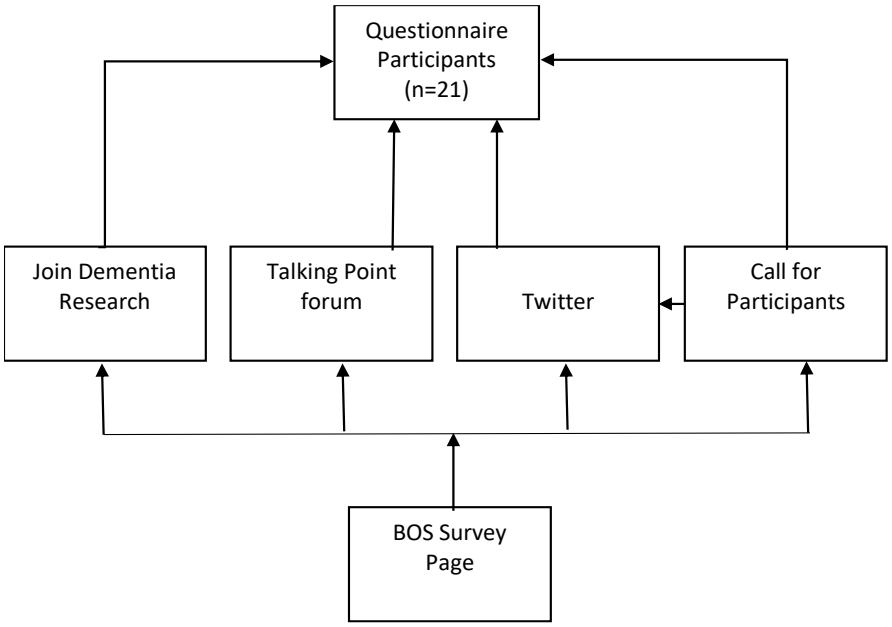


Figure 3-5 Group 2 Questionnaire distribution

3.3.5 Participants

Participants in this group were labelled as IP2-1 to IP2-10 to indicate their participation as an index interview participant. Partners of index participants have the suffix P, such as IP2-1P. Questionnaire respondents are labelled as QR2-1 to QR2-21. Interview participants retained their original participant numbers, with IP2-1 and IP2-1P having both interviews included under the same tag. Further participant details are included in Chapter 5.

As discussed in the next section, quotes were not taken from Talking Point and participants from this group are not identified further in this thesis.

3.3.6 Analysis

The analysis of data collected from Group 2 participants was done based on the same iterative methodology as the data from Group 1. The questionnaire and interview data will therefore be discussed as

one, although they remained distinct data sets. After analysing the data together for Group 1 I had considered combining the two data sets, but ultimately decided not to due to the multistrand approach to the questionnaire and the different focus of the two data. The interviews were mainly with people living with EOD, whilst the questionnaire responses were mainly from friends and family members of someone with EOD about their experiences. The methods used for this group were the same. This includes the coding and grouping approaches to the data.

The interview transcripts were sent to an external company contracted to the University of Nottingham for transcribing.

Once all transcripts were collected, I began to code the data in line with the coding principles established in the analysis of Group 1 interviews. In this analysis there was an element of deductive as well as inductive coding involved (Fereday and Muir-Cochrane, 2006) as more specific questions had been added into the interview schedule. These were related to the considerations around digital legacy and continued internet use, which had not been included in the Group 1 schedule. Though this is similar to both an inductive approach (Thomas, 2006) and the early stages of a grounded theory approach (Corbin and Strauss, 1990), it does not follow either in going on to develop a model or theory, and instead continues to focus on the experiences of the participants in the groups.

After the first round of open coding was completed, this was then followed by a second iterative stage and a consolidation third stage into the main themes that are used to discuss the findings in Chapter 5. Following the same path as Group 1, questionnaire data from the free text responses was also subject to open coding and were added to the final themes in Chapter 5. These participants are indicated using the labelling strategy outlined in the participant labelling section that preceded this (section 3.3.5).

Chapter 5 was written based on the combined coding and analysis from the interview and questionnaire data and supplemented by limited analysis of forum data discussed at the end of this chapter section.

In addition to this, the main themes from both Group 1 and Group 2 were compared and used to frame the comparative discussion in Chapter 6.

3.3.7 Talking Point forum data

In addition to the questionnaire and interview data, for Group 2 I added an additional stream of data from the Alzheimer's Society Talking Point forum. This covered three years of posts and was downloaded by the moderator of the Young People with Dementia forum pages on my behalf after negotiating access and receiving approval from the charity's data protection compliance team. This additional data would be used to check whether themes from the interviews were present in the experiences of a larger group of both people with EOD and their family members, and to assess the validity of the findings from the questionnaire and interview. If possible, some quotes would be used to illustrate the wider applicability, though it was later determined this would not be possible. These data were intended to be a third stream of data, used mainly for validity, and not be incorporated into the findings of the questionnaire and interviews with Group 2. With this goal, the additional data would not compromise the comparability of the data collected between the two participant groups or impact on the findings for either group.

The literature search on social support and information seeking online had shown that online forums were often used by people living with physical disabilities for both purposes, and that they had been used in research to assess the efficacy of online peer support (Kummervold et al., 2002). However, some of this literature is dated, as the focus has

moved towards social media (Sarasohn-Kahn, 2008) and other uses of technology in the lives of people living with disabilities (Ellis and Kent, 2011; Hersh and Johnson, 2008). I had previously used the forums of charities to share questionnaire links, notably Scope for Group 1, so in an attempt to recruit participants for Group 2 interviews I sought and received permission to share on the Alzheimer's Society forum pages.

Before seeking consent of the moderators in line with forum rules at the time, I had spent time looking over the Alzheimer's Society forum, Talking Point, in order to check the suitability of the forum for posting and the appropriateness of doing so. After this, I made contact with the forum moderators in order to receive permission to post the links to the questionnaire information page. When it was decided to move forward on the plan to use data collected from these forums, I made contact with the moderators again, and began working with them and the data protection team within the Alzheimer's Society to get access to the relevant data whilst keeping in mind additional privacy concerns of forum users.

As part of the agreement it was decided that to best fit the terms and conditions of the Talking Point forums, the data team would extract and anonymise data from the previous three years of posts on the 'Young People with Dementia' forum, covering May 2015 to May 2018. The data collects 433 threads consisting of 3083 separate comments posted during the agreed time period. These data were shared with me via a secure email link which provided access to the data set to be downloaded for a period of one week. Once I received this link, the anonymised data set was downloaded ready for analysis.

3.3.7.1 Netography and Talking Point forum data. – additional concerns over consent and privacy.

The use of forum data from the younger persons pages on Talking Point presented a different set of ethical issues to those in the interviews and questionnaires. Not least of these were the concerns over the ownership of the data and appropriateness of their use in preserving the anonymity of forum users.

Ownership of data is one of the main ethical concerns of online research, and has been discussed extensively by Kozinets and by Trevisan and Reilly (Kozinets Robert V., 2016; Trevisan and Reilly, 2014), particularly in relation to the 'right to participate' or gain consent from users within the dataset. This was an area which was additionally complicated by the Talking Point data: while only approved users can post on Talking Point pages, the posts that have been made are publicly viewable through a simple search of the pages. These publicly viewable posts could potentially be viewed in the same mind-set as public tweets, which by tweeting are assumed as having given consent by posting in a public setting. However, unlike most tweets, these posts are far more likely to contain identifiable information which could easily be traced back to an area or an individual, owing to the relative size of the population and the complexities of the diagnoses being discussed.

3.3.7.2 Analysis

The methods used to analyse this data set were word frequency analysis and content analysis based on the themes extracted from the interviews and questionnaires. These methods were applied to a set of 3803 comments retrieved by the data security and informatics teams at the Alzheimer's Society from the 'Young People with Dementia' sub-forum hosted on Talking Point.

The data was organised into a spreadsheet which was uploaded into NVivo due to its wide range of tools for qualitative analysis. The first method used was a word frequency count in order to gain an overview of the data and look for any similarities in commonly used words. At this stage the word “quote” was excluded from the analysis, as it appeared in the comment text anywhere that a user had quoted and replied to another user’s comment, as is commonplace in forums. In this data set it was the fourth most frequent word and appeared 1850 times. To place that number in context, the word “dementia” was the third most frequent word used across the forum and appeared 2072 times.

After the general word frequency count was done on the data set, searches for specific words identified as part of the main themes were utilised to assess the associated content. These included “forum”, “internet”, “online”, and “support”, and were used as keywords to try and draw out quotes from users focusing on the main themes discussed later in the study chapters.

While quotes were initially extracted, it was ultimately decided not to use direct quotes from the participants in order to preserve the anonymity of forum users. This was due to the searchability of forum posts through simple browser searches. Instead, the themes drawn out from the forum data were used to validate the interview themes by confirming their presence in a data source from a larger number of participants and a presumably extended geographic range.

3.4 Ethical considerations

Ethical issues around research with potentially vulnerable groups were a major concern, as were the measures needed in order to ensure fair participation and confidentiality for all participants. This applied not only to the people living with physical disabilities or Early Onset Dementia (EOD), but also to the support workers and family members

who may potentially be present or taking part in this study. In this section I am going to discuss the concerns around capacity, confidentiality, and distress, and how these impacted on the planning and running of data collection activities for this thesis.

3.4.1 Ethics approvals

Ethics approvals were received for each of the main data collection projects in this thesis. The questionnaires and interviews for each group were processed by internal University of Nottingham ethics procedures in cooperation with the relevant external bodies: Nottinghamshire County Council for Group 1 and Join Dementia Research for Group 2.

Questionnaires for both groups were approved by the School of Computer Science ethics process. The information and consent pages for each questionnaire are shown in appendix 9.1 for Group 1 and appendix 9.6 for Group 2.

The interviews required more ethical approvals due to their face-to-face nature and the amount of data collected. Group 1 interviews were approved by the School of Computer Science ethics process and the Nottinghamshire County Council internal ethics process to allow the letters to be sent out to potential participants. These forms are shown in appendix 9.3.

Following the rejection of the Group 2 interviews by the NHS Research Ethics Committee (REC) over researcher safety concerns, the ethics application was amended and sent to the School of Medicine, Division of Psychiatry and Applied Psychology ethics panel. This amended protocol and letter of favourable opinion are shown in appendix 9.8. The protocol was amended to include the necessary additions (highlighted text in the protocol) to allow recruitment to occur through Join Dementia Research once a favourable opinion was received.

The exception to these internal approvals was the data received from the Alzheimer's Society. These were extracted from the Talking Point forum and approved for use by the Alzheimer's Society data protection officers. They were handled in accordance with the agreement between myself and the officer I was in contact with to ensure users remained anonymous. As this was otherwise publicly available information, formal ethics approval was not needed.

3.4.2 Capacity concerns

Mental capacity was one of the topics which arose in the literature around dementia and internet use (Batchelor et al., 2012). Indeed, one of the main areas addressed in the ethics applications for both the study with people with dementia and the study with people with physical disabilities was the issue of capacity and ability to consent (Warner et al., 2008).

In the questionnaires this was taken as implicit: if a participant was able to complete the questionnaire, the consent given on the first page was taken as valid. However, it was also decided that if a response appeared "random" or incoherent then that response would be removed from analysis, although there was no such instance in the responses. This was a particular consideration in the online questionnaire for people living with early onset dementia, but it was also a consideration for the questionnaire for people with physical disabilities, which could also have included people with intellectual disabilities. This strategy aimed to be in keeping with the first principle of the Mental Capacity Act 2005 by assuming capacity unless otherwise evident through the previously stated criteria.

It is this principle which underpinned the assessment of capacity throughout both the questionnaires and the interviews. As the onus fell on the participant to contact myself as the researcher in order to take part and arrange an interview, initial consent was implied at this stage.

Developing from the research with Group 1, when it became apparent that participants had not fully understood the aims of the research prior to me arriving to conduct interviews, participants living with EOD involved in the second study were sent the information sheet in advance of the interview with multiple opportunities to ask any questions. At each stage, their understanding of the study was assessed and their capacity to participate taken as presented. This was repeated at the time of the face-to-face interview. Before the start of each interview the participant was given a copy of the information sheet to read, and a chance to ask any questions they had about the information sheet or consent form before it was signed. They were also given a signed copy of the consent form with my contact details in case they had questions after the interview. Verbal confirmation of consent was also taken that the participant was happy for the interview to proceed, for me to take notes throughout, and for it to be audio recorded for later transcription. If all of these were consented to, only then did I start the recorder and begin the interview. This was all to ensure that the participant was actively giving me permission to proceed with the interview. It also allowed myself as the researcher a greater opportunity to assess whether the participant had understood the requirements of participation and the aims of the study, whether there was continuing consent to being interviewed, and to ensure it would not induce distress.

3.4.3 Confidentiality

Steps were taken at each stage of the research in order to ensure the confidentiality of participants. These steps were approved for each study by ethics committees in the University of Nottingham: Computer Science for both questionnaires and interviews for Group 1, and the School of Medicine for the interviews for Group 2.

For the online questionnaire, all responses were assigned a number by the website hosting the questionnaire and used as participant numbers. In the case of the first questionnaire for participants with physical disabilities, there was an option to include an email address to be contacted if further studies arose; but when it proved this was not the case, these data were deleted in order to ensure anonymity. This was not an option for the second survey for people with Early Onset Dementia and their family members, and participants are identified only by the numbers given by the website. These are the participant numbers used throughout the study chapters, with each group starting again at one, identifying each as a separate data set. The links to these questionnaires were then shared through my personal Twitter account, with shares being generated by appropriate charities and community pages. The questionnaire for Group 2 was also hosted on 'Join Dementia Research' (from hence referred to as JDR), but also provided just a link to the study page, with no contact between myself as the researcher and any potential participants.

Additional steps were taken during interview recruitment in order to protect the anonymity of potential participants. During recruitment for Group 1, participants were initially contacted by the County Council, with contact details included in the letter for people to make contact if they were potentially interested in taking part. At this stage, if contact was made and the potential participant was interested in taking part, further details were taken to enable me to travel to their house to conduct the interview. No other information was collected from people making contact, and the addresses of the participants were known only to myself.

Protecting the anonymity of participants in Group 2 required additional steps owing to the differences in recruitment, since Group 2 recruitment was done through a number of online recruitment sites and methods. Initially this was done through the creation of a study page on the recruitment website 'Call for Participants' (CfP), which was then shared through my personal Twitter account and network, garnering

shares from the PhD group and also appropriate charities and community members. This link was also shared through the DEEP and Young Dementia UK newsletters, reaching a wider network of people beyond Twitter. In addition to the CfP page, the study was later added to JDR in order to reach more people living with EOD who had already expressed an interest in research. This recruitment was conducted in line with the study protocol, included as appendix 9.8.2, which was updated to conform with JDR policies. Recruitment through JDR involved contacting potential participants who were matched with the study through the criteria provided to JDR. In this instance, participants' contact details were viewable only by me, and further details of the study were sent and discussed only if the potential participant replied as interested in the study from the initial email. The location was originally restricted to an area within 50 miles of Nottingham, but this was extended to 75 miles when there was still difficulty recruiting participants.

3.4.4 Research and distress

The potential of the interviews to distress participants was one which was considered for both studies, but particularly for the Group 2 study involving people living with, or supporting a person with, early onset dementia. This was therefore included in the Group 2 protocol (included as appendix 9.8.2). Although it did not occur in either study, plans were put in place to pause interviews if it appeared a participant was becoming distressed, with the option to pause or conclude the interview early if that was the participant wished. The literature related to distress in research environments and dementia deals almost entirely with caregiver and family distress (Feast et al., 2016; McPherson et al., 2016; Mourik et al., 2004; Spenceley et al., 2017), while distress in people living with dementia is focused on distress in residential care environments or pharmaceutical interventions (Palmer, 2017). This literature also refers to older people with dementia and

those who are at a more advanced stage of the condition than those who participated in this PhD research.

3.4.5 Researcher safety

All the interviews were carried out by me in participant's homes. As such, these interviews were conducted in accordance with the University of Nottingham's lone working policy, which ensured that I had a communication network in place to let people know where I was during each interview. This comprised a text and email system that meant I let a text group know that I was going out on an interview, roughly where I would be without giving the participant's address, and roughly how long I was likely to be. I would then send a message to the group letting them know that I had finished the interview and was on my way back. If I was heading home rather than to the office, I would then send another message to let them know I had got back from the interview.

In addition to the arrival and leaving messages, I kept my phone close to me at all times, and notes were taken in addition to the audio recording so I could take notes on safety and location if needed. It was also planned that if I felt unsafe at any time during the interviews, I would conclude the interview and leave. Thankfully this was not the case in any of the interviews conducted, and the messaging system worked effectively.

3.4.6 Data management

Data collected in each of the studies were managed according to University of Nottingham Policies, a practice which was agreed on with both Nottinghamshire County Council and the Alzheimer's Society as external research partners for the studies. This meant that after data were collected and anonymised, all data were stored on a secure

folder on the shared research drive on the university's servers, which only myself and my supervisors could access. These are stored in accordance with the university's policies for seven years from the date they were saved, at which point they will be deleted. Information about the storage procedure was included in the information sheets for the studies requiring them, and participants were given the opportunity to ask questions about this before signing the consent forms for the studies.

3.5 Reflections

This section discusses the motivations behind the methodological choices made during the course of this PhD, and reflects on the experience of carrying out data collection as a result of those choices. The initial research question was aimed at understanding how two different groups used the internet and were affected in their use by their medical diagnoses of a physical disability or Early Onset Dementia (EOD). It was then expanded into the five comparative questions set out in the introduction of this thesis.

Over the course of this PhD, numerous challenges arose during the planning of methods to be used and in the data collection stage for both research groups. These challenges shaped the direction of the research and the approaches taken, not least in the selection of the methods used and the duration of data collection. This section will reflect on these challenges, outlining what they were and the eventual impact on the final project.

The choice to use qualitative methods was in part informed by my previous experience in using selected qualitative methods while completing my previous degrees in anthropology. This led to the initial choice to carry out an ethnographic study with people living with EOD and their families over the course of a year, with an interview study with people living with physical disabilities acting as a scoping study

for the levels of online information use and to test the initial interview script. However, this was not the final data collection method used, as discussed below.

The early plan for carrying out the ethnographic research with people with Early Onset Dementia was to work with the NHS Working Age Dementia clinic in Nottinghamshire to recruit participants and their families, which required NHS ethical approval. Early plans had been agreed with staff at the clinic, as well as the local REC panel. However, the process of applying for ethical approval and attending the Research Ethics Committee in Cambridge took longer than anticipated, during which time plans were already being revised. In the time between applying and attending the meeting, the online questionnaire was launched in order to start data collection. With ethical approval being granted by the University of Nottingham, it was a much faster process to get off the ground and running.

The interview study was ultimately met with an unfavourable opinion from NHS ethics. This forced a change in plan for the recruitment of potential participants for Group 2, as well as a change in the scale of the study owing to the time constraints that arose from the wait for the REC opinion and the time needed to reapply for ethics approval. At this stage I elected to recruit a non-patient group of people living with EOD and recruit outside of NHS clinical settings. This meant I was no longer required to seek ethical approval via the NHS, and instead applied through the School of Medicine, Division of Psychiatry and Applied Psychology ethics panel.

Part of this PhD was sponsored by Nottinghamshire County Council (NCC), but the exact nature of this partnership was not explicitly agreed in advance; it evolved from the initial meeting in the first months of my PhD. The lack of explicitly stated responsibilities in the partnership proved to be problematic when trying to set up the first interview study. At the outset, the plan had been to use the interviews with people with physical disabilities conducted through the council as

a pilot study to test the interview plan, and to see whether a group of a similar demographic profile in terms of age and potential access problems was accessing information and support online.

Secondary to this was using the interviews to assist NCC with understanding whether their service users were interacting with a new directory website they had launched at the same time recruitment for my study started. Although the plan was agreed with initial contacts at NCC, it was hard to connect with the right people and find support within the council to move along their internal ethics processes before recruitment could start. This led to long delays in the planned timeline. The concern that the interviews would not be able to happen at all through that route led to the designing and implementation of the first online questionnaire to kickstart data collection with people with physical disabilities, albeit on a national rather than county level.

The relationship with NCC had become somewhat confused by the time I completed my internship with the Public Health department, in large part because the contact point for my partnership moved from Adult Social Services to Public Health after a staff reshuffle. The internship did however provide me with new experience in trying to use my research to influence policy makers and decision making, and in writing policy documents. While writing the Health Needs Assessment for people with Early Onset Dementia in Nottinghamshire, I was able to learn skills in epidemiology and conducting research outside of an academic environment. At the time of the internship it also gave me time to find supporting information for my ongoing ethics applications and raised my own awareness of the number of age-specific services for people living with EOD in the county.

Both sets of interviews were significantly impacted by delays and setbacks in the ethics application process. This led me to re-evaluate my data collection strategies and consider where else I could recruit potential participants. It also ultimately led to me recruiting more participants with physical disabilities due to a higher than expected

response rate to the letters sent out, and travelling further afield to interview people with Early Onset Dementia than originally planned in order to recruit enough interview participants.

The quicker ethics approval process and shorter time from planning to launch meant that an online questionnaire for data collection was employed while in the ethics process for the interviews with people with Early Onset Dementia and their families. Particularly for the latter group, this meant that data collection could start before the interview study was approved. As discussed earlier in this section, the study was ultimately not approved by NHS ethics, which prompted another rethink of strategy. It moved from six interviews over six months to two interviews over four months, with the second follow up interview an optional element. The protocol and timeline were revised and sent to the School of Medicine, Division of Psychiatry and Applied Psychology ethics subcommittee, where it was approved for recruitment to start online.

During this time, I had also been in discussion with the Alzheimer's Society to access and use data from their support forum 'Talking Point' because of concerns that I would not have enough data to make a meaningful comparison between the two participant groups. This process was not as straightforward as initially thought, and took a long time due to the need to draft privacy and use agreements from the Alzheimer's Society. These were ultimately replaced by the new GDPR data protection laws in April 2018, but they set a precedent for how other researchers at the University of Nottingham would engage with the forum moderators to access data. The plan had been to carry out a full thematic analysis on the data extracted from the forum, but due to constraints on quotes being used and the time it took to access, full analysis was not possible. The data were used to validate themes on a broader scale outside of the interview and questionnaire data, rather than being integrated as initially planned.

As a consequence of these challenges, the structure of this PhD changed from a pilot and main study to two comparator data sets. Correspondingly the research questions were refined as data were collected, to bring the complexities of the two different groups into focus. This meant that the research questions set out in the introduction shifted from being focused solely on the internet use of people living with Early Onset Dementia to including people with physical disabilities. Each question was then further split to allow for separate answers to be provided for each group, before drawing them together in the final question. The final questions are set out in section 1.4 in the introduction.

Though these questions were shaped by challenges, they better reflect the work undertaken to complete this PhD thesis and the progression of ideas than if I attempted to push on with the original plan of conducting a multiple interview study focusing only on people living with Early Onset Dementia.

3.6 Summary

This chapter has described the recruitment of participants to the two participant groups involved in this PhD research, followed by the mix of methods used to gather and analyse the data. In the next two chapters, I will present the findings from each group before moving on to a comparison of online experiences in Chapter 6.

Chapter 4 Group 1: Internet use amongst people living with physical disabilities in Nottinghamshire

This chapter presents the findings from data collection with Group 1 (people living with physical disabilities in Nottinghamshire) and looks more generally at the internet use habits of people with physical disabilities in an attempt to update the literature in the field. Previous studies on disability and technology use have focused on adaptations to technology or the use of online support forums by people with similar conditions (Barak et al., 2008; Braithwaite et al., 1999; Kummervold et al., 2002). This chapter looks at not just the how but also the why, and moves to update ideas about support networks to those not only based on dedicated forums or charity websites but also on personal blogs and social media. It also explores the choices people with physical disabilities are making online and the rationale behind them.

As discussed in Chapter 3.5, this group was originally planned to act as a pilot for the interviews with Group 2, people living with Early Onset Dementia (EOD). It was felt that was the best way to explore the use of the internet amongst people 45+ who were confronting additional medical issues which could make access to the internet or use of information technologies (IT) difficult, such as reduced mobility or cognitive difficulties. It was also thought that by increasing the understanding of how people with physical disabilities use the internet for information and to access support networks, this insight may also be applicable for how people who are already active online when diagnosed with a dementia may continue to utilise and expand an existing digital presence and networks to incorporate new sources of information and necessary support features.

4.1 Participants

This section shows the demographics of participants in this group. The questionnaire had 29 complete responses from 442 landing page views. Table 4.1 shows the demographics of this group: just over half were aged 50-67, and there were more women than men.

Participant ID	Age	Gender
QR1-1	30-49	Female
QR1-2	50-67	Male
QR1-3	18-29	Male
QR1-4	30-49	Male
QR1-5	50-67	Male
QR1-6	50-67	Female
QR1-7	18-29	Female
QR1-8	50-67	Female
QR1-9	50-67	Male
QR1-10	68+	Female
QR1-11	30-49	Female
QR1-12	50-67	Female
QR1-13	50-67	Female
QR1-14	18-29	Female
QR1-15	50-67	Male
QR1-16	18-29	Female
QR1-17	50-67	Male
QR1-18	50-67	Female
QR1-19	18-29	Female
QR1-20	30-49	Female
QR1-21	50-67	Male
QR1-22	50-67	Female
QR1-23	50-67	Male
QR1-24	68+	Male

QR1-25	50-67	Female
QR1-26	30-49	Male
QR1-27	50-67	Male
QR1-28	50-67	Female
QR1-29	30-49	Male

Table 4-1 Group 1 Questionnaire respondents

From the 1500 letters sent out by Nottinghamshire County Council, 200 responses were received. 150 of these responses were over the phone, with 97 (48%) of these expressing interest in the interviews but being unable to take part due to lack of internet or computer access. Many of those who responded over the phone replied on behalf of multiple residents of residential homes who did not have access to the internet, and would not have had the ability to access it if the facility was in place.

A further 55 (27%) of responses expressed no interest in taking part and did not wish to be contacted again as part of further research.

The remaining 51 (25%) of respondents were both interested and able to take part in the interviews. From this group, 16 people were recruited into Group 1, with the rest being placed on a reserve list in case of dropouts. Although there was potential to carry out more interviews, the cut off was at 18 due to the initial plan for this group to act as a pilot for Group 2, meaning higher numbers were not required. An additional response was dropped at the transcribing stage due to problems with the recording. The age range of interview participants was 24-82, and further demographics for this group are shown in Table 4.2.

Participant ID	Age	Gender
IP1-1	50-67	Male
IP1-2	50-67	Male
IP1-3	18-29	Female
IP1-4	68+	Female
IP1-5	50-67	Female
IP1-6	50-67	Male
IP1-7	50-67	Female
IP1-8	68+	Female
IP1-9	68+	Male
IP1-10	68+	Male
IP1-11	30-49	Female
IP1-12	68+	Male
IP1-13	50-67	Female
IP1-14	50-67	Male
IP1-15	68+	Female

Table 4-2 Group 1 Interview participant demographics

4.2 Findings

Following analysis, the findings from the questionnaires and interviews completed by this group were grouped into three main themes: online activity, social support, and accessibility. Although these themes are broad and contain intersecting themes, they provide the best framework for a discussion of the uses and issues presented by participants in both the questionnaire and interview studies. All of these themes are discussed in greater detail in the following sections, but below is a brief introduction to each one and some of the rationale for including each header as it is.

The section on online activities comprises more general uses of the internet which were not explicitly utilised for finding a social support

base or dealing with issues of physical and virtual accessibility. There is some crossover of themes, particularly between this and the social support sections, largely due to the cross-purpose use of social media and the wide range of interests represented across those sites.

Social support covers the wide range of formal and informal support networks, and how the use of the internet supports their maintenance and formation. This includes interactions with condition-specific charities and the creation and maintenance of informal support networks and friendships.

Accessibility was a theme that had not necessarily been considered as a main discussion outcome of these studies. This was in part because of the considered biases in approaching for questionnaires online only, and because a lack of internet access excluded over half of respondents from the interview. However, because of this exclusion criterion and the presence of the theme across interviews, it seemed pertinent to include it as a theme of discussion in these findings - and perhaps most significantly, a take forward message for the PhD project as a whole.

4.2.1 Online activity

Though broad, this theme was identified to isolate online activities that were conducted separately from accessing social support, or internet and technology use which was prompted by the differing accessibility needs of the user, both online and offline. While there is some crossover, particularly within social networks' use for social support and research for accessibility, most activity discussed in this section focuses on the other functions that the internet and associated technologies play in the everyday lives of people living with a physical disability. This is particularly the case in the social networking section (section 4.2.1.1) which focuses explicitly on whether participants were active on social networking sites and why, whilst the social support

section focuses more on the interactions with peers and the emotional benefits of these. While the activities discussed below are not necessarily distinct from online activities carried out by people living without physical disabilities, many of the affordances utilised by participants and the necessity of them may be.

4.2.1.1 Social Networking

With the use of online social networks becoming widely considered as ubiquitous (Buchegger, 2009) in current society, it was perhaps unsurprising that 25 of the 29 of the questionnaire respondents and seven of the 15 interview respondents were active on social media. All of these seven interview participants identified Facebook as their main social network. As the relevant question in the questionnaire grouped all social networking sites together there was less information as to which site or sites the participants used; social networking sites including Facebook, Twitter, LinkedIn, and Tumblr were grouped into one response under the umbrella of social media in the questionnaire. The users of social media in the responses from the combined interview and questionnaire groups was from across the demographic profile of the group, with the notable (although perhaps not surprising) exception of the participants aged over 80, neither of whom had social media and only one of whom had access to the internet.

With Facebook being the social network most frequently identified by interview participants, it is evident that it has a role to play in everyday life. Seven participants were active on the site, with the remaining seven with internet access either not having an account or seeing no use for the site. For example, in the case of IP1-6, the final interview participant did not have access to the internet in any form and thus did not have social media. The seven users who were not active on Facebook were also not active on any other social networking sites,

and outlined their internet use as primarily for research, shopping, or other hobbies.

This was also the case in the questionnaire respondents, of whom 25 of the 29 indicated that they used the internet to access social networks of some description. In this instance the four remaining respondents were not able to indicate why they did not use social networks, as a free text option explicitly for this was not provided. The not active group was not isolated to a specific demographic or gender in either the interview or questionnaire participants.

4.2.1.2 Leisure and Social Activities

What perhaps differs from the more accepted use of social networking sites in this group is the targeted way in which they are used to interact with charities and peers living with similar conditions, as well as friends and others with similar interests. Three participants (two interview, one questionnaire) indicated that their main use of social networks was to connect with relevant charity and peer support groups. This is something which will be explored in greater detail in the social support section of this chapter. With the exception of the charity and support groups accessed through the site, usage remains typical of what is expected on social media. The accounts are used to stay in contact with friends and family, as well as participating in special interest pages relevant to the participants' specific hobbies. IP1-3 for example interacted with sports fan pages and IP1-11 interacted with their Boccia team, while IP1-6 was involved with crafting and buying and selling pages on Facebook.

4.2.1.3 Presentation of the self

Several participants were able to discuss the idea of playing with the presentation of their self through the selective sharing of information (Gee, 2008; Giddens, 2013; Goffman, 1999; Latour and LaTour, 2005; Miller, n.d.). IP1-3 in particular highlighted the ability to communicate differently online and use an "*online profile to talk to them like a normal person"* - to get people to see them first, rather than the wheelchair. This was an area of particular frustration for this participant, to get people to see *"the wheelchair is just an object, it's not who we are*". This is something which was similarly echoed by IP1-1, who felt more confident to say what they thought or be more cutting in their statements online without people being able to see the Parkinson's disease. This *"freedom of talking to someone without being focused on what they see"* (IP1-3) is something which is reflected in the literature, particularly around disability and online spaces. It is also found in online games in which avatars can be created with or without showing a disability, depending on what the player wants (Boellstorff, 2015; Nardi, 2010). Being able to communicate with friends and peers through social networks and to do so in their own time was something which was particularly valuable to IP1-3 and others, for whom verbal communication could be difficult at times. Although this was not a consideration of the majority of interview participants, this use of social networks as not just a connection but also as a communication tool leads into the next section focusing on the online activities of the participant surrounding communication.

4.2.1.4 Social Communication

Whether communicating with friends, family, or services, the internet has a key role to play in facilitating many of these connections. While it was common to mention emails with the social services, by far the

most common use was communication with friends and peers online. This intersects with the use of social media previously discussed and the social support section of this chapter, but needs a distinct section for discussion. With mobility being an issue for all of the participants, a number of different communication methods over the internet were identified as being crucial to staying in touch with friends and family. IP1-4 for example used Facetime on an iPad to stay in touch with family members when they were not able to visit, while IP1-6 identified online classes and skill sharing websites as methods they used to stay in touch with friends around the world with similar interests. It is important to note that while these uses are not distinct to this user group, video calling has become widely used enough to be used in studies as a measure to support e-health research. Its use can form a crucial connection in a group for whom travel can present an issue. IP1-7 in particular highlighted this theme well:

"Using the internet is a way of me being able to keep in touch with my friends all over the country. Not just through Facebook but by other medias and stuff like that … I'm on the internet most of the day … just to keep me from going potty. When you've been sat in the same chair for 12 years your head starts to go" (IP1-7)

While not all participants used the internet to this extent, the 14 interview participants who had access to the internet all utilised it for communication purposes, either alone or with support, in order to reach out to services and friends. Although their use of the internet was more selective, IP1-6 also viewed communications over the internet as something that "*helps to keep me sane*" after several months of being housebound.

Several who were more limited in their internet use highlighted this area specifically as a reason they wished they understood more about the devices and affordances of them. IP1-9 highlighted that they would "*love to know where these people are*" regarding old friends they had

lost touch with, and knew in theory that social networks and other searches could help them reconnect.

An unexpected finding was the benefit some participants found in using predictive text, both for sending texts and emails. This was highlighted by participants who were also dyslexic, who found that the predictive text was helpful in formulating coherent messages between family members and friends. This led to further conversation which will be discussed later in the accessibility section around the accessibility of website design, communication of messages from the social services to their user groups, and training which could support people with comprehension difficulties in their activities online.

4.2.1.5 Research and information seeking

"I do like researching things. I don't just look at things at face value, I like to get into…" (IP1-6)

The most commonly identified use of the internet by participants with access to the internet was research and information seeking. Whether this was related to a health concern, travel, or just cinema times, information seeking activities were the most commonly identified use of the internet by both questionnaire and interview participants. While this is by no means a distinct use of the internet by people with physical disabilities, it is one of the ways identified in which it can "*become a lifeline*" (QR1-11) for this group.

Information seeking behaviours related to health have become an established body of research, stemming from the early years of email boards allowing for people to share diagnostic experiences to the present time when information on treatments and medication from around the world is available to all online (Braithwaite et al., 1999; Bussone et al., 2017; Ellis and Kent, 2011; Huws et al., 2001; Leydon et al., 2000; Liang and Xue, 2013; Lupton, 2017; Miller and Bell, 2012).

While these often focus on the experiences of a specific group, such as people living with cancer, the search for information following the diagnosis of any disabling condition can be very similar. This is also the case for many people living with Early Onset Dementia, something that will be discussed in Chapter 5.

Several participants were actively engaged with academic learning online, with one questionnaire participant taking courses from the Open University and an interview participant taking university courses in Nottingham. This obviously shaped the content that they were researching online, as a significant portion was course-based, although neither disclosed what the courses were on. This online focus enabled them to continue their studies without having to travel, making the courses more accessible than they may otherwise have been - a topic which has been increasingly present in the literature as the shift towards e-learning and support has intensified (Arbaugh, 2000; Egan et al., 2004; Kent, 2015).

Participants highlighted several areas of research, such as travel or cinema information. Much of the information sought by participants was identified as being explicitly linked to their health or medical condition. Participants commented on the volume of potential information online, and the challenges of sorting what is relevant or useful to them. They then went on to comment on the strategies they used when assessing information and its sources. One participant (IP1-1) described his experience post diagnosis as *"got diagnosed, came home, went on the internet … looked up Parkinson's … just about shit myself*" when confronted with information on the potential progressions of the disease, before learning to *"become more restrictive in what I'm looking at"* and going mainly to the Parkinson's UK charity page as a reliable source of information.

The increased use of the internet to look for health or medical condition related information is perhaps to be expected in a group of people who have a medical condition to research. After all, someone who does not

have a medical condition would have no need to do *"a great deal of research into ... medical conditions"* (IP1-6). This perhaps also applies to the research into accessible technologies or devices and travel. IP1-5 identified one of their key reasons for accessing the internet was *"looking for certain equipmen*t", while IP1-3 ran and researched for a website which gave specific additional information related to travelling with a wheelchair, such as accessible hotels and travel companies. Searches for this kind of information can be critical in determining whether a person with disability even sets out on a journey at all. IP1-1 had also started a project to translate an information card provided by Parkinson's UK into French in advance of an upcoming trip. This project had involved getting in touch with the French charities to see if they offered an equivalent product, and then beginning the translation with support from a French-speaking family member. IP1-3 then planned to share the card with other members of the Parkinson's Facebook group once it was complete.

In addition to research on health conditions, searching for equipment and accessible or adaptive technologies was also identified by participants of both studies. This finding is consistent with findings from the published literature, which also report searching for assistive and adaptive technologies (Cheatham, 2012; Hersh and Johnson, 2008).

It is important here to distinguish between assistive and adaptive technologies identified in the literature. Assistive technologies typically refer to specific purpose devices which 'assist' in daily living, such as wheelchairs or speech devices. Adaptive technologies usually refer to a device which is taking advantage of an existing affordance or technology, such as touch screens and simplified interfaces, or the possum unit, which makes use of voice control through a computer to adapt the controls of many devices in the home. The latter device was utilised by one interview participant to control not only their computer, but also the television, heating, phone, and even front door access to her home. This device also enabled the participant to look up film times

and coordinate cinema visits with a friend. Questionnaire respondents in particular cited their disabilities as prompting research into available technologies, and the adaptations they could make to their existing devices as their circumstances changed. The use of assistive and adaptive technologies is something which will be touched on again in the accessibility section of this chapter, as it has implications beyond information finding and research activities online.

4.2.1.6 Online Shopping

The online retailer Amazon ships over 600 million packages worldwide each year, leading to a net worth jump from $11bn (US dollars) in 2006, to $136bn (US dollars) in 2016 (Favors, 2017; Statista, 2019a). Relatively little specific research has been done into the adoption of online shopping habits in the UK; however, there has been a significant amount worldwide. When combined with the Amazon data and clear presence of online shopping options, it is clear that the UK is part of this trend (Kamarulzaman, 2007; Li et al., 1999; Molesworth and Suortti, 2002). From the data collected in this group, it also presents as a trend in this population; 22 of the 29 questionnaire respondents indicated they used the internet for some form of online shopping, as did seven of the 14 respondents with internet access. IP1-11 initially gave "*buy things*" as the response to the question 'what do you use the internet for', with social networks and messaging acting as a secondary purpose when prompted further.

For the interview participants, the convenience of online shopping was especially highlighted for grocery shopping. Now that all the main supermarkets offer home delivery, a similar (if not greater) choice of products is offered through most of their delivery services. This service was deemed to be of great benefit for people when they "*can't walk for very long*" (IP1-1) or are having a "*really bad*" day (IP1-7) and can't get to the shop in person. It also offers the opportunity to take longer, or

to shop from more than one store if the individual may otherwise be unable to.

Aside from convenience, the price and selection of products online also made shopping online preferable. IP1-5 and their partner highlighted their frequent use of Amazon to purchase healthcare products, such as a catheter bag stand, which the care service had not been able to provide. In this instance the participants also took a "*sort it out yourself*" attitude due to delays with other items from the social services. They tended to "*look on the Amazon site quite a bit*" for items they might need, which were at a better price and usually more convenient for them than going through social services.

Shopping online also helps to facilitate hobbies, particularly when individuals may be unable to travel to specialist stores or unwilling to pay the prices that they charge. IP1-6 used Facebook groups to buy craft supplies at a lower price than would have been charged in stores by waiting a few weeks after release, while IP1-15 used Amazon and other specialist websites to purchase art supplies and guitar making kits.

Online shopping can also be a stigma free experience. IP1-15 initially switched to shopping online due to stigma faced when out shopping on the high street, while IP1-1 can avoid hearing the phrase "*smile, it might never happen*". While it is positive that online interactions can remove the initial stigma faced by physically disabled people in the streets, it is confounding and problematic that this stigma should have such a prominent impact on people that they begin to feel more socially isolated, and turn to online shopping rather than feeling free to visit the high street when they are able.

4.2.1.7 Online Banking

Online banking was a frequent topic in both the interview and questionnaire responses. However, this was an area of divergence between the two groups: only three interview participants were users of online banking, whilst 22 of the 29 questionnaire respondents identified online banking as one of their activities online. Several interview participants did however use phone banking, but had no interest in moving to online banking. Indeed, they expressed a distrust in the security of online banking systems and the safety of managing their finances online.

During the analysis process, it was surprising that this theme was not mirrored between the two groups, when others (like online shopping) were prominent in both. It is particularly surprising, given the distrust of online banking and payment management, that online shopping was so well received and utilised amongst both groups.

4.2.1.8 Hobbies, pastimes, and entertainment

This subtheme covers a myriad of other online activities undertaken by people in this group across both the interviews and questionnaires. These range from selling homemade crafts, creating support groups, and watching movies via streaming services to acting as a ‘dark angel’ and attempting to moderate the dark web. For the most part, this section seeks to illustrate that there is little difference between the online activities of someone who lives with physical disabilities and someone who does not. Both groups display a wide and varied use of the internet.

As discussed in the previous sections, these activities can be facilitated through online shopping (by giving access to specialist supplies for art and crafting) and social networks (by allowing people

with similar interests to connect, whether those interests are sport, crafts, weight loss, or scooters). For some participants, the internet has also facilitated the setting up of community and interest groups. It came to light during an interview that internet research and a drive for community engagement enabled a village-wide network for services and support in Nottinghamshire. IP1-6 called it "*self-help on a big scale*" which was developed during their months of being housebound and unable to engage in a conventional way.

In a wider sense, the internet has also enabled other participants to set up and access online support groups and blogs specific to their diagnosis, which will be discussed more in the social support section of this chapter.

4.2.2 Social support

This section discusses the ways in which social networking was identified to play two distinct roles: one, to stay in touch with friends and family; and two, as a source of social support amongst peers. In interviews these topics were discussed as two distinctly different uses of technology, and in particular of social networking sites. The line was less distinct in the questionnaires, although this was largely due to the nature of the questions and categories used, rather than the participants not identifying outlets of social support. The themes discussed under the following subheadings were specifically in reference to support, rather than a general online activity.

Although this is partly covered in the previous section, the role of the internet in providing social support is perhaps best summed up by one participant who had become housebound and increasingly dependent on online interactions: *"I have got friends on the internet, I belong to an art group where I teach digital art. And some of the people that I've been with maybe 10/15 years doing that, they've become friends. And real friends at that you know, I mean over a period of many, many*

years, even though you haven't met yet, you still get to know people you know" (IP1-6).

4.2.2.1 Social Networking

This was one of the major areas of discussion in the interviews and provided an important source of support for several of the interview participants in this group. While this focuses primarily on Facebook and WhatsApp use, two of the participants specifically identified networking through other sites related to hobbies rather than general social media. IP1-6 and IP1-14 both identified art-related forums and sites, digital and traditional respectively, as a means of social support as well as supporting hobbies. IP1-6 in particular identified friends made over the forum as a significant source of social support. For example, one of them had sent IP1-6 a new computer knowing that the existing machine was ageing into obsolescence.

While social media use was identified as reducing a feeling of social isolation and promoting emotional wellbeing during a difficult time (Young et al., 2018), it was also identified as a means of connecting with peers with similar disabilities or life experiences in order to share information and day-to-day activities. IP1-1 specifically identified Facebook as allowing them to identify members of the community living with Parkinson's disease and events related to fund or awareness raising.

The support provided by social networking was not always related to the participant's disabilities. IP1-7 was using Facebook to find peer support not only with friends and family for their disability, but also to actively engage with the online Slimming World community to share recipes and deals related to their weight loss goals. Similarly, IP1-11 used Facebook to interact with their Boccia team as a means of support and to catch up and share photos after games.

This is also the role largely fulfilled by WhatsApp in the social support context. Both IP1-3 and IP1-7 actively used WhatsApp to stay in contact with family and friends who lived further away or outside of the UK. In some contexts, WhatsApp has replaced SMS messaging as the default messaging service, as it is focused on data use rather than a set number of SMS messages allowed by the service provider (Church and de Oliveira, 2013; Unuth, 2018). It also allows for the free and (significantly for IP1-7) more secure sending of picture messages to share images between family members in a group without each member having to pay to receive the image and subsequent messages. In the case of IP1-3, WhatsApp and Facebook Messenger fulfil the role of free messaging services between countries. They also provide an atemporal space which will tell group participants when they are typing, letting the group know that the participant is still active in the conversation when they are taking the time to type a reply.

4.2.2.2 Charity Pages and Peer Support

Linked to social networking sites was the use of charity pages in order to access peer support and advice. This was a particularly significant theme for IP1-1 and IP1-12, who both interacted with relevant charities on Facebook and subsequently the charities' own forums and information pages. In the case of IP1-1, these pages were used mutually, with the Facebook posts providing a synopsis and the participant then deciding if they wanted to read further on the charity page. IP1-12 worked largely from the charity pages first for information, and then used the associated social networking pages to gain further information. The main example given by them was of recipes provided by the Diabetes Society and looking on social media to see what other users of the pages had shared for recipes and meal adaptations. This participant was also active on the Alzheimer's Society pages, both on the forums and social media, to find information for their partner.

In addition to accessing existing charity support and information, participants of both the questionnaire and interview studies were involved with, or interested in, setting up facilities for social support for their peers beyond traditional sources. IP1-6 expressed an interest in setting up their own group to provide support in the community, having found their own elsewhere, and as an activity to engage their minds more effectively than Netflix. IP1-3 had already set up a travel information website for travellers in wheelchairs to fill a gap in the required knowledge for their peer group. QR1-4 also engaged similarly in social support by running a charity dedicated to disabled access rights. Both IP1-3 and QR1-4 blur the boundaries of formal and informal social support through the nature of their websites, which were based on peer information and support in setting up, but were also becoming formal sources of information which could be shared by other peer group members.

4.2.2.3 Formal vs Informal Social Support

For the interview participants, one of the key differences between online and offline support is the distinction between formal and informal social support. The majority of formal support is linked to offline activities such as carers, personal assistants, and county council support, whereas informal support is frequently linked to online activities such as peer-to-peer support through charity forums or Facebook pages. Informal support is also notable in that it can occur solely online, as in the case of IP1-6, rather than strictly requiring an offline component. That is not to say that formal support cannot take place online, as charities and other groups can provide formal support and counselling online; nor is it to say that informal support occurs solely online. This is relevant for several of the participants who interacted mainly with their social support networks online, but also used online communication to set up offline meet-ups related to their

diagnoses and hobbies. The needs of the participants are central to setting up these meet-ups and to the requirements of social support networks, in terms of both physical and intellectual accessibility.

As part of the interviews, it was important to explore whether participants were engaging online with Nottinghamshire County Council, as the council was proposing to move towards an increased reliance on digital access to services and information. It became evident that while people were looking for information online, it was not necessarily from the source the council had planned. Indeed, only one participant had looked at the website prior to the interview, and two looked at it during the interview; the remaining 12 had not seen it before. The website was not asked about in the questionnaire as it was nationwide and not Nottinghamshire specific.

4.2.3 Accessibility

Following the grounded theory analysis of both the interview and questionnaire data, it was evident that accessibility forms a crucial theme in how many people with physical disabilities are accessing the internet (if indeed they are). The data can provide both a positive and a negative snapshot of the accessibility of the internet and associated technologies. It was important for me to consider not only the interviews conducted and questionnaires received, but the other responses received during recruitment for the interviews. Across all the calls, emails, and texts received, the reasons for not participating, if the respondent was interested in participating, or if the respondent became a participant, were recorded - initially to have a record of the number of responses received. However, upon review, a significant theme emerged from this data. Over half of the responses received were from people who were unable to take part in the research because they had no access to the internet, whether through a lack of device or lack of connection. Initially this raised significant questions

around the accessibility of the website the County Council had asked for feedback on, but it also led to wider questions of the accessibility of support and information in a time when increasingly the first point of access is online.

4.2.3.1 Accessing the internet

It is almost taken for granted that people will have access to the internet, whether in their home, on their phones, or the ability to go to a library to use a public computer. However, for many of the people who responded over the phone regarding interview participation, this was not the case.

One participant in the interviews, IP1-8, was unable to access the internet due to a lack of an appropriate device and connection. They also did not wish to access the internet or online services, and had only recently conceded to relatives and begun using a mobile phone. This participant was included in the interviews due to a mutual misunderstanding about the nature and purpose of the research. It was only once I had travelled to their home and begun the interview that it became clear that the participant did not want to talk about online services, and had instead taken the chance to use the interview as a way to provide feedback to the county council over the state of their nursing homes and adult social services. After an initial discussion of care homes, IP1-8 stated *"I'm not on the internet … Because you know with… I can't see very well*". IP1-8 was registered blind, but unlike IP1-10 (another visually impaired participant), did not have any interest in assistive technologies or devices which could support computer use, such as text readers or magnifying overlays for screens. They also had no interest in learning how to use the internet and used no services that required online interaction. Although online banking had been offered to them, IP1-8 did not trust it as a system and continued to use telephone banking as they were now unable to visit in branch.

This interview is in the analysis as the theme of accessibility had already been raised in other interviews (for example, IP1-4 identified an iPad and the ability to Facetime as a "*lifeline*", but was not able to access the web browser or other apps due to being partially sighted).

Arguably, including this participant provides a counterpoint in an attempt to balance out some of the inherent biases created in doing an online questionnaire which had a primary distribution method of social media. During the recruitment stage of the interviews, I received multiple phone calls from nursing homes and care facilities from staff who were responding on behalf of numerous people in each location. They had received invitation to participate letters from the County Council, but did not have access to the internet or the technology required to do so. Approximately 100 of the responses received during the recruitment were from individuals who were not active online and were therefore unable to participate in the interviews. Many of them wanted to share their views that the council should not place all of their information online. It is not known how many people each of the nursing home or care facility responses represented. The inclusion of IP1-8 in the final group for analysis is an attempt to give a representative case study of these responses, mitigate some of the online bias of the studies, and acknowledge the different levels of digital inclusion in the 68+ age category within this participant group.

4.2.3.2 Training and confidence in access

Alongside a physical lack of access to the internet, whether through lack of connected technology or connection through an internet service provider, the next major obstacle to internet use was a lack of confidence in carrying out activities online. This could be due to a lack of awareness or training for the device being used for access (whether that is a computer, tablet, or phone) or a lack of confidence due to changing operating systems and interfaces.

Two participants (IP1-2 and IP1-6) had made the choice to stay on older operating systems on computers rather than upgrading to the current system, Windows 10. IP1-6 - who considered themselves generally technically savvy and adept on the computer - was now facing issues with programs not updating and losing support, as they had remained on Windows XP. When we discussed the reasons for this, they concluded that it was mostly fear and apprehension of learning the workings of a new operating system that had prevented them from upgrading. In their words, the problem with internet access was *"not through ignorance, it's through sheer inability"* and a lack of appropriate training to change this.

IP1-2 identified a lack of appropriate training for their limited use of the internet. They felt that existing training courses implied a level of implicit knowledge and understanding, which they had lost owing to their diagnosis of multiple sclerosis (MS). They also faced difficulties with reading information presented on screens and comprehending information at the speed it was presented due to damage to their cognitive processing abilities. This was similarly identified as a problem in their comprehension of information provided online and as a barrier to information gathering online which strongly impacted the participant's confidence in access. IP1-2 had undertaken training at various times in order to use the internet on various types of technology - particularly smartphone, tablet, and laptop - but had found the pace of the training and the assumed knowledge to be a barrier to learning how to use the devices and access the internet effectively.

However, lack of understanding and fear of change were not always the main barriers to technology or internet access. Instead, factors relating to the nature of participants' disabilities were also important, as discussed in the next section.

4.2.3.3 Conditions impacting access

This subtheme was perhaps the most relevant to take forward to Group 2, people living with Early Onset Dementia. There are conditions which can affect an individual's ability to access the internet and/or use the necessary technology for it. These conditions can also change over time, whether they be visual, physical, or cognitive impairment. For example, IP1-15 was resistant to updating their computer operating system or peripherals due to their recent diagnosis of dementia. While their physical disabilities influenced their ability to use IT, particularly through touch screen interfaces, the main difficulties they faced were linked to changing passwords and desktop icons or layout. This was highlighted as a particular point of interest to be followed up on in Group 2 with people living with Early Onset Dementia.

Similarly, participants with deteriorating eyesight faced different issues in learning how to use new interfaces or interact meaningfully with many devices and websites. For example, as highlighted previously IP1-4 called an iPad a *"lifeline",* but due to deteriorating eyesight was only able to use it for Facetime calls when on her own, or YouTube when assistance was provided to find the app and search bar in order to utilise the voice search feature.

One factor which was highlighted as impacting access through the questionnaires but not the interviews was the issue of fatigue. While not all of the 29 questionnaire participants left additional comments in the free text boxes of the questionnaire, four of the 13 who did highlighted fatigue and pain as issues which have impacted their internet use and technology access. On occasion, this led people to require support and assistance to continue using technology. Eight of the 29 respondents required occasional support from family members or assistants with a variety of tasks, from reading out content (QR1-12)

to untangling cables and resetting the internet router as required (QR1-16).

However, not all conditions limiting access were physical. Several participants identified cognitive challenges that impacted on their comprehension of information online and confidence in accessing it. As a subtheme this was present in several forms and impacted on the ability to access online services and information. As mentioned in the previous section, IP1-2 struggled to effectively comprehend the information provided online and to retain the training provided to access this information owing to the cognitive difficulties caused by MS. This led to a distrust in themselves when searching online, and a preference for leaving searches to their partner or children. This was also linked to fatigue impacting on internet use, with the difficulties arising or being exacerbated as a result of fatigue. QR1-12 specifically identified pain and fatigue as factors which necessitated them asking for assistance due to *"[…] length of time I can concentrate is much much smaller due to pain, acute and chronic. So need help to access*". Indeed, four of the eight questionnaire respondents identified that they needed occasional support in using technology and accessing the internet. This support usually included reading information from webpages and assisting in the understanding of it where needed.

Dyslexia was also a significant barrier faced by participants. IP1-11 highlighted this and was the only interview participant who actively discussed using predictive text when composing text on mobile to assist in their struggles with dyslexia. They also raised this as an issue in the design of websites as part of the move to place information about health care services online, rather than receiving it in person or on the phone. Accessible website design has been a subject of focus in literature (Clark, 2001; Mankoff et al., 2005; Paciello, 2000), but ultimately, the options for accessible reading on most websites remain limited and difficult to find from the main home page of non-disability specific websites. This interview also highlighted the issues faced by many people when access to services is moved online:

"I don't use the internet, I'm dyslexic and it's like oh, right. And it's like forms, everybody is can you fill in this form, can you fill in that form? No, I'm dyslexic." (IP1-11).

IP1-11 elaborated further; for a person living with dyslexia and also in receipt of services for a physical disability, simply sending the form in the post with no support is no more accessible than being told to fill it in online:

"So it's like well how do people in my situation go when you've got these forms, them forms and all these forms to fill in? It is shit. And everybody thinks that everybody can just fill in forms and go on the internet and fill this form in or oh, we'll send you a form out in the post. And it's like … but that's no have to get away with filling in the forms or they should be prepared to come out themselves and help you fill it in." (IP1-11)

Difficulty with completing forms online was also raised by IP1-1, who had struggled with government webpages timing out before they were able to answer all of the questions on days when their Parkinson's disease was slowing them down. This also raises questions around privacy when people require support to fill in forms that may be vital to the continuation of care or services: people living with disabilities may not be happy to share with everyone the information that is required on the form. Much like accessing other services and sites on the internet, as well as using many devices, this is an issue which would also be applicable to many other people with additional conditions that affect their reading comprehension or eyesight who may struggle to read on screens due to size and contrast.

4.2.3.4 Benefits of Online Access

Despite the challenges of online access, participants nonetheless identified some positive aspects of being able to access services

online rather than offline when conditions may have made this difficult. This could therefore be considered to have a net positive impact on the physical and mental wellbeing of participants (Young et al., 2018) by allowing services to come to them, rather than them going to the services. Examples include IP1-1 and IP1-7 using online shopping when their conditions may have prevented them from going in person, and as touched on in the previous section on social support, IP1-6 and IP1-7 using online communication to prevent a growing sense of social isolation and retaining contact with existing friends.

For some participants the online interactions allowed them a sense of freedom and safety which they struggled to access in offline or real world interactions. IP1-14 in particular identified feelings of being judged and a lack of safety when out in public, either when out socially or attending medical appointments at hospitals, leading to a preference for online shopping and online information seeking. They specifically identified the stigma around visible disabilities and expendable income: "*Whereas not buying online you've got to go out and you've got people pointing the finger and I've actually been spat at*", as well as the issues faced by people with physical disabilities when in public. These included issues with accessing public transport with wheelchairs as well as issues with communication with members of the public around their specific condition, such as IP1-1 being accused of being drunk by a police officer before they were able to explain they had Parkinson's or people refusing to talk to IP1-3 and talking to their friends or assistant instead. While both IP1-1 and IP1-3 were able to resolve these interactions in public, they both ultimately preferred being able to mitigate this through online communication, which allowed them more time to respond and gave them the ability to present themselves in a manner of their choosing.

Lupton (Lupton and Seymour, 2000) touches on how the internet can allow the "normalisation" of users, as well as the limitations of this. Most internet spaces are designed with the able-bodied in mind, which can potentially limit the accurate representation of self for those with

disabilities, or indeed increase the stigma faced by people who choose to represent themselves the same both online and offline. Although this is not viewed as an issue by all people with disabilities - such as IP1-3 who found the ability to present themselves without a wheelchair liberating - it is problematic for some in the community. Increasingly, the lack of options to represent disabilities in role playing games or simulators such as The Sims, or in older instances Second Life, has become an issue for their user base. Some companies, such as Lego, are now moving to be more inclusive of all of their fans by creating a wider range of characters for consumers. (Atkinson, 2016; Ellis and Kent, 2011).

4.3 Discussion

The main finding with this group is that while many people living with physical disabilities are as active online as their able-bodied peers and in similar ways, it is too early to assume that most people are ready or prepared to cope with online-only services from local authorities, national government, or condition-specific charities. Whether through preference or ability, these are not services that everyone is prepared to use at this time, making them unsuitable for use in isolation from offline and face-to-face options for the same choices.

Many of the findings in this chapter may seem common sense, in that the participants of Group 1 are using the internet the same way people living without physical disabilities are perceived to. This stands in contrast to studies which indicate that people with physical disabilities use the internet and technologies for specific, different purposes (Cheatham, 2012; Englert et al., 2007; Raghavendra et al., 2012). It is important to emphasise that this distinct difference is not always present, and that much of the day-to-day use of smartphones and social networks is similar, if not the same, as people living without physical disabilities. Although this group does not represent a large

sample of this population, it is enough to inform a small trend within the county which should not be discounted when designing services that are appropriate to the whole user group.

One of the main findings for Group 1 was that age was not entirely predictive of internet use. Across all participants, younger participants (aged 65 and under) were more likely to be active online generally, but there were several in the older categories who were also highly active. The differences in age were most reflected in participation on social networks and use of online banking. Particularly for the latter, there was a greater level of distrust in the service and lack of interest in its use. Younger participants were more likely to be active on social media, whether to stay in touch with family and friends or to engage with other groups, such as those related to crafting hobbies or football fan groups.

Across all of the data presented in this chapter, it is pertinent to be mindful that the methods of distribution and inclusion criteria create an inherent bias in the data towards people living with physical disabilities who are able to access the internet and technology. Bearing in mind that 50% of initial interview respondents were unable to access the internet, this creates an incomplete view of the information finding behaviours of this group. It also overlooks the needs for non-online sources of information and support to be provided to an already isolated group.

This is a consideration often omitted in a time when internet access is taken for granted, as devices are ever more able to connect and provide limited adaptations and online resources are put forward as a more cost-effective measure to reach a wider audience. This is one of the most crucial messages in the planning and running of the main thesis project with people living with Early Onset Dementia and their families: that recruitment through online sources is likely to bias the recruitment pool, and therefore the findings presented in this thesis, towards those people who have been able to access the recruitment

pages. It potentially limits the views of people who are not in receipt of the services or pages the information was shared on.

While the data collected in the questionnaire proved to be a helpful and insightful addition to the main interview data, it has to be considered as adding in an element of bias towards internet use within the group as a whole due to its publication online and methods of dissemination. It is possible, and indeed seems probable given the evidence from the interview recruitment, that access to the internet is a far greater issue within this population than the data collected from the questionnaire would suggest.

Based on the findings with Group 1, it was anticipated that the participants in Group 2 (those living with Early Onset Dementia or their family members) would be similarly active online in seeking out information post diagnosis from both charity and peer sources. It was also hypothesised that not all participants would be active on social media, although the percentage active would be higher due to the more limited age range of the participants. These findings and the assumption that people living with Early Onset Dementia would be similarly engaged online and use the internet for similar social support and information gathering purposes informed the design of both the questionnaire and interview guide to be used at the outset of Group 2.

Chapter 5 Group 2: Internet use by people living with Early Onset Dementia and their families

This chapter presents the findings of the research with participants of Group 2: people living with Early Onset Dementia (EOD) and their family members. As discussed in the introduction, family members were included in this group if they wished to take part in interviews or complete questionnaires to try and give a more comprehensive picture of how EOD affects internet use over time. Due to the change in methods discussed in Chapter 3.5, this was not necessarily needed as interviews were conducted as a one-off, or as initial and follow up for one dyad. Change over time was not explored in as much depth as had initially been planned. However, it was decided to keep family members as participants if they were happy to participate for additional breadth to the data and to more fully explore aspects of 'digital legacy' planning.

In this context, 'digital legacy' focuses on people's online accounts - whether social media, banking, email, or other digital assets such as photo or music collections - and how these will be managed or accessed by family members after the loss of capacity or death. With the increase of accounts in use online, little has been written about how people plan for these accounts and data in the context of dementia (Batchelor et al., 2012). Planning of this type is particularly relevant to social media accounts such as Twitter, which were shown in the literature to be an important aspect of community and information sharing amongst this particular group (Robillard et al., 2013).

5.1 Participants

This section shows the demographics of the participants in this group. In total, there were 19 questionnaire respondents and ten interviews with people with EOD. Seven of the questionnaire respondents were people with EOD (six male, one female), and the other 12 (four male, eight female) were family members or friends of the person with EOD (see Table 5.1). Interview participants consisted of five males and five females (see Table 5.2). Seven interviews also included a partner, identified with the suffix of P on the participant number. As the questionnaire comprised three paths, the second column of the table below is used to indicate whether the response was completed by a person with Early Onset Dementia, or a friend or family member.

Participant ID	Completed by person with Early Onset Dementia	Person with Early Onset Dementia demographics		Family/friend, person assisting demographics	
		Age	Gender	Age	Gender
QR2-1	N	50-64	Male	30-49	Female
QR2-2	N	50-64	Female	30-49	Female
QR2-3	N	50-64	Male	18-29	Female
QR2-4	N	50-64	Male	30-49	Female
QR2-5	N	50-64	Female	50-64	Male
QR2-6	N	50-64	Male	50-64	Female
QR2-7	N	50-64	Male	50-64	Female
QR2-8	Y	50-64	Male		
QR2-9	N	50-64	Male	30-49	Female
QR2-10	Y	65+	Male		
QR2-11	Y	50-64	Male		
QR2-12	Y	50-64	Male		
QR2-13	N	65+	Male	50-64	Male

QR2-14	Y	50-64	Male		
QR2-15	N	50-64	Female	50-64	Male
QR2-16	N	65+	Male	65+	Female
QR2-17	Y	65+	Male		
QR2-18	Y	50-64	Female		
QR2-19	N	50-64	Female	50-64	Male

Table 5-1 Group 2 Questionnaire respondents

Interview participant demographics were collected using the same age groupings as the questionnaire for comparability. The age range of interview participants was 38-67. The participants who are 65+ (IP2-1 and IP2-7) were both diagnosed before the age of 65 and less than five years before taking part in this research. Participants IP2-2, IP2-4, and IP2-9 were interviewed individually and not with a family member present, and so do not have an entry in the family member columns. Partners present in interviews are designated with a P following the participant number, for example IP2-1 and IP2-1P. This couple were the only participants interviewed twice as part of the originally planned follow up.

Participant ID	Person with Early Onset Dementia demographics		Family member demographics (where applicable)	
	Age	Gender	Age	Gender
IP2-1	65+	Male	65+	Female
IP2-2	50-64	Male		
IP2-3	50-64	Male	50-64	Female
IP2-4	50-64	Female		
IP2-5	50-64	Female	50-64	Male
IP2-6	50-64	Female	65+	Male
IP2-7	65+	Male	65+	Female
IP2-8	30-49	Female	30-49	Male
IP2-9	50-64	Female		
IP2-10	50-64	Male	50-64	Female

Table 5-2 Group 2 Interview participants

Participant data was not extracted from the forum data provided by the Alzheimer's Society. Demographic data was not provided in order to maintain the anonymity of users on the forum, and it was agreed not to disclose usernames as part of the data agreement. As no direct quotes are extracted, the data were used to look for the presence of trends rather than input from specific users.

5.2 Findings

Three main themes emerged from the interview, questionnaire and fourm data. As with Group 1, the three themes presented in the following sections are broad and have many intersections with each other, but also provide the best framework to facilitate the discussion of each of the main subjects.

The first theme (Change in use) addresses the changing dynamics of internet use for the person living with EOD and their families. This covers both people becoming less or entirely inactive online, and people who have become more active online both in general and as part of an online community based around people living with EOD.

This intersects significantly with the second main theme (Post diagnostic support): how people are seeking out post diagnostic support and information. Post diagnostic support covers the methods through which people find information and support after diagnosis. As this is a relatively geographically sparse group, people living with EOD may have to take more steps in order to find appropriate information and social activities, many of which are explored in this section.

The final theme (Accessibility – access issues and solutions) covers the online accessibility issues faced by people living with EOD and their families. This includes some of the reasons for the changes in internet use and the methods that individuals use to mitigate these

changes, including strategies for password and account management, changes to the technology used, and maintenance of known devices.

5.2.1 Change in use

In contrast to Group 1, in which participants spoke quite generally about their internet use and habits across both the interviews and questionnaires, one of the major themes to emerge with Group 2 was how the experience of living with dementia had led to changes in internet and IT use. This is a particular difference between living with a progressive neurodegenerative condition and the relatively static nature of many of the physical disabilities of participants in Group 1. This theme reflects both the reductions and increases in use by both the person living with EOD and their family member, as well as the changes in technology being used to access social media, email, information, and other online resources. As mentioned at the start of section 5.2, some of these themes do intersect with the themes discussed in the post diagnostic support section, but also have broader implications for general use which have led to their discussion here. Some of the themes will also be touched on again in section 5.2.3, which will focus more specifically on the changing access needs for the person living with EOD and the steps which have been put in place to allow them to continue to access the internet.

This section discusses first the reduction in IT and internet use experienced by people living with EOD and their family members, and then moves on to discuss some of the scenarios where internet or IT use by either party has increased post diagnosis.

5.2.1.1 Reductions in internet use

As would have been expected from the literature on the experiences of people living with EOD, several participants experienced negative changes in their ability to use the internet and IT and subsequent reductions in access and use. Of the 19 questionnaire participants, 11 were assisting people with EOD more frequently or about the same as they were before. Of this group, five were unable to access the internet at all, and one significantly less than before diagnosis. There was also one response from a person living with EOD who remarked later through the survey that they were also unable to use the internet without assistance at that time. It is significant to note here that the level of assistance in use is not known, as five of the 11 responses did not indicate the level to which they were assisting with online activities. Of the three responses which said they were helping less, there is no way to know if this is because the person with EOD has been using the internet less or needs less assistance with their activities.

This general reduction in use suggested in the questionnaires was also supported in the interview data. Of the ten index participants with EOD, six suggested that they were using the internet less, and for less diverse purposes than before their diagnosis. That is not to say that these participants had become wholly inactive, but that all in this group were unable to continue to use the internet and IT devices in ways that they previously had or would like to do. The latter point is of significance for all ten of the interview participants, and the four other questionnaire participants who had been diagnosed with dementia and were still active online. This is significant for all participants as the remaining four participants who were still active online were not active in the same way as they had been pre-diagnosis. This change in use and ability was a point of frustration for five of the 14 participants, including partners present, who were active online.

The change in ability to use internet service or IT devices was one of the significant changes faced by the participants, and presented a number of challenges which individuals needed to adapt to relatively early on in the post diagnostic journey. Social media, for example, had significantly reduced use amongst the participants who had been active; Facebook in particular was one service which had been heavily reduced in use amongst this cohort when they began struggling online. This is in part due to a shift in focus, with the majority of active participants losing interest in the site, but also in part due to an acknowledged loss of inhibition and 'filter'. IP2-7 for example had not been particularly active on Facebook previously, but was no longer active at all due to the likelihood they would inadvertently post something that other people would see as inflammatory. Although it was not generally considered as such, the move away from previously active networks also reduces the amount of social support the person living with EOD can find online. This continued access to peer support through social media was something which came out of interview data as an incidental positive of continued internet use for both the person living with EOD and their partners.

One of the issues that emerged, mainly in the interviews, was the change in day-to-day administrative activities that had previously been unthought-of until prompted during the course of the discussion. This included changes in online banking, email management, and names on bills and official documents. The means of accessing these accounts will be discussed in more detail in section 5.2.3.2 on accessibility and account management, with the impact of the changes being considered here. Across the ten interviews, this was not an area that either their participants or their partners had considered as part of a change in internet use, but they had already confronted it as part of a change in responsibilities post diagnosis. For some of the participants, such as IP2-10, IP2-8, and IP2-5, married couples' online banking was relatively easy to negotiate due to joint accounts and dual logins which allowed one partner to manage finances without having

to change routines. For other participants, such as IP2-4 who lived alone, financial planning and online banking management was something that had to be confronted in the future with children and other family members in line with Lasting Power of Attorney (LPA) arrangements. There is no mention of this handover in the questionnaire or the extent of assistance, but four of the 11 participants assisting a person with EOD online were helping them use financial services such as banking and bill payments.

Interestingly, this was also not a theme commented on by members of the Talking Point forums. Across the 3803 posts collected in the data set, there were 55 references to “online” as a search term, with only one reference to online banking. This user explicitly referenced online banking as part of an LPA set up for their partner which included them taking control of financial as well as medical decisions. One aspect of financial handover which was discussed in more detail was the transfer of names on accounts. IP2-10P specifically spoke about the difficulties in getting bills transferred over to their name when their partner struggled to remember account passwords and details needed for the security questions. They also reiterated the challenges faced when trying to assist the person with EOD in conveying to customer service representatives the information required for the security questions. This was additionally complicated for this participant’s family because they had not finished setting up a LPA, and therefore both partners had to be present to complete name transfers on household bills.

5.2.1.2 Increases in internet use

Although the changes in internet use for the person living with EOD were mainly in the direction of reduced use, there were some exceptions amongst the interview and questionnaire participants. The experiences of participants’ partners in the interviews were also

markedly different in terms of both type and frequency of internet use. Across the interviews and questionnaires, partners of people living with EOD found that they were using the internet more than before the diagnosis, albeit with a different focus. Initially this use was linked heavily to information seeking related to the diagnosis of dementia, services in the areas, and support for both themselves and the person diagnosed. This did not materialise as continued use in all cases: for the families who do find a meaningful engagement online, this can form a source of significant support for that person. IP2-3P began by exploring support and information online and was already active on Twitter for work, keeping family and social interactions on Facebook. This information seeking then turned into engagement with the "#AlzChat" and "#DiverseAlz" chats on Twitter which provided a significant amount of information and ultimately began to form a support network as time progressed. During the interview they spoke about a day they had a "*complete meltdown*" and posted on Twitter "*I can't do this anymore*", at which time people they spoke to in the chats replied to provide support and check in with them to try and help. This had also extended to a WhatsApp group which they engaged with on a daily basis as a method of social support and engagement with other people in a similar situation.

Twitter has played a significant role in creating social support amongst people living with EOD and their partners in recent years. While this area of social media use is something which will be discussed in section 5.3.2 on post diagnostic support, the advocacy and engagement element of social media use is something that can be discussed here as more positive side effects of changes in internet use and focus. Although this engagement occurs across all major social media platforms, Twitter hosts an active community of people living with EOD, partners of people with EOD, researchers, and primary and tertiary care workers. These groups tend to engage most through chat by following hashtags; they are also engaged through following #dementia and #eod.

Although the majority of positive engagement online was evident in the partners of people living with EOD, there was also evidence in the interviews of people with EOD becoming more active online after receiving their diagnosis. IP2-2, for example, was significantly more active on Twitter after receiving their diagnosis and had become heavily involved in dementia advocacy across research and politics in the local area. This participant was involved in establishing and running a support and information service for the area, which was something I was able to share with other participants near the area who had not come across the social media pages beforehand. Anecdotally, there were several people who were active in the dementia chats who had become more active online in general post diagnosis and have been the using micro-blogging format to share their experiences in an attempt to dispel some of the myths around EOD. These were people who were rarely active online or on social media prior to diagnosis and had begun to use it after. IP2-4 was also active online, not just over Twitter, but also by using cooking videos and timers in order to support independent living using methods they had not found effective non-internet interventions for.

In a non-support setting, a number of participants had shifted in their internet use to assist their partner with EOD in maintaining hobbies and interests online. IP2-7P had begun to assist with their partner with emails and online shopping so they could continue looking as normal, whilst IP2-3P had begun to use the internet in order to sustain their partner's interests when they asked questions about something of interest. This was a significant change in internet use by this couple, and was referred to as a '*Google moment'* in the interview. By this, they were referring to occasions when IP2-3 has a thought or asks a question about something that interests them. A *'Google moment'* was a flag to hold the thought until they get home, when they could research the question online; then they would often organise trips related to these moments. It was considered a significant change from previous internet practice, when IP2-3 would have been able to look it

up independently, but also a positive change as it kept them engaged and interested with their previous hobbies related to local and military history and weather forecasting.

5.2.1.3 Change in purpose

This section focuses on the change in purpose prompted by dementia, transecting with the following two sections as both a change in technology use and as a means of seeking post-diagnostic support, but also dealing with the change in purpose of online browsing and internet use. It can be argued as either a negative or a positive change, and therefore seemed to merit its own section, setting it apart from the other two. The change in purpose is perhaps best illustrated from the Talking Point forums: for both the individual diagnosed and their family members, for a time after diagnosis the purpose of the internet becomes to find out as much about the diagnosis as possible.

This was also a trend across 18 of the 19 questionnaires, all of whom had gone online to look for more information after their own or a family member's diagnosis. Four of the five people living with EOD completing the questionnaire said they had continued to use the internet mostly for searches related to dementia, and six of the 11 family members said their relative's diagnosis had caused them to start using the internet mostly for dementia research or related health concerns. This was replicated in the interviews, all ten of whom said they had initially gone online to find out all they could about diagnosis, and nine said that related health concerns now made up the majority of their health searches. The exception to this was IP2-4 who predominantly used web searches for directions, recipe searches, and selling art online. Although this change of purpose was closely linked to positive or negative change in use, it was also strongly linked to changes in technology use and the changes in ability of the person with dementia to use technology.

5.2.1.4 Changes in technology use

One of the crucial elements in the change in use theme for this group was the ways in which people changed how they interacted with technology and the devices they were able to continue using post diagnosis. This covered both negative and positive internet use, and is an area not often discussed in the literature on dementia and technology interventions: how people are continuing to access their current devices and accounts. While some studies have focused on providing IT training to test interventions (Cash, 2003; Cutler et al., 2016; Olsson et al., 2015; Rosenberg and Nygård, 2011; Waller et al., 2017), this section discusses specifically how participants have continued to use devices they already used as part of their daily lives.

One of the best examples of changes in technology use influenced by dementia came from IP2-3. They had been gradually losing their ability to write; however, they were still able to use their existing smartphone and the shared desktop computer. They were able to continue to use their smartphone to search for information as they think of it during TV shows in "*Google moments"* by using Siri, although unable to easily use the touch screen interface. However, they were still able to use the full computer keyboard to type online and the weather reports written with the assistance of their partner or personal assistant. Interestingly, in this case IP2-3P states that their partner's typing ability had improved, despite losing their ability to write using pen and paper. Their typing ability had also improved against the trend of increasingly struggling to type on their phone and other touch screen devices.

For many of the interview participants, those using smartphones had retained the same phone as before their diagnosis. In five of the ten interviews, the participant living with EOD had retained their pre-diagnosis phone due to familiarity: four of these had kept using previous generation iPhones which had not been updated to more current operating systems in order to keep the interface as familiar as

possible. IP2-3P commented their partner was "*on iPhone, so that's where […] got to stay because that's what […] understands. And […] uses Facebook, uses WhatsApp*". IP2-7P talked about their partner's phone not updating yet in case of significant changes in icon design or interaction. These are changes in technology use which are usually not considered, and yet are hugely significant in this context. This change was also significant for IP2-8, who had begun playing "brain training" games on the Nintendo DS and tablet to try to continually support verbal and maths skills.

Alongside the use of smartphones was the use of voice search on phones, tablets, and dedicated smart home devices. These voice assistants fulfilled a number of roles in participants' use of technology, from searching for contacts to call (IP2-3), setting reminders, and managing appointments (IP2-4) to general internet searches (QR2-5) and listening to music (IP2-9). For all of the participants using the voice assistants, this was a recent change which had allowed them to continue using existing devices more easily, and in a manner which worked better for them. IP2-9, for example, was also beginning to struggle with reading - particularly text on CD cases - and the use of an Amazon Echo allowed them to continue to listen to music by just asking for what they wanted to hear.

These changes in technology and internet use (whether positive or negative) also play an important role in how participants sought out post diagnostic support and information, which will be discussed in the next section.

5.2.2 Post diagnostic support

This section covers one of the major themes from the interviews and Talking Point data: the availability and appropriateness of post diagnostic support for people living with EOD across the UK. Although the theme of support for family members was not directly broached, it

was a prominent theme across Talking Point data, and was a strong influence in the more positive ways in which family members from the interview group were using the internet in terms of searching for support and accessing it directly. This section discusses the social support provided online, offline support and geographic variation, and the necessity of age appropriate support and information.

5.2.2.1 Online social support

As mentioned in section 5.2.1.2 on increases in internet use, several of the interview participants had become increasingly active online after they or their partner received a diagnosis of EOD. This had allowed them to develop large peer support networks around the condition, and also act as a source of information and advocacy for the community.

Although Twitter has become a major hub for finding and accessing this support, a number of charities (such as the Alzheimer's Society and Young Dementia UK) run forums that are designed to facilitate support and information seeking. The Rare Dementia group, running out of University College London, maintains a forum on the main website that is often signposted on the group's social media channels. One of the main forums for people living with EOD is a specific sub-forum on the Alzheimer's Society Talking Point pages. These pages are populated by people living with EOD, their family members and friends, and researchers looking for assistance in projects, though the latter is less common as it requires moderator approval. It was posts from this sub-forum that were the third data source for Group 2 and contributed a significant amount to the wider understanding of how this group were searching for post-diagnostic support.

In addition to sharing experiences via Talking Point and Twitter, these sites are also an important source of information post diagnosis. Although much of the information is anecdotal and based on users'

experiences, such as where to buy useful products, there is also a significant amount of signposting to other information sources and research studies. There is also signposting to researchers and medical professionals on Twitter who may be able to answer more in-depth or area-specific questions through weekly chats, such as '#Alzchat' and '#Diversealz', mentioned in the prior section on increased internet use. Given the comparative uncommonness of a diagnosis of EOD, there are still relatively few information sources on the general umbrella diagnosis and less on the rare dementias more common in this group, such as Frontotemporal Dementia (FTD) or Alzheimer's with posterior cortical atrophy (PCA). Links and information shared over these sites allow newly diagnosed people or their family members to connect with others in a similar situation and find sources to fill in some of the gaps in information provided at the point of diagnosis.

Across the entire data set, all of the main threads were looking for support or information about various aspects of life around a diagnosis of dementia. The requests range from practical requests such as where to find information or helpful products to emotional requests and people looking for other people to talk to. Interestingly, this led to one of the more controversial posts on the forum, which was whether teenagers and young people should be allowed to post on those pages. One user had seen several posts by teenagers seeking support after a parent being diagnosed and had commented on one stating that they didn't believe they should be allowed to post there, which led to a discussion between users about the rights of others to post on there. Within the terms and conditions of the site, it states that users under 13 must have their parents' or guardians' permission to join and post on the boards; however, all the posts from young people were from people aged 14 and up. Ultimately it seems that the complainant left the site over this issue, but it highlights the difference in impact between early and late onset dementia, and supports the presumption that people living with EOD are more likely to have young families and dependants. It also highlights the need for more specific support and

information for people with EOD, as will be discussed further in section 5.2.2.3.

The posts by teenagers also illustrate the number of different concerns faced by people in this group, from concerns over being a young carer and where to find support for themselves to counselling over genetic testing results and finding support for their parent or grandparent. While many of the replies on these threads are from moderators and other users directing the original poster to young carer support groups, both locally to them and on social media, others are from other young people on the site, allowing them to share their respective experiences of living with a parent with EOD in their teens. This allows the users to share experiences and information that have helped them and discuss more specific concerns for this group, such as feelings over residential care or being listed as one of the names on a parent's Lasting Power of Attorney.

Social support fills an important gap in the support and information provision for people living with EOD. It allows people to share their experiences and information with others in a similar situation, and in return receive peer support from them. By accessing this support online, people are able to create a support network and safe space that they are able to access regardless of geographic distance from other group members and time of the day. This means it can effectively work around other work, family, or life commitments. Importantly, by creating and sharing in a group of peers - whether on Talking Point, chats on Twitter, or Facebook pages - participants of these groups are creating a source of age appropriate information that members of this group often struggle to find offline.

5.2.2.2 Offline support and geographic variation

This theme emerged from both the interviews and their locations. It was also picked up across the Talking Point posts of people looking

for post diagnostic support. Owing to the relatively small number of people living with EOD, there is a huge disparity in the types and accessibility of services and support available to this group. This is expressed, for example, in the time it takes to receive a diagnosis, the service the diagnosis is received through, and the support available to the family afterwards.

Due to the wide geographic range of Group 2 participants, I was able to talk to people who could access effective support and activities in the period after diagnosis, and people who did not have access to any. Perhaps the starkest examples of the difference were between IP2-2 near Manchester, and IP2-8 in rural Lincolnshire. While IP2-2 was active in sharing information online, there was also a wide range of activities available to them in terms of appropriate support and opportunities to engage with decision makers in their local NHS trust to create more local support facilities. As a contrast, IP2-8 was less active online, due to personal discomfort with social media and the speed of the internet available in the area, but was also severely limited in the offline support available to them. Outside of the doctor's surgery where they received their diagnosis, there were no support or information groups in the local area, and limited opportunities when they were able to travel further. There was one group for people living with EOD in South Lincolnshire, which is difficult to contact and join due to their waiting list. Participant IP2-9 and their partner also lived in South Lincolnshire and spoke about the difficulties of engaging with support groups, as all took over an hour to get to and were rarely relevant or appropriate to their needs. They also spoke of the need to keep their driving licence for as long as possible due to the remote nature of their house and the feelings of isolation associated with not being able to go out, something echoed by IP2-8 who was in a similar position.

In these instances, participants were aware of support groups they could attend, but their ability to do so was either enabled (in the case of IP2-2) or limited (in the case of IP2-8 and IP2-9) by the distance to

the group. In the case of many Talking Point participants and IP2-7, there was a general lack of awareness of the support available to this group - again due to the disparity in services between areas and the different levels of information given to people post diagnosis. IP2-7 had been told of a general dementia group, but was advised against attending it by their former colleagues due to the age difference between them and participants. IP2-6 was given a list of groups by a support worker, but no guidance on the activities of each group or the average age of the participants. Both of these scenarios highlighted the importance of age appropriate information and groups, as well as promoting the groups which are available more effectively.

5.2.2.3 Age appropriateness

This area was one of the major side themes present across the literature review, interviews and Talking Point data: that there is a lack of age appropriate information and support for people living with EOD across the UK, and the resources which are available appear relatively unknown. For example, all of the interview participants had engaged with the Alzheimer's Society online to look at information post diagnosis and to see the groups available in their area, but only two of the ten families had looked at Young Dementia UK for advice and just one of these had found Rare Dementia UK.

Although all three charities provide information for younger people with dementia, the Alzheimer's Society is more general about other diagnoses and provides less information specifically for younger people. Young Dementia UK and Rare Dementia UK both provide additional specific information for younger people related to staying in work and the impact of diagnosis on family benefits. Both of these organisations also offer groups around the country, and provide listings of specific groups for younger people with dementia and their families in other areas or organised by other groups, such as the

Forget Me Nots (Parkes and Ward, 2014). However, these listings are of little use if people are not signposted to them in the information provided post diagnosis.

Lack of age appropriate services was a common theme amongst people looking for residential care information on the Talking Point forum threads. While local authorities have limited provision for dementia care in residential settings, this provision was even more limited for younger people with dementia. In Nottinghamshire, for example, there were over 50 residential and care homes which have provision for dementia care. Of these, only two stated they had some provision for caring for people aged from 50 upwards. This excludes people who may need the care on a residential or respite basis. It was also provided in the same setting as the rest of the residential care, making the activities and routines potentially unsuitable for a younger person.

The main cause of concern for people living with EOD and their families when attending social support events, such as memory cafes or singing for the brain events, was the nature of the activities on offer. IP2-5P for example spoke about the events that they and their partner had attended, at which they were the youngest people there (including some of the other attendees' children) and found that the music played at the events was not generationally appropriate for them. The choice of music at events was a particular concern for several of the interview participants, who had come across big band music and references to teddy boys rather than music of their generation. IP2-3P particularly highlighted this generational issue:

"…*they're singing Vera Lynn songs. Well actually, no, Stones, Hendrix, some of those. When you're going old people's homes… I mean my brother-in-law and sister are nearly in their 70s. They're listening to Cream and Fleetwood Mac. When do you go into an old people's home and hear that? They don't. They're just stuck in this*" (IP2-3P).

Aside from the groups and information for the person living with EOD, the information provided for the friends and family members is also often not age appropriate. As touched on in the previous section on increases in internet use (5.2.1.2), a number of members of the Talking Point forums were young people looking for support in caring for their parents. Although they were directed to young carers groups elsewhere online, there are limited resources for teenagers and children whose parents are living with EOD. Although some research has been done to raise awareness of the narrative and attempt to create some resources (Gelman and Rhames, 2018; Hall and Sikes, 2018, 2017; Pullan, 2016; Sikes and Hall, 2018, 2017b; Svanberg et al., 2011b; Young Dementia UK, n.d., n.d.), more could be done in this area to provide effective post diagnostic support to these family members.

It is possible that with more age appropriate information about both the diagnosis and groups, more younger people would become involved in peer support and information sharing, helping to fill some of the sparsity of services in areas across the UK. The literature would indicate that this would be a more effective way to deliver support (A. Mayrhofer et al., 2018b; Parkes and Ward, 2014) than providing younger diagnosed people with the same information as a person who may have been diagnosed in their 80s. This is an area which will be considered again in the discussion section of this chapter. It is also possible that shared knowledge within the community of people living with EOD and their family members could reduce some accessibility issues around knowledge of service availability and access, and changing technology (both interfaces and devices). These accessibility issues of changing preferences, abilities, and technology use will be addressed in the next section, as well as some of the methods participants in this group have employed to address them.

5.2.3 Accessibility – access issues and solutions

One of the aims of this research was to understand how internet and technology use had changed for people living with EOD and their families. As with people living with physical disabilities in Group 1, one of the themes centred on accessibility. In this context it refers to the methods of access (such as interfaces and peripherals) and also the means by which the technology and websites become accessible; for instance, through design, or more directly through assistance from others.

As an inductive coding approach was used again for these data, it was initially unknown whether this would be a theme to mirror the findings of Group 1. This section is based almost exclusively on the findings from the questionnaires and interviews; of the 3803 Talking Point forum posts, only approximately five were made by a person living with EOD, and these did not cover any themes contained in this section.

This theme focuses on the more practical steps participants in Group 2 have taken to mitigate the changes in use: to either adapt and continue using technology, or adapt to enable the person living with dementia to stop while accounts are still accessible if needed. This section will first discuss three subthemes: accessing technology and the internet; account management; and supporting continued access. Rather than focusing on the emotional impact of these changes and if they have had a negative or positive impact, as discussed in section 5.2.1, it will focus on how the changes in accessing technology and the internet have occurred and the steps put in place by diagnosed people or their family members to negotiate it. Following this, the discussion will move to the password and account management plans participants have put in place in order to mitigate past and future changes in ability to access. This section will close with an expanded discussion on the adaptations participants and their partners have made in order to support continued internet and IT access.

5.2.3.1 Accessing technology and the internet

This discussion of changes in use of technology and the internet focuses more on the changes than whether they can be considered positive or negative. Indeed, some of the changes in use cannot really be seen as having an impact in this way: they are just changes. A good example of this is IP2-7: they had deleted the Facebook app off their iPhone by accident sometime after diagnosis and could not remember how to download it again. However, they still received alert emails from Facebook when friends updated or posted pictures, which they then could check in the browser on their computer. Although they were less engaged with Facebook and no longer had interest in posting on it, they were still engaged with friends' posts and knowing what was happening amongst their family and friends. This was a change in use and engagement that does not have a particularly different end result to the level of use they had been maintaining previously.

For the majority of participants, as their dementia progressed, their changes in use became more pronounced. IP2-10 for example had initially continued to use all the functions of their iPhone until relatively recently before the interview, but had subsequently stopped playing games and browsing on it as they were beginning to struggle with a lack of feedback from the screen. They were, however, still able to use their laptop with its keyboard and larger screen. This allowed them to continue to browse the internet when they felt able to do so.

While for some participants changes in use meant a loss of ability to use some aspects of technology, or a decision to stop using some websites, for others it meant changing the way they were currently using the technology to better support them. IP2-4 for example took advantage of the portable nature of the iPad and used it as support when they were travelling. Rather than using the device as a GPS or route planner, they looked at the routes in advance and planned out lists of where they needed to be and when across several modes of

transport. By planning in this way and taking the plan with them, they had been able to negotiate a trip to the Caribbean post-hurricane destruction, despite the layout of the airport being wholly unfamiliar. This participant had also started using the same iPad to assist with cooking, so they were able to maintain a healthier diet than they initially had post diagnosis. Rather than relying on the microwave meals that had been their staple when they first became worried about cooking, they used the Buzzfeed 'Tasty' videos to guide them through a recipe, pausing at each stage, and combining this with a timer to make sure the recipe was cooked to the video's directions. Although their daughter had originally bought the iPad for easier video calls between family members around the world and to watch iPlayer and Netflix on, IP2-4 had found an additional use for it which allowed them to live a more active and social lifestyle.

5.2.3.2 Account management

Alongside the obvious change in use, such as participants stopping using Facebook (IP2-7), deleting all their emails (IP2-3), and booking holidays for the wrong dates (IP2-6), one of the main themes present in the interviews concerned the strategies put in place by participants and their families to manage online accounts and passwords. For several of the married couples, this was easily solved by having always had joint bank accounts that were manageable from two different logins, as well as having a system which allowed them to work out what the other's passwords were. IP2-5P for example had worked out the passwords they did not know by working from the ones they did. Of the nine couples interviewed (IP2-2 and IP2-9 were both married but participated on their own, and only IP2-4 was unmarried at the time of interviewing), five of the partners were able to work out passwords in order to access important accounts they had not previously had access to, including banking, phone and internet bills, and government

gateway services. The exceptions to this group were IP2-1 and IP2-6. IP2-1 was particularly strict on internet security and maintained a separate laptop that did not use Wi-Fi because they "*don't regard it as secure*"; their partner could not access it and did not know how to. When I asked about their password security, they replied "*Basically the password for my computer is just under 50 characters long. It's designed not to make it very easy for anyone to guess that*". They were reasonably certain their partner would be able to guess it, but their partner was less confident about that.

As the exceptions to the shared password trends, both IP2-1 and IP2-6 were meant to be teaching their partners how to access their laptops and online accounts - such as emails and photo storage - in the event they were not able to. In practice, when I went to interview each couple, these lessons had not been going well and the partner was none the wiser about how to find these passwords. For example, by the time of the second interview with IP2-1, they had started to talk with their children about what to do should they become unable to access their accounts and the plans they would put in place to assist with online bank accounts. However, they had not gotten any further in planning with their partner what to do with their own accounts should they become unable to access them before they were "*studying at Oxford*" (a euphemism IP2-1 used for brain donation).

With the exception of IP2-1, IP2-6, and IP2-8 (who had already stopped using anything that needed a password by the time of the interview out of preference), the other seven participants had plans in place for account management in terms of a partner or child accessing them, even if they had not considered the legacy aspect of what they would like to happen to these accounts in the future. These plans were, as most would expect, that the passwords were written down in a safe space if they forgot and needed to check which combination of similar passwords had been used for which account. IP2-4 did not have these written down, but had discussed them with their daughter in case of a similar event so that she would be able to access the accounts on the

iPad if necessary. Given the worry over passwords amongst this group, it was perhaps predictable that password management software was not particularly trusted by any of them. This was either because forgetting one password meant you'd lose all of them, or one password could be hacked and they would lose access to everything that way. Using a paper storage method also builds on familiarity, something which was important in the choice and use of devices and peripherals to enable the partner with dementia to continue using the internet and IT in the home.

5.2.3.3 Supporting continued access

Where possible, the participants and their partners in Group 2 had attempted to make adjustments around the symptoms of dementia to allow them to continue to use some of their devices to access the internet for various purposes. The exception to this across both the interviews and the questionnaires was IP2-8, who had stopped using the internet almost entirely shortly after their diagnosis. In part this was due to a lack of interest (which was exacerbated by the confusion of forgetting steps in how to do things) but also due to their dyslexia, which had already made taking to the internet later in life more difficult and something they were not particularly interested in. This was not the universal experience of the participants in the interviews and questionnaires; again, it was hard to ascertain the extent to which people living with EOD were being supported in continuing to access IT and the internet. It remained difficult using Talking Point data for this purpose due to the nature of the messages posted and the minimal explicit posting by an individual with EOD.

It is likely that the family members who filled out the questionnaire were assisting people who were living with far more advanced symptoms of dementia than some of the interview participants. Of the eight who used the free text box to elaborate on how the person with dementia's

internet use had changed, five stated that the person they were assisting was unable to use the internet at all otherwise, two said that they had to find and indicate the information the person with EOD had wanted to look at, and one said that the person was less confident in their use and more suspicious of information provided online. Of the 11 total responses by people assisting a person living with EOD, just one thought that the person living with EOD was still better at using IT and the internet than themselves. Of the interview participants, two thought that they were still better at using IT and the internet than their partners, though to what extent this view was insightful or correct is unclear.

One of the main themes in continued access was the divide caused by touchscreen technology. For some participants, the continued familiarity with the touchscreen interfaces of phones and tablets allowed people to continue using them. Touchscreens also offer a greater level of customisation in terms of contrast and sizing than a traditional keyboard to assist with finding letters and functions. IP2-4 for example found magnification on the screen enough to watch videos and read books, which they had not previously been able to do due to the size of the letters, and the swipe commands between instructions online were intuitive enough for use. IP2-3 however struggled with the size of the buttons on the phone and lack of haptic feedback on the edges of the buttons. But while they were losing the ability to write and type on touchscreens, by using a traditional keyboard on the family computer their typing and written communication had actually improved.

Although it seems the interface issues could be easily solved, operating system updates are not so easily addressed. Changes in operating systems had caused two of the participants to realise something was out of the ordinary at work when they were unable to learn and understand new operating systems and programs put in place. This ultimately led to IP2-2 and IP2-6 leaving work and beginning the path to being diagnosed with EOD. Updating the

operating system on devices at home could cause issues for even the most computer literate of my participants. Between the two interviews, IP2-1 got a new phone with a new Android operating system. The home and call answer screens were sufficiently different from their previous phone that they were no longer able to answer their phone, nor recognise it when it rang due to a differently pitched ring tone. Some of these issues could be addressed in settings, such as the contrast to make it easier to read and the ringtone, but the different swipe commands in order to achieve this were proving prohibitive at the time. As discussed in section 5.2.1.4, several participants had retained the same phone they had before diagnosis as a precaution against this. Computer operating systems appear to be no easier to negotiate: QR2-6 had successfully continued in their computer use after diagnosis until the computer had to be updated past Windows XP. Once the operating system changed they were unable to learn the new one, after which they lost their typing skills and forgot passwords and how to interact with sites. This participant was still interested in engaging with the internet, but was unable to do so without someone else to show them the information they were interested in.

This is by far the most direct form of addressing accessibility concerns: a partner or friend assisting the person living with EOD in their use of devices, such as IP2-6P assisting their partner with online shopping. More directly, partners or friends could use the devices themselves to find the information or programme that the person living with EOD was looking for, such as IP2-5P finding TV shows (either on TV or a streaming site) for IP2-5 to watch as they were unable to use the controls unassisted. In a less technology orientated sense, IP2-6P was also assisting IP2-6 in maintaining hobbies and routines by reading to them in bed, carrying on their previous habits even when they were unable to follow a full page themselves.

5.3 Discussion

Compared to Group 1 there was slightly more diversity amongst the participants of this group. As with Group 1, limited demographic data were collected about the questionnaire participants, though most of the participants were friends and family members of a person living with EOD rather than a person living with EOD. The geographic distribution of these participants is not known. Beyond knowing that all questionnaire participants were UK based, I have no further information on distribution.

It is uncertain how many people viewed the landing page on Call for Participants or saw the adverts in newsletters for this round of interviews. However, of the 77 potential participants identified on JDR, 68 were contacted and four recruited. In total, ten participants with dementia were recruited, with one participant taking part in the two-interview version of the study and nine in the one-interview iteration. These interviews were occurring while other data collection was ongoing.

There was a relatively wide range of ages and living situations. One participant was in their late 60s, having been diagnosed before the age of 65, whilst another was in their mid-30s when diagnosed and late 30s when interviewed. This age range therefore leads to a different range of family situations than was present in Group 1; in fact, more of the participants from Group 2 had children than those in Group 1. It is also likely that these factors impacted on the requirements of services, as well as the ability to attend those available in the area.

As with Group 1, there is a selection bias towards people who were internet active. However, overall representativeness was not the main aim of this study; rather, it was intended to describe patterns of usage and related issues. Although some of the interview participants were approached via post if that was their preferred method of contact, and indeed one participant was recruited via this method, this does not

remove some of the inherent bias in the data towards people who were active online in some capacity. Whether it is the person with dementia or their family member who responded to the email about the interview, completed the questionnaire, or posted on the Talking Point forum, there is some engagement with dementia information and dementia research online even in a limited capacity.

It is pertinent to note in this section that some of the interviews had minimal input from the person living with EOD. This was partly due to the progression of the condition, and not through lack of trying to engage on my part in interviews. In each of these instances the partner also tried to get the person with EOD to take part, but their level of engagement was set by themselves and fluctuated throughout the time I was at each of the locations. The extreme case of this was IP2-3, who did not wish to take part on the day; the interview was conducted entirely with their partner IP2-3P, while they came in towards the end of the interview to say hello and ask a question. It is therefore likely that this influenced the findings of the discussion and meant that I was not able to capture a full view of that person's experiences of navigating the internet and IT while living with dementia.

All of these aspects combined create a number of different influences on the participants which are likely to have impacted the ways in which they use the internet, collect information, and plan for their digital futures, therefore influencing the findings of this research.

Despite the challenges faced by both people living with EOD and their family members in adapting their current internet and IT practices around the difficulties posed by the dementia diagnosis and changes accompanying it, it seems apparent that the internet has an important role to play in the information and support seeking behaviours of this group. It is also significant to note that despite the long period of information seeking post diagnosis, participants still struggled to find appropriate information and advice relating to diagnosis at a younger age and the different issues that were likely to arise (such as planning

finances and benefits, and enabling people to stay in work for longer if they were able). Although the number of participants in this research group was quite small, they provide a useful picture of the post-diagnostic experience of people across different areas of England and highlight the disparity in service access and support across these areas. All of these trends will be discussed further in the next chapter, which aims to compare and contrast the experiences of the two groups of people in Group 1 and Group 2.

Chapter 6 Discussion

This chapter aims to draw together the findings of the two groups involved in this PhD to compare and contrast the emergent themes from each. It will directly compare the experiences of internet and technology use amongst people with physical disabilities and younger people living with dementia, while also providing additional context about the differences between the studies and participant groups.

I will start by providing a summary of the findings, and then move on to discuss the challenges faced during the planning and conducting of these research projects and the subsequent limitations, as well as some of the surprise positive side effects. After this I will move on to discussing the differences and similarities between the two participant groups, many of which are likely to have had an impact on the findings of the studies. This section will be followed by a discussion and comparison of the main themes from each group, with these finally leading to a section on the 'digital legacy' aspect of the findings and then the implications of these findings on a broader scale.

6.1 Summary of findings

The main aim of this thesis is to compare the online experiences of people living with Early Onset Dementia and people living with physical disabilities. The qualitative research conducted with each allowed me to collect in-depth data with two relatively small cohorts. Despite the small size of the research cohorts, there was sufficient data to assess trends of use in each group and draw comparisons between the two. There are similarities in the experiences online of the two groups, particularly in the general activities of each group, and the high levels of health research and health related interactions. Following analysis of the data in each of the findings chapters, the

main areas of intersection (access, information, support, and legacy) are all discussed in the themes section below. This section concludes with a discussion of the general internet use by participants in each group and draws comparisons between the groups and the habits of the general population.

Although there are some significant differences in how the participants of each group resolved the issues posed to them by their respective conditions, the intent behind them is very similar, as is the end result. Across the two studies, it is often the case that the experiences of people living with physical disabilities and the family members of people living with EOD are similar in the cohorts involved in these groups. However, this is largely dictated by the experiences of the person with EOD and the stage their condition has reached. For several participants it is their own experiences which are more similar to participants of Group 1, with their family members still having relatively little knowledge of their online and IT based activities and even less influence over what they were doing. Much like the Group 1 participants, this group of online active Group 2 participants were using the internet to support their daily lives and supplement information that they were having trouble remembering or translating into action, such as using cooking videos for timing and to remember the processes required for meal preparation. These findings are likely to have been influenced by the recruitment methods used during data collection, both positively and negatively.

6.2 Themes

This section looks at the main themes which emerged from the two studies, and explores the similarities and differences in experiences between the two participant groups.

6.2.1 General internet use

This was an area that had an impact across the subsequent themes in this section (access, information, support, and legacy). It also leads to two different comparisons: firstly, the participants of Group 1 (people living with physical disabilities) and the index participants of Group 2, the people living with Early Onset Dementia (EOD); and secondly, the participants of Group 1 and the partners participating in Group 2. This is likely due to the differences between living with a degenerative neurological condition compared to a relatively static physical disability or being a partner with generally good health.

The differences in general internet use were far more pronounced between Group 1 and the index participants of Group 2 with a diagnosis of EOD. While the majority of Group 1's internet use had remained static and had adapted around a long-term disability, more than half of the index participants of Group 2 had reduced their use, leading to them abandoning some services or devices entirely. IP2-9 for example had stopped using the home computer as they could no longer remember any passwords. Similarly IP2-8 had stopped using social media due to a combination of forgetting passwords and that they had an account in the first place after accidentally deleting the Facebook app from their phone. Amongst the participants who had remained similarly active online, both groups were using the internet to find relevant information and peer support. Indeed, several participants of both groups had become more active online after receiving their diagnoses in order to connect and share information; IP1-1, IP1-3, and IP2-2 were all active in condition-related peer support networks on social media. However, the experiences of continued internet use tended to be more divergent than similar, owing to the reduced use in Group 2 and the move away from social media amongst the still online active participants.

The greatest areas of similarity in use came between the participants of Group 1 and the partner participants in Group 2. Both groups had remained fairly active online, and the new activities added into the daily routine had more similarities to those of the Group 2 index participants. This included greater levels of social media for support and information seeking behaviours, both of which will be discussed further in later sections of this chapter. This is likely due to the relative stability of the participants' health and capacity to act online. It is also possible that the similarities between these participants are reflected in the general internet use of the wider population. Trends of increased online shopping and the acceptance of smart home assistants are reflected in the two groups, as is the use of smartphones for day-to-day admin tasks such as online banking. The next sections discuss the similarities and differences in specific facets of internet and technology use between the two groups.

6.2.2 Access

This section looks at the topics of access and accessibility across the two studies in this thesis. Having acknowledged there is some bias in the data regarding recruitment methods and having digitally active participants, it is then important to consider and compare how active these participants were and how they spoke about their internet and IT use. With the exception of IP1-9, all of the participants involved in both Group 1 and Group 2 were either currently active online or had been previously. The level to which participants were active varied considerably: some participants in Group 1 were active online and on smart devices all day, while some participants in Group 2 only used the internet to support their cooking and travel needs on a daily basis. One participant in Group 1 could only look online when their partner moved the computer and assisted them in its use, while some participants in Group 2 had all but stopped using the internet and their

smartphone, but spent time each day playing brain training games on a Nintendo DS. These examples also speak to the range of devices being used by the participants to access the internet, from smartphones to running the house on a ‘possum’ device which responded to voice commands and could unlock the front door as well as facilitate entertainment and communication activities.

Age was not an indicator of the frequency of access or the ability of participants. In both Group 1 and Group 2, the older participants were those who were the most active on their computers for both practical and entertainment purposes; although it was IP1-9, the oldest participant across both studies, who did not use the internet or IT at all. Age was also not an indicator of use of smart technology, and participants across both studies were utilizing the voice assistants on phones or smart devices around the home to set reminders and alarms or perform impromptu internet searches. This is something which has been explored in other research to some extent. I believe it will continue as people see smart devices in their homes not as assistive or monitoring devices, but as an object of everyday convenience like smartphones and tablets (Dewsbury et al., 2003; Dewsbury and Edge, 2001).

Access and accessibility were major themes in the findings of both studies, and indeed in the literature for both Early Onset Dementia and physical disabilities in Chapter 2. These were the experiences of the participants that had the most similarities, but also the most differences. Based on Group 1, anecdotal evidence, and conversations I had with people in the time between the two studies, this was an area I had expected to be far more similar than it transpired to be. This was based on the reported issues with touchscreens, interface changes in operating systems, the number of passwords people had, and issues of websites timing out that people in Group 1 and people providing the anecdotal evidence had told me about. In reality, these were issues in Group 2 - but the ways in which participants and their partners have worked around them meant that

access issues for the person with EOD were more linked to ability and interest in remaining active than forgetting passwords or websites posing problems.

The ways that participants had been able to work around their conditions was an area which was significantly different between the two studies. In many instances, the accessibility issues expressed around touchscreens or passwords in Group 2 were actually those of the partner who did not have dementia and who was taking responsibility for the online accounts. For Group 1 participants, rather than having a person assist in using devices, the participants would use different peripherals - such as additional magnifying devices or larger screens for vision, different keyboards or mice for dexterity problems, or voice controls (Campos et al., 2014; Lupton and Seymour, 2000). In Group 2, many of the issues of access and accessibility were transferred to the index participant's partner. A notable exception to this this was IP2-3, who had begun to have more problems using the touchscreen on their iPhone and had started to stop using it at about the same time they had begun to have trouble writing. However, when using a standard keyboard, IP2-3 was still able to use this to type and had been improving when providing written communication in this way. Their partner IP2-3P was able to promote this by having a care worker support IP2-3 in typing up weather reports.

Much like six other Group 2 participants, IP2-3P had taken over responsibility for the passwords and secure accounts, which had previously been split between themselves and their partner. Also similarly to the rest of this group, there had been little difficulty in managing the passwords. They either had a joint system for accounts so that both partners would be able to access any accounts as needed, or they were written down in a password book - by far the most common method of password management across both of my studies. The notable exceptions to this trend in Group 2 were the two participants who followed much closer to the Group 1 trend of continuing on without assistance, but not changing devices or

operating systems so that they remained familiar with the appearance and functionality of the device.

Topics of access and accessibility were only one area of similarity between the two groups. In the next section I will discuss the similarities in information seeking and sharing practices between the two studies.

6.2.3 Information

This section discusses the information seeking and sharing practices of the participants in both studies. Information sought in these studies covered all aspects of life, from health specific information to travel and route guidance and from google searches on random thoughts to television shows. This was a significant theme across the two studies, and one which had the most similarities between the two groups, especially the health information seeking practices.

Of all the information seeking topics, it was health information that was the most common subject of internet searching amongst these research cohorts. These searches ranged from immediate post diagnosis searching to supplement the information given to them at their appointment to searches on medication changes to find out what the medication was meant to do and any potential side effects. This is also one of the areas that all of the index participants with Early Onset Dementia in Group 2 had been involved in, even if their interest had later dropped away. This was less so the case in Group 1, in which some participants had been disabled since they were young children, or the cause of their disability was so clear it did not need searching (such as the participant who was wheelchair-bound after an engine was dropped on their legs). These participants were far more engaged in searching for information on medication and alternative treatment options than on their original condition. Group 1 participants with

disease-based disabilities such as MS or Parkinson's disease followed a similar information seeking route to the Group 2 participants.

For these participants, the search for information starts almost immediately after an official diagnosis has been given, if not before. This information supplements or replaces that which was provided by the doctor, and in the case of Group 2, was usually sought to answer some of the questions they had not thought to ask at the appointment, or to research concerns that had occurred to them. This initial search took a similar format for participants of both studies and was aimed at gathering the most information possible from the widest range of sources. It usually started as a general Google search to identify as many sources as possible, which were then searched though and checked for trustworthiness and relevance. In practice this usually ended up in a search of condition-specific charity and information websites, and especially Wikipedia, as it gathers together a wide range of sources into one complete article on the needed subject. At this stage some websites were also excluded as being untrustworthy, irrelevant, or inaccurate. Universally across Group 2 participants, American research websites were rejected as trusted sources of information for being misleading or trying to sell a cure that doesn't exist yet. This mistrust was echoed by one of the Group 1 participants. But most did not have any issues with other countries' websites as a source of information, although the information contained on them may not be relevant to the treatment or experiences in the UK.

Especially for Group 2, this searching was usually carried out to seek out more age appropriate information (and often age appropriate support) than had otherwise been given to that point. For several of the index participants, their diagnosis was the first time their doctors had seen that form of dementia in a patient, which left them ill-suited to provide information on the progression of their condition. This area is one where the information seeking practices of the two groups begins to diverge. While after diagnosis Group 2 participants looked for peer provided information, this was not the case with Group 1. It is

possible that this is due to the more limited information resources available to people living with EOD and their families, or that the searches related to EOD go on for longer as the family members continue to look for more information on the condition and support. Group 1 participants' searches turn towards information on specific aspects of support needed, such as medication information and wheelchair acquisition or repairs.

Searches for practical and emotional support were significant in both studies, but not for all of the participants. In Group 1, when discussed these searches were mostly practical, focused on finding assistive devices or care and support related to their condition. Peer support searches were uncommon and largely incidental, with one participant sharing information and experiences with a school friend who happened to have the same condition as themselves. Two further participants sought to provide support for others, rather than seeking it out for themselves. This is in contrast to Group 2, in which peer support and information sharing was far more prevalent. These searches were not normally conducted by the person with EOD, but by their partner and other family members who were looking for support and peers in a similar situation with whom they could share their experiences and frustrations.

While finding information about support formed part of the information seeking activities of this group, it is discussed in more detail in the next section of the chapter which will compare the support needs and facilities for these two research cohorts.

6.2.4 Support

This section deals with the use of the internet for finding and accessing support by participants in Group 1 and Group 2. This is another area where participants had similar strategies for seeking out the support, but used it for different purposes and had different levels of

engagement once it was found. These strategies are similar to those used for finding information, as discussed in the last section. For both groups, this included types of formal and informal social support online as well as interactions with condition-specific groups, charity groups, hobby groups, and family and friends.

There were many occasions when these groups would intersect and members could fall into multiple groups. However, the groups remained distinct and the concerns of each group were kept separate. For example, IP1-8 was a member of several Facebook groups, each with a specific interest. They would not discuss their health concerns with members of a Slimming World or craft group, but they would with a friend who also happened to be a member of both groups. These groups provided support not only for their intended purpose, but also social support in a more general sense by facilitating interactions on days when they were otherwise unable to leave the house. This was the case for many of the participants across both studies, who were involved in social networks that gave them general support.

A smaller group of participants across the studies were also involved in condition-specific groups and support. This was far more common in Group 2 and was a trend supported by the Talking Point data. Indeed, the purpose of the Talking Point forums is explicitly to provide support and information amongst peers. In Group 1, condition-specific support was limited to IP1-1 who engaged with Parkinson's UK on their forums and Facebook, and also worked to contribute to some of the support resources available by sharing their experiences and fundraising to raise the profile of the group.

The giving of support was a more common theme in Group 1, with several participants working to provide support and resources rather than seeking to find them. This was one of the major areas of contrast between the two groups; while both groups talked about seeking out support initially, this was a far more important topic for the participants of Group 2. While Group 1 participants were often trying to provide

support, Group 2 participants were almost always trying to find out where to access it.

It is possible that the greater focus on support as a topic in Group 2 was due to the more limited resources available to the group. As there was significant disparity of services across the areas the participants lived in and for people with EOD in general, it may be a reflection that the family members of this group spent more time looking because the services were harder to find. The family members of people with EOD and the people with EOD themselves were generally more willing to engage with the support they found and were able to access than participants in Group 1, as long as it was age appropriate. This included a willingness to travel further to attend support or activity groups and meetings, or set something up in their own area if there was nothing on offer. This seeking out of support was particularly noticeable in the Twitter use of participants of Group 2, who were more active on social media for health reasons in general, but also used it to access support from both peers and charities. Several of the participants in Group 2 were frequent users of Twitter chats as both active participants and passive “lurkers” who didn’t necessarily speak in each of the chats. This gave these participants the opportunity to both share their own experiences and knowledge with their peers, but also gain social support and relevant information about groups or studies which may be starting in their area. Twitter use amongst Group 2 participants was also linked to activism and awareness raising activities linked to diagnoses of EOD and the need for more services and information in this area. For the group of participants active on Twitter, social support and information sharing were heavily intertwined, which was mirrored with only one of the Group 1 participants.

The majority of support, either given or received, in both groups was online. This led to questions of account use and preservation should they not be able to access these accounts or the internet in the future, and if they had any wishes set out with family and friends about this.

This formed the start of many conversations around digital legacies, which are discussed in the next section.

6.2.5 Legacy

This theme ran through interviews only due to prompting by myself during them. It is not an area which was asked about in the questionnaires or mentioned in the forum data. However, as discussed in section 2.5.4 of the literature chapter, it is an area which seems increasingly relevant with more resources online and it is a movement that is developing in communities associated with other terminal diseases. It is one of the themes that has the most similarity between the two groups (alongside information seeking practices).

In large part, the two groups were most similar on this theme because it was not an area that participants had thought of in advance in terms of either practical or social accounts. Alongside Amazon and Facebook accounts, photo management accounts were the area where participants were most concerned about longevity and sharing with family members. It was also, unusually, not an area that had been considered as part of participants' password management strategies.

Possibly due to the average age of participants across the two studies and the changing interests of younger people with dementia, there was not as much consideration given to the future of social media accounts as there is amongst the young people with assistance from the Digital Legacy Association (Digital Legacy Association, 2017). In fact, of the 26 interview participants, none of them had any interest in preserving social media accounts when they are no longer able to access it or in having someone post on their behalf on existing accounts. This potentially has interesting implications for social media account management in the future when taking peoples' long-term wishes into account; this area needs more research.

6.3 Comparison

This section draws together the similarities and differences in findings from the two research groups, and will then compare them with the online activities of the general population in the UK. I will present first the similarities, moving through into a separate subsection focusing on the differences, then finally the subsection on comparison with online activities in the general population of the UK.

6.3.1 Similarities

There were a number of key similarities between the two participant groups involved in this comparative study. While there were similarities between all participants active online, there are more significant similarities between the participants of Group 1 and the family members participating in Group 2.

For all participants, age was not a factor in how active they were online. This was influenced more by factors such as trust in types of online activity, for example online banking, and their confidence with the necessary technologies. Both groups were active users of social networking sites, though more were active on Facebook in Group 1, and Twitter amongst both index participants and family participants of Group 2. These sites were used casually as a way to connect with both friends and family, and also to connect with peers living in a similar circumstance to themselves. This peer connection was far more common amongst the family members of people living with EOD than the person themselves within my participant group.

Participants of both groups had engaged with online information resources related to their relevant situation and had similar views on the trustworthiness of information found. This was particularly in relation to information from the USA which was not always directly

applicable in the UK, whether due to the lack of availability of devices or treatment, or the participants' own scepticism around the credibility of the information. The family members of people living with EOD were more likely to be actively seeking information than the person diagnosed, both about the diagnosis and the services and support available to them. This was more similar to the activities of participants in Group 1, who would personally be searching for the information. This could in part be due to the decision not to include family members as participants in Group 1, as the original research design was different for interview recruitment and loss of capacity was not as prevalent a concern for this group.

The internet and technology provided a considerable source of social and peer support for the participants of both groups who were active online. These sources allowed participants to stay in touch with friends and family from around the world when they themselves may not have been able to travel, and to engage with wider communities related to their hobbies and interests. As hinted at in the later broader comparison section, this is not a use of the internet unique to people living with or supporting someone with a long-term medical condition; it is prevalent in the general population too, as is shown in the widespread use of social networking sites. For the participants in these groups (particularly participants living with physical disabilities) and the family members of people living with EOD, the sources allowed them to continue to engage with their communities of choice after a change in circumstance when they otherwise might have been unable to remain active.

This section has set out some of the similarities between the two groups. The next section will look at some of the key differences between the participants of the two groups before moving on to a more general comparison of internet use in the UK.

6.3.2 Differences

Although there were similarities in experiences between Group 1 and Group 2, there were also several noticeable differences. These differences were primarily between the participants of Group 1 (people living with physical disabilities) and the index participants of Group 2 (people living with Early Onset Dementia).

The key difference between these two groups was the use of adaptive technology to facilitate continued internet use, and indeed the nature of the continued internet use. Participants in Group 1 were more likely to be using assistive and adaptive technology to support their internet use, from voice searches and voice assistants on tablets to voice controlled systems which controlled not only the computer but also the participants' home security system. This group was also more aware of accessibility options on websites to assist with reading difficulties resulting from partial sightedness and dyslexia. As a contrast, only one of the Group 2 participants used voice searches through an Amazon Echo to assist with finding music; another used Siri on their phone to search Google for answers, but could only do so with support from their partner.

Index participants in Group 2 were also likely to be more limited in the number and types of internet services they accessed. This is largely down to the differences between the dementia diagnoses and the types of physical disability represented in Group 1, as few were neurodegenerative conditions and had not had a significant impact on the person's ability to access content. More broadly, these differences were shown by Group 1 using the internet and technologies to search for information related to their conditions, alongside the more casual use of social networking sites and search engines shown in Group 2.

Another key difference in the findings between the two groups was the thought given to the legacy of their digital presence. In part this was down to myself not focusing on this aspect in the interviews with Group

1, but it is also possibly due to the nature of the conditions present in each group. For the participants of Group 1, continued access as a result of their disability was not an area of large concern. Therefore, they had not given significant thought to what they would like to happen to their online accounts after they were unable to access them personally, or after their deaths. As a contrast, the continued use of and access to online accounts was something that the majority of participants in Group 2 had confronted - both the index participant and their partner being interviewed. This was rarely focused on the social media aspects of digital legacy, but the more practical side of online account management - such as access to online banking and bill management, where passwords had needed to be changed or shared, or accounts transferred into the partner's name in order to ensure continued access. This therefore mitigated some of the accessibility issues faced by participants of Group 1, such as pages timing out before login or tasks have been completed, as these were not challenges faced by any of the partners in Group 2.

The next section discusses some of the findings in broader comparison to the wider UK population, and situates the experiences and internet use of the two participant groups in a more general context.

6.3.3 Broader comparisons

This section will deal with broader comparisons to online activity and experiences across the adult population of the UK as a whole. It will also look at some of the limitations of the participant groups and the impact of this as a broader comparison.

Although the participant groups in this study were categorised generally as people living with physical disabilities and people living with EOD and their family members, each of these groups could then have been broken down into several smaller, more specific groups.

Both of the groups could have been broken down further by age of participant, length of time since diagnosis, or specific diagnosis received. Each of these would have specific implications for internet access and use; for example, a lifetime disability rather than acquired disability. Learning to use IT and the internet could have been different for each group. This could also have been significant with regards to the type of dementia diagnosed. While dementia is typically linked with memory problems, this is not necessarily the case for all subtypes, and indeed was not for all of the index participants in Group 2. Post cortical atrophy (PCA) and frontotemporal dementia (FTD) in this group presented with difficulties with IT interfaces and behaviour changes respectively, which have different implications for sustained or continued internet use than memory loss associated with Alzheimer's disease. Future research may want to target each of these conditions more specifically in order to create more effective solutions to the ongoing accessibility problems highlighted in chapters 4 and 5 of this thesis.

However, despite the limitations of the participant groups, there are a number of broader comparisons that can be made between the two groups and with the internet using habits of the wider UK population. Again, this is an area of research which needs to be expanded on outside of health conditions, as the majority of research in this area from the UK focuses on specific population groups rather than the population in general as has been done in the USA and Norway (Jacobs et al., 2017; Wangberg et al., 2009). It is possible to argue that high rates of health information seeking are linked to feelings of wellbeing and vulnerability, rather than specific conditions. These rates are higher and more investigated around specific diagnoses for friends and family, and more vulnerable groups such as older people and children. Considering the current health climate that this thesis is being completed in with the influence of COVID-19, it is possible that this is influencing health information seeking in a more general sense,

and drawing the general population to an equivalent level of that seen in participants of Group 1 and Group 2 of this PhD study.

As highlighted in the literature section, approximately a quarter of UK households owned a smart home device in 2018 (Feldman, 2018). This is a comparable figure to the participants of both Group 1 and Group 2, whose interviews took place from 2016 through to early 2018. The uptake of these devices was broadly down to how acceptable participants found it to have these devices in the home, rather than the potential for voice activated media control or Internet of Things connectivity, which appears to be consistent with the wider UK population trends.

Without more generalised research into the internet use habits of the UK population or larger participant groups, it is hard to draw significant comparisons between the participants. The trends in social media and online shopping use are mirrored between the general population data and the data collected from these two participant groups, as is the prevalence of smartphone use. It is however possible to see that more broadly, there are similarities in general internet use between people with physical disabilities, people living with Early Onset Dementia, the family members of people living with Early Onset Dementia, and the wider UK population. The key differences lie in how each of these groups experience the internet and the interactions facilitated by it. These are all areas which require further research in order to better understand the needs and experiences of each group.

Chapter 7 Conclusions

This chapter draws together the findings and discussion from this thesis to provide answers to the research questions posed in the introductory chapter. It will also suggest topics for further research and provide final conclusions on the studies presented through the thesis.

7.1 Return to research questions

1. A) Are people with Early Onset Dementia (EOD) and their families using the internet to find information and services?

Across all the participants and their partners in Group 2, the whole cohort had looked online at some point since their diagnosis to find further information about their diagnosis and the services available in their area. This was particularly prominent in the Talking Point data set, in which most of the posts were either requesting or sharing information gained through experience. It is evident from the data that information and support is sought out online due to the limited number of services for people with EOD in many areas across England and the wide range of routes taken by participants to diagnosis. While these searches were usually conducted after the diagnosis was officially given, some participants or their family members had looked into information on dementia when initial health concerns arose. This was mainly in families where there was a known history of dementia, but also when participants were waiting for testing or for a diagnosis to be confirmed.

Participants also used the internet to seek out services related to the dementia diagnosis, in particular what services were available in the area and the age range of current participants. This also led to participants seeking out more age specific information and services

which would account for being in work, existing financial commitments, and preferences over what they spent their time doing and who with.

From this cohort of participants and from the Talking Point data, it seems that it is the family members of the person with EOD who are more likely to be engaged with searching for information and services online. However, some people with EOD remain active in this area too, and should not be overlooked.

B) Are people living with physical disabilities using the internet to find information and services?

Health information seeking literature indicates that people with physical disabilities use the internet to find information and support linked to their condition. The participants of Group 1 did engage in health seeking behaviours, but were far more active in searching for a wider range of information and services. With the exception of three of the 15 participants, all had been involved in looking online for information and services. These searches related to a wide range of other information, such as accessible travel, cinema times, and social groups related to hobbies. Participants of Group 1 were also using the internet to find information on local services such as bus timetables, rubbish collections, and local tradespeople for accessibility adaptations to their houses. While the nature of searches by Group 1 participants differed from those in Group 2, people with physical disabilities were still using the internet to access relevant information and support. However, several participants also used the internet and computers generally minimally, and their experiences of information seeking and service use without the internet should not be overlooked when considering the importance of the internet in this way.

2. A) What role does online information play in the understanding of the diagnosis of Early Onset Dementia for both the individual and their family?

Online information plays a significant role in the post diagnostic period for both people with EOD, and people with physical disabilities if they have their onset later in life. These resources allow people the opportunity to find out more in-depth information and to revisit information after the doctor's appointment when the diagnosis was given. This post appointment time was highlighted in both studies as a time when the initial information given by the doctor was not absorbed by either the person being diagnosed or their family members. Online information resources allowed them to revisit the information in their own time, and often in far more depth than had been provided at the appointment. For some participants of the study, this information allowed them to connect with peers in the same position. For others, it allowed them to search out alternatives for support in their daily activities, such as finding assistive technologies or diet and supplement protocols to try to slow the progression of the dementia.

Seeking out this information and assessing the reliability of sources for each condition and individual were an important part of accepting the diagnosis and how it was likely to affect them in the future. Being able to revisit information is also important, as it allows the understanding of the diagnosis to grow as the condition and the person's needs change over time. For example, this includes finding different consultants, or talking to peers to find support and understanding for the person living with EOD and their family members or carers.

B) What role does online information play in the understanding of their diagnosis for the person living with physical disabilities?

This was a harder question to answer owing to the types of disabilities present in the cohort for Group 1. Of the 15 participants, 14 had long-term degenerative conditions. Of the two remaining participants, only one had sought out information related to their disability and the management of their medications. For the participants with long-term conditions, one had gone online after diagnosis to find out more about the course the disease may take, but had not looked for diagnosis specific information since. It appeared that after the initial Google search, the participants understood their disability better than a website, and would relate better to experience when consulting with healthcare professionals and sharing information with newly diagnosed peers.

3. A) How valuable is online support and information for the individual diagnosed with Early Onset Dementia and their family?

It is hard to say how valuable online support is for all participants in Group 2, as not all participants and their families were engaged in online support networks. This is similar to Group 1, in which not all participants used the internet to access online support networks or indeed information about their particular condition.

For Group 2, online information sources were valuable in supplementing information given at the point of diagnosis. They were particularly valuable when it came to finding information about rarer types of dementia and age appropriate information - for example, support that didn't talk about dementia as a disease of the elderly and base life expectancy on this.

It is hard to say how valuable the online support was in general, as not all participants engaged in online support networks, but for the participants who were involved in these networks the support was of tremendous value. The information shared through these networks also has an impact on a wider scale as it disseminates to a wider audience.

B) How valuable is online support and information for the individual living with physical disabilities?

As stated in the previous section, not all participants of Group 1 were engaged with online support networks. However, for the participants who were involved in seeking support and information online about their condition, these resources were of huge value and made up a large part of those participants' online interactions. Unlike participants in Group 2, the information sought was rarely to supplement information given to them post diagnosis, as several of the participants had long-term degenerative conditions and were well aware of their own symptoms and progression of their condition. Rather than health information, the valuable information sought related to management of assistance payments, travel, and accessible hobbies - all of which linked to social and formal support networks.

4. A) Do people with Early Onset Dementia have a plan for the maintenance of their digital legacy or management of digital assets?

To some extent, the participants of Group 2 had already made plans for the maintenance of digital accounts and assets through the sharing of password information with partners and children. This was not necessarily a fully-fledged plan for management, and many of the

people diagnosed and their partners had not considered prior to the interview what would happen to these accounts in the longer term. It became evident throughout Group 2 that the participants had only limited ideas of what a digital legacy would be composed of, and discussed it mainly in terms of online accounts such as Facebook, Twitter, and Amazon. Few participants had also considered the implications of the names on bills and other practicalities. What had not been considered, and therefore not planned for, was the management or preservation of cloud storage solutions, digital photos, or music libraries in the future. Similarly, little thought had been given to the management of digital assets such as files saved on personal computers, tablets, or phones. Indeed, this area of legacy management was not mentioned by any of the participants in either Group 2 or Group 1 when the topic of digital legacy was discussed.

While some people living with EOD may have had a plan for their social media, email, and online shopping accounts, it is not reasonable to conclude that these comprised an individual's entire digital legacy; nor did these plans include long-term management beyond the initial wishes shared with family members. More conversations need to be prompted about a broader understanding of what makes up a digital legacy in order to assist people with EOD (and indeed the digitally active population as a whole) form effective and cohesive plans for their digital legacy management.

B) Do people living with physical disabilities have a plan for the maintenance of their digital legacy or management of digital assets?

Unlike Group 2, in which participants had given a greater level of thought to the hand-over of account information such as passwords out of necessity, Group 1 participants did not have a plan for their digital legacy. This is an area which arose in only five of the 15 interviews after prompting from myself. Beyond a universal desire to

close social media accounts after death, no further thought had been given to this area.

5. Are there similarities or differences in the online practices between younger people with dementia and adults living with physical disabilities?

Across the two studies in this thesis, it has been shown that there were similarities in the online practices of people living with EOD and people living with physical disabilities. Both groups engaged more heavily in health information seeking than would be expected of the general population, with more time being given to research on medications, testing procedures, and general health than otherwise appears typical in the general population. It appeared that participants of both studies also engaged more with peer support than the general population. While some participants received online support for non-condition-related activities (such as weight loss or e-learning), many participants received peer support from people who were living in a comparable situation - either as a person living with EOD or a physical disability, or as a family member of someone in these groups. Many of the family members in Group 2 had engaged other people who were supporting a family member with dementia in order to share their experiences, while participants in Group 1 shared experiences based on mobility restrictions and travel which would go unnoticed by most of the able-bodied population.

There were also similarities in the access issues faced by each of the groups, such as difficulties with comprehending information displayed on screens or with using devices to access the internet if they had an unfamiliar interface or touchscreen. However, the ways in which these difficulties are negotiated were quite different. For most of the Group 1 cohort, using assistive peripherals and accessibility settings for reading would allow them to mitigate the difficulty, whereas for Group

2 these difficulties were usually indicative of changing abilities in IT use - or simply a shift in interest away from using that site or device, with peripherals often having little or no benefit to the individual.

It is possibly more accurate to conclude that there are more similarities between the family members of people living with Early Onset Dementia and people living with physical disabilities in these research cohorts. While people with Early Onset Dementia are active online, in the Group 2 cohort it was the family members and partners who were primarily seeking out the support and information in a manner similar to participants in Group 1.

7.2 Future directions

As discussed in section 6.3 on implications, this research has highlighted a number of areas which require more attention before any concrete conclusions can be drawn about the uses of the internet and IT by people living with Early Onset Dementia (or indeed the percentage of the population with physical disabilities in general). Although there are similarities, each individual experience is distinct, shaped by the technology available to them and the services in their area. Future research would need to be done with a larger cohort of participants living with Early Onset Dementia before the changes and uses discussed in this thesis can be judged to be widely applicable. This research would also need to include more participants with Early Onset Dementia who were still actively using the internet and were willing to answer more questions about general internet and IT use in order to better compare with a similar group of people with physical disabilities. Further research would also take into account existing conversations on digital legacies and wills, and work on greater information on how passwords and other information can be safely passed on in this way. Although relatively small, this cohort is large enough to act as a starting point for further research into this area, and

provides some background which was not present at the outset of this PhD.

7.3 Summary of contributions

While this research may have created limited tangible outcomes, those it did create are no less significant, and highlight the need for further research. Listed below are the contributions of this thesis.

- The writing of the Health Needs Assessment during my mandatory PhD internship raised awareness of the population living with Early Onset Dementia in Nottinghamshire. Prior to my internship, few people in Public Health were aware of Early Onset Dementia as a condition or the scale of need within the county. This project means research has now been done in the Nottinghamshire Public Health department and that staff members are now more aware of the group's needs.
- Conversations have been prompted amongst the participant groups about the management of digital legacies and what that might entail. This has also prompted conversations about what kind of advice should be given on the subject and its timing. For example, should advice on management of digital assets be given after a diagnosis of dementia, or as part of creating a digital will alongside a traditional will?
- The research has further highlighted the need for local authorities and charities to provide non-digital services and information for people who are unable, or do not want, to access online services or support.
- Conversations have been prompted about Early Onset Dementia, helping to raise awareness of the condition amongst people outside dementia and memory research, and outside of the community of people who have dementia or who are caring for someone living with it.

The next section will discuss the implications of these contributions and the thesis as a whole.

7.4 Implications

Perhaps the main implication of this thesis is that it highlights the need for further research into this area for both groups. Despite the high levels of research into accessible and adaptive technologies, health interventions for people with physical disabilities, and dementia in general, there has been little done on the role the internet plays generally in the daily lives of these two groups. This means that there is a lower level of understanding in this area which could be built on. While there is little research into internet use and Early Onset Dementia, this is also the case in dementia research in general. This is an area which is likely to continue to evolve and become a greater issue in the future. Age was not an indicator of how active the participants of Group 2 were online, and several of the older participants in Group 1 were more active than their younger counterparts.

Continuing from the need for further research into the online activities in these groups is the need for further conversations about the nature of digital legacy, and what it means to have plans in place for this. Effective conversations should be held about wishes for legacy management in the general population, but particularly for people living with EOD or other progressive conditions. This subject should be broached in a similar way to will making, with ideals for social media, online accounts, and other digital files set out in the same way as physical or financial assets. This is an area where advice could come from a number of sources, such as: inclusion in diagnosis pamphlets at the doctors' or specialists' office; relevant charities, such as condition-specific groups; or even the Citizens Advice Bureau. Prompting this conversation at an earlier stage may enable people to

have conversations about changing over named responsibilities for utility bills and accounts at an easier time, potentially reducing the anxiety and stress caused by having to do this at a later stage in the condition. It would also ensure that future wishes about methods of staying in contact with friends and distant relatives are preserved, including who and when.

The following sections will set out the implications for three main areas in turn: future research with these participant groups; policy implications; and technology implications and recommendations.

7.4.1 Future research

At the core of the comparison was the experiences of people living with physical disabilities and people living with Early Onset Dementia (EOD). As many of the people living with EOD were interviewed with a partner, and were assisted by them in accessing at least some websites and services, it is of vital importance to consider in future research studies whether it is the authentic voice of the person with EOD being recorded or one that is largely led by their partner, even with the best of intentions (McKeown et al., 2010; Pipon-Young et al., 2012). While not relevant for all, topics which particularly touch on financial matters such as online shopping could be influenced by the partner or carer. For example, IP2-7P was assisting IP2-7 with online shopping, and could therefore be influencing purchasing behaviours. This is also relevant in the group of people living with physical disabilities who need to be assisted online; their reported online interactions could be guided as much by the person assisting as by themselves. It is therefore important to try as hard as possible to collect the views of the person living with EOD from themselves, rather than through a partner. This was acted on in my interviews by ensuring that questions were asked specifically to the index participant with EOD, or seeking clarification from them if they were more limited in their level

of verbal engagement. These actions were also taken in Group 1 when needed. This is particularly important to consider in future research on the topic of internet use with these groups.

7.4.2 Policy implications

Conducting the research for this PhD has facilitated a number of conversations with local public health and NHS trusts about the current available services for people living with Early Onset Dementia, and the suitability of existing online service provision for people living with physical disabilities. Some of these conversations have broader policy implications for the groups of participants in question.

These implications are largely around the design and roll out of services to ensure that all users have equity of access to necessary information and support. Prior to the research conducted as part of this PhD and its linked internship with Nottinghamshire County Council (NCC), a specific needs and service availability assessment had not been carried out for people living with Early Onset Dementia in the county. This work then raised awareness of the lack of age appropriate services and geographic disparity of those services available, so that this group could then be given consideration as part of the local dementia strategy.

Similarly, work with the council highlighted the importance of effective service roll-out to ensure that new technology solutions are used, something that is touched on more in the next section. In the interviews conducted with Group 1, feedback was also collected for NCC. This found that lack of awareness of the new website, as well as problems with the layout and accessibility of it, were preventing participants in this group from accessing it.

The key policy implication from this research is the need to ensure that services are meeting the needs of the users through consultation, and

that they have equity of access across the condition and geography. This is particularly the case for people living with Early Onset Dementia and physical disabilities, who already have limited specific services to access. They may be further restricted by not living in a city, having limited ability to travel, or indeed lacking the skills or confidence to use online-only services. In order to effectively address these problems and ensure that these conditions get the attention they deserve, more funding needs to be given to carry out research with people living with Early Onset Dementia and physical disabilities, as suggested in the future research section previously.

7.4.3 Technology implications

Beyond academic research, there are also implications for the design and consultation process for new services and changes to existing services to ensure that the needs of service users are met effectively. This is particularly relevant for local authorities, national services, and the charities which serve these groups.

One of the issues raised by both groups was having information and help features more clearly signposted and easier to find on the websites, with additional thought given to colour scheme and font choices. This was particularly raised by participants with PCA and dyslexia across both studies, as some layouts made websites particularly difficult to navigate. As touched on in the accessibility section previously, website timeouts made some services particularly hard to use for both groups, whether in terms of time to fill out the page or the time needed to work out the responses for security questions and details. Both of these raise implications for stakeholders regarding how the design of their websites may affect the uptake of service use.

In order to best meet the needs of their users, stakeholders should consult with the relevant groups during the development and consultation phases of service and technology development to ensure

that the service is appropriate and useful for those users. By including the end users at this early stage, it helps to ensure the service or technology is usable, and should improve uptake and use over time.

Where this is not an option and the service or technology is already in use, it is important to consider issues of accessibility and how easy it is for users to configure it for their best benefit. For example, how accessible is a website colour scheme to people who are dyslexic, and how easy are the accessibility options to find on the home page? Do your images include text descriptions suitable for text-to-voice programs for the visually impaired? If solutions are not already readily available, accessibility options should be updated when possible. Guidance from the Web Accessibility Initiative is readily available to advise on how best to make websites accessible (Lawton Henry, 2019), and also has specific guidelines for accessibility for cognitive or learning disabilities (Lee et al., 2019) that should be utilised to ensure equity of access.

These implications were all considered when answering the research questions set out in the introductory chapter of this thesis and in drawing final conclusions in the final section of this chapter.

7.5 Final conclusions

This research highlights the internet use of people living with Early Onset Dementia and their families in a way which had not yet been addressed in literature published at the time of writing. It highlights the importance of age appropriate information and services for both the person with dementia and their family members, particularly younger adults and children. The study also raises concerns about the locating of services online and the problems that can arise when transferring ownership of accounts and bills to an LPA when an individual has been active online and then is not in a position to remember security

questions - something which will increasingly be an issue in the future if online shopping and banking trends continue.

The thesis also draws comparisons between the online experiences of people living with Early Onset Dementia and people living with physical disabilities. While there were similarities in the uses of the internet, the frequency and manner in which the two groups accessed it proved to be quite different within the cohorts in Group 1 and Group 2. This should be a topic of future research with larger groups in the future.

It is evident that while its use is specific to each individual, the internet plays a significant role in the post diagnostic period for both people living with Early Onset Dementia and physical disabilities. It is also clear that, while the internet plays an important role during this period for gathering information and support, online interactions cannot fully replace positive face-to-face and other offline interactions.

It is therefore fair to conclude that there are similarities in the experiences of people living with Early Onset Dementia and people living with physical disabilities within these cohorts, and that there is potential for this to be a more broadly applicable trend in each of the research populations.

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Chapter 9: Appendices

9.1 Group 1 questionnaire information and consent

Questionnaire Participant Information Sheet

Who can take part?

If you live in the UK, are over 18, and have a physical disability you can participate in this questionnaire project.

Why take part?

The aim of this research is to understand how people with physical disabilities are accessing and using the internet. The aim is to shine a light on your experiences, and the responses you provide will be extremely valuable to the project. These answers will allow the researcher to better understand the needs of your group on the internet, which can then be used to inform service design for local authority services and academics.

How long will the questionnaire take?

This is a relatively short questionnaire and should take around 10 to 15 minutes to complete.

What happens after I've agreed to take part in the questionnaire?

At the end of this information section there is a tick box next to the statement 'I agree and understand the information and consent to take part in this study'. Please tick the box to provide an electronic signature and click next to start the questionnaire.

Once you have completed the questionnaire it will be submitted to the online system where the results will be analysed by the primary researcher for insights.

What about my privacy and confidentiality?

Your responses will be completely anonymous and will only be viewed by the researcher and their supervisors at the University of Nottingham. The data will be stored securely on a university computer, in line with the Data Protection Act 1998, and the University Ethical Conduct Policy.

The data you provide - including anonymous quotations - may be used in published writings or conference materials as part of the PhD writing process. No identifiable data will be used and participation will remain entirely anonymous.

At the end of the questionnaire there is a question asking if you mind being contacted for further research in the future. If you do, please leave only your preferred name and email address in the contact form.

If you opt to leave an email for potential further research this will be stored separately from the questionnaires, and will not be linked to your questionnaire responses.

If I agree to take part now, can I change my mind?

Yes, participation is entirely voluntary and you are free to stop completing the survey at any time. If you close the browser window at any stage of the questionnaire your data will not be saved. You are free to complete the questionnaire at another time if you choose to withdraw.

Who developed this questionnaire?

This questionnaire was developed by Alexandra Young, a PhD student at the University of Nottingham. This questionnaire will provide background information in the writing of the thesis project.

It has been reviewed and approved by The Department of Computer Science Ethics Committee, University of Nottingham.

Will I be able to get in touch with the research team?

Yes! If you have any questions about this questionnaire, please get in touch with Alex Young on alexandra.young@nottingham.ac.uk

I agree and understand the information above and consent to take part in this study

-

9.2 Group 1 questionnaire outline

Questionnaire

Age

18-29 30-49 50-67 67+

Preferred Gender

Female male other (text box)

Do you have a long term physical disability?

Yes no (if not route to a thanks for taking part end page)

How often do you access the internet (please select up to 3)

0-5 hrs a day 6-10 hrs a day every day of the week
a few days a week a few times a month once a month
less than once a month never

Do you use the internet to access any of the following? (please tick all that apply)

- Social media (facebook, twitter, tumblr, linkedin etc…)
- Support networks for your diagnosis (online groups, forums, facebook pages etc…)
- Email services (gmail, Hotmail etc)
- Shopping services (Amazon, online groceries and others)
- Financial services (online banking)
- Local authority or government websites (information on financial aid or benefits, housing and technology adaptations, accessible travel and locations)
- Information related to your diagnosis
- Online games
- Other (general browsing etc…)

How do you access the internet? Please tick all that apply

Desktop pc/laptop/tablet/phone/other devices (games consoles, other mobile devices)

Do you require assistance to access the internet or use these devices?

Yes/no/sometimes

If yes or sometimes ‘If you need assistance who is it from?’ please tick all that apply

Spouse/children/siblings/parents/carers/other (text box)

What kind of assistance do they provide? (text box)

Were you diagnosed as an adult?

Yes no

If yes go to ‘do you think your diagnosis has changed the way you use and access the internet and other technologies?’

yes/no/somewhat

how? (text box)

If no go to ‘do you think your disability has shaped how you use and access the internet and other technologies?’

yes/no/somewhat

how? (text box)

Would you be interested in taking part in further research

Yes/no

If yes take to contact info page with name and email box,

If no, take to end.

Thank you for completing this questionnaire, if you have any questions please get in touch at Alexandra.young@nottingham.ac.uk

9.3 Group 1 interview ethics

9.3.1 School of Computer Science ethics form

School of Computer Science
Research Ethics Checklist

for PGR students & staff

- This checklist must be completed for every research project that involves human participants, use of personal data and/or biological material, b*efore* potential participants are approached to take part in any research.
- Any significant change in the design or implementation of the research should be notified to cs-ethicsadmin@cs.nott.ac.uk and may require a new application for ethics approval.
- It is the applicant's responsibility to follow the University of Nottingham Code of Research Conduct and Research Ethics and any relevant academic or professional guidelines in the conduct of the study. **This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.**
- Completion of this form confirms that you have read and understood the guidelines at www.cs.nott.ac.uk/ethics regarding:
  - what is defined as *personal data;*
  - what is required for *valid consent;*
  - the key requirements of the Data Protection Act
- The supervisor/principal investigator is responsible for exercising appropriate professional judgement when completing Section VI of this form.

- **Sections I to V should be completed by the student or researcher undertaking the study. Section VI should be completed by the supervisor/principal investigator.**
- The **supervisor/principal investigator** is responsible for emailing the completed form to cs-ethicsadmin@cs.nott.ac.uk, and for providing feedback to the student/researcher.

SECTION I: Applicant Details	
1. Applicant's name	Alexandra Young
2. UoN Email address	psxay@nottingham.ac.uk
3. Status	**PGR Student ~~/ Staff~~** (delete as appropriate)
4. Student ID (PGR students only)	**4237199**
5. Supervisor/PI's name	Prof. Chris Greenhalgh
6. Supervisor/PI's email address	Chris.greenhalgh@nottingham.ac.uk

SECTION II: Project Details	
1. Project title	**PhD Pilot**
2. Proposed start date and period of study	**Proposed start date 1st January 2016 for 4 months**
3. Is this a re-submission?	**Yes / ~~No~~** (delete as appropriate) If Yes, please give details of how the project has been revised in response to the reviewers' comments below. **Details of revisions included at the end of description section.**

4. Description of Project, including aims and objectives. *Please include any information which may affect the consideration of the ethics involved, eg location of study, unusual circumstances, age range of participants:*

This project is a short interview based project based on the views of people who receive services from the adult social services of Nottinghamshire County Councils. This is based on a semi -structured interview which will last no longer than 90 minutes and be centred on daily technology use and the role of online resources in planning for care and daily activities.

The interviews will be carried out in accordance with the University's lone working policy in the participant's place of residence. These will be split between 2 locations; Rushcliffe in Nottingham and Newark, with an appropriate measure of contact and support in place for each.

The participants of this study will be individuals aged between 25 -50 living with their families in their own homes, not in a residential care setting. The participants will be in receipt of services from the adult social services of Nottinghamshire County Council for physical disabilities, but not cognitive or communicative impairments.

The aim of the project is to collect information through interviews about how people with physical disabilities are using online services and technology in their daily lives to plan care and activities, with the objectives of better understanding the field outside of a gerontology or educational background, and in order to provide anonymised feedback to the county council in the form of a publishable report with the aims of improving their existing and developing online social service provision.

Consent will be gained through the initial response to the invitation to participate, and again before the interview starts and once any potential questions have been asked and answered. This will include consent for the interview to be recorded and then transcribed, as well as for anonymous quotations to be used in publications and reports.

The recruitment process is described in section IV, and no compensation is being offered to participants.

Please find attached copies of the consent form, information sheet, and initial contact letter at the end of this form.

Revised copies of the consent form, information sheet and initial contact letter have been attached in order to provide more consistent information in line with reviewers comments, and to ensure that the time for the interviews in consistent across all documents participants will see. The time has been changed from 90 minutes to an hour and a half in the attached documents.

4. Will personal data or biological materials be collected, recorded and/or analysed?

Yes / ~~No~~ (delete as appropriate)

If Yes, please give details of the data or materials and the methods to be used and describe how safe storage will be maintained according to the Data Protection Act:

The interviews will be recorded as audio only. The data collected will be transcribed and used to analyse how people are interacting with council services online.

Data will be stored in accordance with the Data Protection Act 1998, namely on a password protected drive in a secure facility and only for the duration for which it is required. It will only be accessible by those directly involved in the research.

All data will be anonymised at the analysis stage. Any data used for publications will be anonymous to protect your identity. Publishing data could result in information becoming available on the internet to those who wish to access it.

SECTION III: Research Ethics Checklist (Part 1)	
Please answer all questions:	**Yes/ No**
1. Does the study involve participants who are particularly vulnerable or unable to give informed consent (e.g., children, people with learning disabilities, prisoners, your own students)?	N
2. Will the study require the co-operation of a gatekeeper for the initial access to the groups of individuals to be recruited (e.g., students at school, members of a self-help group, residents of a nursing home)?	Y
3. Will it be necessary for participants to take part in the study without their knowledge and consent at the time (e.g., covert observation of people in non-public places)?	N
4. Will the study involve the discussion of sensitive topics (e.g., sexual activity, drug use)?	N
5. Will participants be asked to discuss anything or partake in any activity that they may find embarrassing or traumatic?	N
6. Is it likely that the study will cause offence to participants for reasons of ethnicity, religion, gender, sexual orientation or culture?	N
7. Are drugs, placebos or other substances (e.g., food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	N
8. Will body fluids or biological material samples be obtained from participants? (e.g., blood, tissue etc)	N
9. Is pain or more than mild discomfort likely to result from the study?	N
10. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	N
11. Will the study involve prolonged or repetitive testing for each participant?	N

12. Will financial inducement (other than reasonable expenses and compensation for time) be offered to participants?	N
13. Will the study involve the recruitment of patients, staff, tissue sample, records or other data through the NHS or involve NHS sites and other property? If Yes, NHS REC and R&D approvals from the relevant Trusts must be sought prior to the research being undertaken.	N

SECTION III: Research Ethics Checklist (Part 2)	
Please answer all questions:	**Yes/No/NA**
1. For research conducted in public, non-governmental and private organisations and institutions (such as schools, charities, companies and offices), will approval be gained in advance from the appropriate authorities?	Y
2. If the research uses human participants, personal data or the use of biological material, will written consent be gained?	Y
3. Will participants be informed of their right to withdraw from the study at any time, without giving explanation?	Y
4. If data is being collected, will this data be anonymised?	Y
5. Will participants be assured of the confidentiality of any data?	Y
6. Will all data be stored in accordance with the Data Protection Act 1998	Y
7. Will participants be informed about who will have access to the data?	Y
8. If quotations from participants will be used, will participants be asked for consent?	Y
9. If audio-visual media (voice recording, video, photographs etc) will be used, will participants be asked for consent?	Y
10. If digital media (eg computer records, http traffic, location logs etc) will be used, will participants be asked for consent?	N/A
11. If the research involves contact with children, will the researchers have appropriate DBS checks?	N/A

- If you have answered 'No' to all questions in SECTION III Part 1 and 'Yes' to all relevant questions in SECTION III Part 2 the project is deemed to involve **minimal risk** - go to the signature page.

- If you have answered ‘Yes’ to any of the questions in Part 1 or ‘No’ to any of the questions in Part 2 the project is deemed to involve **more than minimal risk**. Please explain in SECTION IV why this is necessary and how you plan to deal with the ethical issues raised.

SECTION IV: If the project involves more than minimal risk, please explain why this is necessary and how you plan to deal with the ethical issues raised
This project requires Nottinghamshire County Council to act as gatekeepers for the participants and send out the request letters. This is done as part of the partnership with the council and in line with their own Privacy Impact Assessment carried out for this study. **By the council sending out the letters there is no breach in the privacy of the individuals using the adult social services as no personal details are revealed to myself apart from by the participants themselves when a response to participate is returned. It therefore minimises the ethical issues for both the participants and myself, as the details of those approached who do not wish to participate are never known or shared by any party.** **The council will also send the letters out to targeted areas with their own correspondence, allowing the project to focus on services users in two distinct areas without their personal details being revealed to a person independent of the council.** **Once the council has sent out the participation letters all responses will be anonymised and the data stored in line with the 1998 data protection act. All feedback received by the council will be anonymised with any other names or locations redacted in publications. This ensures that once the council have sent out the requests, they do not know who has responded or from which location, as this data will be stored separately and securely at the University of Nottingham.** **This method of participant recruitment has been selected as being the most ethical approach by both Nottinghamshire County Council and the researcher as it promotes anonymity from the Council for the participants and includes an initial granting of consent for the researcher to make contact from the participant by sending back a reply to the response. Beyond the researcher conducting the interview, the participants identity and identifying features will be anonymised.**

RESEARCH ETHICS CHECKLIST – SIGNATURE PAGE

SECTION V: Applicant Declaration	
Please confirm each of the following statements:	**Yes/ No**
The project is deemed to involve **minimal risk** as defined in SECTION IV	**Y**
I confirm that I have read the University of Nottingham Code of Research Conduct and Research Ethics	Y
I confirm that I have read the guidance documents listed on page 1	Y
I confirm that the information provided in this application is correct	Y
Signature of applicant*	Alexandra Young
Date	9/10/2015

SECTION VI: Supervisor/PI Declaration	
Please confirm each of the following statements:	**Yes/ No**
The participant information sheet or leaflet is appropriate for this research project**	
The procedures for recruiting participants and obtaining informed consent are appropriate**	
The data collection and storage methods are in accordance with the Data Protection Act	
Signature of supervisor/PI*	
Date	

** For email submission, please type your name in place of a signature.*

***All applications for projects involving human participants (or their tissue) must be accompanied by an information sheet and consent form.*

- The **supervisor/principal investigator** is responsible for emailing the completed form, together with any information sheets and consent forms, to cs-ethicsadmin@cs.nott.ac.uk.

- The **supervisor/principal investigator** is also responsible for providing feedback to the student/researcher following Ethics Committee consideration.

SECTION VII: For completion by a School Research Ethics Committee Member	
Name of REC member	
Comments or suggestions	
Decision	**Approve** **Revise** **Reject** (delete as appropriate)
Signature of REC member	
Date	

On completion, an email confirming the decision should be sent to the **supervisor/principal investigator** with a copy to the student/researcher. The completed form will be kept by the School Office.

9.3.2 Nottinghamshire County Council Privacy Impact Assessment forms

Privacy Impact Assessment

PIA - Section 1 – Initiative aim and contact details

Section 1a – Name and details of initiative Nb. Initiative means – idea, plan, program, programme, project, proposal, scheme and the term initiative is therefore used throughout this document
Initiative name/title: Alex Young PhD Pilot.
Link to any wider initiative (if applicable) e.g. Smarter Working; Digital First; The Transformation Agenda etc. Digital First
Description and purpose of the initiative – Include how many individuals will be affected by the initiative? State the detail in relation to the user group affected e.g. adults with disability; looked after children. Include the benefits to the organisation, the individual and to other stakeholders: ***attach any applicable documents that will explain the detail:*** Please see attached information sheet
Who are the stakeholders? List all those with an interest or need to know i.e. service users, providers, commissioners, other bodies **Internal: Nottinghamshire County Council adult social services and communication teams, contacts listed below.** **External: University of Nottingham, Horizon Center for Doctoral Training**

Section 1b - Contact details for initiative

Person completing this assessment (Author)	
Name	Alexandra Young
Job Title	PhD Researcher
Department/Directorate name	University Of Nottingham
Contact address	29 Broad Oak Drive Stapleford, NG9 7AX
Email address	psxay@nottingham.ac.uk
Telephone number	07906261164
Connection to initiative	Author and primary investigator

Other person(s) with responsibility for this initiative e.g. Project Manager/Director, Senior Responsible Officer (SRO)

Name	Prof. Tom Dening
Job Title	Lead Supervisor, Professor of Dementia Research,
Department/Directorate name	University Of Nottingham, Faculty of Medicine and Health Sciences
Contact address	
Email address	Tom.dening@nottingham.ac.uk
Telephone number	
Connection to initiative e.g. SRO	Lead Supervisor
Other person(s) with responsibility for this initiative e.g. Project Manager/Director, Senior Responsible Officer (SRO)	
Name	Andrew Lowe
Job Title	Senior Digital Officer
Department/Directorate name	Nottinghamshire County Council, Digital Team
Contact address	County Hall West Bridgford Nottingham NG2 7QP
Email address	andrew.lowe@nottscc.gov.uk
Telephone number	0115 9772738
Connection to initiative e.g. SRO	Primary Council Contact
Other person(s) with responsibility for this initiative e.g. Project Manager/Director, Senior Responsible Officer (SRO)	
Name	Paul McKay
Job Title	Service Director Access and Public Protection
Department/Directorate name	Nottinghamshire County Council, Service Director Access and Public Protection
Contact address	County Hall West Bridgford Nottingham NG2 7QP
Email address	paul.mckay@nottscc.gov.uk
Telephone number	0115 9774416
Connection to initiative e.g. SRO	Senior Council Stakeholder.

Date PIA commenced:

9th September 2015

Section 2

2a – Purpose and activity

This is a project with existing users of the adult social services. It will aim at recruiting those people with physical

disabilities and no cognitive impairment aged between 25 and 50, living at home with their families. The study itself is a qualitative study comprising of interviews and limited observation lasting for approximately an hour and a half, which could take place over multiple meetings if the participant would prefer.
The purpose of these interviews is to ascertain how people are using the services, what their experiences of them have been, their internet practices and if the current adult social services website is being used for information signposting as intended or whether it is serving another function to meet the needs of the individual. The interviews will also cover what other services people are using online and how these fit into their daily lives, such as social media and online banking services.

2b - Screening questions – you may have already considered the screening questions prior to completing this template e.g. as part of the requirements gathering process. Documenting here which of the screening questions are applicable to your initiative will help to draw out the particular privacy considerations that will help formulate your risk register later in the template. This will also assist in ensuring that the investment the organisation makes is proportionate to the risks involved: **Remember! – imagine this initiative involved the use of your own information or that of a relative**

		Yes	No	Unsure	Comments - document the initial comments on the issue and the privacy impacts or clarification for why this is not an issue or why you are unsure
i	Is the information about individuals likely to raise privacy concerns or expectations e.g. health records, criminal records or other information		X		

	people would consider particularly private?				
ii	Will the initiative involve the collection of new information about individuals?	X			Data about online activity has not previously been collected for this participant group
iii	Are you using information about individuals for a purpose it is not currently used for, or in a way it is not currently used?	X			Data not previously or currently being collected, or used for insight into internet use and role in daily life.
iv	Will the initiative require you to contact individuals in ways which they may find intrusive[1]?	X			Initial contact made through county council and post, some people may not want to participate or find the request intrusive
v	Will information about individuals be disclosed to organisations or people who have not previously had		X		All data will be anonymised prior to any publication,

[1] Intrusion can come in the form of collection of excessive personal information, disclosure of personal information without consent and misuse of such information. It can include the collection of information through the surveillance or monitoring of how people act in public or private spaces and through the monitoring of communications whether by post, phone or online and extends to monitoring the records of senders and recipients as well as the content of messages

	routine access to the information?				removing any individual identifiers. Themes rather than individual information will be discussed. Council as an organisation always had potential access to this information.
vi	Can the information be minimised, anonymised or psuedonomised?	X			All data will be anonymised with personal identifiers removed from anything published.
vii	Does the initiative involve you using new technology which might be perceived as being privacy intrusive e.g. biometrics or facial recognition?		X		Initiative data collection from interview only.
viii	Will the initiative result in you making decisions or taking action against individuals in ways which can have a significant impact on them?		X		
ix	Will the initiative compel individuals to provide information about themselves?		X		The initiative will not compel individuals to provide

					personal information about themselves. The methods and aims of the initiative will reveal individuals habits, but no more than the individual wishes to share.

If you answered **No** to all of the above, and you can evidence/justify your answers in the comments box above, you do not need to continue with the Privacy Impact Assessment as it will not apply to the initiative. However, should the initiative change at any point in the future so that it does use personal information you will need to complete the screening questions again.

Section 2c - Data flows

Describe the data flows (collection, storage, use and deletion):			
What data is being collected? If there is a chart or diagram to explain attach it as an appendix			
Data Classes – the class no. and definition is defined by the Information Commissioners office and are an easy way of listing what data is being collected and used. They have been put in the order that is applicable to health and social care purposes and therefore the class numbers are not in number order. Classes have been omitted where they are not applicable to health and social care.		**Justifications –** there must be justification for collecting the particular items and these must be specified here – consider which data items you could remove, without compromising the needs of the initiative?	
Class no.	**Description**	**Specific data item (s)**	**Justification –** reason that the data item(s) is/are needed

C200: Personal Details	Information that identifies the individual and their personal characteristics	Name, address, postcode Phone number Email address Age	To post out the request to participate. For responses from the participants and to make contact if consent is given. Confirm old enough to give consent and in specified age group.
C210: Physical or mental health or condition	Information relating to the individual's physical or mental health or condition NB. For mental health this would also include the Mental Health status i.e. whether detained or voluntary under the Mental Health Act	Yes List the data items below or attach as an appendix: Not applicable ☐ Physical disability No cognitive impairment Yes/no question with no details	Yes/no question to assess suitability for participation in initiative, no details required. Any potentially identifying comments which arise in interviews will be redacted before use.
C211: Sexual identity and life	Information relating to the individual's sexual life	Not applicable	
C201: Family, lifestyle and social circumstances	Information relating to the family of the individual and the individuals lifestyle and social	Marital/partnership status ☐ Next of kin ☐ Carers/relatives **X** Children/dependents ☐ Social status e.g.	In order to discuss the level of support or assistance, where relevant, and how this is provided

	circumstances	Housing ☐ Not applicable ☐	and received.
C212: Offences including alleged offences	Information relating to any offences committed or alleged to be committed by the individual	N/A	
C213: Criminal proceedings, outcomes and sentences	Information relating to criminal proceedings, outcomes and sentences regarding the individual	N/A	
C202: Education and training details	Information which relates to the education and any professional training of the individual	N/A	
C203: Employment details	Employment and career history	N/A	
C204: Financial details	Information relating to the financial affairs of the individual	Income ☐ Salary ☐ Benefits ☐ Other ☐ Not applicable **X**	
C208: Religious or other beliefs of a similar nature	Information relating to the individual's religion or other beliefs	N/A	

C209: Trade union membership	Information relating to the individual's membership of a trade union	N/A	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
Legal compliance – is it fair and lawful?	1. What is the legal basis for processing the information? *This should include which conditions for processing under the Data Protection Act 1998 apply and the common law duty of confidentiality therefore you may need the input of Information Governance support if the legal basis has not yet been identified or*	**Research for PhD project with full informed and written consent from participants. Project has ethical approval from the University of Nottingham.**	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	needs clarifying.		
	2. a - Is the processing of individual's information likely to interfere with the 'right to privacy' under Article 8 of the Human Rights Act? b - Have you identified the social need and aims of the initiative and are the planned actions a proportionate response to the social need? Y*ou may need the input of Information Governance support if you are not familiar with*	**No** **Yes**	Discover a level of understanding about how this particular user group are using online services as part of their daily routines with the aims of creating recommendations for improvement for engagement from the

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	the Human Rights Act and public sector responsibilities.		council perspective through the data collected in the interviews.
	3. It is important that individuals affected by the initiative are informed as to what is happening with their information. Is this covered by fair processing information already provided to individual's or is a new or revised communication needed? What is your patient consultation programme for this?	New communication with the individuals needed. Consent will be gained at each stage of the research process, including consent for recording, and consent for the use of anonymised quotations in publications.	Please see letter, information sheet and consent forms attached at the end of this form.

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	4. If you are relying on consent to process personal data, how will consent be obtained and recorded, what information will be provided to support the consent process and what will you do if permission is withheld or given but later withdrawn?	Physical signature prior to the interview commencing after talking through the included information sheet and consent form. Explicit consent will be gained for recording the interview, and for the use of anonymised quotations in publications. If consent is withheld the process will stop for that participant. If later withdrawn the data will be removed from the study.	
Purpose	5. Does the initiative involve the use of existing personal data for new purposes?	No	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	6. Are potential new purposes likely to be identified as the scope of the initiative expands?	Potentially	If the pilot reveals information which could be further researched, a new initiative will be planned and a new Privacy Impact Assessment will be completed and submitted
Adequacy	7. Is the information you are using likely to be of good enough quality for the purposes it is used for?	Yes	
Accurate and up to date	8. Are you able to amend information when necessary to ensure it is up to date?	Yes, although not necessary as capturing a snapshot through interview	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	9. How are you ensuring that personal data obtained from individuals or other organisations is accurate?	Trust and efficacy of responses. Clarifying significant details before interview.	
Retention	10. What are the retention periods for the personal information and how will this be implemented?	The data gathered through the interviews will be retained for 7 years, in line with university policy. This will be stored securely on the university servers on the personal drive of the applicant until the drive is closed after the completion of the PhD when the account will be closed	
	11. Are there any exceptional circumstances for retaining certain data for longer than the normal period?	No	
	12. How will information be fully anonymised or destroyed after it is no	Data anonymised at source, kept until after phd thesis has been accepted and will then remain on the university servers for 7 years until the data is fully deleted. Paper copies of consent forms will	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	longer necessary?	be securely stored until the 7 year time period is up when they will be destroyed. Backups will be deleted at the source as permanently as is achievable.	
Rights of the individual	13. How will you action requests from individuals (or someone acting on their behalf) for access to their personal information once held?	Not really applicable, but if requested can send a copy of the anonymised transcript and final report to the individual. Notes will not contain identifiable information. Recordings will be erased after transcription has been completed. Records of names and addresses will be securely stored offline. After the 7 year period is up these records will be destroyed.	
Appropriate technical and organisational measures	14. What procedures are in place to ensure that all staff with access to the information have adequate information governance training?	Training at the university to cover appropriate storage and management of data and confidential information, plus meetings with county council and supervisors to update if needed.	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	15. If you are using an electronic system to process the information, what security measures are in place?	N/A Data anonymised at source prior to processing	
	16. How will the information be provided, collated and used?	Information will be provided freely in interview and recorded. It will then be transcribed and analysed and used for publication in a PhD thesis and to give anonymous feedback to the council	
	17. What security measures will be used to transfer the identifiable information?	N/A – identifiable information not being transferred.	
	18. Who is/are the data controller(s) ?	Applicant, Alexandra Young, sole data controller. 3 PhD supervisors at University of Nottingham will also be able to see the data once anonymised on the secure drive.	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	19. Are there any data processors? If yes, provide the name and contact details.	~~Yes~~ No N/A Processing done by applicant If Yes, is there a data processing agreement already in place? ~~Yes~~ ~~No~~ N/A	
Transfers both internal and external including outside of the EEA	20. Will individual's personal information be disclosed internally/externally in identifiable form and if so to who, how and why?	Individuals address will be revealed to the researcher to plan the interview, either by return in the post, over the phone, or in an email depending on how the individual chooses to make contact. It will not be revealed to anyone else. The council will not provide addresses to the researcher, contact will be voluntary between the service user and the researcher after a request has been on their behalf .	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	21. Will personal data be transferred to a country outside of the European Economic Area? If yes, what arrangements will be in place to safeguard the personal data?	No	
Consultation	22. Who should you consult to identify the privacy risks and how will you do this? Identify both internal and external stakeholders. *Link back to stakeholders on page 1.*	Consultation with council representative to start and discuss PIA, Consultation with Supervision team at University of Nottingham about ethics and PIA	

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
	23. Following the consultation – what privacy risks have been raised? E.g. Legal basis for collecting and using the information, security of the information in transit etc.	Privacy risks raised in consultation prior to the completion of this PIA have been addressed in this form and the creation of the study procedure, such as the move to secure anonymity for participants and safely store the data. The data will also be safely held in transit in a private vehicle which it will not be left in for an extended period of time or in a visible location.	Any further risks raised and not addressed in this PIA will be addressed through changes to the procedure of the study and through consultation as to the appropriateness of the measure with relevant council staff and university supervisors.

	Section 2d – Data flows continued and next actions		
	Question – the questions are designed to 'tease out' the particular privacy issues (see the guidance notes to this template for more information)	**Response –** if the answers are already documented anywhere e.g. in an Information Sharing Agreement you could attach that here	**What do you need to do next, by when and who will do it?** E.g. contact Information governance
Guidance used	24. List any national guidance applicable to the initiative that is referred to.	**N/A**	

Section 3 – Privacy issues identified and risk analysis

The risks should be reviewed and incorporated into the Information risk register, which is held on the Information Management One Space

Privacy issues identified such as the sharing of address from participant to researcher mitigated by allowing the participants to make contact with the researcher should they wish to take part. This therefore allows them anonymity from the council who will not know who has replied to the request, and from the researcher who will never receive any of their details if they do not respond to the invitation sent out.

All anonymization which is not completed in the initial recording will be completed in the analysis stage by the primary researcher. No other person will see the data before this stage has been completed so that names and identities are protected fully. Any risk of unauthorised access mitigated and prevented by the storage of data within a secure user account.

Potential risk to researcher conducting interviews in participants home has been mitigated by putting in place lone work agreements with colleagues which will either be a text or proximity based agreement depending on the location and feeling of safety from the researcher. Colleagues will not receive any information about the participant and are present in the area

to comply with the University's lone working policies and enhance the safety of the researcher.

9.4 Group 1 Information Sheet

This project looks at how people with physical disabilities use the internet, particularly people who receive support services from Nottinghamshire County Council.

It is based on an interview which will last no longer than an hour and a half. The interview will focus on the way we use technology every day and how we use the internet to plan our care support and activities. It will focus on how people interact with council services online.

The interviews will be recorded as audio only.

Interview content will not in any way affect the services you receive from the County Council.

Your data will be stored on a password protected drive in a secure facility and only for the duration for which it is required, in accordance with the Data Protection Act 1998. It will only be accessible by those directly involved in the research.

You may withdraw consent from the research at any time during or after the task for any reason without penalty by contacting me at the address or by the email listed below. If you do this, I will delete the information you have given me.

I will keep all the information anonymous when I analyse it. Anonymous information may also be passed on to Nottinghamshire County Council, which could be used to improve the way the Council provides online services in the future.

You may contact me at any time for information about the research or in relation to your consent, my address details are:

Alexandra Young

c/o PhD Office

Institute of Mental Health
University of Nottingham Innovation Park
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NG7 2TU

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9.5 Group 1 example transcript

P4 Interview

Interview in living room, P4 sat next to assistant, R on chair opposite. (UNSURE) indicate times when cannot make out what is being said, P4 has speech issues which are exacerbated when animated or during long sentences

R: Alright, brilliant. Right, it's on and going. So I guess the first one is always, do you mind introducing yourself a bit and saying why you were interested in the letter you got?

P4: Well, I'm NAME and I recently came to the UK from South Africa, so I'm new to the system. Basically, well I like helping people. (NOT SURE) People feel the need to help

R: I'm hoping this will help people at the minute. It's a bit vague at the minute the project. Alright, brilliant. So, how often do you go online?

P4: Quite often (laughs) I'm online all the time. I use it for everything. My voice is kind of off sometimes so communication wise it's easier for me so

R: okay

P4: And connecting to my friends in South Africa from home.

R: So what bought you to the UK?

P4: My disability. Things weren't happy in South Africa. If you had a disability you were kind of cast out. You weren't really important. So In our free time we were locked up in our houses, waiting for someone to take notice, and waiting to do something about it, but it never happened, so we said ok fine we'll take you here. So for the school we came here.

R: Nottingham's a funny place to end up

P4: We have family here as well in Nottingham

R: Ah

P4: My cousin lives here, she's lived here for four years now

R: ah okay.

P4: yeah I have family in London so, but between the two, we're more country people so...

R: yeah that makes sense. So would you mind talking me through what you'd normally do when you go online? SO kind of from when you log on, and then where you go from there, if there is a routine

p4: there's not really a routine everyday, but mostly I kind of do a lot of research, because that's what I do for my course, so I do a lot of research. But basically going on facebook, doing the normal kind of things. Communicating with friends, doing emails. Mostly emails, I've got a lot of emails, trying to get through all of that, plus doing some research, so basically it depends on the day. But yeah, I mean the internet for me is good for research,

R: okay, brilliant, what kind of stuff are you researching?

p4; different things to do with wheelchairs for wheelchair people, hotels, holidays they can go on, stuff like that

R: oh okay cool

p4: what equipment is out there for us, what countries are wheelchair friendly, which ones are not, passports, stuff like that. We can fix stuff (UNSURE), it's a lot of research

r: yeah I can imagine

p4 so erm it started with my dads project, and I kind of took over. He kind of pushed me to, like I didn't have a choice, but okay...

r okay, so have you come across the county council online?

p4: online? a couple of times, but i've never really looked through their website

r that's fair. it's erm, it's an unusual website. I think they just launched a new one, a couple of weeks ago,

p4 oh really, i've not seen that then

r: I actually only found out because there's a poster for it up near IKEA, one of the ones they stick on the lightposts

p4 oh wow (laughs)

r so there's one up on there for it. It's like a directory for phone numbers and stuff online, for I guess if you need the social services, anything like that, it's like a big yellow pages online.

p4 (UNSURE) but yeah, I never ring, (UNSURE) I don't normally go on their website unless I'm trying to talk to a specific person.

r: sorry, my notes are taking me a bit longer this morning, I seem to be having an issue with spelling. Having that thing where you write it down and go, no that is not right.

p4 (laughs)

r: I did yesterday too, there's some very interesting notes from yesterday when I just looked and thought, that is not what I meant to say. Excellent. Okay. So I guess if you're doing research for people do you use it to find support online? Do you use it to connect with other people with disabilities?

p4 erm. basically connecting with other people, trying to find services, but mostly products for wheelchairs because the main problem I have is that I don't have a nice wheelchair, this is a South African wheelchair, so if it breaks, no one wants to touch it, so... and what happens when I have no wheelchair, its fine. I literally had 3 different wheelchairs in South Africa, but here you need one wheelchair that can do everything. And to get onto buses and stuff like that is quite difficult, because it's so big, you don't want to hit anyone, like guys (laughs)

r: like please don't run anyone over

p4 like guys, if you're looking forward (UNSURE) ... going over bumps without hitting people and kind of getting over helping the person in the wheelchair (UNSURE) so we need a wheelchair that helps us to be independent, it can

change the way we look at things, so it's quite interesting to see what is out there

r yeah

p4 yeah there's wheelchairs that stand up, there's wheelchairs that let you go anywhere, but when you look at the price you go (hiss)

r oooh kay, not that one. I remember, unusually there was one on kickstarter a few months ago, a wheelchair that could go on hiking trails and stuff like that, and there was a lot of people, like this was a great idea but it costs as much as a car guys!

p4: yeah, could you just ... bring it down a just a little
r yeah, just a little bit, like great idea, can't afford it.

p4 you know you can get cars that wheelchairs fit in to so you can drive them, they're all a great idea but the price is so high you can't afford it

r yeah

p4 so can we use these inventions and make them more accessible to everyone, and that's kind of what I think would be sensible. So that's kind of what I am, I'm one of those people who says here's a problem, what's the solution? So it's about helping people and it was father daughter thing where we said can we find a solution to this please

r cool, excellent. I think we definitely need more actual solutions, rather than, this is a nice hypothetical but we can't do it. This would be great, but we can't afford it. Okay, so I guess one of the, there's a vaguer question on here about online identity. So how, if you think how you are online is different to how you are offline, and if you can, you know, that kind of thing...

p4 yeah I definitely am different online, it's confidence. I can contact people without them seeing the wheelchair so they think you're lovable and not you poor thing, like I have a wheelchair and they're like whaaat. So like in real life instead of imposing a view on me, I'm just a normal girl, talk to her and see where it goes. You can figure out how to be confident online, you want to show people know you really are, but you tell them you're in a wheelchair and they get all funny, but I'm just a normal person and they don't realise that. So I use the online profile to talk to them like a normal person. And then you kind of try to draw them out to show them I'm just a normal person in a wheelchair, but people don't see that so you have to (UNSURE) people don't really, like everyone is confident and I can go up to someone and talk to them, and I'm used to people coming up to me and being like, how do you do that, what do you have, why are you in a wheelchair, like can we not... I guess more online I can talk to people without being in the wheelchair, it's a freedom in a way.

r yeah

p4 which (UNSURE) but truthfully, all wheelchair people want to have that freedom, of talking to someone without being focused on what they see, and just talk to a person. But people aren't like that anymore

r that's really sad, but yeah, I guess on the internet is helpful for that, and hopefully, if you do it enough online, people might realise online and start being less odd in the street.

p4 yeah I mean, I try going out to people but they just give me a look on their face or (UNSURE) bye... In South Africa it was a lot worse because it's sort of a third world country and they didn't have the education and system that works, so people just kind of pushed you out the way, like I don't want to be near you just go away,

but I learned to deal with it, so... I'm very strong when I come to a normally they say oh my god here she comes everyone just act normal. But I mean because I'm friends (UNSURE) it was like, okay, we're cool. The other day, a guy bumped into me and called me an idiot, and I was like, okay, bye, and when he walked off other people were like, are you okay, are you okay, and it was like I'm fine (UNSURE, gesture?)

r yeah

p4 the wheelchair is just an object, it's not who we are. But people don't really see that. So I don't know, I think that it might take a while before people when you learn at a young age how to talk to wheelchair people, how to communicate with them, but till we get to that point we deal with it when we're there.

r yeah, it goes in circles. It's always easier to start with the kids when you're trying to change things. Eventually, eventually the parents catch on and stuff don't they, I think. Yeah, me and my housemate were talking about it last night, about mental health, that you have to teach children that it's, not, you know, a terrible thing, and then eventually it kind of catches up a bit.
p4 I mean I know a girl too, and she sort of talks to me, and no one understands, why this girl is talking to me, she doesn't see a wheelchair, she sees me as a person (UNSURE) people don't understand that. (UNSURE) I don't feel differently. She's only like four, but she understands that I'm a person so. And if you teach kids at that age, it'll be a lot easier won't it. Brining them up knowing how to communicate with a person in a wheelchair.

r yeah

p4 they don't even know how to communicate with you and look at you. Okay what is this person saying to this person. I mean she does all the talking for me because I get irritated often and it's just talk to her.

r okay brilliant. So I think we actually covered all of the questions pretty fast there, so I guess, what kind of thing do you... do you have a desktop, or a laptop, or a tablet

p4 a laptop, and a tablet

r nice

p4 I got a tablet from my cousin because I was using hers (UNSURE) thank you

r thanks, cool. No that's more so we know what the website needs to be designed for, to see how people are actually going on it because I guess...

p4 yeah because they have to get me because I can't always use the laptop, (UNSURE) so you get one that does both

r yeah, I quite like those

p4 (YAWN) When we were in school we were given a tablet and a laptop, but when you were trying to do an essay or something, I mean whaat.

r yeah, it needs to do both

p4 I couldn't write on it in class, so my teacher was like what are you doing? I I was like I'm waiting until I get home. them I could do school work and more work (UNSURE) but then it was like here we go

r yeah I've stopped taking my tablet into university with me, it's like a first

generation ipad, so it's getting to that point that apple things get to when they get old and it just starts to not work a lot of the time. And it's like you know what, it's easier just to not take it, rather than have it crash on you in the middle of a lecture, it can just stay at home, nope.

p4 yeah, in South Africa we have, had internet and stuff, so we were stuck at school, we had our laptops we had to pay for, but we had no electricity, so we were couldn't do our work, we were stuck you know? And when the teacher was looking, it was like, don't look at me I can't do anything about it. (UNSURE) It was worse when we were doing exams. You'd be halfway through your exam and the power would go off. Like. I'll have to do my exam all over again. Lovely.

r yeah that would've been bad, I never liked exams. We had a really weird exam set up in my first year at uni. We had a class called information skills, which was about how to use a computer; so like, this is how you use microsoft word, and this is what a computer desktop looks like. And everybody was like, but I'm at university, I've probably seen a computer desktop before. And part of the exam was to draw a desktop, in the exam paper. And then we found out the people who got extra time and stuff, they actually did their exam on a computer. And everybody was like, does that not defeat the point? So they'd all just put a screenshot in instead, going, this is what the desktop looks like, while I'm doing this, right now. Like this is really odd guys; here's how to use a computer, while you're doing your exam, on a computer. It was one of those, if you didn't know before, you were really stuck now. You'd be so stuck.

p4 when you've got to do your exam (UNSURE)

r yeah, it was a very odd university. It was a very, very odd course that one. Okay, so we've actually gone through all of the questions, so is there anything else you want to add, anything?

p4 is there anything you want to ask?

r (laughs) I guess you've spoken about pretty much everything I was going to ask you, you've kind of just picked up as its gone along. Erm so I guess, do you run a website?

p4 yeah, it's called (WEBSITE NAME), my dad kind of set it up, it's going to be a website for wheelchair people to find out everything about wheelchairs. So like, holidays, hotels, even restaurants, all over the world. So you can say, like, I'm going to Russia for a week, where can I go, what transport can I get.

r oh alright,

p4 a website to help people get on, and see what can you do. And showing you can do it anyway. My dads really kind of, evolved it, so I'm here doing all the research, and he's saying, do that, do that. Okay so I'm doing my own business on the side, so there's two businesses whilst going into school in September, and I'm like (gestures)

r that's pretty intense

p4 what have I done? But I don't stop, I have to do everything before I can. We wanted to, on April fools day, which is my dads happy day (UNSURE) okay. But yeah, my dad's very involved with all of that (UNSURE) but you have to do all the research, but that's all the hard work (UNSURE) So between my dad and that (UNSURE) I don't think he realises how big it is, so, because apparently there's 60 million wheelchair users in the world. So I'm like (gestures) okay, 60 million, I'm not going to get through that, but okay. Dad's like, well you're going to have people working for you but (UNSURE) but it keeps me out of trouble

r well, yeah (laugh)

p4 because I kind of grew up in the company on my own. Being on computers, and being on the internet kind of brought it up, doing everything. 'Cause I've got trophies for computers, and people said, you know what, you're good at what you do, just go with that

r yeah

p4 I needed help with (UNSURE) and different things (UNSURE) I men, I've learned to do word, powerpoint, excel, access, and then all of them. I'm not one of those people who says lets just seem what happens, go with it. When it came to the internet I kind of just went, wait, I can do whatever I want, when I want. It started with online gaming, because I was a typical teenage girl but I loved gaming, so it became a way to get on

r I've done that, which ones did you start with?

p4 I loved racing cars, and people would think I was a typical girly girl, with the hair and makeup, but when I won, I'd be like, I love racing cars and beating you! My brother kind of did it too, he had a ps3, so he used to do all the cheats and that (UNSURE) But I couldn't really go out, so gaming, online gaming, talking to friends online, now more on the phone for 24/7 on the wifi (UNSURE) but you kind of get used to it, going on facebook all the time, posting your stuff (UNSURE) when you go out and look and it's like I forgot my phone (UNSURE, very animated) do you want to go for coffee, okay

r no that's cool. I've had a bit of a break from online gaming the past few weeks

p4 I haven't gamed since, gosh, since I was 17 I think, when I was at school, we were there from about 7 in the morning till about 4 in the afternoon, I just kind of didn't have time, you'd get back and be like, urgh I have homework. And by the time you finish, you're ready to go to sleep

r yeah that's why I've stopped. I had one of those fun moments, that I didn't really think happened online, because I don't normally use a microphone when I'm online, and I was on dungeons and dragons online, and we were in the middle of a thing, and about halfway through, somebody turned round and went oh my god, there's a girl in the group. And it was like, yes? We've been on for 3 hours, how have you only just noticed?

p4 oh my god

r what whaaat? And then it was like, well I'm going now, also there's a massive time difference, you're in America, and I didn't think this really happened online, I thought it was like a myth. Like no no, great, well I'm going now, you're being ridiculous.

p4 yeah they did that to me once, like oh my god it's a girl, like what? I'm a normal person doing normal things. They're like how do you do those things? Well just like you, and now I'm not helping you, sort it yourself, bye

r yeah, bye..

p4 they got irritated with me because my group kind of took over their group and they were like who are you, and I said I'm a girl, that's what you told me, I'm a girl. (UNSURE) it should be everyone is equal, if everyone was equal, life would be easier

r yeah, it would

p4 but noooo, boys are much stronger than girls, and girls should paint their nails, and wear high heels. I hate high heels. I'm such a sneaker girl, like these ones

r oh yeah, for sure. I've got converse.

p4 (UNUSRE) it's such a dumb world

r yeah definitely. I've asked everything I was going to

p4 I'm glad to help

r It's been really interesting, it's been really useful, so I'm gonna turn this off, I think...

END

9.6 Group 2 questionnaire information and consent page

Who can take part?

If you live in the UK, are over 18, and were diagnosed with dementia before the age of 65, or if someone in your family, or someone you care for/assist was, you can take part in this project.

Why take part?

The aim of this research project is to understand how people with working age dementia (diagnosed before the age of 65), and their family members are accessing and using the internet. The aim is to shine a light on your experiences, and the responses you provide will be extremely valuable to the project. These answers will allow the researcher to better understand the needs of your group on the internet, which can then be used to inform service design for local authority services and academics.

How long will the questionnaire take?

This is a relatively short questionnaire and should take around 10 to 15 minutes to complete.

What happens after I've agreed to take part in the questionnaire?

At the end of this information section there is a tick box next to the statement 'I agree and understand the information and consent to take part in this study'. Please tick the box to provide an electronic signature and click next to start the questionnaire.

Once you have completed the questionnaire it will be submitted to the online system where the results will be analysed by the primary researcher for insights.

What about my privacy and confidentiality?

Your responses will be completely anonymous and will only be viewed by the researcher and their supervisors at the University of Nottingham. The data will be stored securely on the host website (Bristol Online Surveys) in the researchers account and on secure research storage within the University. Data is stored in line with the Data Protection Act 1998, and the University Ethical Conduct Policy.

The data you provide - including anonymous quotations - may be used in published writings or conference materials as part of the PhD writing process. No identifiable data will be used and participation will remain entirely anonymous.

If I agree to take part now, can I change my mind?

Yes, participation is entirely voluntary and you are free to stop completing the survey at any time. If you close the browser window at any stage of the questionnaire your data will not be saved. You are free to complete the questionnaire at another time if you choose to withdraw.

Once you have completed the survey, your answers will be anonymous and cannot be withdrawn.

Who developed this questionnaire?

This questionnaire was developed by Alexandra Young, a PhD student at the University of Nottingham. This questionnaire will provide background information in the writing of the thesis project.

It has been reviewed and approved by The Department of Computer Science Ethics Committee, University of Nottingham.

Will I be able to get in touch with the research team?

Yes! If you have any questions about this questionnaire, please get in touch with Alex Young on alexandra.young@nottingham.ac.uk

I agree and understand the information above and consent to take part in this study

9.7 Group 2 questionnaire outline

WAD questionnaire

Page 1

Working age dementia is a term used for a dementia first diagnosed when the person is under 65. It is also called early onset or young onset dementia, but all three refer to the same diagnosis.

Please select one of the following options

Were you diagnosed with working age dementia

y

Are you assisting someone who has been diagnosed with working age dementia

y

Are you a family member or relative of someone who has been diagnosed with working age dementia

Y

Please click next to continue

Page 2

Age

18-29 30-49 50-65 66+

Gender

Female
Male
Other (text box)

Page 3

Age of the person diagnosed with dementia

18-29 30-49 50-65 66+

Gender of person diagnosed with dementia

Your age

18-29 30-49 50-65 66+

Your gender

Page 4

Age of the your friend/relative who has been diagnosed with dementia

18-29 30-49 50-65 66+

Gender of person diagnosed

Your age

18-29 30-49 50-65 66+

Your gender

Page 5

At what age were you diagnosed with dementia?

(text box)

Page 6

At what age was the person you are assisting diagnosed with dementia

(text box)

Page 7

At what age was your friend/relative diagnosed with dementia?

(text box)

Page 8

Were you active online before you were diagnosed with dementia?

For example, did you have a social media account, use emails, or do banking or shopping online

Y / N

Page 9

Was the person you are assisting / person you know active online before they were diagnosed with dementia

For example, did you have a social media account, use emails, or do banking or shopping online

Y / N

Page 10

Was your friend/relative active online before they were diagnosed with dementia?

For example, did you have a social media account, use emails, or do banking or shopping online

Y/N

Page 11

After you were diagnosed with dementia, did you look for support and information online?

y/n

What kind of support/information did you look for?

Support for Family

Support for Yourself

Financial information and support

Legal information and support

Social services

Other (text box)

Did not look – was there a particular reason why not? (text box)

If you did, where did you look? (text box)

Page 12

After the person you are helping was diagnosed, did you look for support and information online?

Y / n

What kind of support/information did you look for?

Support for them

Support for family

Support and information for yourself

Financial information and support

Legal information and support

Social services

Other (text box)

Did not look – was there a particular reason why not? (text box)

If you did, where did you look? (text box)

Page 13

After your friend/relative was diagnosed, did you look for support and information online?

Y / n

What kind of support/information did you look for?

Support for them

Support for their family

Support and information for yourself

Financial information and support for them

Legal information and support for them

Social services

Other (text box)

Did not look – was there a particular reason why not? (text box)

If you did, where did you look? (text box)

Page 14

How often do you go on the internet

0-5 hrs a day 6-10 hrs a day every day of the week
a few days a week a few times a month once a month
less than once a month never

Is this more or less than before?

More/ less/about the same

Page 15

How often do you assist them on the internet?

0-5 hrs a day 6-10 hrs a day every day of the week
a few days a week a few times a month once a month
less than once a month never

Is this more or less than before?

More/ less/about the same

Page 16

How often do you assist them on the internet / do you go on the internet for related information

0-5 hrs a day 6-10 hrs a day every day of the week
a few days a week a few times a month once a month
less than once a month never

Is this more or less than before?

More/ less/about the same

Page 17

Do you use the internet to access any of the following? (please tick all that apply)

- Social media (facebook, twitter, tumblr, linkedin etc…)
- Support networks for your diagnosis (online groups, forums, facebook pages etc…)
- Email services (gmail, Hotmail etc)
- Shopping services (Amazon, online groceries and others)
- Financial services (online banking)
- Local authority or government websites (information on financial aid or benefits, housing and technology adaptations, accessible travel and locations)
- Information related to your diagnosis
- Online games
- Other (general browsing etc…)

How do you access the internet? Please tick all that apply

Desktop pc/laptop/tablet/phone/other devices (games consoles, other mobile devices)

Page 18

Do you assist the person diagnosed in using the internet to access any of the following? (please tick all that apply)

- Social media (facebook, twitter, tumblr, linkedin etc…)
- Support networks for their diagnosis (online groups, forums, facebook pages etc…)
- Email services (gmail, Hotmail etc)
- Shopping services (Amazon, online groceries and others)
- Financial services (online banking)

- Local authority or government websites (information on financial aid or benefits, housing and technology adaptations, accessible travel and locations)
- Information related to their diagnosis
- Online games
- Other (general browsing etc…)

How do you access the internet? Please tick all that apply

Desktop pc/laptop/tablet/phone/other devices (games consoles, other mobile devices)

Page 19

Do you use the internet to access any of the following? (please tick all that apply)

- Social media (facebook, twitter, tumblr, linkedin etc…)
- Support networks for their diagnosis (online groups, forums, facebook pages etc…)
- Email services (gmail, Hotmail etc)
- Shopping services (Amazon, online groceries and others)
- Financial services (online banking)
- Local authority or government websites (information on financial aid or benefits, housing and technology adaptations, accessible travel and locations)
- Information related to their diagnosis
- Online games
- Other (general browsing etc…)

How do you access the internet? Please tick all that apply

Desktop pc/laptop/tablet/phone/other devices (games consoles, other mobile devices)

Page 20

Do you think your diagnosis has changed how you use technology and the internet?

Yes/no/somewhat

How?

Do you think your diagnosis has changed what content you look at online?

Yes/no/somewhat

How?

Page 21

Do you think the diagnosis has effected the way the person you are assisting uses the internet?

Yes/no/somewhat

How?

Do you think their diagnosis has changed the content you look at online?

Yes/no/somewhat

How?

Page 22

Do you think the diagnosis has effected how you use the internet?

Yes/no/somewhat

How?

Do you think their diagnosis has changed the content you look at online?

Yes/no/somewhat

How?

Pages 23/24/25

Are there any further comments or feedback you would like to leave

(text box)

Page 26

Thank you for completing this questionnaire, if you have any questions please get in touch at Alexandra.young@nottingham.ac.uk

Question flow

Y to WAD: 1, 2, 5, 8, 11, 14, 17, 20, 23, 26

Y to assisting: 1, 3, 6, 9, 12, 15, 18, 21, 24, 26

Y to relative: 1, 4, 7, 10, 13, 19, 22, 25, 26

9.8 Group 2 interview ethics and protocol

9.8.1 School of Medicine outcome

The University of Nottingham

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Investigators : Tom Dening and Alex Young

Title of study: Online services and support for younger people with dementia

Duration of study: Until September 2018

Ethics reference number: 237

Wednesday 14th June 2017

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application, and adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved. If any amendments to the study are required, an amendment should be submitted to the committee for approval.

David Daley (Professor)

Co-Chair of DPAP Ethics Subcommittee

Amanda Griffiths (Professor)

Co-Chair of DPAP Ethics Subcommittee

9.8.2 School of Medicine Protocol

Short title: ***Online services and support for those with early onset dementia.***

FMHS REC reference:

Study Sponsor: University of Nottingham

Funded by: ***Horizon Centre for Doctoral Training at the University of Nottingham (RCUK Grant No. EP/L015463/1) and by the RCUK's Horizon Digital Economy Research Institute (RCUK Grant No. EP/G065802/1)***

STUDY PERSONNEL AND CONTACT DETAILS

Sponsor: University of Nottingham

Chief investigator:
Professor Tom Dening,
Institute of Mental Health
University of Nottingham Innovation Park
Triumph Road
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Phone: 0115 8230421
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Co-investigators:
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University of Nottingham Innovation Park
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Study Coordinating Centre:
Department of Psychiatry & Applied Psychology
Institute of Mental Health
University of Nottingham Innovation Park
Triumph Road
Nottingham, NG7 2TU

SYNOPSIS

Title	An ethnographic approach to understanding the significance of an existing digital presence for service use by people diagnosed with working age dementia and their families.
Short title	Online services and support for those with early onset dementia
Chief Investigator	Prof Tom Dening
Objectives	To explore the factors which influence the use of online services and support following the diagnosis of early onset dementia in a family setting.
Study Configuration	Exploratory study based on qualitative analysis of interview and observational data conducted with people with early onset dementia, their family and carers. Single centre, with interviews conducted in participant's homes, study of responses around internet use following a diagnosis of early onset dementia in a family setting.
Setting	Interviews to be conducted in participants home or location of choice
Sample size estimate	We aim to recruit 15-20 people diagnosed with early onset dementia and their families, with an average of 3 family members expected per person diagnosed
Number of participants	45-60 including families
Eligibility criteria	Index participants will have been diagnosed with a dementia before the age of 65 Have been diagnosed for less than 5 years. Have capacity at beginning of study Be living at home with family at outset of study (can be spouse/parents/children) Family members also willing to consent and participate. Adequate verbal communication skills and hearing. Participants are English speaking.

Description of interventions	A one to one and a half hour interview set up in a time span appropriate to the patient and their family. 2 interviews carried out 4 -5 weeks apart,
Duration of study	Interviews will take place four to five weeks apart. With time allowed for recruitment, the interviews will take place from May/June 2017 to January 2018, with recruitment taking place between May and September 2017.
Methods of analysis	Qualitative methods, thematic and content analysis of interviews.

STUDY BACKGROUND INFORMATION AND RATIONALE

In 2014, the Alzheimer's Society estimated that 856,700 people would be diagnosed with dementia by 2015, with this number continuing to increase annually. Of this group, around 43,000 will have a diagnosis of working age dementia, a diagnosis received before the age of 65 (Adams, 2014). Awareness of this condition is growing, and supported with connections made through social networks and blogs, groups are growing to support people diagnosed with working age dementia and their families while also spreading information about the condition to others, such as Dementia Diaries and the dementia friend initiative. Research has shown that continuing daily activities can be beneficial to the wellbeing of the individual diagnosed, such as the ability to keep their job, or continue to walk to dog and attend social events("Dementia Diaries - Home," n.d.; Öhman A et al., 2001; Roach et al., 2012). By maintaining the health and wellbeing of the diagnosed individual, this is often shown to have a positive effect on the health and wellbeing of carers.

With the internet becoming increasingly part of everyday life, its continued use should be assumed for people diagnosed and their families. It can provide a significant amount of information and support for both the individual and their family, such as access to relevant support circles. This is alongside the daily management tasks online, such as managing an online presence on social networks or through email, online banking, or accessing information and services needed. A number of people diagnosed with working age dementia have become present on Twitter and other blogging sites, sharing their daily experiences of trying to 'live well' with dementia, as well as sharing

links for support services and condition related information. This illustrates the need for research into this area and to assess the impact of this online information on individuals and their families following a diagnosis of working age dementia.

As well as NHS services, such as the Working Age Dementia Clinic in Nottinghamshire, people with working age dementia often access support through voluntary sector groups, such as those set up and run by the Alzheimer's society. In Leicestershire, the Alzheimer's Society provides groups specifically for younger people diagnosed with a dementia, and another for their carers.

It is hoped that research into this area might highlight information seeking behaviours which can be supported by services in the future and encourage a discussion of personal data management, and its place in an advanced care plan, to support the daily lives of people with working age dementia.

STUDY OBJECTIVES AND PURPOSE

PURPOSE

With access to services being located primarily online, and the increased use of the internet in managing day-to-day life, the aim of this study is to understand how people with working age dementia are using these services and continuing to access the internet over a period of 3-4 months while living with a diagnosis.

PRIMARY OBJECTIVE

The primary object of this study is to see how people diagnosed with working age dementia access information and services, and how this fits into their daily routines and care plans.

SECONDARY OBJECTIVES

The secondary objective of this study is to see how the diagnosis of working age dementia affects the family dynamic, and how this shapes to facilitate online interactions and identity, such as the management of online banking and other services, email or social networks, for example. This will allow for a deeper understanding of how working age dementia impacts information seeking behaviours and service access in the longer term.

STUDY DESIGN

STUDY CONFIGURATION

This study is an interview based study, with recruitment taking place through support and social groups for younger people with dementia and carers groups. Interviews will take place in the participant's homes, after initial meetings and a chance to ask questions at a group meeting. Participation will last between 3-4 months with the second interview following approximately 4-5 weeks after the first, but longer if needed. By including a follow up interview with the person diagnosed and their family it is hoped that there will be a greater build-up of information, around service access and support finding behaviours online, and if anything changes over this time period.

STUDY MANAGEMENT

The study will be carried out by the student researcher as part of a PHD thesis project, under the supervision of Tom Dening and Chris Greenhalgh.

The Chief Investigator has overall responsibility for the study and shall oversee all study management with support from the student researcher.

The data custodian will be the Chief Investigator. The other investigators at the University of Nottingham and the student researcher will have access to the data during the project. Personal, observational and interview data will be kept securely on a password protected computer.

The student researcher will be supported in the preparation for interviews by the supervisors, who will also be available for advice, should any problems arise.

DURATION OF THE STUDY AND PARTICIPANT INVOLVEMENT

Study Duration:

Enrolment into the study will take place during the second half of 2017. The study will run for approximately 6 months, closing in the first quarter of 2018.

Participant Duration:

Each participant family will take part in 2 interviews over a 4 month period, with each interview taking around an hour to an hour and a half.

After this 4 month period, there is potential for follow up interviews, but active involvement will cease when the last interview has been conducted by the end of the first quarter of 2018.

End of the Study

The end of the study will be the last interview of the last participant.

SELECTION AND WITHDRAWAL OF PARTICIPANTS

Recruitment

Potential participants will be approached at support or social group meetings specifically for younger people with dementia, e.g groups for people with dementia under 65. At these meetings the student will introduce the research project and invite volunteers to participate, at which time letters reiterating study details, as well as providing contact details will be given out to interested parties. If the family member is also in attendance and also wishes to take part, an interview date will be set up, at which time consent will be taken from those wishing to be involved. Participants will be approached at meetings the student has been invited to attend by the co-ordinator to give an introduction to this research project.

"In addition to registering the study on Call for Participants, we will also be using Join Dementia Research (JDR) as a recruitment tool. This is an online self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research.

The purpose of JDR is to allow such volunteers to be identified by researchers as potentially eligible for their studies. Researchers can then contact volunteers, in line with the volunteers' preferred method of contact, to further discuss potential inclusion.

JDR is funded by Department of Health working in partnership with the charities Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society and is Health Research Authority (HRA) endorsed. The online service and all associated documentation, methods of contacting volunteers and handling of data, were reviewed by a specially convened HRA committee which included experts in research ethics, data protection and information governance. Formal endorsement was issued by the HRA in a letter dated 20 May 2014."

Participants will not be expected to decide on their participation immediately, owing to the necessity of discussing it as a family. Index

participants and their family will be approached at the same time about the study and provided with information and contact details if they have any further questions. It is assumed that index participants will attend the clinic with a family member, or potentially carer, who would be provided with the information and contact details. However, if this is not the case and a potential participant is interested, information sheets would be available to take be to discuss with family, and contact details provided for any follow up questions. As it is unlikely that all family members will attend the clinic together, and the timing for participation is likely to be during an emotionally trying time for the family as a whole, it is expected that this decision to participate could take a couple of weeks, and up to a maximum of 2 months.

Informed consent will be taken from all participants by the student researcher. Participants will be provided with an information sheet and consent form. The information sheet is available in an easy read format if needed, for example if larger print is needed, for younger children or teenagers, or for people who self-identify as struggling with the language used in the main consent sheet. . Participants will have the opportunity to ask any questions while talking through the forms with the researcher. Two copies of the consent forms will be signed by the participant and the researcher, with one copy retained by each party.

It will be explained to the potential participant that entry into the study is entirely voluntary and that their treatment and care will not be affected by their decision. It will also be explained that they can withdraw at any time but attempts will be made to avoid this occurrence. In the event of their withdrawal it will be explained that their data collected so far cannot be erased and we will seek consent to use the data in the final analyses where appropriate.

Translation services and interpreters will not be used at the start of the study as an understanding of English and no impairment to verbal communication are aspects of the inclusion criteria. Participants who do not fit this at the recruitment stage will not be included in the study. This is due to the length of the project and the difficulty in finding translators for this period of time for interviews taking place in an individual's home. It is also in part due to the academic background and experience of the student who feels this would be an issue in developing rapport and recruitment.

It is however recognized that as the index participants dementia advances during the year, there may be a greater need for translators or interpreters if English was the index participant's second language. In which case the participant's ability and desire to continue in the study will be assessed, at which time services will be found in order to

facilitate participation, or the participant will be withdrawn from the study from that point forward.

Eligibility criteria

Inclusion criteria

Index participants will have been diagnosed with a dementia before the age of 65

Have been diagnosed for less than 5 years.

Have capacity at beginning of study

Be living at home with family at outset of study (can be spouse/parents/children)

Family members also willing to consent and participate. Children under 18 must have parental consent and be willing to provide assent to take part.

Family members have adequate communication and hearing skills

Family members have capacity to consent for themselves and children

Children under 18 willing to provide assent to take part

Participating Children are over 13

Family members are English speaking.

Adequate verbal communication skills and hearing.

Participants are English speaking.

Exclusion criteria

diagnosis after the age of 65

diagnosis not confirmed as a dementia

no capacity to consent at the outset of study, or loses capacity to continue during study.

other comorbidities which may impact ability to consent and participate in the studies such as learning difficulties or advanced physical degenerative conditions

living alone or in assisted living facilities at the start of the study

verbal communication skills lost or significantly impaired.

family members do not wish to participate.

Expected duration of participant participation

Study participants will be participating in the study for approximately 4-5 months.

Participant Withdrawal

Participants may be withdrawn from the study either at their own request or at the discretion of the Investigator. The participants will be made aware that this will not affect their future care. Participants will be made aware (via the information sheet and consent form) that should they withdraw the data collected to date cannot be erased and may still be used in the final analysis.

Informed consent

All participants will provide written informed consent. The Consent Form will be signed and dated by the participant before they enter the study. The Investigator will explain the details of the study and provide a Participant Information Sheet, ensuring that the participant has sufficient time to consider participating or not. The Investigator will answer any questions that the participant has concerning study participation.

Informed consent will be taken from all participants by the researcher. Participants will be provided with an information sheet and consent form, written in an easy to read format. Participants will have the opportunity to ask any questions while talking through the forms with the researcher. Two copies of the consent forms will be signed by the participant and the researcher, with one copy retained by each party.

Separate consent forms are available for the individual diagnosed and other adults, and the parent/guardian of any children, with an assent section for children. Information sheets are also available for these groups, with those written for children in an easy to read format.

It will be fully explained that taking part is entirely voluntary and will not affect any treatments or support that the individuals may receive.

Consent is taken to last the duration of the study at the initial meeting when consent is taken. This will be the procedure for family members who may not be present at the initial meeting and become involved after this stage. In the event that the index participant loses capacity during the study, continued participation will be discussed with the rest of the family. If the rest of the family wishes to continue taking part in the study, the index participant would be withdrawn from the study and

the rest of the family members would continue to take part. Should they not wish to continue, they will be withdrawn from the study, and the data gathered up to that point being included in the study for analysis. If there is dispute amongst family members over participating after the withdrawal of the index participant, the family will be removed from the study in an attempt to mitigate against family conflict.

STUDY REGIMEN

When participants have agreed to take part the initial interview will take place in the participant's home, or a location of their choice, such as memory café.

The initial interview will be used to discuss the participants existing support and information seeking behaviours related to their diagnosis, such as sources of information, peer support, and how they may have found the group they were recruited through. It will also be used to gain an understanding of how the participants conceive the idea of digital footprints and what sources that might entail, and how the use of social media, forums, online banking or shopping, and other online activities fits into their plans for the future.

Following on from the initial interview, at which time consent will be attained, a second interview will be held with each participating family, both with individuals and as a group, about the impact of the diagnosis of working age dementia, and also about information and support seeking behaviours online. The researcher will not be directing participants to information online, and the interviews will focus solely on what has been found without intervention. This second interview will take place 4-5 weeks after the first, and follow up on the topics raised in the initial interview. This will particularly focus on if there has been changes in the sources of support and information, or if additional though has been given to the integration of online activities into future care planning. It will also focus on if the participant's online activities, both index and family members, have changed during the period since the initial interview and potential reasons why if this is the case. Some observations and notes will be taken through each of the interviews in order to give greater context to the interview, and also to record key points of interest or topics to be avoided. No interview schedule has been written at this stage, and will be worked out with each family on a case-by-case basis to best fit around existing commitments. The interviews will be conducted as a group initially, but the follow up interview may be conducted individually if appropriate.

Interviews will be audio recorded and transcribed in order to anonymise the data for analysis in NVivio. The notes taken in interviews will be typed up in addition to the transcripts and used as data during the analysis stage. All identifiers will be removed from the transcripts. The data will be stored securely in the student office at the

Institute of Mental Health at the University of Nottingham under the supervision of the Chief Investigator.

Compliance

Compliance will be defined as a willingness to take part in the interviews for the study, and providing a safe environment for these to take place. Should participants not appear willing to take part, there would be a discussion with the participants to try and resolve these issues, which if not resolved may lead to withdrawal from the study. If this was the case the participants would be thanked for their time and informed that their existing data may still be used in the final write up of the study and the reason for withdrawal would be noted.

Criteria for terminating the study

The study would be discontinued if there were practical problems which prevented its continuation, such as losing all participants, or the researcher no longer being able to complete the study.

ANALYSES

Methods

Interviews with individuals with working age dementia and their families will be audio recorded and transcribed. Transcription will anonymise participants to protect their identities. Transcripts will be analysed in NVivo using thematic and content analysis, allowing for comparison across groups and time, and without requiring assumptions to be made prior to this stage. Any observation data and notes will be integrated at the analysis stage.

The analysis will be conducted by the student investigator and moderated by the supervisors.

Sample size and justification

Not applicable as this is an exploratory qualitative study

ADVERSE EVENTS

The occurrence of an adverse event as a result of participation within this study is not expected and no adverse event data will be collected.

ETHICAL AND REGULATORY ASPECTS

Subjects covered in the interviews are likely to cover personal experience, and may be sensitive in nature. These discussions may provoke strong emotions, which may cause distress for the individuals involved in the interview. Participants will be reassured that their discussions are confidential and will not be discussed outside of the interview setting, and any quotes they consent to be used will be fully anonymised for their protection. If the participants do become distressed in individual interviews, particularly for the individuals diagnosed with working age dementia, it may be necessary to share information about that with family members or carers. Participants will have the opportunity to stop or suspend the interview at any time, and strong emotional triggers will be recorded by the researcher to be avoided or more carefully dealt with in future.

Although there is not expected to be any adverse effects from participating in this study, it is possible that the interviews may elicit a strong emotional response from both the individual diagnosed and their family members. If this should arise, the researcher would try to accommodate and address this during the interview. However, if this was not the case, or an individual was becoming particularly distressed, the recording and interview would be stopped or paused, whichever the participant prefers. Should the participant wish, the researcher can leave until they feel happy to continue. If the distress is particularly pronounced, efforts will be made to inform appropriate parties, such as care providers or staff at the working age dementia clinic.

Details of the triggering event will be noted down as topics to avoid in future interactions, or as reasons for withdrawal from the study should that be the outcome.

As the research will be conducted in the participant's home, the researcher will adhere to the University Of Nottingham lone working policy by either ensuring another staff member is in the area for support, or remaining in contact with a designated individual for safety. This individual will know where the researcher is going and will be contacted on arrival, and when leaving by phone or by email depending on individual preference.

ETHICS COMMITTEE AND REGULATORY APPROVALS

The study will not be initiated before the protocol, consent forms and participant information sheets have received approval / favourable opinion from the Research Ethics Committee (REC).

The study will be conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, 1996; the principles of Good Clinical Practice, and the Department of Health Research Governance Framework for Health and Social care, 2005.

INFORMED CONSENT AND PARTICIPANT INFORMATION

The process for obtaining participant informed consent or assent and parent / guardian informed consent will be in accordance with the REC guidance, and Good Clinical Practice (GCP) and any other regulatory requirements that might be introduced. The investigator or their nominee and the participant shall both sign and date the Consent Form before the person can participate in the study.

The participant will receive a copy of the signed and dated forms and the original will be retained in the Study records. A second copy will be filed in the participant's medical notes and a signed and dated note made in the notes that informed consent was obtained for the study.

The decision regarding participation in the study is entirely voluntary. The investigator or their nominee shall emphasize to them that consent regarding study participation may be withdrawn at any time without penalty or affecting the quality or quantity of their future medical care, or loss of benefits to which the participant is otherwise entitled. No study-specific interventions will be done before informed consent has been obtained.

The investigator will inform the participant of any relevant information that becomes available during the course of the study, and will discuss with them, whether they wish to continue with the study. If applicable they will be asked to sign revised consent forms.

If the Consent Form is amended during the study, the investigator shall follow all applicable regulatory requirements pertaining to approval of the amended Consent Form by the REC and use of the amended form (including for ongoing participants).

Consent forms will be treated as confidential documents and will be held securely in accordance with regulations. Consent form access

shall be restricted to those personnel approved by the Chief or local Investigator and recorded as such in the study records.

All paper forms shall be filled in using black ballpoint pen. Errors shall be lined out but not obliterated by using correction fluid and the correction inserted, initialled and dated.

The Chief or local Investigator shall sign a declaration ensuring accuracy of data recorded in the records.

RECORDS

Participating families will be assigned participant numbers, with individuals within the family being assigned numbers within that group so as to identify speakers in interviews, and signatories on CRFs. Index participants will be assigned a different number format to identify them in interviews and on forms, but still in keeping with the family grouping in order to prevent miss-assignment on forms and in the project dataset. The family participant number will be comprised of the first letter of the surname and the date of the initial meeting, with the name code and date separated with a dash; should there be two families with the same first letter, it would then be followed by a number in order to prevent it becoming easier to determine the surname, for example S1 and S2 rather than Sm and Su. Index participants will be assigned the suffix IP to identify them with the family unit and on forms as being the person diagnosed with working age dementia and approached for the study. Other family members will also be assigned identifying suffixes in transcripts and notes; spouses with an ‘s’, parents as ‘pm’ or pf’ for mother and father, and parents in law with ‘pilm’ or ‘pilf’ respectively. Children will be given the suffix ‘c’ followed by gender; ‘m’ or ‘f’, and a number to indicate age order if needed; 1 for oldest and so on. An example number for an index participant number is S1-21216IP for an index participant with the surname Smith and an initial meeting on the 12 December 2016.

CRFs will be treated as confidential documents and held securely in accordance with regulations. The investigator will make a separate confidential record of the participant’s name and Participant Study Number, to permit identification of all participants enrolled in the study, in case additional follow-up is required.

CRFs shall be restricted to those personnel approved by the Chief or local Investigator and recorded as such in the study records.

Records in this study will include audio recording and transcripts of interviews, and field notes and observations made by the investigator. Personal identifiers will be removed or redacted in transcripts and field notes through the use of participant numbers or pseudonyms. Field notes and observations will be held securely by the investigator and

separate from the CRFs to ensure surety of anonymization for the index participants and their families.

No access to clinical records of the participant or their family is required.

Source documents

Source documents shall be filed at the investigator's site and may include but are not limited to, consent forms, study records, field notes, interview transcriptions and audio records. A CRF may also completely serve as its own source data. Only study staff shall have access to study documentation other than the regulatory requirements listed below.

Direct access to source data / documents

The CRF and all source documents shall made be available at all times for review by the Chief Investigator, Sponsor's designee and inspection by relevant regulatory authorities.

DATA PROTECTION

All study staff and investigators will endeavour to protect the rights of the study's participants to privacy and informed consent, and will adhere to the Data Protection Act, 1998. The CRF will only collect the minimum required information for the purposes of the study. CRFs will be held securely, in a locked room, or locked cupboard or cabinet. Access to the information will be limited to the study staff and investigators and any relevant regulatory authorities (see above). Computer held data including the study database will be held securely and password protected. All data will be stored on a secure dedicated web server. Access will be restricted by user identifiers and passwords (encrypted using a one way encryption method).

Data held during transit will be surely held in one of two ways; if paper based note the data will be securely held by the researcher in a locked cabinet inside a locked office, and if digital, the data will be stored on a password protected drive on the university system, the password for which will also be securely held by the researcher. All digital data will be stored on the university drive which can be accessed remotely by the researcher using a secure login on a university laptop, removing the need for data to be stored on external drives. Fully anonymised transcripts will be uploaded to a secure file on the research drive, accessible only to the student and supervisors for this project.

Electronic data will be backed up every 24 hours to both local and remote media in encrypted format.

QUALITY ASSURANCE & AUDIT

INSURANCE AND INDEMNITY

Insurance and indemnity for clinical study participants and study staff is covered within the NHS Indemnity Arrangements for clinical negligence claims in the NHS, issued under cover of HSG (96)48. There are no special compensation arrangements, but study participants may have recourse through the NHS complaints procedures.

The University of Nottingham as research Sponsor indemnifies its staff, research participants and research protocols with both public liability insurance and clinical trials insurance. These policies include provision for indemnity in the event of a successful litigious claim for proven non-negligent harm.

STUDY CONDUCT

Study conduct may be subject to systems audit for inclusion of essential documents; permissions to conduct the study; CVs of study staff and training received; local document control procedures; consent procedures and recruitment logs; adherence to procedures defined in the protocol (e.g. inclusion / exclusion criteria, timeliness of visits); accountability of study materials and equipment calibration logs.

STUDY DATA

Monitoring of study data shall include confirmation of informed consent; source data verification; data storage and data transfer procedures; local quality control checks and procedures, back-up and disaster recovery of any local databases and validation of data manipulation. The Study Coordinator/Academic Supervisor, or where required, a nominated designee of the Sponsor, shall carry out monitoring of study data as an ongoing activity.

Entries on CRFs will be verified by inspection against the source data. A sample of CRFs (10% or as per the study risk assessment) will be checked on a regular basis for verification of all entries made. In addition the subsequent capture of the data on the study database will be checked. Where corrections are required these will carry a full audit trail and justification.

Study data and evidence of monitoring and systems audits will be made available for inspection by the REC as required.

RECORD RETENTION AND ARCHIVING

In compliance with the ICH/GCP guidelines, regulations and in accordance with the University of Nottingham Code of Research Conduct and Research Ethics, the Chief or local Principal Investigator will maintain all records and documents regarding the conduct of the study. These will be retained for at least 7 years or for longer if required. If the responsible investigator is no longer able to maintain the study records, a second person will be nominated to take over this responsibility.

The study documents held by the Chief Investigator on behalf of the Sponsor shall be finally archived at secure archive facilities at the University of Nottingham. This archive shall include all anonymised audio recordings, study databases and associated meta-data encryption codes.

DISCONTINUATION OF THE STUDY BY THE SPONSOR

The Sponsor reserves the right to discontinue this study at any time for failure to meet expected enrolment goals, for safety or any other administrative reasons. The Sponsor shall take advice as appropriate in making this decision.

STATEMENT OF CONFIDENTIALITY

Individual participant medical or personal information obtained as a result of this study are considered confidential and disclosure to third parties is prohibited with the exceptions noted above.

Participant confidentiality will be further ensured by utilising identification code numbers to correspond to treatment data in the computer files.

Such medical information may be given to the participant's medical team and all appropriate medical personnel responsible for the participant's welfare.

If information is disclosed during the study that could pose a risk of harm to the participant or others, the researcher will discuss this with the CI and where appropriate report accordingly.

Data generated as a result of this study will be available for inspection on request by the participating physicians, the University of Nottingham representatives, the REC, local R&D Departments and the regulatory authorities.

PUBLICATION AND DISSEMINATION POLICY

Data collected in this study will be used in the write up of a PhD thesis, and is intended to be used to write a submission for a peer review academic journal and conference at various stages of the project.

Participants will not be identified in any publications.

USER AND PUBLIC INVOLVEMENT

This study was designed with input from a representative of the Working Age Dementia Clinic in Nottingham. Questions and approaches for the interview are being informed by an initial project conducted as an online questionnaire and face-to-face interviews in order to refine questions for the initial meetings and interviews. The following interviews will be informed by themes that become apparent as the study progresses, allowing the participants to continually shape the direction of the study.

STUDY FINANCES

Funding source

This study is funded by Horizon Centre for Doctoral Training at the University of Nottingham (RCUK Grant No. EP/L015463/1) and by the RCUK's Horizon Digital Economy Research Institute (RCUK Grant No. EP/G065802/1)

Participant stipends and payments

Participants will not be paid to participate in the study. Travel expenses for participants will not be needed as they are making no additional journeys.

SIGNATURE PAGES

Signatories to Protocol:

Chief Investigator: (name)_____

Signature:_____

Date: _____

Adams, Beth

N.d. Dementia 2014 Infographic. http://www.alzheimers.org.uk/infographic, accessed May 22, 2015.

Dementia Diaries - Home

N.d. Dementia Diaries. http://dementiadiaries.org/, accessed March 8, 2016.

Öhman A, Nygård L, and Borell L

2001 The Vocational Situation in Cases of Memory Deficits or Younger-Onset Dementia. Scandinavian Journal of Caring Sciences 15(1): 34–43 10p.

Roach, P., J. Keady, and P. Bee

2012 “It”s Easier Just to Separate Them’: Practice Constructions in the Mental Health Care and Support of Younger People with Dementia and Their Families. Journal of Psychiatric & Mental Health Nursing 19(6): 555–562.

9.9 Group 2 Information Sheet

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

PARTICIPANT INFORMATION

Division of Psychiatry & Applied Psychology

School of Medicine, Faculty of Medicine & Health Sciences

Project Title: Online services and support for younger people with dementia

Researcher: [Name] Alexandra Young [e-mail] *alexandra.young@nottingham.ac.uk*

Supervisor : [Name] Prof Tom Dening [e-mail] tom.dening@nottingham.ac.uk

Ethics Reference Number: 237

This is an invitation to take part in a research study about how people with early onset dementias, and their families, are using the internet to find and access support and useful information after a diagnosis.This information is designed to tell you what it will involve.

Your participation is voluntary, and you may change your mind about being involved, or decline to answer a particular question. You are free to withdraw at any point before or during the study. Withdrawal does not require a reason.

What is the project about?

As moves are made to place access to social services online first, in line with other online services, such as banking, social networks, shopping and support networks, how younger people who have been diagnosed with dementia and their families are continuing to use and

expand on these services will become increasingly relevant. It is also important to consider not just how they are used now, in an early stage of diagnosis, but how they will continue to be used and managed in the future.

The aim of this study is therefore to see how people are accessing and using these online services, what else they are using the internet for and how that may help or impact their daily lives, and to ask people is they have thought about what will happen to their digital presence and access in the future when their dementia changes. This information will be used to assess how people with dementia and their families find information and support for their condition, and how they maintain the normal running of their online lives. Results from this study will be used to inform the development of online services and information sources, and also as a point of reference for the people who may be designing these services. They may also be used to create a set of guideline that can act as advice for how to plan what happens to online accounts and data in the future.

Who is being asked to take part, and why?

You have been invited to take part because you have experience in living with early onset dementia. You and your family members have been invited to take part to help researchers understand what support you need, and how you are finding out about the support and groups that are already out there.

What will I be asked to do?

If you chose to participate in this project, you will be asked to take part in two interviews, roughly two months apart. During these interview you will be asked to talk about your habits on the internet, and if they have changed, particularly with what you might be looking for online, and if you have found new groups to help with information about your diagnosis, such as the Alzheimer's Society Talking Point site. You may also be asked how you think it might change in the future, and what support you might want.

You may decline at any time to answer a particular question, or continue to participate if you no longer wish to without giving a reason. Withdrawing will not change the care and services you currently receive. .

Will the research be of any personal benefit to me?

The information you provide during your participation in this study will help us to understand how people diagnosed with early onset dementia and their families use the internet to access services and

information, how this helps, and what we need to know to inform the design of these services and support in the future

What will happen to the information I provide?

All information you provide will be anonymised and stored securely at the University of Nottingham. Copies of your signed consent form will be kept securely locked in a lockable cabinet, and interview recording will be stored securely on a password protected drive.

The audio recordings will be transcribed, and all personal details or references will be avoided or removed when they are transcribed. The recording will be transcribed by the researcher, or an approved transcribed, and the transcript saved on a secure university drive. The audio recording will be deleted after this is done. The transcript will be analysed by the researcher using Nvivo, a piece analysis software. We would like to be able to quote you in the thesis or publications and will ensure your anonymity is protected at all times. If you do not wish to be quoted, please let me know.

What will you do with the data?

The data you provide during this project will be used in writing up my PhD thesis, and potentially in publications written at the same time. If you want to know more about the project, or the final results of the project, please contact me at Alexandra.young@nottingham.ac.uk

At the end of the project, all raw data will be kept securely by the University under the terms of the Data Protection Act. The data will not be kept elsewhere.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the above address.

THANK YOU FOR YOUR PARTICIPATION

If you have any queries or complaints about this study, please contact the student's supervisor in the first instance. If this does not resolve the query to your satisfaction, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee (MS-DPAPEthics@nottingham.ac.uk, +44 (0)115 8232214) who will pass your query to the Chair of the Committee.

9.10 Group 2 example transcript excerpt

IV Interviewer

IP2-3P Participant 3 partner

IP2-3 Participant 3

IV Hopefully it will work. Okay, should be fine, I assume it will just tick along in the background.

IP2-3P That's fine.

IV Okay, so, I guess to start off, would you mind introducing yourself a little bit, going with why you were interested in taking part.

IP2-3P My husband was diagnosed with young onset Alzheimer's, finally diagnosed four and a half years ago. My sons and I persuaded him to give up work seven years ago because he was in danger of being performance managed out of work because he was showing enough symptoms. And as a family, the three of us decided we'd rather he left of his own volition.

IV Rather than being forced out.

IP2-3P Rather than being forced out, which is not the way you want somebody to remember their… So, IP2-3 left with his head held high. He wasn't aware, at that stage, that we thought he had dementia.

IV Okay.

IP2-3P So, he was 55 when we persuaded him to leave work. He's 62 now. I gave up work two and half years ago now to care for him full time. I did that because I worked at the Open University. I was head of the Department of Education. It involved me going into Milton Keynes four days a week and I realised some days when I got home, that something had gone wrong just after breakfast for IP2-3.

And he'd just been sitting on the settee waiting for me to come home, which could be anything up to 12 hours after I'd left him. And he was going downhill very, very rapidly. So, I decided to give up work. I rather pompously thought I could improve his quality of life and I also equally pompously think I have.

IV That's alright.

IP2-3P He started doing a lot more because I can help with some things that enable him to move onto the next stage and so on. And we do a lot of things. Obviously, he's got me to talk to during the day and it just made a huge difference.

IV Yes, there's no gaps, I guess. With care companies, there's been gaps in the day where people aren't here. So, what did IP2-3 do?

IP2-3P He was a local authority youth officer.

IV Okay, that's a pretty intense job.

IP2-3P And he started turning up to the wrong meetings with the wrong notes on the wrong days. You know, any permutation of that. Wrong day, wrong place, wrong notes, wrong person.

IV Yes, things that can kind of get skipped over for a while, and then people start to notice. Okay, so, was it something that you expected to happen? Has he got a family history of dementia?

IP2-3P His mum had dementia, not as young as he had. And his maternal grandfather had dementia, but not as young as he had. But young-ish. And they were both in their 60s.

IV Sorry, my handwriting is slow and horrible today because I've been typing a lot, so it's kind of gone a bit weird.

IP2-3P That's alright, I haven't got to read it.

IV That's true, that is the downside, when I have to translate my own notes later on. So, you kind of alluded to the fact that the diagnosis took a long time.

IP2-3P Yes, we'd been trying to get support from the GP. And the GP's first diagnosis was work-related stress and put him on antidepressants. He said he wasn't sleeping particularly well. They thought there might have been some workplace bullying, which I think there perhaps was related to this. They were starting to move him down the performance management route.

And if you only view that from the person being performance managed, it can look like bullying. I was aware of what they were doing because of the position I was in at work. I was performance managing people, so I could tell, yes, right, that's why.

IV Kind of see both sides.

IP2-3P Yes, I could see where it was going. So, the GP was convinced it's work-related stress, so we went in and said okay, he's given up work. He said, well we'll need to monitor it over the next six months, give it six months, it should work its way through the system and over those six months, he gradually got worse.

And then, they said, right, we need to, yes, accept this isn't workplace stress. I can't remember whether they gave him some CBT, I'm not sure they did, I think they had it as an option, but he didn't actually get that.

They then, because of his age, needed to do scans to check for tumours and did various. He had to be referred to a neurologist to check there wasn't a nerve-related thing because he had restless legs and things as well.

So, there were so many hoops that they had to go through. And then, eventually we got him referred to a dementia specialist. And they sort of said, well the only way we can say for definite is to do a SPECT scan. So, I said, can we do a SPECT scan then? And there was this sort of pause at the other side of the table and they said, I suppose so, yes.

We then got the SPECT scan. And that came back with the confirmation that he'd got young onset Alzheimer's, likely. Yes, because they can't confirm until after death, can they? It just took a very long time and even once they'd decided the next route was the dementia specialist, there was something like a three or four month waiting list to see him and then there's a couple of months before the SPECT scan comes through. Then it's a couple of months before you see the specialist again. So, you know, there we are, eight months.

IV Yes, it kind of piles up.

IP2-3P And then, at that point where he said, the scan shows, yes, there are some cold areas in the brain. That is a sign that there are bits of the brain that are atrophying. The radiologist thinks it is likely that it's Alzheimer's. So, because of your age, it's young onset Alzheimer's.

You need to understand the average life expectancy upon diagnosis is six to eight years, and we expect the last two years of that to be in an institution because you will have deteriorated so far. Any questions?

IV Nice and positive.

IP2-3P And that was the last time we saw a specialist.

IV Yes, that makes sense. It seems to be a really big issue with that, at the point of diagnosis, where they're just like, yes, this is pretty much it now. It's like that does not seem like a good approach, guys. And also, it turns out it's not really that accurate either. So, when confronted with that, did you then go away and do research into it yourself?

IP2-3P Yes.

IV Okay, so, where did you go for that?

IP2-3P I started off on the Alzheimer's society pages, read through their leaflets, followed up some of the reading that they had as references. This is where my academic background comes in of course. Did some research on various databases that I had available because I was still an honorary associate at the Open University, so I had access to their library, so I did one or two bits of reading.

I'm trying to think when I started following up the diet thing. He got involved in a piece of research, clinical research that was looking at Tau proteins and IP2-3 was involved in that for over two years.

So, in lots of ways, I sort of stopped doing much more research because some of my information came from them. When I'd noticed deterioration, they were saying, yes, this is in line with what we would expect. And we clearly take on any other drugs whilst he was on this trial. I can't remember whether it was two or three years. It felt like a very long time.

And I knew from the various commissions we were given that they were moving towards publication point. Their original licence was finishing. And so, I kept an eye and picked up the conference paper, where they said that it had actually failed. There was no evidence that these drugs were having any positive effect at all, which was interesting because IP2-3 perceived them to be having a positive impact. He felt better having been on them.

So, my concern was, when we lost the tablets, if that was purely placebo, he was going to take a real tumble. So, before I told IP2-3, I'd found out the trial was a failure, I tried to find out if there was something else I could involve him in so that he had, okay, that's failed, but look, we've got this.

And that's when I found out about the research by Dale Bredesen in America that looks at a dietary response. I found a nutritional therapist in Uppingham, who was prepared to support us in doing that. So, I then told IP2-3 about the failure of this trial and told him about this dietary thing that was a possibility.

We managed to finish the trial. We finished with them on the trial and started straight away on the dietary response. There was actually an improvement in his scores because they had to monitor him for so many months after he stopped the tablets. And in fact, his scores improved. They were quite surprised. So, if it's all down to placebo, it was a stronger placebo than they're telling us.

IV Yes, if it was having a positive impact, then either way kind of thing. How's the diet going? Do the dietary changes seem to be helping?

IP2-3P IP2-3 feels they are. It's actually, I found out about the dietary response initially, and then as I read more of his papers and so on, it's more of a protocol. It's more of a lifestyle change. So, it's dietary plus sleep plus exercise. And we realised that actually, some of this, IP2-3 had been doing while he was on the trial.

Because he's always done a lot of exercise because he used to go out cycling with our sons. And he'd kept his cycling up. So, the exercise bit, he'd already been doing. We just needed to do some of the dietary changes.

Yes, he is progressing downwards in some ways, but nowhere near as fast as I think anything you read would predict. And certainly, people locally say that they can't notice much deterioration. And I lost three and a half stone. I love it.

IV That's alright then, always a bonus.

IP2-3P I've been trying to lose weight for years. I can't do the whole hungry bit, so dieting, I just didn't manage it. You don't feel hungry in this.

IV That's good. That's brilliant. I actually think I was in a video conference with him a few months ago with somebody from New Zealand as well. And they're looking at a more holistic lifestyle

protocol that involves a kind of diet and exercise. And some vitamins and some elements of brain training in it as well. And that was an enlightening thing.

IP2-3P The brain training bit is the one bit that IP2-3 can't do because when we followed it up, the nutritional therapist went on and a couple of his training sessions, he came over and did a British tour for a while, she managed to get on some of his things and he thought IP2-3's Alzheimer's was too advanced to see it as very positive.

Because he almost says, you can cure Alzheimer's if you catch it in the early stages. And we've since, she got him as far as she could on the supplements, and then she referred us onto a doctor who could give slightly stronger supplements. And that doctor said a similar thing. He was in contact with Dale. And in a way, they're following IP2-3 as an interesting case of someone who's following it from further down the line.

That stage, it was too late for IP2-3 to take on brain training. Because I almost think he's got the PCA variant of Alzheimer's. We're waiting for a referral to London because it's all visual, visual spatial. So, he can watch a television programme on ancient Athens, and watch one on ancient Rome, and then he can sit and have a conversation with you about the difference between the philosophy in Greece and the philosophy in Rome and how that impacted on their buildings. He struggles to use a knife and fork.

IV Yes, that does sound more like the PCA variant. Yes.

IP2-3P So, brain training is the one piece he can't do.

IV Yes, that would not help. Okay, so, I guess, more of the rest of this is about kind of social media use for you, and IP2-3 as well, actually. So, when you were researching, did you also look for support online? So, did you come across Talking Point?

IP2-3P I did. And I have had a look at it a couple of times, but I found an awful lot of it was related to older people. And I think possibly because IP2-3's, as I now realise, again through doing a lot of research, that it might be more PCA than standard young onset. So many of the difficulties people were having, we weren't having.

Some of the difficulties we were having, where they were similar, they'd got a lot of other things. So, by the time somebody can't use a knife and fork very well, they're actually moving well, they're not doing this, they're not doing that. Whereas, IP2-3 is still an active young man.

IV Yes. So, what was on there wasn't applicable, really.

IP2-3P No. And I didn't have the patience to go through everything that something that might be, was one of the other issues.

IV Yes, that's fair. Do you use Facebook or Twitter or any of those?

IP2-3P I use Facebook and Twitter. Predominantly use Twitter for Alzheimer's related things. It started out as work and I didn't mix personal and work. So, Facebook stayed social. Twitter was work. And then, I became Facebook stayed friends etc., and Twitter moved towards politics stroke Alzheimer's because the two often, some of the things I feel strongly about that link to IP2-3's disabilities are political. So, I often, you know…

IV Yes, good to have a separate space for it.

IP2-3P So, I sort of do all of that on Twitter.

IV So, have you connected with other people through Twitter?

IP2-3P Yes, there's a couple of Twitter conversations. There's one on a Monday night. I usually join the one on the Monday night called Alz Chat.

IV Yes, they are. I'm normally ticking along on there.

IP2-3P So, I'm Biker Wise. I usually say something completely opposite to everybody else, but there we go. Sometimes, I'm just very quiet because it doesn't quite apply. And there's another one on a Thursday and I'm trying to… Diverse Alz.

IV Yes. I think I've taken part in that one like once.

IP2-3P It's not every week.

IV No. I think I've only caught it a couple of times.

IP2-3P And they are quite directed. They usually have three or four questions that they want to address. Whereas, Alz Chat is just a bit… They put up a topic and everybody has a free for all.

And I found some things on there, sometimes you say something, and somebody will pick up an undertone in your Tweet and you get a message or you get something. There's sometimes some advice on there. So, I think I've probably, other than the stuff on Dale Bredesen and I cannot remember how I ever got onto that in the first place.

I think most of the links I've then followed up have come through those Twitter links, where people have suggested publications, or they've said things like, do you know what, you should have had an occupational therapy assessment. I didn't know that. Yes, he's entitled to that. That should have happened. So, I sort of started following that up with the local authority.

IV Did there seem to be some confusion between the different areas, as to who gets told what, which is ridiculous?

IP2-3P I mean because when IP2-3 was first off work, I was also caring for my father-in-law who was local and was house-bound. Good time for a nervous breakdown, isn't it? So, I was in touch with a local authority and they sussed that I was looking after Bob.

And then, through the conversation, they realised I had IP2-3 as well. So, they gave me a carer's assessment very early on. And

they have been brilliant. We got some personal assistant hours and so on. But there are other ways in which they haven't been as good.

So, the person who looks after me is part of the carer's team, has tried to get IP2-3 a social services referral in his own right. They should have assessed what his needs are, and they won't do that. I had a telephone assessment of IP2-3's needs. He's never seen an occupational therapist.

We had somebody who came out to assess with the house, what's called a house MOT. She wasn't a qualified OT, and basically the two things that I had concerns about, she's paid for the work to be done.

IV Yes, it's quite hard. It does seem to be a bit of a, almost like a postcode lottery, as it's a, which councils will be helpful with which things?

IP2-3P But I would never have thought to follow it up, had I not…

IV Had somebody not said.

IP2-3P Yes, in that Twitter conversation.

IV Yes. Is that something you've found quite helpful then, the information sharing and stuff over that?

IP2-3P Yes. And there was one day I just had a complete meltdown. I can't remember what it was over. And I just walked out the door, got in the car, drove off to somewhere where I was just staring out at the countryside and just put on Twitter. I just walked out the door, driven to a stop, placed on the top of the hill. I can't do this anymore.

And within minutes, all the different people I talk to on Alz Chat were, okay, let's just stop. Before we go any further Christine, can you just tell me exactly where you are?

IV So, it's quite a supportive group. That's good. Yes, no that is good that even if the forums weren't helpful, you've found support with people elsewhere. That's a fairly big bit of this, about how people are going about finding support, whether it's in person, online, how you come across that network, whether or not it's a planned thing or it's like I found a chat and I've connected with people through that and moving forward. So, yes, some of these are, I guess, are standard. Do you use online shopping?

IP2-3P Yes, I do. I usually have at least one Sainsbury's delivery every week. I do buy most of IP2-3's supplements online because some of them come from all over the world. The standard Amazon stuff. Partly because I can't get out shopping very easily. So, yes, I do online shopping.

IV Okay. Would you say how you use the Internet has changed since IP2-3's diagnosis, in terms of what you use it for, if you're, I guess, using it slightly differently to before? So, are you doing online shopping more because you can't get out as easily now, or is it about the same just for slightly different things?

IP2-3P Supermarket shopping is probably about the same because I used to often do a big shop on my way home from work one night. But then, I used to do a top-up shop. And I used to get my father-in-law's delivered to him once he couldn't shop. And he used to get quite excited the day Sainsbury's arrived and the chap used to carry it in for him and he got to discover what I'd ordered for him that week.

Amazon type stuff, I suspect, A, there's more stuff that I'm ordering that I didn't used to because we're not quite eating the norm and the supplements aren't the norm. And some of it is because I can't get out to shop as easily. It's a mix of the two.

IV I don't know whether you will have come across this in your readings about early onset dementia, there's not a lot on computer use. And what there is mostly assumes that you then don't use it ever.

IP2-3P Right. We've tried to keep IP2-3 using the computer. He predominantly uses his iPhone. I'd like to get him on Android because I'm on Android. But he was on iPhone, so that's where he's got to stay because that's what he understands. And he uses Facebook, uses WhatsApp.

He has, in the last year, stopped using email, he just deletes everything. So, I had to start gradually getting his emails that were important sent to me. I'd just discovered he was just deleting everything. One of the major issues there is he's losing the ability to read. Reading is a real struggle for him. So, he just couldn't understand the email, so he just thought it was rubbish and deleted it.

He can no longer physically write, but he can still type. And he used to do something called weatherman. He did weather forecasting for fun, a hobby. We had the weather station on the top of the house. And when he first gave up work, he used to do a weekly weather forecast for Uppingham.

And then, I discovered that had sort of died a death. So, one of the personal assistants that we have come in when I go to Pilates sits with him and on a Monday morning, they do the weather forecast. And she sits, and she does the writing of the notes, as he's predicting from the MET Office charts and the weather station. He predicts what the weather's going to be. She writes it down. And then, she sits here while he types it up. But he uses the full-size keyboard and he's not accurate enough to type on the iPhone.

IV Although, I think a lot of people start to have that issue, don't they?

IP2-3P Yes, I mean that's why I've got a Note, you get a stylus, not as unique. So, they sit and do that on a Monday. And actually, his typing is improving a little bit.

IV That's good. Okay, so, that does lead me to one of the main aspects of this, which is the digital legacy aspect of the research, which would be… So, you've spoken about emails and you've

transitioned them to you, do you and IP2-3 have a plan for what would happen with his Facebook account? Say, would you be able to access it on his behalf, or would he want you to?

IP2-3P I wouldn't at the moment. It's one of those, I think, at the moment, I have access to his email account. So, if I'm expecting something to come through I can keep an eye on it. And that's partly how I've managed to move things across.

I do know what all his passwords are on Facebook actually, so I could just go on and pretend I was him. Legally, I need to get something sorted. I've got power of attorney, you see, so, that's already… He has no idea what his passwords are. I've got them all on a list upstairs.

00:32:18

IV I'm assuming that you would do the online, if you did online banking, that would be something you would do. So, did he do that previously? Is that something that you've transitioned over?

IP2-3P He's never done online banking. He had an online banking account for a long time, but he would always go into the bank to do whatever he needed. And at least, initially, he kept the books and did that and went in and physically did it. And then, gradually, he got that he couldn't cope with that because again, the PCA, we now realise numbers is one of the things that goes.

So, he still has a bank account, but both of our bank accounts are joint. I have one that I look after completely. And that's our main one and we have another one that is normally IP2-3's. That's the one he has a card to if he wants to go and draw out £200 and throw it in the air in the market square, that's his choice. But I look after it, if you know what I mean.

IV Yes, that makes sense.

IP2-3P The same way he has a credit card. But if he wanted to go out and buy something expensive, he has the ability to do it. Of course, it does mean, unfortunately, you can never change the PIN number. Because as soon as you change the PIN number, he will never learn the new one. So, it's a matter of, is it more secure to leave the PIN number the same and he remembers it, or to change the PIN number and he writes it down?

00:34:08

IV Yes, that is a problem. Although, I guess, if nobody else really knows the first one, it doesn't matter so much.

IP2-3P No. I mean he's been in the Post Office to collect cash and they've been in there when I've been there with him and he goes to put the PIN number in. He says, I can't remember. I said, yes you can, it's the same one its always been. I can't remember what it is. Close your eyes, you're in front of the bank machine, what numbers do you put in? Oh, yes.

And then, when he went in one day without me. And he stood there, and he said, I can't remember the number, she said, close your eyes, you're in front of the bank and he did it. Because it's the local, everybody in the town knows.