# Supporting Memory Services to Enable People with Dementia and their Families to Gain Timely Access to Assistive Technology

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# Abstract

**Background:** Assistive Technology (AT) could help people with dementia (PwD) to live independently. In England, Memory Services (MS) are usually the first post dementia diagnostic service for information provision. This study aimed to determine current MS practice with regard to giving information on AT and supporting PwD, and their families, to access AT.

**Methods:** This mixed-methods, sequential study involved: 1) two national, cross-sectional surveys exploring current MS provision and individual professional practice regarding AT, and 2) a qualitative study comprising focus groups (n=2) and semi-structured interviews (n=10) to explore professional practice in depth. Surveys were distributed to 117 MS in England.

**Results:** Although MS described a typical 'AT care pathway', there was considerable variation in the knowledge/resources they had available. Professionals highlighted an inequality of provision on many levels, with considerable professional unease around knowledge of AT and the associated costs to PwD. Despite being positive about AT, professionals were driven by patient safety and risk, which shaped the discussions they had with PwD. The term AT was confusing; professionals found introducing AT challenging, especially the timing of such discussions, and often deferred to an 'in house expert', usually an occupational therapist. They described a poorly developed 'AT ecosystem' and identified the need for system wide improvements around information, implementation and monitoring. Notwithstanding these issues, professionals suggested a range of improvements, including: a national AT database, specific training, and access to demonstration resources. Organisations with more advanced services described clear leadership, structures, processes for change and people with drive.

**Conclusions:** This thesis highlights the challenges of implementing a complex intervention, in a complex setting, with a complex group of patients. Despite working in a poorly developed AT ecosystem, professionals are positive about this aspect of dementia care and provided sensible solutions to embed AT into MS everyday practice.

# Acknowledgements

I am eternally grateful to my supervisor, Dame Louise Robinson, who nurtured my research interest and always had faith in my abilities; without her support and encouragement, I would not have achieved so much. I am also very grateful to Prof. Katie Brittain and Prof. John Paul Taylor for their collective wisdom and support throughout this journey.

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Thank you to Barbara Wilson from the Northeast NIHR CRN, who helped me to manage the governance challenges around recruiting memory services via the NIHR CRN. I would also like to say thank you to Sharon Pointer who helped proofread my thesis.

Finally, thank you to my children, Dylan and Josie, who are my number one supporters, and to my partner Paul, who has brought joy to my life and has spurred me on to complete this thesis.

# COVID19 Impact Statement

The COVID19 pandemic and the subsequent national and local lockdowns have had a significant impact on the completion of this thesis. The following statement outlines the challenges faced in completing the study due to COVID19, following university guidance on the COVID19 impact. COVID19 restrictions caused several disruptions to this thesis.

Firstly, it impacted the conducting of field work. My second focus group was planned and the day it was scheduled to occur my son developed a cough. This was the same day national guidance stipulated that a full household should isolate for two weeks. I therefore had to cancel the focus group. Due to the ongoing pandemic, it was challenging to recruit to a further focus group and took months to rearrange. This delayed data gathering.

Secondly, the original fellowship application planned for face-to-face interviews in the homes of people with dementia throughout the UK. The restrictions and uncertainty over the evolving pandemic made this impossible and so I had to re-design the second stage of the fellowship to allow interviews locally with personal protective equipment. Even though the funder agreed to the changes and I managed to obtain ethical approval, it became apparent that the pandemic was unpredictable, and even attempting to achieve this form of data collection was too risky. I therefore decided to reduce data collection to include only qualitative data collection via online platforms and telephone interviews with professionals and to complete my doctoral as an MD rather than the intended PhD. Finally, restrictions impacted how I could access library resources. Rather than being able to check out a book instantly, I had to pre-order textbooks, which could take weeks.

The COVID19 pandemic also caused significant disruption to my personal and clinical life. I had to take two periods of interruption to studies and two COVID19 extensions. Initially, this was because I had to home school my two children and my clinical work took priority; I am a GP and we had sickness and isolation of staff due to COVID19. The later COVID19 extensions were because of the continuous pressure of the clinical job as, despite the wider population and country opening up, we still had the ongoing pressure of staff having to isolate or being sick. This has continued up to the point of submission.[1]

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[1] Newcastle University. Covid-19 Impact Statement Guidance 2021 [Available from: https://www.ncl.ac.uk/media/wwwnclacuk/studentprogress/files/pgr/2021/Final%20C19%20Impact%20Statement%20Guidance%20-%20March%202021.pdf.

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# List of Abbreviations

| | |
|---|---|
| **ACF** | Academic Clinical Fellowship |
| **ADL** | Activities of daily living |
| **AT** | Assistive Technology |
| **ATTILA** | Assistive Technology and Telecare to maintain Independent Living At Home for People with Dementia |
| **AI** | Artificial Intelligence |
| **BPSD** | Behavioural and psychological symptoms of dementia |
| **BSG** | British Society of Gerontology |
| **CMHT** | Community mental health team |
| **CQC** | Care Quality Commission |
| **FAST** | Foundation for Assistive Technology Research Database |
| **GP** | General Practitioner |
| **IADL** | Instrumental Activities of Daily Living |
| **IAT** | Intelligent assistive technologies |
| **QOL** | Quality of life |
| **MDT** | Multidisciplinary team |
| **MRC** | Medical Research Council |
| **MS** | Memory Services |
| **MSNAP** | Memory Services National Accreditation Programme |
| **NIHR** | National Institute for Health Research |
| **OT** | Occupational therapists |
| **PDSA** | Plan Do Study Act |

| | |
|---|---|
| **PPI** | Public involvement |
| **PwD** | People with dementia |
| **RCGP** | Royal College of General Practitioners |
| **SALT** | Speech and Language Therapists |
| **SCIE** | Social Care Institute for Excellence |
| **SMART** | Smart House Technology |
| **YOD** | Young onset dementia |

# Chapter 1. Introduction

## 1.1 Chapter Overview

This is a study of the current practices of memory service professionals regarding the provision of information and supporting access to assistive technology (AT). This is an umbrella term for:

> Any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed (Cowan and Turner-Smith, 1999).

This introductory chapter starts with an explanation of how I became interested in AT, before moving on to describe how I developed a project and obtained a national fellowship from the Alzheimer's Society. It ends with the rationale for this much-needed study and my contribution to it, as well as an overview of the thesis.

## 1.2 Developing Interest in AT

My natural interest in technology was developed during the time I spent as a chemical engineer, prior to studying medicine. As a junior doctor, I witnessed many older adults, often those living with dementia, experiencing long admissions to hospital. In many cases, they were discharged to residential or care homes due to concerns they could not live independently at home. I observed that the most common reason for this was a professional concern for the safety of the person living with dementia. For example, two familiar safety concerns raised by professionals which often precipitated a move to residential or care home were: the potential for the person with dementia to leave a gas cooker on and cause a fire; or, the potential for them to become lost while out walking. I found this frustrating as solutions to such concerns could allow people to remain at home.

I was fortunate to be successful in obtaining a National Institute for Health Research (NIHR) Academic Clinical Fellowship (ACF), which allowed me to continue to develop my interest in technology while also helping older adults live independently at home. Through the fellowship, I completed a Master's in Clinical Research and interviewed general practitioners (GPs) to explore their views and experiences of the AT used in dementia care. During my ACF and GP training, I was also awarded a small grant from the Royal College of General Practitioners (RCGP) to complete the master's work (SFB-2014-02). The results of this study have been presented at national and international conferences as oral or poster presentations and were also reported in the RCGP's Clinical Newsletter. Additionally, these results were disseminated in a paper in the BMJ Open (Newton *et al.*, 2016) and educational articles on AT used in dementia care for GPs (Newton and Robinson, 2013) and social and healthcare audiences (Newton and Robinson, 2015), including a podcast on AT (Newton, 2013). Each of these experiences allowed me to develop my interest further.

### 1.3 Project Development and Funding

The following subsections describe how I developed the project and then obtained funding from the Alzheimer's Society.

### 1.4 Project Development

Several factors have contributed to the generation of this thesis, including the results of the abovementioned master's project, a review of the surrounding literature, patient and public involvement (PPI), and discussions with experts in the field of AT and dementia. My interest in AT and supporting people with dementia to live independently developed over time and, through this process, I built the research idea. The master's project enabled the exploration of the views and experiences of GPs towards the AT used with dementia patients. What this highlighted was that the pathways for professionals to obtain information were confusing, with professionals assuming that information and support with access were managed by memory services (MS). The literature shows that people with dementia find it hard to obtain information on AT and often happened upon AT by chance rather than it being introduced by a professional (see Chapter 2 for further details).

PPI involvement was key to the origin of this study; I involved a local Age UK dementia group to gauge whether the research topic was important to the groups and whether my proposal could be refined. When I went to the dementia group, the families in attendance hoped I would provide them with information on AT and explain how to obtain it; indeed, the fact that I was seen as an information resource reflected the findings from the literature. As well as Age UK, members of the Alzheimer's Society Research network were used to develop the project and other key stakeholders were consulted from the clinical and research community. For example, the study design was reviewed and refined with feedback from the NIHR Northeast research design service. I developed and refined the project further via discussion with GPs working in the Northeast and professionals working at local MS. Further feedback was received from leading researchers in AT when I presented the results of my master's at national and international conferences, including a symposium on AT held at the British Society of Gerontology (BSG). All of the above helped refine and crystallise the project.

### 1.5 Obtaining Funding from the Alzheimer's Society

In 2010, the Alzheimer's Society's Research Group identified AT as a key priority for future research (Alzheimer's Society, 2011), and so my project proposal topic was a priority for the funder to which I applied. Following a positive review by peers and members of the Alzheimer's Society Research Network, I was awarded an Alzheimer's Society Clinical Training fellowship. Surprisingly, the fellowship application and award were the most straightforward aspects of this thesis as throughout the project I have encountered numerous significant challenges (see Chapter 3 and Appendix 10).

### 1.6 Why This Study is Needed

Chapter 2 presents a detailed background to the study and its aims and objectives. However, the main objectives were to determine the current practice of memory service professionals with regard to providing information and supporting access to AT to those wishing to use it, and to seek examples of good practice to inform NHS care. The following key statements illustrate why the study is required and each statement is explored further in Chapter 2:

- AT has the potential to help people with dementia live independently for longer;
- Research has highlighted a complex system surrounding the provision of AT;
- GPs and families living with dementia do not know where to obtain information on AT or how to access it;
- Pathways need to be clarified to help people with dementia obtain AT.

This project focuses on the provision of MS as the first service providing information after diagnosis. The study starts with the hypotheses that:

1. People want information on AT;
2. Memory services are the best setting to provide information on AT and access to it;

3. Professionals within memory services already provide information and help people with dementia to access AT.

The validity of these statements will be studied in the thesis.

### 1.7 My Contribution

I built the project by developing my interest in AT during my master's, reading the literature, and holding discussions with key stakeholders. I have been fortunate to work with two supervisors who also have an interest in AT, Professor Louise Robinson, and Professor Katie Brittain, as well as a third supervisor who is a national leader in dementia research, Professor John-Paul Taylor. All three were fundamental in helping me refine the project, which was developed under their supervision and submitted as a successful doctoral fellowship application. I designed and developed all the data analysis instruments, such as surveys and interview schedules, analysed all the data and synthesised the findings. This was not without great challenges (see Chapter 3 and Appendix 11.Appendix 10:).

### 1.8 Thesis Overview

**Chapter 2 Background and Review of the Literature**

This chapter outlines the background to the study and reviews the relevant literature, including the definition of AT, evidence for its use, and the evolution of memory services. It then outlines the aim and objectives of the study.

**Chapter 3 Methodology and Methods**

This chapter describes the study design, important methodological considerations, the methods employed, and the numerous challenges encountered.

**Chapter 4 Overview of the Results**

After presenting an overview of participant recruitment for both surveys and focus groups and one-to-one interviews, the chapter gives an outline of what is covered in the empirical chapters of the thesis.

**Chapter 5 National Survey of Memory Services: An Overview of Service characteristics and individual professional practice**

This chapter outlines the results of two national surveys by giving an overview of service characteristics and individual professional practices. Data from this chapter were used to inform the focus groups and one-to-one interviews.

**Chapter 6 Memory Services Enactment in Practice**

This chapter describes a typical memory service care pathway and how memory services enact AT, before describing the consequences of the typical pathways, including inequalities of provision and professional uneasiness.

**Chapter 7 Challenges and Solutions**

This chapter explains the considerable challenges encountered by memory services and the professionals working within them, and then presents the solutions the latter suggested to these challenges.

**Chapter 8 Factors influencing memory services' ability to enact AT: information, support, and access**

This chapter explores the external and internal factors influencing information provision, support, and access to AT.

**Chapter 9 Discussion and Conclusions**

This chapter discusses the key findings and makes recommendations for practice, research, and policy.

# Chapter 2. Background and Review of the Literature

## 2.1 Chapter Overview

This chapter contains a review of the relevant literature and explains the reasoning for this study. It begins with an explanation of assistive technology and its definition as used in this study, before providing details of what dementia is and how it affects both the families who live with it and the economy. Next, after evidence is given for the use of AT by older adults and people with dementia, including the types of AT used, important ethical considerations are addressed. Finally, to understand the setting of the study, a description is provided of how the memory service model of care developed, which includes the national standards on how memory services should operate.

## 2.2 Definition of AT

Through my master's work in conducting qualitative interviews with GPs, it became apparent that GPs found the term AT both unhelpful and unclearly defined. The same finding was revealed in qualitative research with people with dementia and their family carers, with one carer eloquently commenting, when they say 'technology, what the hell does that mean?'. Interestingly, even when people with dementia used aids and devices which could be defined as AT in their own homes, they did not associate the items with the term AT (Gibson, Dickinson, Brittain and Robinson, 2015). When reviewing the literature, I found there was a wide variation in the definitions given for AT. In the following section, there is a description of the different definitions of AT and I explain why having a clearly defined common term is important. I then provide the definition used in this thesis.

### *2.2.1 Different definitions*

Table 2.1 illustrates the variation in definitions of AT used by national organisations and within the academic community, highlighting the differences in how the term is defined and what some would classify as AT. One main difference concerns whether AT includes both electronic and non-electronic items. For instance, a recent Cochrane review only includes electronic AT (Van der Roest *et al.*, 2017), while the Alzheimer's Society uses a more general term which could include non-electronic solutions (Cowan and Turner-Smith, 1999). Other terms have also evolved to describe more sophisticated electronic solutions to the problems encountered by people with dementia, such as issues with health and social care, and these solutions could be classified as AT under this umbrella term. The various terms are defined in Table 2.2 and include telecare, telehealth, intelligent AT, and smart home technology (SHT). More recently, Leroi et al. (2018) coined the term ‘psychogeritechnology’. Covering many devices which could be described as AT, they define psychogeritechnology as ‘the range of technology approaches to the prevention, prediction, screening, assessment, diagnosis, management, and monitoring of people at risk of, or living with, dementia’ (Leroi, Watanabe, Hird and Sugihara, 2018).

| **Source** | **Definition or Description of AT** | **Comments** |
|---|---|---|
| Social Care Institute for Excellence (SCIE) | 'Assistive technology refers to devices and systems that help people maintain or improve their independence, safety, and wellbeing' (Social Care Institute for Excellence, 2019) | The SCIE website describes AT in terms of function, such as helping someone cook, providing reminders and maintaining communication, etc. It describes AT as predominantly electronic in nature |
| Foundation for Assistive Technology Research Database (FAST) | '…any product or service designed to enable independence for disabled and older people' (FAST, 2007) | Does not exclude non-electronic devices |
| The Royal Commission on Long Term Care | 'any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed' (Cowan and Turner-Smith, 1999) | Does not exclude non-electronic devices. Used by the Alzheimer's Society as their definition of AT (Cowan and Turner-Smith, 1999) |
| Royal College of Psychiatry Memory Services National Accreditation Programme (MSNAP) | 'Devices that promote greater independence by enabling people to perform tasks that they were formerly unable to/or found difficult to accomplish' (Royal College of Psychiatrists, 2014) | Does not exclude non-electronic devices<br>Does not give any specifics on the purpose of AT and when it can be used |

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| Systematic Review<br>Topo et al. (Topo, 2009) | No definition but a description is given of the 1995 work of Mary Marshall, who stated AT was: ‘an extension of aids and the provision of adaptations beyond static pieces of equipment’ (Marshall, 1995 cited in Topo, 2009)<br>Marshall’s list of AT proposes to care and support people with dementia by:<br>1. providing reminders<br>2. improving safety<br>3. providing stimulation<br>4. managing behaviours<br>5. controlling assistance<br>6. co-ordinating services (Marshall, 1995 cited in Topo, 2009)<br>Topo et al. added aiding communication to this list (Wey, 2004 cited in Topo, 2009). Topo et al. also refer to Stephen Wey’s description of the role of AT in rehabilitation:<br>1. to support memory and orientation<br>2. to enable PwD to perform tasks that are becoming more difficult<br>3. to facilitate meaningful occupation and the | No definition is given but the discussion implies AT can be either electronic or non-electronic. It does, however, outline the purpose and roles of AT and gives a comprehensive overview of what would be included in the term. The discussion focusses on the purpose or scope of AT rather than what it is made from or how it is obtained. The description would exclude medical technology such as telehealth. |

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| | maintenance of social roles (family and social networks)<br>4. to ensure PwD safety<br>5. to reassure carers (Wey, 2004 cited in Topo, 2009)<br>Topo et al. leave the definition of technology open and state: ‘The only two criteria used were that the technology should be something concrete and should not be medical technology’ (Topo, 2009) | |
| Systematic Review<br>(Fleming and Sum, 2014)<br>Brims and Oliver (2018) | This review took the definition given by the Australian Dementia Resources Guide as a starting point for its definition of AT (Peut, 2007 cited in Fleming and Sum, 2014) but modified it slightly to supplement the concept of quality of life (QOL): ‘AT refers to a product, equipment or device, usually electronic or mechanical in nature, which helps people with disabilities to maintain their independence or improve their quality of life’ (Fleming and Sum, 2014) | Modified the definition given by the Australian Dementia Resources Guide (Peut, 2007 cited in Fleming and Sum, 2014). This systematic review gave a very comprehensive and descriptive outline of different definitions and why they chose this as their definition. It states usual electronic or mechanical which suggests it could also include non-electronic solutions. The systematic review by Brims et al. (2018) uses the same definition as Fleming & Sum (2014) |
| Systematic Review | ‘Information Communication Technology (ICT) devices designed to support PwD are usually referred to as Assistive Technology (AT) or | The definition included only electronically driven devices. They give some explanation of the purpose of AT. |

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|---|---|---|
| Van Der Roest et al. (Van der Roest *et al.*, 2017) | Electronic Assistive Technology (EAT)' (Van der Roest *et al.*, 2017). They went on to say 'by using AT in this review we refer to electronic assistive devices' (Van der Roest *et al.*, 2017)<br>They divided devices into four groups:<br>1. To support information provision (general and personal)<br>2. To offer support with memory problems<br>3. To support social interaction<br>4. To support safety and health (Van der Roest *et al.*, 2017) | |
| European position paper on AT<br>Meiland et al. (2017) | 'Any item, piece of equipment, product or system driven by electronics, whether acquired commercially, off-the-shelf, modified or customized, that is used to help persons with dementia in dealing with the consequences of dementia' (Meiland *et al.*, 2017) | A definition is given but no description of how it was defined. They reference Mary Marshall's research (2004, cited in Topo, 2009) and ISO9999 but do not state how they used these sources to arrive at their definition. The definition states it is driven by electronics and outlines how the AT is obtained. It does not include much detail on how it helps PwD as opposed |

| | | |
|---|---|---|
| | | to earlier descriptions or definitions |
| Systematic Review (Klimova, Valis and Kuca, 2018) | ‘any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities’ (Assistive Technology Act of 1998, as amended 2004) cited in (Klimova, Valis and Kuca, 2018) | Uses the definition from the AT Act (Assistive Technology Act of 1998, as amended, 2004 cited in Klimova, Valis and Kuca, 2018). The authors then explain this can means simple non-electronic (e.g., a walking stick) and electronic. Uses AS categories for AT. Other terms used explained—AAL (ambient assistive living), telecare, etc. The definition includes how AT is acquired and focuses on function |

**Table 2.1. Definitions of AT**

| **Term** | **Definition** |
|---|---|
| Telehealth | ‘A subtype of AT including technology-supported medical or nursing tasks undertaken in a person’s home or other remote site, especially sending biometric data from the patient to the health care system and/or sending advice, instructions or reminders from the health care system to the patient’ (Greenhalgh *et al.*, 2012) |
| Telecare | ‘A subtype of AT which usually involves the remote monitoring of people living in their own homes, communicating with them at a distance via telephony and the internet’ (Gibson *et al.*, 2014) |
| Intelligent assistive technologies (IATs) | ‘Technologies that sense and respond to user needs are adaptable to changing situations and compensate either for physical or cognitive deficits’ (Bharucha *et al.*, 2009) |
| Smart house technology (SHT) | ‘implies installing devices such as fall sensors, global positioning systems (GPS), and smoke detectors to enable elderly people to live longer in their homes’ (Aanesen, Lotherington and Olsen, 2011)<br>‘Homes with a range of built-in sensors (e.g., temperature, pressure, fall detector) that monitor an individual’s daily functioning and provide prompts for task completion as needed’ (Bharucha *et al.*, 2009). |
| Psychogeritechnology | ‘the range of technology approaches to the prevention, prediction, screening, assessment, diagnosis, management, and monitoring of people at risk of, or living with, dementia’ (Leroi, Kitagawa, Vatter and Sugihara, 2018; Leroi, Watanabe, Hird and Sugihara, 2018) |

**Table 2.2. Other terms associated with AT**

### *2.2.2 Why definitions are important*

There is a paucity of research into the terminology used for AT used in dementia. A recent European position paper on AT acknowledged the enormous challenge of 'dynamic definitions and various understandings of what ATs are' (Fleming and Sum, 2014), highlighting that this challenge is compounded when AT is used in dementia care. Such variation in terminology poses a challenge for all stakeholders as the term AT may be interpreted differently by each group, including people with dementia, carers, professionals (health and social care and voluntary), commissioners, academic researchers, and industry. This could affect communications between groups, information provision and access to AT, the commissioning of services, and the generation of evidence for AT use. It is important that clear and consistent definitions are achieved. These must also specifically state whether AT includes non-electronic forms, such as signage, or whether another term should be used for these low-grade solutions. To achieve harmonisation with AT definitions, research is required on the term AT to determine how key stakeholders understand the term. A critical question concerns whether people with dementia and carers understand and recognise AT.

### *2.2.3 The definition of AT adopted in this thesis*

In summary, the fact that there are several definitions of AT poses a substantial challenge. In this thesis, the definition given by Cowan and Turner-Smith is used because it is not restricted to electronic devices and includes all potentially helpful solutions for families living with dementia. It is:

> any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed (1999)

## 2.3 Dementia: the Illness and its Consequences

In 2021, an estimated 900,000 people in the UK were living with dementia and this figure is projected to increase to 1.6 million by 2040. Globally, it is suggested that dementia is one of the most important conditions of our generation (World Health Organisation, 2012). At this point, it is necessary to describe what dementia is, how it is treated, how it affects an individual and their family, and how it impacts the economy.

## 2.4 Dementia

Rather than being a disease, dementia is a collection of symptoms occurring because of the effect of neurological disease on a person's memory, behaviour, and thinking, as well as their ability to function socially and live independently in their own home (Gauthier, Rosa-Neto, Morais and Webster, 2021). Neurological conditions which cause dementia symptoms include Alzheimer's disease, vascular dementia, Lewy body dementia, frontal temporal dementia, Parkinson's disease dementia, and post-stroke dementia. What these have in common is that they present with a range of symptoms including, but not limited to: memory loss, disorientation, challenging behaviour, language difficulties, and physical symptoms affecting mobility and sight (Gauthier, Rosa-Neto, Morais and Webster, 2021). Dementia is chronic and progressive, with different symptoms experienced depending on the stage and specific type of dementia; consequently, each individual living with dementia encounters a very personal set of symptoms and challenges. Unfortunately, there is no cure. Current drug treatments are available which can alter and reverse symptoms, but these cannot stop the neurodegenerative process. For these reasons, research into how we can care for people living with dementia is now a priority for UK research (Department of Health, 2015; Kelly *et al.*, 2015; National Insitute for Health Research, 2022). In 2016, the James Lind Alliance, working in partnership with patients and the public, identified their top ten research areas (Kelly *et al.*, 2015), two of which related to helping people remain independent:

> Priority 1: What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?
>
> Priority 7 What are the most effective ways of supporting carers of people with dementia living at home? (Kelly *et al.*, 2015)

### *2.4.1 How does dementia affect an individual and their family?*

Dementia affects both the individuals living with it and their family or support network. It is a leading cause of death in UK; in July, 2022 it was the number one cause of death in England (Office for National Statistics, 2022). As described in Section 2.3.1, dementia causes a range of physical and psychological symptoms individual to the person with dementia. It is clear, as dementia progresses, that it increases the likelihood of entry into formal care compared to people without dementia (Toot *et al.*, 2017). Moreover, someone living with dementia has a higher likelihood of being admitted to hospital and, when there, to experience higher morbidity and mortality (Toot *et al.*, 2013). The carers of people living with dementia experience poorer health and higher stress (Alzheimer's Research UK, 2015).

Being able to live independently at home for as long as possible is important to people living with dementia. Entry into care settings occurs due to a complex mixture of factors, including: the symptoms a patient experiences, their family support, the environment in which they live, and the support they can access, either through public or private social care (Toot *et al.*, 2017). Carer burden is the number one predictor for entry to care homes (Verbeek *et al.*, 2015) and this point will be discussed further in the subsection below. The second predictor is a person's ability to perform activities of daily living (ADLs) (Verbeek *et al.*, 2015). Other factors include whether someone has behavioural and psychological symptoms of dementia (BPSD) that can be challenging for carers or whether someone with dementia frequently becomes lost when outside their home (McShane *et al.*, 1998).

Living day to day with dementia can be challenging due to symptoms that deteriorate with time and affect multiple domains, including memory, language, and executive and physical functioning. Not surprisingly, dementia affects all aspects of someone's life, from being able to accomplish simple ADL tasks, such as dressing, bathing, cooking, and continence (Giebel, Sutcliffe and Challis, 2017; Giebel *et al.*, 2014), to more complex instrumental activities of daily living (IADL), such as shopping, managing finances, using computers, socialising and taking part in leisure activities (Giebel, Sutcliffe and Challis, 2017)—these are particularly important to people with young onset dementia who may be carers themselves or trying to work. As dementia progresses, some people with dementia struggle to initiate any task (Giebel, Sutcliffe and Challis, 2017) and require prompting; for this reason, interventions such as AT are attractive as many can give prompts. All these challenges could be helped with psychological interventions by AT.

Carers and family members are also affected by the complexity of dementia. It is estimated that around 700,000 family and friends provide support for those with dementia to enable them to live at home (Alzheimer's Research UK, 2015). Carers report prioritising the health of the person with dementia over their own (Alzheimer's Research UK, 2015), and unsurprisingly they experience higher levels of ill health as a result (Meiland *et al.*, 2017). The effects of caring for someone with dementia are well researched (Alzheimer's Research UK, 2015; Bleijlevens *et al.*, 2015; Sutcliffe *et al.*, 2017). As noted, higher carer burden is a key factor determining whether someone living with dementia moves to formal care (Assistive Technology Act of

1998, as amended 2004), and this burden is higher in dementia compared to other conditions (Sutcliffe *et al.*, 2017). Carer burden is higher for females, and for those who: look after their relative with dementia at home (Sutcliffe *et al.*, 2017); have scarce informal support; are the children of the person with dementia; and, spend a great deal of time with the person with dementia (Sutcliffe, Giebel, Jolley and Challis, 2016). It is also higher in people who care for people with BPSD, especially if these neuropsychiatric symptoms occur at night (Sutcliffe, Giebel, Jolley and Challis, 2016; 2017). Other factors reported to increase carer burden, and hence swifter movement to formal care, include: a carer reporting elevated levels of stress or a subjective feeling of being imprisoned; a carer having ill health or an unsatisfactory caring relationship or poor attachment to the person living with dementia (Toot *et al.*, 2017). Further research is required to determine which of these factors elevating carer burden are more likely to influence transition to a care home. In so doing, modifiable factors can be targeted to reduce carer burden and hence early transitions to formal care. For instance, it is important to know what causes higher carer stress. If a carer is concerned for a person with dementia's safety, perhaps interventions such as AT can help.

In summary, dementia has a huge impact on families living with dementia. Interventions such as AT, which can help with ADLs and support independence, can potentially help people remain in their own homes for longer and reduce carer burden. This scenario is attractive as social care costs the UK economy a substantial amount of money, which is the subject of the following section.

#### ***2.4.2 The economic impact of dementia and the political argument for increased use of AT***

Dementia incurs considerable financial and psychological costs for families living with dementia but also has staggering costs for the UK economy. It is estimated that dementia costs the UK economy £29.5 billion a year and this is estimated to increase (Wittenberg, Hu, Barraza-Araiza and Rehill, 2019). Regarding these cost estimates, 14% are incurred by the NHS, 45% by social care (public and privately funded), and 40% by unpaid care (Wittenberg, Hu, Barraza-Araiza and Rehill, 2019), making it one of the UK's most expensive conditions (House of Commons All Party Parliamentary Group on Dementia, 2011). Two important factors related to increased dementia expenses are the huge costs of caring for people living with dementia (Alzheimer's Society, 2015), and the funding of rising costs for hospital admissions

(Luengo-Fernandez, Leal and Gray, 2010). The economic impact of dementia care has thus made it a national priority (Department of Health, 2009a; Department of Health, 2015).

Most people with dementia live at home and prefer to remain there as long as possible (Gauthier, Rosa-Neto, Morais and Webster, 2021; Knapp *et al.*, 2007); in the UK, it is estimated that around 60% of people with dementia live in the community (Gauthier, Rosa-Neto, Morais and Webster, 2021), with the remaining percentage living in long-term care (Knapp *et al.*, 2007; Prince *et al.*, 2014). Staying at home for longer, thus delaying entry to formal care, is attractive both to people living with dementia and the UK government as formal care is incredibly expensive (Department of Health, 2015). Funding UK dementia care also poses a huge challenge for health and social care organisations with limited budgets. In this context, the UK government aims to help people live at home for longer, and AT is a potential solution which can not only help people to live at home for longer but also delay transition to formal care (Department of Health, 2009b; Alzheimer's Society, 2011). The following sections cover what AT is and how it is used with older adults and people living with dementia.

## 2.5 AT Use in Older Adults

There is great concern over whether current health and social care systems can cope with the rapidly aging population. New ways of dealing with this immense challenge have been proposed, including AT (Dementia Policy Team, 2016). In the UK, national policy, such as the National Health Service and Community Care Act 1990 and the Care Act 2014 proposes that older adults be cared for in their own homes for as long as possible, utilising a mixed economy of care provision. Despite AT being promoted as a way to support older adults wishing to remain at home and to ‘age in place’ (put simply, to remain independent at home as opposed to living in formal care (Wiles *et al.*, 2012), it is underused in the UK (Audit Commission, 2004; House of Lords Select Committee on Science and Technology, 2005). A large cohort study on the use of AT with older adults >85 years (the Newcastle 85+ study) found that the most common AT were walking sticks and AT used to help with ADLs, including dressing, kitchen tasks, and bathing equipment (Robinson *et al.*, 2013; Jagger *et al.*, 2011). Many older adults have dementia and therefore it is not a surprise that the view of AT within UK policy is that it may be an attractive solution to the increasing costs of care (Department of Health, 2015; Department of Health, 2009b). The following section covers AT used in dementia.

## 2.6 AT in Dementia Care

The following section on the different types of AT used in dementia is split into three subsections on the available AT, key stakeholders' opinions of AT, and the ethical challenges surrounding AT use.

### *2.6.1 Which AT is available*

The term AT describes a broad spectrum of solutions to the challenges families living with dementia may have. There are different ways to classify AT used in dementia, including:

1. That used by AT Dementia, which is an interactive webpage specifically for people with dementia. It groups AT by the area that it facilitates, such as safety, leisure, prompts and reminders, and communication (AT Dementia, 2014). This website can now be found under the webpage AskSARA/Living Made Easy (Disabled Living Foundation, 2022). Table 2.3 gives examples of AT under each heading.
2. A framework that classifies AT by how a person with dementia interacts/uses AT. That is, it groups AT according to whether the AT is used by, with and/or on the person with dementia, reflecting how the AT changes with time as the condition progresses. Table 2.4 gives examples of AT under this framework (Gibson *et al.*, 2014).
3. That given by the Alzheimer's Society, which groups AT into either supportive AT (to help an individual complete tasks), preventative AT (to reduce risk and raise alarms), and responsive AT (to prevent harm and raise alarms). Table 2.5 gives some examples under these headings (Alzheimer's Society, 2020).
4. Categorising AT by how it is accessed, as described in a paper by Gibson, Dickinson, Brittain and Robinson (2015). 'Formal' AT is acquired via health and social care services after an assessment of needs, 'off the shelf' is purchased privately, and or `do it yourself' AT covers devices or systems tailored to the person's individual needs by the family/carer) (Gibson, Dickinson, Brittain and Robinson, 2015).

Please be aware that the examples of AT given under each framework are not exhaustive. Most types of AT are designed to be used with others or for someone to respond to alerts and so they are not always suitable for people living alone. It is hoped they are used as part of a care package rather than to replace care. There is also more than one solution to overcome a challenge encountered by a person with dementia. For instance, if someone forgets important dates or meetings, they can use a range of electronic (smart phone or Google Home alarms) or non-electronic reminders (notice boards and diaries). Interestingly, when observed in their own homes, families living with dementia were often buying ‘off the shelf AT’ or making their own ‘DIY’ AT solutions by using and adapting existing technology to fit the needs of the individual in their own environment (Gibson, Dickinson, Brittain and Robinson, 2018). This ‘bricolage’ of AT solutions produces personalised AT rather than the fixed offer from social services (Gibson, Dickinson, Brittain and Robinson, 2018). The fact that families are making their own solutions raises a question about the adequacy of the current provision by health and social care (Gibson, Dickinson, Brittain and Robinson, 2018). However, it may be as simple as a family not being aware of what AT exists or how it can be accessed. The next subsection covers what key stakeholders think of AT.

| **Category** | **Examples of AT** |
|---|---|
| Safety | GPS trackers<br>Fall detectors<br>Movement detectors<br>Detectors which can raise an alarm or shut off valves for gas, flood, extreme temperature, or carbon monoxide |
| Leisure | Reminiscence materials<br>Simplified remote controls |
| Prompts and reminders | Item locator devices<br>Use of diaries and notice boards<br>Clocks to aid orientation<br>Dementia friendly signage |
| Communication | Talking mats<br>Telephone with pictures<br>Skype/touch screen communication technology |

**Table 2.3. Framework of AT used in dementia with examples (copied from my progress year 1 report (Newton, 2018)**

| Category | Examples of AT |
|---|---|
| Used 'by' people with dementia | Clocks<br>Signage<br>Alerts<br>Automated lighting |
| Used 'with' people with dementia | Reminiscence books, software, or objects<br>Puzzle and games |
| Used 'on' people with dementia | Telecare systems<br>Fall detectors<br>GPS locators |

**Table 2.4. Framework categorising AT into groups according to whether it is used by, with or on the person with dementia, with examples of AT. Adapted from Gibson *et al.* (2014)**

| Category | Examples of AT |
|---|---|
| Supportive AT | Memo minders<br>Talking mats |
| Preventative AT | Temperature, smoke, and carbon monoxide detectors |
| Responsive AT | Telecare |

**Table 2.5. Alzheimer's Society categories for AT (Alzheimer's Society, 2020)**

### *2.6.2 Evidence for AT in dementia care*

This section covers the evidence for the AT used in dementia care and the challenges of 'proving' whether it is effective or not. There is a paucity of robust research evidence for the use of AT in dementia (Fleming and Sum, 2014; Meiland *et al.*, 2017; Van der Roest *et al.*, 2017). Original research exploring the AT used in dementia involved small, uncontrolled studies  and, although some found positive effects (Fleming and Sum, 2014; Topo, 2009; Lauriks *et al.*, 2007; Woolham, 2005), these results have to be interpreted with caution due to small sample sizes and uncontrolled designs (Fleming and Sum, 2014; Meiland *et al.*, 2017; Lauriks *et al.*, 2007; Woolham, 2005). Initial reviews of the evidence were comprehensive but did not follow the systematic review methods which have been used more recently (Fleming and Sum, 2014; Topo, 2009; Lauriks *et al.*, 2007; Woolham, 2005) Except for a European position paper which did not follow such methods , later reviews were systematic(Meiland *et al.*, 2017). However, the systematic review approach limits the number of studies which can be reviewed, thus excluding many studies which do not meet the strict criteria of the target research. The more recent systematic reviews of the evidence on the AT used in dementia are thus affected in this regard. Indeed, a Cochrane review found no studies which met its inclusion criteria (Van der Roest *et al.*, 2017). Some of the reviews identified the need for larger, controlled trials to evaluate the effectiveness of AT (Brims and Oliver, 2018; Lauriks *et al.*, 2007; Van der Roest *et al.*, 2017),and one large RCT on chronic illness and AT found no benefit in its use (Steventon *et al.*, 2013).

In England, the ATTILA (assistive technology and telecare to maintain independent living at home for people with dementia) trial produced a series of research studies to address the research gap on whether AT can effectively delay entry to formal care (Leroi *et al.*, 2013). This pragmatic multicentre RCT compared whether people with dementia who received AT were less likely to move in to care than those who did not (Leroi *et al.*, 2013). One such study conducted in the UK looked at whether AT delayed entry to care home (Forsyth *et al.*, 2019). The primary outcome was to measure the duration from randomisation to entry to formal care and cost effectiveness. There were several secondary outcomes, which included carer quality of life and burden, participants' adverse events (including hospital admissions), and how acceptable, applicable and reliable the technology was (Leroi *et al.*, 2013). It was unblinded. One arm included an AT assessment of needs and tailored AT installed (including telecare), while the other involved a 'semi-structured' needs assessment and only smoke and carbon monoxide detectors and pendant alarms. Assessing for, deploying, and funding AT was performed through local authorities and not the trial.

Overall, the study found no benefit in AT use (Davies *et al.*, 2020; Gathercole *et al.*, 2021; Howard *et al.*, 2021; Lariviere *et al.*, 2021). There was no benefit from using AT in terms of delaying entry to formal care and it was not cost effective (Howard *et al.*, 2021). No benefit was found for carer burden, anxiety, and depression (Davies *et al.*, 2020). Assessment recommendations were found to be routinely disregarded when AT was installed. This highlights the need to understand the wider AT ecosystem, since one can recommend AT but this does not transfer into what is installed in a real-life setting (Forsyth *et al.*, 2019). As such, the lack of installation of what was needed constitutes a major limitation of this study. There was also some evidence that certain local authorities took short cuts in the assessments, which may be related to managing tight budgets (Forsyth *et al.*, 2019). The study had an embedded ethnography which found that AT had unintended and unplanned consequences for people with dementia living in their own homes (Lariviere *et al.*, 2021). It highlighted how people with dementia fit AT into their everyday life and how AT could replace some carer duties and disrupt usual routines (Lariviere *et al.*, 2021). The need to chart and understand changing AT needs for people over time was also identified (Lariviere *et al.*, 2021). Nevertheless, the evidence gathered in this study so far has many limitations, and therefore it is now appropriate to consider the challenges with gathering AT data and suggest methods for gathering evidence.

### *2.6.3 What do key stakeholders make of AT?*

Research with people with dementia and their carers suggests they are positive about using AT to help maintain independence (Robinson *et al.*, 2009) and found it useful (Cahill, Begley, Faulkner and Hagen, 2007). Carers described AT as giving them ‘peace of mind’ when trying to maintain their relatives’ safety at home (Gibson, Dickinson, Brittain and Robinson, 2015) and found AT beneficial when they reached crisis point (Toot *et al.*, 2013). However, one study with carers of people involved with young onset dementia described AT as a ‘mixed blessing’ since, although it gave relief in reducing some carer tasks when introduced at the right time, as the dementia progressed their relative could no longer use it (Holthe, Jentoft, Arntzen and Thorsen, 2017). Some carers reported that AT helped them continue working while caring for relatives (Gibson, Dickinson, Brittain and Robinson, 2015).

A systematic review found that AT decreased carer burden by reducing the time, energy and levels of assistance needed to care for a relative, increasing their relative’s independence while helping to lower carer anxiety and fear around their relative’s safety(Sriram, Jenkinson and Peters, 2019). Another systematic review found that carers’ overall experience of AT was positive in several ways. It helped carers build a better relationship with their loved ones and improved the person with dementia's freedom and autonomy as carers could use AT rather than more traditional restrictive methods, such as locking them in the house. It also helped carers maintain their relatives' safety (e.g., GPS tracking), improved carers' quality of life by helping to reduce worry, and aided the person with dementia's ability to perform tasks competently, such as using a remote control (Sriram, Jenkinson and Peters, 2019).

However, carers also voiced the negative aspects of AT, which became more evident as the dementia progressed. Some carers worried AT had the potential to reduce human contact or remove the 'person' part of caring, or indeed produce strain in their caring relationship if the AT did not work or a person could no longer use it (Sriram, Jenkinson and Peters, 2019). Some carers worried about their competence in using AT (Sriram, Jenkinson and Peters, 2019), whereas others reported their quality of life was reduced as the AT required a carer to assist, creating more dependence on the carer and increasing the carer burden (Sriram, Jenkinson and Peters, 2019). People living with dementia described 'tolerating' AT as they found it reduced their carers' anxiety (Gibson, Dickinson, Brittain and Robinson, 2015). Overall, people with dementia and carers were positive about the use of AT. The next section details the evidence for AT.

### *2.6.4 Challenges of gathering evidence on dementia care AT*

The many challenges with gathering evidence on AT relate to the condition itself, the technology used, study design, and the definition of AT. Reviews have highlighted several challenges with gathering evidence on AT, including:

1. Having no agreed definition of AT, as noted previously, hinders database searches for studies and prevents comparison of studies and potential meta-analysis (Van der Roest, Wenborn, Dröes and Orrell, 2012);
2. Strict ethical guidance surrounding AT research in dementia may prevent large RCTs (Van der Roest, Wenborn, Dröes and Orrell, 2012) ;
3. It is challenging to tailor AT to individual needs while gathering robust evidence;
4. The technology may have poor design and performance (Fleming and Sum, 2014);
5. There is a high participant dropout rate (Fleming and Sum, 2014);
6. During trials, participants deteriorate too much to continue participating (Fleming and Sum, 2014).

These challenges can be categorised as either dementia specific, technology-based (including terminology) and study specific.

### *2.6.5 Dementia specific challenges*

As noted previously, dementia is an umbrella term for many distinct neurological conditions, including Alzheimer's disease, vascular dementia, Lewy body, and frontal temporal. Each subtype has different presentations and a person living with the condition may have different and unique challenges with which AT can assist. To compound matters, dementia is progressive, and any intervention implemented and studied may no longer be effective during a study; this was seen in the systematic review by Fleming and Sum (2014), which found some studies had high dropout with severe dementia (Fleming and Sum, 2014). A recent position paper also highlighted the challenges around gathering evidence, in particular with the well-known gold standard RCT, as these may not be possible due to strict ethical guidance around conducting research with people with dementia (Meiland *et al.*, 2017).

### *2.6.6 Technology-based challenges*

A key finding in many of the reviews was how the lack of a clear definition of AT impedes evidence gathering and the ability to compare studies (Topo, 2009; Meiland *et al.*, 2017; Van der Roest *et al.*, 2017). Interestingly, the European position paper on AT in dementia does not mention the lack of a clear definition and this could be viewed as a missed opportunity to produce clarity around the term (Meiland *et al.*, 2017). Discussion around AT and evidence gathering will be challenging if no single term is used by researchers, industry, professionals, and people living with dementia. Continued variation in the 'core term' makes it challenging to synthesise the research literature and produce a reliable discourse on AT. Another technology challenge is remaining current with change, and indeed this is a huge undertaking as technology is developing so quickly that many studies produce results on potentially out-of-date technology (Leroi, Watanabe, Hird and Sugihara, 2018). This, it could be argued, is unethical.

### *2.6.7 Study-specific challenges*

The design and performance of the targeted technology was also an issue. For instance, one study described a tracking device with an aerial which had to be worn on a person's belt;

unsurprisingly, many participants did not want to wear it (Fleming and Sum, 2014). Many studies found it difficult to compare results due to a wide variation in outcome measures and thus they called for standardised outcome measures based on need rather than individual devices allowing for personalised AT solutions (Meiland *et al.*, 2017). Moreover, many studies did not include the negative effects of AT and any harm its use might pose to a person with dementia, either regarding the environment where it was being used or the stage of dementia, as well as any ethical issues raised by AT (Van der Roest *et al.*, 2017; Lauriks *et al.*, 2007). Some questioned whether outcome measures should be related to the device or the needs of the participants (Topo, 2009; Van der Roest *et al.*, 2017). One recent RCT selected the latter (Forsyth *et al.*, 2019) but it could be argued that the researchers were targeting different types of dementia, at different stages. This complex intervention highlights issues with evidence gathering, in that such a needs-based package of several potentially different devices, possibly of different brands and designs of AT, inevitably makes comparison difficult. The fact that many studies only included positive outcomes and did not address any harms AT could pose (Van der Roest *et al.*, 2017; Lauriks *et al.*, 2007) did improve with future studies, but this is not standard. For instance, the Cochrane review did not look for negative effects of AT (Van der Roest *et al.*, 2017), even though it is crucial to ensure evidence of harm is gathered. Moreover, some studies considered outcomes for carers not the people with dementia, highlighting the ethical dilemma of for whom the intervention is intended (Topo, 2009). Studies also did not look at how AT use changes with the stage and severity of dementia and the results so far may reflect the study design rather than the technology itself. Furthermore, study setting varied and what works at home may not work in the care home setting or hospital.

### *2.6.8 Suggested solutions to gathering evidence on AT*

Despite most systematic reviews and European guidance calling for large RCTs (Van der Roest *et al.*, 2017; Meiland *et al.*, 2017), many recognised the limitations with traditional RCTs when gathering evidence on AT, and thus called for other types such as stratified block designs (Van der Roest *et al.*, 2017; Meiland *et al.*, 2017), or trials following MRC guidance on complex interventions (Van der Roest *et al.*, 2017). The European position paper stressed the need for faster methods of gathering evidence such as 'logging use and ecological momentary assessments', but did not define these (Meiland *et al.*, 2017). On the same point, Leroi (2018) called for quicker methods, and noted the following: Plan Do Study Act (PDSA) cycles—widely used in hospital medicine; methods used in computer design, such as user-centred design as seen in the SOPRANO study; and, collaborative projects, such as that between the respective Japanese and Finnish research institutes, AIST and VTT, called METESE (Leroi, Kitagawa, Vatter and Sugihara, 2018; Leroi, Watanabe, Hird and Sugihara, 2018).

## 2.7 Section summary

In summary, gathering and synthesising evidence for AT dementia care is challenging as it involves studying a heterogeneous group of people living with a condition which deteriorates over time, and the interventions are studies which constantly change and adapt due to rapid technology evolution. This makes it a uniquely challenging intervention on which to gather evidence. Future studies must address these issues when assessing technologies tailored to the individual needs of the person with dementia over time. Further evidence is also required on the cost effectiveness of AT, as well as AT designed for people with dementia, including an ethical assessment and data gathering on the harm of using AT, not just its benefits (Meiland *et al.*, 2017). To achieve these goals, global approaches to research are required, as called for in the recent nature article (Cataldi *et al.*, 2023). Critically this should include research specifically on AT. The following subsection outlines ethical challenges surrounding the use of AT.

### *2.7.1 Ethical challenges of AT dementia use*

Using AT with people with dementia and their families raises several ethical dilemmas and concerns often related to how AT is used with individuals rather than the technology itself. The main ethical issues raised are:

1. The concern that AT causes a conflict between ethical principles such as respect for autonomy, beneficence, and non-maleficence (Beauchamp and Childress, 2001). For instance, preserving privacy and respect for autonomy while safeguarding safety and risk reduction (Meiland *et al.*, 2017);
2. The maintenance and consideration of an individual's human rights (Meiland *et al.*, 2017);
3. The potential of AT to reduce human contact (Woolham, Gibson and Clarke, 2006; Nuffield Council on Bioethics, 2009);

4. The concern that there will be a possible over reliance on AT, resulting in the abuse of people with dementia (Perry and Beyer, 2012);
5. The risk of faulty devices causing harm to people with dementia (Perry and Beyer, 2012);
6. The difficulty of obtaining informed consent for AT when a person with dementia might not understand or even be aware of AT use as their condition progresses (Meiland *et al.*, 2017). Achieving informed consent is challenging as a person with dementia's capacity to make specific decisions may fluctuate.

One dilemma which highlights a number of these issues is the use of GPS tracking to support safe walking. This tracking could be acceptable, despite posing a risk to an individual's privacy, because it increases a person's independence (Perry and Beyer, 2012); such decisions are often personal to the individual and their family living with dementia. One large ethical study produced guidance which promoted early discussion around GPS use (Landau and Werner, 2012). The authors asked carers and professionals about whom to consult on the decision to use GPS and the participants felt that a person with dementia would be low on the list; while many identified the need for people with dementia to consent, a few would just use GPS tracking, and some families proposed electronically tagging their family member with dementia (Landau and Werner, 2012). This raises the concern that some families will take control of AT due to a lack of guidance and thus its application may be unethical.

There is a paucity of ethical research on the use of AT in dementia care. In the limited research to date, many concerns have been raised, including the need for improved information on AT, the integration of health and social care services, timely introduction with quicker assessment and delivery of AT, and an ability to try any recommended AT (Perry and Beyer, 2012). Regarding timeliness, if AT is introduced when someone has advanced dementia and can no longer use it, the need for earlier introduction is clear (Perry and Beyer, 2012). Families also want information on AT to be actively introduced to them earlier to help them make informed decisions, as opposed to having to research AT themselves (Perry and Beyer, 2012). Not only is there little ethical research on the use of AT with people with dementia, but ethical concerns are also often not included in research on technology with people with dementia. In this regard, the recent European position paper on AT advised that all research should include an ethical evaluation (Meiland *et al.*, 2017), and indeed this is reiterated in a systematic review (Topo, 2009).

To navigate these ethical dilemmas and considerations, practical guidance (Alzheimer's Society, 2011; AT Dementia) and codes of practice (Perry and Beyer, 2012) emphasise the need for a balance between appropriate use of AT while ensuring its use does not reduce human contact and care. Also, it is important to incorporate needs assessment to identify and reduce the potential harm of using AT (Perry and Beyer, 2012). To guide professionals in assessing people with dementia, a framework was produced which improves the timeliness of introducing AT; this is an essential development since dementia symptoms are not static (Godwin, 2012). The framework raises many questions, such as:

1. Who benefits from AT use?
2. What defines benefit in the context of AT?
3. What are the harms of using AT?
4. What are the associated costs and benefits of using AT and to whom does this apply?
5. Are there any alternatives to AT (Godwin, 2012)?

There are many ethical challenges to using AT by, with or on people with dementia. More research is required with people, their families and the professionals dealing with dementia concerning the questions elicited by the professional framework above. The provision of good information on AT and the need for joined up services are key themes in the literature, and these will be explored further in the sections below. Having explained the ethical challenges of using AT, the next section explores key stakeholders’ awareness of AT and how people can obtain information and access AT if they wish to use it.

## 2.8 Awareness, Information, and Access to AT

It is essential for families with dementia to be aware that AT solutions exist and to know where to obtain AT information and support for accessing it. The following section explores key stakeholders’ awareness of AT and the current pathways to obtaining information and access to AT.

### *2.8.1 Awareness of AT*

In 2011, the Alzheimer’s Society published a position paper which stressed there was a general lack of AT awareness among patients, carers, and health and social care professionals (Alzheimer's Society, 2011). A similar finding was reported by other studies with people with dementia and carers (Gibson, Dickinson, Brittain and Robinson, 2015), professionals (e.g., GPs) (Newton *et al.*, 2016), and occupational therapists (Jarvis, Clemson and MacKenzie, 2017; McGrath *et al.*, 2017). However, the reasons for the lack of awareness among families with dementia and professionals have not been explored. One potential reason may be the current provision of AT information by health and social care organisations, since it is unclear how patients and carers can obtain AT information and access to it (Gibson, Dickinson, Brittain and Robinson, 2015). Research with families living with dementia found that people with dementia were making their own electronic solutions to problems they encountered, rather than being made aware of, obtaining information on, or accessing AT through, health or social care professionals (Gibson, Dickinson, Brittain and Robinson, 2015). This study also highlighted how families were unaware of the available AT solutions (Gibson, Dickinson, Brittain and Robinson, 2015). In 2017, the Dementia Action Alliance task group was formed as a result of a prime ministerial dementia challenge (Department of Health, 2015) to overcome this issue and to promote the Alzheimer's Society Technology Charter (Alzheimer's Society, 2014). The Alliance produced a series of information resources for families with dementia and professionals on AT, attempting to answer critical questions on how to access AT, where to obtain more information, and the funding of AT (Dementia Action Alliance, 2017). Interestingly, these information sheets were not targeted at the key professionals who see people throughout their dementia journey, such as GPs, or at the first group of professionals giving information after diagnosis, the memory services professionals. Not targeting these key professional groups may be a missed opportunity for raising awareness among families with dementia, as such groups are most likely to consult with people with dementia during their journey; they can thus introduce AT and provide further information, answer questions, and signpost to services.

### *2.8.2 Information provision*

Families living with dementia can obtain information on AT either in person or online via a myriad of routes (Newton and Robinson, 2013), including health and social care professionals, voluntary organisations (e.g., the Alzheimer's Society (Alzheimer's Society), Age UK (Age UK, 2020), Dementia UK (Dementia UK, 2022), and AT Dementia (AT Dementia, 2014), private companies (for example, Unforgettable), and social services  (2015; Newton and Robinson, 2013). The Alzheimer's Society has an online AT catalogue which is useful for families living with dementia (Alzheimer's Society, 2016). Another useful resource created by Trent Dementia Services Development Centre (previously AT Dementia and now AskSARA) provides AT information to people with dementia, carers, and professionals. This includes an AT guide which suggests AT based on the problem a person with dementia has, such as losing their keys (Burrow and Brooks, 2012). Even the well-recognised consumer magazine Which? has a guide for people with dementia on AT (Which?, 2022). Moreover, a relative of someone with dementia developed the private catalogue called Unforgettable (Unforgettable). Some families with dementia are fortunate to have access to local demonstration sites which provide information and allow people to try AT (Newton and Robinson, 2013).

Despite the existence of numerous places to obtain information on AT, research with families living with dementia (Gibson, Dickinson, Brittain and Robinson, 2015; Perry and Beyer, 2012; Wherton *et al.*, 2015), professionals such as GPs (Newton *et al.*, 2016), and occupational therapists (Jarvis, Clemson and MacKenzie, 2017) has found there is a lack of effective and easily accessible information on AT. The paucity of information sources is a key challenge, as identified in a recent, collaborative position paper on AT in dementia care written by leading international researchers (Meiland *et al.*, 2017) as well as in national (Audit Commission, 2004) and voluntary organisation publications (Alzheimer's Society, 2011; Alzheimer's Society, 2014). Further research is required to consider more specifically the information required by all stakeholders on AT. Regarding such information, the research should explore what, when, and in which format do families with people with dementia want this information, as well as by whom should it be provided. It is also important to determine what information professionals want or need. Despite comprehensive resources being developed for families living with dementia, such as the Alzheimer’s Society catalogue and the AT Dementia website (Burrow and Brooks, 2012), neither have been evaluated to see whether they are used by families with dementia and professionals.

In summary, there is no clear information pathway for families with dementia who want to know more about which types of AT may be helpful. Whether this is because existing resources are ineffective or whether families living with dementia are just unaware of them remains to be seen.

### *2.8.3 Accessing AT*

There is a mixed economy of AT provision in the UK which includes health and social care, housing, and private sources of AT. Telecare provision by local authorities dominates UK provision and there is little other AT specific to dementia (Gibson *et al.*, 2014), although some non-personalised AT solutions are offered (Gibson, Dickinson, Brittain and Robinson, 2018). Interestingly, research has shown that fewer than half of local authorities provide information on access to AT and associated costs to help people with dementia make an informed decision (Gibson *et al.*, 2014). Private companies supplying AT support local authority provision (Gibson *et al.*, 2014), which is now also supplemented by people with dementia and family carers using other technology, such as Google Home and Alexa.

In practical terms, families living with dementia can access AT through their local authority or housing provider, NHS service, or a private company (Newton and Robinson, 2013). Whether the current system for AT provision through local authorities is working is debatable, as studies with people with dementia have found that patients find their own solutions, and that they could have accessed these directly via their local telecare provider (Gibson, Dickinson, Brittain and Robinson, 2015). However, accessing AT is not just challenging for families living with dementia. In a qualitative study, GPs described a complex system for the provision of AT, with some pointing to the need for a single point of access to navigate the current system (Newton *et al.*, 2016). This suggestion was also made in a recent Alzheimer's Society report (Alzheimer's Society, 2011) and in large national and international studies with families living with dementia (Górska *et al.*, 2013; Karlsson *et al.*, 2015).

More research is required to identify how families living with dementia access AT, including how they pay for it, in a real-life setting which involves the navigation of the present mixed economy provision. Further research is also required on how professionals help people with dementia navigate this mixed economy and support their access to AT. Many AT solutions fall between the domains of health and social care provision; for instance, automatic light sensors help prevent falls and can help someone to live independently but also help to prevent an injury which may need medical attention. Overall, more research is therefore required to see whether AT is more challenging to commission as it spans both health and social care.

In summary, many families living with dementia and carers are unaware of the available AT solutions. Better information sources and support to access is required.

## 2.9 The Development of Memory Services and their National Standards

This section covers the formation of the memory service model of care and its role in providing AT information and supporting families to access AT. Although I have used the term memory services (MS) throughout this thesis, they are also known by other terms, including memory assessment services, memory clinics, or even memory protection services. In 2014, there were an estimated 222 MS in England. In the UK, they are predominantly led by mental health services, while in other countries they may be led by general medicine, older age medicine or neurology (Jolley and Moniz-Cook, 2009). MS are now widespread in the UK and are the most common service primary care refer to when they suspect someone has dementia. However, in the UK, this is not the only referral pathway to achieve a diagnosis of dementia; just as in other countries, GPs can refer to old age medicine and neurology clinics. There is no definition of what constitutes MS but they all share the purpose of diagnosing dementia. Attempts to classify memory clinics in order to perform an economic analysis of services failed due to the wide heterogeneity of services, such as staff and the services provided (Chrysanthaki, Fernandes, Smith and Black, 2017). Despite the national dementia strategy giving a definition of what constitutes MS (Dementia Policy Team, 2016), provision varies greatly (Chrysanthaki, Fernandes, Smith and Black, 2017).

MS are the first place for people with dementia to obtain information after diagnosis. Research with GPs shows that they assume MS provide information and support to people with dementia on AT (Newton *et al.*, 2016). However, there is no research into whether MS provide information and post-diagnostic support around AT. In this section, the development of the MS model of care is explored alongside the current challenges associated with the model, followed by the development of the Memory Services National Accreditation Programme (MSNAP) and their standards for MS.

### *2.9.1 Development of the MS model of care*

The earliest memory clinics were seen in America in the 1970s and they predominately comprised specialist services focused on researching the causes of dementia, in addition to offering diagnosis, treatment and advice in an outpatient clinic environment (Banerjee, 2013). This model rapidly evolved and the numbers of clinics grew quickly over the next few decades. The UK's first memory clinic was based at St Pancreas hospital in 1983 and the number of MS quickly grew to reach 222 in 2014 (Banerjee, 2013). However, there is currently no national list of MS and thus their total number in the UK can only be estimated through audits (Royal College of Psychiatrists, 2015) and data registered with MSNAP (Royal College of Psychiatrists, 2022). Furthermore, there are MS models which do not include old age psychiatry and thus the total number of MS will be more than that indicated by audit data and MSNAP. Over this period, the primary focus of such services moved from researching dementia to providing early diagnosis and support; less focus, due to resource limitations, was placed on longer term management and patients were frequently discharged back to primary care. This change became evident when the term ‘memory services’ was used to describe the Croydon Memory Service Model, a multidisciplinary team model of care developed through collaboration between health, social care and the voluntary sector. The main aim of this model of care was developed in consultation with the local population: to diagnose dementia early while engaging people living with dementia and their families within a service which provides comprehensive assessment, diagnosis and treatment (Banerjee *et al.*, 2007). This model of an outpatient clinic with a multidisciplinary team who assess and diagnose dementia has become the most widely used model of care for dementia services in the UK.

Despite this fast evolution in services, the development of MS has been described as haphazard and lacking a single, national good practice model for MS; the services differ not only in their quality but also what constitutes an MS and what it provides (Doncaster, McGeorge and Orrell, 2011). The development of MSNAP and its standards was an attempt to address this gap (more details in Section 2.8). The following subsections discuss the challenges associated with the current model of care.

### *2.9.2 Challenges with the current model*

There are many challenges with the current MS model, including:

- A lack of a clear definition of what constitutes a MS has resulted in heterogeneous services;
- An increasing number of people needing a diagnosis has made the current model unsustainable;
- The current model fails to consider that people with dementia have complex physical needs, such as multimorbidity and frailty.

I will discuss each of these challenges in turn.

The current model has evolved to provide great variation in service provision. With chronic diseases such as diabetes, or when a patient is referred under a two-week rule for cancer, patients have a very typical care pathway; however, individual people with dementia can enter services which provide a completely different offering in terms of setting (psychiatry, old age medicine or neurology), multidisciplinary team composition, services provided, resources available, and collaboration between internal and external services. With the current provision of information and support to access AT in this setting, there is thus no guarantee that every person referred to a MS in England will have the same, or at least a baseline, standard for care. The consequences of such marked heterogeneity concern the difficulty of ensuring the quality and equality of provision, and even the ability to compare services. These consequences became evident in a government-commissioned study seeking to categorise MS and compare them on economic grounds using models of provision of care; the study was unable to categorise MS due to their vast heterogeneity (Chrysanthaki, Fernandes, Smith and Black, 2017).

As noted at the beginning of the chapter, the number of people with dementia is rapidly increasing and it is estimated that one million people will have dementia by 2025 (Wittenberg, Hu, Barraza-Araiza and Rehill, 2019) This demand will quickly out strip the ability of MS to see and diagnose patients, and this has been recognised as a critical future challenge; other models of care have been proposed but, for now, the current model of an MS prevails.

People with dementia have mental health needs and multimorbidity, as well as an estimated 4.6 other conditions. Around one quarter have heart failure, arthritis, diabetes, osteoporosis, and a history of stroke and/or fall (Welsh, 2019). This results in families often being under multiple services, including health, mental health and social services, to ensure their complex needs are met. This is a huge strain for those living with dementia and their families as they must navigate many different systems and often supplement care with support from the voluntary sector. In the current model of care, the focus is predominantly on mental health challenges, to the detriment of the physical health needs of this complex patient population, whose physical health challenges are dealt with in the community in primary care.

In summary, the MS model has evolved over time but has produced several challenges. The lack of a clear definition of what constitutes MS has resulted in great heterogeneity of provision. Moreover, there is concern that the current model is unsustainable given the increasing number of people estimated to need a diagnosis of dementia. People with dementia have complex needs, with most having multimorbidity and requiring support with both health and mental health needs. The current MS are predominantly delivered by mental health trusts who focus mainly on mental health needs. Acknowledging the complexity of care and/or the increasing numbers to diagnose, other models of care have been proposed, including more community-based dementia care led by primary care (Dodd *et al.*, 2014) or brain health clinics (Wellcome Centre for Integrative Imaging, 2022).

## 2.10 Formation of the MSNAP and National Standards

One way of trying to improve quality while overcoming the challenging lack of a consistent definition and purpose of MS has been to develop national standards. In 2009, the Royal College of Psychiatrists identified the need to improve the quality of MS provision and developed and piloted a set of national standards based on the success of quality standards in other disciplines such as primary care for other chronic conditions (Doncaster, McGeorge and Orrell, 2011). It called these quality standards the Memory Services National Accreditation Programme (MSNAP) (Doncaster, McGeorge and Orrell, 2011).

MSNAP accreditation is voluntary and MS who want to take part pay an annual fee. MSNAP includes a definition of what constitutes an MS multidisciplinary team and provides overarching principles of care and a series of standards on provision of care, including staff training. When I started this project in 2016, the fifth MSNAP standards were then current; the latest edition is the seventh, with an eighth update planned this year. Neither MSNAP's definition of AT (contained in overarching Principle 2) nor its standard relating to AT (no. 188) have changed since the fifth edition.

### *2.10.1 MSNAP definitions, overarching principles, standards and training*

MSNAP acknowledges there is no clear definition of MS and that services vary in how they are set up and organised, in who works there, and the services they provide (Royal College of Psychiatrists, 2020). MSNAP does, however, give guidance on what an MS multidisciplinary team (MDT) should include and a definition of AT. Table 2.6 shows the composition of an MDT and the definition of AT, while Table 2.7 presents the overarching principles, of which Principle 2 is relevant to AT provision.

| **Area to define** | **Definition** | **Comments** |
|---|---|---|
| Memory Service MDT | A medical practitioner and two others (mental health nurse, occupational therapist, clinical psychologist, or neuropsychologist)<br>Can access:<br>Peer support worker SALT, dietician, geriatrician, social worker, physiotherapist, geriatrician, old age psychiatrist and neurologist (Royal College of Psychiatrists, 2020) | Note that an occupational therapist is not a compulsory member of the memory service MDT team. This definition allows a wide variation in who can define themselves as an MS, based on the professionals they employ |
| Assistive Technology | 'Devices that promote greater independence by enabling people to perform tasks that they were formerly unable to/or found difficult to accomplish' (Royal College of Psychiatrists, 2020) | Interestingly, there is no clarification on whether this includes non-electronic solutions |

**Table 2.6. MSNAP definitions**

**Overarching principle**

1 'People living with dementia/suspected dementia have fair access to assessment, care and treatment on the basis of need, irrespective of age, gender, social or cultural background, and are not excluded from services because of their diagnosis, age or co-existing disabilities/medical problems' (Royal College of Psychiatrists, 2020)

2 ‘People living with dementia/suspected dementia and their carers receive a service that is person-centred and takes into account their unique and changing personal, psychosocial and physical needs’ (Royal College of Psychiatrists, 2020)

**Table 2.7. Overarching Principles**

The number of evidence-based standards has grown since the fifth edition from 148 to 195 (Royal College of Psychiatrists, 2020). Memory services were accredited using internal and peer review processes. Initially, they were accredited with one of four ratings but later this changed to achieving accreditation or not. Currently, six areas are covered by the standards:

1. Management
2. Resources to support assessment and diagnosis
3. Assessment and diagnosis
4. Ongoing care management and follow-up
5. Pharmacological interventions
6. Psychosocial Interventions

Table 2.8 below gives the standard related to AT.

| **Number** | **Standard** |
|---|---|
| 188 | ‘the memory service has access to advice and support on assistive technology and telecare solutions designed to assist people with activities of daily living’ (Royal College of Psychiatrists, 2020) |

**Table 2.8. MSNAP standard relevant to AT**

With regards to training, clinical staff should complete a minimum training from Health Education England on Dementia Core Skills which includes person-centred care and living well with dementia and promoting independence (Training 7th edition) (Health Education England, 2018). This framework includes the following key learning outcome relevant to AT, found in Table 2.9Table 2.9.

| | |
|---|---|
| **Tier 2—staff regularly work with people with dementia** | ‘be able to incorporate assistive technology to support self-care and meaningful activity’ (Health Education England, 2018) |
| **Tier 3—Key staff (experts) regularly work and provide leadership in transforming care, including social care and managers and leaders** | ‘To be able to lead in the introduction of assistive technology to support self-care and meaningful activity’ (Health Education England, 2018)<br>‘To be able to provide dementia specific advice and guidance in adapting the physical and social environment to ensure physical safety and emotional security’ (Health Education England, 2018) |

**Table 2.9. Learning outcomes regarding AT**

### *2.10.2 Challenges of MSNAP*

Critically, not all MS are accredited. The NHS Care Quality Commission is the national organisation producing compulsory standards of care for health organisations, and there are clear consequences if these are not met. MSNAP accreditation, however, is voluntary and merely requires an annual fee. As of January, 2020 around 70 MS were accredited, fewer than a third of the MS in England, and this figure changes constantly as members join and leave (Royal College of Psychiatrists, 2022). Therefore, it does not cover all MS in England and more MS than not are failing to work towards any agreed standard. Moreover, the standards agreed are often vague and only included if there is an evidence base; this is acceptable for many interventions but for one such as AT, where gathering evidence is inherently difficult, the result is that AT does not feature significantly in the standards.

To define good practice, NHS England and Improvement Cymru commissioned the Centre for Dementia Research at Leeds Beckett University to produce a practical guide on MS (Surr *et al.*, 2021). This guide stresses the need for personalised care and the placement of the person with dementia at the centre of care provision. Although it provides guidance on the MS pathway, including how support is offered at the point of diagnosis (Surr *et al.*, 2021), it has no specific guidance on AT.

## 2.11 Rationale for Research and Aims and Objectives

The following section contains a summary of the limitations of the current literature and how this study builds on these, before stating the aims and objectives of the study.

### *2.11.1 Limitations of the current literature*

There is very little evidence on how people with dementia and carers obtain AT information and are supported to access it via community health and social care, i.e., little is known of what happens in terms of current practice in real world settings. From the literature, we do know families living with dementia are positive about using AT but find it hard both to obtain AT information and to access it. People with dementia and carers, when observed in their own homes, use AT but do not identify this term with what they use. Moreover, family carers were finding their own solutions, which questions whether the current pathway to obtaining AT is working. GPs reported not only that they did not think of AT when they reviewed people with dementia but also that they did not know how to access it. Studies on ethics and the effectiveness of AT have highlighted how the wider ecosystem for AT needs to be considered, including how we assess, implement, and deploy AT. The MS is often the first place from which people with dementia obtain information after diagnosis. However, despite national guidance being developed on how MS should operate, very little guidance is provided with regards to AT.

### *2.11.2 Building on these limitations*

The key areas to work on are:

- To support people with dementia and family carers to obtain information and access AT if they wish to use it. Research is required to explore the current professional practices of MS professionals;
- To explore the views of professionals in terms of AT information provision and supporting access to it;
- To identify barriers and facilitators to giving information on AT and providing AT to people with dementia and to map current care pathways regarding access and provision of AT;

- To address the above gaps, this project explores the knowledge and experiences of MS professionals in providing information on and access to AT.

### *2.11.3 Aims and objectives*

With the background and rationale for research in view, this doctoral thesis aims to understand and explain current information and referral pathways for AT used in dementia care, to identify best practice to enable families living with dementia to have more timely access to AT. I also explore the professional practice of the MS, which is the first to give information to people with dementia after diagnosis. I aim to understand how, when, and in what form they provide information on, and support to access, AT to people with dementia and their family carers, and also why they provide it. Moreover, the goal is to identify any barriers and facilitators to providing information and support to access AT. With these aims in sight, the following objectives are explored:

1. To determine the current practices of MS professionals in the provision of information on, and access to, AT for families living with dementia;
2. To describe and understand the experiences of professionals working in MS of giving information to people with dementia and their family carers and supporting them in accessing AT if they wish to use it;
3. To use data from 1) and 2) to identify good professional practice to support timely access to AT.

# Chapter 3. Methodology and Methods

## 3.1 Introduction

This chapter presents an outline of the processes I undertook to design, develop, and implement the study. As recommended by Silverman (2017), I use the first person to describe the decisions made and challenges faced regarding my methodological and method choices, and data analysis (Silverman, 2017). Firstly, I explain the methodological decisions I made to gather the most appropriate data for the aims and my theoretical perspective. Practical steps to design, distribute, and analyse two national surveys and conduct and analyse qualitative focus groups and one-to one interviews are also described. My choice of framework is explained and important research considerations, such as reflexivity, rigour, and validity, are discussed. The concluding section explores the challenges encountered during each stage of the study, including survey distribution and recruiting to qualitative focus groups and interviews during a pandemic. My original research plans were adapted due to the COVID19 pandemic so that the study could be safely and effectively completed.

## 3.2 Study Design

The aims and objectives of the study are presented in 2.11.3 above. Originally, the study was funded as a three-stage process involving a survey and qualitative interviews and focus groups with professionals, then national qualitative interviews with families with dementia in their own home, and a co-design (Figure 3.1). Because the study was redesigned and refocused due to the COVID19 pandemic (see 3.10 Study Challenges and Having a Flexible Approach), I focused on the first stage and explored the views and experiences of professionals working in MS. This was identified as a gap in the literature in Chapter 2. Figure 3.2 illustrates the study outline concerning the link between the objectives and each stage of the study design.

**WS1- MS: current professional practice re AT**

WS1(a) National Survey: MS

a) Usual care
b) Good practice

WS1(b) Qualitative study: professional practice in usual care and good practice study sites

a) Usual care - Focus Group (n=2)
b) Good practice- 1-1 interviews (n=8)

**WS2- MS: People with dementia and carer views on AT**

1-1 interviews with people with dementia and carers

a) Usual care (n=20)
b) Good practice (n=20)

**WS3 – Co-design of information and referral pathways**

**WS3 (a) Project team workshops**

Develop blueprint of 'best practice' & prototype educational resources

**WS3 (b) Expert Stakeholder task groups**

i) **Health and social care professionals**
ii) **PPI and Alzheimer's Society**

Develop blueprint of 'best practice' & prototype educational resources

**Figure 3.1. Initial study design**

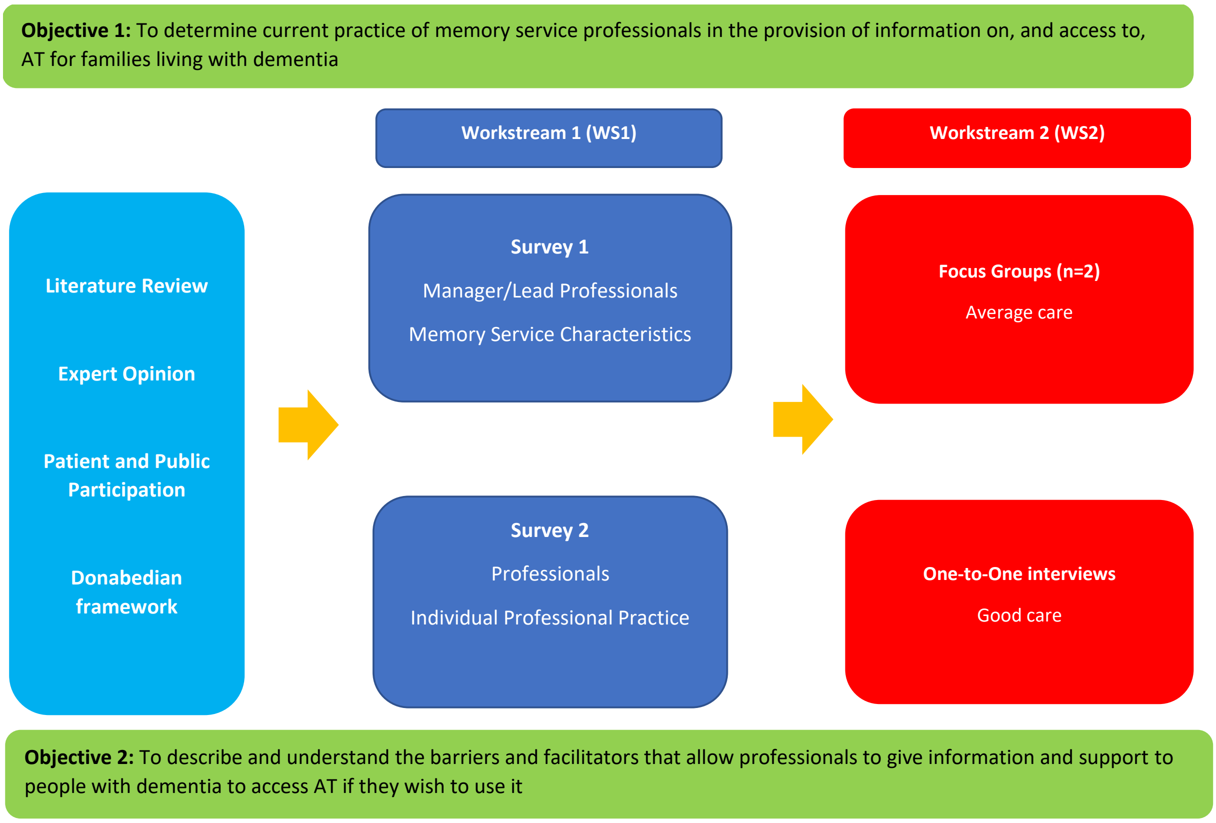

**Figure 3.2. Final study design**

## 3.3 Methodological Considerations: A Predominantly Qualitative Study

In keeping with my pragmatist perspective (see Section 3.5), I chose to do a two-stage study as little is known about current professional practice with regards to AT in MS. The study's main objective was to explore professional practice surrounding AT among MS professionals and therefore this topic is naturally suited to qualitative methods. However, because little is known about what current structures and processes are at play in MS, I chose to start with a survey to obtain a snapshot of current practice. I followed the prominent Morgan's priority-sequential model of 1998 to produce a quant QUAL design, whose principal method is qualitative with a preliminary supplementary quantitative method (Morgan, 1998), as opposed to other strategies which combine both methods.

### *3.3.1 The priority-sequential model: quant QUAL design*

Morgan identified two important decisions required when using both quantitative and qualitative methods: the sequence in which these methods are performed, and which method takes priority (Morgan, 1998). This sequence utilises the idea of complementarity of methods rather than triangulation or convergence and as such allows the smaller survey to help focus purposive sampling and data collection by identifying areas to explore in the larger qualitative work (Morgan, 1998). Each method has a specific complementary role, with the qualitative part being the more substantial. Using more than one method in research is common and it is recognised that mixing quantitative and qualitative methods can gather more data to help understand the complex nature of social phenomena (Caracelli & Greene, 1997 cited in Creswell, Plano Clark, Gutmann and Hanson, 2003). An informed decision was made on the prioritisation and sequencing of the methods (Creswell, Plano Clark, Gutmann and Hanson, 2003) and I based this on pragmatic principles.

### *3.3.2 Quantitative versus qualitative methods*

The first part of the study was a supplementary workstream involving two electronic cross-sectional surveys using Online Surveys (previously called Bristol Online, see Appendix 3). Quantitative methods have specific strengths, as outlined by Castro et al.:

a) accurate operationalisation and measurement of a specific construct;
b) the capacity to conduct group comparisons;
c) the capacity to examine the strength of association between variables of interest;
d) the capacity for model specification and the testing of research hypotheses (Castro, Kellison, Boyd and Kopak, 2010).

However, quantitative methods result in data which do not reflect the real world setting and this has been described as decontextualisation (Viruell-Fuentes, 2007 cited in Castro, Kellison, Boyd and Kopak, 2010). Despite this limitation, quantitative methods can illuminate the current structures and processes at play in the social structure being explored, in this case MS. The data generated from this workstream were then used to inform the second, more substantial or priority stage involving qualitative focus groups and interviews.

This principal, qualitative workstream was used to gather more rich data on the organisational and professional practices at play in MS. Compared to quantitative methods which look to quantify the world around us, qualitative methods aim to develop explanations for the social world. In this study, these are MS, and the meaning and perspectives of the participants, the professionals working in MS. Pope and May eloquently summarise qualitative methods as, ‘reaching the parts other methods cannot reach’ (Pope and Mays, 1995, p. 42). Moreover, unlike quantitative data, qualitative data permit the whole person to be viewed and wholly contextualised (Gelo, Braakman & Benetka, 2008 cited in Castro, Kellison, Boyd and Kopak, 2010). Guba and Lincoln suggest that one strength of qualitative methods is the generation of rich accounts of the emotions, beliefs, and behaviours people experience, which can then be examined in the unique setting in which they occur (Guba & Lincoln, 1994 cited in Castro, Kellison, Boyd and Kopak, 2010).

The qualitative methods used in this study included focus groups and one-to-one interviews. Supplementary quantitative surveys were used to identify MS providing ‘usual care’ around AT in order to recruit for the focus groups. Memory services identified by the survey as providing ‘good practice’ or innovative services with regards to AT were selected as sites for one-to-one interviews. The following section describes why I chose focus groups and interviews for each group and the benefits of using these in combination.

### *3.3.3 Focus groups versus one-to-one interviews*

I decided to use focus groups to explore ‘usual care’ practice in MS because they allowed me to gather simultaneously a range of views from different professionals. Focus groups are a popular method in health care research (Kitzinger, 1995; Barbour, 2018) and can be good for orientating oneself to a new field (Flick, 2018). Moreover, they are a good means of examining experiences and how and why people think and gain knowledge (Kitzinger, 1995). The results of these focus groups informed the semi-structured interviews and individual professional survey results.

There are many definitions of a focus group (Barbour, 2018), but a helpful and pragmatic definition is given by Green and Thorogood:

> In essence, a focus group is a small (usually 6–12 people) group brought together to discuss a particular issue (such as local health services, or a particular health promotion campaign) under the direction of a facilitator, who has a list of topics to discuss (2009, p. 127).

Powell and Single (1996) highlighted that a benefit of focus groups over in-depth interviews is that the researcher can quickly identify a wide range of perspectives on a topic and, due to their inherent nature, they allow participants to expand their contribution based on information raised by others. Despite their positive attributes, focus groups often only allow a superficial exploration of a topic (Powell and Single, 1996). This, however, is adequate for the purpose of the focus group to explore the ‘usual care’ of MS and to build on the results of the survey.

Interviews are commonplace in society and indeed Silverman describes an ‘interview society’, in which we use interviews to make sense of the world around us (Silverman, 1997, p. 248 cited in Gubrium and Holstein, 2002). Qualitative interviews allowed me to explore areas in more depth than during the focus groups. This was particularly relevant to this stage of the study as I wanted to explore why some MS provided ‘good practice’ or extended services. I also used one-to-one interviews with professionals who could not attend the focus groups to ensure I included all relevant stakeholders’ perspectives (Morgan, 1996). These interviews allowed me to probe any areas of interest and explore services in more depth compared to the focus groups. Semi-structured interviews were chosen over structured and in depth interviews because they allowed me to explore predefined areas of interest identified from the survey results; moreover, they provide the scope to explore interesting areas which arise in more depth (Britten, 1995). In summary, I chose to use a combination of focus groups and interviews in the principal study (work stream 2), with each method having different purposes that utilised the strengths of each; it is known that using them in combination can produce richer data (Morgan, 1998).

### 3.4 My Theoretical Perspective

My approach to this study fits most clearly with the philosophical perspective of pragmatism. Pragmatists do not favour one method over another but rather use the method most suited to answering a question in a given situation; this approach fits well with mixed methods research. Morgan (2007) places methodology at the centre of pragmatic knowledge enquiry, with connections to both philosophical assumptions and the practical methods employed, while also acknowledging that how individual researchers make choices regarding research is important and appropriate, based on personal experience and social background and any cultural assumptions they make. This moves away from the traditional top down or hierarchical approach to knowledge generation which prioritises ontology and epistemological considerations (Morgan, 2007).

Pragmatism can be seen as a paradigm (Morgan, 2007) or theoretical framework in which a person's beliefs and values not only include ontological and epistemological assumptions and method preferences, but also issues relating to democracy and social justice (Allemang, Sitter and Dimitropoulos, 2022). John Dewey, a founder of pragmatism, promoted it throughout his career by moving away from abstract thinking around knowledge acquisition to focus more on the importance of human experience; this experience is constructed of individual beliefs and the meanings of human actions (Morgan, 2014). Compared to other perspectives such as post-positivism, pragmatism as a paradigm places value on experience above all else, as well as the continued interaction between beliefs and action (Morgan, 2014). Pragmatists also value 'shared meaning and joint action' (Morgan, 2007); that is, they accept that not everyone has the same understanding—rather, a shared understanding and resulting behaviours come from our shared understanding.

My pragmatic perspective has allowed me to make clear decisions around the topic to study, my research questions, the framework, and the methods I feel were the best to answer these questions. It also helped me to deal with and overcome the numerous challenges which presented themselves during the study (see Section 3.11). This perspective acknowledges my previous experience as a chemical engineer and GP, and how that has influenced my approach to this study.

## 3.5 WS1 National Surveys to Memory Services

Two national surveys were designed, developed, distributed, and analysed. The following sections outline the survey design, including piloting, study population and sampling, dissemination, data collection and analysis.

### *3.5.1 Survey design*

I developed the survey content based on the results of the literature review, expert opinion, the Donabedian framework, and discussion with my supervisors. Experts included leaders in the research field (Gail Mountain, Louise Robinson) and the Chair of the MSNAP, Martin Orell, who is MSNAP's manager and an expert in the structure and priorities of MS in England. The content and layout of the surveys were designed using the training I received on survey design during my Master's in Clinical Research at Newcastle University (Survey Design Handbook, McColl and Thomas, 2016), external training from Bristol University, and relevant literature around survey design (Dillman, 2011; Fowler Jr. and Fowler, 1995; McColl *et al.*, 2001).

Both surveys contained fixed response, Likert scale, and free text questions. The latter were used when it was impossible to have fixed response options due to it being unclear if the fixed responses were required, for example, when professionals refer people with dementia to for AT. Before piloting, I presented my survey and received feedback at a survey training course delivered by Bristol University.

I chose to use an electronic survey method for pragmatic reasons such as the ease of distribution (potentially reaching more professionals and MS), reduced cost compared to postal surveys, easier access to data, and reduced manual data entry (Dillman, 2011). Moreover, this method is now routinely used for survey distribution (Dillman, 2011). Electronic surveys are a widely used and acceptable mode of delivering surveys and have become embedded in culture (Dillman, 2011). From the surveys, my intention was to create a snapshot of MS' structures and processes to inform the next stage of qualitative focus groups and one-to-one interviews, rather than to achieve a representative sample.

Initially, I developed one survey which covered both MS characteristics and professional practice but, after initial piloting, reflection, and discussion with supervisors, I decided to create two surveys to reduce the burden on respondents. This split also ensured that data on characteristics could be provided by one professional or manager with the knowledge and expertise to answer specific questions on structural elements of services, such as commissioning. The result was that one survey was sent to MS managers/lead clinicians focus on specific service characteristics (Survey 1) and another was sent to individual professionals to explore their practices regarding AT (Survey 2).

### *3.5.2 Piloting*

The surveys were piloted with several MS professionals using an iterative process which resulted in the clarification of questions and refinement of the surveys. Figure 3.3 illustrates the piloting process.

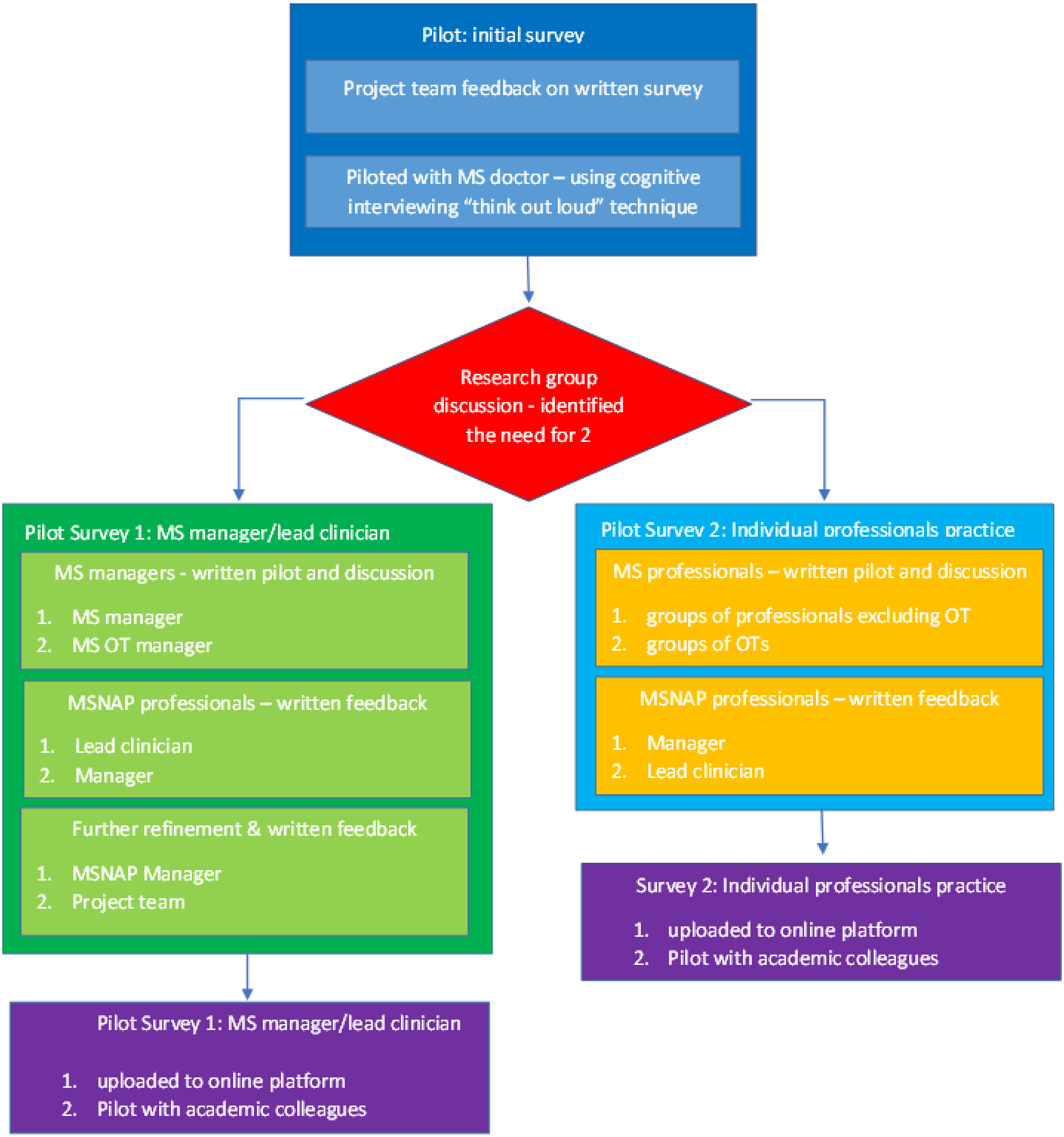

**Figure 3.3. Survey piloting process**

Throughout the piloting, I used cognitive interviewing, which is a structured method of critically evaluating written materials to ensure the recipient has received the intended information correctly (Willis, 2004). It uses two techniques called think aloud and verbal probing to clarify whether the recipient or subject understands the questions as the design intends (Willis, 2004). I decided to try both techniques during the initial pilot of the survey, i.e., before there were two surveys, when all the questions on MS characteristics and individual professionals' practices remained in combination. Working with a psychiatrist in the MS at the Centre for Ageing and Vitality at Newcastle University, I quickly realised not only that I needed to clarify some questions but also, crucially, that two discrete surveys were needed. Moreover, when I asked my participant probing questions on service characteristics and requested that they think out loud, I realised they were not the right person to answer the questions. At the end of this process, I decided that twin surveys were needed for two reasons: first, so that the survey questions could be answered by the correct people; and, second, so that the survey was not overly burdensome to participants.

The original survey was thus split into two surveys incorporating the feedback from the first pilot. I hoped to use cognitive interviewing with individual professionals working in a local MS I had approached to help with piloting but, unfortunately, I relied on service managers to gain access to professionals. Despite asking to meet individual professionals for the pilot, I was faced with a large multidisciplinary group of more than ten MS professionals and so I had to alter my pilot to explain the survey with everyone to check content, understanding, and layout. Although I was disappointed not to continue cognitive interviewing, the experience was still fruitful and allowed me to refine the two surveys further. Unfortunately, occupational therapists, a key group with regards to AT, could not attend so a further pilot was set up with them. I incorporated the feedback for the second pilot and then met with six occupational therapists as a group to go through the survey. Covering each question in turn, I used probing and think aloud questions. After gathering all this feedback and updating the survey, I uploaded both surveys to Bristol's online portal. I had to change the format of some of the survey questions due to technical constraints with the online platform's question design. I then piloted both online surveys with three clinical academic colleagues and incorporated their feedback.

### *3.5.3 Study population*

This study explores the practice of MS professionals regarding AT, and thus there are two types of study population to consider: individual MS, and individual health professionals working in MS. First, I looked to identify how many MS there were in the UK and if there was a list of these, but there was no main list of MS in England. Although the national MS audit included 222 services (Royal College of Psychiatrists, 2015), not all MS were included and so it was anticipated that the actual number was higher. During the distribution of the survey to MS, a number of issues became evident. For example, not all MS consisted of a single clinic with professionals. An MS could consist of a trust or site with multiple clinics which were defined as one MS; in contrast, one hospital trust or site could define itself as having multiple MS. This reflects the MSNAP guidance and literature on what is an MS (see Chapter 2).

I used MSNAP guidance stipulating which professionals can work in an MS. This guidance gives the combination of professionals deemed essential and those deemed additional (see Chapter 2). Individual professionals included but were not limited to doctors (psychiatrists, geriatrics, or neurologists), mental health nurses, occupational therapists (OT), clinical psychologists or neuropsychologists, social workers, physiotherapists or healthcare assistants. My definition for the study was any professional who encountered a person with dementia and gave them information or potentially supported someone to gain access to AT if they wished to use it.

### *3.5.4 Sampling*

The purpose of the sampling strategy was to include as many MS as possible as well as a wide range of professionals who see people with dementia, enabling as much data as possible to be gathered. Managers, lead clinicians and professionals currently working in an MS in England, and who had direct contact with people living with dementia, were included in the study.

### *3.5.5 Survey dissemination*

I approached the Chair of the Royal College of Psychiatrists' Memory Services National Accreditation Programme and its manager to see if I could use the national audit list and secure their help to distribute the survey. Unfortunately, they did not agree to this as they felt it would be overly burdensome to MS as they had not signed up to being asked to complete more surveys. They suggested that I use their Memory-Chat e-mail discussion group for MSNAP members as a forum for distributing the survey. Unfortunately, despite two reminder e-mails, only 57 professionals completed the survey, with a response rate of 10.6%. As the survey was funded by a national charity, it was possible to add it to the NIHR portfolio. The survey was then also distributed by the National Institute for Health Research Clinical Research Network Portfolio to 42 hospital trusts, and thus it reached over 117 MS. For more information on the challenges of distributing the survey, please see Section 3.10.

### *3.5.6 Data collection*

The survey was self-administered and web-based using the Bristol online survey portal. I made a pragmatic decision to use an online survey to attempt to reach as many professionals as possible. As noted, the surveys used a fixed response, Likert scale, and open-ended questions. Fixed response questions were used to gather information on topics where there was a clear answer, such as whether training was provided or a protocol existed. Likert scales were used to explore confidence, such as in providing information on AT. Open-ended questions were used for topics where there was little information on referral processes.

### *3.5.7 Data analysis*

This section describes the analysis of the free text comment data from the quantitative and qualitative surveys, which I decided to do separately. Descriptive statistics were used to describe quantitative survey data using STATA software (version 16.0). This involved extracting data from the Bristol online portal and developing a data codebook to help interpret the data from the statistical package. Copies of the surveys can be found in Appendix 3. Before data analysis began, I had to learn to use STATA via online training (Stata, 2022), reading the literature (Survey Design and Analysis Services, 2018), and discussions with my supervisor, Joy Adamson. The free text questions were analysed individually, like a transcript, and then as a whole data set. Free text comments and transcripts were analysed separately. I used thematic analysis (Braun and Clarke, 2006) and was guided by the experience I gained on the Master's in Clinical Research qualitative data analysis module, other courses I had attended, and guidance from my supervisors. Qualitative data were analysed iteratively and inductively.

## 3.6 Qualitative interviews and focus groups

The results of both surveys to MS professionals were used to inform the principal qualitative phase of the study. Combinations of qualitative methods were used in this phase of the study, including focus groups and one-to-one interviews. The focus groups were used to explore MS 'usual care' with regards to AT, and the one-to-one interviews were used to explore 'good practice' or services which provided innovative AT services.

### *3.6.1 Study design*

The interview schedules developed for the focus groups and semi-structured interviews were based on the literature review and survey results as well as the Donabedian framework on structure, process, and outcome. During the semi-structured interviews, I also used each participant's answers as prompts to the survey to explore areas that arose about the service, such as the provision of training, demonstrations, or personalised solutions. I used a telephone or online platform to interview participants from MS throughout England. Although interviewing participants using online platforms was unfamiliar to me, it is slowly becoming more common for qualitative research (Archibald, Ambagtsheer, Casey and Lawless, 2019). I chose to use the platform which professionals were already using for their clinical work, and mostly this was Microsoft Teams.

### *3.6.2 Study population*

The survey population included MS in England who had completed the initial survey.

### *3.6.3 Study sampling*

The survey results were used to stratify MS into groups:

1. Memory services which provide 'usual care' regarding AT;
2. Memory services which provided 'good practice' regarding AT and included:
    a. Providing training and/or having a protocol on AT and/or lead AT professional
    b. In-house OT and /or social worker
    c. Providing a demonstration of AT
    d. Provision of group education
    e. Forming links with research
    f. Forming collaborations with NHS, voluntary, private and local authority organisations.

### *3.6.4 Study Recruitment*

The method of approach was different for the focus groups and one-to-one interviews. The focus group participants were recruited via the study sponsor Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW). Research leads for each MS within the sponsor trust were approached by the sponsor contact, which also worked for the National Institute for Health Research (NIHR) portfolio team. The research lead was asked to approach professional members of the MS, explain the study, and ask for potential participants. The professionals in the focus groups were not chosen so as to represent a typical MS team. Due to the challenges of having to recruit through a pandemic, I had to be pragmatic in my choice of participants, but this has likely led to more motivated and interested participants. The first focus group was conducted before the COVID19 pandemic, was face to face, and involved more participants. The second was during the second wave of the COVID19 pandemic and was conducted via Microsoft Teams. Unfortunately, only three professionals could attend the second focus group. The research lead explained that many potential participants were too busy due to increased clinical demands because of the pandemic. Participants who were interested in the study but could not attend the focus group were offered a one-to-one interview. One consultant psychiatrist took up this offer and had a one-to-one interview via Microsoft Teams.

Interview participants were approached directly after providing consent when they had completed the online survey. Participants were approached using an e-mail which included details of the survey and a copy of the participant information leaflet. Two reminder e-mails were sent. The interview participants were purposively sampled (Patton, 1990) to include managers/lead clinicians from sites providing 'good' or extended services. One participant no longer worked at the service but discussed with a colleague who took over her role and they consented to be interviewed. Initially, I approached one participant working in MS who was doing additional work around AT, aiming to have one manager/lead professional from each site. A site was defined as an individual hospital trust. However, due to the ongoing pandemic, recruitment became incredibly frustrating and challenging, and after discussion with my supervisors, I opened recruitment to services providing average provision and to more than one professional from each trust/site.

### *3.6.5 Data collection*

I conducted focus groups under observation by my supervisor, Professor Louise Robinson. The first was face to face at the MS and the second was via Microsoft Teams. Interviews used a mixture of telephone or Microsoft Teams or Zoom. A university approved digital device recorded the focus groups and interviews. Both were guided by schedules which were refined between focus groups/interviews. I used a conversational approach to put participants at ease and encourage discussion. The results from the interview participants were also used to help direct questions. I actively encouraged all participants' views and took notes during the focus groups and interviews, and later wrote up reflective notes.

### *3.6.6 Data analysis*

I followed Braun and Clarke's six phases of thematic data analysis (Braun and Clarke, 2006). Data analysis was iterative and evolved over the course of collection. Telephone interviews were analysed first and then the focus groups and the additional focus group interview. Box 1 at the end of the chapter provides a description of the qualitative data analysis (see Supplementary Box 1: Qualitative data analysis journey).

## 3.7 Deciding on the Study Framework

Having considered several frameworks, I decided to use the Donabedian as:

a) It is simple and fitted naturally with my training as a chemical engineer; as an engineer, I am trained to examine materials, processes, and outcomes and how these interrelate and affect one another;
b) The study explores how MS work regarding AT; to this end, I needed to understand what resources and processes they had, and again this fitted well with the simpler Donabedian framework;
c) It fitted well with my pragmatic perspective concerning the elements of structure, process and outcome which can be explored by viewing participants' experiences and the meanings of their actions.

Table 3.1 outlines the six frameworks I considered, including the Donabedian. The following section describes the Donabedian framework and how it fits with my study.

| Theoretical Framework | Description | Positives | Negatives |
|---|---|---|---|
| **Normalisation process theory (May *et al.*, 2007)** | Used to explain processes by which a complex intervention is embedded into practice. Uses a formal structure to identify factors that promote or inhibit a complex intervention, embedded in four categories:<br>1. interactional workability<br>2. relational integration<br>3. skill-set workability<br>4. contextual integration | Very comprehensive and uses questions to help guide data gathering on the inhibitors and promoters for the adoption of a complex intervention. The aim is to normalise the intervention into routine practice | My study involves exploring an existing intervention of which we have very little knowledge. I found this a good theory but too complex for the purpose of my study |
| **Consolidated framework for the implementation of research (Damschroder *et al.*, 2009)** | A construct developed by pulling together many theories and which fits in five domains:<br>1. intervention characteristics<br>2. outer setting<br>3. inner setting<br>4. characteristics of the individuals involved | Looks at what works but also where and why. Pulls together many theories and frameworks into one and describes itself as 'meta-theoretical'. Builds on a previous model of Greenhalgh et al. | Although I found some elements of this theory helpful and formative, similar to normalisation process theory, I found it too complex for my study |

| | | | |
|---|---|---|---|
| | 5. the process of implementation | (Greenhalgh *et al.*, 2004)<br>Provides a list of constructs for identifying barriers to the adoption of a complex intervention | |
| **Implementation of change model (Grol *et al.*, 2007)** | This model was developed to help plan change and has ten stages under five domains:<br>1. Orientation<br>- Awareness of intervention<br>- Interest, involvement<br>2. Insight<br>- Understanding<br>- Insight into own routines<br>3. Acceptance<br>- Positive attitude<br>- Decision to change<br>4. Change<br>- Actual adoption, try out<br>- Confirmation of change<br>5. Maintenance | Integrates several psychological and behavioural theories to produce a ten-step framework to explore why change occurs. Helps identify barriers to change and steps to overcome them based on psychological and behavioural theory | This model would have been helpful to explore why some MS professionals and organisations may be doing more than others, but it did not help me frame other factors that may influence change |

|  |  |  |  |
|---|---|---|---|
|  | - New practice integrated into routines<br>- New practices integrated into organisation |  |  |
| **Theory of change (De Silva *et al.*, 2014)** | Builds on the MRC complex intervention framework to include the theory change; a pragmatic framework to explain how an intervention effects change (De Silva *et al.*, 2014) | This framework helps obtain more depth on why change does or does not occur at each stage of the MRC complex intervention framework | Although this was interesting and would be helpful for any intervention, I found it too complex for my study as I wanted to determine what was currently happening on the ground, and I was not introducing an intervention |
| **Non-adoption, abandonment, scale-up, spread, and sustainability (NASSS) framework (Hendy *et al.*, 2012)** | It includes questions on seven domains:<br>1. condition or illness<br>2. technology<br>3. value propositions<br>4. adopter system (comprising professional staff, patient, and lay caregivers), the organisation(s) | Identifies challenges over the seven domains and categorises them as simple or complex. The domains are very helpful and include aspects such as whether the technology would be funded as well as | This was an excellent framework but focused on the adoption of individual devices, whereas my focus is on all the AT |

|  |  |  |  |
|---|---|---|---|
|  | 5. wider (institutional and societal) context<br>6. interaction and mutual adaptation between all these domains over time | professional and organisational factors. Relates to technology adoption which has specific challenges |  |
| **Donabedian framework (Donabedian, 1988)** | This framework consists of only three areas and helps explore how we measure quality in healthcare. The three areas are:<br>1. Structure<br>2. Process<br>3. Outcome<br>These are explained more in the following section | Aims to link the key components affecting delivery of healthcare, including the structural elements of organisations, processes at play, and health outcomes. It is simple and looks to understand the entire process |  |

**Table 3.1. Potential frameworks**

Donabedian’s seminal framework has three key areas: structure, process, and outcome (Donabedian, 1988). I used each area to help focus data collection. Figure 3.4 outlines each area with respect to this study, and it is followed by an explanation of each area and specific questions to explore within them.

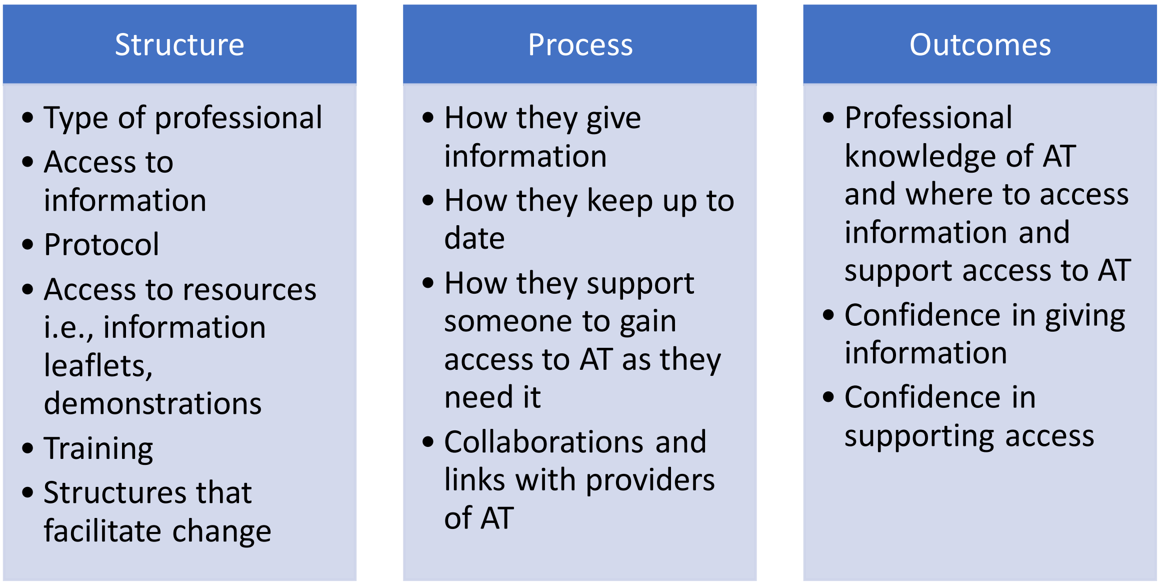

**Figure 3.4. Donabedian framework in relation to this study**

Structure is defined by Donabedian as 'the attributes of the settings in which care occurs' (Donabedian, 1988, p. 1745) and can include the materials, staff, and organisational structures. In my study, this relates to considering how professionals provide information and support to access AT in MS, through the following questions:

1. Which professionals work in the MS, including an AT lead?
2. What professional information sources are available to staff?
3. Does the MS have a protocol on AT?
4. What resources on AT are available to staff, such as information leaflets and access to demonstration facilities?
5. Does the MS provide training on AT?
6. How is the MS organised to implement post-diagnostic support on AT?
7. Are there structural processes to facilitate change?

However, there is no single clear MS structure as these vary in the composition of their staff, purpose, and available resources (see Chapter 2). This study therefore explored structural aspects to see which structural areas facilitated, or were barriers to, information provision and support to access AT.

Process is defined as ‘what is actually done in giving and receiving care’ (Donabedian, 1988, p. 1745). In this study, the key process areas included:

1. How do professionals keep up to date with available technology?
2. Which current pathways are available to professionals to obtain and provide information on AT and to support families to gain access to AT?
3. How do the professionals provide information on AT?
4. How do the professionals support someone with dementia and their family to gain access to AT if they wish to use it?
5. Do the professionals refer a person to be assessed for AT themselves or signpost?
6. On an organisational level, how do MS form collaborations and link to external providers of AT to provide information and support access to it?

This study explored which process areas facilitated, or were barriers to, the professionals giving information or support to access AT.

Outcome is defined as ‘the effects of care on the health status of patients and populations’ (Donabedian, 1988, p. 1745). In this study outcome is more challenging to gather data on as memory services do not routinely monitor their performance regarding AT. Indeed, there are no agreed standards to what comprises good practice with regards AT information provision or support with access. Standards in the MSNAP guidance are vague and not prescriptive enough to outline which outcomes are desirable (see Chapter 2). Clear outcomes are desirable to good service delivery regarding AT and may be identified from this study. However, I explored professional knowledge and how confident professionals were at providing information or supporting access. For this study, the outcome area I explored was:

1. How do the current structural and process elements of MS and the pathways available impact on individual professional practices, views, and experiences of providing information and supporting people with dementia to access AT?

Ideally, in the wider context of AT delivery in MS, it would have been interesting to explore how the knowledge of people with dementia and their family carers improved, or how satisfied they were with the current service. Unfortunately, I was unable to interview these potential participants as planned and instead had to focus on professionals (see Section 3.11). With regards MS provision of AT many outcomes could be explored, over and above giving information on and supporting access to AT, including whether MS provides AT, whether it is used by individuals and helpful for them to live independently. Research outcome measures, specific for AT used in dementia, are discussed further in section 9.3.3.

## 3.8 Research Considerations: Reflexivity, Rigour and Validity

The following subsections explore the key research considerations of reflexivity, rigour, and validity.

### *3.8.1 Reflexivity*

In keeping with my pragmatic perspective, I acknowledge I have had an active role in how I chose a study to conduct and how I approached generating knowledge throughout it. My background as a chemical engineer and GP has rightly or wrongly influenced my approach, as has my personal experience of dementia and the challenges people living with it face. These social and personal experiences have influenced how I approached decisions on the methods and gathering and analysis of data, and how I chose to frame the study using the Donabedian framework. The methods I employed to be reflexive included a research journal and notebook on evolving themes and discussing data generated with my supervisors. I kept a research journal and later a notebook on data analysis where I would note and record my thoughts about important areas of interest and emerging themes. I also wrote about how focus groups and interviews went and noted interactions. For instance, during one focus group, the manager was trying to sell me the service, which I interpreted to be because of my role as a local GP. During focus groups and interviews, it was evident my role as a GP was influencing the data collection as some participants assumed I knew about certain service characteristics, but many also seemed to be more open with a fellow clinician working during the pandemic.

I had regular meetings with my supervisors and discussed study design, methods selection, and data collection and analysis. During these meetings, I was challenged about my assumptions or approach and was stretched to question my approach to data collection and analysis and learn about my skills in data collection. For instance, as a GP, I am naturally prompt and summarise as a recognised technique (Neighbour, 2018) in consultations, but I actively had to try and shed these methods during interviews. My supervisor, Professor Louise Robinson, was present at both of my focus groups, and after the first she gave me feedback by giving me an example of when I had used a more clinical technique and advised this could be seen as leading. I reflected on this in my journal and actively worked to prevent it happening again in future focus groups and interviews. This was very challenging as my consultation skills have developed over many years and become natural and so it was difficult not to regress into more comfortable methods of conversing during data collection.

### *3.8.2 Rigour and validity*

Although most of the data generated were from the qualitative research phase, most of the methods employed to ensure rigour can include those most often associated with quantitative research, such as reliability, validity, and generalisability (Noble and Smith, 2015). A checklist such as the COREQ (Booth *et al.*, 2014) is a requirement for NHS ethics and HRA approval. It includes a large, detailed list of areas to consider such as approach and sampling. During my application to the HRA, I had to complete the checklist and this was helpful as a prompt but, as Barbour notes in her critique of using a checklist, it is not a 'systematic and thorough application of the principles of qualitative research' (Barbour, 2001, p. 1115).

One way to address concerns over the trustworthiness of results is to consider the study's validity. In this vein, Polit and Beck defined validity as the 'degree to which inferences made in a study are accurate and well-founded' (Polit & Beck, 2008, p. 745 cited in Morse, 2015). Several methods have been identified to show validity in qualitative research (Morse, 2015), and Creswell advised researchers to engage with at least two (Creswell and Poth, 2016). To ensure the research had trustworthy findings, I employed several techniques, such as ensuring an adequate and appropriate sample size, negative case analysis, understanding and factoring in researcher background and bias, and supervisor review and debriefing.

Ensuring the sample size was adequate and appropriate was incredibly challenging due to trying to recruit during a global pandemic (see Section 3.11). However, with great effort and persistence, I managed to recruit sufficient participants, and this was suggested during the data analyses and writing up as the same topics and themes arose repeatedly. As such, the sample provides a sufficient theoretical account (Dey, 1999). Critically, it must be noted that the decision to stop collecting data was also influenced by the ongoing pandemic and the ability to recruit participants. Positively, participants described both their own and others' experiences, defined as 'shadow data', meaning the 'true' number of participants was greater than those recruited to the study (Morse, 2015).

Another method I used to ensure the trustworthiness of the data was through actively looking for deviant cases (Mays and Pope, 2000), i.e., data which were different or stood out from other data during analysis. I also purposively sampled deviant sites which did not provide typical MS provision via one-to-one interview. For instance, this might be selecting non-NHS sites such as an MS run by a not-for-profit organisation or a site which collaborates with health and social care to provide a dementia pathway. Deviant cases where participants had different views or experiences from the 'norm' allowed me to explore areas they illuminated in more depth by comparing them with other transcripts and then exploring in further depth in future interviews.

Understanding my background and how it impacted the study design and data collection was also important to ensure the trustworthiness of the findings. My background is as a chemical engineer and GP. My engineering background naturally lent me to prefer frameworks such as the Donabedian framework as it fitted naturally with my experience and perspective as an engineer. My role as a GP may have influenced data collection during focus groups and interviews as I would refer to my local MS and thus the professionals and managers/leads' responses may have been influenced because I was another professional who routinely referred into MS. In one focus group, it did feel this was the case as the manager seemed to sell the service and explain how quickly they 'saw patient from referral', which was very different from my experience as a clinician. However, I actively worked to gain rapport at the start of the focus group or interview by explaining the study and my role, allowing me to gain rapport with the participants and appear less threatening.

Finally, I also discussed focus groups and interviews with my supervisors. One supervisor was the second person at both focus groups. After each, we debriefed and I reflected on my performance and ability to gather data. The feedback was used in subsequent focus groups or interviews. I shared my writing with my supervisor, who gave feedback and helped me ensure that my work was of an appropriate standard and valid.

### 3.9 Ethics and HRA Approvals

NHS ethics was not required as no NHS patients were involved. Instead, Newcastle University Ethics Committee granted approval (Ref: 2821/2017), as did the NHS Health Research Authority (HRA) (IRAS ID 230850). Halfway through this stage of the study, an amendment was required due to the COVID19 pandemic to change how the participants were approached and to allow the use of online meeting platforms to conduct focus groups and interviews. Further amendments were required to extend the time and use online methods of data collection. These amendments are given in Appendix 9.

### 3.10 Study Challenges and Having a Flexible Approach

During the study I encountered numerous challenges, described in depth in Appendix 10. They included the challenge of having no clear definition of what constitutes an MS and the multiple terms used for an MS by participating professionals and sites. Approaching MS was difficult as there is no national list. Initially, I used MSNAP but had to reassess my approach when few responses to the survey were received. I then used the NIHR CRN network and this was successful at recruiting sites for the survey distribution but involved numerous governance challenges, including navigating ethical and HRA approvals and amendments and managing NIHR portfolio research accruals. This was challenging due to the number of sites (42) involved, as each site required a contract and thus each amendment, even one as simple as an extension of time, had to be updated at each site. My study was also sponsored by the local mental health trust CNTW and during the study I had two sponsor site audits.

The COVID19 pandemic brought further challenges. Recruiting to qualitative focus groups and interviews became impossible and, as a result, I had to redesign the project. The ongoing uncertainty surrounding the pandemic made it challenging to complete data collection and so I decided to convert to an MD. I also had to change how I conducted qualitative research to include online platforms. Finally, during my studies I had three changes of supervisors. This was challenging as I had to keep developing relationships with different supervisors but, fortunately, they were all incredibly supportive and helped me adapt. Figure 3.5 presents more information.

### 3.11 Chapter Summary

In summary, this chapter has outlined how I designed, developed, and implemented the study using a pragmatic approach, and gives an account of the process I undertook to increase validity of the findings. It also describes the enormous challenges I experienced during the completion of the study. The following chapter introduces the results.

1. I first familiarised myself with the transcripts from the focus groups and interviews by reading and checking them against the digital audio recordings. Free text comments from the survey were collated under each free text question and treated individually like a transcript. This was often a few weeks after the data had been collected and allowed me to familiarise myself with them. I read and re-read each transcript line by line looking for interesting comments, actions or repetitions and anything that stood out. Interesting excerpts were highlighted, and initial thoughts were noted down at the side of the transcript. I tried to be as inclusive as possible at this stage in terms of everything I found interesting or which stood out. I also found it helpful to have a notebook to write down anything of interest in the data. After I made the initial transcript, I often found data that were familiar from other transcripts, but also some that were surprising and I made a note of this at the side.
2. I then generated initial codes by re-reading each transcript and noting down initial codes which highlighted interesting features in the data. I did this for individual transcripts and then the entire data set. I analysed the free text comment data first as these were used to inform the qualitative focus groups and one-to-one interviews. This was an iterative process, during which, if a code seemed to work, I challenged its use and went back and refined codes or developed new ones. I continued to use a notepad for my thoughts about each transcript to help me familiarise myself with the data. I reflected throughout this process and it sometimes resulted in restarting the analysis on a full transcript with a clean copy, as with the first focus group. I found the gap in studies due to COVID19 resulted in having to re-familiarise myself with the data. As this progressed, I became more confident in which areas should be coded and in the codes I was generating. This took some time as occasionally I felt overwhelmed with data. I also actively looked for and noted down any deviant cases that stood out as different or contradictory to the rest of the data set (Mays and Pope, 2000). At first, I used NVivo but this hindered my thought process and instead I worked with paper as I am more visual; this helped me become more intimate with the data. I used tables to organise codes with excerpts. At first, I tended to use more semantic coding but actively tried to see latent codes (Braun and Clarke, 2006).
3. Having generated initial codes, I then grouped these into potential themes. This sometimes involved promoting an important code to a theme, e.g., ‘Timing is not easy’ and clustering together similar codes under one theme. I did this by using sticky notes of codes and moving them around to help identify themes. This again was an iterative process and involved looking at all the codes and how they inter-related; I found drawing this out helpful to try and make connections. I then collated data under themes. At this stage, I tried to work out what story the data were telling me. I found it challenging to step away from the detail and to look at the wider picture and this took numerous iterations. I used the initial theme to develop thematic maps to identify connections and see relationships and contrasts in the data.

4. Once I had a set of themes, I went through each and reflected on whether it worked for the data and refined the theme names. At each stage, I redrew the thematic map. I used the themes to develop thematic maps to identify connections and see relationships and contrasts in the data. I then refined the maps further. I found this helpful as it allowed me to see the data better. This was used to refine the themes further and identify the whole story described by the data set.
5. Once I was satisfied with the generated themes, I ensured each had a label; sometimes I tended to use domain summary types of theme names, but after reflection and discussion with my supervisor I moved away from this . I wrote a paragraph explaining each theme to distil what each theme represented. This again made me reflect and refine the themes further. I revised my naming of themes after reviewing the data, reflecting, and discussing with my supervisors. At times I felt overwhelmed with data and had to decide which themes were essential and helped tell the story being generated. It was hard to let go of data.
6. I then started writing up the results and themes as a report with commentary and excerpts of data. This was again iterative and involved revising structure and themes to ensure I could tell the story the data were presenting. At this stage, I tried relating data to the wider research question. I also had to let go of non-essential data and this was extremely challenging and involved several iterations. However, what did help was producing a PowerPoint presentation and presenting the data to my supervisors. This helped crystallise the overall story the data were telling. Eventually, I produced three thesis chapters on the main story of the data.

**Figure 3.5. Qualitative data analysis journey**

# Chapter 4. Overview of Results

## 4.1 Introduction

This short chapter begins with a description of how the data are presented in the empirical chapters, and then gives an overview of participant recruitment for the surveys, focus groups, and one-to-one interviews. It ends with an overview of the empirical chapters.

## 4.2 Data Presentation

### *4.2.1 Surveys*

Excerpts from the participants' free text comments are used to illustrate the themes which arose from the qualitative analysis provided in Section 5.3. Each participant in both surveys was allocated a unique identifier, starting with the letter P. I also included gender, role and years working with people with dementia.

### *4.2.2 Focus groups and interviews*

In the results chapters, focus group participants are identified by the focus group number and a participant number, e.g., FG1 P1. Their professional role within the memory service is also included. For the interview participants, these are identified with TI and then a participant number, e.g., TI1, and I also included whether, at the time of the interview, they were a manager or lead clinician; if they were from a professional group, their professional role within the memory service is also identified.

## 4.3 Surveys

The following subsections outline the survey response rate, demographics of the participants, and quantity of free text comments.

### *4.3.1 Survey response rate*

An initial approach to memory services was made via the Royal College of Psychiatry Memory Service National Accreditation Programme (MSNAP). Their Memory-Chat distribution list, which is a discussion group of MSNAP members, was used to identify potential sites/members (n=537 members) as candidates for participation. However, only 57 members completed the survey, despite being sent two reminders, leaving a response rate of 10.6%. The survey was then distributed via the NIHR (National Institute for Health Research) to 15 CRNs (clinical research networks) in England, who advertised the study to at least 54 hospital trusts. Using this information and the information from the first distribution method, the survey reached 42 trusts and at least 117 memory services (MS). Definitions of what constituted a service varied from trust to trust, with some indicating they had one overarching MS across multiple sites and others defining several different services across their geographic spread. In 2014, there were an estimated 222 MS in England (Royal College of Psychiatrists, 2015), and so the surveys reached approximately half (55%) of the MS in England. Since there is no up-to-date list of MS or staff, it is impossible to calculate an accurate total response rate. However, with each trust distributing the survey separately, response rates within trusts ranged between 18–93% for those trusts which became involved with the distribution of the survey and responded to calls for data on its distribution. Further details are given in Appendix 4.

### *4.3.2 Survey participant demographics*

Participant demographics were analysed using descriptive statistics with the aid of STATA (version 16.1). Eighty-seven managers or lead clinicians and 578 healthcare professionals completed Survey 2. There was a wide range of professionals (Figure 4.1) and several lead clinicians and managers who completed Survey 1 (Figure 4.4). Of the 87 MS managers/lead clinicians who completed Survey 1 on MS characteristics, 37 (43%) were managers and 39 (45%) lead clinicians, with 11 (12%) stating they had other roles (see Appendix 5). Professionals who completed the Survey 2 included: nurses (n=242, 42%), doctors (n=85, 15%), and occupational therapists (n=79, 14%), as well as other professionals such as psychologists (n=30, 5%) and various support staff who selected other as their role (n=142, 25%) (see Appendix 5). This wide variation in types of professional role aligns with other research on MS (Chrysanthaki, Fernandes, Smith and Black, 2017).

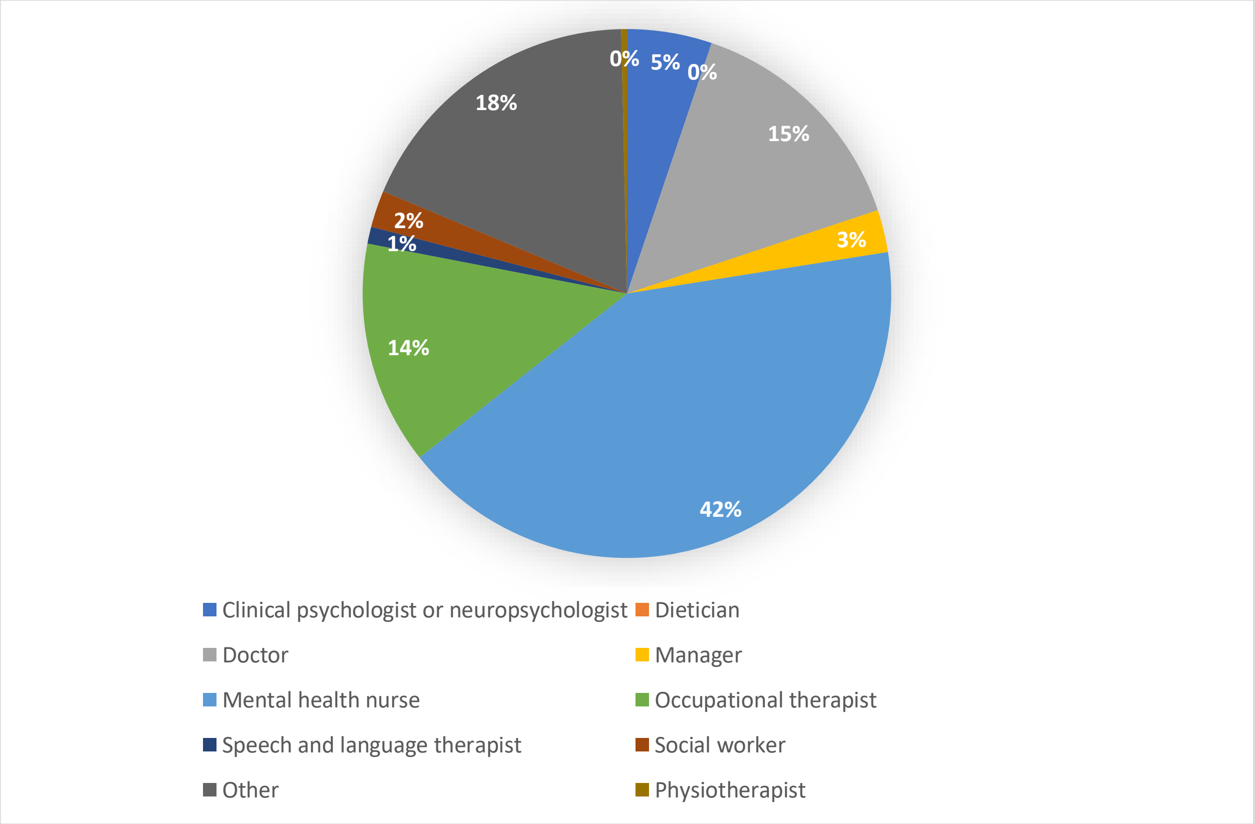

**Figure 4.1. Survey 2 professionals' group**

Most of the participants were female (manager/lead clinician survey, n=73 [84%]; healthcare professional survey, n=70 [81%]), as would be expected in health settings (NHS Employers, 2019) (see Figure 4.2 and Figure 4.5). Most of the responding professionals had worked with people with dementia for a considerable length of time, averaging over 13 years, while for the managers/lead clinicians this figure was 18 years (see Figure 4.3 and Figure 4.6).

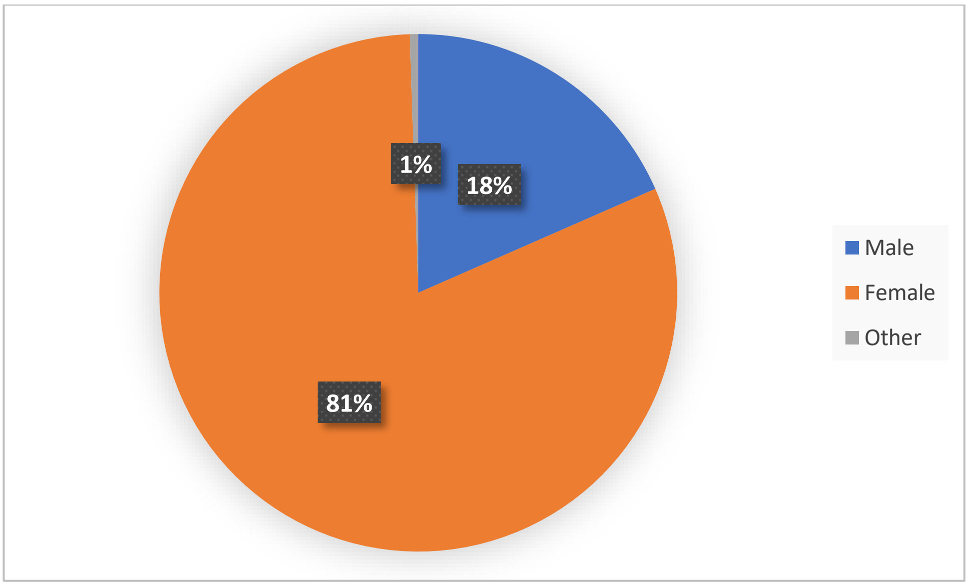

**Figure 4.2. Gender breakdown of the professionals taking Survey 2**

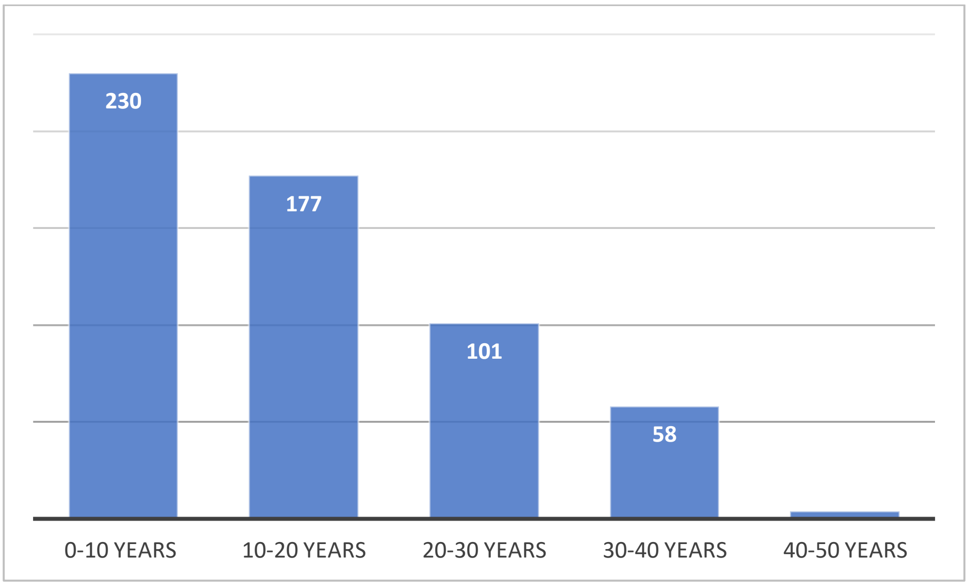

**Figure 4.3. Time the surveyed professionals spent working with people with dementia**

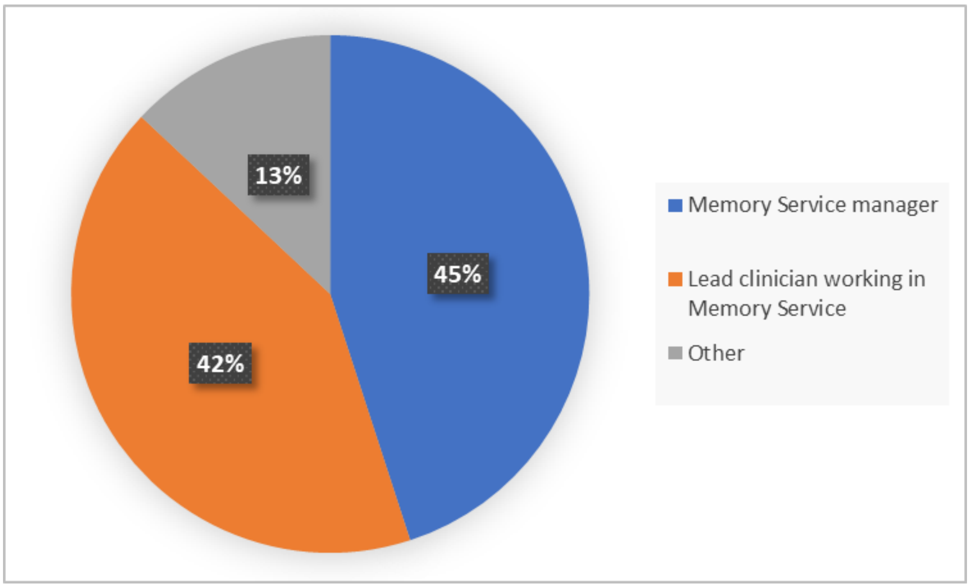

Figure 4.4. Manager/lead clinician roles of Survey 1 participants

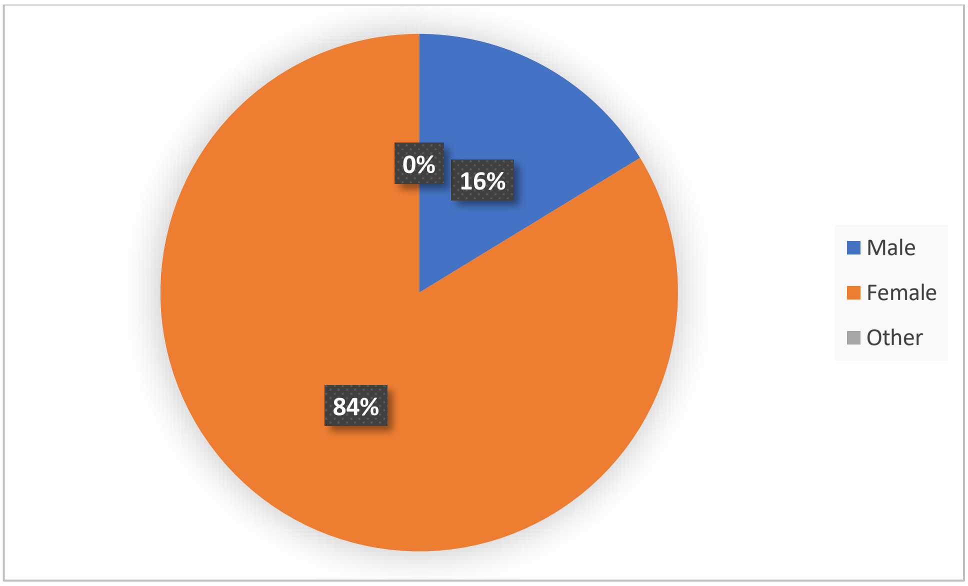

Figure 4.5. Gender breakdown of managers/lead professionals taking Survey 1

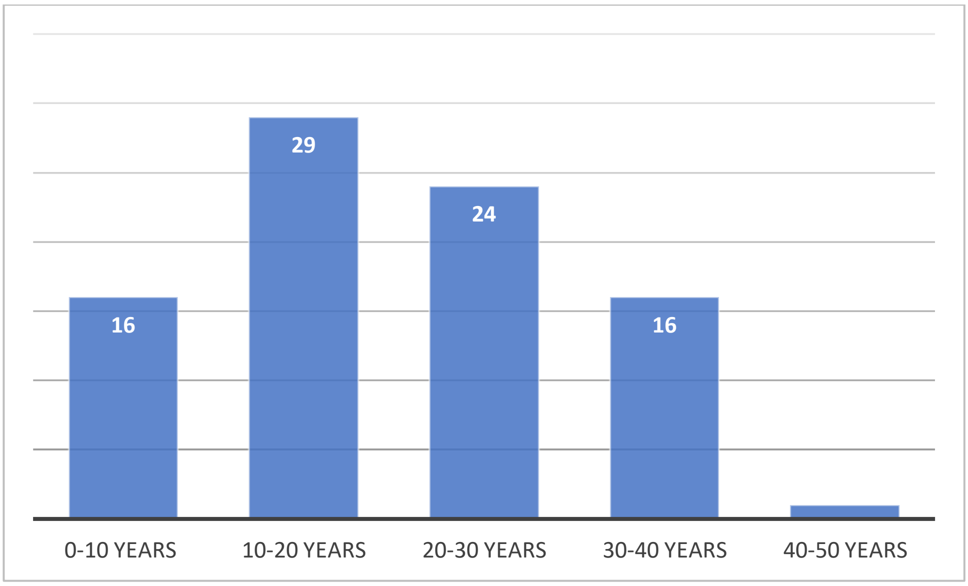

**Figure 4.6. Time the surveyed managers/lead clinicians spent working with people with dementia**

### *4.3.3 Quantity of free text comments*

The full list of all free text comments is presented in Appendix 8. Table 4.1 and Table 4.2 list the major free text comments, i.e., comments in response to a specific question rather than those requesting further information, such as asking for more detail when an ‘other option’ choice was selected, e.g., role from managers/lead clinicians and professionals, respectively. Table 4.1 and 4.2 includes the number of responses for each free text question to illustrate the size of the data set analysed.

| **Question Number** | **Free text comment question** | **Number completed (%)** |
|---|---|---|
| 10c | If only if required [to give information on AT], please give details on why information would be provided and who you would give information to? | 45 (52%) |
| 11aiaii | What criteria is used to make the decision on whether to discuss Assistive Technology? Please provide details in the box provided | 39 (45%) |
| 11aiaiii | What provision is in place for other people with dementia [those who have not had AT discussed with them]? Please give details in the box provided: | 39 (45%) |

| | | |
|---|---|---|
| 13. | Does your Memory Services offer extended services regarding Assistive Technology? If yes, please give details below: | 45 (52%) |
| 14 | Does your Memory Services have access to local initiatives on Assistive Technology? If yes, please give details below: | 53 (60%) |
| 15 | If you have any further comments or suggestions, please use the free text box below. | 49 (56%) |

**Table 4.1. Table Manager or lead clinician free text comments**

| Question Number | Free text comment question | Number completed (%) |
|---|---|---|
| 9. | What prompted you to discuss Assistive Technology with the person with dementia? Please give details in the box below: | 351 (61%) |
| 10. | Where would you refer someone to access assistive technology? Please give details: | 542 (94%) |
| 11a | What made you decide to refer [referred in the last week]? Please give details in the box below: | 271 (47%) |
| 12 | We are really interested in finding out if you have access to any innovative resources to help give information and refer people with dementia to access assistive technology. This may be training materials, websites or local initiatives which help you give people with dementia information or access assistive technology. Please give information in the box below: | 335 (58%) |
| 13 | We are really interested in your view on helping people with dementia obtain information on Assistive Technology or to support them access Assistive Technology. If you have any further comments or suggestions, please use the free text box below. | 233 (40%) |

**Table 4.2. Survey 2 (professional survey) free text comments**

## 4.1 Focus groups and interviews

### *4.1.1 Introduce*

The following subsections outline the recruitment for the focus group and interviews, as well as participant demographics.

### *4.1.2 Recruitment*

Two focus groups were conducted, the first of which comprised eight participants and the second of which had three. A further telephone interview was completed with a clinical psychiatrist who could not attend the second focus group as planned (as per the protocol). Table 4.3 summarises participant demographics. Ten interviews were conducted, nine with memory services managers or lead clinicians and one additional interview with a psychiatrist (FG2 Extra TI) as noted. The nine interviews with managers and lead clinicians included five telephone interviews and four interviews using Microsoft Teams. These participants were a mixture of managers and lead professionals in purposively sampled trusts/sites offering different extended services, and health, voluntary and not-for-profit organisations. Due to the challenges of recruiting managers and lead professionals during the COVID19 pandemic, I also purposively sampled services providing 'usual care'. Table 4.4 presents the demographics for these participants.

### *4.1.3 Participant demographics*

| ***Focus Group (FG) 1*** | | |
|---|---|---|
| ***Participant*** | ***Gender*** | ***Profession*** |
| FG1 P1 | Female | Clinical psychologist |
| FG1 P2 | Female | Nurse |
| FG1 P3 | Female | Nurse |
| FG1 P4 | Female | Specialist doctor |
| FG1 P5 | Female | Clinical lead |
| FG1 P6 | Female | Occupational therapist |
| FG1 P7 | Female | Occupational therapist |
| FG1 P8 | Female | Nurse |

| *Focus Group 2* | | |
|---|---|---|
| FG2 P1 | Female | Nurse |
| FG2 P2 | Female | Occupational therapist |
| FG2 P3 | Female | Occupational therapist |
| FG 2 Extra TI | Male | Psychiatrist |

**Table 4.3. Participant demographics of the focus group professionals**

| **Telephone** | | | | |
|---|---|---|---|---|
| ***Participant*** | ***Gender*** | ***Role*** | ***Years working in dementia*** | ***Extended services*** |
| TI 1 | Female | Lead clinician | 12 | Educational groups<br>Lead occupational therapist (Master's in AT)<br>Links with local authority<br>Memory service teaching on AT<br>Staff attend conferences & share learning<br>Images of AT—information giving<br>Links to local demonstration rooms |
| TI2 | Female | Manager | 15 | Memory Pathway (trust, Alzheimer's Society, local authority)<br>Links with Alzheimer's Society advisors |

| | | | | |
|---|---|---|---|---|
| | | | | Integrated dementia pathways—voluntary and hospital trust<br>Links with local early dementia and support organisation |
| TI3 | Female | Lead clinician | 4 | Not-for-profit organisation<br>Links with research<br>Occupational therapist lead<br>External training AT |
| TI4 | Female | Manager | 14 | None |
| TI8 | Female | Lead clinician | 25 | Links with research |
| **Microsoft Teams** | | | | |
| TI5 | Female | Manager | 18 | Educational group discusses AT<br>Links with local dementia service |
| TI6 | Female | Manager | 28 | Memory group discusses AT<br>Links with voluntary organisation which supplies AT |
| TI7 | Female | Manager | 30 | Links with AT research<br>External training on AT<br>Outside speaker<br>Local demonstration site<br>Dementia navigators |
| TI9 | Female | Clinical lead | 19 | None |

**Table 4.4. Participant demographics for semi-structured interview professionals**

## 4.2 Overview of Empirical Chapters (Chapters 5–8)

Chapter Five presents the results of both surveys and gives an overview of the current MS characteristics and professional practice regarding AT. The results from Chapter Five were used to inform the qualitative focus groups and interviews with professionals. The findings from the focus groups and interviews are given in Chapters Six, Seven and Eight. Further details of these empirical chapters are given below:

| | |
|---|---|
| **Chapter 5** | **National Survey of Memory Services: an overview of service characteristics and individual professional practice**<br>Chapter 5 presents the results of both surveys and gives an overview of MS characteristics and the practice of individual professionals. |
| **Chapter 6** | **Memory Services Enactment in Practice**<br>Chapter 6 gives an overview of the current AT pathway and the resulting consequences for MS users and professionals. |
| **Chapter 7** | **Challenges and Solutions**<br>Chapter 7 explores the challenges faced by MS professionals when enacting AT and solutions identified by participants, where applicable. |
| **Chapter 8** | **Factors Influencing Memory Services’ Ability to Enact AT: information, support, and access**<br>Chapter 8 explores the external and internal factors influencing MS’ ability to enact AT. |

An important and common theme identified throughout the data collection is information provision. This thread runs through all the empirical results chapters in various forms, including how professionals gave information, where and how professionals obtained information on AT, both to share with service users and keep up to date, and how challenging it is to obtain information on AT and associated costs. As such, information provision is an important and crucial theme which is explored in all the results and discussion chapter.

### 4.3 Chapter Summary

This brief chapter has described how data are presented in the empirical chapters. It gives an overview of how participants were recruited to both supplementary quantitative surveys and the principal qualitative stream, demonstrating that a wide range of participants was involved in the study.

# Chapter 5. National Surveys to Memory Services: An Overview of Service Characteristics and Individual Professional Practice

## 5.1 Introduction

The aim of the surveys was to gain an overview of current MS characteristics and professional practice regarding AT, to inform the qualitative stage of the study. In this chapter, an outline is provided of the results of two national surveys sent to MS in England. One survey explored MS characteristics, including the provision of resources for professionals (such as training) and protocols within MS; it also identified the lead professionals on AT. The second survey explored individual professional practices in terms how information and support for access to AT were provided to people with dementia. Donabedian’s structure, process, outcome framework, was used to map the data from both surveys and to answer the following questions regarding MS characteristics and professional practices:

A. What structural resources do MS professionals have at their disposal to equip them to provide information on AT and to support access to AT for families living with dementia?
B. What current pathways are available to professionals to obtain and provide information on AT and to support families to access AT?
C. How do the current structural and process elements of MS and available pathways impact individual professional practices, views, and experiences of providing information and supporting people with dementia to access AT?

This was a pragmatic survey due to the complexity of identifying MS and the challenges of survey distribution (Chapter 3). This chapter begins by describing the quantitative results of both surveys with some descriptive free text analysis results, and then the results of text analyses. This is then followed by a discussion of key areas of interest to be explored further in the qualitative work with professionals.

## 5.2 Quantitative Results with Selected Explanatory Free Text Analysis Results

The following section outlines the quantitative results of both surveys with some explanatory free text analysis. These results provide further detail on, for example, the types of information which were provided and to whom the professionals referred. The results are categorised into three sections corresponding to each of the questions regarding MS characteristics and professional practices given in Section 5.1:

A. Memory service structure
B. Memory service processes
C. Individual professional practice

The following sections present the findings relevant to each of these aspects.

### *5.2.1 Memory service structure*

Elements of MS structure were evaluated to determine if its services support professionals providing patients with AT information and support to access. Table 5.1 summarises the main quantitative results regarding MS structure, highlighting a wide variation in the provision of resources by MS. Each key area on MS structure and processes is described, including the service commissioning and internal and external resources available to MS professionals.

| **Memory Service Characteristic regarding AT** | **Percentage (95% confidence interval)** |
|---|---|
| ***Commissioned to:*** | |
| Give information on assistive technology | 21.8% (14.8–31.1) |
| Support access to assistive technology | 21.8% (14.0–32.5) |
| Provide formal follow-up—general post-diagnostic care | 78.2% (67.2–86.2) |
| ***Provide:*** | |
| Protocol on assistive technology | 6.9% (3.2–14.2) |
| Training on assistive technology | 31.0% (20.7–43.7) |
| A named professional responsible for AT | 37.9% (25.2–52.6) |
| ***Key professional or resource to refer to:*** | |
| Occupational therapist as part of core team | 80.5% (69.2–88.3) |
| Occupational therapist | 19.5% (11.7–30.8) |
| Social services as part of core team | 14.5% (7.8–25.2) |
| Social services | 83.1% (73.1–89.9) |
| Local demonstrator site | 12.2% (6.1–22.8) |

**Table 5.1. Memory Service characteristics regarding AT**

With regards to the commissioning of services, 21.8% (n=19) of the managers/lead professionals stated they were commissioned to provide information on AT. This formed part of the post-diagnostic support they were commissioned to provide, which included education, information provision, and signposting. Providing post-diagnostic information often required utilising internal and external resources such as an in-house occupational therapist (if available) or external organisations such as local telecare companies or research groups.

Some 21.8% (n=19) of MS were commissioned to support access to in-house services to providing AT to people with dementia. 52% (n=10) described the pivotal role of an occupational therapist (42% [n=8] had an in-house OT and 11% [n=2] used external ones) in assessing and referring (if required) to services to provide AT to enable someone with dementia to live independently in their own home. Only a few MS professionals had been trained to assess for AT. However, not all the managers described in-house services when asked to provide more detail, and instead described the local services to which they could refer (e.g., their local Social Service AT team or a local authority occupational therapist specialising in AT).

There was considerable variation in the formal follow-up of a person with dementia by MS. After their initial assessment, such follow-ups represent another opportunity not only to provide information on AT to people with dementia but also to support their access to it. 78.2% (n=68) of the managers/lead clinicians stated that their MS provided formal follow-ups, but the analysis of their free text comments highlighted a large variation in the amount, type, and timing of these follow-ups. Many MS only provided a formal follow-up if a person was prescribed medication, needed a care plan meeting, or had outstanding issues or needs identified in the assessment. For the latter, typical needs might be behavioural needs, interventional requirements (e.g., aids and devices), or a need for additional care or counselling. Follow-up was often provided in groups; those services who provided one-to-one follow-up noted they were finding it increasingly difficult to provide individual follow-up due to an increasing number of referrals to MS. In-house follow-up was provided by various professionals and was often dependent on the needs identified e.g., behavioural issues would be managed by a clinical psychologist while interventional needs would be dealt with by an occupational therapist. Follow-up was often provided by MS, but some liaised with other in-trust services, such as the Community Mental Health Team for those with advanced dementia, or with external third-sector organisations such as the Alzheimer's Society.

Another aspect which varies considerably is the timing of general MS follow-ups. Most followed up for short periods of time and then discharged after an episode of care of between 2–4, 6 or 12 months. Many MS only reviewed people with dementia at 12 months if they were taking medication. Follow-up was then provided by the GP (general practitioner) of the person with dementia or by other agencies/third-sector organisations. Some did have structured review periods but this varied between MS, with some only reviewing once while others reviewed at intervals or provided post-diagnostic reviews from 'diagnosis to end of life'. The location of the follow-up was generally at an MS clinic or the home of the individual with dementia.

Although the commissioning of general and AT services was deemed important by the professionals, they also described how few internal resources were available to them. However, these resources varied between MS and not all professionals had access to key resources such as training on AT. Table 4.1 above illustrates key MS characteristics as identified by the manager/lead clinician survey. These characteristics and other key elements of the internal structure identified by both surveys' quantitative and free text comments are described below.

Only 6.9% (n=6) of the managers/lead clinicians said they had a protocol for AT. Some 31.0% (n=7) said their MS provided training on AT, including in-house training (16.1%, n=14), training by external providers (14.9%, n=13), provision of reading materials (6.9%, n=6), online tutorials (1.2%, n=1), or via clinical supervision (1.2%, n=1) and feedback from the occupational therapist to the MS team (1.2%, n=1). Only 15% (n=9) of those managers/lead professionals who did not provide training said they planned to introduce training. 37.9% (n=33) of the managers/lead clinicians said they had a named professional responsible for AT; 93.9% (n=31) stated this was an occupational therapist and 6.1% (n=2) stated this was a mental health associate practitioner or an occupational therapist working as part of a research team. The analysis of free text comments again identified an in-house occupational therapist to be pivotal as a source of knowledge on AT, but many also provided training to their colleagues (see Section 5.3.3 for more detail).

In England, key professionals and organisations who can support people with dementia to access AT are occupational therapists and social services. 80.5% (n=70) of managers/lead professionals can refer to an occupational therapist as part of their core team and 19.5% (n=17) can refer to an occupational therapist. However, fewer could refer to social services as part of their core team, and more referred to social services outside their core team (83.1%, n=69). Again, the analysis of free text comments identified occupational therapists as pivotal to assessing, identifying AT, and referring for assessment (see Section 5.3.3 for more detail).

Leaflets and brochures were valued by professionals as aids to AT information dissemination. Professionals used leaflets developed and provided either internally by the MS or externally via social services/local authorities, private providers, or voluntary organisations such as the Alzheimer's Society. Leaflets provided by MS and social services/local authorities might include the contact details of local providers and local and national websites giving information or providing AT (e.g., Dementia/Ask Sara, Unforgettable, AT Dementia, the Alzheimer's Society, Tippisnow, Glorious Opportunity). Concerns were raised by some professionals that locally developed leaflets could become out of date due to staff not having time to update them. Many professionals used a private provider leaflet but acknowledged this and informed people with dementia that some advertised AT might be found cheaper elsewhere (e.g., Amazon). A few professionals said they had no AT leaflet to give people with dementia but would welcome having some.

Some 12.2% (n=11) of managers/lead professionals stated they could refer to a local demonstrator site. Many professionals would like the opportunity to have examples of AT to show to people with dementia when they share information or discuss AT. They also wanted to try AT themselves to be confident about what they were recommending. Some MS had already realised the potential of demonstrating AT to people with dementia and offered varying levels of demonstration from a 'box of tricks' to show simple AT to more complex integrated 'live' telecare demonstrator rooms. Other MS simply displayed AT in waiting rooms via simple images/posters and leaflets, or had more technological methods such as tablet demonstrations or waiting room TV presentations. The ability to demonstrate AT is discussed further in Section 5.3.5 on the free text analysis theme of potential solutions.

Analysis of free text comments showed MS had several external resources available to them; however, these varied between MS and often reflected local services which were available on AT and local collaborations with a third sector organisation, local authority, research team or private provider. Professionals utilised many national voluntary organisations such as the Alzheimer's Society and the Disability Living Foundation (DLF) but also physical health charities such as Parkinson UK (United Kingdom), the Blind Association, and the Royal National Institute of Blind People. Some professionals described links with national private suppliers of specific

AT, such as monitoring systems (e.g., Canary Care and Just Checking), auto stove turn-off (e.g., home.org), GPS trackers (e.g., Buddi.co.uk) or interactive tablets with prompts and reminiscence materials (e.g., myhomehelper.co.uk).

Memory services described utilising many local resources. This included local telecare companies (either through social services/local authority), third-sector organisations, housing, fire and rescue, and private organisations. Social services/local authorities were often mentioned, with each local area providing different levels of services from telecare, equipment stores, demonstrator rooms or a dedicated AT team. However, some professionals highlighted limitations with the services provided, including services being abandoned, limited AT provided through social services, or previously helpful services losing key staff, resulting in information being out of date.

Several MS described their local collaborations with third-sector organisations such as the Alzheimer's Society or social services/local authorities. Some local third-sector organisations had people who could provide information on AT or support to access it (e.g., dementia guides or advisors). Some local Alzheimer's Society teams had formed close collaborations with their local MS and were undertaking the role of information provision and signposting. Other MS worked closely with their local authority to provide staff training and updates on AT. A few MS had formed more sophisticated collaborations. One was with the local Alzheimer's Society team and NHS trust for the delivery of a dementia pathway, and another was between local authorities and a Clinical Commissioning Group (CCG). Many MS described forging close links with local research projects on AT (e.g., THIM, test-bed research, electronic bikes, a DESCANT study and virtual reality). They described referring people to the research team to try AT but also used this team as a source of AT information and/or training.

### *5.2.2 Memory service processes*

The evaluation of processes involved exploring how the professionals were providing information on AT to people with dementia as well as supporting them to access it. Data from both surveys are drawn upon to provide information on these processes and the main ones described below concern information and referral pathways, and discussing AT.

The survey data highlighted a complex system regarding how information on AT is obtained. There was no clear pathway either for professionals to obtain information or for them to direct people with dementia along so that they could find further information. The professionals believed it was important to raise awareness of AT and to provide information on AT used in dementia care. Information provision was important to raise awareness of AT, provide choice, and aid future planning. They believed raising awareness of AT is important both for people with dementia and professionals, and some were concerned AT could be overlooked as an intervention.

Information was not provided to all people with dementia at the initial assessment; the free text analysis highlighted how many professionals did give basic information and signposting as part of their post-diagnostic discussion, but only provided more tailored and comprehensive information if they identified a need or risk. Many utilised collaborations with voluntary organisations and deferred information provision on AT to them. The professionals believed information has to be tailored to the individual, with some believing it should be given at various stages as required. The form of information delivery varied between MS. For example, some provided an information leaflet or signposted to websites (e.g., the Alzheimer's Society and many others) or gave invitations to education sessions where AT was discussed or demonstrated via pictures, or in demonstration rooms when available. Several professionals stressed how many people they see have no internet access and cautioned on over-reliance of this as a mode of information provision. The equipment and resources used by the professionals to support information provision varied between MS, and each had developed their own practice in this regard.

The professionals found that both the information designed for themselves as professionals and that suited to people with dementia originated from several sources. Many used the Alzheimer's Society for professional information (69.1%, n=399) and for information for people with dementia (79.2%, n=458) but they also used local social services (information source for professionals 75.4%, n=435; information source for people with dementia 76.2%, n=440). However, they also used multifarious internet resources and organisations. Many obtained information from an occupational therapist (information source for professionals 92.2%, n=533; information source for people with dementia 92%, n=532) or a social worker (information source for professionals 39.7%, n=300; information source for people with dementia 38%, n=220).

Both surveys explored the discussion of AT with people with dementia and, in most cases, the professionals did so only if required, such as when a need or risk was identified, where the risk was viewed negatively, and AT could help. Others discussed AT to raise awareness for current and potential future use, often when they had previous positive experience of AT, or they perceived the person lacked AT knowledge. Other reasons why the professionals discussed AT were: if they observed verbal or visual cues during the consultation (e.g., difficulty in performing specific tasks or a decline in functioning); if a person with dementia already used technology; or, if a person with dementia or a carer raised the possibility and they were open to its use. This could be a general enquiry or in response to a specific concern such as the person with dementia being unable to respond to emergencies or if they did not want a carer. Some professionals said discussing AT formed part of their normal professional practice as part of their diagnostic discussion and routinely discussed specific AT, such as pendant alarms and medibox prompts. Others referred to another team member, e.g., an occupational therapist, or to MS education sessions or voluntary organisations which could discuss AT.

The professionals were asked to quantify the number of people with dementia with whom they had discussed AT in the previous week, and 577 responded. More than a quarter had not discussed AT (28.3%, n=163), while 15.6% (n=90) had discussed AT with all the people with dementia they had seen. Similar findings were evident in the manager/lead clinician survey, in which it was found that only 16.1% (n=14) of managers/lead clinicians responded that AT had been discussed (n=87 answered the question) with all those with dementia at their initial assessment. Around half (52.1%, n=45) of the managers/lead clinicians who said AT had not been discussed at the initial assessment stated that the professionals performed triage to determine which patients they should discuss AT with. Those professionals performing such triage for AT included: mental health nurses (41.1%), occupational therapists (31.5%), old age psychiatrists (20.6%), clinical psychologists or neuropsychologists (11.0%), social workers (6.8%), and a myriad of ‘other’ professionals (6.8%), e.g., Alzheimer’s Society Dementia support worker, speciality doctor, mental health worker, adult nurse, or support worker.

The professionals were also asked how many people with dementia they had referred for AT assessment in the last week and 574 responded. Half (52.8%, n=303) had not referred anyone, while just 4.9% (n=28) had referred all those they had seen. In general, professionals refer a person with dementia because of an identified risk or need. An elevated or increasing level of risk/need would trigger a referral. Primarily, the professionals were concerned about risk versus safety, where risk was viewed negatively. Identified risks often related to people living at home, being alone, when performing specific tasks (e.g., cooking, night-time toilet visits, or leaving the house). Risk was often related to specific locations such as the kitchen, outside the house, or when there was a concern a person with dementia would not respond to an immediate threat such as a fire or flood. Individual needs varied and could be specific to a specific situation (e.g., being outside a great deal or forgetting medications), or a need for a specific type of AT. Professionals also referred people with dementia for AT if they declined to have formal carers and wanted to stay at home. AT was viewed as a solution to problems encountered but also a tool to manage risk.

### *5.2.3 Individual professional practice*

The evaluation of outcomes explores the impact on professional practice and how the professionals experienced information provision and supporting access to AT for people with dementia. In the following sections, there is a description of their attitudes and experiences in this regard, starting with two key outcome areas: professionals' knowledge and experience of AT.

**The professionals were given a list of common ATs available for dementia care and support, and asked about their awareness of them. Most were aware of some devices used in dementia (**

Table 5.2).

| **AT Device** | **n, %, 95% CI** |
|---|---|
| Clocks to aid orientation (e.g., night and day display) | 558, 96.5%, (94.3–97.9) |
| Pendant alarms | 551, 95.3%, (93.2–96.8) |
| Medication reminders and dispensers (e.g., electronic pill dispensers) | 553, 95.7%, (93.9–97.0) |
| Smoke detectors | 553, 95.7%, (93.6–97.1) |
| Carbon monoxide detectors | 536, 92.7%, (89.9–94.8) |
| Signs, notices, and other environmental aids | 519, 89.8%, (86.2–92.6) |
| GPS technology to aid safe walking | 445, 77.0%, (73.0–80.3) |
| Simplified telephones (e.g., with pictures and speed dial) | 463, 80.1%, (75.2–84.2) |
| Gas detectors | 463, 80.1%, (76.1–83.6) |
| Reminiscence materials | 448, 77.5% (72.7–81.7) |

| | |
|---|---|
| Activity monitors | 396, 68.5%, (64.6–72.1) |
| Simplified remote controls (TV and radio) | 395, 68.3%, (63.4–72.9) |
| Item locator devices | 307, 53.1%, (48.2–58.0) |
| Talking mats | 266, 46.0%, (41.5–50.6) |
| Extreme temperature detectors | 247, 42.7% (37.5–48.2) |
| Other **(see Appendix 3Surveys**) | 47, 8.1% (6.3–10.4) |

**Table 5.2. Knowledge of AT**

The most widely known AT devices were clocks to aid orientation (96.5%) and medication reminders and dispensers (96.5%). In contrast, only 46% of respondents were aware of talking mats; 8.1% (n=47) provided other examples of AT, including a varied range of low- and high-tech AT. Examples within the ‘other’ range were activities of daily living (ADL) aids and signage, more complex systems to monitor movement, hazards and raise alarms, and apps and prompts to aid memory using existing technology such as smart phones or artificial intelligence systems such as Alexa.

Although most professionals had knowledge of a range of AT, many reflected in free text comments that they potentially had a knowledge gap, had little training on AT, and found it hard to maintain pace with changes in technology (see Section 5.33). They were positive about receiving further information and clarity around information and referral pathways.

More than 60% of the professionals stated they were confident about knowing where to obtain professional information on AT, and even more (70%) were confident they knew where to direct people with dementia and family carers for information on AT (Figure 5.1).

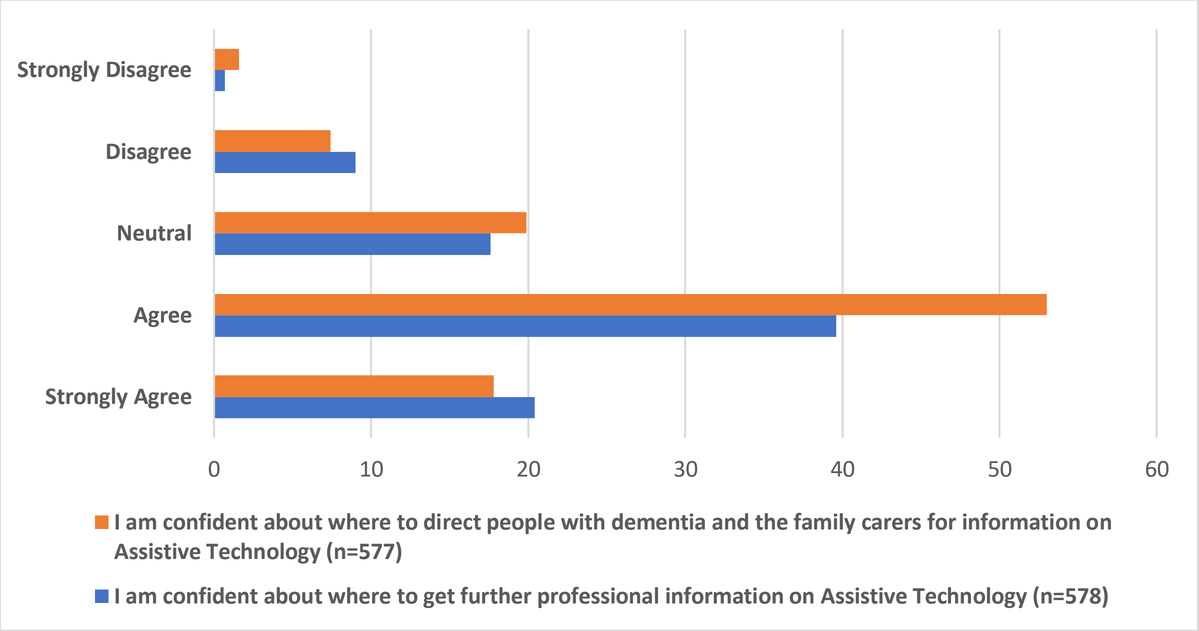

**Figure 5.1. Confidence about where to obtain AT information**

The professionals were asked how confident they were at giving information on and supporting access to AT. More than 60% were either confident or really confident at giving information on AT and more than 55% were confident or really confident at supporting access on AT (Figure 5.2).

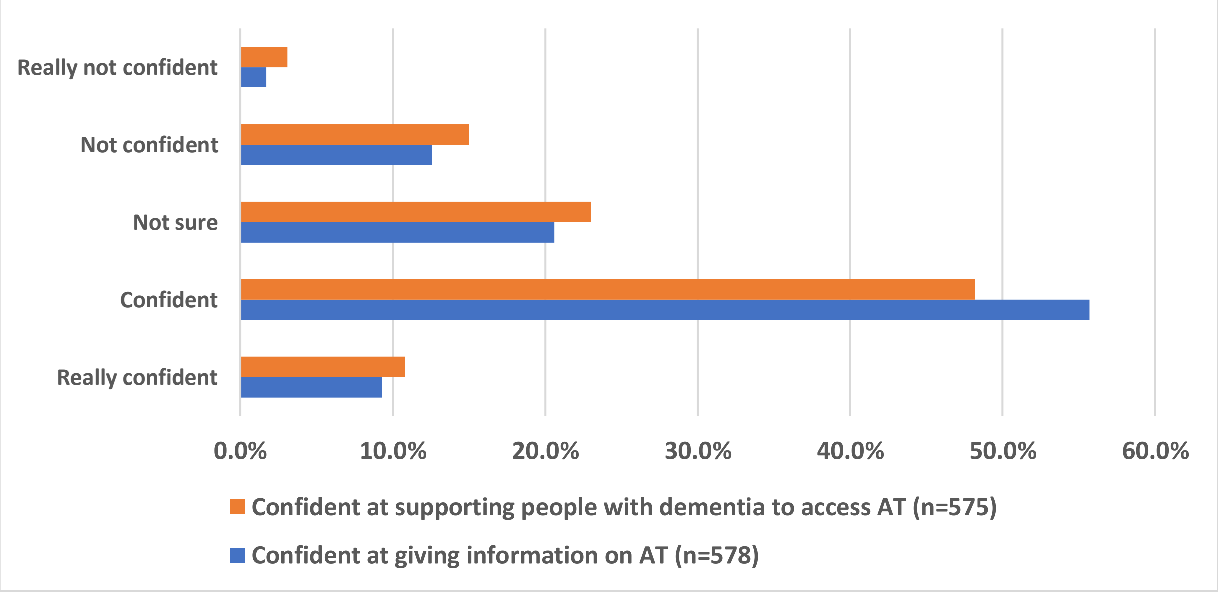

**Figure 5.2. Confidence at giving information and supporting access to AT**

## 5.3 Themes Emerging from the Qualitative Analysis

The analysis of the free text comments (see 3Chapter 3. Methodology and Methods) produced five themes related to professional practice around information sharing and supporting access to AT:

1. Views on AT
2. Balancing needs and risks
3. Challenges around professional knowledge
4. Lack of a clear AT pathway
5. Potential solutions

In this section, I use excerpts from participants' free text comments to illustrate these five themes. The methods of analysis are described in Chapter 3.

### *5.3.1 Views of AT*

The professionals described AT as a solution to a problem encountered by people with dementia when performing everyday tasks:

> They raised an issue I thought could be solved or helped by assistive technology. P115: Female, Assistant Practitioner, 5 years working with people with dementia
>
> Noncompliance of medication and to support the patient live more independently and safely without the need for extra care. P318: Female, Senior Practitioner, 24 years working with people with dementia

Professionals reported that there were many aspects of AT that could be helpful for people with dementia and their carers, particularly around how AT can support the continuation of independent living. These aspects not only include supporting, prolonging, and maintaining independence, helping with the performance of daily tasks and self-care, but also helping people with dementia to cope by empowering them and improving social connections:

> Maintaining them in their own home. Increasing their safety. Alleviating pressure off family members. P199: Female, Social Worker, 4 years working with people with dementia
>
> I feel assistive technology is really important for helping patients/ carers with dementia to empower them to remain as independent as possible and also in some cases alleviate caring tasks/ offer peace of mind. P35: Female, Mental Health Nurse, 15 years working with people with dementia

Respondents also mentioned AT being helpful and supporting independent living when someone with dementia refused to have formal carers:

> Risks identified with cooking and leaving the door unlocked. Family are reluctant to agree to carer input as the person with dementia does not want this in place. To maintain safety and independence. P372: Female, OT, 7 years working with people with dementia

Participants also highlighted the positive aspects of AT for carers of people living with dementia, finding that the carers appreciated how AT could provide reassurance and peace of mind, and reduce stress:

> In my view, these methods used for patients with dementia are appreciated by patients and their families. I was asked for the above assistive technology by family members who live abroad and were concerned about their relative's safety. However, they were content and happy when they learnt about the above measures that can facilitate activities of daily living. P25: Female, Doctor, 4 years working with people with dementia

However, not all comments were positive as some participants described concerns over whether AT was helpful; negative aspects were raised around design and the potential to reduce social interaction with carers (e.g., automated pill dispensers), as well as how AT can require another person to support its use, which can disadvantage someone who lives alone with no supporting family:

> I think that some of the staff have reservations about using technology for one of two reasons. Firstly, there are concerns that it will reduce patient contact from staff and family members. Secondly, surrounding training and how this will fit into already busy teams. P56: Male, Assistant Psychologist, 3 years working with people with dementia
>
> Main difficulty is that assistive technology is often most useful for those living alone. However, this group often have little support from family nearby to help proceed with AT. My experience is that often the resources that we signpost people to e.g., Alzheimer's society or local authority just do more signposting about what is available rather than giving the practical support in form-filling, payment and set up that the person needs. P315: Female, Doctor, 16 years working with people with dementia

With regards to AT design, respondents described how some privately purchased devices could distress people with dementia, such as a device emitting unwanted noise. Moreover, if the user could not learn to use a specific AT, then introducing it could make them feel stressed or lower their confidence:

> I think it can be helpful if the patient is able to learn how to use it, but I do find from personal experience that people with dementia often struggle to learn new things and can get so stressed with the technology that it makes them feel worse. But if they are willing to try then I fully support helping them to gain access to the technology. P126: Female, Assistant Psychologist, 3 years working with people with dementia

Moreover, some people with dementia might not use AT for financial reasons or because of unfamiliarity with it:

> In my experience, older people with dementia are reluctant to use assistive technology due to a fear of the unknown or high costs. P59: Female, Assistant Psychologist, 6 years working with people with dementia

Nonetheless, despite some negative comments, most professionals were positive about the use of AT. One professional voiced her frustration that the landscape of AT provision had not improved over time:

> I heard Prof. Heinz Wolf champion this subject 15 years ago and it is disappointing that progress is so slow in the development of technology and services providing access to this. P94: Female, Doctor, 26 years working with people with dementia

Overall, the professionals were positive about the use of AT in dementia and provided examples of how it could help people overcome problems.

### *5.3.2 Balancing need and risks*

Despite the professionals being positive and valuing the use of AT, their enthusiasm was tempered by a need to assess risk, where risk was viewed negatively and was something MS professionals strived to reduce. A key prompt leading professionals to discuss AT was their concern to maintain the safety of the person with dementia, and thereby attempt to minimise risk:

> If person is presenting with safety concerns or memory difficulties impacting on ability to carry out daily living tasks. P622: Female, MS manager, 25 years working with people with dementia
>
> High residual skills, desire to remain at home but risks associated with it, i.e., to maximise their independence for as long as possible. P471: Male, Doctor, 10 years working with people with dementia

They often stated they performed a risk assessment to identify both potential risks for people with dementia and the least restrictive option. However, they did not explain how they performed a risk assessment:

> I decide when I believe risks to themselves and other increase, through risk behaviour/presentation. P84: Male, Mental Health Nurse, 1 year working with people with dementia
>
> Risk assessment and known benefits. P476: Male, Mental Health Nurse, 15 years working with people with dementia

> As part of least restrictive options and to reduce the risks and improve patient safety. P89: Female, Consultant, 7 years working with people with dementia

As well as the risk of being isolated, the professionals described several other types of risk to which people with dementia could be exposed including environmental (e.g., fire, flood), physical (e.g., falls, not taking medication) or getting lost. As noted, risks could be related to specific locations, i.e., in the kitchen or outside or activities such as: cooking, night-time toilet visits or going outside alone as well as the risks of getting lost, or leaving on the gas or water taps.

Another professional concern was that people with dementia would not be able to respond to an emergency, and AT could potentially be used to help manage this risk:

> Concerns that a lady who is alone at home during the night may not always know how to react in an emergency, e.g., smoke alarms being activated. Discussed having smoke alarms linked to falls sensor/ careline pendant. P272: Female, Mental Health Nurse, 32 years working with people with dementia

Although risk was a key priority for professionals, many also described using AT to address a specific need a person with dementia had. These individual needs could be related to a specific situation such as getting lost, or a specific type of AT (e.g., clock for orientation) or telecare required (e.g., automated pill dispenser), or simply a general need for care:

> One of my patients lives alone, her son has gone out and paid private for the HIVE advertised on TV. He has put cameras in the lounge kitchen and hallway that can be communicated through so, if anyone calls, he can see on his phone who it is. He can speak to them through the cameras and it has stopped his mum from going out in the night and wandering as it alerts him when the front or back door is opened. It has really cut the risks down and made her more manageable and in her own home for longer. P453: Female, Dementia Associate Practitioner, 25 years working with people with dementia

> Disorientated to time, day, date. Therefore, suggested electronic calendar available via the internet. P112: Female, Mental Health Nurse, 13 years working with people with dementia

The professionals described how the level of need or risk often had to be high or increasing to trigger a referral, but did not describe how they measured the level of risk or need:

> I decide when I believe risks to themselves and other increase, through risk behaviour/presentation. P84: Male, Mental Health Nurse, 1 year working with people with dementia

> High level of need. P7: Male, Consultant in Older Adult Psychiatry, 20 years working with people with dementia

The professionals also described balancing needs and risks and provided positive examples of where AT was helpful at reducing risk.

### *5.3.3 Challenges around professional knowledge*

The professionals identified a challenge with acquiring and maintaining professional knowledge, although some disciplines' professional remits were more closely linked with AT and therefore more aligned in terms of their continuing professional development regarding AT. Occupational therapists can be placed in this category. The professionals were aware of a range of available AT but many had concerns about potential knowledge gaps and would consult or defer responsibility to others, such as occupational therapists or dementia advisors:

> No, I don't [know of any innovative resources]. Through completing this survey I feel more aware of how much I rely on my occupational therapy colleague for this, and that it would be helpful and interesting to find out more about it myself. P141: Female, Clinical Psychologist or Neuropsychologist, 6 years working with people with dementia
>
> It would be nice if professionals outside of the OT specialism were given basic information on local initiatives available for assistive technology. It'd also be nice if I were able to point people to what is available rather than always having to rely on my OT colleagues, who are already under enough workload pressures anyway. P299: Female, Mental Health Nurse, 6 years working with people with dementia

Other respondents reflected that AT may be overlooked as an intervention due to lack of professional knowledge:

> I think this is usually only discussed if there is a clear need or issue (e.g., wandering) but otherwise assistive technology may be overlooked in practice. We would need easier ways to direct patients to the right service to access AT. P204: Male, Consultant, 5 years working with people with dementia

Remaining current with rapid technological changes was a key concern for the professionals; this challenge was not only about keeping up to date with what is available, but also associated with costs, where to obtain information, and how to access AT when it is identified. They acknowledged that some of the information they provided could be outdated or that new, better technologies might exist of which they are unaware:

> I find that the products and information changes and so I get confused about what to tell people as the information I had becomes out of date and wrong. P67: Female, Physiotherapist, 10 years working with people with dementia
>
> I find it difficult to stay on top on what is on offer, particularly since follow-up is commissioned in our service to be carried out by AS and Dementia Guides. P30:

> Female, Clinical Psychologist or Neuropsychologist, 14 years working with people with dementia

In this context, the respondents highlighted a wide variation in available training on AT, with some receiving in-house or external training and others working in a different MS receiving none. They welcomed more training on AT and how it could help people with dementia live independently:

> Always happy to receive updates and training on what is available and new products released. Excited to read about how AI [artificial intelligence] technology can be used to help people live well. P29: Female, Mental health Nurse, 14 years working with people with dementia

> It would be useful to have specific training on solutions from the consumer market, for example solutions provided by 'Alexa' or similar. Apps that support remote access to heating systems etc. P91: Female, Clinical Psychologist or Neuropsychologist, 10 years working with people with dementia

> I think training seems to be sparse. This is not good as AT is developing at a rapid pace. P209: Female, Associate Nurse Practitioner, 20 years working with people with dementia

Occupational therapists saw AT as part of their role and were often seen by other professionals in the clinics as experts in AT and were frequently consulted:

> As an OT [occupational therapist], it is a large part of my role to encourage awareness of all external memory aids from basic to electronic devices. P323: Female, Occupational Therapist, 10 years working with people with dementia

> Ask for occupational therapist to assess and advise accordingly—will inform referral to social care who manage assistive technology in our area. P104: Female, Consultant Psychiatrist, 26 years working with people with dementia

> We have OTs [occupational therapists] who have training/knowledge [to support access] on how to provide this. P604: Female, MS manager, 30 years working with people with dementia

Occupational therapists also delivered in-house AT training, with some having a special interest in it and being seen as AT champions within their MS. A few were completing higher degrees on AT or were part of their professional body's special interest group on AT:

> Assistive technology is part of my role within the service as AT champion. We are a demonstration site for local care alarms services, and we are currently taking part in a research project for use of AT with people with dementia. We discuss difficulties in daily life due to dementia at all appointments and often suggest AT as a way to manage the difficulties. P321: Female, Occupational Therapist, 20 years working with people with dementia

> I am a recognised AT Champion. There are many more items that I could list [examples of AT]. P420: Female, Manager, 35 years working with people with dementia

In summary, the professionals found it difficult to keep pace with the available technology and had minimum training on AT. Occupational therapists were seen as experts on AT.

### *5.3.4 Lack of a clear AT pathway*

The theme of knowledge as raised by the professionals was not only isolated with the AT itself, but also how to obtain AT information and how to access AT if someone with dementia or their family carer wanted to use it. Respondents decided which patients they would discuss AT with, being prompted by needs and risks, but it is unclear which criteria, if any, they used for this.

The professionals found existing information and referral pathways confusing and highlighted the lack of a single, clear pathway both to AT information and access. They found it challenging to determine how, in what form, and when information would be given, but also how and where AT can be accessed and its associated costs:

> I think more clarity on where people could access assistive technology would be great not only for the client and their family but for professionals like myself working in the field. P27: Female, Mental Health Nurse, 3 years working with people with dementia

> No [innovative resources], I am very keen to find out more. There is very little in Shropshire and the referral process is confusing. P326: Female, Occupational Therapist, 9 years working with people with dementia

As well as a multitude of websites and organisations, the professionals used a myriad of professionals to obtain information on, and to support, people with dementia to access AT. They often had to utilise local resources and direct people with dementia to purchase AT privately:

> Social Services, if [AT] is available, if not advise to buy on internet privately with guidance. P2: Female, Occupational Therapist 26 years working with people with dementia

> I would advise them to speak to their local social services and also advise them that they are able to purchase AT devices privately. I would advise them to look at the AT listed and explained on the Alzheimer's Society website and to think about what, if any, AT devices might be beneficial to the person with dementia and/or carer. P58: Female, Assistant Clinical Psychologist, 1 year working with people with dementia

> As the OT in the team, we accept all referrals for assistive technology. We conduct joint assessments with specialised technicians for more complex solutions with many

> items over a monitored system. Or we could refer on to Social Services. P90: Female, Occupational Therapist, 2 years working with people with dementia

However, a few respondents described services being fragile, with many being only short-term, decommissioned or no longer available:

> Until very recently, we were able to refer people to Dementia Care specifically for AT as they had aids and devices that could be loaned out. Unfortunately funding for this has recently ceased. P583: Female, MS manager, 38 years working with people with dementia
>
> Not really...social services locally used to run a provision and they managed assessment and tailoring of individual packages. This will cease in Feb. 2019. A list of private providers is available via social services. P310: Male, Mental Health Nurse, 28 years working with people with dementia
>
> We have a pilot at the moment so [I would refer] to that; however, when that runs out, we will not have access to AT, so I would have to signpost them to purchase it privately online—most likely through AT Dementia/Amazon. P199: Female, Social Worker, 4 years working with people with dementia

This led to a push to private purchase through signposting to specific national resources or local providers:

> Social services, who are stopping their provision but provide a list of private providers. P310: Male, Mental Health Nurse, 28 years working with people with dementia
>
> Also, we previously had access to AT via telecare, which was provided at a vastly reduced cost. This is no longer an option. There doesn’t seem to be any monies for this technology at present and therefore people have to purchase items themselves. P443: Female, Occupational Therapist, 13 years working with people with dementia

Moreover, most services only provided a limited number of AT devices, and there was variation in what was offered and the available expertise in each region, forcing people with dementia to purchase AT privately:

> We used to refer to the local authority; however, they did not seem to have any knowledge or couldn’t find the equipment that we were advised they had. P463: Female, Senior Practitioner, 13 years working with people with dementia
>
> I previously worked in a different social services area and that provider would have a ‘great 8’ that had almost everything we needed and for free. I now work in a different social service and such items have to be purchased, and home visits for specialist advice are difficult to get. P218: Female, Mental Health Nurse, 30 years working with people with dementia

In addition to utilising the expertise of occupational therapists, the professionals also valued social services and the Alzheimer’s Society in terms of information and access to AT. Some respondents described referring to an OT who would assess and recommend AT, or would signpost to specific services and encourage family members to investigate and access AT themselves:

> The Alzheimer’s Society is a great resource for carer’s and family members and has some useful links. P13: Female, Occupational Therapist, 12 years working with people with dementia
>
> Families/carers are normally the researchers and implementers—I direct to the internet, brochures, specific specialist organisations, local providers/shops. P121: Male, Occupational Therapist, 17 years working with people with dementia

If AT was recommended, professionals attempted to personalise it to the individual living with dementia and their unique circumstances; the latter included their potential to purchase AT and resulted in a personalised access pathway often using a combination of state, third sector, and private provision. This reflects a mixed economy of care in AT provision, whereby some people are eligible for state funds while others are left to navigate the private market:

> Dependent upon SU (service user) need and ability to access services. It could be local provider, social services or the internet or referral to another professional. P108: Female, Mental Health Nurse, 12 years working with people with dementia
>
> If they were self-funders, it would be Care and Repair in [location]. If they were not self-funders, it would be [location] City Council. P394: Female, Senior Dementia Practitioner, 3 years working with people with dementia

### *5.3.5 Potential solutions*

Overall, the professionals provided an insight into the current practices and challenges with providing information and supporting people with dementia to access AT. They also suggested several ways to improve the current provision.

Many respondents called for better information resources which were kept up to date and maintained, such as information leaflets and booklets. Many valued the ability to demonstrate AT to people with dementia and to have access to systems to loan equipment for people dementia to try AT. There was a large variation in what was available to individual professionals working in different MS; some of the MS professionals did not even have an information leaflet on AT, whereas others had access to ‘live’ demonstrator rooms, video information, or tablets with information on AT in waiting rooms:

> It would be useful if I had a supply of certain AT that I could have instant access to, instead of having to put through a referral and wait on it to be actioned. Also, I could physically show how the item worked not just through pictures. P55: Male, Occupational Therapist, 15 years working with people with dementia

> Our service has a demonstration site for City Wide Care Alarms and for standalone AT that we have. We have two AT champions in the service, myself and an occupational therapist. All staff have had training in AT and what is available. We have a demonstration tablet to show people what is available. We have leaflets, a TV presentation on continuous play. P420: Female, Manager, 35 years working with people with dementia

The professionals suggested ways to improve information and access pathways. Examples include having a single point of access system and 'live' and up to date national databases on AT providing information on which AT is useful, associated costs, and where to source them nationally and locally. Information could also be fed into this database. They also called for direct access to AT:

> It would be better if there was a central point to access all the things, so we are not missing anything. Like I have a dyslexia tutor that helps me to fund my assistive technology for work. P120: Female, Mental Health Nurse, 3 years working with people with dementia

> I really believe we should utilise AT to aid independence, safety and support for people with dementia. It needs a singular central point of knowledge for us all to feed off (and into?) and this service needs to be obtaining the constantly changing (and cheapening costs) products and evaluating through practising and reviewing their use in the real world. P121: Male, Occupational Therapist, 17 years working with people with dementia

Many acknowledged a need for more joined up care between healthcare and housing. Some also highlighted limitations in the current system and a requirement for clinical support/oversight to monitor and respond to any AT implemented:

> What's missing is the clinical support or oversight to monitor and respond to the person's needs if they live alone. A more joined up approach between housing, social care and health would be fantastic to support people to live independently. P22: Female, Occupational Therapist, 25 years working with people with dementia

The professionals identified the need for trained professionals to assess and monitor AT or for an AT champion; some suggested that people with dementia should have an occupational therapist assessment as part of their usual care. They recommended that every MS have an AT champion:

> AT champions across all MAS services to provide expert advice on up-to-date technology solutions. P612: Female, Clinical Director across MAS services, 30 years working with people with dementia

> OT and physiotherapy assessment should routinely be offered to patients diagnosed with dementia and period re-assessment should be arranged. P116: Male, Locum Consultant Psychiatrist, 8 years working with people with dementia

In summary, there was no clear pathway to obtain AT, with access depending on the technology required and the financial reserve of the individual receiving it. The professionals provided suggestions on how the pathway could be improved.

## 5.4 Key Points and Areas of Good Practice Identified by the Surveys

Overall, the survey results highlight that introducing AT is challenging. The following section summarises the key points and areas of good practice identified from the results of both surveys, which then informed the later focus group discussions and telephone interviews with selected professionals. It also summarises areas of good practice used to generate a purposive sample of lead professionals and managers for telephone interviews.

### *5.4.1 Key points*

The following key points were collated using the result of the quantitative and qualitative analysis of both surveys:

- Memory services are not all equipped with basic resources such as an AT protocol, AT training opportunities, or a lead professional on AT;
- Not all the professionals were confident about where to obtain information on AT for themselves or patients, or to give information on AT and how to support people with dementia to access it;
- The professionals were positive about AT but raised concerns over design, potential for reduced social contact, and reliance on someone to respond;
- Safety and risk were a key priority for the professionals when considering AT;
- The professionals found it challenging to keep up to date with rapid changes in AT and how to access AT;
- The professionals wanted more training in AT;
- Occupational therapists saw AT as part of their role and were often seen by other professionals in the clinics as experts in AT;
- Pathways to information and accessing AT were complex and involved numerous online websites, organisations, and a myriad of professionals.

### *5.4.2 Recommendations on good practice*

The analysis of the survey findings highlighted several areas of good practice in terms of MS characteristics and professional practice, used to create a purposive sample of 'good' practice sites for telephone interviews. These areas are:

- Providing training on AT;
- Providing a protocol on AT;
- Identifying a lead on AT;
- Providing access to demonstrations;
- Being involved in research;
- Forging links with external organisations, such as local authorities, voluntary organisations, and researchers;
- Collaborations with other local authority and voluntary services, i.e., to form dementia pathways;
- Providing information resources

## 5.5 Chapter Summary

In this chapter, I have described the results of two surveys sent to MS professionals in England. The analysis of the results has shown that some MS in England has a range of resources available to them such as training, protocol, demonstration, and access to a lead on AT. However, not all MS have access to these resources. On an individual level, not all the professionals felt confident to provide information on AT and support with access to AT. This was reflected in the analysis of free text comments. They were positive about the use of AT but had concerns over design, potential for social isolation and the need for someone to respond. They found it difficult to keep up to date with rapid changes in technology and how patients access AT. They wanted more training on AT and access to better information sources. Concerningly, those services they could refer to were fragile and often offered only short-term options. Occupational therapists were the key professionals to whom other professionals looked to for information and support to access AT, and the professionals promoted having an AT champion in every MS.

The following three chapters present outlines of the results of the analyses of the focus groups and telephone interviews. Chapter 6 deals with how MS enact AT in practice. Chapter 7 presents the challenges encountered when enacting AT, and suggested solutions. Chapter 8 describes how memory services enact AT and the factors which facilitate and hinder innovation. Discussions and conclusions from all three of these results chapters are collated in Chapter 9.

# Chapter 6. Memory Services Enactment in Practice

## 6.1 Introduction

This chapter presents the data analysis from the focus groups and interviews with professionals working in MS, and specifically explores how MS and individual professionals work within their organisation to provide information and support for access to AT. In so doing, important context is provided for what happens on the ground in MS regarding how AT is enacted, so that the challenges and factors driving change in these services can be understood. The chapter is divided into two sections: how MS work, including a typical care pathway; and, the consequences of the typical pathway for service users, that is those with dementia and their families, and service providers, i.e., the professionals.

## 6.2 How Memory Services Work: the Typical Care Pathway

The following subsection begins by outlining the current care pathways for professionals within MS who assess people with dementia. It then focuses on how MS provide information and education on AT to people with dementia, as well as how they support access to AT, provide education and support to its professionals, and collaborate to deliver AT.

Most MS now describe themselves as being purely diagnostic, and this is a model which has evolved over time (outlined in more detail in Chapter 8). The professionals described a typical AT care pathway as including an initial assessment, diagnostic disclosure meeting, and post-diagnostic care, with AT but perhaps via a different team, as illustrated by the memory service nurse below:

> If an OT [occupational therapist] is needed, or a physiotherapist, they get referred to them. And then when all the results are back, they get an appointment to see one of our doctors, they get a diagnosis. If they're going to be started on medication, the doctor will do that then. Then, after that, it'll go into the titration pathway where people check every so often that they're doing alright on their meds, and increase it as needed. But then, us, as the nurses, we go back out to do a post-diagnostic review, and it's usually at that point where we can refer on to other services that might be needed, such as the Alzheimer's Society, social care, things like that. And then basically once they're settled on their medication and we've signposted them to outside agencies, if everything's okay, they get discharged from us then. They may go into the treatment team if things are more complex, and the OT, when they go out, they would refer into social care and get various equipment in place that's been highlighted during their visits. Basically, that's it. FG2 P1: nurse

The specific facets of the AT care pathway are presented below to explore who, what, where, when and how the professionals assessed patients, provided information, and supported people with dementia to gain access to AT if they wished to use it.

### *6.2.1 Who introduces AT? Deferring to the experts*

Any professional working in MS can introduce AT to people living with dementia. However, most participants valued a specific member of the team, namely an occupational therapist, who performed a home assessment to identify individual needs and their strategies for coping with their current difficulties:

> The OT assessment is a really good opportunity because it is looking at skills, it's looking at support, it's looking at values, historical problem-solving strategies and what the needs are within the home. FG1 P7: occupational therapist
>
> Interviewer: You'd written in the survey you've got a lead, like an OT, is that who leads all this stuff, with technology?
>
> TI3 lead clinician: Yes, so, it's mainly the OTs. We'd identify the need for them, and they would do they assessment.

### *6.2.2 What do memory services provide regarding AT?*

Participants described a wide variation in MS in terms of access to AT; however, most only gave information and support to access AT if a need or risk was identified. Participants were positive about the use of AT in dementia care and gave numerous examples of how AT can helpful. Some of these are listed in Table 6.1. The majority signposted patients to voluntary services or local authorities for further information, while others offered a substantial package, including assessment at home and personalised AT interventions. Pathways had to be tailored to the individual and the services available, as described below:

> Then, I make an appointment and do a home visit. Then, what I am doing is looking at every aspect of a person's house, downstairs, upstairs. I will be looking at hotspot areas such as the kitchen area, the bathroom area, the entry and the exit areas. Things like that. We kind of have a conversation around…over say a cup of tea in the kitchen, I'll say, 'How are things? Would you be cooking for yourself?'…From that, when I am in the environment, I am able to get eyes onto the different surfaces, within the fridge itself, things like that, I am looking for clues if you like. TI 1 lead clinician: occupational therapist

Some provided general dementia education to people with dementia and their families through group education sessions, with some including AT in this and others not. Professionals reflected that there was variation in provision nationally:

> I think it is definitely a postcode lottery for dementia support. TI1: manager

Not only was provision of information and support for accessing AT variable between MS, but the level of education and support offered to professionals for them to keep up to date on AT varied. Most professional education on AT was not formalised but delivered in an ad hoc manner via collaborations with outside organisations. Several leads and managers described sharing knowledge, expertise, and successes either internally via regular team meetings or externally with colleagues from Social Services, local authority telecare providers, or even private suppliers. For example:

> I'm in a conversation with a company at the minute, they're providing… they're willing to provide training, rather, on technology built into shoes. TI 1 lead clinician: occupational therapist

Some MS were attempting to help professionals improve their knowledge and acquire information on AT but this was challenging since information was difficult to find and often in multiple locations, making the process more testing. One memory service overcame this by making their own database of technologies they found helpful and could recommend to clients; it was the responsibility of the whole team to keep this up to date:

> We share that information and knowledge, and we have spreadsheets among spreadsheets that are updated regularly in a live document in Teams. So, if people find out something new, or they find out that a service has lost their funding to provide something specific or the fact that adult social care services are no longer using a type of GPS tracker that is available through funding than they were previously, then the team all take responsibility for updating the live document. It is a kind of bible, I suppose. TI2: manager

Others relied on their in-house OT to provide information internally to professionals, as well as to other professionals working externally in local authorities, telecare providers, research groups or private companies. In addition to information provision, some MS facilitated a demonstration of devices via rooms set up with AT, TVs in waiting rooms, and laminated pictures to take on home visits.

> They have a demonstration room on site where the independent living service is. That is where they have all the different pieces of equipment, the assistive technology. So, staff can go there for training. If they're any gadgets that they need to take to people's houses, they're able to do that. They've got a demonstration kit, a mobile kit as well, that they can take out. TI 1 lead clinician: occupational therapist

However, many services did not provide any additional resources (discussed in more detail in Chapter 7, Exploring Gaps in the System).

| **Purpose of AT** | **Examples of helpful AT** |
|---|---|
| Orientation | **Simple night day clocks**<br>‘The digital clocks are fantastic for orientation, keeping people in control and aware of structure of the day and what’s happening on a day-to-day basis. Those clocks are really, really helpful.’ FG2 P2: occupational therapist |
| Monitoring (detectors, sensors, and alerts) | **Just checking system**<br>**‘**We’ve used Just Checking, which has been quite helpful. So, that detects movement in a house... That’s, I think, where it’s been the most beneficial, to help us then provide support to the patient.’ TI3: lead clinician<br>Door sensors to alert if someone leaves home.<br>Motion detector lights to help prevent falls.<br>**GPS trackers**<br>‘I’ve had quite a few people that have had the same GPS devices; a tile or a buddy system that is, yes, exactly the same as FG2 P1 nurse, that allows them to have independence and provides reassurance for the family that actually sometimes people are doing exactly what they say they’re doing’. FG2 P2: occupational therapist<br>**Automated pill dispenser**<br>‘Around the safety and reliability concordance aspect of medications, really, really helpful. So those electronic pill dispensers or reminders’. FG2 extra TI: psychiatrist<br>Smoke/gas detectors |

| | |
|---|---|
| | **Door sensors**<br>'Door sensors and things, those area always really quite helpful for those who may be at risk of leaving their own home'. FG1 P8 nurse<br>**Floor lighting**<br>'The floor lighting when someone gets up during the night, that comes on automatically. I think it's like a strip light that seems to reduce the risk of falls, and that's really helpful'. FG1 P1 |
| Communication & shopping | Skype to interact with family (have breakfast together)<br>World wide web<br>**Alexa as prompts or to order shopping**<br>'I'll just mention, while I remember, people are finding Alexa quite helpful, as well'. TI3: lead clinician.<br>**Zoom**<br>'I think, I mean, especially during COVID, I think the carers have had to really, in terms of sing Zoom, assistive technology in that way, they've found that really, really helpful, because otherwise they would have felt quite isolated, I think, during all this'. TI3: clinical lead |
| Simple AT | **Simple boards with writing**<br>'A visual written reminder on the wall would be effective'. FG1 P6 |
| Cognitive stimulation & leisure | **Apps and games** |

|  |  |
|---|---|
|  | ‘I suppose to enable people to have cognitive stimulation at home, so to be able to use tablets or other means to keep them cognitively stimulated, whether it is through puzzles or games or access to news, etc. So that aspect can be helpful in people who have a milder degree of cognitive problems’. FG2 extra TI: psychiatrist<br>**Dolls and animals**<br>‘So, I think the most useful things I’ve found have been the lifelike dolls and animals that were used with residents in the care homes, which we found very beneficial, especially during COVID because they can’t have their relatives visit’. TI5: manager |

**Table 6.1. Examples of helpful AT**

### *6.2.3 Where do memory services enact AT? Home is best*

Although many MS introduced, assessed, and provided information and support on AT in clinics, many professionals valued seeing people in their own homes, especially for the initial assessment. They considered this a valuable part of the assessment process and felt more useful information could be gathered in terms of functional ability compared to a clinic setting. However, not everyone was seen in their own home, as the following illustrates:

> Also, I think, the clinic is not the right place to identify these needs, is it? I think we only get a little glimpse of what's happening within their family, with the family and in the home environment when you're in a clinic room and you're delivering all that information, like P1 was saying. I think it would be much more efficient to have someone just go and have a look at how somebody is at home. FG1 P4: specialty doctor
>
> Sometimes, for the generation of the 70s and over, they come well-dressed because they've come to see the doctor and it's a sense of, kind of, pride related to values of how they've been brought up. I'm not saying all the time, but the majority of the time. When you actually peel that back and you see somebody in their home environment, you then see how they are actually living. You're not seeing them dressed in a smart suit or outfit. TI1 clinical lead: occupational therapist

Overall, professionals valued seeing a person in their own home to see first-hand how they were coping and to identify any AT that could help.

### *6.2.4 How do memory services introduce, assess, provide information, and support access to AT? Encouraging service users to do the work*

AT was introduced at the point of an assessment or diagnostic appointment if a risk assessment identified an urgent need or safety issue requiring immediate intervention; this overrode any concerns professionals had regarding information overload or gauging the right time:

> But within our service I would think the initial assessment, certainly to identify the priority needs and how that could be initiated with assistive technology, and certainly if things like medication concordance and direct safety, like fire, could be managed at that point. FG2 extra TI: psychiatrist

More often during the initial assessment, professionals advised on non-technological strategies to help with daily routine and did not identify any specific AT in this regard. In addition, there was usually no time to discuss AT at the diagnostic appointment as there were more pressing issues, such as 'breaking bad news' (diagnosis of dementia,) supporting people's emotional response, and discussing medicolegal matters. They felt the post-diagnostic appointment or series of educational sessions, if provided, were better places for providing information on AT, as was referral to another service which might see them further along their dementia journey. For example:

> Do I go down the line of explaining every technology I'm aware of? No. In a diagnostic appointment I won't do that because, to be fair, we have an hour in which to break, usually bad, news, carry the emotion to do with that, making sure everyone is fine, and look also at things like medicolegal matters. It's not quite appropriate. FG1 P1: clinical psychologist

Most professionals signposted patients to other services and/or encouraged families to do their own detective work to access AT. Some MS provided general education on dementia, which sometimes included AT. Memory service professionals felt they did not have time to assess for AT provide it, and thus they encouraged people with dementia and their families to take on this responsibility. As noted above, managers and lead clinicians described considerable variability and processes, but professionals were concerned that recommending families to take the lead would create more work and stress at a time when they already felt overwhelmed:

> I think that fits in well with not being able to try equipment before they buy, because they might say, 'Oh well, actually, I'm all right for now', and put it off sometimes because of the expense or the hassle of even trying to source it. Even if we give them where they can get it from, the hassle of ordering it if they haven't got family to do that for them. So, it's almost like we're going in there to improve things, but sometimes you feel like you're causing more things, like, hurdles for them. FG1 P6: occupational therapist

Notwithstanding this, the professionals would facilitate direct access to AT in certain circumstances, for example when the person with dementia was depressed, had no family support, or the carer was under severe stress, as the following illustrates:

> So, if they are keen to explore that we would either give them the number or, like P5 said, if the carers are really, really stressed we could contact the service on their behalf to get the ball rolling and look at what devices they've got on offer. FG1 P6: occupational therapist

Depending on the type of AT required, the financial situation of the individual, and the local resources available, AT could be obtained via several routes including via the local authority, charities, occupational therapy, stock provided by MS (if they had it), a private purchase (if a person with dementia had the financial means to do this), and/or research projects. Deciding where someone could be direct to was challenging as it depended on the type and complexity of the AT required:

> [For] every patient you got to take part in the study you got £50 towards getting them some memory aids. So, we were getting stuff like Alexas, but we have got a supply of Just Checking devices. The door sensors, and, you know, things that you put on the cooker to automatically turn off. We have to apply for funding for those kinds of things... and the pair link stuff is through a separate agency. So, you know, falls bracelets, and the door sensors, that's done through the local authority. TI3: lead clinician

In terms of accessing AT, many MS could not directly access this for their patients and so pathways had to be tailored to the needs of the individual, what they could afford, and whichever local resources were available to professionals. For example, if telecare were required, they would signpost to the community care alarm company; if a specific risk was identified, they would ask the occupational therapists to assess or, if the patient had overly complex needs, they would refer to social services. Some social services had links with other AT services such as specialist sensory support teams.

Many local voluntary services were fragile in terms of availability, with services being either short-lived or no longer in existence. Some MS used to have social care professionals in their team, which they found helpful, and another used a local dementia charity to support access to AT; however, these were usually temporary arrangements. To complicate matters, some AT had to be privately purchased and this was incredibly challenging for the professionals as they had to navigate the system to recommend devices but had no clear information on cost or clinical effectiveness.

Memory services professionals also signposted people with dementia and their family members to group education to learn about AT, if their service provided this; however, participants in such education described it as being highly variable in both quantity and quality. Most of the group education focused generally on dementia and the topic of AT tended only to be raised by service users, as illustrated by the comprehensive group sessions one memory service provided prior to the COVID19 pandemic:

> So, the memory group was much more, probably, about strategies and adaptions, so yes, they got a big box with MediPacks, whiteboards, and an example clock. So, the memory group would be the main group that assistive technology would be talked about. And I daresay probably the WRAP as well as carers would talk about their issues… Education sessions, often people would drop in… so if anything cropped up then they would be given advice in that group. TI6: manager

Other memory service managers/lead clinicians highlighted the lack of group education on AT and would defer to outside agencies to provide this support:

> So, we can offer advice and the Living Well programme, you know, the six-week course that we refer them to that is run by our trust and the X Council, they do a presentation all about additional aids, adaptions, technologies that can help. TI5: manager

> Well, the Alzheimer's Society is a good place, and sometimes I just use Google, to be very honest. Also, some of the message boards, that's actually where patients or carers tell us, 'Oh, there's an interchange on this, and there's a group where they exchange ideas'. There is Dementia Diaries, which is quite an interesting one and I'm not sure whether you know about that, where people post their stories and, again, exchange ideas, so that's quite a nice one as well. FG1 P1: clinical psychologist

Overall, participants described how the provision of group education varied regarding AT for service users. Memory services also utilised links with research and could refer users both for advice and to access AT. Several services had links with local research projects to which they could refer, and these links were valued by the professionals in terms of the benefits offered by the research, having someone to ask for advice, the occasional provision of funding, and support for access to AT. Some professionals described research as being embedded in their usual day to day work:

> The people who offer the TIHM project, so, we can refer people to them, and they will give the information. TI8 clinical lead: nurse

In summary, most of the services offered a pathway which included an initial assessment, diagnostic disclosure meeting, and post-diagnostic appointment. The professionals valued assessing people in their own home, but not all services had the ability to do so. Occupational therapist home assessments were offered to some people with dementia and were seen as an effective way to identify initial needs and strategies. Overall, it is evident there was no clear pathway for professionals to introduce and obtain AT for their service users. Access to AT was complicated, fragmented, and influenced by factors such as the availability of the resources both in MS and of service users (e.g., finances), who often required the help of family members.

### 6.3 Consequences of the Current Pathway

The following subsections outline the consequences of the current AT pathway for both service users and service providers, e.g., professionals and managers working in MS. The first subsection is specific to service users in terms of inequalities of provision for vulnerable groups; the second considers service providers' professional unease.

### *6.3.1 Inequalities of provision: the neglect of vulnerable groups*

It was evident from the participants that there was considerable variation in AT provision on national, local, individual, and personal levels. Moreover, many participants were concerned that the current provision neglected vulnerable groups such as people with young onset dementia (YOD), those living alone with no family support, or those who were not IT literate.

On the national level, professionals recognised there was a postcode lottery for dementia support and asked for a standardised approach to dementia care:

> I think it's definitely a postcode lottery for dementia support nationally. I think we need to have a more standardised approach, that's down to NHS England who issue the guidance of how people with dementia should be treated and how they should be assessed, how they should be diagnosed. T2: lead clinician

Professionals highlighted how the commissioning of MS leads to inequalities, as each commissioning region has different priorities for their specific population. This means that MS could have a completely different offering with regards to post-diagnostic support, if any, on AT.

At the local level, participants identified inequalities. For example, one trust spanning a large area had two MS with different provisions as they were commissioned by alternative clinical commissioning groups. One memory service offered much more post-diagnostic support to its clients than the other:

> Well, our role in the [rural memory service in a hospital trust] is we only do the assessment and treatment, we don't do the management, whereas [the city memory service in the same hospital trust] has the management bit of it. We're not funded for it, so that's our main thing in our end. FG2 P1: nurse

There was also variation within and between individual trusts regarding some MS. An example of this was how, within the same trust, there were different training opportunities, AT resources and links with social services and voluntary organisations. Moreover, MS had access to different support and funds to support access to AT through voluntary organisations and research projects. These links were fragile, however, and funding from voluntary organisations was often short-term or via research projects.

Even at the individual level, the professionals recognised that a patient could see different professionals within a memory service and receive variable information and support regarding AT. This was due to the wide variation in awareness and professional knowledge of AT solutions and the system and how to access AT, potentially resulting in each person with dementia having a unique, but also unequal, experience of AT information and support with access to AT:

> It’s nearly a bit like medicine; it’s going too fast that the clinicians can’t keep up with it, so therefore, dependent on, it’s the quality of what people are getting is not proportionate because it depends who’s in the office and who knows something at a certain time. It’s really inconsistent. FG2 P2: occupational therapist

Some professionals acknowledged that a person with dementia may not be referred to an occupational therapist if the assessing clinician did not recognise a need to do so. The latter was the gatekeeper to the occupational therapist assessment and the level of their awareness and knowledge of AT could impact the client’s experience. If a person with dementia was assessed by an occupational therapist, the level of assessment and tailored AT approach varied between MS. For example, one highly evolved service created a formal risk assessment document for the occupational therapist to use, both with people in their own home to document AT recommendations and also to undertake a formal risk assessment. This procedure comprised performing a risk assessment both before implementation and after installation, to check the AT ‘prescription’ was appropriate and safe.

> We have risk assessment documents and equipment assessment documents and assistive technology documents. Within that, we say that we’ve had a conversation. It’s been accepted, it’s been declined. There has to be a rationale around that because it’s no good, then, saying, ‘Oh yes, I went to Bill’s house and I explained about the door sensors and I said I’d go back’. Then, if you have not written that up properly and you’ve not said when you’re considering going again, heaven forbid, if something happens to Bill and he goes out wandering, that comes back on you and on him. TI1 clinical lead: occupational therapist

Finally, at a personal level, people with dementia have different financial reserves for purchasing or renting AT. Many were reluctant to recommend specific privately purchased AT due to cost concerns for the patient and a lack of personnel with knowledge of the effectiveness/cost effectiveness of the devices. Therefore, funding for people with dementia to access AT was important. Professionals identified that some of their patients were unable to afford AT, either through private purchase or rental, and indeed many service users could not afford simple AT, let alone more advanced and expensive equipment:

> There's a certain other part of the population who's less affluent, they've never had the means, they might be struggling to even pay their bills… So, it's unlikely that they have the assistive technology and there's a bit of a gap. FG1 P1: clinical psychologist

For some sociodemographic groups, the professionals thus identified financial considerations as being a major barrier for people with dementia to be able to access AT:

> Funds for people to get them because, you know, it's very difficult, not everybody can fork out the money. FG1 P2: nurse
>
> So, cost it stops people, even though you might explain the risk, the safety. That's when you've got to do a thorough capacity assessment on risk and safety, and judgement. Even after that, people will decline because they say that they won't pay it or they don't want to pay it. TI1 lead clinician: occupational therapist

To overcome this inequality, some professionals suggested a minimum basic AT entitlement for all, with specific low-cost items that could help:

> Maybe there could be a threshold of what is a basic entitlement. Like, a clock that orientates time and day, everyone should have that, shouldn't they? FG1 P4: speciality doctor

Many professionals were concerned that the current system does not cater for vulnerable groups, such as people with dementia living at home with no family support, or people with young onset dementia (YOD). For these groups, they believed AT would be immensely helpful. For example, YOD patients have specific needs which were seen as different to the general dementia population, and they often have a higher level of baseline AT use. Those living alone are a group that the professionals felt are very vulnerable and at greater risk as they have no family networks or support and are socially isolated:

> I think my only concern is that occasionally we get people who function very, very well, and they don't have any care needs, but nevertheless it's a progressive disease and it's what do you put in place then if there isn't a carer or anyone that is going to pick up on their deterioration or risks associated with that?...Unfortunately, nothing is ideal, because if you fit somebody with a tracker and there's nobody to monitor that then it isn't going to be any use. If there's nobody that will be aware that they've left the house, they haven't got any friends and family to know that they're missing or that they should be back, or nobody to monitor the tracker, then it's not going to help. TI8 lead clinician: nurse

AT was seen as important in such groups but additionally the professionals described other vulnerable groups who are not information technology (IT) savvy or have no access to the internet or adequate WIFI:

> But a group where there would definitely be more of an onus on social care being involved or groups that actually don't have access to websites and people who are

> quite isolated and not IT savvy, which we see. It is a minority but a significant minority of people who wouldn't be savvy, and they might not have family or anyone else to help them with searching. So, they are often quite a vulnerable group that probably, over time, are later accessing helpful interventions. I think it is about those people who are isolated, to ensure that there is provision made for them, as well as people, well, say, sons and daughters or nephews, nieces, who can help with accessing assistive technology. So, I think that is a group that sometimes do less well at accessing all these assistive technologies. FG2 extra TI: psychiatrist

In summary, the participants identified inequalities of AT provision due to several factors, from the commissioning of services to the individual professional's knowledge, or the ability of a person with dementia to pay for AT. Moreover, memory service professionals also identified vulnerable groups who could be neglected due to their characteristics. The following section outlines another important consequence of the current memory service provision of AT: professional unease.

### *6.3.2 Professional unease*

The current memory service provision of AT has caused many professionals to feel uneasy and anxious concerning: their knowledge of AT and the associated costs for people living with dementia; their role with regards to how AT is causing professional tensions; and, their need to navigate a dyad of tensions and concern over identified ethical dilemmas.

The professionals felt uneasy about their knowledge of AT and associated costs for people living with dementia. As explored in previous sections, many professionals identified that they lacked sufficient knowledge of AT to allow them to make recommendations, and this made them feel uncomfortable:

> It's good to be informed, isn't it, because I feel as if I'm recommending things that I don't really know very much about, and that doesn't feel always so. FG1 P8: nurse

This was even more prominent when people with dementia were asked to purchase or rent AT. The current system involved a mix of private purchase and rental via social services. Due to this mixed economy of provision, which includes health and housing bodies, the local authority, and private provision, people with dementia often had to pay for AT. Affordability is important as some people with dementia could not afford AT, even a small rental amount, while others would have the means to buy or rent, thus leading to inequalities of access:

> Yes, there's a socioeconomic impact, it's a locality-based problem, potentially, in terms of accessing these resources. Certainly, if you look through that Unforgettable catalogue, which I've done with patients and family members this week, I'm saying

> to them, 'Don't look at the price tag, because it's probably cheaper somewhere else'. But, you don't want to then say, 'Actually, I'd go for the one that costs £10 rather than £50', but you do take into account that, kind of, economic status within your client group and you know that a lot of them are struggling. FG1 P8: nurse

This awareness of affordability influenced how a professional gave information or recommended specific AT or where to access it. Many described having to deduce the financial situation of a person with dementia, as it would influence what AT they discussed and recommended. This was because, in some MS, most of their memory service population was socially deprived:

> Because parts of our county are incredibly poor, you know, people there don't seek help, and when they do seek help they are often in a crisis, so if things had been put in earlier they could have been prevented, people could have been well longer, but they can't afford… I mean, because they have got to pay for carers, for instance, coming in, you know, they can't even afford that. So, they're not going to pay for a GPS tracker or something else to help mum or dad because they can't afford even the basics. TI5: manager

Discussing the financial aspects of obtaining AT made professionals uncomfortable as they felt this was not their role. Nevertheless, the professionals felt this to be a critical issue and they often lacked information on cost, had training on how to access AT, or indeed were clear whether it was their role to discuss the financial implications of obtaining AT:

> That's what frustrates me the most because even what some people would class as the most simple thing, like the plug-in digital orientation clock to say the day, the date, whether it's afternoon, evening or morning, a lot of people will just say, 'Oh yes, I'll just buy that' and it's there before my next visit, in place and already being used. Then you recommend similar things to someone else and they literally haven't got the money or the support around them to order online. It's like, 'Is that our role?' You know, how much of our assessment and intervention is actually getting their bank card and purchasing it on their behalf? You're going, almost, into other realms of getting consent. FG1 P6: occupational therapist

Another area which produced professional unease was navigating professional tensions. The challenge around what professionals were commissioned to provide caused professional tension, with many individuals describing how their professional standards for helping people with dementia often overrode the description of their role based on what the service was commissioned to provide; that is, the professionals provided more care than that for which they were commissioned:

> I mean, if you know you're going to be the only person in there, potentially offering advice, it would be, you know, you feel you've got a duty of care; you can't ignore things, can you? So, you might be providing advice or direct links to things. I know

> we're not commissioned to, but there are certain things that we do because you can't ignore them. FG2 P3: occupational therapist

On an individual level, many professionals described feeling that AT could be their role if they had time, but they were torn between providing support to access AT and realising they were not commissioned to do this, or that another service could offer this support:

> But sometimes I will have to say, 'Come on, remember what we're here to do, because we've got a big, long waiting list'. It's that constant balance and justification of what are you here to do, because other… we would love to do all the support and everything else, but there are other organisations around us that can do that, and we do have to keep reminding ourselves of that. TI6: manager

Professionals also found navigating dyad tension around the use of AT challenging. If AT could be implemented to improve the situation of a person with dementia, the family carer, or both, the professionals described how they often had to discuss possibilities with service users. Often, it was more challenging when introducing AT to dyads of people with dementia and a family member as they often had different view of whether AT was required or if it was working. In addition, many people with dementia overestimate their abilities or deny they need help, causing conflict with carers who often say AT is working or there is a problem or need. These dyadic tensions can be challenging for a professional to navigate. Therefore, any introduction of AT could require negotiation with two people having quite different views. This sometimes caused tensions as the person with dementia might not recognise or remember a problem or say that AT was not working, when in contrast the family carer would see a benefit in its use. This added another layer of complexity to identify the timing and introduction of AT:

> What we find, occasionally, is if we ask the service users directly, because they might be already overestimating their own abilities, they don't acknowledge the benefits, but the relatives might say, 'Actually, that's working really well', and they'll not admit it, but it is. FG1 P3: nurse

Sometimes, AT benefited the family carer rather than the person with dementia:

> I suppose, when we've supported people, it's been more about supporting the carer. TI3: clinical lead

Another area causing professional unease concerned the ethical dilemmas associated with AT use. Professionals described many ethical considerations such as: informed consent; best interest decision making; concerns over loss of human contact; causing distress or harm if AT were introduced at the wrong time; data privacy; and, protecting people from exploitation. Many highlighted obtaining consent as a key area for consideration. The professionals were clear that a person’s capacity to agree to the use of AT must be assessed and, if this is lacking, that action must be taken in the best interests of the person with dementia. Families sometimes wanted to introduce AT without the knowledge of the person with dementia and the professionals had to intervene to explain the requirement for consent.

> The ethical element is that sometimes family carers have wanted to give the person the GPS device without their knowledge because they’ve said, ‘Oh, well he wouldn’t like me knowing where he was going when he is out’. Instances like that where we’ve had to be very, very, clear and say, ‘Well, the person has to consent to this and understand what it is for and why etc.’. It’s only if the risk was really, really, high, and we’ve done a thorough capacity assessment, we’d even consider having a conversation around the person not being aware that they have a GPS device. TI1: clinical lead

Some professionals, although generally positive about AT, did highlight concerns about AT reducing human contact and that future AT solutions, such as smart homes, would reduce this contact further. Professionals stressed that AT is not a substitute for care and rather it should be an enabler and could augment care:

> It’s like everything, when there are bits of it that are really helpful, so, I mean, the heating…[smart home] You can make sure that they’re not turning the heating off and it’s warm. But, the presentation I was at was talking about the cost benefits of the reduction in, say, four times daily calls, where you can do that, and you can have the intercom, ‘You need to take your tablets’, and it scared us. I thought, it’s gone too far, because often what people need is that contact. FG1 P5: clinical lead

Specific types of AT evoked unique ethical considerations, such as the fact that alerts, monitoring devices, and GPS tracking created a ‘big brother is watching you’ situation:

> But I think also you need to balance that with, the technology isn’t a substitute for care, you know? It’s something that, they need to be used together. So, I felt that some elements of that flat that we saw, it was a little bit like Big Brother and a remote voice saying, ‘Don’t go out, it’s bedtime’, and there’s a balance. TI8: manager

One professional described how important it was for the service user to be psychologically ready for the introduction of AT, as the topic would also raise the underlying issue that they may no longer be able to do things for themselves, either now or in the future; for example, they might not be able to go for a walk alone without getting lost:

> And gauging when is the right time for that person as well, isn’t it, because some people might be quite upset at the suggestion that, ‘Gosh, I’m going to need this because I’m going to fail’, so it is a real balancing act and I think that’s a really skilful thing to be able to do when you’ve just met somebody, to determine when is the right time to start introducing that sort of thing. FG1: clinical psychologist

The timing of its introduction was crucial as some AT, if introduced too late, would not fulfil the purpose for which it is intended or could be harmful. For example, an automated pill dispenser, if introduced too late could result in it not being used as intended. A person could take the tablet out but forget to swallow it if they were distracted or not respond to the dispenser's alert:

> If it's not already been part of a well-established routine and we're introducing a medication carousel that rotates and dispenses the medication… If that's something they've never had before, and their memory impairment is at a point where they can't learn or retain new information, then we quite often find that they've missed doses because that then continues to beep, and they'll acknowledge the noise but not necessarily what they have to do. FG1 P6: occupational therapist
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> Sometimes actual medication dispensers can be confusing to people, if it is slightly beyond the realms of their cognitive abilities. So, people who are more impaired may actually become more muddled with them and forget that they have it and wonder what it is when it goes off. FG2 extra TI: psychiatrist

The professionals stated that people with dementia were often concerned about the privacy of their data and being vulnerable to exploitation, or did not want people in their home, which in itself could be a barrier to introducing AT:

> If people were using, say, IT as well or apps, whether certain people with cognitive conditions or other conditions could be vulnerable to exploitation in ways. For example, hacking or giving passwords up if they are particularly vulnerable, so how to safeguard that. I have to say most carers of people and family members of people, I think, generally look on the positive side, but occasionally particularly the patient may ask about things like that. FG2 extra TI: psychiatrist
>
> Things like privacy, people who are quite independent not wanting to be monitored or prefer to help themselves, really, rather than having outside help or help from assistive technology, that can certainly be a barrier. FG2 extra TI: psychiatrist

Others worried about needing to safeguard people with dementia from being exploited by buying overpriced or unneeded AT; indeed, the current system for the provision of AT is difficult to navigate in this regard because it involves a complex mixed economy of provision involving health and housing bodies, the voluntary sector, and private purchasing.

In summary, this subsection has reviewed the consequences of the current AT pathway, including inequalities in the provision of AT from MS at the national, local, individual, and personal levels. Moreover, considerable professional unease was identified: first, around the introduction of AT and the lack of knowledge of both AT and its associated costs for people with dementia; and, second, around individual professional role boundaries, navigating dyad tensions when introducing AT, and navigating the ethical dilemmas that the introduction of AT produces.

### 6.4 Chapter Summary

Overall, this chapter illustrates the current pathway and how memory service enact AT and highlights considerable variation in provision with no clear pathways to provide information or to support professionals to access AT for families living with dementia. The consequences of the current pathway are highlighted for both service users (families living with dementia) and service providers (professionals working in MS) and include inequalities of provision on national, local, individual, and personal level and considerable professional unease around professional roles and ethical considerations.

# Chapter 7. Challenges and Solutions

## 7.1 Introduction

In this chapter, a description is presented of how the challenges and gaps in the current system prevent professionals from providing information and support to enable people to access AT. It also covers the solutions that the professionals provided for some of these challenges, of which seven were identified:

1. Confusion around AT terminology
2. Identifying the right time to discuss AT
3. Identifying a need, and risk management
4. Limited professional awareness and knowledge
5. Information and resource issues
6. AT format—ensuring bespoke AT solutions
7. AT ecosystem

Each challenge is now outlined in turn, alongside the solutions the professionals' suggestions, if any.

## 7.2 Confusion around AT Terminology

The confusion over the term AT, seen among both the professionals and families living with dementia, is highlighted by the broad and varied definitions of AT they used. For example, one definition described the outcome the technology produced, such as increased independence and/or improved safety, while another described it as a form of technology, for example digital technology. Some professionals felt that AT included non-electronic devices whereas others clearly excluded them, preferring to use terms such as memory solutions, memory strategies, gadgets, and adaptions. Electronic AT could be described as standalone or linked to a response system (either self-response or a responder carer/family member). The most consistent description given by the participants of what AT encompasses is what would commonly be defined by terms such as telecare and telehealth (see Section 2.2.1 for different definitions of AT):

> I would say, I suppose, anything that would assist an individual to live as happy, fulfilled and safe a life as possible, you know, with their diagnosis. So, ensuring independence and autonomy as much as possible. TI6: manager.

> Well, to me, I would say it's the use of, like, sensors, computers, digital technology, to be able to support someone… I guess anything like a bobble pack for the medication could be, or a community care alarm that they can utilise themselves. TI8: manager

Some professionals reflected on the term and acknowledged they were unclear about its meaning and that the term itself was confusing and unhelpful; however, seeing and/or physically touching AT could help promote understanding among users:

> Tell them about it unless they physically can see it themselves sometimes it doesn't make sense to them… I remember when Telecare was first brought in…there was a flat set up in some sheltered accommodation locally with all the equipment in, and we went along as professionals to have a look at it and to introduce us to it, and if somebody explained it to me, I'd probably wouldn't have understood it until I actually went in and saw really it's just a little thing on the front door and the person wouldn't even notice it was there. You expect it would all be computer screens and everything in your room, but it's not. So, I think, yes, people need to actually see it sometimes to understand it and know it's not going to impact on their life greatly. FG2 P1: nurse

They recognised that the term might be confusing to people with dementia and carers as they could assume that it refers to everyday devices, such as smart phones and computers, when in fact AT encompasses a much wider range of solutions. They felt some older people were frightened of AT and would steer away from it as a result:

> I'm not suggesting that all older people don't get it, because lots do, but that's the way I see in the bigger picture of assistive technologies a lot of people steer away from it because they're frightened of it, and they don't think it's for them because they don't understand because they've never used a computer, but they don't understand that actually a simple clock or a medication or an app on a phone or YouTube is actually assistive technology. I think terminology is part of it. FG2 P2: occupational therapist

In summary, the professionals did not provide a single, clear definition of AT. They recognised the terminology could be discouraging for people with dementia in terms of understanding what AT is, and both the professionals and people living with dementia physically needed to see or experience it to have a better understanding of its applications. The participants did not suggest a solution to this challenge around terminology.

### 7.3 Identifying the Right Time to Discuss AT

Timing the introduction of AT was challenging for all the professionals. Each person living with dementia and their family support network is different and as such this requires consideration about the best time to introduce AT to prevent harm or emotional distress. Many felt introducing AT earlier was more effective but not in the immediate post-diagnostic period. Although most agreed that the earlier this was, the better, there was also concern that people and carers were overwhelmed with information at the point of diagnosis or even at the post-diagnostic appointment:

> I think from working with patients, it seems to be more effective if introduced early on, because trying to introduce it in the later stages was a lot harder, but right after diagnosis was too much for patients. TI3 clinical lead: nurse
>
> I think sometimes it doesn't matter at what point in the journey, they may still find it quite overwhelming if they're given suggestions, it's almost like they are more happy for us to do our assessment and then say, from that, 'This is [sic] specifically some ideas of what we would recommend', but ultimately discussing that with family because it's too much information for them to take on board. FG1 P6: occupational therapist

Moreover, most MS were diagnostic and, thus, by limiting the seeing of people with dementia to the point of diagnosis, they missed opportunities to introduce AT as the illness progresses and the needs of the person with dementia increase. Some suggested AT should be introduced at every memory service encounter. The timing of the introduction of AT was challenging not only because it had to fit with memory service pathways, but also because it had to fit the service user's dementia journey. Many relied on being informed by the person with dementia or the family about when it was the right time to introduce AT. The participants described how the timing was influenced by being service user-led and/or having to introduce and negotiate AT gently through the presentation of various options. The professionals found it difficult to provide the right information at the right time and introducing AT was a balancing act that required an elevated level of professional skill:

> We probably rely on people a lot to tell us when it is the right time, rightly or wrongly. I don't quite know whether that is right because, I think, we want to allow people time to come to terms with the diagnosis that they've been given but, at the same time, we know what you said about getting that information as early as possible. It's a real fine balance, isn't it? FG1 P5: clinical lead
>
> But it's getting that balance right with when is the right time, you know, it's about do we really want to start telling people that are functioning really well and living a full

> and active life, ‘When the time comes that you can’t manage this, this is where you need to go?’. TI6: manager

### *7.3.1 Identified solutions*

Overall, finding the right time to introduce AT in the memory service pathway was challenging; indeed, all the participants reflected on how difficult it was to gauge the right time and they had received no guidance or training to do so. Nevertheless, the participants identified some solutions to this challenge, including:

1. Developing information packs
2. Shifting responsibility for AT to different organisations
3. Shifting the focus to include post-diagnostic care
4. Using smart home technology

Some services had already introduced an information pack that contained information on AT which was given to people living with dementia at the post-diagnostic appointment:

> We’ve got like a post-diagnostic pack that has got information in. Now, what we are really mindful of is, what we don’t want is, people to come to an appointment and go home with a carrier bag of information. It needs to be more suited to their particular need. TI4: lead clinician

Moreover, some MS suggested moving responsibility for AT to different organisations, and in this regard they questioned whether introducing AT would be better suited to other organisations later in the post-diagnostic pathway:

> That would be great, I guess it is about timing. Is the timing with us? It might be for some patients, but not for all of them, and we always refer people on to other organisations, and I think our hope would be that they would gauge when the time is right, and the time is before things crumble, isn’t it? It is getting that right. TI6: manager

For instance, one professional suggested that AT information could be provided by primary care, for instance by having touch screen information pads in GP surgeries:

> You could have, like, an open event or something, where you can just explain what, within the region, this is what’s out there, really, just to promote the awareness of it, because I don’t think everyone knows that there are a lot of devices out there that can help, and technology. TI3: clinical lead

If AT is to be incorporated into the role of the MS, many suggested they would need to shift the focus towards post-diagnostic care, which would be commissioned to provide it. Many reflected on the best way to ensure successful implementation of AT and, to achieve this, memory service staff would need to be provided with the time and investment in post-diagnostic care:

> I think memory services are absolutely in a brilliant position, but we would probably need to have more focus on post-diagnostic at the moment, whereas at the moment we're just an assessment service, and I think the social interventions and assistive technology under that umbrella still have a long way to go in terms of we need the time to be able to provide those groups and things. FG2 P2: occupational therapist

On overcoming the challenges of introducing AT and ensuring personalisation, one professional was excited by the possibility of new smart home designs where we can age in place and our homes can adapt with us, regardless of whether we have dementia.

In summary, the professionals identified solutions to overcome the challenge of identifying the right timing, including developing post-diagnostic information packs containing AT, suggesting AT is implemented by a different organisation later in the dementia pathway, and utilising smart home technology; finally, if AT has to be provided by MS, then they suggested it would need to include post-diagnostic care and the services would need to be commissioned to provide it.

### 7.4 Identifying a Need and Risk Management

All the professionals described the usefulness of identifying a specific patient need or risk to facilitate the introduction of AT to people with dementia or family carers, regardless of the point in the diagnostic pathway, including the immediate post-diagnostic appointment:

> It's if a patient's saying, well, I'm trying to think of an example, 'I'm having problems remembering appointments', and I'll say, 'How do you manage that, then? What systems have you got in place, and then is it working?'. If it's not, I usually say, 'Well, we can get our OTs [occupational therapist] to come out and see if we can get any technology or any aids to help with it'. That's just one example, you know when you're doing the assessment or review, and they're saying, 'Oh, I'm having problems with this area', then that would prompt the discussion around it. TI3: clinical lead
>
> Sometimes, if we find a particular issue at that time, obviously assistive technology is considered. I suppose from our point of view assistive technology would be considered at every point within that pathway. TI3: clinical lead

Once a need or a risk was identified it depended on the professional's knowledge and expertise of whether they would provide more information, sign post, or refer to a more experienced professional or someone they saw as having more knowledge, such as an occupational therapist, local authority AT services, or linked research teams:

> Well, it's either, the options that we have are the people that operate the [X] project, so, we can refer people to them, and they will give them that information. So, it wouldn't be me that would be demonstrating it, because that's their specialism, if you like, so that they would do that. TI8: manager

Many described doing a risk assessment to determine whether they had to take immediate action or if it were something that could wait or be referred to another colleague, such as an occupational therapist. How this was achieved was not explained:

> You know, it is about safety, risk management, and looking at the least restrictive options as well. T1 lead clinician: occupational therapist

The urgency of information provision was dependent on any immediate needs or risks identified: if no need or risk was identified, people with dementia were signposted to other services or resources but safety was a high priority. A psychiatrist who was a clinical lead for their memory service described memory service professionals being conditioned or programmed to think primarily about safety:

> So, there is a safety aspect, which obviously we are probably programmed to think about all the time. FG extra TI: psychiatrist

To overcome the challenge of identifying a need and performing a risk assessment, one service provided innovative services around AT by developing their own risk assessment documentation to aid assessment, facilitate discussions with families, and record decisions in order to protect themselves if things went wrong:

> We have risk assessment documents and equipment assessment documents and assistive technology documents. Within that, we say that we've had a conversation. It's been accepted or declined. There has to be a rationale around that because it's no good then saying, 'Oh, yes. I went to Bill's house and I explained the door sensor and I said I'd go back'. Then, if you've not written that up properly and you've said when you're considering going again, heaven forbid, if something happens to Bill and he goes out wandering then that comes back on you and on him. T1 lead clinician: occupational therapist

Overall, most professionals identified the usefulness of an individual patient or carer's needs, or their risks, as a way of facilitating the introduction of AT to families living with dementia, with safety remaining a natural priority for the professionals. One innovative service developed their own risk assessment documentation to overcome this challenge.

## 7.5 Limited Professional Awareness and Knowledge: the Need for Training

Professionals identified a lack of professional awareness about AT and the AT devices and solutions available to support people with dementia and their families. Many reflected that, as individual professionals, they had limited knowledge of AT; awareness among professionals varied, with occupational therapists being regarded as the AT ‘expert’:

> I think [FG2 P3 OT’s] right; it’s lack of awareness and training from the professionals’ points of view because new stuff’s coming online all the time and nobody tells us, so we don’t know. FG2 P1: nurse

Numerous participants said it was challenging to remain current with knowing which specific devices to recommend, as AT development occurred at such a rapid pace that they could not keep pace:

> But I know there must be an awful lot of stuff out there that I have very little knowledge of, and perhaps aren’t giving people as much information or options as they could or should have, and so that’s certainly a barrier. FG2 P3: occupational therapist
>
> Technology’s moving so quick for everybody. Me, using this [Microsoft Teams] today is massive because I’m set in my ways; I’m old and been around a long time, and it’s going so quick, we can’t keep up with it, so patients are losing out because we don’t know it. FG2 P1: nurse

Many worried that people with dementia and their families would struggle even more to keep up with the rapid development:

> So, there is a lot of information, and sometimes even I get a bit bombarded with stuff and think, ‘Gosh, I can’t see the wood for the trees’. If you imagine somebody was worried or panicky or doesn’t know where to start or they’re not even used to using the internet or don’t have a computer, then it’s even worse. That stops the person from moving forward, because they will say, ‘Oh, forget it, forget it, I’ll just give up, I’ll not bother’. T1 lead clinician: occupational therapist

Many had no training at all on AT and found it a challenge to obtain information and remain current. Their knowledge acquisition was often ad hoc, from colleagues (most often occupational therapists) or even stemmed from people with dementia and their families:

> I started in 2013 and had very little knowledge at all about assistive technology, and I’ve had no training; it’s basically been everything that I’ve learnt on the job from others or kind of gleaned from what you pick up. FG2 P3: occupational therapist
>
> Sometimes we mention [AT] in the carer’s group, and they’ll sometimes have already come up with ideas or suggestions that they then share with other relatives or carers in the group, which sometimes has a bit more weight than if we were suggesting it because it’s almost, like, tried and tested. FG1 P3: nurse

### *7.5.1 Identified solutions*

Participants identified four solutions to the challenge of limited professional awareness and knowledge:

1. Utilising existing information channels to improve professionals' awareness of AT
2. More professional training on AT
3. Better evidence on the effectiveness of AT
4. Up to date information sources

To overcome the challenge of a lack of awareness, the professionals felt that numerous possibilities could be exploited, including the media and the NHS and social care, as well as charity websites:

> I do wonder if it is publicised enough as well, whether we see enough of it in the media, within NHS information or within social care information, leaflets, etc., yes, or websites and things. It is probably not as prominent as it could be, actually. FG2 extra TI: psychiatrist

In addition to having more educational training, the professionals not only wished they could see AT devices in action, they also felt the need for effectiveness evidence to be confident of recommending an AT intervention. They also called for information resources to help them remain current with rapid change (as described in more depth in the following section on information and resource issues):

> But yes, I think there's definitely a need for training and just generally keeping up to date with things, different processes and how you actually go about acquiring these things because as well it can be down to getting grants for people which we're not used to dealing with. FG2 P3: occupational therapist

In summary, the participants highlighted a general lack of awareness and knowledge of AT. They suggested several solutions to overcoming this challenge, including the utilisation of existing information channels to increase awareness, more professional training on AT, better AT effectiveness evidence, and improved up to date information sources on AT.

## 7.6 Information and Resource Issues

A key challenge for professionals was having easily available current information on AT. Obtaining information was challenging, and many recognised there was no single place from which to obtain all their information needs for AT. Many found it hard to stay current and source any AT they suggested, and they would often ‘just Google it’. The lack of information on costs for people often made it challenging to provide information:

> I do think, at the moment, if we were to ask any practitioner in most teams, ‘Where would you go now, say, if on the spot a patient or carer asked for such and such to help them with something? Where would you go?’, and I have to say there isn’t one.
> FG2 extra TI: psychiatrist

Professionals wanted to know that they were directing someone with dementia to a reliable and trusted source of expert information, such as the Alzheimer’s Society website or, in some cases, AT Dementia, assuming the professionals were aware of it. Google and message boards such as Dementia Diaries were also considered.

Overall, staying current was incredibly challenging; most professionals deferred to more expert professionals to provide information and support access. An occupational therapist was seen as a key expert.

### *7.6.1 Identified solutions*

Professionals suggested several solutions for improving the identified information and resource issues so that they would be able to provide more information and support access to AT, including:

1. Obtaining information from people with dementia and carers
2. Referring to, and working with, voluntary and local organisations
3. Asking an in house ‘expert OT’
4. Having a memory service AT champion
5. Having a single point of access for information on AT
6. Having a loans system
7. Demonstrating AT

These will now be described in turn.

Interestingly, many professionals identified that people with dementia and carers were often a source of education and knowledge of AT as they would describe AT they had used which was new to the professional. They often relied on the reviews and feedback of people with dementia and carers on what they found helpful:

> Sometimes, we mention that in the carer's group, and they sometimes will have already come up with ideas or suggestions that they then share with other relatives or carers in the group, which sometimes has a bit more weight than if we were suggesting it because it's almost, like, tried and tested. FG1 P3: nurse

Many preferred trusted sources of information such as the Alzheimer's Society website or links they had made with national or local voluntary services:

> If it was, sort of, on the Alzheimer's Society website then you'd feel confident to recommend it. FG1 P3: nurse

Professionals often used local resources such as the local authorities or a local telecare supplier which could be via their local authorities or private companies or local charities. For instance, one mentioned a local charity, Dementia Matters, which had short-term funding and was a valued resource to which they could refer, and they knew the staff would recommend AT and know about costs etc.:

> I think, obviously, Dementia Matters have their early interventions project. The funding has finished for that, but that was really useful, that they could just signpost people over there and they could take the time to get to know the people a bit better and work out when was the right time to say, 'Have you looked at this? Have you looked at that?'. FG1 P5: clinical lead

Some were confident at recommending AT while others preferred to defer to more experienced team members due to a lack of knowledge, perceived expertise, and their concern that they did not know about AT or could recommend something that was unhelpful. Moreover, many described not having the time to research the AT that they wanted to recommend:

> Time comes into that as well because you're pressed for time and so you don't have the time to go and research things and to do as much digging as you would want to do, or perhaps don't know where to go, so it's the networking around that resource as well. FG2 P3: occupational therapist

Most recognised their in-house occupational therapist, often an occupational therapist with a special interest in AT, as the expert. However, many recognised that there were often not enough occupational therapists or that not all professionals would identify the need for AT and refer to an occupational therapist. Even 'expert' team members such as the occupational therapists found it challenging as there may be many models of individual devices for instance; one participant described nine GP trackers but did not know which was the most effective or cost-efficient model.

AT champions were identified as a key solution to this issue. Professionals called for a consistent approach to AT and access to resources such as a national digital forum and national/local champions. These champions would be the recognised 'expert' in AT who would stay current and be able to answer the professionals' questions and suggest appropriate solutions. Many felt they could not stay current with every type of AT:

> Patients sometimes tell me about things that I've never heard of before, and it's so massive that it's actually quite hard to keep track of; it feels like it would be helpful to have some—like you were saying how do we do this—it would be helpful to have a dedicated digital champion around these things that they could keep on top of. FG2 P2: occupational therapist

The professionals valued the concept of an AT champion and also wanted a comprehensive central resource or single point of access for information on AT which was kept up to date. They wanted this to include a watchdog-type facility to recommend and classify AT solutions, as well as a helpline for professionals to call for advice:

> A centralised resource would be ideal, online, and then, obviously, if there was a dedicated person that you could just tap into periodically just to get updates or they could come and speak to us in a team meeting environment. FG1 P8: nurse

> For myself [laughter], and certainly for patients and carers, I always seem to think that simplicity is best in a way. So if, for example, there was a single place of access for information on assistive technology so that, despite numerous providers and numerous options and numerous types of assistive technology, there could be a hub or a single point of access for information, for both patients and carers and professionals. FG2 extra TI: psychiatrist

> From an OT perspective, obviously for physical aids and adaptations we have online resources where we know 100% that it's been checked, that the equipment there and there are pictures on the online resource where you can see before you order. Having, in an ideal world, something like that, but the equivalent for memory rather than bed leavers, chair leavers. FG1 P6: occupational therapist

AT demonstrations were key to the professionals, who wanted to see and test it for themselves before recommending it to people with dementia and their family carers. They also wanted to have the expertise to demonstrate specific devices to people with dementia and their carers via a simple toolkit that they had to show people with dementia and/or to have access to large demonstration rooms in which people with dementia could test AT:

> I think it would even be good if we knew about all the things that are out there and had a look at them, because then you can gauge much better, 'Is this person going to be able to use it or not, and actually have the dexterity or not?' So, it would be really helpful. FG1 P1: clinical psychologist

> I suppose getting up to date information is central because you get information, and you don’t know whether it’s still up to date. Having examples to show people and having the knowledge and experience to show people what they’re all about. FG1 P2: nurse

Being able to demonstrate AT was important but many professionals also valued the concept of a loan system which would allow people with dementia and the carers to test AT free of charge; this type of system was often already in place for AT used for physical health needs. The professionals would prefer the option to be able to loan AT to families to test before they had to pay for a device they might not like or use, or which might be harmful to their economic situation:

> So, it would be lovely to have a library of resources that you could lend people, because these things are quite often expensive, and how are people going to know that they work?... But I do think it’s a lot of money for people to pay out if these things aren’t going to work, so the ability to lend people things and see how they get on with them, I think would be really useful. TI6: manager

> I’ve made these recommendations on the back of an assessment, but actually I haven’t necessarily always provided them with that. It would be so much, in a perfect world, easier to say, ’This is what I would recommend, why don’t you try it for a couple of weeks and then come back?’. FG1 P6: occupational therapist

Some services had had this facility previously for simple AT solutions such as clocks but wanted to see it reinstated and a wider selection offered for people to try.

Overall, participants found obtaining information on AT incredibly challenging and identified many practical solutions to overcome this challenge.

### 7.7 AT Format—Ensuring Bespoke AT Solutions

It was important to put the right AT in place to complement the life of someone living with dementia without causing harm, but this was challenging either because of concerns over poor AT design or a mismatch between the nature of the device and the reality of living with dementia. Identifying the right AT, if any, to complement the life of a person with dementia was key. To do this, professionals described identifying service users’ current baseline technology use and then suggesting solutions which would fit and integrate into their normal technology use and life:

> It is usually what the patients or relatives have already got in place. So, it might be making recommendations for orientation clocks and things that they can buy or purchase. Then, also, if they’ve got mobile phones, if they’re using those, or iPads

> and linking up with that and making suggestions of how they could use those things that are already in place to build memory in reminders for mediation and things. FG1 P6: occupational therapist

Not only was it important to identify service users' baseline technology use and recommend appropriate AT, it was also important to recognise when AT was not required. Sometimes, professionals felt that using simpler solutions was better. For instance, one professional reflected that they had found how some AT merely replaced simpler techniques of identifying issues, and they did not see the point of using AT for such purposes. For example, fridge contents could be physically checked to monitor whether someone had been into a fridge to eat versus monitoring systems to help people remain independent, such as Just Checking:

> My opinion is, really, I think, how can you know just, somebody might have opened the fridge ten times, but that doesn't really mean they've eaten. You can't say from that, 'Oh, yes, they're eating regularly', because they've opened the fridge ten times. There are other, more obvious ways of monitoring that likelihood, really, aren't there? I mean, you know by the shopping that's coming into the house, and the food waste, and you know by a person's weight monitoring if they're eating, and I think, so, I just feel that's got a limited use. TI8: manager

Even when professionals identified AT they felt would enhance the life of a person with dementia, they were frustrated that current AT design was often suboptimal, and not tailored to the needs of a person with dementia; in this regard, they felt that existing device designs could be more user friendly. They described several negative aspects of existing AT concerning its design, the timing of its introduction, the surrounding environment, and how it fits with the type, stage and symptoms of dementia experienced by AT users. Some AT was not designed specifically for people with cognitive impairment and could not be used successfully because the person with dementia forgot how to use it or could not learn to do so (e.g., forgetting the name of Alexa):

> Yes, the only problem with that is quite a few of our patients forget Alexa's name, and that can cause frustrations. TI3: lead clinician
>
> I think because they're too impaired. I think that they're wandering, and they're on their own, and a remote voice saying, 'Go back to bed', they're not taking that in. TI8: manager

AT would be ineffective if a person with dementia did not have the cognitive ability to engage with AT or even recognise what it is. For instance, some described people with dementia ripping out AT as they did not know what it was or thought someone was watching them, as has been the case with smoke detectors:

> Sometimes, even the smallest piece of equipment, they will rip it out. We have to be mindful of where the device might be. For example, I had one lady, she got the stepladder out and ripped it off the ceiling. That was the smoke sensor. So, it's just considerations like that. People can agree to something, forget, look up, think 'What the heck is that?' Not think of the safety of themselves and rip the piece of equipment down. T1: lead clinician occupational therapist

Usability was another key issue for many professionals. They described how some products on the market did not address the needs of people with dementia, such as the size of the buttons or screens or the aesthetic design of the device being too modern; such products do not appreciate how people at a certain stage of dementia who have retained their long-term memory would benefit from a 'time appropriate' design.

Moreover, some design features could be troublesome for people with dementia, for instance alarms being activated appropriately but a person with dementia not understanding what the alarm was for and therefore finding it intrusive. Similarly, an 'impersonal' voice prompt might not be recognised or understood as a prompt. Many professionals reflected that people who had specific beliefs around technology, or paranoid thinking such as the technology was spying on them, might find voice-prompted AT confusing and frightening:

> I don't think we've had actual harm, but you do have to be a bit careful if people are paranoid, seriously paranoid to the stage of a mental disorder, of paranoia. Because if you've already got a delusional belief that people are spying on you from the television, or the radio is spying on you and sending out waves, and then you install something in the rooms that is actually monitoring you, then it could create a problem. TI7: manager

Design was also important when considered in the context of the stage of dementia. For instance, a patient might have a medibox which prompted them to take their medication, but due to the stage of dementia they were at they might lose the pill dispenser or not actually take the medication. Although the device initially worked appropriately in the earlier stages of the illness, as the dementia progressed, the person with dementia could no longer respond as the design was intended:

> So, there may be things that work for somebody for a time, that they won't work as things progress. For instance, like a sensor, these pill dispensers that you get that are a month's supply of medication and an alarm goes off… that works very well, but in somebody that is really quite impaired, they're not likely to recognise what it is…and they might still move the box and put it somewhere, and then it is lost. TI8: lead clinician

Similarly, cognitive challenges were evident with other devices. For example, GPS trackers or fall detectors require that the person with dementia remember to wear the technology;

moreover, if they were not used to wearing a specific device, such as a GPS watch, they might try to remove it. Again, the device might work as intended but a person with dementia would be unable to use it because they forgot to wear it or did not understand what it was or how to respond:

> I think, sometimes, you know, the tracker bracelets that they've had on, it sometimes feels like an electronic tag, so to speak. If someone has never been used to wearing a watch or a bracelet, you know, they are constantly trying to fiddle to get it off, so I've found that that sometimes has not been good. TI5: manager nurse

### *7.7.1 Identified solutions*

Participants suggested two main solutions to overcome the challenge of the AT format: personalised AT solutions, and improved usability via better design and bespoke implementation solutions. Each of these are described in turn now.

Despite safety being a core concern for professionals, they also identified the important need for any AT provision to provide a personalised solution for the problems of the individual with dementia. Personalisation was seen as an essential and core element as each person with dementia had a unique experience of living with it. As described above, the population of people living with dementia is varied, not just because of the distinct types of dementia and stage of presentation, but also their sociodemographic background, their existing, or lack of, support systems, and their prior knowledge and experience of technology:

> And people come onto the memory pathways at much different points on their journey, so I think it has to be looked at on an individual basis, really. FG2 P3: occupational therapist

Many reflected on the stage of dementia and timing of the introduction and how it often influenced what AT could be used or whether it might be harmful rather than helpful to a person living with dementia and their family. All agreed that, in the more advanced stages of dementia AT, was more challenging as the person might not understand or remember conversations or suggestions made. Moreover, the technology might no longer be suitable or work as intended:

> Initially, it's stuff around the house that can help with prompting and help them manage their symptoms, but as they get to the more severe stages, and there's wandering, and problems with sleep and agitation, it changes what're needed. Instead of using Alexa, you'd be looking at door sensors, and Just Checking, and Carelink. TI3: clinical lead

> It’s something to enhance someone’s life, but it will only work for a window, as well, because obviously it’s a moving, dementia’s progressive. So, there are things that might work for somebody for a time, that they won’t work as things progress. TI8: manager

The type and stage of dementia was not the only variable identified when selecting appropriate AT. For instance, personality, pre-existing comorbidities, mental health symptoms and preconceptions about technology ‘watching them’ could make some people resistant to, or paranoid about, AT use:

> For some people, they may have, you know, a belief system around technologies that needs to be explored before you put anything in the home. And certain noises, you know, the carousels, they’re not always indicated for everybody because of various reasons, you know; it might be a physical reason, but it might be a mental health reason, or an environmental reason or a certain sound reminds, you know, I just think any assistive technology needs to be individually assessed, based on the person’s individual needs. FG2 P2: occupational therapist
>
> When you come across people with different diagnosis that it’s not just fitting well with people that have memory problems, you know, you have a lot of people that have actual complex physical problems as well. FG2 P3: occupational therapist

Other variables necessitated the personalisation of technology solutions, including the baseline technology use of people with dementia, an aspect which might influence their future use of AT. Specific groups, for example people with young onset dementia, often used technology more and had unique needs and priorities (including their parents, workers, and carers). Moreover, some older adults who professionals presumed had little technological experience were in fact very advanced and were early adopters of new technology:

> To be fair, the younger people, they are usually…I mean, this is a generation gap, isn’t it? Those people who are in their…To be fair, I’ve had a patient who’d used a mobile phone before me, and he was in his 90s. That’s many years ago but, still, I thought, ‘I need to get myself a mobile phone’. But, the younger generation are usually fine with it. FG1 P1: clinical psychologist

Participants identified the need for personalised AT solutions appropriate to their type and stage of dementia and their family setup. Participants also called for better usability via improved AT design to suit the needs of an individual person with dementia, as well as bespoke implementation solutions. One clinical lead reflected on the lack of usability of some AT devices, and suggested professionals should have closer working collaboration with companies to improve usability of AT:

> The cons, I would say, is that there needs to be a better interface, and collaboration with companies developing ideas, that actually translates to usability. A lot of the

> time, I can come up with ideas or solutions but when it comes to looking at whatever product it might be on the market, you look at the usability of it and you think, 'Hang on a minute, they've not considered the size of the buttons, they've not considered the size of the screen, or the look of the gadget'. Sometimes, it's about making things look modern but, at the same time, it's looking at harnessing people's skills. If their long-term memory is better, then it's looking back at the era when they would remember and how something looked rather than making things look too fancy, if that makes sense? TI 1: lead clinician

Moreover, one memory service who provided 'good services' on AT recognised the issues around usability, in that people with dementia recognised devices and developed their own bespoke solutions. For example, they overcame the challenge of a person with dementia not recognising the AT device by labelling AT items with text to describe its function.

### 7.8 AT Ecosystem—Implementation and Monitoring

Many described the need for a better ecosystem surrounding the introduction, maintenance, and ongoing monitoring of AT in practice. The wider implementation of AT was challenging because the underlying AT support system was too underdeveloped to support the implementation of AT services and better collaboration between services. Monitoring was also key as many devices require someone to respond, and systems need to be in place to facilitate this:

> Interviewer: Is there anything else that you think, if it wasn't just money? You've got the structure within there if you had an idea, but is there anything else, like staff or any other things that you would need to make that happen?
>
> TI9 lead clinician: Well, the practical thing, of course, would be that you'd need someone to develop it in the first place, and adapt it and make it helpful for the individual, because they'll need to be individualised. It wasn't something that you could spread quickly in a generic way. It needs to be individualised, and I guess, like I think I've mentioned, it will be the access to the supportive infrastructure, like the Wi-Fi, the kit itself, etc. I think there will be, or there could be, need for… a bit like you've got the door sensors, there will be somebody that needs to monitor where things don't go as well as you need it to"
>
> Everything has always been difficult, even to get the mindfulness relaxation group going in the care home, it was just a stumbling block after stumbling block, because then it was up to them to purchase the device, you know, the software to be downloaded. And then it was… then they had issues with making sure that they have got staff that could facilitate that in the care homes, you know? If the activities coordinator is off sick or on holiday, is it going to go ahead? Is it something that could be done on a daily basis? Who is going to take responsibility for this? Everything just seems to get met with, you know, red tape all over, really. TI5: manager

### *7.8.1 Identified solutions*

Participants identified many solutions to the challenge:

- Better AT assessment
- Access to equipment, staff, and infrastructure
- Better access to and support for using AT
- Systems to ensure monitoring and review

These solutions will be described next.

Many professionals wanted better AT assessment and more equal access to occupational therapists to be able to assess people with dementia and provide an individual AT prescription. Some thought this could be an occupational therapist's assistant, while others preferred the higher level of skills provided by an occupational therapist. They also preferred home assessments by an occupational therapist who could identify present and future AT needs:

> It's just important that it's not just assumed, you know, that there is a blanket, 'This piece of equipment is good for this diagnosis, or this group of people', I think there should be a caveat on all assistive technology that actually it has to be properly assessed for, and that's really key. FG2 P2: occupational therapist
>
> The OT assessment is a really good opportunity because it is looking at skills, it's looking at support, it's looking at values, historical problem-solving strategies and what the needs are within the home. FG1 P7: occupational therapist

Participants called for better access to equipment, staff, and infrastructure. During the COVID19 pandemic, the positive use of tablets and iPads was highlighted to many participants regarding how it can help people with dementia to communicate with services and access information. Many felt that equipment such as tablets and free access to WIFI would benefit many people with dementia. One clinical lead had a special interest in the use of how virtual environments can be used to demonstrate how AT might alter the environment of a person living with dementia; to offer this, she needed the physical equipment, staff, and infrastructure to establish and maintain AT, and these were not currently available:

> Well, the practical thing, of course, would be that you'd need someone to develop it in the first place, and adapt it and make it helpful for the individual, because they'll need to be individualised… it will be the access to the supportive infrastructure, like the Wi-Fi, the kit itself, etc. I think there will be, or there could be, a need for… a bit like you've got the door sensors, there will be somebody that needs to monitor where things don't go as well as you need it to. So, yes, it will need… but I imagine that you

> won't need as many to man the virtual environment as you might do with other possible assistive technologies. TI9: lead clinician

Professionals called for better access to and support for using AT. They also wanted to have easier, more streamlined access since it often involved more than one service. With a clearer implementation and monitoring pathway, they felt they would be able to identify AT and have it installed and set up with systems in place to support the person with dementia to use it appropriately. Currently, people with dementia are either unsupported or obtain help from their families or professionals, if they have the skills:

> You've got certain situations where you've got a client and you're looking at a certain piece of equipment, and I'm not terribly—I can work some things out, but there's certain things that I struggle with. I know [another OT in Memory Service], GPS systems, she has actually, she has, you know, gone out and helped—it's actually helping people to set these things up and use them, and now that is a barrier to me because I don't know where to start; I don't feel comfortable or confident in doing that sort of thing. I would feel much better if somebody showed me how to do it first before I went out and showed somebody how to use it. FG2 P3: occupational therapist

The professionals wanted to have better integration of social care, healthcare, and voluntary services to allow knowledge sharing, better collaboration, and more efficient care pathways. Moreover, they identified how the system in which they worked separates physical and mental health, requiring close collaboration with local authorities and social care. Although this worked successfully in some MS, others had strained relationships with social services as the levels of collaboration and interaction fluctuated with service reorganisation:

> So, the local authority are [sic] part of the team, if you like, in terms of a named social worker, not embedded, but is part of the team. With the CCG, there's a regular review of services with the CCGs. I guess there's been a driver over the past five years where, because of the high diagnosis rate that we've been able to achieve, it's, kind of, stimulated the CCG to be more supportive than I am aware of in other neighbouring trusts. So, we do have quite close links with the CCG in that way, and the local authority in terms of them being part of the service. TI9: lead clinician

> Social care are very precious about certain things, and then we've got to stick to our script because we're only allowed to do certain things. It's hard, really hard. And as I say, we're integrated a lot of years ago; it was fine, but now we're not integrated with social care and it's like they're the enemy. And like [FG2 P3: occupational therapist] says, they will push; I've seen referrals come in here where they're asking for, or phone calls come in asking for us to refer for this to happen, and no, that's because of their physical health, that's your job. FG2 P3: occupational therapist

To improve the current situation many professionals suggested some novel ways of approaching AT provision. One professional's experience of working in another region revealed that the memory service worked collaboratively with voluntary services to provide digital tea parties so that people could try the technology in a non-threatening environment. Another professional suggested closer collaboration with primary care and the initiation of timely AT discussion as symptoms arose, rather than at the point of diagnosis, in order for AT suggestions be more relevant and less daunting. The idea of AT could thus be gently implemented in group sessions in primary care:

> I think it would be helpful to have some partnership working with primary care and there would be group sessions available to people… not diagnosis specific, but more symptom led. So, rather than if you've got this diagnosis, you're probably going to need this, or you might need this, but rather, symptom-led and group work whereby you could introduce—particularly for our client group, when you mention assistive technology, we have people that sometimes actually are a bit scared of using a smart phone, you know. I mean, we had in [another MS]—that's why we had what we call digital tea parties, and it was this really supportive way of introducing technology without it being scary, in bitesize chunks, and introducing, informing people about how varied that was and how simple some of the equipment was, to how complex it was. FG2 P2: occupational therapists

Just as having the physical equipment, staff, infrastructure, and collaborations to support AT use was important, so was having appropriate systems for monitoring and review. For example, several devices required someone to help set up and monitor them, or for the person with dementia or carer to respond, without which the AT could be harmful. Equally, if someone responded too often it could become over burdensome and stressful for both service users and providers:

> I think that's the problem with assistive technology. Any technology is very heavily dependent on the support of another person, be it a care package, or a relative, or somebody living at home. Yes. There has been some really great success, but I think there's a long way to go, really, still. TI7: manager
>
> The door sensors are generally helpful, but only where there is that external support from maybe the third sector agencies who will respond to it, and also follow-up, not by phone calls to the relative who might get… you know, say you had several alerts in the middle of the night, if there's just the one person who gets phoned up every time, that in itself is harmful to the relative or the carer. So, not helpful in that respect, but supportive and tends to give peace of mind to others that their relative is safe. TI9: lead clinician

Some AT required a person with dementia to wear and/or charge a device and/or react to a stimulus, requiring some cognitive ability or family/carer help:

> I have known people with dementia who have had care alarms, and it's the classic thing, they're not wearing them. They've left it by the bed, or forgotten, just not had the cognition to use it themselves if they have fallen, whereas I know that you can

> get sensors that people can wear that would trigger the alarm automatically. TI8: manager

Moreover, if any AT was introduced by a memory service the team did not review it to see whether it was helpful or indeed harmful to someone living with dementia. Often the memory service referred to another organisation to assess or install the AT. Professionals described needing to review the use of AT to check that the implemented technology was being used as intended and not causing distress or harm:

> This is the problem that comes back time and time again […] somebody's wandering, 'Shall we suggest a tracker, but who's going to monitor the tracker and raise the alarm?'. TI8 lead clinician: nurse

Also, individual items of AT had to be assessed within the wider AT system in the home; for instance, if the fire alarm is alerted but the door sensor tells the people with dementia to stay in, this could have catastrophic consequences if they did not have the cognitive ability to understand they had to ignore the door sensor:

> It's a sensor whereby when somebody walks past it, you record a message on it and it can tell you to, you know, not go out because it's late at night, and it reminds people to stay in the house... again you just have to really assess to make sure that somebody has got the capacity to override it, should it be—you know, if there was a fire in the house—you're not convincing somebody that they have to stay inside, so you have to assess for it to make sure, yes, that somebody has the capacity to know when they would actually need to leave the house in case of emergency. FG2 P2: occupational therapist

Overall, the participants described an underdeveloped AT implementation ecosystem and how incredibly challenging it was to have the right AT used within a clear, streamlined implementation and monitoring system. To overcome these challenges, many participants identified the need for a 'whole systems' improvement' with an increase in the number of home assessments and reviews of implemented technology, more timely delivery of AT, and better integration of AT within the services.

### 7.9 Chapter Summary

In summary, Chapter 7 has illustrated the challenges professionals face when enacting AT in real life settings and the gaps in the current AT system. Enacting AT is complex and requires professionals to overcome several challenges, including limited professional knowledge of AT, information and resource issues, and working in an underdeveloped AT ecosystem. Despite these, professionals identified numerous solutions to help enable them to enact AT including:

developing better information resources (information packs, single point of access for information on AT, loan system and demonstration, AT champion); improving awareness and professional training; shifting focus to post-diagnostic care or shifting responsibility to different organisations; improved AT format via personalised AT solutions and improved design; and, an improved AT ecosystem to ensure effective implementation and monitoring.

# Chapter 8. Factors Influencing How Memory Services Enact AT: Information, Support, and Access

## 8.1 Introduction

In this chapter, I present the results of the qualitative analysis of the focus groups and one-to-one interviews with professionals working in memory services; these include MS managers and lead clinical professionals. It is important to understand the overall context of the service provision in which AT is being enacted and the factors influencing this before addressing the specific factors that impact service provision around AT. Following Chapters 6–7 (the results of how individual professionals enact AT within MS and the challenges they face), this chapter describes how MS function in general. The findings reveal how services experienced considerable and continuous organisational changes, with provision influenced by both external and internal factors. The chapter is split into two sections on external and internal drivers, respectively.

## 8.2 External Factors Influencing Service Provision

The external factors influencing service change can be grouped into five areas:

1. Pre-COVID19 national drivers—the shift to diagnosis only
2. COVID19 as a global driver aggravating and accelerating further change
3. Vague guidance and research on AT
4. Priorities and funding
5. External stakeholders

### *8.2.1 Pre-COVID19 national drivers—the shift to diagnosis only*

Most professionals described their memory service as being purely diagnostic, with only a minority caring for people after diagnosis and during their dementia journey. Many acknowledged the service had to evolve over time to adapt to frequently changing demands; for the majority, this resulted in a shift from a diagnosis and support service to a purely diagnostic one. There were numerous reasons for this evolution, including: national policy initiatives and clinical guidance which prioritised earlier diagnosis, leading to increased referrals for assessment, the development of dementia medications to reduce the rate of cognitive decline, and service pressures. For example, this could include a caseload with increasing numbers of routine reviews of stable patients and this limited their ability to assess urgent referrals:

> We developed really on two lines, one around our commissioners wanting us to increase our diagnostic rates. Also, us advising that year on year, if we increase our diagnostics then actually, we've got, year on year, more and more patients that would sit within our service. Previously, we didn't discharge people to the GPs. They stayed with us forever and that obviously then created a really big door into the service or really small door out. TI4: manager
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> There was a push a while ago though, I think—and forgive me [FG2 P1: nurse], if this is not right here—but the memory services across the country, really a lot of them have been, I guess, encouraged potentially to become assessment services. FG2 P2: occupational therapist
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> So, it's more of an emphasis on the earlier diagnosis, and so, but we had a lot more people referred to us for memory assessments now than, say, I mean, certainly 20 years ago. TI8 lead clinician: nurse

Service leads reflected that the new way of working by only performing diagnostic assessments was beneficial as they were seeing more patients at an earlier stage and diagnosing greater numbers, leading to less severe presentations. However, some were also concerned they had lost the continuity of post-diagnostic care which was not only beneficial for people with dementia; notably, many felt they had lost the professional satisfaction of following people up and managing their care:

> I was pretty heartbroken when we did change the model from memory clinics to a diagnostic and post-diagnostic pathway because the continuity wasn't there, and the continuity felt as if it should fall to the dementia navigators. But they're not resourced either. TI7: manager, occupational therapist

Despite most participants describing a move to a diagnostic only service, many commented on the continuous evolution of MS; one psychiatrist reflected that regular management meetings were required to remain current with such constant change:

> We identify the need to have a meeting like that because memory services are changing all the time. Their referrals could change, and demand can change, personnel can change, and, equally, what is available to us, to help us, can change." FG2 extra TI psychiatrist

Thus, the majority of MS described a move to a diagnostic only service, although this move occurred during a period of constant change due to several factors.

### *8.2.2 COVID19 as a global driver aggravating and accelerating further change*

Not surprisingly, factors outside organisational control, such as the COVID19 pandemic, had had an enormous impact on service provision, with many changing their model of care not only to focus solely on diagnosis but to offer fewer face-to-face reviews and more online interaction. As a consequence of COVID19, organisational change varied from complete service remodelling, to attempts at offering the same service as before the pandemic, or to a complete cessation of usual care. In addition, the pandemic widened the service variations seen before the pandemic, with some services providing more patient choice by offering consultation options, e.g., being seen in person at home, online, or via the telephone. Others, however, struggled and after reviewing the risk of face-to-face assessment during the pandemic, decided not to see people in person:

> So, we started seeing patients again in June, with very, very rigorous safety checks. So, what has been added into the pathway is triage… questions you ask at triage are about, you know, you've been referred to us for assessment, how would you like that assessment? You've got three options: face-to-face appointment, an online consultation, or a telephone assessment. 80% of our people are saying face to face appointments. And then we have to come up with a very good rationale and document in the notes why we think that that is safe. TI6: manager

Those leads who were interviewed after the start of the pandemic described having to adapt their pathway swiftly due to safety concerns. Most rapidly moved to using online platforms such as Zoom or an NHS-approved online consultation platform called Attend Anywhere, which allowed them to still 'see' patients. They routinely discussed and triaged cases on the merits and risk of a face-to-face appointment:

> That is part of the advances we've made in technology. The staff team, we've had to learn how to do Zoom and Attend Anywhere and Microsoft Teams, and we're doing everything. Not everything. We're still doing face-to-face as well, in person, I mean, not just virtually face-to-face. In fact, our service didn't ever stop seeing people face-to-face. We said, 'No. We can't get a waiting list going. We've just got to keep going the best way we can and adjust and learn and go from there'. TI7: manager, occupational therapist

As the pandemic progressed, some services described how they re-evaluated their risk assessment procedure and refined their service to offer patient choice on how to be seen; if a patient preferred face-to-face this still was triaged for risk assessment but was more acceptable to offer. Although online platforms were used for seeing/evaluating patients, some more adaptable services quickly moved educational resources online to offer people with dementia/carers ongoing support. In so doing, service user education was also disrupted, as some users adapted easily to moving education to online platforms such as Zoom, while others reduced or stopped services:

> We're able to offer, or we're starting to work on an offer to offer, CrISP courses, which are a carers education programme. That's moving onto Zoom and Teams. The team, at the moment, are working together... They're doing some training on the technology and things like that, to get that rolling out across the area. TI2: manager

Participants recognised the value of seeing people in their own home but, due to safety concerns, they had shifted away from face-to-face consultations. Many had concerns over these changes in practice during the pandemic. They worried whether people would be able to access services and if the changes might increase the isolation of people with dementia and carers. One participant described how a patient with dementia had died due to lack of food as they were already very socially isolated before the pandemic and the latter aggravated his isolation:

> Early on in the COVID situation, some gentleman that lived alone and he just hadn't gone out, and he died of hunger, basically. He had no one to feed him. I can't remember the exact circumstance, but I remember being horribly shocked to think that people in this country could be living in a situation of such isolation, not understanding what the rules were and how to get food. He had no technology. TI7: manager, occupational therapist

Online platforms were viewed positively as an option for seeing patients face-to-face without risk so that people with dementia and their carers could be supported and provided with access to services. One consultant was involved in a research trial to use online approaches for cognitive assessment which previously had been face-to-face:

> So, one of the difficulties since COVID, of course, and we've moved to virtual, is people being able to participate in that cognitive assessment. So, the ACE, which is what we use primarily, has been difficult over videos. So, this one that we're piloting certainly has visual displays that the patient can interact with the assessor online. TI: clinical lead, psychiatrist

The professionals preferred online platforms to the telephone but many supporting people with dementia and carers used both options. Many service users rapidly learned how to use such platforms, but some participants reported that they needed more help and others struggled with not having equipment or WIFI, or found it difficult due to sensory impairments, i.e., hearing or visual loss:

> Throughout COVID, as we've found today, using assistive technology or virtual technology, I suppose, to engage with people. We haven't been able to do the face-to-face, we're able to WhatsApp and Skype and set people up on Zoom so that we

> can talk to them and still have that face-to-face element of services rather than just being on the phone. People with dementia often can't communicate on the phone and find it difficult. We need to work to find different ways of doing things. TI2 manager

> I think, I mean, especially during COVID, I think the carers have had to really, in terms of using Zoom, assistive technology in that way, they've found that really, really helpful, because otherwise they would have felt quite isolated, I think, during all this. TI3 Clinical lead: nurse

> Then later, now, we're thinking, 'Oh, my gosh. So many people we need to do appointments by these platforms, Attend Anywhere platforms, Zoom. But actually, people are needing help with either obtaining that equipment, or how to use them. We've begun to realise, the OT world in our Trust, has begun to realise that we probably need to put together some interventions around that in itself. I have enormous sympathy for anybody trying to struggle. I need help [laughter]. Actually, I'm joking, but in a way, that is part of the advances we've made in technology. The staff team, we've had to learn how to do Zoom and Attend Anywhere and Microsoft Teams, and we're doing everything. TI7: manager, occupational therapist

> Overall, a major disrupter of how memory services operated, were able to see people with dementia and offered AT was the global COVID19 pandemic. This caused many services to change their provision.

### *8.2.3 Vague guidance and research on AT*

National policy recommendations and clinical professional guidance were recognised as external levers to implement change; these included NHS England, NICE, and the Memory Services National Accreditation Programme (MSNAP) guidance:

> I think the start of it was, and really we were very lucky, it was that… because CST training is not easy to come by, and it was starting to be mooted about in MSNAP that to get accredited you should be offering CST and also obviously NICE guidelines were starting to come out about what sort of post-diagnostic support should be offered. TI6: manager

A few leads described using MSNAP guidance as the lever by which to ask for further funding within their organisation to increase resources allocated to AT:

> I think to some extent the national MSNAP programme has driven a change, the memory service's accreditation scheme has driven best practice up. So most of us who are team leaders and advanced practitioners, or sector managers have been on the peer training, so that you can go to another service and see what's best practice. But hopefully, we collect Your Views Matter. I don't know whether that's a national scheme, or not. It's very inadequate, really, but it gives you some flavour of what the patients' experiences are. We try and keep the patients' views central. TI7: manager occupational therapist

However, despite some participants placing value on national guidance such as MSNAP for its role as a key lever for organisational change, many leads commented that even this national guidance was often very vague and out of date compared to the rapid pace of technological change:

> Some of the standards are just quite generic. So, in terms of, like, what we provide, in terms of interventions everything's lumped together. I think it just needs to be in line with, you know, technology is moving on, and there's a lot more out there than there was out there ten years ago. So, I think the standards need to reflect that, really. TI3: clinical lead, nurse

As well as identifying a lack of specific and clear guidance on implementing AT in MS, the professionals also called for better AT research. Nevertheless, although such research was important, the leads stressed that some forms of research were potentially unethical and too challenging for people with dementia, and indeed they stressed that some AT research was unrealistic or designed appropriately to address a given problem:

> I know the gold standard in research, it always goes for double-blinded trials, but you can't do that. It's not moral and ethical, I don't think, in terms of older people with dementia. They haven't got time to do double-blinded trials. It feels like deprivation, in a way. TI7: manager, occupational therapist
>
> I mean, that's why the TIHM project was extended for COVID, because we were aware that… The problem has been it couldn't be implemented when there wasn't a live-in carer, or a full-time carer. But actually, those are probably still not the patients that are really at risk, because part of that monitoring was about temperatures, and noticing whether somebody had got a temperature more quickly. If you think about it, the person living alone is the least likely to notice if they've got a temperature and take any action, or not. So, it still hasn't really met the most vulnerable people's needs. TI7: manager, occupational therapist

Despite guidance being a driver of organisational change, the professionals called for more clarity and specific guidance to help them push for change. Research was seen as important, but the participants questioned the design of some studies and whether the current gold standard RCT was ethical when applied to the dementia population.

### *8.2.4 Priority and funding*

Another external factor which influenced memory service provision, and thus AT enactment in services, includes political drivers such as how services are commissioned and therefore funded in health and social care. Individual local authorities and CCGs had different local priorities, making AT more or less of a priority. If AT was not a priority in a local area, then no funding reached the service or they were not commissioned to provide post-diagnostic support, including AT:

> But the barriers to that, even that project, in the end, were funding, you know, which it always come down to that, doesn't it? It's always funding that is the crux of the issue. TI5: manager

Funding was not only through commissioners but also through local charities and organisations. One memory service nurse actively sought funding for an AT intervention that she saw as a priority:

> She secured voluntary funds through Friends of X Hospital I would think it was at the time. She managed to secure some funds to fund the rental, because you had to pay a rental on it, and got it going without Trust permission, really. She knew this was going to help, and now, of course, the Trust are behind the Canary. We've got a proper budget and we can use it, we can implement it, and all the contracts are in place. TI7: manager, occupational therapist

Another key issue in this area was that funding sources were often short-term with no guarantee that they would continue. Moreover, those local services which were valued and utilised by MS were often no longer available, leading to fragility with the service provision:

> I think, obviously, Dementia Matters have their early interventions project. The funding has finished for that, but that was really useful, that they could just signpost people over there and they could take the time to get to know the people a bit better and work out when was the right time to say, 'Have you looked at this? Have you looked at that?'. FG1 P5: clinical lead

Such changes, as well as affecting service provision, also impacted how people with dementia paid for AT. For instance, some services which may have provided AT in the past now no longer provided it, and the people with dementia had to then pay for AT themselves. These regional differences in priorities and funding resulted in a postcode lottery of what was being provided to families with dementia, with some receiving a great deal of advice, information, and practical support and others receiving little or none.

Commissioning not only influenced what was offered to people with dementia but also the structures and post-diagnostic pathway available. Most MS were single units commissioned by a single CCG; however, some had more complex setups in collaboration with other organisations, rather than just health. Some services were also commissioned as non-NHS or local authority and were run by not-for-profits or private companies:

> I'm actually employed by the Alzheimer's Society, but we are commissioned partners of a memory clinic pathway in X with the X Partnership Foundation Trust. We're

> commissioned by X County Council to work alongside the clinical NHS team to provide assessment, diagnosis… then, the post-diagnostic support element is basically our element of the pathway. TI2: manager
>
> So, we're a community interest company. So, non-profit, but we're paid by the NHS and just provide the services on behalf of the NHS. TI3: lead clinician, nurse

While the professionals may have wanted to provide services that reached a certain standard, they were restrained by what had been commissioned or had to rely on other services to provide these. Overall, priorities and funding not only influenced what was offered to people with dementia in terms of AT, but also how the services were established, with some structures being single units versus more complex collaborations between services.

### *8.2.5 External stakeholders*

External stakeholders were also viewed as important players who could influence change, especially service commissioners (CCGs) and service users, but less so primary care providers, such as GPs:

> But on the whole, I don't know. I think it's shared. I'm not sure who fully drives things forward. We'd like to think that we have some influence from the bottom upwards, but sometimes, it's commissioners insisting [Laughter]. They're entitled to, they're paying, aren't they? TI7: manager, occupational therapist

Moreover, organisational questionnaires, feedback from service users, and prevalence data were also used to help justify funding and resources to shape change within an organisation:

> In our organisation, it is patient feedback. So, what patients say we can improve on. TI3: lead clinician, nurse

Other external stakeholders such as research funders and service awards bodies helped facilitate organisational change. Moreover, AT being recognised as a priority through, for instance national policy linked financial incentives, could also be used to help drive change in organisations:

> And I think there might have been some sequence in relation to rolling out digital technology; you know when it was the buzz thing to introduce older people and suddenly all the tertiary third sector groups were all promoting digital technology to older people, and there were some targets around getting people to, you know, text messaging their pharmacy for repeat prescriptions and things like that which is all assistive technology… there was financial gains to be had, and I think if there's one of those behind it, it might only be short lived, but that tends to – suddenly digital champions appear. FG2 P2: occupational therapist

The involvement of many external stakeholders could help facilitate organisational change, as could MS being awarded grants and prestigious awards, or utilising national guidance or financial incentives.

### 8.3 Internal Factors Influencing Service Provision

Although external drivers were important for organisational change, internal factors specific to individual MS could also be influential. These included:

- Professional positivity towards the use of AT
- The culture
- AT advocates being there from the outset
- AT being a memory services responsibility

#### *8.3.1 Professional positivity towards the use of AT*

Professionals were positive about the use of AT and most of the benefits they described were those introduced to keep people with dementia safe and reduce the risk of harm. However, professionals identified other wide-ranging benefits of AT for users, including: cognitive stimulation; improving quality of life and wellbeing; enabling independent living in their own home; delaying entrance to care homes; and, supporting their autonomy and control of their lives:

> It is probably a mixture of things, really. Safety-related, quality of life, and stimulation and help summoning related. Also, probably the slightly more ethically challenging aspect of surveillance and keeping an eye on people. So, they are probably some of the main categories that I have found helpful over the years, really. FG2 extra TI: psychiatrist

Regarding the activities of daily living, they also described AT as being practically useful in identifying if the person with dementia needed help or assistance, as well as helping them to stay connected or reminisce, prompting medication and ensuring concordance, planning their day and future care planning, and responding to risks or crises (falls, wandering etc). The benefits were not restricted to people with dementia, as the professionals reported that AT could give carers peace of mind, thus reducing their stress and increasing their free time:

> The only one I’ve got different to [FG2 P2 OT] is, not too long ago, a gentleman who used to work on the buses, so he used to go off wandering and get the bus all over the place; that was his pattern, but his family were getting more concerned as his

> memory deteriorated. And they had, like, a tracker put on him so that they could look on the computer where he was, so if he was away longer than they thought, they could actually find out where he was, usually quite often in Amble or something, miles away from home, but that was normal for him. And that gave them peace of mind to let him have his independence still; they could still see where he was, and if he was too long, they could go and find him themselves. So that was really good for him. FG2 P1: nurse

With the COVID19 pandemic, additional benefits have been identified, including using AT to review, assess and support people with dementia, and to prevent isolation. However, this often required a family member to support AT use:

> What's really interesting, actually, the bit of assistive technology that I overlooked, really, in all of this, was the video conferencing, which I guess you'll be using, but, again, you'll see, like, I've found with one or two people who've had a carer that can support that, it's been lovely. I've been able to do a remote assessment with somebody, and to see their face, and for them to see my face, it was lovely, but unfortunately very few people with dementia and their carers can really cope with that. TI8: manager

Some professionals were excited about future possibilities with AT, such as a smart house that adapts to the person living in it as their future needs change, or special lighting which changes through the day to help sundowning.

### *8.3.2 The culture*

Services within a trust which regarded AT as a priority or had dynamic people (AT leaders) within their organisation often described more advanced AT services. Often, the leadership within such hospital trusts was receptive to suggestions on how to improve. Also, it helped if all the team were aligned and had the same clear goals:

> I mean I think we do a lot more than other memory services, and I couldn't really put my finger on that, other than it's what is important to people, and I think we have a, kind of, joint team philosophy about things. So, I don't have to persuade anybody, everybody is fully on board … And I don't know whether I'm just lucky, I don't know how that has happened, but yes, it's… no, I think, as I say, I think leadership plays a big part in that, really. TI6: manager

Organisations which offered more AT provision often had clear structures to facilitate suggestions from staff working directly with service users. For instance, many described clear pathways for implementing change, including a range of different meetings on structural levels, such as a core team, governance, and business meetings. Importantly, the route for influencing change was clear to the leads and staff. Some had quality improvement teams or events where professionals could propose ideas and obtain advice about how to progress these and embed them into practice. In so doing, peer support was offered which helped influence change:

> We’ve got a transformation team in the trust, so they do a lot of helping with, you know change and better ways of working, but as staff ourselves we are able to put our ideas to them and then they are able to look at, you know, what they can do to help to make those suggestions a reality, really. TI5: manager
>
> We’ve got something called the ‘Innovation Nation’, which is a yearly event [at which] all staff in the trust are able to showcase what they’ve done differently, and it doesn’t have to be big, however they’ve changed their service…there’s a route from that event that takes it to the next level, to proof of concept and commitment to fund, so yes. TI9: lead clinician

While these internal priorities and structures were important drivers, what was also of key importance was an internal culture within these organisations whereby value was ascribed to knowledge exchange and quality improvement, either through specific teams (i.e., community treatment teams) or external collaborations with organisations such as local authorities and national charities. There were clear pathways for instigating and implementing change in services which provided advanced offerings around AT, with some mentioning that their structure was less hierarchical and more flattened or team-centric than it had previously been, and this was seen as a positive factor for innovation:

> So, a lot of it is about hierarchy, I guess. And I’ve never felt constrained, as long as I can give a good rationale as to why we think this needs to happen, I’ve never had anybody come and say, ‘No, no, no, you’ve got to get all those assessments done, you’ve got to do this, you’ve got to do that’. As long as you can give the rationale as to why you think something should happen, we do have a quality, QI, team that can come out and work with teams on innovations, and I think the trust generally is quite supportive of innovation and change. TI6: manager

Moreover, some described how having allied health professionals in leadership roles for example on the Trust board, created a more inclusive, innovative environment:

> It has got flattened out a bit, the hierarchical system, there are not too many levels. I certainly feel that I could approach our chief executive about matters. She’s always asking for immediate direct contact to her about issues. So, from when I started with the Trust, there were far too many levels and you’d never really feel that you were properly connected to the top of the Trust, the Trust board. One of our OTs [occupational therapists] has taken a board director role, so, I mean, all sorts of people do influence change. TI7 manager: occupational therapist

Overall, organisations who fostered a spirit of valuing knowledge, teamwork and collaboration often had more extended services around AT.

### *8.3.3 AT advocates being there from the onset*

Another important driver of organisational change was having the right people working within the memory service who could advocate for the introduction and delivery of AT. Such leaders, or AT advocates, are a key ingredient for service innovation and increased AT provision. Such leads working in innovative MS described distinct personal qualities, including a passion and drive to improve services; they also felt their role was eased by having others in their team with similar qualities:

> The team. And I think, for me, our consultant who is currently on maternity leave is a real innovator for change, and I think when you get that relationship right, so [psychiatrist] it is, and I can work together to innovate change. And because I know she is extremely hard working and will go the extra mile, I will do that for her, and she will do that for me. So, there is something about that, you know, if I had a consultant that really wasn't bothered about change, I would find it much more difficult. TI6: manager

> I think that there's quite a lot of innovative individuals and I think the ideas really come from the shopfloor, and by that I mean the practitioners in the team. You know, certainly how to promote that innovation, there are a number of things within the trust, I suppose, that helps that. TI9: lead clinician

In addition, such people were caring and altruistic as well as being innovators and often had personal experience of a relative with dementia or extensive professional expertise in dementia care:

> I always look at trying to look at new ways of working, because, you know, I didn't become a nurse to be a millionaire, you know? If I wanted to be a millionaire, I would be an accountant like my sister, you know? I actually became a nurse because I actually care about people, and even though the things that we put in, sometimes the things that we suggest are so basic, things can make a massive difference to people's lives. TI5: manager

Interestingly, others reflected on the fact they might need AT in the future when they are old, and they often described having an interest in AT or having had experience in research. They were clear networkers who formed links and collaborations internal and external to their organisation to promote their service. They understood the value of personal relationships and proactively interacting with external agencies to share knowledge and learning. They were clear educators who valued sharing knowledge through 'show and tell' approaches. For instance, the occupational therapists who realised other team members did not understand their role undertook team education via presentations. They understood how to work within their organisation to achieve change, including the use of forums, organisational structures such as department or trust meetings, and trigger language (such as risk assessment or least restrictive option) to promote a case for change.

Unfortunately, however, not all professionals and managers had such knowledge and drive to develop AT services, as many participants from MS providing more extended AT services, as well as those who provided usual care, described several barriers to organisational change. One of the main barriers was a general lack of awareness about AT among people with dementia, carers, and professionals. The professionals identified as lacking awareness included individual professionals working in MS, local authorities, and GPs:

> I don't know if it's a combination of the media, and some of the practitioners themselves don't know, so, if the practitioners don't know, the patients aren't. I know adult social care, and some of the GPs aren't aware, as well. TI3 lead clinician: nurse

While service leads acknowledged that occupational therapists were natural AT advocates due to their better knowledge and awareness of AT, some occupational therapists still struggled to remain current with rapidly advancing technological changes:

> Often, the changes that do come is [sic] by just somebody's sheer determination. We use Just Checking ...was one OT's experience that she'd used it in a previous job, and she was determined that we would implement it here in the Trust. TI7 manager: occupational therapist
>
> But I know there must be an awful lot of stuff out there that I have very little knowledge of, and perhaps aren't giving people as much information or options as they could or should have, and so that's certainly a barrier. FG2 P2: occupational therapist
>
> So there's a lot of information, and sometimes I get bombarded with stuff and think, 'Gosh, I can't see the wood for the trees'. TI 1: lead clinician, occupational therapist

Overall, managers and lead clinicians working in MS which offered extended AT services showed clear personal qualities and a drive to improve the care of their patients. However, not all the professionals were aware of AT and a lack of awareness of it was seen as a barrier to service change. Most participants agreed that occupational therapists would naturally be the clinical professionals who would advocate or lead on AT; however, this was not always the case and some occupational therapists found it hard to remain current with the rapid pace of technological change.

Memory service managers and leads also described the importance of timing in terms of being in a position to mould and shape the service, for example, by having worked in MS from its conception; the development of a service with embedded AT took time to establish. These influencers then used external and internal levers such as national guidance and patient feedback to make the case for including AT in service provision. They described their service as a blank canvas that they could shape:

> I suppose it helped, the fact that when I first came into post that's when the memory services were commissioned. So, I was a new member of staff with the whole rest of the team. So, we could kind of shape what we wanted…we had, I suppose, the luxury of time in the beginning to look at, 'Right, okay, this is our wish list. What would we want to be able to deliver? What's important? What are the priorities?'. TI1: clinical lead, occupational therapist

Often, it was timing in addition to having clear, structural resources and approachable leadership that made change achievable. The process of developing a memory service with extended services also took a long time. One lead with an advanced AT service described its development taking about eight years from identifying the case for AT provision to it being embedded into everyday practice:

> It was a step-by-step process. From, what would be, eight years, I would suppose. T1: lead clinician

In summary, the leads who offered extended services described clear, personal qualities and being involved with the setup of MS, which they identified as an important time for being able to influence change.

### *8.3.4 AT as a memory services responsibility*

While many memory service leads identify AT as a key intervention to help people with dementia live more independently, they were also unsure whether the memory service was the right place to provide information and assess or refer for AT. In this regard, several reasons were suggested, including commissioning priorities and shifting to a diagnostic service. Several professionals described not being commissioned to provide post-diagnostic support and being limited to the provision of what had been commissioned. In the past, more post-diagnostic work had been undertaken; however, since they were now only seeing people with dementia at diagnosis, some professionals reflected that MS might not be the best service to implement AT. By placing AT in MS, opportunities would be missed as people with dementia would not be seen when they required AT. The professionals also identified other services within mental health trusts which might be better positioned to see people with needs or risks and thus better able to assess the need for AT, i.e., community treatment teams. This caused many systems and professional tensions. For instance, one memory service decided to provide some post-diagnostic support even though this had not been commissioned:

> There are a lot of memory services that don't provide post-diagnostic groups, and I think sometimes there could be a bit of query about: is it our job to do that? TI6: manager

> Memory services described being a diagnostic only service, resulting in them seeing people too early in the post-diagnostic period when there was little need for AT. Moreover, they discharged people and did not follow through to more advanced dementia:

> I think it needs to be—I think memory services are absolutely in a brilliant position, but we would probably need to have more focus on post-diagnostic at the moment, whereas at the moment we're just an assessment service, and I think the social interventions and assistive technology under that umbrella still has a long way to go in terms of we need the time to be able to provide those groups and things. FG2 P2: occupational therapist

> It's a bit more difficult for us because we're memory assessment. We tend to catch people right at the beginning of their journey, if you like, so really, we get people earlier and earlier, I think because of the publicity around dementia now and, 'Go and get an assessment'. TI6: manager

One nurse reflected on how placing AT within MS was limiting the access of people with dementia to AT and would be better delivered outside MS:

> I think it's probably best placed in a wider setting, because we don't tend to keep people on long-term, either. So, its limiting people's access, really… So, if it was more accessible in terms, I don't know if it can be, it needs to be accessible to everyone, not just people that are open to the service. TI3: lead clinician, nurse

Currently, they described limited contact with people with dementia and therefore opportunities to assess whether AT would be beneficial were limited and currently only involved the initial assessment visit: a diagnostic disclosure meeting, post-diagnostic appointment, or during any intervention offered, e.g., group education:

> I would also say that, essentially, we have those two appointments; the initial assessment and then the post-diagnostic appointment; they're essentially the basic two appointments that we have in terms of our current role in the memory service, and at either of those appointments, we could link in and refer for some sort of assistive technology. FG2 P2: occupational therapist

For all these reasons, they suggested that other community services might be more relevant for the provision of AT. This might include general practice, where people with dementia are seen throughout their journey, or the community pharmacy, which already offers some AT for other chronic diseases, such as blood pressure machines for hypertension. Some professionals reflected that little had changed regarding AT over the last 20 years.

### 8.4 Chapter Summary

This chapter has highlighted several key external and internal drivers which influence how MS can enact AT in practice. External drivers such as national policy and guidance have facilitated a move to a diagnostic service, while drivers such as the COVID19 pandemic disrupted normal provision and pushed services to remodel and adapt their offerings. The internal factors included: professionals being positive about AT; working in a culture which valued the AT used in dementia care and was able to implement change; and, having AT advocates. More often, the latter was an occupational therapist with a special interest in dementia who had been present at the inception of their memory service and was a driver of change. However, despite these drivers, some MS questioned whether AT was their responsibility and wondered whether other services such as primary care would be better placed to implement AT.

# Chapter 9. Discussion and Conclusions

## 9.1 Introduction

This thesis highlights that ‘doing AT’ in real clinical life settings is incredibly challenging because of the multiple, interlinked levels of complexity, i.e., it involves introducing a complex intervention to a complex group of patients in a complex environment spanning health, social care, and the voluntary and private sectors. It is also important to note that the current provision of information and support to access AT by MS results in geographical inequalities of provision. In this chapter, I first discuss the key findings around ‘complex complexity’, i.e., intervention, population and setting, as well as the recurring theme across all the chapters of the difficulty of obtaining information on AT. I then discuss how these findings link with previous research, the methodological strengths and limitations of my work, and their potential impact on the results. Finally, I discuss implications for policy and practice.

## 9.2 Summary and Discussion of the Key Findings

It was hypothesised at the beginning of the thesis that MS are the best setting to introduce and provide information and support to enable access to AT as it is the first service to give post- diagnostic support. The empirical chapters illuminated the difficulty of ‘doing AT’ in real life settings. In the following subsections, I explore each of these areas of complexity, as well as the common theme weaving throughout the thesis of how and where to obtain information on AT.

## 9.3 A Complex Group of Patients—People Living with Dementia

The literature review and empirical chapters demonstrated that implementing AT with people living with dementia is incredibly challenging. Firstly, dementia is chronic and progressive, with each person experiencing an individual set of symptoms (including memory loss, disorientation, challenging behaviour, language difficulties, and physical symptoms affecting mobility and sight) and challenges which change over time. Influences on this include, for example, the sub-types of dementia, the stage of disease, and the social network of support available to them. Often, they present with a family member or friend who has ill health themselves and experience significant stress and carer burden. Importantly, people living with dementia have other chronic health conditions which affect both their physical and mental health. This personalised experience of dementia (specific sub-type, stage of dementia and individual support network) makes it very challenging to identify the right type of AT and the appropriate time to introduce it without causing harm (see Chapter 6. Memory Services Enactment in Practice and Chapter 7. Challenges and Solutions).

The empirical chapters further illustrated and explained the complexity of implementing AT with people with dementia in real life clinical settings, essentially due to many population factors. People have to have the cognitive ability required to engage with AT regarding the intended design and use of a device. Moreover, both dementia symptoms and individual abilities to interact with AT are dynamic; some existing technologies cannot be used successfully if the person with dementia forgets, or cannot learn, how to use it; rather, they must have the cognitive ability to use and understand how the technology works (e.g., respond to an alert or, in the worst case, not responding to a smoke detector alarm). Chapter 7. Challenges and Solutions highlighted this complexity further, as a person with dementia may, due to their residual cognitive function, under or over respond to a technology alert, which could cause harm to themselves or their family carer (e.g., through repeated calls). Despite people with dementia having other chronic diseases, the types of AT suggested mainly addressed mental and cognitive health challenges rather than physical needs.

A further complexity was identified by professionals concerning some patients being particularly vulnerable and neglected because the current provision did not cater for them (see Chapter 6. Memory Services Enactment in Practice). This includes people with specific characteristics or available resources, such as those with young onset dementia or those living alone, as well as those not being IT literate or having access to Wi-Fi or the internet. Families with dementia's ability to pay for any AT recommended was a critical resource factor, resulting in inequalities of access with AT out with many peoples reach. An ability to pay for AT influenced AT recommended and the AT access pathway. For instance, whether private purchase was suggested. No data was produced on professional's experience of giving information and supporting ethnic minorities to access AT. Furthermore, some had specific neuropsychiatric symptoms such as paranoid thoughts around the technology, which made them more susceptible to harm from some of the suggested AT solutions (e.g., such as alerts with voices). All of these issues must be identified and navigated for professionals to implement AT successfully.

Overall, dementia patients are complex for several reasons. They experience unique, dynamic cognitive symptoms and struggles which deteriorate and change over time. They experience both physical and mental health challenges and their support networks and financial resources vary. All these factors are important when identifying appropriate AT for the problems they encounter, making it very challenging to introduce a complex intervention such as AT.

### *9.3.1 Complex setting—memory services*

As this thesis has demonstrated, MS are complex in nature, composition, and setting, and this makes it more challenging to implement a complex intervention like AT to a complex group of patients, such as those living with dementia. The literature review revealed this complexity by describing the historical landscape, the haphazard development of MS, and the lack of a clear definition on what a memory service encompasses. Memory services can be set in psychiatry, old age medicine, or neurology clinics and can have array of MDT professionals. The MSNAP guidance has attempted to address this variation by defining which professionals should be included in the team but, despite this guidance, there is wide variation in the MDT setup. The setting is complex on several levels, including individual memory service internal structures and the services they provide, their wider collaborative network in the community they serve, and the wider ecosystem in which they are placed. Each of these factors increases the complexity of providing an intervention and makes implementing AT very challenging, and they are described in turn below.

Chapter 6. Memory Services Enactment in Practice provided the context for what is happening with regards to AT in MS on the ground. It described how MS and individual professionals work within their organisation to provide information and support to enable people with dementia to access AT; it also presented a description of the typical pathway for a patient being assessed in MS, which includes an initial assessment, diagnostic disclosure meeting, and post-diagnostic care. Most MS now, however, describe themselves as purely diagnostic services. This model continues to evolve, with individual MS' provision of AT influenced by many internal and external drivers (Chapter 8. Factors Influencing How Memory Services Enact AT: Information, Support, and Access). This move to a diagnostic only service produces professional tension, as many professionals questioned whether MS were the correct setting for AT as they are not involved in an individual's post-diagnostic dementia journey.

Chapter 6. Memory Services Enactment in Practice described great variation in what MS provided in terms of accessing AT. Most signpost to voluntary services or local authorities for future information, with only a minority offering a substantial package that included assessment at home and personalised AT interventions. Training on AT for families living with dementia and professionals was only provided by a small number of MS. This was further demonstrated in Chapter 5. National Surveys to Memory Services: An Overview of Service Characteristics and Individual Professional Practice, which described the resources available to MS, including access to key professionals such as an occupational therapist or a social worker; most have access to an in-house occupational therapist. Many MS do not have access to simple resources such as an AT protocol, AT training, or a lead professional responsible for AT, never mind access to demonstration or loan facilities. Also, provision of formal follow-up by MS of a person with dementia varied considerably, despite this being an opportunity for professionals to introduce and suggest AT after the initial disclosure of diagnosis.

Chapters 5 and 6 revealed the wider collaborative network developed by, and available to, MS for AT in their local areas. Memory services established relationships with different organisations such as local authorities, voluntary organisations, private companies, and research centres; some formed formal collaborations to produce dementia pathways (e.g., a local Alzheimer's Society team and NHS trust or local authorities and CCGs). These collaborations helped MS deliver AT but produced greater variability in provision, with professionals having to make tailored AT suggestions and pathways to access AT based not only on an individual's needs and financial circumstances but also the locally available resources. However, for each service with some AT provision, it was noted that these services were fragile as many voluntary services' offerings were only short lived. The commissioning of MS and the wider community services was a crucial factor as it facilitated inequalities, as each commissioning region had different priorities for their specific population. This means that MS can have a completely different offering regarding post-diagnostic support, if any, on AT.

Another complexity was demonstrated in Chapter 7. Challenges and Solutions, which described the wider underdeveloped ecosystem in which AT was placed, i.e., the surrounding system to introduce, maintain, and provide ongoing monitoring of AT in practice. With regard to the variation in what MS provided, some solutions were suggested, including: better AT assessment; access to equipment; staff and infrastructure; support to use AT; and, systems to ensure monitoring and review. Critically, the professionals called for easier and more streamlined access to AT as it often involved more than one service.

In summary, MS are complex for several reasons, such as internal characteristics, wider collaborative networks, and the poorly developed AT ecosystem in which AT is enacted. This thesis began with the assumption that MS would be the best setting for AT, but this may not be the case due to their limited involvement with patients post-diagnosis. Perhaps, as the professionals suggested (Chapter 8), other services would be better placed to enact AT. This is discussed further in Section 9.6.1, Identifying the right place to do AT.

### *9.3.2 A complex intervention*

The initial suggestion that AT is a complex intervention was introduced in the literature review. The first reason for this is that the terminology is inconsistent, with no common language around what AT is or harmonisation of its definition for all stakeholders. Second, it was highlighted that AT encompasses a wide range of solutions for the problems encountered by people with dementia, and that it is challenging to obtain information on, and enable access to, AT. Moreover, the complexity surrounding the intervention also extends to the process of gathering evidence on AT effectiveness, as well as navigating the many ethical challenges evoked by AT use with people with dementia. This complexity was further demonstrated in the substantive results chapters and it can be broken down into four factors: 1) technology-related; 2) professional; 3) wider system factors; and, 4) the need for personalisation. It must be stressed these are often dynamic and change over time, for instance the types of AT and models of available devices are constantly being developed, making the intervention even more complex when professionals tried to enact AT in real world settings.

Technological factors are outlined in the substantive chapters. Chapter 7 highlights that the professionals found the term AT confusing and unhelpful and had different views on whether this included non-electronic devices. There is also further complexity in the fact there may be more than one AT solution for a problem a person encounters or more than one model of the same device. Although Chapters 6 and 7 illustrated that most professionals were positive about the use of AT, some had concerns with AT design, which they described as suboptimal; equally, the functioning of the device might rely on the action of another, or it might emit noises that could cause distress. There is also the assumption that people have sufficient baseline cognitive function to be able to use the AT. This complexity was compounded when professionals had to consider any ethical dilemmas the technology might pose. Although the technology itself should not generate ethical dilemmas, when used by people with cognitive impairment, it creates numerous ethical challenges which professionals must navigate with little guidance or support; this was explored in Chapter 6.

The professional factors which made this a complex intervention include maintaining up to date professional knowledge and awareness of AT (interventions and cost to patients), and information and access pathways (see Chapters 5, 6, 7, 8). Although it was demonstrated in Chapter 5 that the professionals had a good knowledge of commonly used AT devices, many professionals worried they had a knowledge gap, found it very challenging to stay current, and lacked adequate information resources. Chapter 7 sheds light on the challenge of improving awareness and remaining current with fast-paced technological change; in response, the professionals called for MS to provide training on AT. There were concerns that AT could be overlooked as an intervention due to professionals being both unaware of available solutions and driven by safety concerns; they often only introduced AT if a specific need or risk was identified (Chapters 5, 6 and 7). This was further demonstrated when professionals described having to overcome considerable professional unease over their role regarding AT and their concerns over a lack of knowledge about AT solutions and clear associated costs (Chapter 6). Even when professionals identified the device to use, they still had to identify which was the best and most effective model, with no guidance or resources.

Additional complexity became evident in how the professionals had to navigate the wider system in which AT is placed, including the mixed economy of provision. In Chapter 7, they described making a bespoke AT access pathway depending on the financial means of the individual with dementia and the local resources available. They thus had to keep up to date with constantly changing technology and related information. In addition, there was professional unease concerning the need to inquire about the financial means of a person with dementia, in order to recommend AT which they could afford and access (see Chapter 6). Unease was also evident around professional role with participants describing tension between advocacy for people with dementia and carers and what they were commissioned to provide, with many MS not being commissioned to provide information or access to AT. Some MS had professionals due to their own professional interest drove change and developed AT services. Again this results in inequality of provision generating a postcode lottery in terms of memory service provision and leadership. It is not surprising, therefore, that many preferred to defer responsibility to other professionals, such as occupational therapists, who they saw as experts in AT (see Chapter 5 and 6). This poses questions concerning who the lead on AT should lead be, and whether AT should be a skill area for all professionals working in MS, or the occupational therapist, or a new role.

This complexity was revealed in Chapter 7 when it explored the AT format and the need for personalisation and bespoke solutions. In this regard, an AT assessment is required which includes the patient's symptoms of dementia, current baseline technology use, financial means, and support network, followed by the suggestion of appropriate solutions and integration of these into their normal technology use and routines (Chapters 5, 6, and 7). Thus, the professionals needed to understand and recommend AT while navigating the mixed economy of provision, involving health, housing, the voluntary sector, and private purchase, making the implementation of AT very challenging. While doing this, the professionals also often had to navigate the views not just of the person with dementia but also their family or informal carer (Chapter 6). It is unsurprising that some of the professionals reported having no time for AT and preferred to defer it to other professionals such as occupational therapists.

Critically, the professionals were driven by a concern to keep people with dementia safe and to manage the risks associated with people experiencing cognitive loss (see Chapter 5, 6 and 7). Specific symptoms experienced by people with dementia, such as becoming disorientated when outside, induced innate professional concerns around safety and required a risk assessment. Another complexity around AT in this group was that, due to the memory problems people with dementia reported to professionals, the patients felt vulnerable about personal data being exposed or having people in their home (see Chapter 6). Again, this must be taken into consideration when a professional assesses a person with dementia.

In summary, AT is a complex intervention for several reasons and on many levels. The professionals must navigate multiple technological issues (e.g., terminology, type of AT, evidence, costs, ethics), ensuring the suggested technology meets the person with dementia's needs, baseline technology use, home setup and financial situation. They must remain current with the range and type of technologies available, and pathways to obtain information on and access to AT; this was often in the context of a lack of clear guidance on how to manage the complex ethical dilemmas surrounding AT use in dementia and the mixed economy of provision. Currently, many of the professionals reported a lack of essential knowledge and skills to implement AT, such as guidance, protocols, clear pathways, information on types, evidence, and costs of AT as well as how to access it. Crucially, any AT interventions suggested need to be personalised to the individual and family living with dementia.

### *9.3.3 A recurring theme: where to obtain information on AT*

A common theme introduced in the literature review and running through all the empirical chapters is the challenge for professionals to obtain information on AT. The literature revealed the difficulty families living with dementia have when obtaining information on AT, and that professionals such as GPs experienced a lack of effective and easily accessible information.

Chapter 5 revealed there was no clear pathway for acquiring professional information or for directing people with dementia toward to obtain further information. Information was obtained from a myriad of sources, including national charities such as the Alzheimer's Society, and local social services, as well as a multitude of internet resources and organisations (e.g., Dementia/AskSara, Unforgettable, AT Dementia, the Alzheimer's Society, Tippisnow, and Glorious Opportunity). Many would ask an occupational therapist. Despite the majority of professionals (>60%) stating they were confident about knowing where to obtain professional information on AT and how to direct people with dementia and family carers to do the same (>70%), many commented in free text responses that they recognised how keeping up to date with fast-paced changes in technology was very challenging. They were concerned that any information they provided could be out of date or that new, better technologies might exist of which they were unaware.

Chapter 6 further described this challenge of getting information and how professionals found it difficult to find information on AT, as it was often in multiple locations. To overcome this one service developed their own database which all professionals were responsible for keeping up to date. Many relied on their in-house occupational therapists or other professionals working externally in local authorities, telecare providers, research groups or private companies. Chapter 7 further highlighted the challenge of getting information on AT and keeping up to date with many gathering knowledge ad hoc often via occupational therapists or interestingly via people with dementia or their families.

Critically, professionals identified the need for easily accessible, up to date information on AT not only to raise awareness, but also to help themselves as professionals give information on AT and remain current with changes. Solutions identified to this challenge included: expert AT champions (who stayed up to date, could answer professionals’ questions, and suggest appropriate solutions); access to resources such as a national digital forum; access to demonstrations on AT to ‘see’ for themselves how AT works; and, a comprehensive central resource or single point of access for information on AT which was kept up to date.

## 9.4 Links to Previous Research

In the following section, a more detailed discussion of the key findings is presented in terms of links with previous research.

### *9.4.1 A complex group of patients*

A key finding from this study was that people with dementia are a complex group of patients and to ‘do AT’ properly, solutions needed to be personalised to the individual. Population complexity was identified by Greenhalgh *et al.* (2015) in their ethnography work stream in the Assistive Technologies for Healthy Living in Elders: Needs Assessment by Ethnography (ATHENE) study. They found a huge variation in personal and family set up; health conditions; physical and cognitive abilities; housing situations; baseline technology use and linked support network. All of these factors could change over time (Greenhalgh *et al.*, 2015). They found a huge variation in personal and family setup, health conditions, physical and cognitive abilities, housing situations, baseline technology use, and linked support networks. All of these factors could change over time. However, the study involved older adults in general and was not specific to people with dementia; the degree of complexity would be higher in dementia.

To overcome this complexity, personalisation is key. Meiland et al. (2017) stressed the importance of a personalised approach to the use of AT in dementia care in their European consensus position paper. Likewise, Gibson, Dickinson, Brittain and Robinson (2018) found personalisation to be important when they explored how people with dementia and carers make AT work for them. They found that carers often drove AT use rather than the professionals they encountered, and that the former engaged in more creative, individualised use of AT, supported by health and social care. The authors used the term ‘bricolage’, first coined by Greenhalgh in 2013 (Procter *et al.*, 2013), to describe the pragmatic, personalised customisation of devices combining old and new technology, rather than a ‘one size fit all approach’ (Gibson, Dickinson, Brittain and Robinson, 2018). Personalisation has also been recognised in a recent white paper produced by Digital Health and Care Innovation Centre Scotland on User Requirements for Co-Managed Digital Health and Care (Digital Health & Care Innovation Centre, 2022). One of its key themes was around personalisation, focusing on the person and their holistic needs and what is important to them, instead of the specific illness (Digital Health & Care Innovation Centre, 2022).

### *9.4.2 A complex setting*

Memory services represents a complex setting on many levels, from their internal structure and varied collaborations to the wider AT ecosystem. Previous research has highlighted the wide variation in provision by MS regarding structural and process characteristics (Chrysanthaki, Fernandes, Smith and Black, 2017) and also post-diagnostic care (Frost *et al.*, 2020). Information was often provided by the voluntary sector or local authorities but post-diagnostic care was provided by many organisations and was often fragmented (Frost *et al.*, 2020). These findings are replicated in the current study. The thesis has highlighted how MS are constantly evolving, in line with in a national survey on post-diagnostic care in which over half of MS acknowledged they would change their offering for post-diagnostic care over the next five years (Frost *et al.*, 2020).

The national MS accreditation system, MSNAP, has attempted to improve the quality of care provided by MS by producing standards for MS to work towards. However, the standards do not address what constitutes an MS and only provides guidance on the MDT constituents. In this thesis, it was found that although the standards could be used as a lever to implement change in MS, the professionals found them vague and lacking detail on AT provision. This finding contradicts a recent study which assessed whether a specific MS would benefit from being accredited, as Sweeney found that the standards helped professionals identify areas for general service improvement (Sweeney, Foley, Fitzsimons and Denihan, 2019); this contradiction may reflect the complexity of AT as an intervention and the challenge of producing standards. Critically, it is not compulsory for MS to join MSNAP to be accredited and to join they must pay an annual fee, as opposed to the national Care Quality Commission (CQC) system, which is compulsory. Perhaps, MSNAP guidance should be used by the national CQC system to measure quality, but MSNAP standards have not been validated. NHS England commissioned Professor Claire Surr to investigate innovative practice in MS and share good practice. These new recommendations act as '[a] guide to supporting continuous development, improvement, and innovation in memory assessment services' and showcase innovative practice in the UK with personalised care at its core, ensuring needs-led services that ensure equity of access (Surr *et al.*, 2021). However, as with MSNAP guidance, these new recommendations are not compulsory and may not influence wider variations in provision.

The thesis has identified an undeveloped wider AT ecosystem, a concept which has been recognised globally in policy documents such as the United Nations 2030 development agenda 'Transforming our World: the 2030 Agenda for Sustainable Development'. The agenda includes a call for investment in infrastructure (Desa, 2016). The later World Health Organisation (WHO) Global Strategy and Action Plan on Ageing and Health calls for better knowledge mobilisation and technological transfer, as requirements for improved capacity at all system levels, but also for better collaboration across organisations (World Health Organisation, 2017). The more recent WHO initiative Digital and Assistive Technology for Ageing (DATA) aims to facilitate the crossing of boundaries between users, healthcare, care, communities and industry, to ensure consistent, organised and better governed AT services for older people (Khasnabis, Holloway and MacLachlan, 2020).

In practical terms, the European position paper on AT by Meiland *et al.* (2017) highlighted many issues with regards to ensuring effective deployment of AT, including information issues (the need for trusted and high quality information on AT), professional constraints (involving a number of bodies (health and social care, and business) which cover areas such as standards, models for finance and business, professionals' skills, and knowing what is available) and user factors (usability, poor design and function of AT etc.). Also, the need for all stakeholders to have education and training on AT was highlighted. Many barriers to the use of AT in dementia care were identified by the position paper, in alignment with those elicited in this study. These included: poor usability of technology; a lack of professional training; workflow issues; system development issues (confidentiality of patient information); a mismatch with current health care practices; a lack of standards; and, problems around payment compensation (Meiland *et al.*, 2017).

Another key issue remains the limited evidence on the successful implementation of technology for older adults in general as well as those living with dementia. During their co-design workshops, the ATHENE study, which looked at telecare and telehealth in older adults, Greenhalgh *et al.* (2015) used ethnographic data but also gathered the views of key stakeholders (service users and family, service providers, and technology suppliers) on their experiences, to identify technological and service design improvements. A significant finding was the need for a comprehensive home visit which allowed time to become acquainted with the person and their family, to be able to produce fully personalised, bespoke solutions; this finding was also identified in the current study. Again, this highlights the importance of personalisation and demonstrates the complexity of the surrounding AT ecosystem, with many players in a complex service delivery characterised by little integration and information sharing and the subcontracting of different aspects of delivery, such as implementation and monitoring. Monitoring was also highlighted as important as users had varying social networks, with some requiring assistance even with simple issues such as technology battery changes (Greenhalgh *et al.*, 2015).

The ATHENE study produced the ARCHIE (anchored, realistic, continuously co-created, human, integrated, evaluated) framework to guide the design, installation and monitoring of telehealth and telecare services for older people (Greenhalgh *et al.*, 2015). Further research with key stakeholders (older adults, professionals, managers involved in care and social work, technology designers and suppliers, and policy makers) revealed a lack of AT knowledge and the need for changes on many levels for effective AT implementation, including political, organisational (such as contractual), managerial, and operational levels (Peek, Wouters, Luijkx and Vrijhoef, 2016). Peek's study hinted at a tension between ensuring personalisation versus deploying AT to the masses, which would facilitate commercial investment in AT and thus make it more affordable. The same tension was also evident in the ATILLA trial, which found that recommended AT was not implemented in practice due to different services assessing and implementing AT (Howard *et al.*, 2021). To do 'AT' effectively, I propose streamlining services to achieve better integration and information sharing and ensure the correct, appropriate AT is in place for maximum benefit.

Greenhalgh et al. conducted the SCALS study (Studies in Cocreating Assisted Living Solutions), which built on the ATHENE study's finding of the need for 'bricolage' or adaptive needs-based interventions (Greenhalgh *et al.*, 2016). They aimed to explore the complexity of health and social care organisations attempting to implement AT to enable older adults to live independently (Greenhalgh *et al.*, 2016). In doing so, they described a fourth-generation paradigm of organisational, social, and political contexts and a plan to explore multiple levels, including the micro (people's experience of AT), meso (organisational experience of AT), and macro (national, international and political) (Greenhalgh *et al.*, 2016). This will aid further exploration of the wider AT ecosystem.

### *9.4.3 A complex intervention*

This thesis has highlighted that AT is a complex intervention for many reasons. The professionals were preoccupied with safety and found it hard to remain current with the fast pace of technology, often deferring to other professionals who were more aligned, such as their in-house occupational therapists, to help assess and navigate the mixed economy of AT provision. The professionals in this study were preoccupied with safety and suggested AT when there was a need or risk identified. Sugihara et al. suggested there are three sub-periods of health technology development covering the period 2012–2030: between 2012–2015, it was predominantly focused on ensuring safety but this shifted to a focus on evidence-based provision, and then to organisational knowledge-based care (Sugihara, Fujinami & Moriyama, 2019, cited in Leroi, Watanabe, Hird and Sugihara, 2018). Memory services seem to be fixed in the first sub-period as they are predominately concerned with keeping people with dementia safe and minimisation of risk. A shift in focus to post-diagnostic support, which encompasses all aspects of life, not just risk, may facilitate a transition out of this period. To do this, national guidance and funding are needed for MS to be able to provide post-diagnostic support. Moreover, closer collaboration is required with private companies developing AT, to support independent living among people with dementia so that they can enjoy meaningful activities, rather than just be safe.

Outcome measures to research the use of AT in dementia can include;

- Service specific outcomes. Whether they give information on AT, support access to AT or even provide AT interventions themselves. If they provide AT but users do not find it helpful, this is still a useful outcome as an individual can try out the AT without having to purchase it privately. A cost benefit analysis to determine whether MS should invest in AT.
- User specific outcomes. Whether people with dementia or their family carers use any AT provided? when is best to introduce AT? do users abandon the use of AT and if so, why? How is any AT provided used over time? Can users afford any AT suggested and if not what is required to facilitate them being able to purchase/acquire any AT suggested?

- Technology specific outcomes. Does specific AT help support people living at home and prevent admission to care homes? Does it work to overcome problems someone with dementia encounter, does it cause harm? What benefit does each type of AT have and is there variability between models of the same AT?

Gathering research evidence on whether AT is effective is challenging as the gold standard RCT takes a long time, which is difficult as any AT studied may be outdated by the time the study is complete. Chosen study methods should follow principles of implementation research to explore the use of AT by users as an intervention in real life settings (Peters *et al.*, 2013). Implementation research methods include: pragmatic trials, effectiveness-implementation hybrid trials, quality improvement studies, participatory action research and mixed method studies (Peters *et al.*, 2013). The method chosen to gather evidence would be influenced by the research question being explored and the outcome measure chosen would preferably be a balance of user and service outcomes, provided evidence is available for individual technological solutions. Which outcome to study will depend on the research question being explored.

The most critical outcome measure in my opinion are patient outcomes, in particular whether AT is  helpful or could cause harm. However, I would argue that exploring technological and user outcomes should take precedence over service outcomes, as if they do not have a benefit then it would be unethical to suggest their use. Other methods of gathering evidence may be more appropriate such as stratified block designs or trials following the MRC complex intervention guidance (Craig *et al.*, 2008). Interestingly, simpler, and less time-consuming designs, like the quality improvement PDSA cycle design as suggested by Leroi may be more appropriate to gather evidence (Leroi, Kitagawa, Vatter and Sugihara, 2018).  This would avoid the ethical concerns raised by participants, around the traditional RCT design taking time, which people with dementia do not have. Other methods such as implementation hybrid trials are also attractive as the intervention is not fixed.  Nevertheless, they would again take more time to complete and may result in evaluations of interventions which are out dated by the time the trial ends.

This thesis has highlighted the complexity and many challenges of implementing AT with people with dementia and indeed these are also recognised in the wider literature. Neves et al. (2022) emphasised the challenges that digital technologies pose for older adults, exemplified by poor access to technology, reduced digital literacy, support for payment/reimbursement, a lack of legal and regulatory frameworks, and concerns about maintaining data security. However, this list does include the complex nature of the symptoms experienced by people living with dementia.

Accessing AT was found to be complex. The professionals described identifying bespoke access pathways determined by the financial means of the person with dementia. This demonstrates the mixed economy of AT provision in action and provides evidence that the fragmented, mixed economy of AT provision described by Gibson *et al.* (2014). These authors found that non-safety AT was mostly provided by private companies and only rarely by AT services; on this point, the professionals described how decisions on signposting were based on a person's ability to buy privately (Gibson *et al.*, 2014).

The professionals in the present study often deferred to the expertise of their in-house occupational therapists, suggesting they would be the best person to lead on AT. Indeed, although they have been described as the gatekeepers of AT, little research has been conducted with them (McGrath *et al.*, 2017). Qualitative research with occupational therapists in England and Scotland found five enabling factors to their adoption of AT, including a positive client–therapist relationship, affordable AT, having time for AT, the provision of increased awareness, education and training on AT (current and future AT needs of individuals and what AT is available), and whether AT design achieved the identified need of the individual (McGrath *et al.*, 2017). A survey with Irish occupational therapists found that although the majority felt they should be able to assess for and prescribe AT, only a third said they could (Verdonck, McCormack and Chard, 2011). A UK survey of occupational therapists found 98% of respondents prescribed AT (Swinson *et al.*, 2016), suggesting that some do lead on AT. Claire Surr's 2021 guidance for MS stipulates a post-diagnostic occupational therapist assessment to maximise independence and function, and identify personalised interventions such as AT (Surr *et al.*, 2021).

A recent survey of community mental health teams (CMHTs) in England was aimed at identifying the staff roles and skills mix of specialist services diagnosing and supporting people with dementia. It found that occupational therapists undertook both a specialist role, in terms of providing therapy and information, and a more generic role in assessing patients for a diagnosis of dementia (Ahmed *et al.*, 2018). This finding is in line with those of another study on what occupational therapists do in CMHTs: 81% did initial assessments; 85% worked as care co-ordinators; and only 15% undertook specialist roles (Abendstern *et al.*, 2017). This goes against their professional body's recommendation that most of their work should be specialist; that is, they are experts in the occupational needs of individuals with mental health problems (College of Occupational Therapists, 2006) rather than the generic mental health worker model or care coordinator (Pettican and Bryant, 2007). Therefore, although the present study suggests occupational therapists should enact AT, most are doing initial assessments rather than specialist work and many need training and education on what AT is available to identify the current and future AT needs of individuals.

The question which arises here concerns whether professionals other than occupational therapists should lead on AT. A study by Kristiansen et al. looked at dementia co-ordinators in Denmark and found that it was often nurses trained to diploma level who supported families with daily living, their navigation of healthcare, and emotional wellbeing. In line with the findings from professionals in the current study, Kristiansen et al. found that keeping up to date with technological advances was challenging and that AT was not part of the job role (Kristiansen, Beck, Kabir and Konradsen, 2022). Interestingly, a recent study conducted by Scottish Care has introduced the possibility of a different professional for AT. They recognised the challenge of keeping up to date and introducing AT, and as such have completed a successful six-month care technologists pilot which has been expanded to a larger trial in two additional locations. The trial provides a personalised assessment by a care technologist and a technology plan which fits with a person's current technology use and wishes, before providing those involved with AT. This new role of a care technologist provides dedicated support and guidance with technology to the care team, with a focus on embedding AT within social care to support independence, participation and inclusion (Healthcare News Scotland Limited, 2022; Scottish Care, 2022). The care technologist's role is to speak with individuals and recommend personalised technology solutions to improve wellbeing, health and quality of life while also taking into consideration an individual's current technology use and preferences. They are from a social care background and preferably have qualifications in social care and/or a technology-related discipline (Scottish Care, 2022).

To overcome this complexity a global approach is required. In the UK the importance of AT research has been recognised by the Alzheimer's Society, Medical Research Council (MRC) and Alzheimer's Research UK when they funded the national Care Research and Technology Centre (UK Dementia Research Institute, 2023). Internationally, there have been collaborations to evaluate AT such as the European study led by Norway, ENABLE (Cahill, Begley, Faulkner and Hagen, 2007). Indeed, Europe has formed academic collaborations to try and overcome the numerous challenges posed by dementia including living independently, INTERDEM (Early detection and timely INTERvention in DEMentia (Interdem, 2023). They have produced the European position paper on AT(Meiland *et al.*, 2017) and more recently a manifesto which included a statement on AT aiming to harness modern technology to help people with dementia (Vernooij-Dassen *et al.*, 2021). However, despite their significant efforts this European network there is a need to increase collaborations outside of Europe and to form and develop global collaborations in AT used in dementia. The need for a global approach to dementia research is recognised in a recent article in Nature medicine(Cataldi *et al.*, 2023), however this call failed to include the often-forgotten area of caring for people with dementia (Monnet, Dupont and Pivodic, 2023), which includes interventions such as AT.

### *9.4.4 Obtaining information on AT*

Difficulty in obtaining information on AT was a finding which spanned all the empirical chapters. To overcome this challenge, professionals called for a national database of information on AT and the possibility of a loan facility. This need is reflected in the European position paper (Meiland *et al.*, 2017) and a recent study with carers in the UK on their experience of AT in dementia; they called for policy change to provide a centrally funded AT information resource and the establishment of a loan system for devices (Sriram, Jenkinson and Peters, 2021). The lack of clear information resources is not specific to AT as it is well recognised that families living with dementia struggle to obtain general dementia information. For example, a recent systematic review found that carers had difficulty accessing information (Francis and Hanna, 2022; Newton *et al.*, 2016), and another study with people with dementia and carers identified the need for clear information on dementia (Innes, Szymczynska and Stark, 2014). Other studies have called for a single point of access for information, similar to the participants in the present study (Górska *et al.*, 2013). This is despite policy drives for personalised information on post-diagnostic support, including an 'annual information prescription' (Dementia Policy Team, 2016) and national guidance (National Institute for Health and Care Excellence (NICE), 2018; Scottish Intercollegiate Guidelines Network, 2006, cited in Innes, Szymczynska and Stark, 2014) which not only identifies information provision as a specific need but also clearly outlines the importance and responsibility to professionals of providing adequate information (National Institute for Health and Care Excellence (NICE), 2018).

Obtaining information on AT used in dementia is more challenging due to the complexity of the intervention and the population. This study has highlighted that the professionals struggled to find information on which devices were more effective than others. Mathews et al. also identified this need for accurate and trustworthy information on types and models of AT (Mathews *et al.*, 2019). On a wider scale, they identified the need for all stakeholders, from the patients, doctors, and industry to the regulators, to have confidence in healthcare technology, which would include AT (Mathews *et al.*, 2019). Identifying which technology provides real value is challenging and they called for a robust validation pathway for digital healthcare to include accurate claims of benefit, evidence of effectiveness, and integration into users lives and wider systems (technical interoperability and service interoperability) (Mathews *et al.*, 2019). To provide professionals with a centralised information resource on the type, model and effectiveness of each AT used in dementia, a considerable amount of work remains to be undertaken.

### *9.4.5 Section summary*

In summary, the findings of the study fit with a complex intervention with a complex group of patients in a complex setting. To explore the AT used in dementia further, a different approach is required compared to the traditional methods used in health and social care. Greenhalgh and Papoutsi (2018) suggested that an effective study of the complexity in health services requires an urgent paradigm shift to include a complexity-informed approach which utilises a 'systems mindset' that recognises how parts of the system relate to each other and how they adapt to change.

## 9.5 Strengths and Limitations of this Study

In this section, I reflect upon the methodological approaches used and discuss the study's strengths and limitations.

### *9.5.1 Overall study design*

The discussion of the strengths and weaknesses of the study precedes an in-depth exploration of these in relation to each data collection method. The work has several strengths. Importantly, it is the first study looking at MS' professional practice around AT used in dementia and as such it provides new and unique insights. The supplementary quantitative stream involved two surveys which were used to inform the later more substantial qualitative stage of the study. These were distributed to 117 MS and completed by numerous participants (578 professionals and 87 managers). The responses were used during the telephone interviews as prompts to explore good practice further (i.e., provision of training). The survey was also used to recruit participants for the qualitative stages.

This study was only conducted in England, which could be seen as a weakness as it excludes other countries in the United Kingdom (UK), such as Scotland, which may provide 'good care' regarding AT (Scottish Government, 2017, National Dementia Strategy 2017–2020). The principal qualitative stream involving focus groups and semi-structured interviews separated participants from their normal social, cultural, and professional working environments; other approaches, such as an ethnography, would have observed the participants in their natural environment. This could be seen as a limitation; however, I believe the semi-structured methods employed are appropriate due to the huge variation in the setup of the MS. An ethnographic approach, although producing valuable data, would not have adequately explored the phenomena under investigation or answered the study objectives. Finally, data were collected only from those who agreed to participate and as such may not be representative of the entire professional MS group.

### *9.5.2 Survey: design, recruitment, sampling, and analysis*

Despite this being a pragmatic survey, it has several strengths. It was the first study to explore the topic area and was extensively piloted and refined. As noted, it was widely distributed and this generated many free text comments in response to open-ended questions (1,655). However, it was not without limitations. It was not a validated survey and the use of gatekeepers to pilot the survey with professionals made it challenging to use methods such as cognitive interviewing to reduce potential for responder bias. Therefore, despite piloting and refining the questions, some responses may have reduced validity and reliability (McColl and Thomas, 2016). Keeping track of the survey response rates was impossible. With no formal national list of MS, I recruited sites via the NIHR CRN. Interested MS then distributed the survey to professionals via their own internal processes, producing variations in approach by each hospital trust using their local 'gatekeeper' to disseminate the survey. Due to the use of gatekeepers and the large number of MS involved, it was difficult to track survey responses as many trusts did not respond when asked how many professionals they had contacted about the survey. Thus, it was a pragmatic study and the variation in the response rate between hospital trusts and data generated could over or underrepresent the views of all the professional groups.

Further barriers to survey recruitment could have included the time needed to complete the survey, and the topic area, AT. The results demonstrated that many professionals did not understand the term AT; as such, this may have discouraged participants by questioning their professional knowledge. The participants voluntarily completed the survey, introducing the possibility of self-selection and subsequently reducing the external validity of the recruited sample. However, it must be stressed that the purpose of the survey was not to gather a representative sample of each professional group but rather to include a wide range of professionals and to use the survey data to inform the later, more substantial, qualitative stage and in this it was successful.

The approach to participants impacted the ability to analyse data at the level of MS. Some hospital trusts described themselves as having one MS which encompassed several physical sites, while other trusts defined themselves as having several MS, reflecting individual physical sites. These facts only became apparent during the study and is further evidence supporting my main finding that MS represent a complex setting.

A strength of the survey was that it provided an additional source of qualitative data in the form of the large number of free text comments (1,655). These were used to explore areas where there was insufficient information on processes, such as whether they provided extended AT services. A positive effect of the free text comments was that they required professionals to reflect on practice and record their thoughts. Many wrote detailed descriptions of the challenges they faced and these added to the richness of the data.

Although the descriptive analysis of the free text comments did not permit a deep analysis, it was in keeping with the purpose of the survey in terms of identifying key areas for further exploration in the substantive qualitative stage.

### *9.5.3 Focus groups*

The aim of the focus groups was to capture the perspectives of professionals working in 'average' MS. The potential limitations of focus group data include: the number conducted, sample achieved, influence of my role as a researcher and GP, and change in mode from face to face to remote online platforms. It may be questioned whether the focus groups of eight and three participants, respectively, provided sufficient data to explore the phenomena of interest. However, a key area to consider here is whether data saturation was achieved, although it is difficult to measure objectively and there are no clear guidelines on how to do so. Guided by my pragmatic theoretical perspective, I looked to achieve theoretical sufficiency in that my data provided a sufficient theoretical account (Dey, 1999).

Sampling is another area to consider. The study employed purposeful sampling and attempted to reflect the normal constituents of a memory service's MDT. Focus groups were conducted before and during the COVID19 pandemic; the first was before the pandemic and was well attended with eight participants from a range of disciplines, reflecting a typical MDT. The second occurred during the pandemic, had only three professionals, and did not reflect the full MDT. It is likely that if the second focus group had occurred before the pandemic, without the pressures of trying to maintain routine services, there would have been better attendance. Despite this, the study achieved its aim of gathering the views of a wide range of professionals working in MS, doing so across both focus groups and the additional telephone interview with a consultant psychiatrist.

The first focus group was conducted at a local MS to which I referred in my GP role; this impacted data collection as the service manager seemed to be promoting the service. In contrast, the second focus group was outside my region and I did not have the same concerns over participants promoting their service. The evolving pandemic also influenced how data were collected; the first focus group was conducted face to face, whereas the second was conducted using Microsoft Teams. This change in mode of delivery to an online platform could have impacted data collection as I found that even though I could 'see' participants and respond to cues and body language, the new mode was less fluent and did not feel as comfortable as face to face.

### *9.5.4 Interviews*

Despite the interview participants being purposively sampled to include key characteristics such as training and demonstration, external validity could have been decreased as those who responded self-selected and some who were purposively sampled did not respond to invitations. The COVID-19 pandemic was a huge barrier to recruiting as managers and lead professionals were preoccupied with reconfiguring services to maintain ‘normal’ MS provision; at the beginning, managers and lead professionals did not respond to invitations but as services adapted and stabilised, they did so. To overcome the challenge of recruitment, I decided to include services which provided ‘average’ AT provision to explore barriers to providing more innovative services. This change in sampling strategy helped to produce rich data and produce a better account of the challenges the services faced.

Interestingly, during the pandemic, the professionals themselves had to use AT to assess and review patients. This change in practice may have influenced those views elicited before and during the pandemic. As such, this reflects the dynamic nature of the MS provision and pace of change of technology adoption, with services having to adapt to provide routine services during the pandemic. In terms of time, interviews ranged from 14–77 minutes. Some interviews had time constraints imposed by participants due to clinical commitments while others had no constraints and produced longer interviews. The data gathered from the time-constrained interviews whereas adequate but not as rich or wide ranging as the longer unconstrained interviews. The mode of delivery changed through the pandemic; the original intention was for telephone interviews, but this expanded to include online platforms as the pandemic progressed. This allowed me to ‘see’ participants and interpret body language and non-verbal cues, as opposed to asynchronous communication by telephone (Sturges and Hanrahan, 2004). This change in mode of delivery could also have impacted data collection. One interview was difficult as both interviewer and interviewee were learning to use Microsoft Teams, but this difficulty rapidly changed during the study and was became standard practice for meetings. As a researcher, I found using the telephone more challenging as I did not have any visual cues such as body language.

## 9.6 Recommendations for Policy, Practice, and Future Research

The findings of this thesis have highlighted several important implications for policy and practice regarding the implementation of AT by MS, i.e., that it comprises delivery of a complex intervention to a complex group of patients within an underdeveloped AT ecosystem. To overcome the complexity of 'doing AT', a number of key decisions must be made, including: 1) identifying the right people, time and place for AT, especially the role of the lead professional; and, 2) developing a robust and fit-for-purpose AT ecosystem to enable implementation and ongoing monitoring. The current processes and surrounding AT ecosystem are unnecessarily complex, likely due to commissioning criteria and priorities resulting in complex systems and numerous stakeholders involved to provide information, assess, deliver, implement, and review AT recommended. Thus, policy change is required to prioritise the commissioning of the whole pathway with one overarching organisation in charge of ensuring the smooth operation of the whole system and with either less stakeholder organisations or better communication between groups involved.

### *9.6.1 Identifying the right place to do AT*

The finding of this study has demonstrated that implementing AT is complicated. The assumption at the beginning of the study was that MS undertake this role and, indeed, the study has determined that MS do introduce AT to families with dementia where there is a need or elevated risk. However, they do not routinely provide information and help people with dementia to access AT. The professionals working within the teams questioned whether MS were the best setting for AT, as they had moved to become a diagnostic only service and therefore did not consult with people with dementia throughout their dementia journey. Moreover, they are not all equipped with the knowledge, skills, and resources they need for enacting AT, such as having detailed information on AT, both to give to people with dementia and to demonstrate AT to those wishing to use it. This is demonstrated by the professional unease they experience around financial ability to access AT, their knowledge, and professional tensions around their role resulting in a post code lottery in terms of AT provision. To overcome this professional unease and even out the resulting inequalities seen by professionals, a radical change in how AT is funded and commissioned by government is required. For instance, to overcome inequalities due to disparity in financial means of families, a universal basic entitlement on AT and/or a reduction in private companies cost of devices, something that is likely to be unattractive as it would affect their profit. If MS are indeed the appropriate service to implement AT, a shift in policy and priority is required and this will impact the funding needed to provide post-diagnostic support. This would require policy resulting in a change in commissioning priority and clear guidance on what each service would need to provide. If another service were to enact AT, questions remain concerning which one, what structure, and where it would it fit in the wider AT ecosystem. The options suggested include primary care, who 'see' patients throughout their dementia journey. New roles within primary care, such as primary care navigators or social prescribers, may be an option (Health Education Enlgand, 2016). NHS England includes social prescribing as a pivotal factor in their Universal Personalised Care model (NHS England, 2023a). Social prescribing allows several agencies including health, local authority, and voluntary sectors to refer into a social prescribing link worker who can work with the patients to produce a personalised care and support plan. Social prescribing link workers connect people to support in their local communities to improve their health and wellbeing, often forging links with health, social and voluntary services to produce personalised care (NHS England, 2023b).

The NHS long term plan has facilitated the embedding of social prescribing in primary care through contracts with Primary Care Networks (PCN's) such as the network Direct Enhanced Service (NHS England, 2022). This model has been driven by NHS England without clear evidence for its use (Kiely *et al.*, 2022). Essentially, evidence is trying to catch up with practice (Bickerdike *et al.*; Husk *et al.*, 2020). Variation in implementation of social prescribing in the UK has resulted in diversity of what is provided (Husk *et al.*, 2019). To overcome this paucity of evidence for link workers in primary care a RCT exploring the use of link workers working with patients with multimorbidity is proposed(Kiely *et al.*, 2021a) after a successful pilot (Kiely *et al.*, 2021b).

Despite this lack of clear evidence and huge diversity of offering, social prescribing has great potential and could be used as a conduit to drive AT in dementia care, as primary care see people with dementia throughout their dementia journey. Nevertheless, even with this great potential, they will still have the challenge of needing the same resources identified by MS professionals, including being trained to identify suitable AT which would give personalised solutions to problems people living with dementia face. Crucially, funding is required, which may be possible via the PCN DES Additional Roles Reimbursement Scheme. However, to have a social prescriber with expertise in AT, individual PCNs' would need to identify such a role as a priority. This may be challenging given the lack of awareness of AT among professionals including GPs (Newton *et al.*, 2016) but also due to the multiple competing interests PCN face in trying to develop services in their individual communities.

Furthermore, clarity around outcome measures for services are required, especially around defining whose outcome are we measuring. Is it whether the services, MS, or other identified service, gives information or provides AT or rather whether AT is used and found to be helpful to families living with dementia? A positive outcome may be if a service provides AT but the person does not find it helpful, as they have at least had the opportunity to try out the technology without having to purchase it themselves.

Regardless of which service is responsible for leading on AT, it will still have to work within a poorly defined and fragmented ecosystem. It will also have to navigate a mixed economy of provision, in which health and social care organisations are constrained by safety while private companies are much freer. To utilise the benefits of AT fully, a bridge between both settings is required, not only to keep people with dementia safe but also to use technology to enhance their lives. The current system is more complicated than required and would benefit from simplification, clearer communication, more effective working and collaboration between organisations involved in information provision, assessment, implementation, delivery, and review of any AT identified. This could be achieved through commissioning of services to streamline processes and have a lead organisation responsible for delivery of the whole pathway. This intervention is greater than one organisation and requires close collaboration between many organisations and a clear lineation of responsibilities.

### *9.6.2 Identifying the right professional to lead on AT*

A key consideration for the effective enactment of AT is determining the right professional to lead on AT. Data from this thesis suggest this could be an occupational therapist as they were seen as best placed; however, a wider review of the literature around this professional group's knowledge of AT, in conjunction with the development of their role within MS in moving toward assessment, call into question whether they are indeed the best group. The assumption that an occupational therapist would be the best AT lead is reasonable given they help 'people of all ages overcome challenges completing everyday tasks or activities' (Royal College of Occupational Therapists, 2022), which fits with the implementation of an intervention such as AT. However, from the limited evidence we have, it may be that the wider occupational therapist group has limited knowledge of AT, as reflected in this thesis' finding. Interestingly, other occupational therapists in this study had advanced knowledge of AT and were able to suggest and implement more advanced solutions. These professionals often had a special interest and some had completed higher degrees such as a master's with a specific project on AT. Therefore, it cannot be assumed that all occupational therapists have equivalent AT knowledge. If they are to lead on AT, it must be featured in their professional standards and currently this is not the case (Royal College of Occupational Therapists, 2021).

Research has also highlighted the evolving role of the occupational therapists in MS and how many are now assessing with a view to providing a diagnosis or working as care co-ordinators, rather than using their advanced skills to help people live independently (Ahmed *et al.*, 2018). This shift in professional role reflects the evolution of the MS to move to diagnostic only services. It is, therefore, questionable in the current MS climate of focusing on diagnosis whether occupational therapists would be the best professionals to lead on AT. For them to do so, several changes would be required: a shift to post-diagnostic care; a move toward utilising occupational therapists only to support independent living rather than diagnosis; and, an emphasis on AT in occupational therapist standards.

This thesis illuminated the pivotal role of the occupational therapist in MS and how professionals viewed them as knowledgeable and trusted team members who were best placed to do AT. A move towards having occupational therapists only supporting independent living is attractive, however given the shift in their role to also support diagnosis this is unlikely to be realised. Interestingly, this thesis highlighted that with regards AT knowledge not all occupational therapists are the same with some having increased knowledge, often through completing further education such as a master's on AT. Unfortunately, this opportunity is not available to all occupational therapists. Ensuring AT is part of the occupational therapists' curriculum is a crucial first step; to shift the role of the occupational therapists to include utilising and integrating technological solutions using the technology already widely used by many of their clients. Then, perhaps developing a post-registration qualification specifically on AT, which is funded, and available to all occupational therapists. This would facilitate the development of the role of an AT specialist who can assess and identify personalised AT solutions for families living with dementia, whether by producing occupational therapists with expertise in AT in every MS or a local expert providing knowledge to a geographical footprint or even a national advice centre providing support to all occupational therapists /MS professionals. Critically, occupational therapists with expertise in AT would need to be identified as a priority for policy makers and commissioners to ensure that all MS are shaped to include and recognise occupational therapists as experts in AT and ensuring independent living.

Other options for leading on AT would be for all professionals to have knowledge of every AT solution, or for a new role to be created for an AT champion, from any discipline, who has a special interest in AT. The first of these options would be very challenging, as evidence from this thesis has highlighted how professionals struggle to keep up to date and lack the resources to do so. As such, this may be an unrealistic expectation unless national resources become available to support all professionals, such as a national database and helpline. The second may be an option, through the development of a specialist technology advisor. That is a new role whereby an individual has specific training on AT and works only to assess and suggest technology solutions. They could come from many backgrounds but will likely be placed where they are commissioned and where funding is available, either via MS, voluntary organisations, local authorities, or even private organisations. This is illustrated by the Scottish Technology pilot. However, the development of a specialist role, only being expert in AT, may produce advisors who only look at technological solutions rather than the broader remit of the occupational therapist who will also look at simpler, none technological solutions. As with the suggestion of an occupational therapists with a specialist role in AT, but again resources are required to support both this role and the development of a robust and fit-for-purpose ecosystem. Unsurprisingly, the current, constrained system cannot support either option. On this point, the following section describes the possible development of a robust and fit-for-purpose AT ecosystem.

### *9.6.3 Developing a robust and fit for purpose AT ecosystem*

To ensure AT is utilised to its full potential in dementia care at the right time, with the right person, the AT ecosystem in which it is used needs to be developed. The ecosystem can be defined as the interacting system involving organisations, structures, and processes involved in introducing, maintaining and to provide ongoing monitoring of AT. Elements of the AT ecosystem were identified from reviewing literature and via participants description of doing AT. It can be depicted in Figure 9.1.

A key facet of the AT ecosystem is Government which introduces policy which can be used by professionals as a lever to develop and drive change. The government produce guidance and policy which can influence commissioning and research pathways. CCGs commissioned services during the period this thesis was undertaken. These have now been replaced by Integrated Care Boards. Commissioning priorities are defined for each region which then influences what services introduce, monitor and maintain AT. These services can include health, local authorities and voluntary organisations. Government policy and funding can influence research organisations through funding projects on AT which can then be a route for professionals to get advice on AT and for families to access AT. Some MS have then developed collaborations with other organisations in their local area to deliver a bespoke dementia pathway which can include AT. Others work in isolation with fragmentation of service delivery. This has led to inequalities of provision of AT. Separate to this, a key driver in the AT ecosystem is private organisations who design and develop AT for people with dementia. Some MS have made collaborations with these organisations to help deliver their AT pathway, utilizing them for training and accessing AT. Overall, the AT ecosystem reflects the mixed economy of provision that families with dementia experience when they are recommended AT by MS professionals, with AT recommended based on their financial means. A single point for access for information, training and access on AT was identified by professionals as a gap in the current AT ecosystem which would help them do AT.

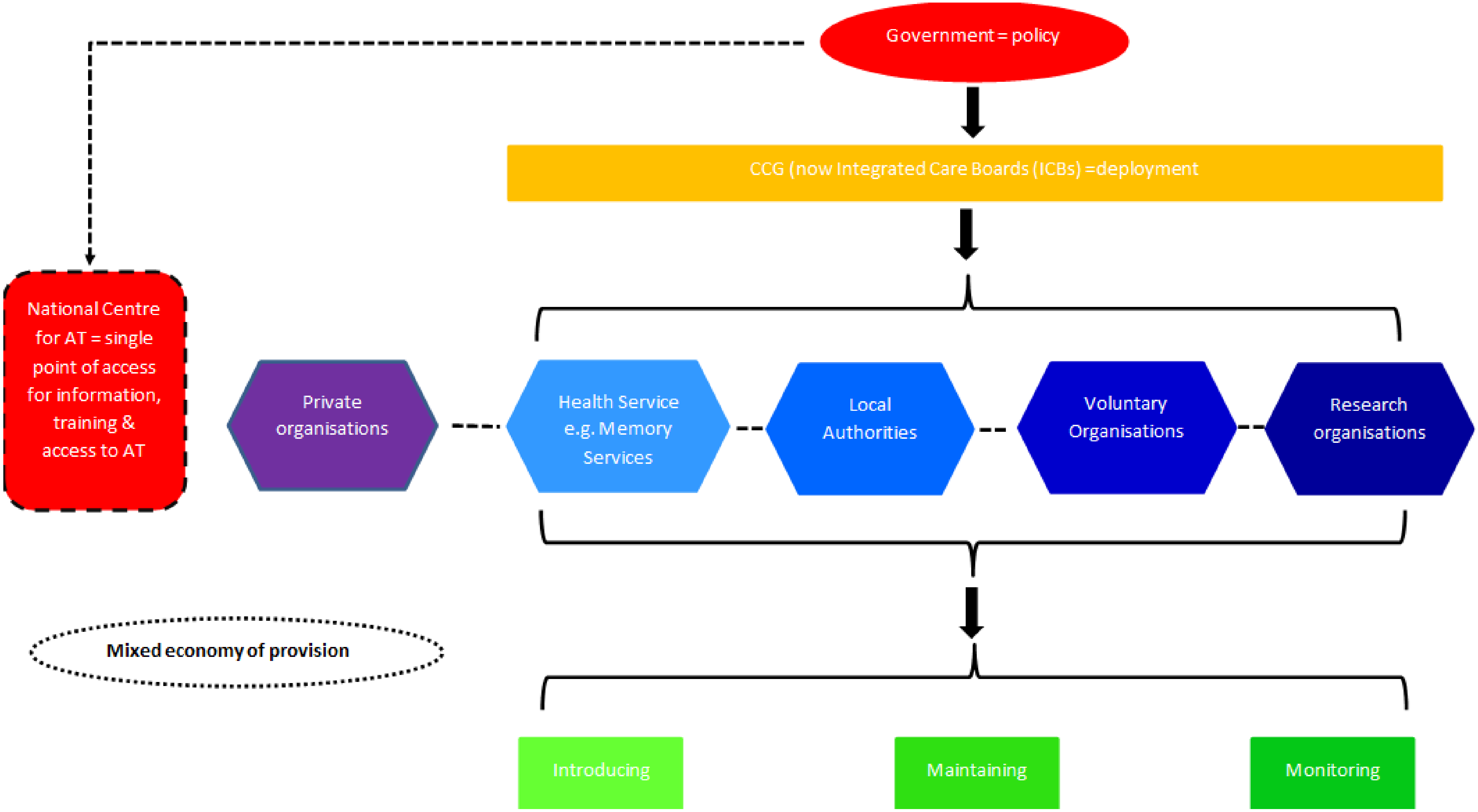

**Figure 9.1 AT Ecosystem**

Firstly, to introduce AT effectively, the professional, whether working in MS or other organisations such as primary care or social care, must be equipped with the resources to identify the need for AT and to introduce bespoke solutions to the problems people with dementia encounter. The resources required include training on available AT, assessing individual needs, and navigating ethical considerations, protocols, guidance, and access to demonstration and loan facilities. Most importantly, professionals need access to current information on AT, its costs to people with dementia, and how it can be accessed if needed. Ideally, this could be via a national database and helpline.

Once AT is identified as a need for individual patients, national and local pathways must be delineated to help people access AT and determine how they can fund it. National guidance is required to clarify both the roles and responsibilities regarding the assessment, implementation, and maintenance of AT, to ensure it is fit-for-purpose and causes no harm. If any implemented AT requires a response, it must be clear who should respond and maintain the AT. Crucially, if more than one organisation is involved with an aspect of the pathway, from assessment to implementation and then monitoring, then clear guidance is required on role and responsibilities and how to ensure effective communication between organisations. This study and previous literature highlight the current system is very complex, this is most likely a result of complex commissioning resulting in fragmentation of services with many organisations or teams involved in the pathway to provide information, assess, implement, deliver, and review AT recommended. However, this can be simplified and streamlined through developing guidance and standards. Giving standards on each stakeholder involved in the assessment and implementation chain's roles and expectations, crucially involving timelines to prevent delays in implementation to ensure any AT recommended is delivered while it has the potential work. Thus, a change in approach is required to simplify the system and commission the whole pathway to ensure personalised AT solutions which are responsive and easily available to families living with dementia, perhaps through a national centre for independence. Overall, a multipronged improvement is required of the wider ecosystem.

For many, AT is beyond reach due to the financial burden incurred. This has produced inequalities of provision and tailored pathways that are dependent on individual financial means. To overcome this, a basic financial entitlement on AT might help. Future developments of the AT landscape are likely to be driven by private provision. Technology adoption reflects the 'mixed economy' landscape with private provision being more expensive and out of the reach of some families due to lack of finances. That is, less well-off individuals in society will have limited access to more novel or advanced AT due to cost; essentially narrowing the technology spectrum they can access. Therefore, at any point in time there will be inequalities of access based on financial means. However, technology will become cheaper over time, shifting previously unattainable technology into a more affordable cost bracket and mainstream resulting in more access due to reduced cost and thus potential wider adoption. But things will not stay steady, more technology will be developed at higher cost which will again produce inequalities with only those with more financial means accessing them.

This cycle will continue unless the private firms shift their priority and make any new technology at a cost that all can access or governments subsidising more expensive devices. The former could happen if companies adopted a more utilitarian approach, the latter is less likely given the current UK economic crisis. Therefore, it is more likely the cycle will continue with private innovation and development shaping the future AT economy. Essentially private provision driving innovation and the AT landscape and makeup of the mixed economy. For governments to identify AT as a priority, the evidence needs to be stronger. Unfortunately, there is a paucity of evidence for the use of AT in dementia. Therefore, to achieve the above recommendations, gathering evidence on AT is important.

The outlook for dementia and indeed AT research is bleak. Government policy has the potential to facilitate funding of research and ensure deployment of technology is a priority. Considerable progress has been made in dementia research through David Cameron's Prime Minister's Challenge (Department of Health, 2015), through ensuring dementia is a focus for research and is appropriately funded. This has been recognised through the NIHR's call for research projects (National Institute for Health Research, 2023). However, since his resignation the current conservative government has had little leadership stability, with numerous changes in prime and cabinet ministers. Despite the conservative 2019 manifesto pledging to find a cure for dementia; a pledge recognised by the term "Dementia Moonshot" (Parkin E and Baker C, 2021). Little has been done to make this pledge a reality or indeed to tackle the huge challenges faced for people living with dementia; funded research focuses predominantly on cure rather than care. Despite this pledge subsequent prime ministers and cabinet ministers have not prioritised dementia or continued David Cameron's legacy. That is apart from Sajid Javid who in in May 2022 announced another 10 year plan would be produced later that year(GOV.uk, 2022). However, his role as health secretary ended the following month with no subsequent publication of a new 10-year plan. Apart from this glimmer of action other ministers have not recognised the public health crisis dementia poses by providing funding and producing guidance on how to tackle the crisis. Indeed, they have, understandably, focussed on the COVID19 pandemic with its subsequent health and economic consequences; as well as the other multiple economic challenges the UK face. These include Brexit, increasing fuel costs and now the cost-of-living crisis. This lack of action on the governments part does little to help the thousands of people and families living with dementia who are trying to cope with the challenging symptoms it produces. Unless the economic climate improves then government funded research may be limited. Moreover, charitable funded research may reduce as they rely on donations, which in future are likely to reduce due to the cost-of-living crisis.

In comparison to dementia, recent policy on research on AT is even more bleak. The situation looked more promising when the Alzheimer's Society recognised AT as a priority through funding a £20million Care Research and Technology Centre. This centre aims to produce dementia-friendly homes through development and use of novel technologies (Alzheimer's Society, 2019). The NIHR also funded the ATILLA trial, however as described previously, it did not show a benefit of AT. UK policy on AT has stagnated, likely because of the governments instability and multiple competing priorities. This makes AT research and deployment a luxury, never mind being able to provide a basic entitlement of AT.

### *9.6.4 Areas for future research*

This study focused on MS provision and professional practice with regards to AT. It identified several key stakeholders and other organisations involved in the assessment, deployment, and evaluation of AT. Fundamental issues remain, such as identifying the right AT for each problem a person encounters, and knowing when it should be introduced and when it would cause harm. This information is key to developing more in depth and helpful guidance on the use of AT in dementia (including the ethical challenges that could be encountered). To address the three key recommendations identified in this thesis—identifying the right place and professional lead for AT and developing a robust AT ecosystem—further research is required to gather data on the perspectives of the key players and organisations involved in assessing for AT, and of those working in the wider AT ecosystem.

The most important perspective is the views of people with dementia and their support network of either family, friends, or formal carers. Unfortunately, in this study their views were not captured as was originally planned as part of the fellowship application. However, the study has identified key areas to explore with members of this group, including:

- what they understand by the term AT;
- which information and support they would like to have to help them access AT, if they wish to use it;
- when they think it would be appropriate to introduce AT and who should introduce it;
- whether they have a preference for where to receive information and support on AT;
- which barriers and facilitators prevent/enable having information on and access to AT;
- whether the cost of AT prohibits their use and access;
- whether they have solutions to the challenges of obtaining information on and access to AT.

This study has highlighted a complex network of stakeholders in the AT field, such as local authorities, social services, the voluntary sector, charities, private companies, and researchers. Each potentially plays a role in the delivery of AT, as do other groups who may be better placed to enact AT, such as GPs or pharmacists. Research seeking to find these groups' views and how they work in collaboration would allow a greater understanding of the AT ecosystem. Wider research with these key players, in the context of the mixed economy of provision of AT, could gather data on their perspectives regarding which is the best setting for AT and who should lead on it. It could also cover how we can evolve and refine the wider AT ecosystem to ensure that any AT which is recommended by the identified AT lead is assessed, deployed and evaluated effectively. Essentially with the aim to identify ways to simplify the current processes and remove the current complexity around information provision, assessment, implementation, delivery, and review. This will help ensure the best AT solutions are implemented to enhance the life of a person with dementia without causing harm. More information on how the current AT ecosystem works and how it can be enhanced and evolved is essential. Other wider perspectives are also required, such as from community teams in primary care, social prescribers, and local community pharmacies.

AT is currently not identified in key clinical standards such as NICE, likely due to the lack of robust evidence for its use. However, gathering evidence is challenging for the reasons identified in this thesis. It is a complex intervention, being implemented in a complex group of patients in a complex setting. Other methods of gathering evidence on the effectiveness of AT are required. Currently, without this, AT is unrepresented in national dementia guidance. Moreover, it is essential that we also gather views on which practical guidance and standards are required to help key stakeholders design and assess services regarding quality of provision. One key area of the Donabedian framework is the assessment of the outcomes of an intervention to check whether a service provides quality. AT provision is in its infancy in terms of service configuration, as reflected in the underdeveloped AT ecosystem and the recommendations of the recent European position paper (Meiland *et al.*, 2017). More research is required to identify quality outcomes we can measure on AT in dementia care to help services monitor quality, including identifying whose outcomes should be measured the services or families with dementia, or whether the AT is used or is helpful for individuals.

Finally, we need research into what all stakeholders understand by the term AT and what it encompasses, from the users of the technology to the players in the current AT ecosystem. Without this common language and harmonisation of understanding, it will be difficult to ensure conversations are clear, whether in a one-to-one consultation between service user and professionals, or in how policies are interpreted into the commissioning of services. Crucially, research on AT needs a global approach with collaborations and a united voice to drive research and development of services and process which can deliver effective AT interventions to families living with dementia.

## 9.7 Conclusions

This final chapter has presented and discussed the findings of a predominantly qualitative study exploring MS professional practice regarding the AT used in dementia care. It finds that implementing AT is very challenging since the patient group, setting, and intervention are all complex. This finding illuminates wider and deeper service deficits and issues such as identifying the best place to enact AT, which professional group should lead on AT, and how to ensure a better developed and robust AT ecosystem.

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# Appendices

## Appendix 1: Consent form

Centre Number: IRAS ID: 230850

Study Number:

Participant Identification Number for this trial:

### CONSENT FORM

Title of Project: **Memory Service professional practice regarding Assistive Technology**

Name of Researcher: Lisa Newton

Please initial box

1. I confirm that I have read the information 17/8/17 (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐

3. I understand that the information collected during the study may be looked at by the research team and secretarial staff from Newcastle University, the designated transcription agency used by Newcastle University, and authorised persons employed by the responsible research and development department. ☐

4. I agree to the use of audiotaping to record the focus/interview and agree that the content of this audiotape can be transcribed verbatim. ☐

5. I agree to anonymous direct quotes that have been recorded and transcribed from the Focus group/interview may be used by the researcher when publishing or presenting results. ☐

6. I understand that the information collected will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

____________________ ____________________ ________

Name of Participant Date Signature

____________________ ____________________ ________

Name of Person taking consent Date Signature

When completed: 1 for participant; 1 for researcher site file

Version 1.0 20/11/17

## Appendix 2: Participant information leaflet

Memory Service professional practice regarding Assistive Technology Version 1.0 17/8/17

# Participant Information Leaflet

## Memory Service professional practice regarding Assistive Technology

You are being invited to take part in a research study. The study will look at current practice of professionals working in Memory Services (MS) in the provision of information on and helping families living with dementia to access Assistive Technology (AT). Before you decide whether or not you wish to take part, it is important for you to know why we want to carry out this research and what taking part would mean for you. Please take time to read the following information carefully. Please discuss it with others if you wish.

## What is the study about?

There is growing interest in the role of assistive technology (AT) to support people with dementia to live as independently as long as possible. AT is any aid or device which helps someone become more independent. The term AT encompasses a wide spectrum of aids and devices. Examples of AT used in dementia include clocks to help orientation, automated pill dispensers and the more controversial Global Positioning System tracking devices. GPs are often the first port of call for families living with dementia but a previous study found they were unclear where to get information on AT and who was responsible for providing AT. Some GPs suggested the MS for such advice but they were unsure whether MS clinics provided information on AT or supported people to access AT. The Memory Services National Accreditation Programme (MSNAP) works with MS to assure and improve quality of services for people with dementia and their carers. One of their standards is that MS should have access to advice and support on AT and telecare solutions designed to assist people with activities of daily living.

This project hopes to determine current practice of professionals working in MS in the provision of information on and access to AT for families living with dementia. It also looks to identify any areas with extended services or innovative working with voluntary or other organisations. It involves two surveys to professionals working in MS in England (one to MS managers and another to MS professionals) and focus groups and interviews. Results will be used alongside interviews with people with dementia and their carers to provide data to design information and referral pathways to help people with dementia get timely information on AT and support to access AT if they which to.

## Who is organising the research?

Dr Lisa Newton, who is being funded by the Alzheimer's Society to carry out this project. She is the researcher responsible for the day-to-day running of the project. Professor Louise Robinson and Professor Joy Adamson will provide expertise in the field of dementia research and study methods.

## Why have I been invited?

We are contacting you because you are a manager or professional working in a MS who may have experience of giving information or helping people with dementia access AT. We are really interested in your views on giving information and supporting people with dementia to access AT.

## Do I have to take part?

It is up to you to decide whether or not to take part. If you are happy to take part in the survey, please follow the link provided in the e-mail. We are interested in a small number of participants being involved in focus groups or telephone interviews. If you are happy to be approached to have a focus group or telephone interview, please tick the appropriate box at the end of the survey. If you do decide to take part in a focus group or telephone interview you will be asked to sign a consent form. Taking part is voluntary.

## If I agree to take part, will I be able to change my mind?

You are still free to change your mind at any time and withdraw from the study without giving a reason.

**What might be the benefits of taking part?**

The research hopes to determine current practice of professionals working in MS in the provision of information on and access to AT for families living with dementia. It is hoped this project will help design information and referral pathways for AT which will help people with dementia get timely information on AT and support to access AT if they wish to use it.

**Will I come to any harm taking part?**

You are unlikely to come to any harm while undertaking the research. If you do not want to answer a question in the survey, please miss it out. If you participate in a focus group or interview and become distressed while discussing a topic we will check with you that you are happy to carry on with the focus group or telephone interview. You do not have to answer any questions if you would prefer not to.

**What will happen if I decide to take part?**

Survey:

If you are interested in taking part, please follow the link provided and complete the survey. The survey will ask some questions about your experience and current professional practice around AT and how your MS give information on AT and supports access to AT. AT the end you will be asked minimum questions about yourself such as age, profession and number of years of experience of working with people with dementia. At the end of the survey you will be given the option to allow the research team to contact you in the future to be involved with a focus group or telephone interview.

Focus group or telephone interview:

If you have consented to be approached and are contacted by the research team to attend a focus group or to have a telephone interview the research team will allow you to ask any questions and will arrange a focus group at your place of work or a venue close to your work. The researcher will try and find a suitable time for you to attend or be telephoned. On the day of the focus group or telephone interview we will first ask you if you are still happy to take part. If you are, we will then ask you to sign a consent form which says you give us permission to talk to you and use the information you give us in our study. We will send this to you beforehand if you are having a telephone interview.

With your permission, we would like to record the focus group discussion or telephone interview. Typically focus groups or interviews will take between 30 minutes and 1.5 hour. It will take no longer than 2 hours.

## Expenses and payments

Participants who complete the survey will be given the option to sign up to a prize draw to win a £50 gift voucher.

## Will my taking part be kept confidential?

Yes, all information collected about you will be kept confidential. We are bound by a strict code of confidentiality. Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

A small number of participants, who have agreed to be contacted to be involved in a focus group or have a telephone interview, will be invited to take part. To undertake the focus groups or telephone interviews we will need to keep a record of your work contact details. We will conduct focus groups or telephone you during work hours unless this is not convenient for you. With your consent we will also keep recordings of your interview. All of this information will be anonymised and stored securely at Newcastle University. At the end of the study the recordings will be destroyed in line with the Newcastle University data protection policy.

Once we have undertaken the focus group or telephone interviews, we will only use non-identifiable personal information to analyse the data and report the findings. Your own name will not be used and no personal information about yourself will be given in any final reports except your profession or length of time working in dementia. Your comments may be used in the study report but your name will be removed from any quotations.

If you join the study, the data collected will be looked at by the research team, their secretarial staff and the transcription agency approved by Newcastle University. Authorised persons employed by the responsible research and development department will also have access to the data to check that the study is being carried out correctly. All persons will have a duty of confidentiality to you as a research participant.

**What if there is a problem?**

If you have concerns about any aspect of this study you should ask to speak to a member of the research team who will do their best to answer your questions. The researcher Lisa Newton can be contacted on 0191 208 83032 (Tuesday, Wednesdays and Thursdays) or by e-mail lisa.newton@newcastle.ac.uk.

**What will happen to the results of the research study?**

We will discuss the findings of this study in a report. The results will be combined with interviews we will do with people with dementia and their carers. Papers and articles which describe the results of the study will also be written for academic journals. You will not be personally identified in any reports. You will be sent a summary of the study findings.

**Who is paying for the research?**

The research is being funded by the Alzheimer’s Society. It will form part of a doctoral project.

**Who has reviewed this study?**

The study has been reviewed and approved by Newcastle University Research Ethics Committee.

**What should I do now?**

If you would like to take part, please follow the link to the survey. At the end of the survey you will be given the option to allow the research team to contact you regarding future focus groups or telephone interviews.

**Where can I get some more information?**

*For information regarding this specific research study:*

Dr Lisa Newton

Alzheimer's Society Clinician Training Fellow

Institute of Health and Society

Biomedical Research Building

Newcastle upon Tyne, NE2 4AX

Email: lisa.newton@newcastle.ac.uk

Tel: 0191 208 83032

*For information about participating in research in general:*

Mr Scott Bonner

Policy and Information Officer

Research and Enterprise Services

2nd Floor Research Beehive

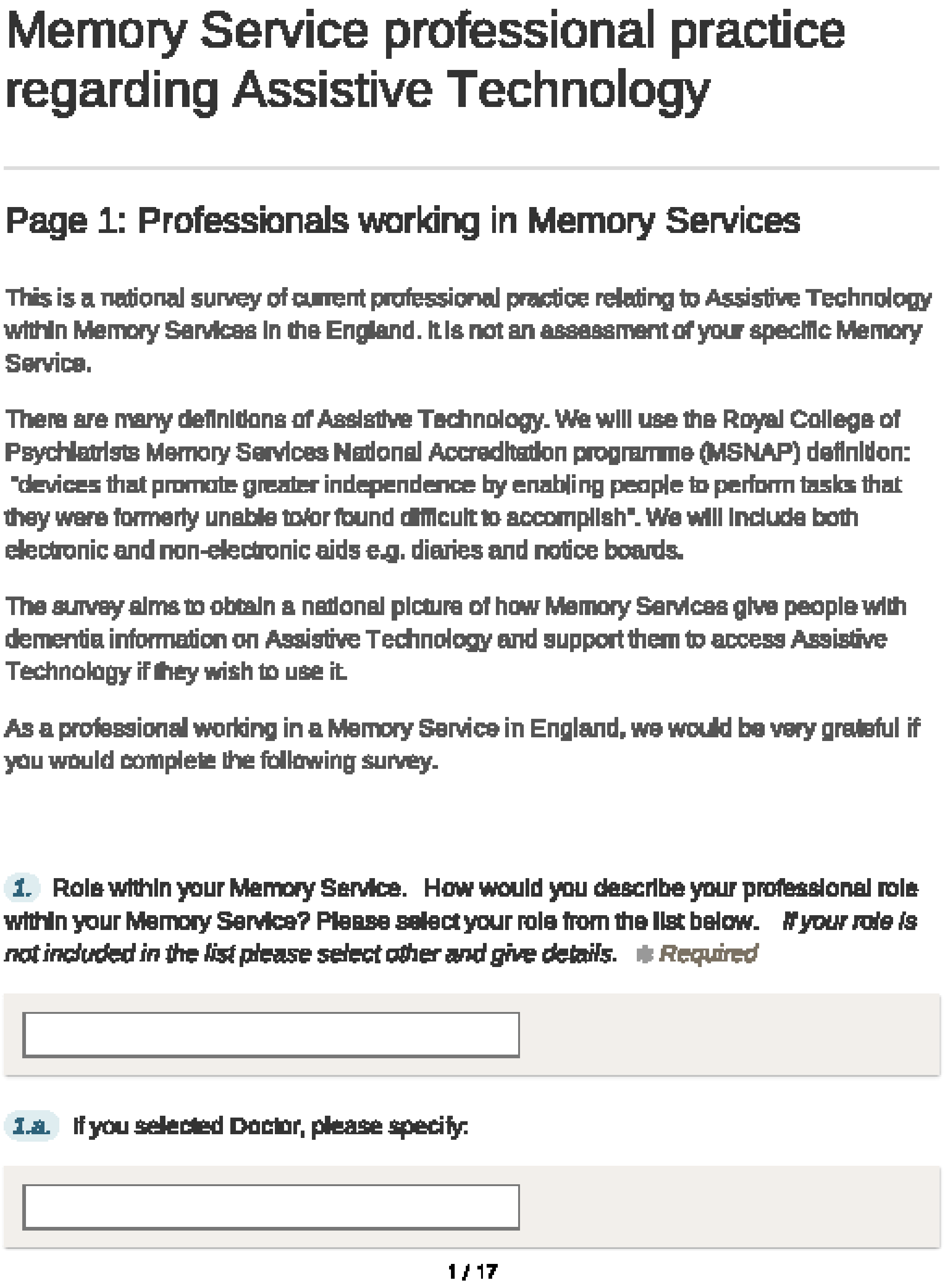
Newcastle University

Newcastle upon Tyne, NE1 7RU

Email: Scott.Bonner@newcastle.ac.uk

Tel: 0191 208 5499

**Appendix 3: Surveys**



# Memory Service professional practice regarding Assistive Technology

## Page 1: Professionals working in Memory Services

This is a national survey of current professional practice relating to Assistive Technology within Memory Services in the England. It is not an assessment of your specific Memory Service.

There are many definitions of Assistive Technology. We will use the Royal College of Psychiatrists Memory Services National Accreditation programme (MSNAP) definition: "devices that promote greater independence by enabling people to perform tasks that they were formerly unable to/or found difficult to accomplish". We will include both electronic and non-electronic aids e.g. diaries and notice boards.

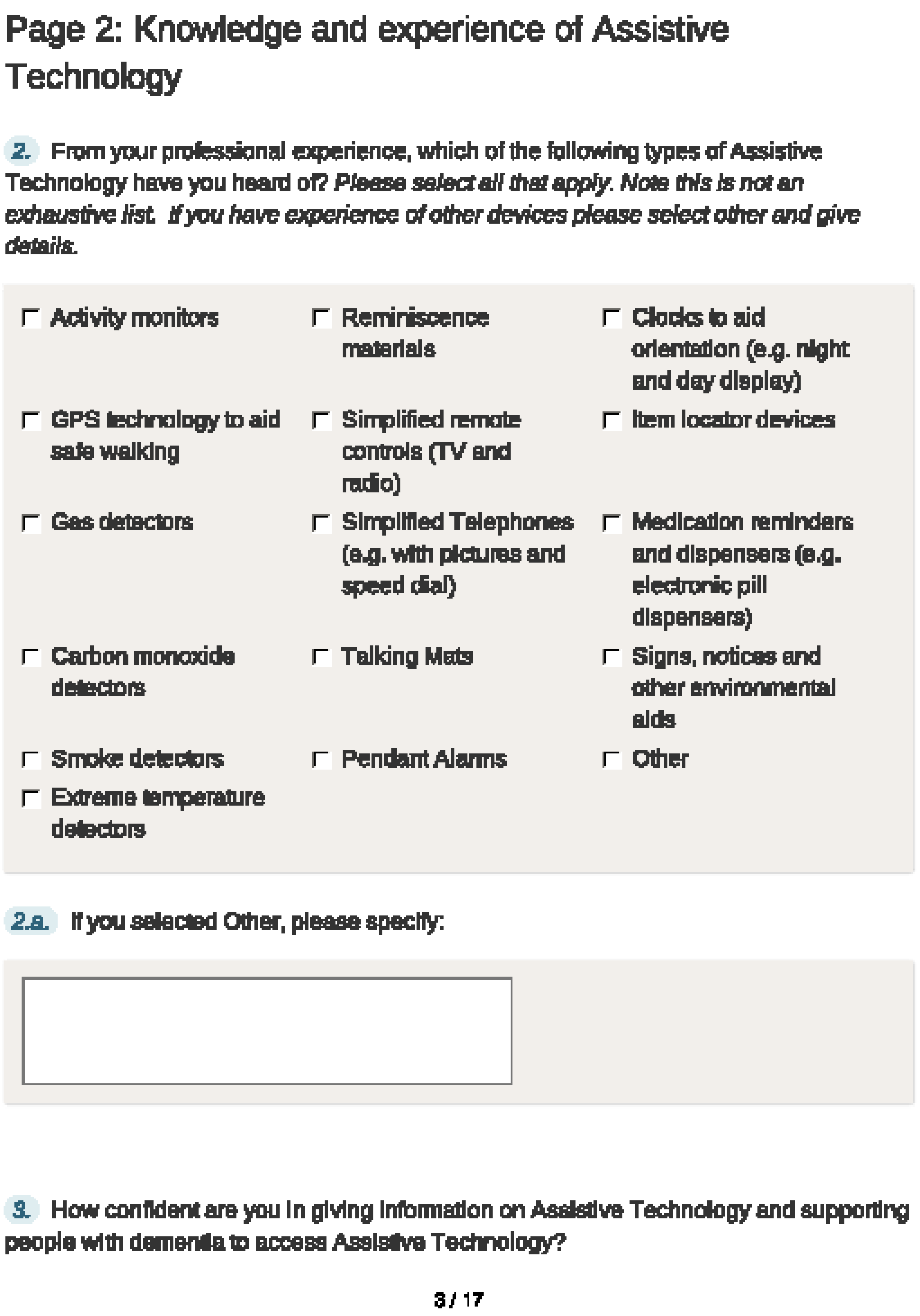
The survey aims to obtain a national picture of how Memory Services give people with dementia information on Assistive Technology and support them to access Assistive Technology if they wish to use it.

As a professional working in a Memory Service in England, we would be very grateful if you would complete the following survey.

**1.** Role within your Memory Service. How would you describe your professional role within your Memory Service? Please select your role from the list below. *If your role is not included in the list please select other and give details.* ✱ *Required*

**1.a.** If you selected Doctor, please specify:

**1.b.** If you selected Other, please specify:



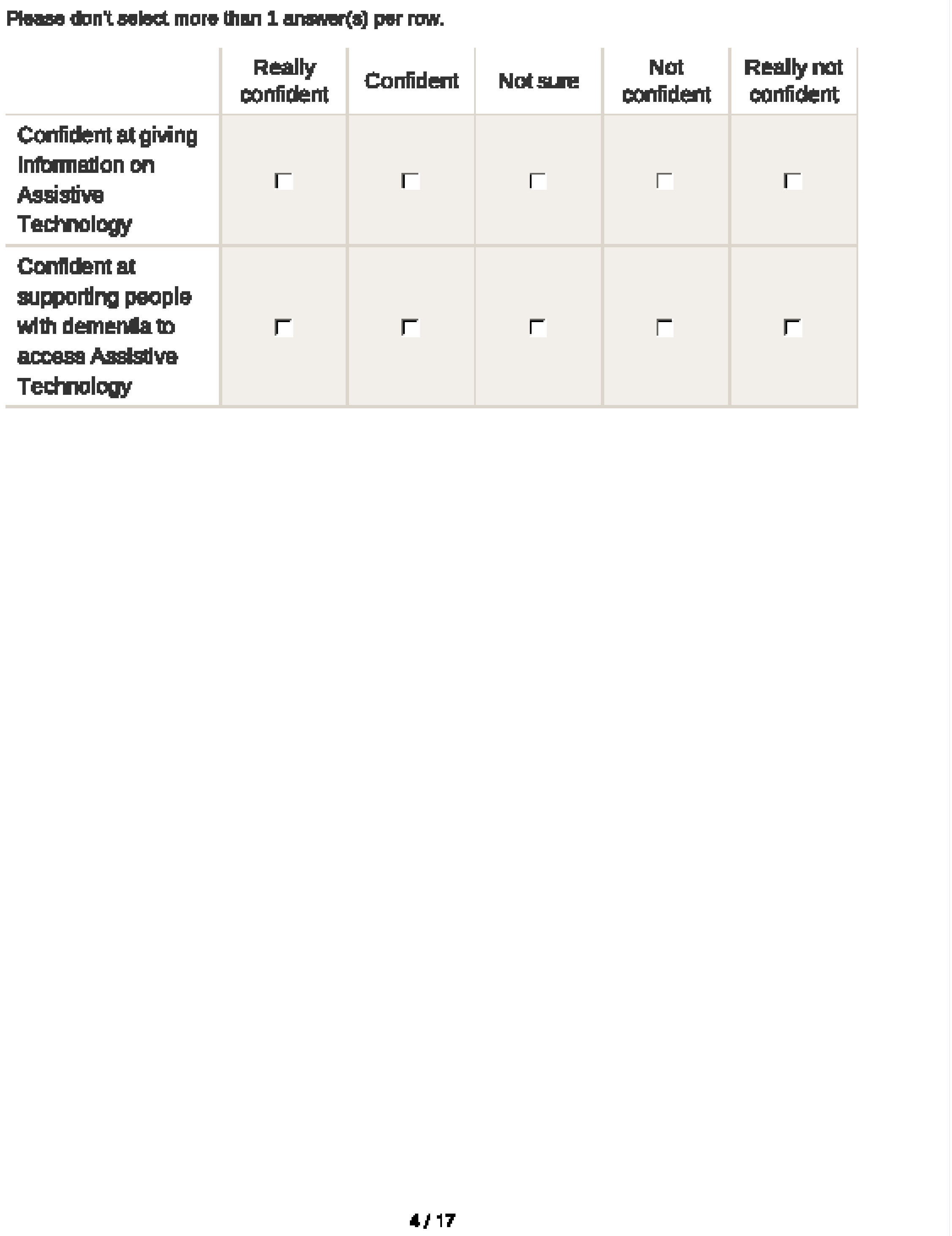
## Page 2: Knowledge and experience of Assistive Technology

**2.** From your professional experience, which of the following types of Assistive Technology have you heard of? *Please select all that apply. Note this is not an exhaustive list. If you have experience of other devices please select other and give details.*

☐ Activity monitors
☐ GPS technology to aid safe walking
☐ Gas detectors
☐ Carbon monoxide detectors
☐ Smoke detectors
☐ Extreme temperature detectors
☐ Reminiscence materials
☐ Simplified remote controls (TV and radio)
☐ Simplified Telephones (e.g. with pictures and speed dial)
☐ Talking Mats
☐ Pendant Alarms
☐ Clocks to aid orientation (e.g. night and day display)
☐ Item locator devices
☐ Medication reminders and dispensers (e.g. electronic pill dispensers)
☐ Signs, notices and other environmental aids
☐ Other

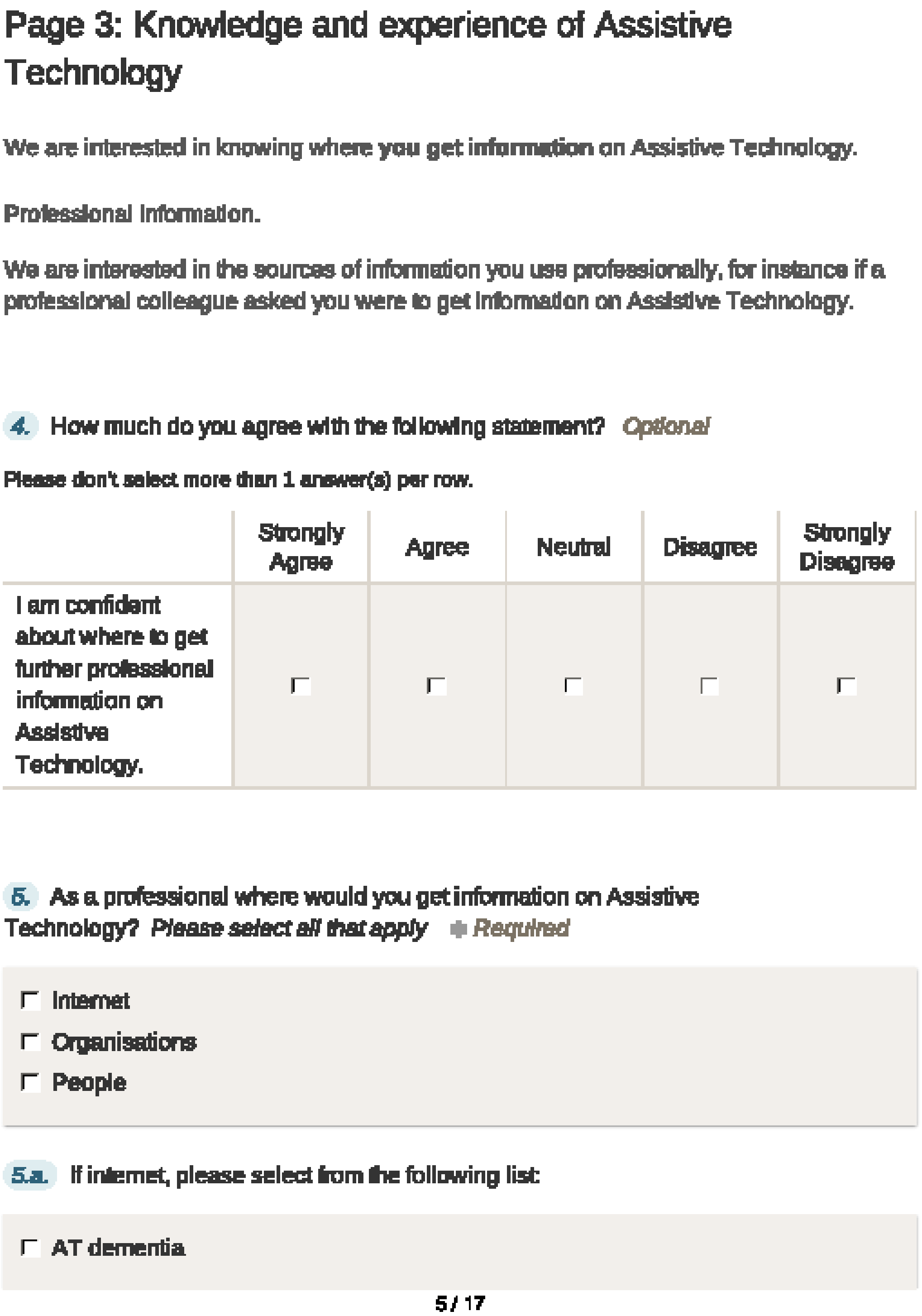
**2.a.** If you selected Other, please specify:

**3.** How confident are you in giving information on Assistive Technology and supporting people with dementia to access Assistive Technology?



Please don't select more than 1 answer(s) per row.

| | Really confident | Confident | Not sure | Not confident | Really not confident |
|---|---|---|---|---|---|
| Confident at giving information on Assistive Technology | ☐ | ☐ | ☐ | ☐ | ☐ |
| Confident at supporting people with dementia to access Assistive Technology | ☐ | ☐ | ☐ | ☐ | ☐ |



# Page 3: Knowledge and experience of Assistive Technology

We are interested in knowing where you get information on Assistive Technology.

Professional Information.

We are interested in the sources of information you use professionally, for instance if a professional colleague asked you were to get information on Assistive Technology.

**4.** How much do you agree with the following statement? *Optional*

**Please don't select more than 1 answer(s) per row.**

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| I am confident about where to get further professional information on Assistive Technology. | ☐ | ☐ | ☐ | ☐ | ☐ |

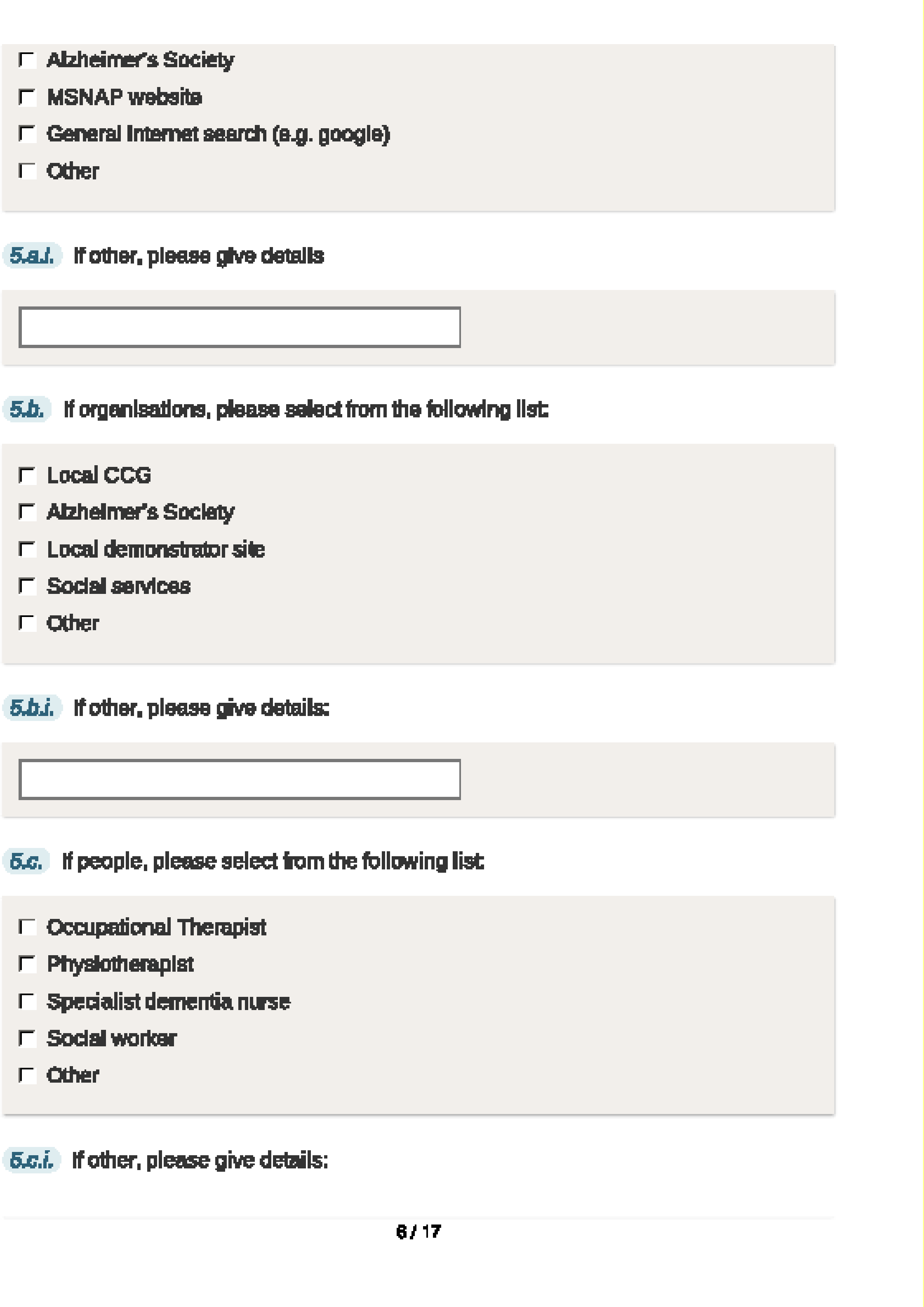
**5.** As a professional where would you get information on Assistive Technology? *Please select all that apply* ✚ *Required*

☐ Internet
☐ Organisations
☐ People

**5.a.** If internet, please select from the following list:

☐ AT dementia

**5 / 17**



☐ Alzheimer's Society
☐ MSNAP website
☐ General Internet search (e.g. google)
☐ Other

**5.a.i.** If other, please give details

**5.b.** If organisations, please select from the following list:

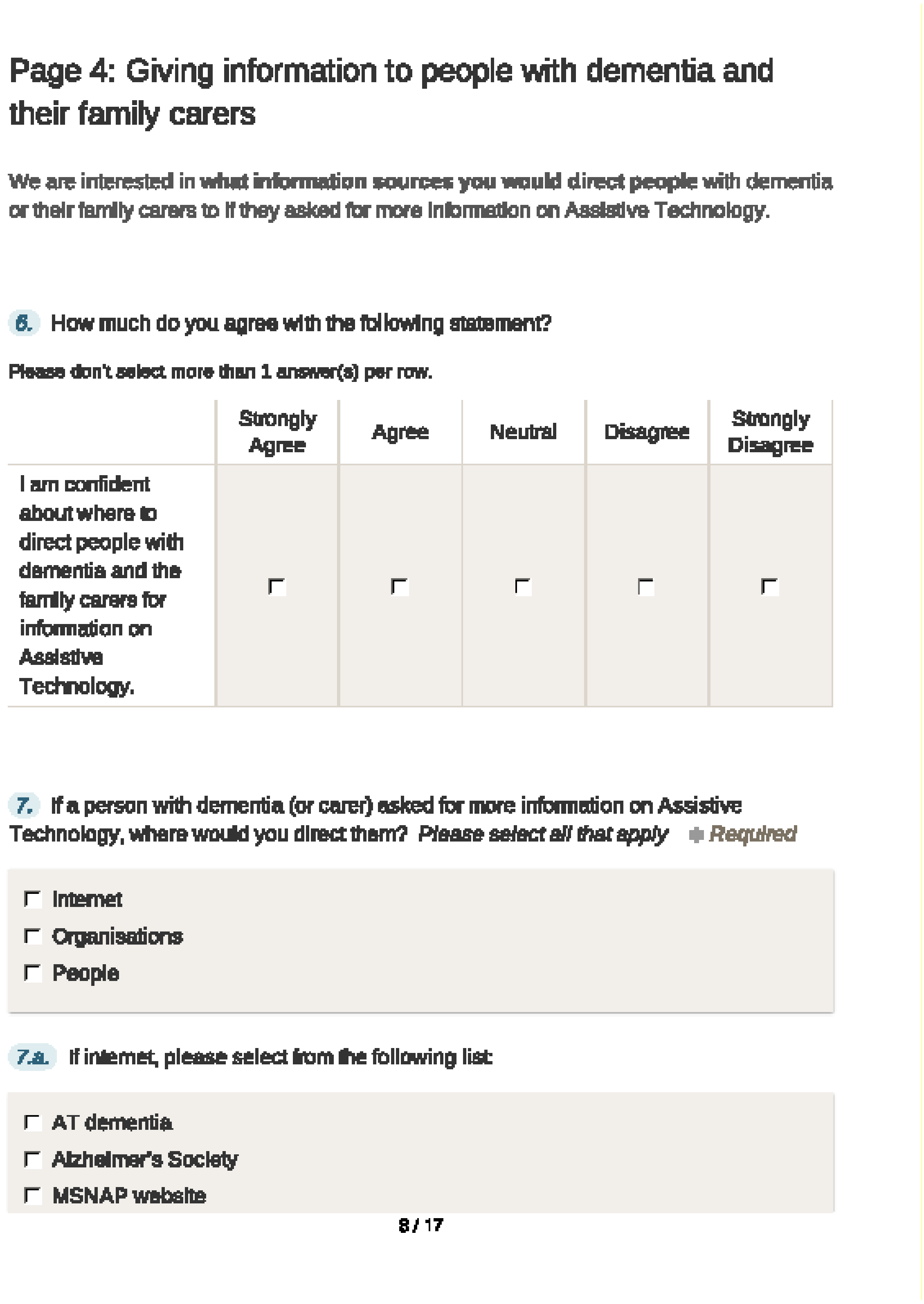
☐ Local CCG
☐ Alzheimer's Society
☐ Local demonstrator site
☐ Social services
☐ Other

**5.b.i.** If other, please give details:

**5.c.** If people, please select from the following list:

☐ Occupational Therapist
☐ Physiotherapist
☐ Specialist dementia nurse
☐ Social worker
☐ Other

**5.c.i.** If other, please give details:



## Page 4: Giving information to people with dementia and their family carers

We are interested in what information sources you would direct people with dementia or their family carers to if they asked for more information on Assistive Technology.

**6.** How much do you agree with the following statement?

Please don't select more than 1 answer(s) per row.

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| I am confident about where to direct people with dementia and the family carers for information on Assistive Technology. | ☐ | ☐ | ☐ | ☐ | ☐ |

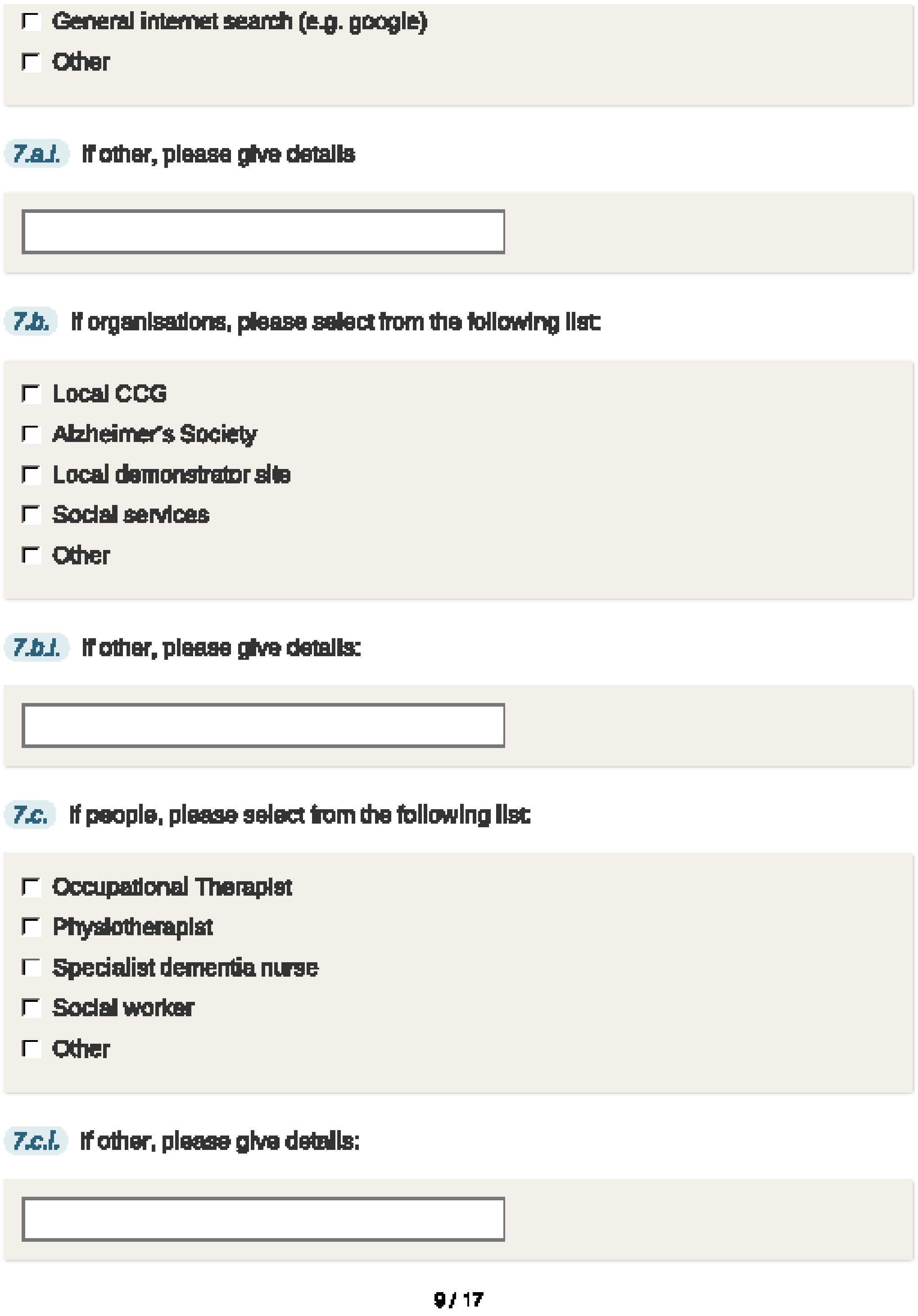
**7.** If a person with dementia (or carer) asked for more information on Assistive Technology, where would you direct them? *Please select all that apply* *Required*

- ☐ Internet
- ☐ Organisations
- ☐ People

**7.a.** If internet, please select from the following list:

- ☐ AT dementia
- ☐ Alzheimer's Society
- ☐ MSNAP website

8 / 17



☐ General internet search (e.g. google)
☐ Other

7.a.i. If other, please give details

7.b. If organisations, please select from the following list:

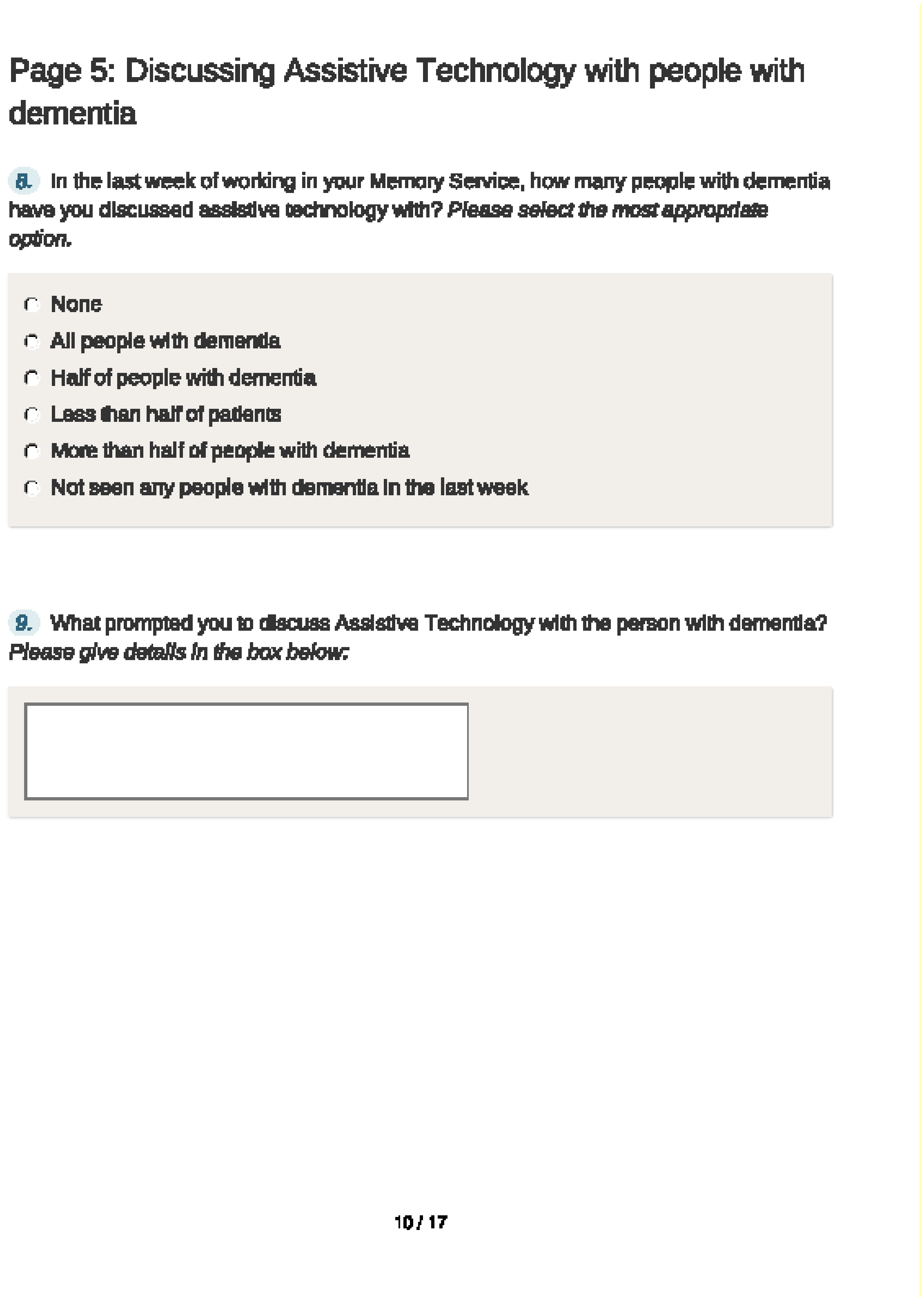
☐ Local CCG
☐ Alzheimer's Society
☐ Local demonstrator site
☐ Social services
☐ Other

7.b.i. If other, please give details:

7.c. If people, please select from the following list:

☐ Occupational Therapist
☐ Physiotherapist
☐ Specialist dementia nurse
☐ Social worker
☐ Other

7.c.i. If other, please give details:

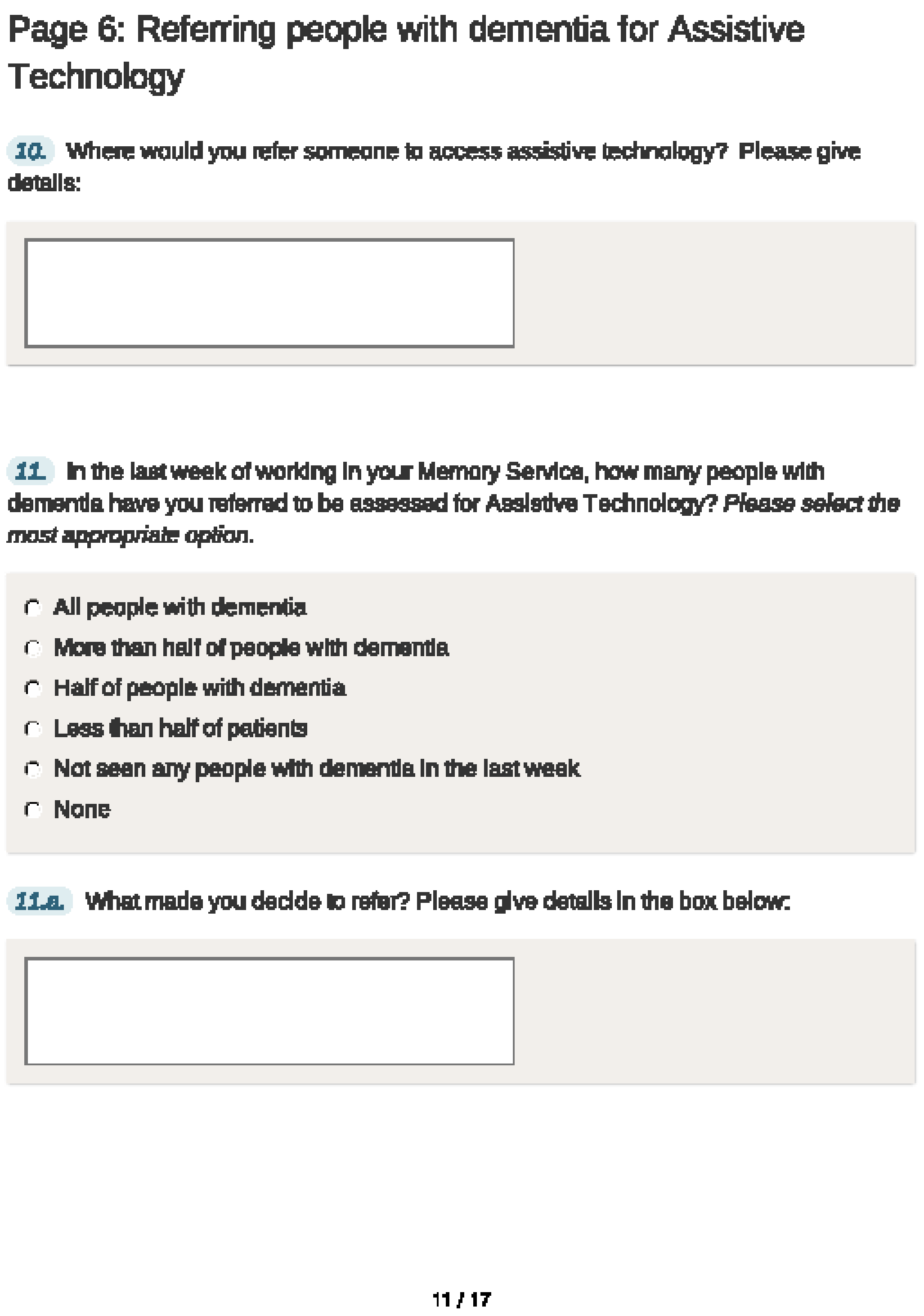


## Page 5: Discussing Assistive Technology with people with dementia

**8.** In the last week of working in your Memory Service, how many people with dementia have you discussed assistive technology with? *Please select the most appropriate option.*

○ None
○ All people with dementia
○ Half of people with dementia
○ Less than half of patients
○ More than half of people with dementia
○ Not seen any people with dementia in the last week

**9.** What prompted you to discuss Assistive Technology with the person with dementia? *Please give details in the box below:*



## Page 6: Referring people with dementia for Assistive Technology

**10.** **Where would you refer someone to access assistive technology? Please give details:**

**11.** **In the last week of working in your Memory Service, how many people with dementia have you referred to be assessed for Assistive Technology?** ***Please select the most appropriate option.***

- ○ All people with dementia
- ○ More than half of people with dementia
- ○ Half of people with dementia
- ○ Less than half of patients
- ○ Not seen any people with dementia in the last week
- ○ None

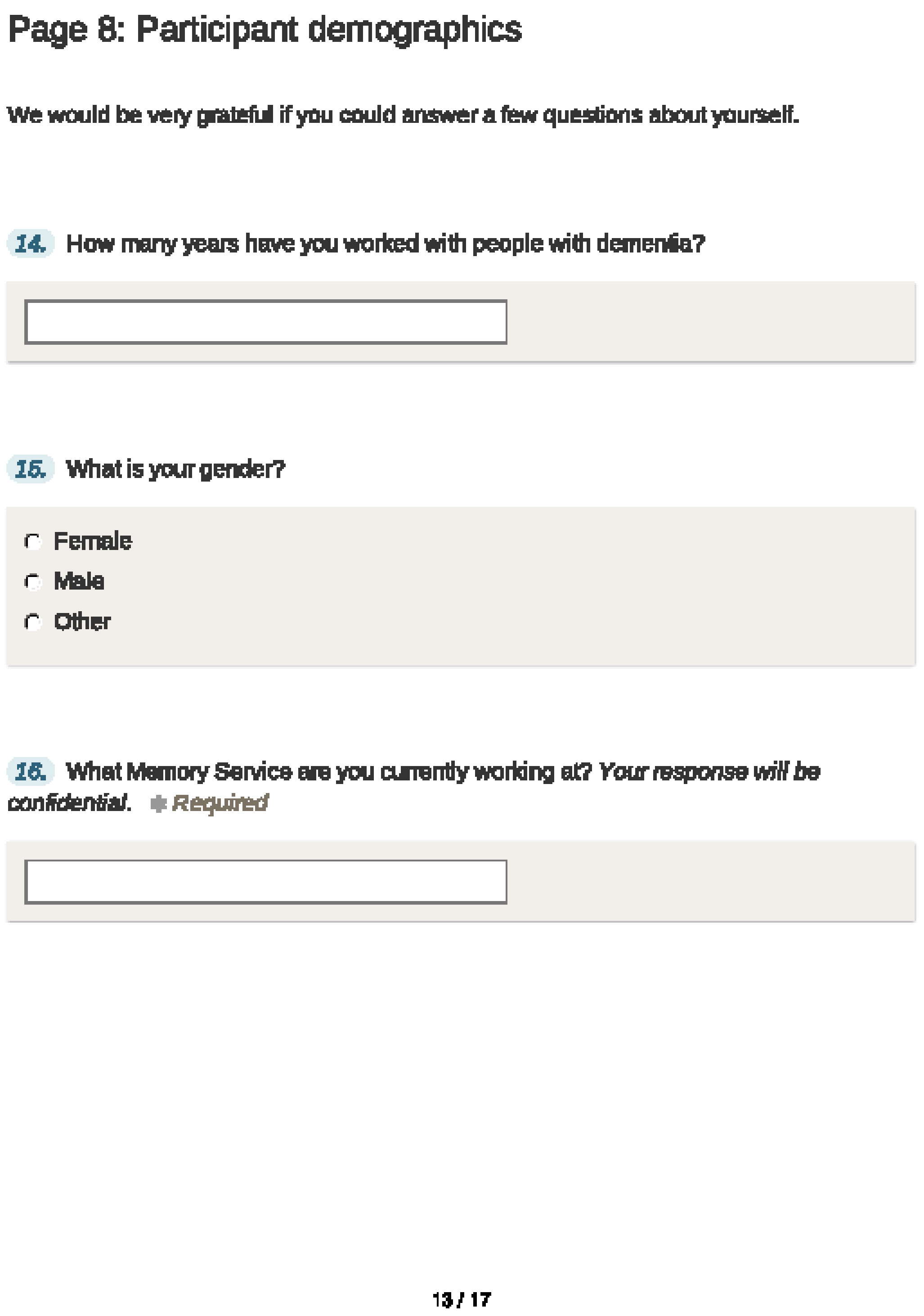
**11.a.** **What made you decide to refer? Please give details in the box below:**

11 / 17

## Page 7: Further information

**12.** We are really interested in finding out if you have access to any innovative resources to help give information and refer people with dementia to access assistive technology. This may be training materials, websites or local initiatives which help you give people with dementia information or access assistive technology. Please give information in the box below:

**13.** We are really interested in your view on helping people with dementia obtain information on Assistive Technology or to support them access Assistive Technology. If you have any further comments or suggestions please use the free text box below.



## Page 8: Participant demographics

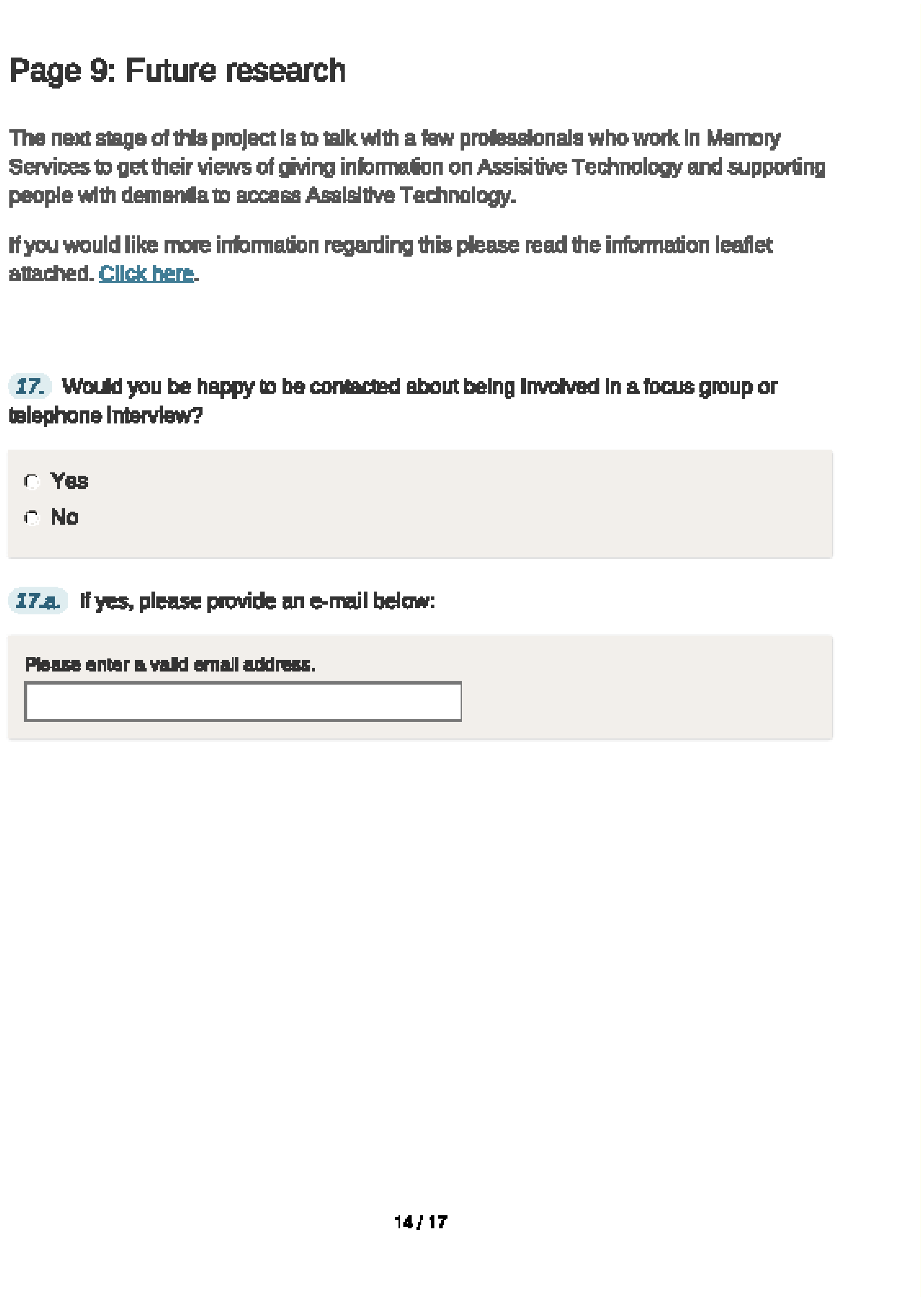
**We would be very grateful if you could answer a few questions about yourself.**

**14.** How many years have you worked with people with dementia?

**15.** What is your gender?

○ Female
○ Male
○ Other

**16.** What Memory Service are you currently working at? *Your response will be confidential.* *Required*



## Page 9: Future research

The next stage of this project is to talk with a few professionals who work in Memory Services to get their views of giving information on Assistive Technology and supporting people with dementia to access Assistive Technology.

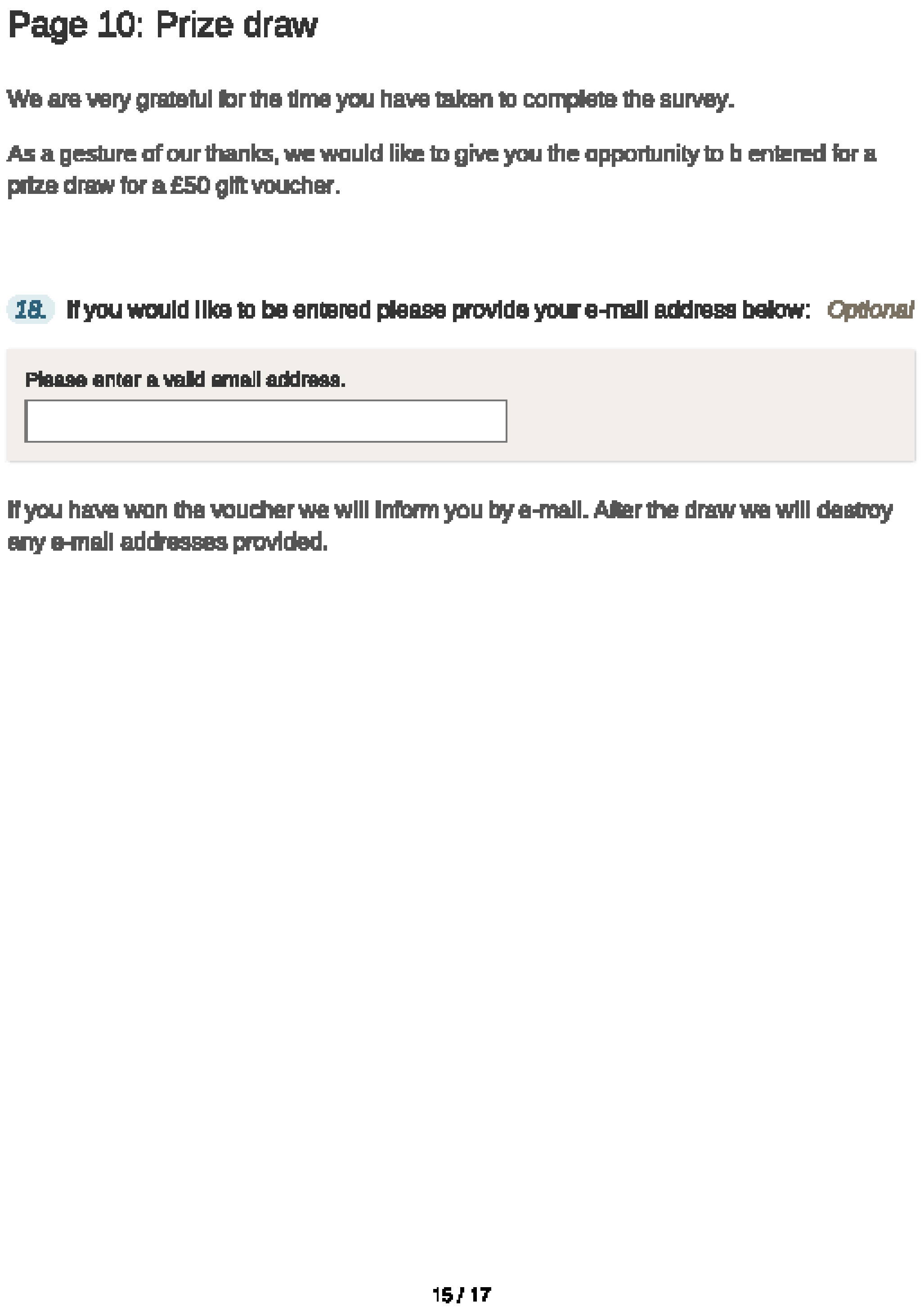
If you would like more information regarding this please read the information leaflet attached. Click here.

**17.** Would you be happy to be contacted about being involved in a focus group or telephone interview?

○ Yes
○ No

**17.a.** If yes, please provide an e-mail below:

Please enter a valid email address.



## Page 10: Prize draw

We are very grateful for the time you have taken to complete the survey.

As a gesture of our thanks, we would like to give you the opportunity to b entered for a prize draw for a £50 gift voucher.

18. If you would like to be entered please provide your e-mail address below: *Optional*

Please enter a valid email address.

If you have won the voucher we will inform you by e-mail. After the draw we will destroy any e-mail addresses provided.

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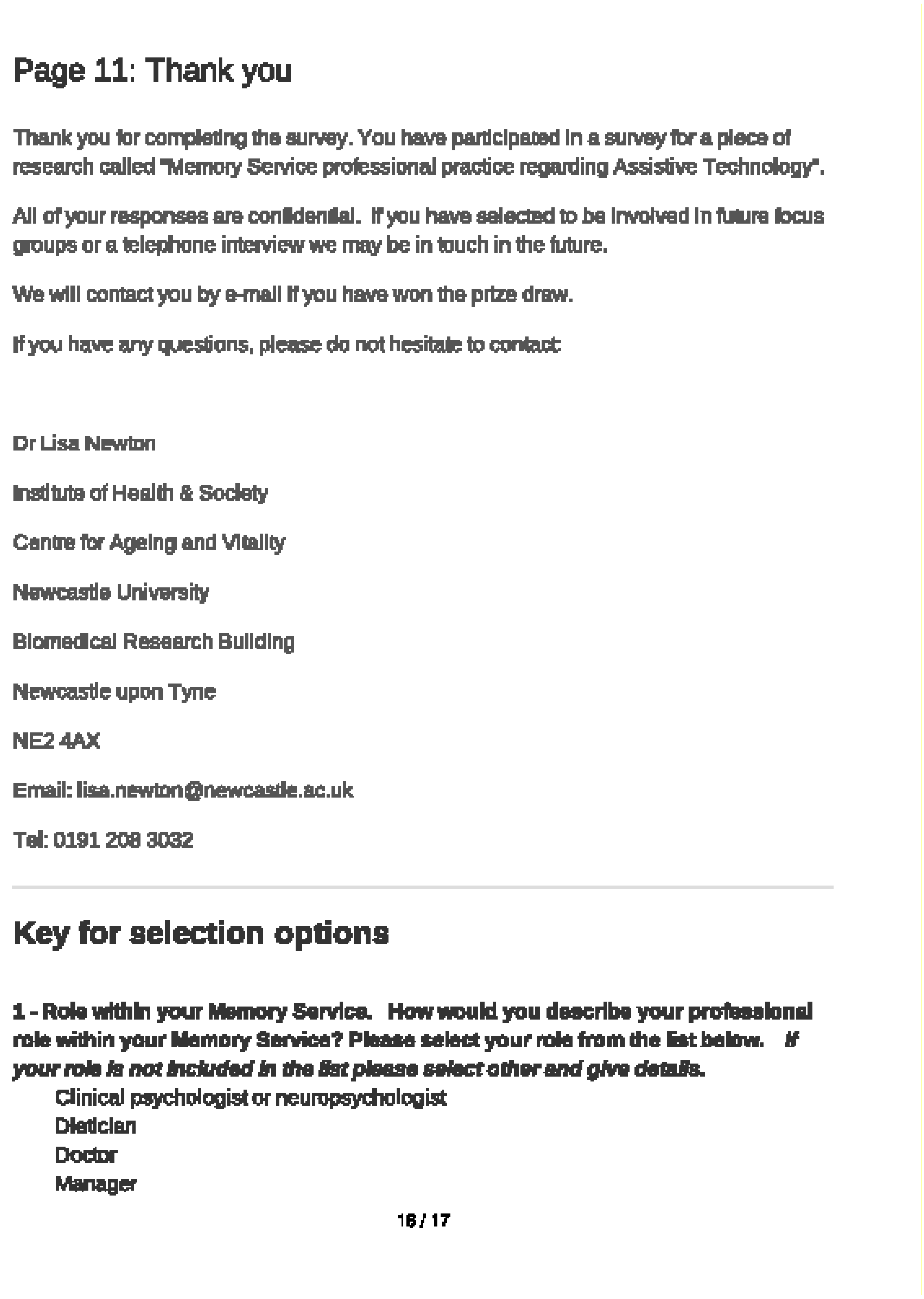

## Page 11: Thank you

Thank you for completing the survey. You have participated in a survey for a piece of research called "Memory Service professional practice regarding Assistive Technology".

All of your responses are confidential. If you have selected to be involved in future focus groups or a telephone interview we may be in touch in the future.

We will contact you by e-mail if you have won the prize draw.

If you have any questions, please do not hesitate to contact:

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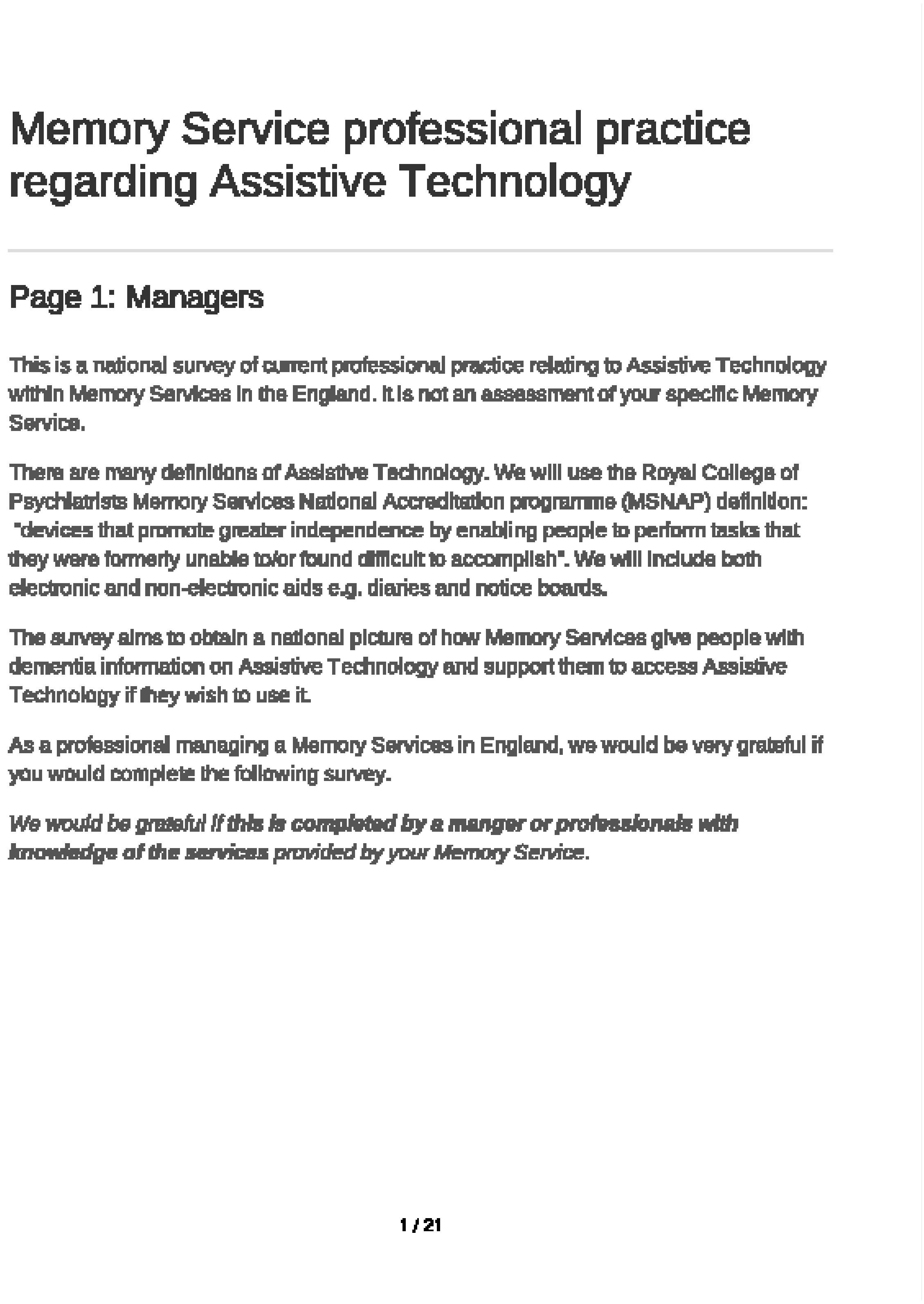
## Key for selection options

**1 - Role within your Memory Service. How would you describe your professional role within your Memory Service? Please select your role from the list below.** ***If your role is not included in the list please select other and give details.***

Clinical psychologist or neuropsychologist
Dietician
Doctor
Manager

Mental health Nurse
Occupational Therapist
Physiotherapist
Speech and Language Therapist
Social Worker
Other



# Memory Service professional practice regarding Assistive Technology

## Page 1: Managers

This is a national survey of current professional practice relating to Assistive Technology within Memory Services in the England. It is not an assessment of your specific Memory Service.

There are many definitions of Assistive Technology. We will use the Royal College of Psychiatrists Memory Services National Accreditation programme (MSNAP) definition: "devices that promote greater independence by enabling people to perform tasks that they were formerly unable to/or found difficult to accomplish". We will include both electronic and non-electronic aids e.g. diaries and notice boards.

The survey aims to obtain a national picture of how Memory Services give people with dementia information on Assistive Technology and support them to access Assistive Technology if they wish to use it.

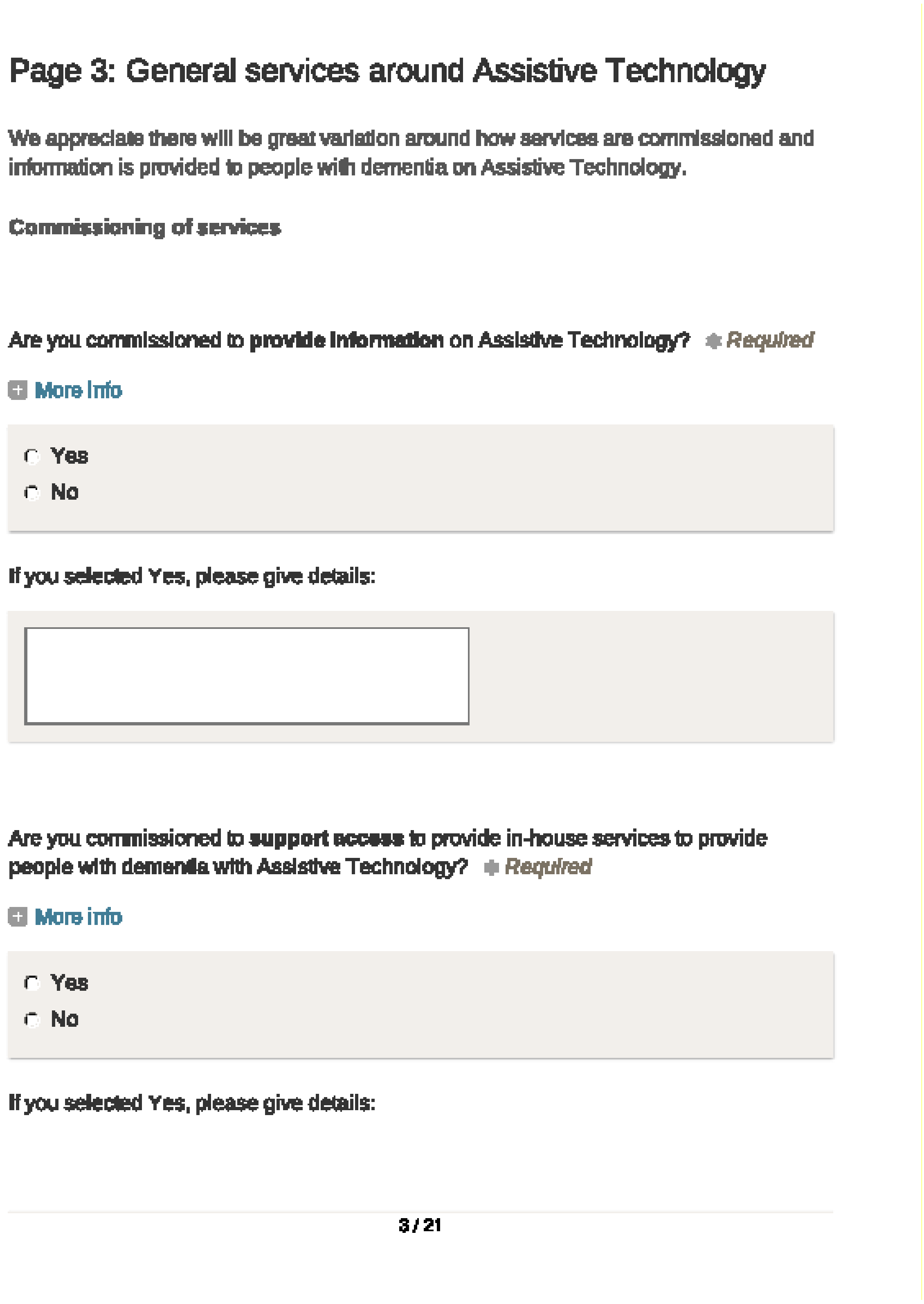
As a professional managing a Memory Services in England, we would be very grateful if you would complete the following survey.

*We would be grateful if this is completed by a manger or professionals with knowledge of the services provided by your Memory Service.*

## Page 2: Management role

**How would you describe your professional role within your Memory Service? *Please select the most appropriate response below.*** ** Required*

**If you selected Other, please specify:**



# Page 3: General services around Assistive Technology

We appreciate there will be great variation around how services are commissioned and information is provided to people with dementia on Assistive Technology.

**Commissioning of services**

Are you commissioned to **provide information** on Assistive Technology? ✱ *Required*

⊞ More info

○ Yes
○ No

If you selected Yes, please give details:

Are you commissioned to **support access** to provide in-house services to provide people with dementia with Assistive Technology? ✱ *Required*

⊞ More info

○ Yes
○ No

If you selected Yes, please give details:

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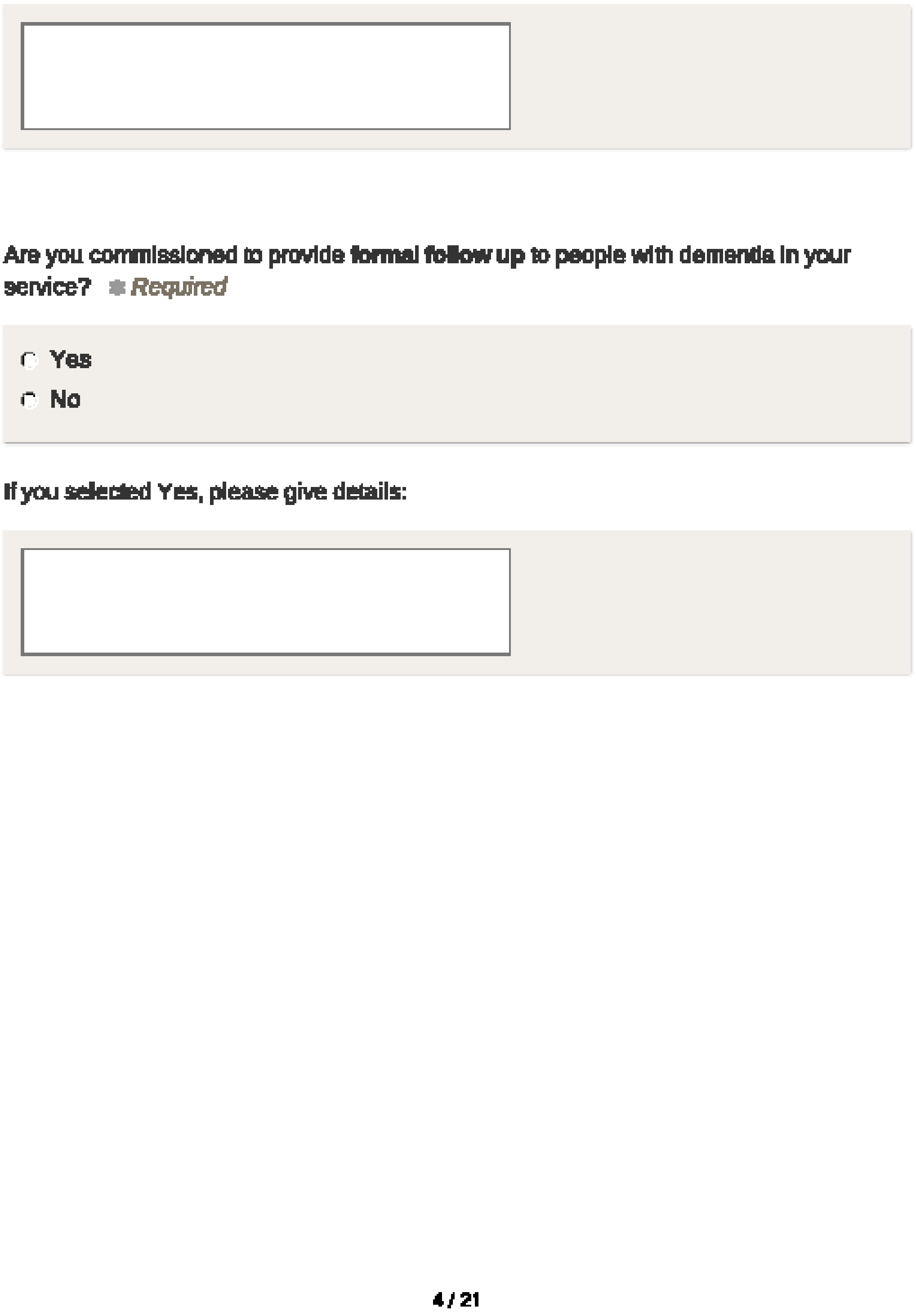

Are you commissioned to provide **formal follow up** to people with dementia in your service? ✱ *Required*

○ Yes
○ No

If you selected Yes, please give details:

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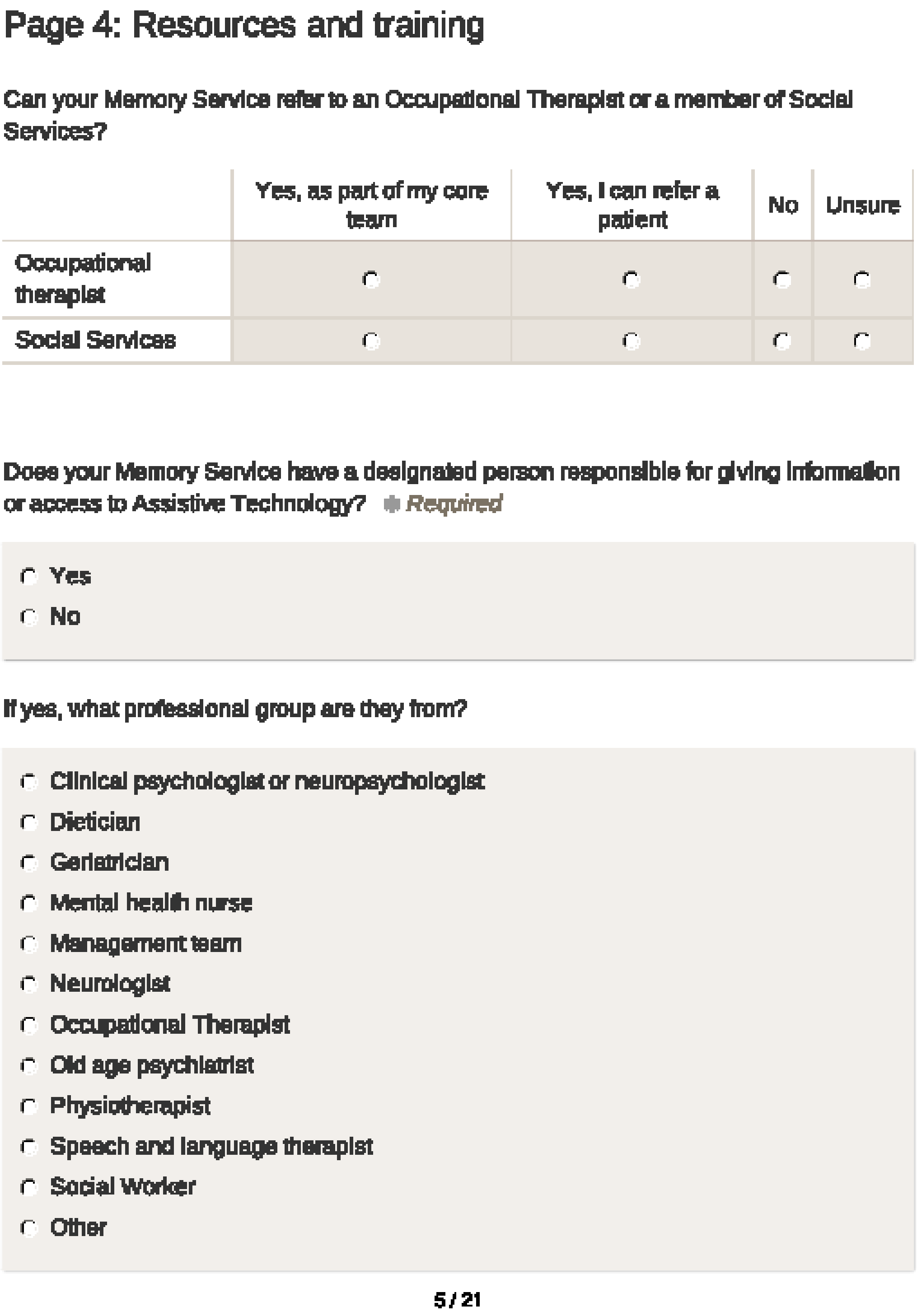

## Page 4: Resources and training

**Can your Memory Service refer to an Occupational Therapist or a member of Social Services?**

| | Yes, as part of my core team | Yes, I can refer a patient | No | Unsure |
|---|---|---|---|---|
| Occupational therapist | ○ | ○ | ○ | ○ |
| Social Services | ○ | ○ | ○ | ○ |

**Does your Memory Service have a designated person responsible for giving information or access to Assistive Technology?** *✱ Required*

○ Yes
○ No

**If yes, what professional group are they from?**

○ Clinical psychologist or neuropsychologist
○ Dietician
○ Geriatrician
○ Mental health nurse
○ Management team
○ Neurologist
○ Occupational Therapist
○ Old age psychiatrist
○ Physiotherapist
○ Speech and language therapist
○ Social Worker
○ Other

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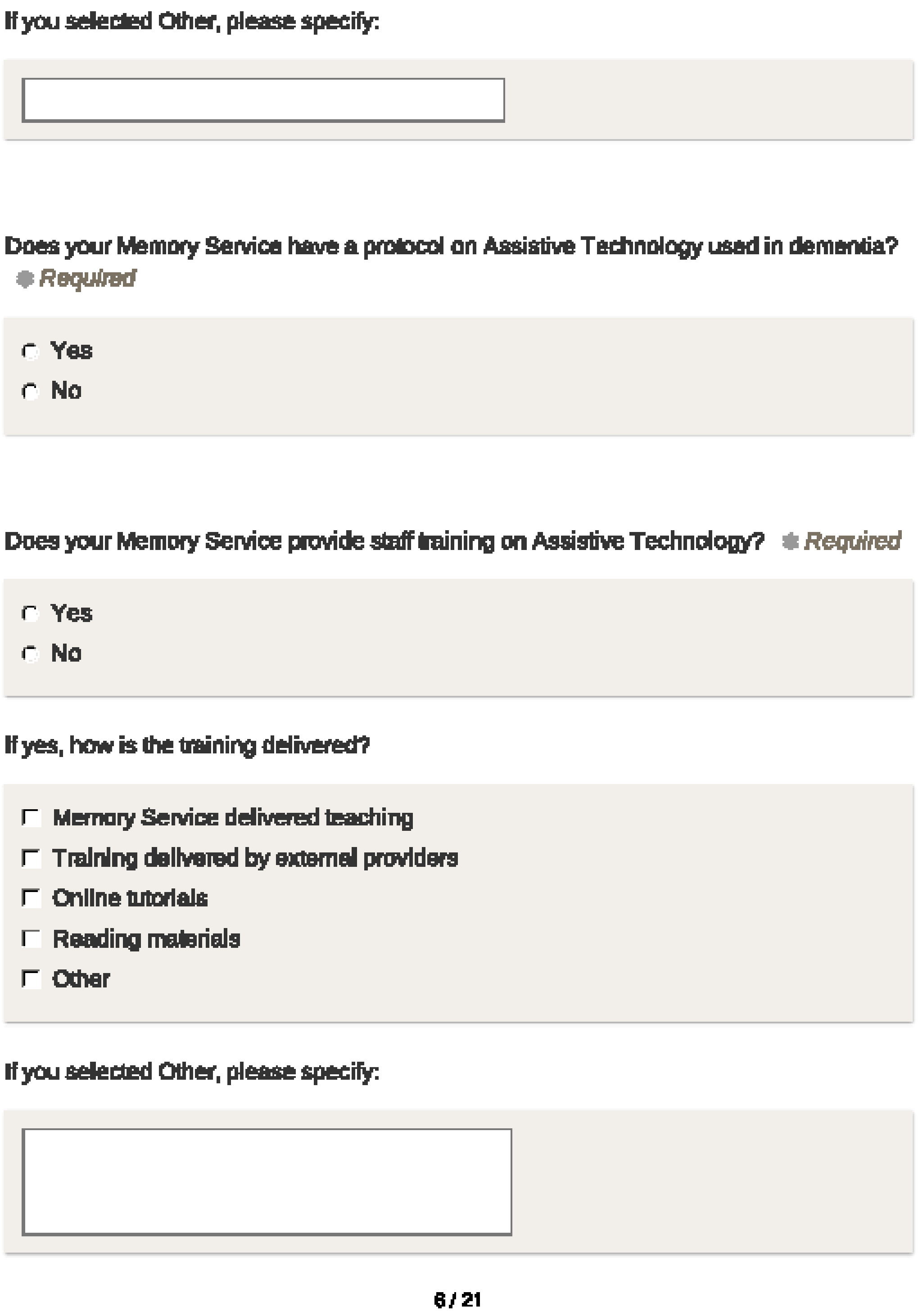

If you selected Other, please specify:

Does your Memory Service have a protocol on Assistive Technology used in dementia? ✱ *Required*

○ Yes
○ No

Does your Memory Service provide staff training on Assistive Technology? ✱ *Required*

○ Yes
○ No

If yes, how is the training delivered?

☐ Memory Service delivered teaching
☐ Training delivered by external providers
☐ Online tutorials
☐ Reading materials
☐ Other

If you selected Other, please specify:

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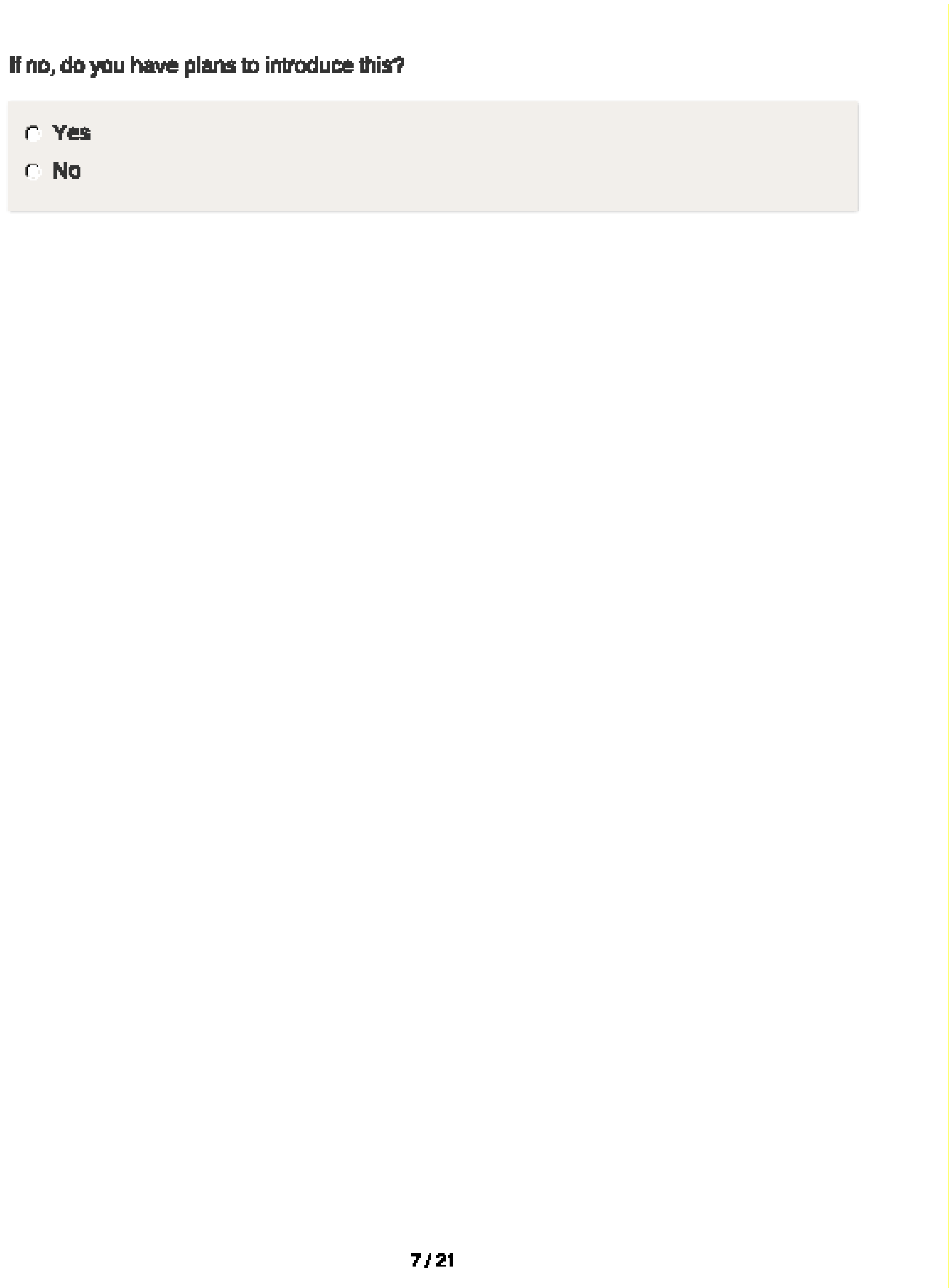
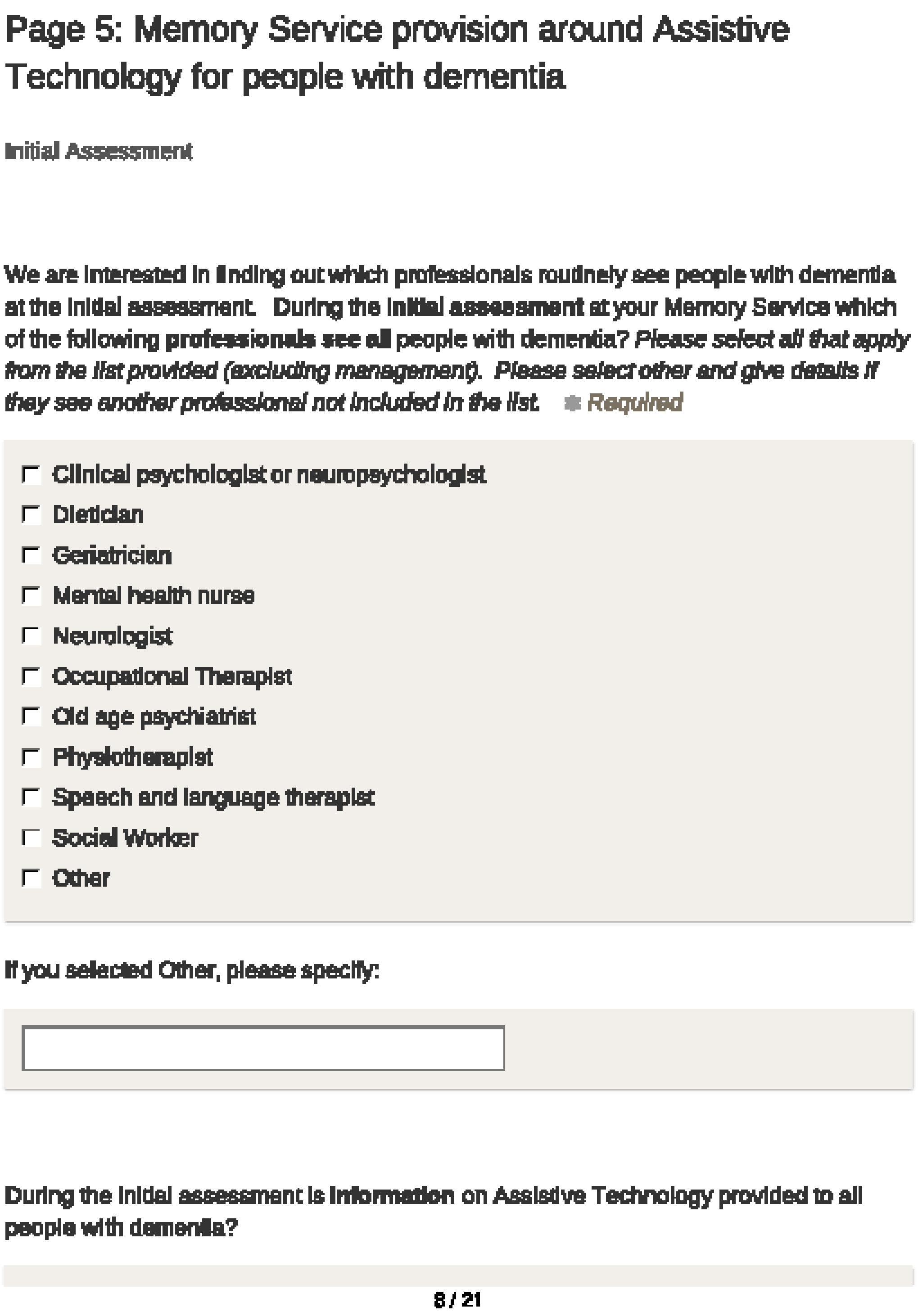


**If no, do you have plans to introduce this?**

○ Yes
○ No



# Page 5: Memory Service provision around Assistive Technology for people with dementia

Initial Assessment

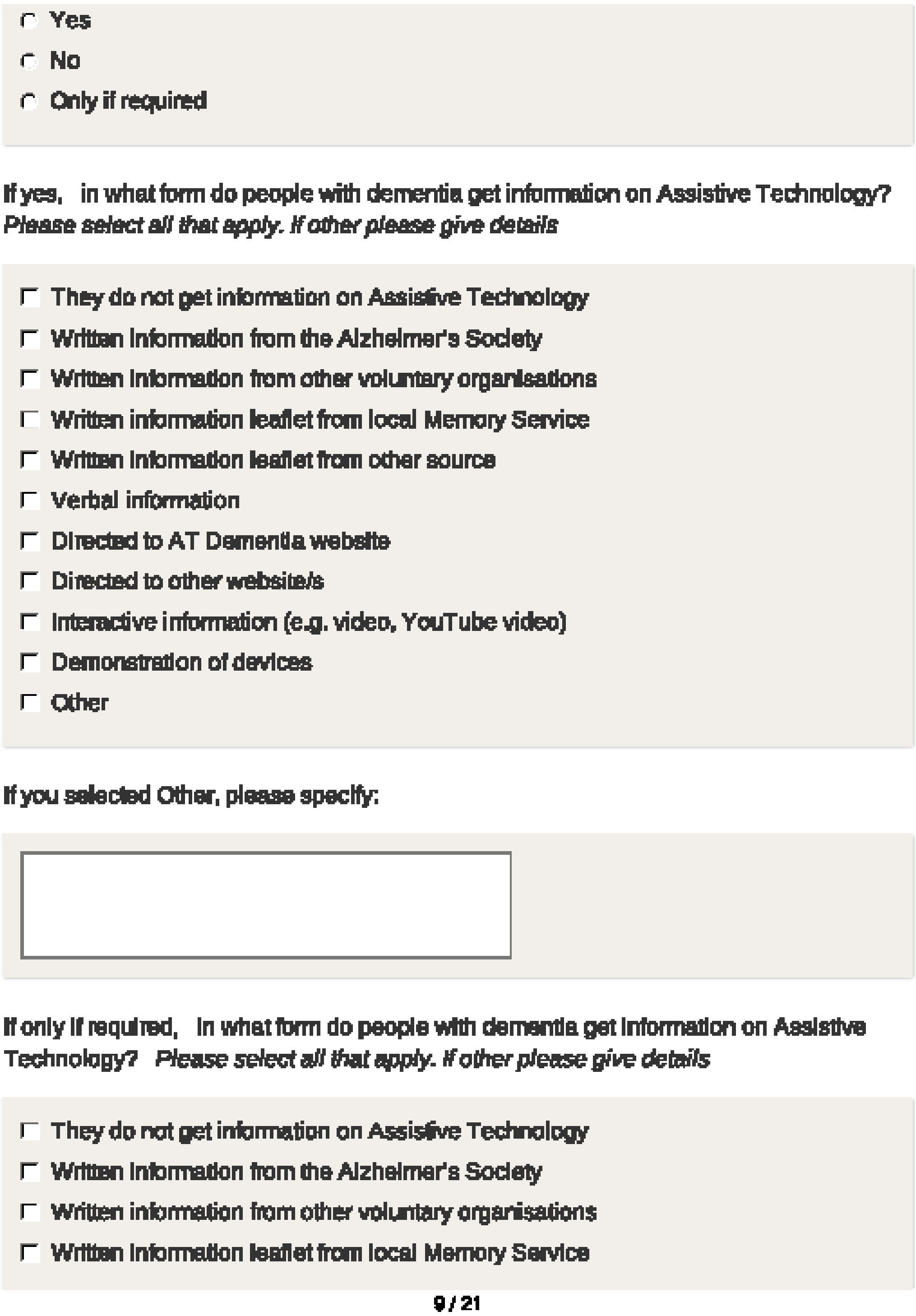
We are interested in finding out which professionals routinely see people with dementia at the initial assessment. During the **initial assessment** at your Memory Service which of the following **professionals see all** people with dementia? *Please select all that apply from the list provided (excluding management). Please select other and give details if they see another professional not included in the list.* ✱ *Required*

☐ Clinical psychologist or neuropsychologist
☐ Dietician
☐ Geriatrician
☐ Mental health nurse
☐ Neurologist
☐ Occupational Therapist
☐ Old age psychiatrist
☐ Physiotherapist
☐ Speech and language therapist
☐ Social Worker
☐ Other

If you selected Other, please specify:

☐

During the initial assessment is **information** on Assistive Technology provided to all people with dementia?



○ Yes

○ No

○ Only if required

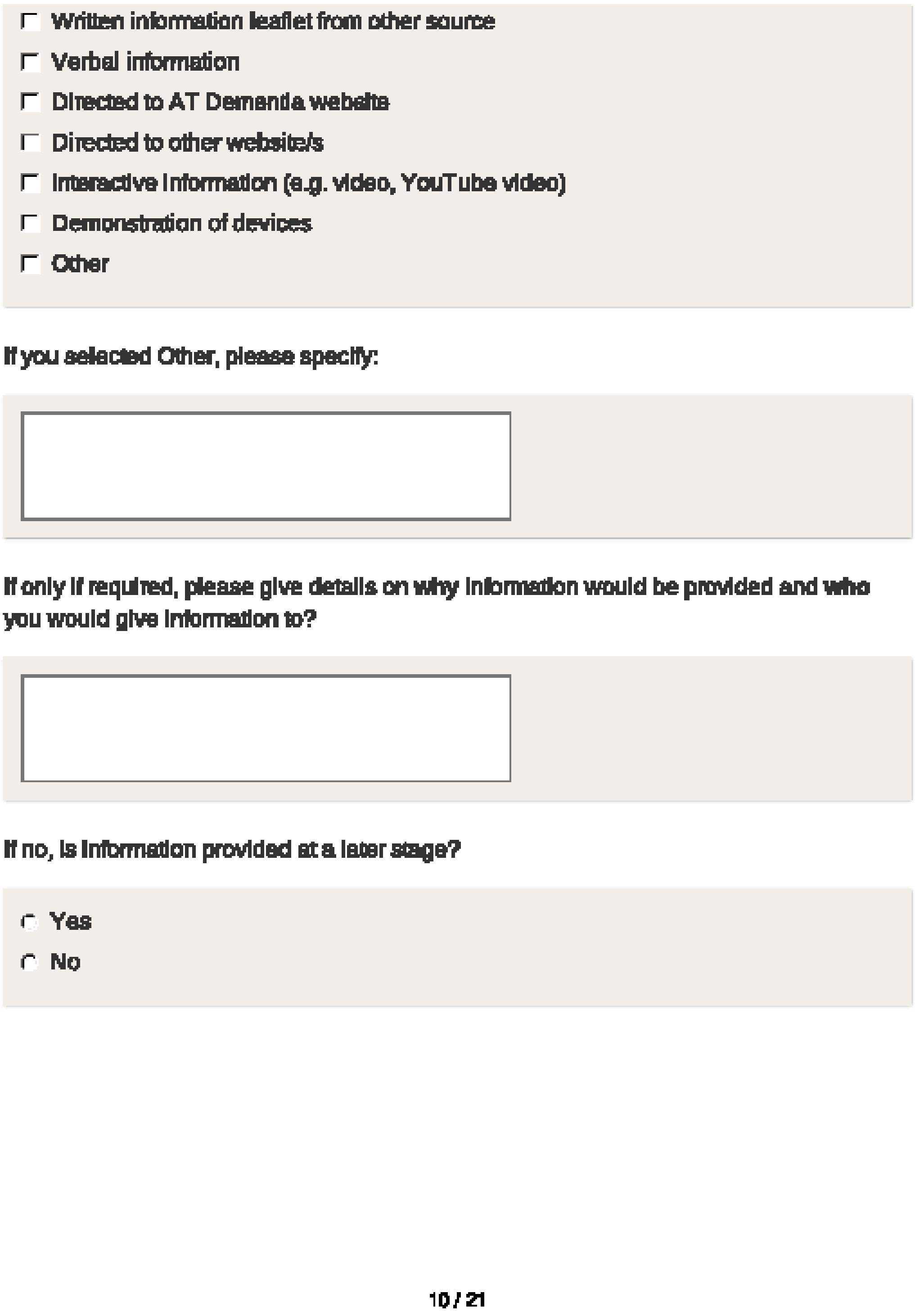
**If yes, in what form do people with dementia get information on Assistive Technology?**
*Please select all that apply. If other please give details*

☐ They do not get information on Assistive Technology
☐ Written information from the Alzheimer's Society
☐ Written information from other voluntary organisations
☐ Written information leaflet from local Memory Service
☐ Written information leaflet from other source
☐ Verbal information
☐ Directed to AT Dementia website
☐ Directed to other website/s
☐ Interactive information (e.g. video, YouTube video)
☐ Demonstration of devices
☐ Other

**If you selected Other, please specify:**

**If only if required, in what form do people with dementia get information on Assistive Technology?** *Please select all that apply. If other please give details*

☐ They do not get information on Assistive Technology
☐ Written information from the Alzheimer's Society
☐ Written information from other voluntary organisations
☐ Written information leaflet from local Memory Service



☐ Written information leaflet from other source
☐ Verbal information
☐ Directed to AT Dementia website
☐ Directed to other website/s
☐ Interactive information (e.g. video, YouTube video)
☐ Demonstration of devices
☐ Other

If you selected Other, please specify:

If only if required, please give details on why information would be provided and who you would give information to?

If no, is information provided at a later stage?

○ Yes
○ No

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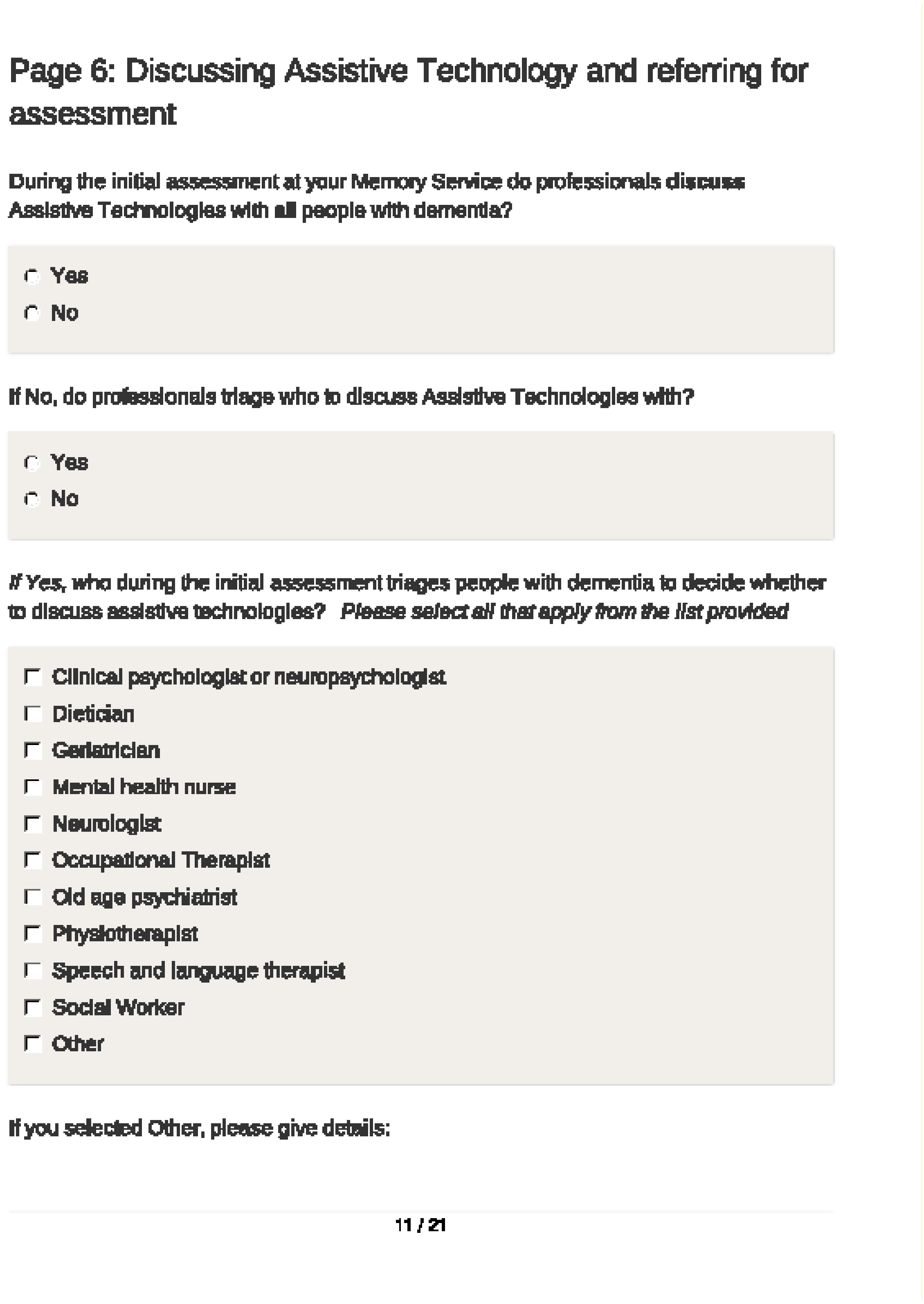

## Page 6: Discussing Assistive Technology and referring for assessment

**During the initial assessment at your Memory Service do professionals discuss Assistive Technologies with all people with dementia?**

○ Yes
○ No

**If No, do professionals triage who to discuss Assistive Technologies with?**

○ Yes
○ No

***If Yes*, who during the initial assessment triages people with dementia to decide whether to discuss assistive technologies?** ***Please select all that apply from the list provided***

☐ Clinical psychologist or neuropsychologist
☐ Dietician
☐ Geriatrician
☐ Mental health nurse
☐ Neurologist
☐ Occupational Therapist
☐ Old age psychiatrist
☐ Physiotherapist
☐ Speech and language therapist
☐ Social Worker
☐ Other

**If you selected Other, please give details:**

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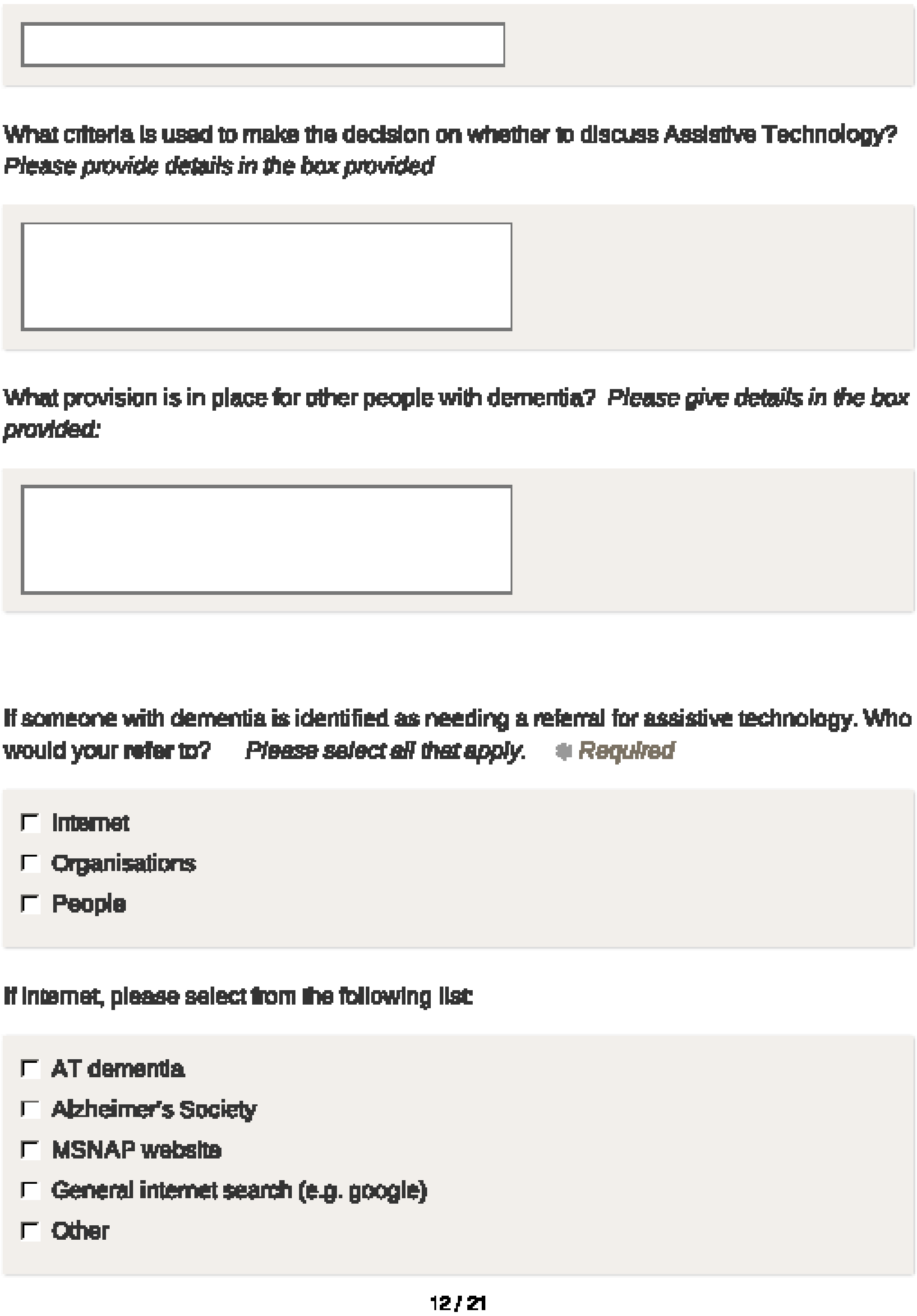

What criteria is used to make the decision on whether to discuss Assistive Technology? *Please provide details in the box provided*

What provision is in place for other people with dementia? *Please give details in the box provided:*

If someone with dementia is identified as needing a referral for assistive technology. Who would your refer to? *Please select all that apply.* ✱ *Required*

☐ Internet
☐ Organisations
☐ People

If Internet, please select from the following list:

☐ AT dementia
☐ Alzheimer's Society
☐ MSNAP website
☐ General internet search (e.g. google)
☐ Other

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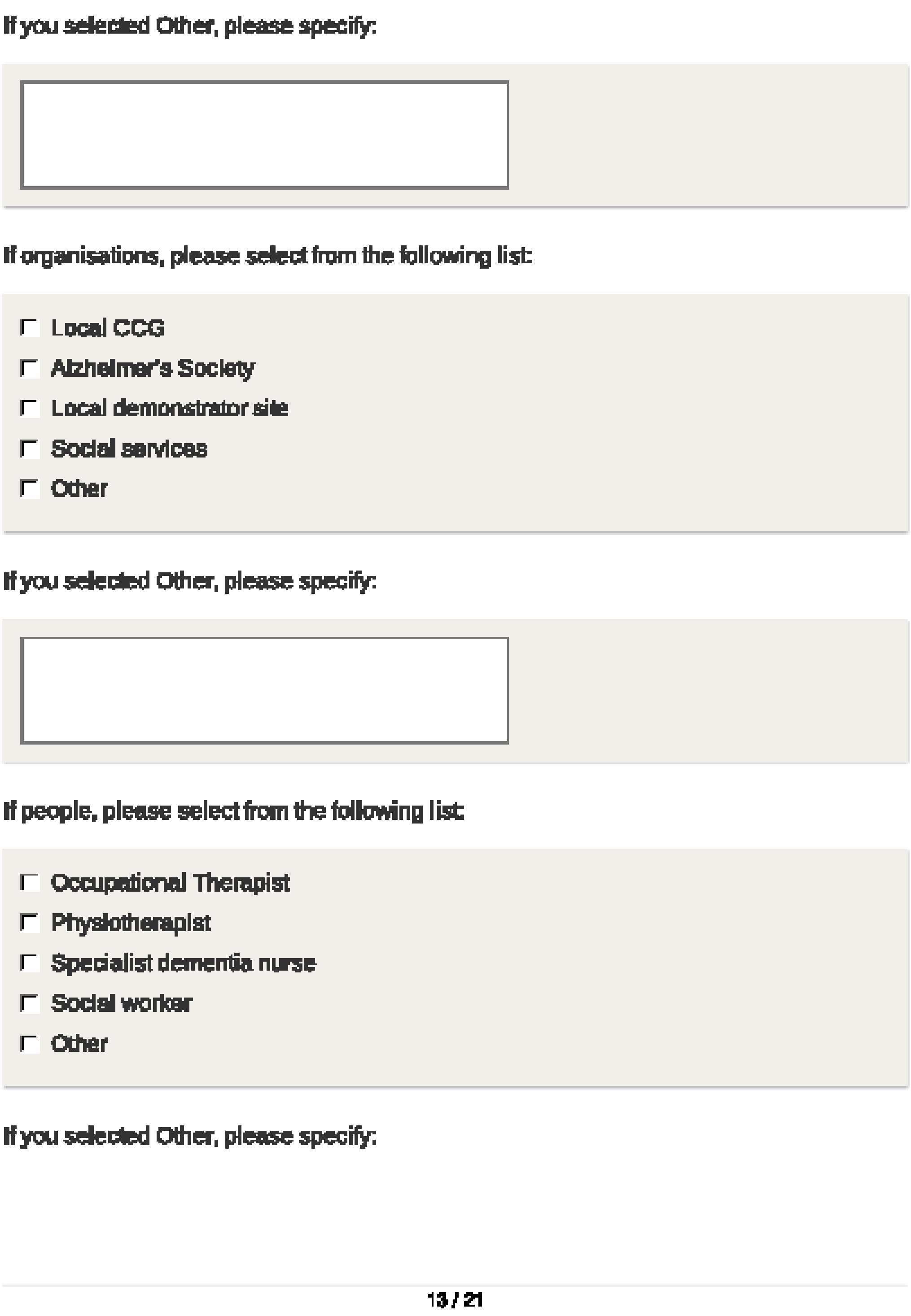


If you selected Other, please specify:

If organisations, please select from the following list:

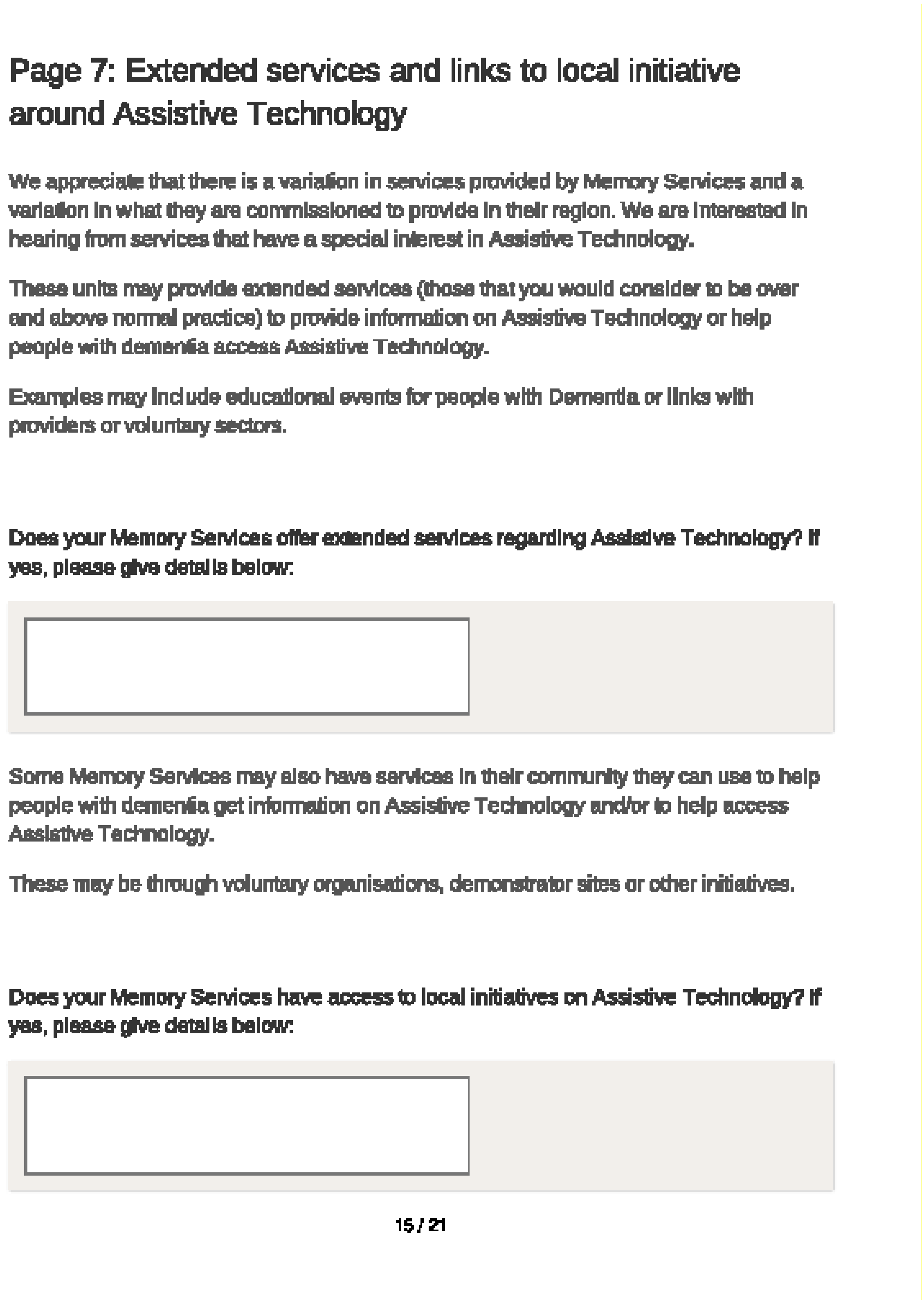
☐ Local CCG
☐ Alzheimer's Society
☐ Local demonstrator site
☐ Social services
☐ Other

If you selected Other, please specify:

If people, please select from the following list:

☐ Occupational Therapist
☐ Physiotherapist
☐ Specialist dementia nurse
☐ Social worker
☐ Other

If you selected Other, please specify:



## Page 7: Extended services and links to local initiative around Assistive Technology

We appreciate that there is a variation in services provided by Memory Services and a variation in what they are commissioned to provide in their region. We are interested in hearing from services that have a special interest in Assistive Technology.

These units may provide extended services (those that you would consider to be over and above normal practice) to provide information on Assistive Technology or help people with dementia access Assistive Technology.

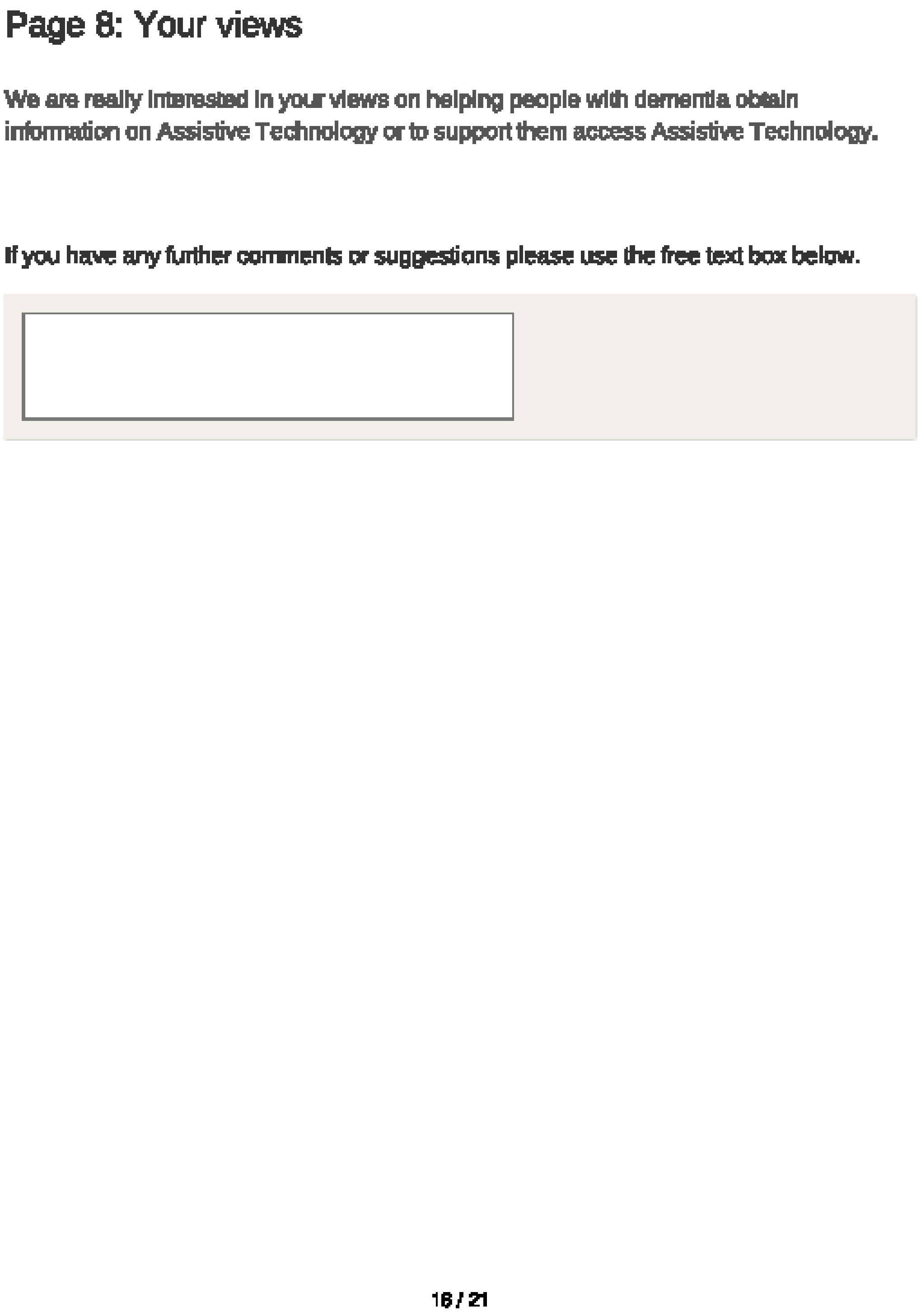
Examples may include educational events for people with Dementia or links with providers or voluntary sectors.

**Does your Memory Services offer extended services regarding Assistive Technology? If yes, please give details below:**

Some Memory Services may also have services in their community they can use to help people with dementia get information on Assistive Technology and/or to help access Assistive Technology.

These may be through voluntary organisations, demonstrator sites or other initiatives.

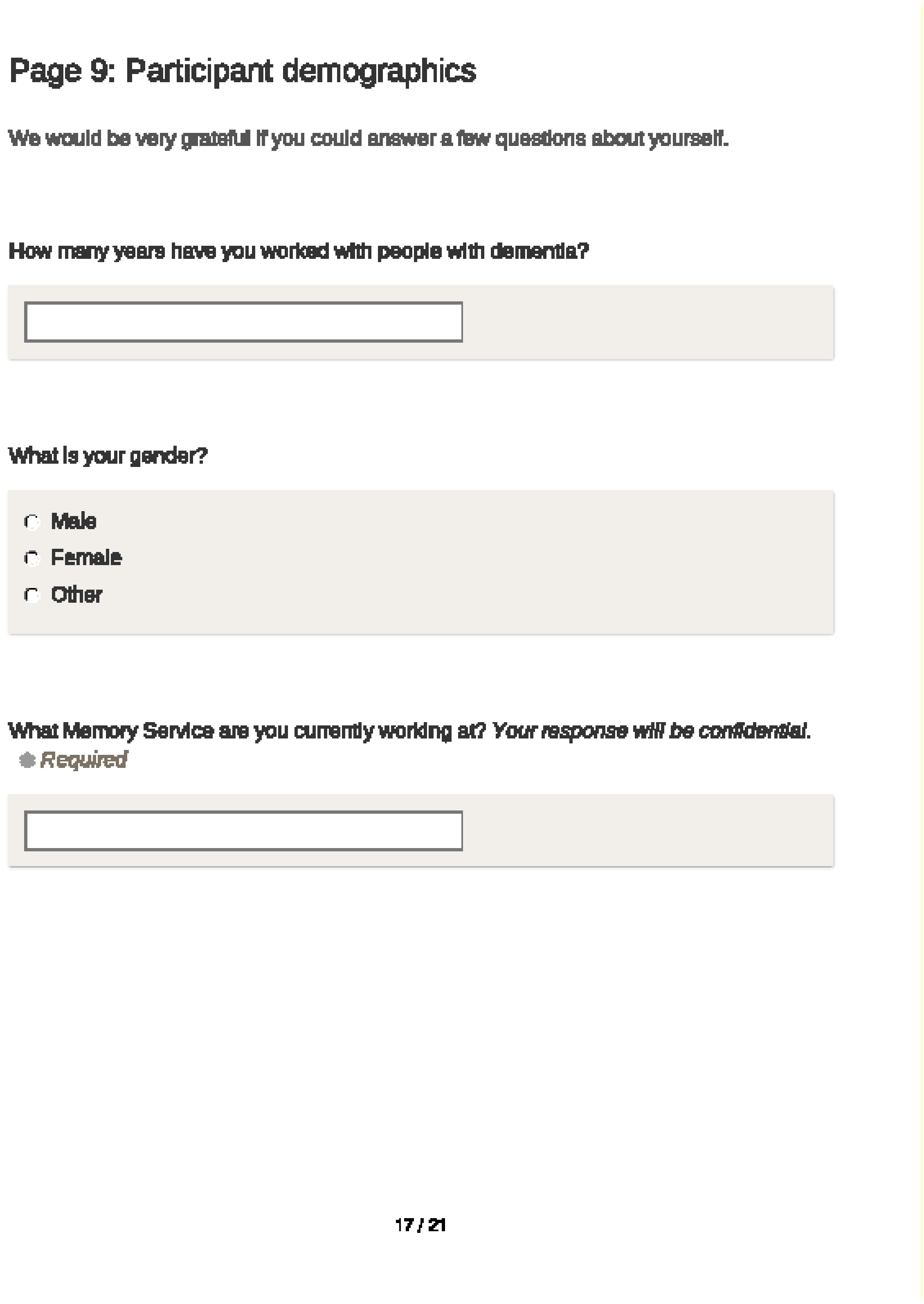
**Does your Memory Services have access to local initiatives on Assistive Technology? If yes, please give details below:**



## Page 8: Your views

We are really interested in your views on helping people with dementia obtain information on Assistive Technology or to support them access Assistive Technology.

If you have any further comments or suggestions please use the free text box below.



## Page 9: Participant demographics

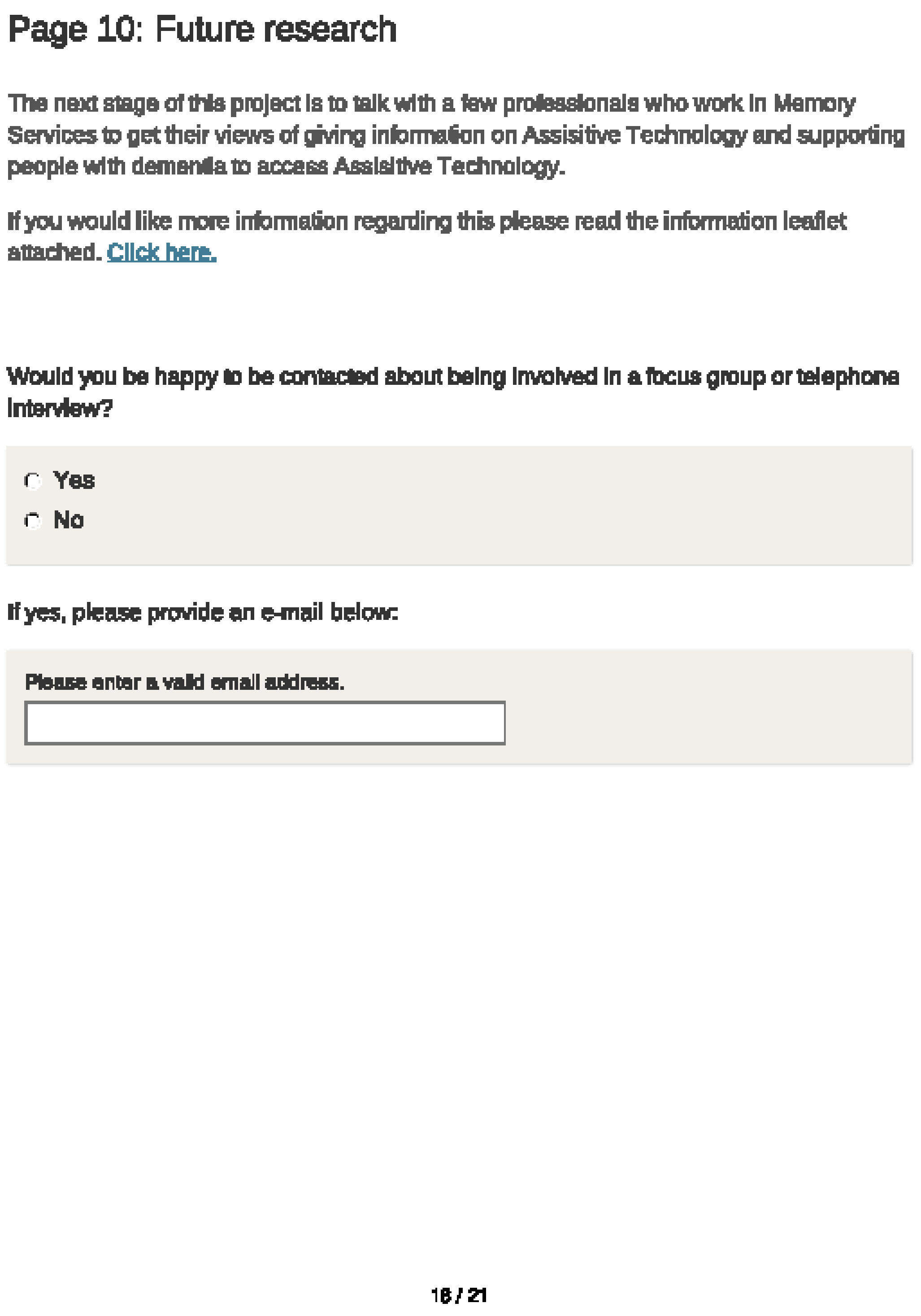
We would be very grateful if you could answer a few questions about yourself.

**How many years have you worked with people with dementia?**

**What is your gender?**

○ Male
○ Female
○ Other

**What Memory Service are you currently working at?** *Your response will be confidential.*
✱ *Required*



## Page 10: Future research

The next stage of this project is to talk with a few professionals who work in Memory Services to get their views of giving information on Assistive Technology and supporting people with dementia to access Assistive Technology.

If you would like more information regarding this please read the information leaflet attached. Click here.

**Would you be happy to be contacted about being involved in a focus group or telephone interview?**

○ Yes
○ No

**If yes, please provide an e-mail below:**

**Please enter a valid email address.**

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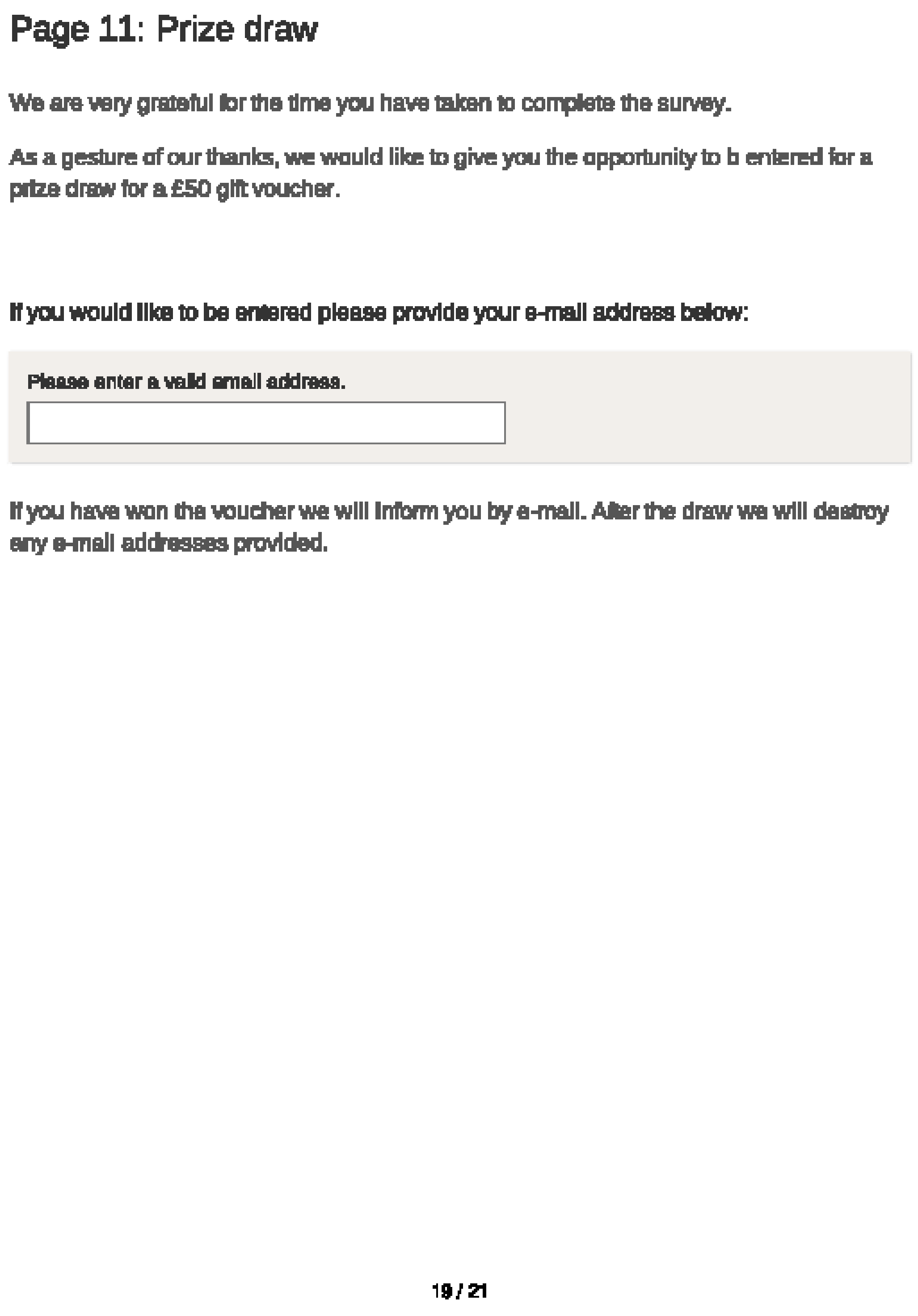

## Page 11: Prize draw

We are very grateful for the time you have taken to complete the survey.

As a gesture of our thanks, we would like to give you the opportunity to b entered for a prize draw for a £50 gift voucher.

**If you would like to be entered please provide your e-mail address below:**

**Please enter a valid email address.**

If you have won the voucher we will inform you by e-mail. After the draw we will destroy any e-mail addresses provided.

## Page 12: Thank you

Thank you for completing the survey. You have participated in a survey for a piece of research called "Memory Service professional practice regarding Assistive Technology".

All of your responses are confidential. If you have selected to be involved in future focus groups or a telephone interview we may be in touch in the future.

We will contact you by e-mail if you have won the prize draw.

If you have any questions, please do not hesitate to contact:

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Institute of Health & Society

Centre for Ageing and Vitality

Newcastle University

Biomedical Research Building

Newcastle upon Tyne

NE2 4AX

Email: lisa.newton@newcastle.ac.uk

Tel: 0191 208 3032

## Key for selection options

**1 - How would you describe your professional role within your Memory Service?** ***Please select the most appropriate response below.***

I am a Memory Service manager
I am a lead clinician working in my Memory Service
Other

## Appendix 4: Survey response rates

| Trust/site | Number sent to | Number responded | Response rate (%) |
|---|---|---|---|
| 2 | 8 | 5 | 62.5 |
| 3 | 60 | 11 | 18.3 |
| 4 | 30 | 28 | 93.3 |
| 5 | 16 | 8 | 50 |
| 11 | 63 | 48 | 76.2 |
| 13 | 73 | 17 | 23.3 |
| 19 | 27 | 19 | 70.4 |
| 29 | 9 | 6 | 66.7 |

## Appendix 5: ‘Other’ professionals who completed the manager and professionals’ surveys

*Details below of participant characteristics for the manager survey who responded ‘other’ when asked about their profession.*

Clinical Director across MS services (n=1)

Service manager (n=2)

Sector manager (n=2)

Quality lead (n=1)

Supervisor of OT in memory service (n=1)

Deputy team Leader (n=1)

Memory clinic nurse (n=1)

liaison nurse (n=1)

Community Mental Health Nurse (n=1)

GP (n=1)

*Details below of participant characteristics for the professional survey who responded 'other' when asked about their profession.*

Assistant Psychologist (n=13)

Trainee Clinical Psychologist (n=2)

Nurse (n=2)

Student nurse (n=1)

Admiral Nurse (n=1)

Learning Disabilities Nurse (n=1)

Associate Nurse Practitioner (n=1)

Advanced Dementia Practitioner (n=1)

OT assistant (n=2)

STR (n=1)

Navigator (n=1)

Support worker (n=13)

Memory Clinic Assistant (n=1)

Assistant Practitioner (n=4)

## Appendix 6: Topic guides

Memory Service professional practice regarding assistive technology

WS1: topic Guide Version 1.0 21/11/17

### *6.1 Focus group with 'usual care' groups*

Focus group professional make up:

- Identify the professional groups represented in the focus group

MS usual practice around dementia:

- What type of people with dementia do they see? Types of dementia, early onset etc?
- Do they follow them up?
- What professionals are in the core team?
- Which professionals do all patients see and who can they refer to?
- Do all people with dementia see an Occupational Therapist?
- Is there training on AT?
- Is there a person responsible for AT?
- Which professional group do they believe should be the lead on AT?

Definition of terms:

- What do they understand by the term AT? Give examples

Experience of AT:

- From their professional practice have they found AT to be helpful to people with dementia and/or their carers?

- Give examples – positive and negative.

MS usual practice around AT:

- Exploration of "usual" practice – what do they do at their service? Give example cases
- Do they give information to all patient with dementia? If not, why not?
- What form do they provide information in – written, online, video etc? Explore examples given.
- Where do they get information on AT? Professional information and information for people with dementia?

- Where would you direct a person with dementia or their family member for information on AT?
- Do they discuss AT with all people with dementia or specific people? What makes them decide to discuss it? Who makes that decision to discuss AT? What provision is in place for the other people with dementia?
- Are there any barriers to giving information on AT?
- Are there any facilitators to giving information on AT?

Helping people access AT:

- Where do they refer people with dementia for an assessment for AT?
- Do they refer everyone? If not, who do they refer and why?
- Who makes the decision whether to refer?
- Would they refer a person to privately purchase AT? Or would they only a person with dementia to be assessed for formal AT (electronic AT provided by social services)?
- Are there any barriers or facilitators to referring people with dementia for an assessment? Both privately purchased and formal AT?
- If they do not refer are people with dementia told how they can get an assessment in the future? Is this verbally or in written guidance?

Information resources:

- Explore in more depth the information resources they use – pros and cons
- Give examples of national resources such AT Dementia and Alzheimer's Society website? What do think of them and would they use them? Pros and cons
- What do they want from information sources for professional and to direct people to do? What makes an information source more reliable or more likely to be used? – for instance would a resource need to be NHS endorsed or would the AT need to have a Kite mark?

Current pathways to information and referral:

- Are they happy with the current pathway to get information or refer for AT? If so, why? If not, how can the current pathway be improved?
- Do they have access to community initiatives or extended services – if so please give examples and do they find them useful?

Any other comments about AT information provision or supporting people to access it?

### *6.2 Telephone interviews with 'good care' group*

Role in MS

- Manager or lead clinician
- Responsibilities within MS

MS usual practice around dementia:

- Explore a typical pathway for a person with dementia? Do they follow up, what types of people do they see?
- What professionals are in the core team? Which professionals do people see and who can they refer to?
- Do they have someone responsible for AT? Which profession?

Definition of terms:

- What do they understand by the term AT? Give examples

Experience of AT:

- From their professional practice have they found AT to be helpful to people with dementia and/or their carers?
- Give examples – positive and negative.

MS usual practice around AT:

- Exploration of "usual" practice – what do they do with everyone with dementia?
- Do they triage information provision, discussing AT or referral? If so how and by who?

Explore example of good practice in depth:

- They have been identified as providing “good” practice – explore this in depth? Ask for case examples.
- If good practice around information provision, how is this down and why is it novel? Give example cases.
- If good practice is around referral and links to community services, how is this down and give examples?
- If good practice is around systems and training, how is this done? Give examples?
- Do all people or professionals have access to this? Is this triaged? If so how is it triaged?

Information provision and referral pathways:

- Are there any barriers or facilitators to giving information on and signposting/access to AT?
- What do they want from information sources? Professional information or information for patients?
- Have they heard of common resources available such as ATdementia or the Alzheimer’s Society website? If yes, what do they think of them? If, no why not?
- What do they want from a pathways for patients to get information on and access to AT?

Any other comments about AT information provision or supporting people to access it?

## Appendix 7: Survey results—other types of AT

Professional survey Q2: From your professional experience, which of the following types of Assistive Technology have you heard of? Please select all that apply. Note this is not an exhaustive list. If you have experience of other devices, please select other and give details.

The table below lists them into categories. If a respondent explained what the AT was I have included this.

| **Category** | **Example given** |
|---|---|
| Electronic memory aids | • Memo Minder<br>• My Home Helper - Tablet set with client specific information and reminders.<br>• Neuropage<br>• SenseCam<br>• Memex |
| Monitoring | • Self-management monitoring systems e.g. Doccabo<br>• Door exit monitors<br>• seizure monitors<br>• automated lights<br>• GPS tech. One example given was Kit watch, a GPS tracker but also simple access out and about to call and speak to help centre who store limited professionals and crisis team and family contact numbers<br>• Canary Care system<br>• Just checking,<br>• pillow alert/ carer pager,<br>• visual camera for family/ carer to observe doorways etc<br>• indoor/outdoor cctv |
| Item locators | • Keyringer |
| Sensors produce alarms or automation | • door sensor alarms<br>• chair sensors<br>• Bed mats sensors. One example given mattress sensor to activate bedside light and alert 3rd party if client does not return to bed.<br>• Enuresis alarms<br>• flood detector,<br>• tap shut off<br>• Fire safety equipment including natural gas detector, or a device to cut off electrical supply to hob and oven but can be switched on by carer, also the device will automatically switch off the hob/oven or vibrating smoke alarms<br>• panic alarm,<br>• extreme temperature sensor,<br>• epilepsy detector,<br>• voice activated alarms, |

| | |
|---|---|
| App using smart phone/tablet | • The use of mobiles and tablets with apps to suit individuals' needs. An example given was apps for tablet / smart phone that break down tasks to component parts, e.g. making cup of tea.<br>• mobiles simple and with GPS<br>• wrist watches—talk / GPS<br>• 'my vitals'—recording devise of critical information<br>• iPad speech apps |
| Intelligent personal assistant: Alexa | • Alexa<br>• Google home<br>• robots |
| Simple AT | • lockable plug covers<br>• MagiPlug<br>• plug in night lights<br>• Falls mat.<br>• Modified cups, plates, and cutlery<br>• grab rails, toilet frames & seats, chair raisers, bath boards/ seats/ lifts, perching stools, kitchen trolleys<br>• Communication books & charts<br>Picture placements for mealtimes<br>Picture Meal/drinks charts/advice<br>• touch lamps, simplified watches. |
| Sensory | • Hearing aid amplifiers<br>• technological aids available through sensory impairment service<br>• induction loop, sounder beacon, visual call beacon |
| Other | • Interactive IT board<br>• Virtual reality |

## Appendix 8: Survey list of free text comments

Manager survey free comments:

| Question Number | Free text comment question | Number completed (%) |
|---|---|---|
| Q2a. | Are you commissioned to provide information on Assistive Technology? If you selected Yes, please give details: | 19 (22%) |

| | | |
|---|---|---|
| Q3. | Are you commissioned to support access to provide in-house services to provide people with dementia with Assistive Technology? If you selected Yes, please give details: | 18 (21%) |
| Q4. | Are you commissioned to provide formal follow up to people with dementia in your service?<br>If you selected Yes, please give details: | 59 (68%) |
| 10c | If only if required [to give information on AT], please give details on why information would be provided and who you would give information to? | 45 (52%) |
| 11aiaii | What criteria is used to make the decision on whether to discuss Assistive Technology? Please provide details in the box provided | 39 (45%) |
| 11aiaiii | What provision is in place for other people with dementia [those who have not had AT discussed with them]? Please give details in the box provided: | 39 (45%) |
| Q12.a | If someone with dementia is identified as needing a referral for assistive technology. Who would you refer to? Please select all that apply. Internet, Organisations, People<br>Internet options:<br>AT dementia<br>Alzheimer's Society<br>MSNAP website<br>General internet search (e.g. google)<br>Other | 7 (8%) |

| | | |
|---|---|---|
| Q12b | 1If someone with dementia is identified as needing a referral for assistive technology. Who would you refer to? Please select all that apply. Internet, Organisations, People<br>If organisations:<br>Local CCG<br>Alzheimer's Society<br>Local demonstrator site<br>Social services<br>Others | 23 (26%) |
| Q12c | If someone with dementia is identified as needing a referral for assistive technology. Who would you refer to? Please select all that apply. Internet, Organisations, People<br>If people, please select from the following list:<br>Occupational Therapist<br>Physiotherapist<br>Specialist dementia nurse<br>Social worker<br>Other | 6 (7%) |
| 13. | Does your Memory Services offer extended services regarding Assistive Technology? If yes, please give details below: | 45 (52%) |
| 14 | Does your Memory Services have access to local initiatives on Assistive Technology? If yes, please give details below: | 53 (60%) |

|  |  |  |
|---|---|---|
| 15 | If you have any further comments or suggestions, please use the free text box below. | 49 (56%) |

| Question Number | Free text comment question | Number completed (%) |
|---|---|---|
| Q2 | From your professional experience, which of the following types of Assistive Technology have you heard of? Please select all that apply. Note this is not an exhaustive list. If you have experience of other devices please select other and give details. | 45 (8%) |
| Q5a | As a professional where would you get information on Assistive Technology? Please select all that apply.<br>Option given: Internet, organisation or people<br>Q5a If internet – asked to select from:<br>AT dementia<br>Alzheimer's Society<br>MSNAP website<br>General internet search (e.g. google)<br>Other<br>If other please give details: | 46 (8%) |
| Q 5.b: | If organisations, please select from the following list:<br>Local CCG | 59 (11%) |

|  |  |  |
|---|---|---|
|  | Alzheimer's Society<br>Local demonstrator site<br>Social services<br>Other:<br>If other, please give details: |  |
| Q5.c: | If people, please select from the following list:<br>Occupational Therapist<br>Physiotherapist<br>Specialist dementia nurse<br>Social worker<br>Other<br>If other, please give details: | 53 (9%) |
| Q7.a: | If a person with dementia (or carer) asked for more information on Assistive Technology, where would you direct them? Please select all that apply Internet, organisation, people<br>Internet options:<br>AT dementia<br>Alzheimer's Society<br>MSNAP website<br>General internet search (e.g. google)<br>Other<br>If other please give details: | 49 (8%) |

| | | |
|---|---|---|
| Q7b: | If a person with dementia (or carer) asked for more information on Assistive Technology, where would you direct them? Please select all that apply Internet, organisation, people<br><br>If organisations, please select from the following list:<br>Local CCG<br>Alzheimer's Society<br>Local demonstrator site<br>Social services<br>Other:<br>If other please give details: | 61 (11%) |
| 7c: | If a person with dementia (or carer) asked for more information on Assistive Technology, where would you direct them? Please select all that apply Internet, organisation, people<br><br>If people:<br>Occupational Therapist<br>Physiotherapist<br>Specialist dementia nurse<br>Social worker<br>Other:<br>If other please give details: | 31(5%) |
| Q9. | What prompted you to discuss Assistive Technology with the person with dementia? Please give details in the box below: | 351 (61%) |

| | | |
|---|---|---|
| Q10: | Where would you refer someone to access assistive technology? Please give details: | 542 (94%) |
| 11a | What made you decide to refer [referred in the last week]? Please give details in the box below: | 271 (47%) |
| 12 | We are really interested in finding out if you have access to any innovative resources to help give information and refer people with dementia to access assistive technology. This may be training materials, websites or local initiatives which help you give people with dementia information or access assistive technology. Please give information in the box below: | 335 (58%) |
| 13 | We are really interested in your view on helping people with dementia obtain information on Assistive Technology or to support them access Assistive Technology. If you have any further comments or suggestions, please use the free text box below. | 233 (40%) |

## Appendix 9: List of ethics and HRA approval amendments

| **Approval** | **Details** |
|---|---|
| **Ethics** | **Ref: 2821/2017** |
| Amendment 1 | Time extension |
| Amendment 2 | Time extension |
| **HRA** | **IRAS ID 230850** |
| Minor Amendment 1 | To expand recruitment to survey due to poor response distributing via MSNAP. Required a new site type to include a site to distribute the surveys to memory services Professionals via expert links and |

| | |
|---|---|
| | other existing research and clinical network or via direct telephone contact with memory services. |
| Minor Amendment 2 | Change in approach to recruit to focus groups. Originally was if they consented during the survey however this was exceptionally burdensome. It was changed to be able to recruit via the Principal Investigator at the sponsor site. |
| Minor Amendment 3 | Extend date of the study to allow me to complete the focus groups and telephone interviews. Also, to reduce the number of sites for the qualitative work stream. |
| Minor Amendment 4 | To extend the end sate of the study due to COVID19. Initially I planned to only have telephone interviews but after the COVID19 pandemic an amendment was submitted which allowed the use of online video platforms such as Zoom, or Teams and later participants were offered the option to either use telephone or an online platform. This amendment involved a change to protocol, PIL and consent form. |

## Appendix 10: Study challenges and having to use a flexible approach

During the study I encountered numerous challenges including:

1. Having no clear definition of what constitutes a memory service
2. There being multiple terms for memory services
3. Approaching memory services to distribute the survey
4. Navigating and managing governance and HRA
5. Recruiting during a pandemic
6. Conducting qualitative research during a pandemic

7. Changes in supervision

Each challenge is described in the subsections below.

### *1. Having clear definition of what constitutes a memory service*

Unfortunately, there is not one clear definition of what memory services are and what services should be called. National MSNAP guidance tries to address this but only stipulates some criteria such as what they should provide and the potential groups of professionals who can work there (see Chapter 2). This recognising the heterogeneity of services. Having read the MSNAP guidance and the most recent national audit at the [22], I had a predetermined definition of what a memory service was. However, during survey distribution it became evident that my assumptions were limited. Some hospital trusts classed themselves as having one memory service even though they had multiple clinical sites, while other hospital trusts said they had multiple memory services defining them by individual sites. Services approached me to be involved in the survey who only worked with care homes, I decided that this was too limited and advised they could not be included, however, it highlighted there is not a clear definition of what constitutes a memory service.

### *2. There are multiple terms for memory services*

Language was also problematic. Originally the term Memory Assessment Service was used in the fellowship application but when I trialled the survey with MSNAP, and they asked me to use the term memory service instead. However, some comments in the free text survey comments referred to services as memory assessment or memory protection services, among others.

### *3. Approaching memory services to distribute the survey*

I hoped to distribute the survey to all memory services on the national audit list. MSNAP distributed the audit to memory services. I met with the MSNAP Chair Professor Martin Orrell and the manager Sophie Hodge, but they did not give permission for me to use the list because the memory services had not signed up to be approached for further surveys. They did, however, offer the use of MSNAP's Memory Chat e-mail group. This was an e-mail list of interested memory services in the UK used to share ideas and to network. Unfortunately, it included regions outside England and was an optional sign up for any professional, essentially an uncontrolled list of potential participants. I did share the survey but had an extremely poor response despite two reminders. I therefore had to alter my approach to memory services.

The study is funded by the Alzheimer's Society and therefore qualified to be added to the NIHR research portfolio. I therefore submitted an HRA amendment to allow me to approach professionals via NIHR portfolio. This took some time and involved liaising with numerous NIHR CRNs in England. My sponsor CNTW was excellent and allocated me a study coordinator who helped me with all contracts (see more below under Navigating and managing governance and HRA).

### *4. Navigating and managing governance and HRA*

I encountered numerous governances and HRA challenges including obtaining ethical and HRA approvals, managing NIHR portfolio research accruals, ethical and HRA amendment and sponsor audits

The study did not require ethical approval as it did not involve patients as research participants. Therefore, university ethical approval was obtained. However, as it involved recruiting NHS staff as participants and may involve NHS sites to collect data during focus groups and interviews, it did require HRA approval. Initially this was obtained for approaching survey participants via MSNAP, but an amendment was required to alter the approach via the NIHR portfolio (see amendment table in section 3.10). This approach via the NIHR portfolio was considerably more involved and time consuming. Unfortunately, guidance had changed that previously would have allowed the sponsor to the by the main site and any another trust involved to be added as Participant Identification (PICs) sites. This would have avoided the need for a contract with every site to distribute the survey. The requirement was that each trust who expressed an interest, via the CRN portfolio network, to distribute the survey would require a contract with the sponsor site. For each of the 42 sites who signed up to distribute the survey a contract was drawn between the sponsor and the site. This was no mean task to communicate with each site to recruit to the study, produce contracts and track progress.

There was a lot of interest in the survey and 42 sites signed up to distribute. It became apparent after many e-mails of inquiry, that there was an external driver for the interest in the form of research accruals. Prior to starting the study, I had not encountered this term accruals but quickly learned it was an important driver for trusts. Research accruals are awarded to each participant in the study, and each trust strives to increase research accrual to obtain further research funding from the NIHR and to show research activity [40]. For every survey completed a trust could have an accrual which was a very easy research win compared to other complicated studies. The study was therefore very popular and lots of trusts expressed an interest in taking part. To allocate an accrual to each participant, every month I had to track each survey completed to the memory service and trust. This was no easy task as there was no national list of memory services which prevented me adding a drop-down option on the surveys which would make it easy to track; respondents had to write the name in a free text box and numerous participants entered old names for the services or the geographical area in which the memory service worked rather than the official name. This therefore took a considerable amount of time to allocate accruals.

Each time the study had a change I had to submit and amendment both to the university ethics and the HRA. A full list of amendments is given in Table 3.2. Some of these amendments took a considerable amount of time to write and then time to be assessed by the HRA team. Each amendment then had to be communicated to 42 research sites.

As the study sponsor was an NHS organisation, I had to follow their research governance processes. During the study I had to complete two sponsor site audits of my study and research file. Keeping the research file was a huge task given I had 42 number of sites/hospital trusts and went through four amendments. I passed each audit.

### 5. *Recruiting during a pandemic*

The survey was distributed, and one focus group completed before the COVID19 pandemic. Recruitment after that was incredibly challenging for both researcher, and participants reasons. The day the national guidance changed to have whole house holds isolated when someone had a cough, my son was coughing through the night. I had to cancel my second focus group which took a long time set up. After that it was impossible to get managers or lead professionals to sign up as they were focused on dealing with the ongoing pandemic. It took me months to rearrange and even then, only three people could attend. Interviews were similar. I managed to have a few interviews with lead professionals at the beginning of the pandemic but after the pandemic developed it was incredible challenging to have people sign up and those who had agreed to interview no longer had time. Due to clinical priority or no longer responding to my emails. I, as a clinician, was also feeling the pressure and had to take two interruptions of studies to focus on my clinical work as there were not enough GPs to see patients'; the vaccination program became a priority. However, I continued to approach participants and found after opening interview recruitment to include usual care sites I managed to get enough data.

The original final stage of the fellowship was to interview people all over the UK in their homes. With the pandemic and uncertainty and the university policy preventing travel during the pandemic, it became impossible to do this. I redesigned the final stage and approached NHS ethics and Alzheimer's society. Unfortunately, it became apparent there was a substantial risk I would not get data and the uncertainty was overwhelming. I, therefore, after reviewing my data with my supervisors, decided to complete as an MD.

### *6. Conducting qualitative research during a pandemic*

To complete the research in the pandemic I had to redesign how I gathered data and use other methods for focus groups such as using online platforms such as zoom and Microsoft teams. This required a HRA amendment. Using online platforms for data collection was a new way of working for me and gathering research but was not a completely unusual method of data collection (Archibald, Ambagtsheer, Casey and Lawless, 2019). I therefore had my final focus groups through teams and some of the interviews using online platforms. Like my participants describing the use of online platforms I had to adapt to the pandemic.

### *7. Change in supervision*

During my studies I had three changes of supervisors. Before I submitted the fellowship Professor Louise Robinson and Dr Katie Brittain supported me and helped me shape my fellowship application. The plan was that Katie would be my supervisor for the qualitative work. However, she was successful in receiving a Senior Lectureship at Northumberland University. I then had Professor Joy Adamson takes over who had experience of both quantitative and qualitative work. She helped me through the survey stage. She then left to work at York University, fortunately when I had just finished the survey quantitative analysis stage which she advised me on. Kate then came back to Newcastle University as a professor. At this time also Professor John Paul Taylor came on board with his extensive experience in dementia research. This was challenging as I had to keep developing relationships with different supervisors but fortunately, they all were incredibly supportive and helped me to adapt.