Enabling people with dementia and mild cognitive impairment to maintain physically active lives: what role can technology play?

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Abstract

People with dementia and mild cognitive impairment (MCI) tend to be inactive, despite evidence that physical activity can improve cognition. To date, interventions to support physical activity have been lacking. This thesis explores the barriers, motivators and facilitators of physical activity for people with mild dementia and MCI and the opportunities for digital technologies to facilitate more active lives.

In the first of three stages of human-centred design research, eight people with mild dementia, seven with MCI and eleven of their spouses shared their experiences of physical activity through diary-probe led interviews. Next, in design workshops with experts in health research, engineering and design, concepts for technologies to support physical activity were developed, informed by personas that described participants' experiences. Finally, storyboard illustrations of the concept technologies were presented to participants for their critique in focus groups. Thematic data analysis was conducted at each stage.

This thesis makes three key contributions to the literature on physical activity in MCI and dementia. First, the importance of everyday activities for an active and fulfilled life is revealed. Second, for people with dementia a variety of barriers to activity are identified, including motivational impairment and difficulties performing everyday activities, whereas MCI appears to have negligible impact. Third, the significance of partners in an active life is revealed, particularly for those with dementia. In response to these findings, technologies to support physical activity in dementia are proposed, however, participants' responses indicate that human interventions and low-tech solutions should be prioritised. This enquiry also provides novel insights into methods for human-centred design with people with MCI and mild dementia.

This thesis highlights the importance of working with people with dementia and MCI to develop technologies and services that facilitate the valued, purposeful activities that contribute to physically active and fulfilled lives.

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Abbreviations

FG1	Focus group one
FG2	Focus group two
NHS	National Health Service
MCI	Mild cognitive impairment
P	Partner of a participant with dementia
PWD	Participant with dementia or person with dementia
PWMCI	Participant with mild cognitive impairment

Chapter 1. Introduction

1.1. Introduction

This thesis explores the barriers, motivators and facilitators to physical activity for people with mild dementia and mild cognitive impairment (MCI) and the opportunities for digital technologies to support physically active lifestyles.

In this introductory chapter I begin by outlining the motivation for this research and its potential value. Next, in section 1.4 I provide an overview of relevant literature regarding physical activity policies and recommendations. In section 1.3 I briefly describe dementia and MCI, which I refer to jointly as later life cognitive impairment throughout this thesis. In section 1.5 I describe the origins of this research and how the aims evolved in response to emerging evidence and collaborators priorities, leading to my research questions. Finally, in section 1.6 I provide an overview of the chapters that make up this thesis.

1.2. Motivation

Over 46 million people are estimated to be living with dementia worldwide and this figure is predicted to rise to around 75 million by 2030 as the global population ages (Prince *et al.*, 2013). Dementia is a chronic, terminal condition, characterised by progressive decline in cognitive function in the vast majority of cases (World Health Organization, 2016; Brodaty and Burns, 2012). There is no cure for the main causes of dementia and current drug treatments have minimal effects on cognition, which are often outweighed by adverse side-effects (Buckley and Salpeter, 2015; Ströhle *et al.*, 2015; Hickey and Bourgeois, 2017; Yates and Woodward, 2017).

When an individual experiences cognitive decline that is abnormal for their age, but not severe enough to be dementia, a diagnosis of mild cognitive impairment (MCI) may be given. MCI has been estimated to effect around 15 to 20 percent of people aged 60 and over (Petersen, 2016; Hu *et al.*, 2017). Current drug treatments for MCI have not been found to improve cognitive function or slow cognitive decline (Fink *et al.*, 2018)

Given the limited benefits and undesirable side effects of drug treatments there is a great deal of interest in the potential for non-pharmacological therapies to improve the cognition and wider health and wellbeing of people with dementia and MCI (Douglas, James and Ballard, 2004; Brodaty and Arasaratnam, 2012; Cooper *et al.*, 2013; Rodakowski *et al.*, 2015; Couch *et al.*, 2020). Improving the physical activity levels of people with later life cognitive impairment has been identified as a promising approach, with mounting evidence that physical activity can have a positive effect on cognitive function in people with dementia and MCI (Hernandez *et al.*, 2015; Ströhle *et al.*, 2015, 2015; Cai and Abrahamson, 2016; Groot *et al.*, 2016; Lee, Park and Park, 2016; Cammisuli, Innocenti and Fusi, 2018; Du *et al.*, 2018; Gomaa *et al.*, 2018; Guitar *et al.*, 2018; Song *et al.*, 2018; Jia *et al.*, 2019; Wang *et al.*, 2019). Research also suggests that physical activity can have a positive effect on people with dementia's capacity to perform activities of daily living and potentially improve functional independence (Forbes *et al.*, 2015; Groot *et al.*, 2016; Lee, Park and Park, 2016; Lam *et al.*, 2018; Brown and Yoward, 2019). There is also evidence that physical activity may alleviate a number of psychiatric and behavioural symptoms related to dementia (de Souto Barreto et al., 2015; Hernandez et al., 2015; Veronese et al., 2019).

Importantly there are indications that physical activity may have a greater effect on cognition than current drug treatments in dementia and MCI (Ströhle *et al.*, 2015; Groot *et al.*, 2016). With lower risk of side effects, and potentially lower costs, physical activity interventions may be appealing to both individuals living with later life cognitive impairment and the health services that support them. Consequently, physical activity has been proposed as a promising alternative or adjunct to drug treatments for people with dementia and MCI (Ströhle *et al.*, 2015; Groot *et al.*, 2016; Cammisuli, Innocenti and Fusi, 2018; Du *et al.*, 2018; Guitar *et al.*, 2018). However, despite significant efforts to establish the benefits of physical activity, there has been little research to identify practical ways to engage people with MCI and dementia in physical activity outside research trials.

Reflecting the imperative for healthier lifestyles, in recent years there has been a proliferation of fitness technologies intended to motivate physical activity, including mobile phone-based apps and stand-alone activity monitors, for instance the popular FitBit devices (Bunn *et al.*, 2018). There is a great deal of interest in the potential for such activity monitoring technologies to facilitate health behaviour change, in both consumer and healthcare settings (Michie *et al.*, 2017; Sullivan and Lachman, 2017) and mounting evidence that they can be an effective tool to motivate physical activity in older adults (Muellmann *et al.*, 2018). It has also been suggested that there may be a role for technologies to enable people with later life cognitive impairment to engage in physical activity (van Alphen, Hortobágyi and van Heuvelen, 2016; van der Wardt *et al.*, 2017).

Despite evidence of the benefits of physical activity, and the opportunities for technologies to support physical activity, the development of technologies for people with later life cognitive impairment has predominantly been for the purposes of exercise trials. Little consideration has been given to the design of technologies for widespread, personal use. There is also limited understanding of the barriers, motivators and facilitators of physical activity for people with later life cognitive impairment (van Alphen, Hortobágyi and van Heuvelen, 2016; van der Wardt *et al.*, 2017), which is necessary to inform the design of technologies to effectively support physical activity.

These findings provide the basis for this investigation into the barriers, motivators and facilitators to physical activity for people with mild dementia and mild cognitive impairment (MCI) and the opportunities for digital technologies to support active lifestyles.

1.3. Later life cognitive impairment

This thesis is concerned with two types of later life cognitive impairment: dementia and mild cognitive impairment. In this section I provide a brief explanation of these two conditions and the relationship between them.

1.3.1. Mild cognitive impairment

Mild cognitive impairment, commonly referred to as MCI, describes a stage of cognitive impairment between normal age-related cognitive decline and mild dementia. Memory loss is common, but not always present. Language, attention, planning and problem solving can also be impaired, to differing degrees (Brandt *et al.*, 2009; Petersen *et al.*, 2014). Unlike in dementia, functional independence is considered to be largely preserved in MCI (Petersen, 2016). For those with MCI, the risk of developing dementia has been found to be around 30 to 40%, with cognitive function remaining stable or even reverting to normal levels in other cases (Mitchell and Shiri-Feshki, 2009; Hu *et al.*, 2017).

1.3.2. Dementia

Dementia is not a disease itself, but a syndrome caused by various diseases, the most common of which is Alzheimer's disease. Symptoms include impairments in memory, thinking, comprehension, learning and orientation. Dementia normally occurs in people aged 65 and over, with incidence increasing with age. Dementia before 65 is rare and is referred to as early or young onset dementia (Whalley and Breitner, 2009; World Health Organization, 2016).

Alzheimer's disease is implicated in around 60% of cases of dementia, while the second most common form, vascular dementia is thought to cause around 20% of cases. Rarer forms include dementia with Lewy bodies, frontotemporal dementia and dementia in Parkinson's disease. In many cases, a mixture of underlying pathologies co-exist, most often a combination of Alzheimer's disease and vascular dementia (Dhanasiri *et al.*, 2007; World Health Organization, 2012). Although the different forms of dementia share similar symptoms, the presentation of the disease varies depending on the type, or combination of pathologies present, as well as it's unique manifestation in the individual (Perrin, May and Milwain, 2008).

Memory loss, perhaps the most well-known symptom of dementia, is the hallmark of Alzheimer's disease, in which memory lapses are a common early symptom. However, memory loss is not always the predominant symptom of dementia. For instance, impaired executive function is common, particularly in vascular dementia and can make planning, organising and initiating tasks increasingly difficult. In addition, mood changes, such as depression and apathy are common in vascular dementia. Memory is also relatively well preserved in the early stages of dementia with Lewy bodies, which has distinctive early symptoms, including hallucinations, attentional deficits and fluctuations between periods of confusion and clarity. Visuospatial problems, difficulties with orientation and judging distances are common in dementia with Lewy bodies but can also occur in the early stages of other forms of dementia. Other areas of cognitive function that can be affected include language, reasoning and gait. Although this overview covers only the commonest symptoms, it illustrates that dementia is a complex, multifaceted condition which effects more than just memory (Graham, Emery and Hodges, 2004; Perrin, May and Milwain, 2008; Alzheimer's Society, 2011, 2014, 2016; Hickey and Bourgeois, 2011).

Although symptoms vary, in the vast majority of cases symptoms accrue and get progressively worse. As dementia progresses, memory and other cognitive functions tend to decline, and an individual is likely to require assistance in everyday activities such as dressing and washing. In the later stages of dementia, basic activities such as eating and walking can become severely impaired and memory impairments can lead to loss of recognition of close relatives and surroundings (Hughes *et al.*, 1982;

Perrin, May and Milwain, 2008; Hickey and Bourgeois, 2011; Alzheimer's Society, 2014).

This enquiry is focused on the needs of people with MCI and mild-moderate dementia due to the potential for greater improvements in cognition and higher likelihood of adopting technologies to support physical activity, as I will describe in the penultimate section of this chapter, as well as the literature review.

1.4. Physical activity

There are no physical activity guidelines specifically for people with MCI or dementia. However, the World Health Organization (WHO) recommends that adults aged 65 and over perform 150 minutes of moderate-intensity aerobic physical activity a week, or an equivalent[1] (World Health Organization, 2010). Physical activity does not just refer to exercise but encompasses everyday activities that expend energy (Caspersen, Powell and Christenson, 1985), although guidelines typically suggest that such activities should be undertaken at a moderate intensity (i.e. resulting in noticeable increases in heart rate). Moderate intensity activities might include brisk walking, dancing or gardening, although the level of activity required depends on an individual's fitness (Taylor, 2014). Muscle-strengthening activities are also recommended for older adults and those with poor mobility are advised to undertake balance exercises (World Health Organization, 2010).

Despite similar recommendations being adopted by many nations (U.S. Department of Health and Human Services, 2008; Kahlmeier *et al.*, 2015) less than half of older adults worldwide are estimated to meet the WHO physical activity target (World Health Organization, 2014). Physical activity levels are particularly low in the

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[1] Alternatively, the WHO recommends 75 minutes of vigorous aerobic physical activity each week, or an equivalent combination. This should be performed in bouts of at least 10 minutes duration. Those that cannot meet the guidelines are advised to be as physically active as they are able (World Health Organization, 2010)

Americas and Europe, with only 10% to 15% of older adults in the US and UK meeting the WHO targets for aerobic activity (World Health Organization, 2014; Sparling *et al.*, 2015), and those with dementia and MCI have been found to be even less active than their peers (James *et al.*, 2012; Watts *et al.*, 2013; van Alphen *et al.*, 2016; Falck *et al.*, 2017; Vancampfort *et al.*, 2017; Hartman *et al.*, 2018).

People with dementia and MCI have also been found to be particularly prone to sedentariness. Studies conducted in Europe and Canada indicate that community dwelling people with dementia and MCI spend around 60% of their waking time in a sedentary state (van Alphen *et al.*, 2016; Hartman *et al.*, 2018). This is a concern as sedentariness may contribute to ill health, independent of the amount of physical activity a person undertakes (Machado de Rezende *et al.*, 2014). Sparling *et al.* (2015) argue that reducing sedentariness should be prioritised over physical activity guidelines which are considered unrealistic for many older adults. Reducing sedentariness may result in greater population-wide health improvements since the greatest health gains occur when those who are inactive start to engage in low-level physical activity. Consequently, a 'whole day' approach to physical activity promotion, where physical activity is embedded into everyday activities and routines has been recommended (Sparling *et al.*, 2015; Silva *et al.*, 2017). Silva *et al.* also highlight a need to look beyond the direct physical health benefits of physical activity to consider its psychological and social benefits. They recommend a holistic approach to physical activity promotion that recognises the role of physical activity in people's everyday lives, including supporting relationships with others and engagement in the community.

Emerging literature on physical activity promotion suggests that, for people with later life cognitive impairment, who tend to be particularly inactive, interventions should aim to reduce sedentariness and consider ways to enable people to embed physical activity in their daily lives, rather than promoting exercise per se. The suitability of this approach is considered further in the following literature review chapter.

1.5. Aims, objectives and approach

In this section I describe how the research aims evolved throughout the course of the investigation, in response to emerging evidence as well as the industrial collaboration with the health-technology company, Philips. I will describe how this development led to my research questions and the design research approach chosen for this enquiry.

This research was undertaken in response to an Engineering Physical Sciences Research Council (EPSRC) call for an *'exploration into the potential of technology to help people with dementia, particularly around physical activity'*, conceived by Professor Michael Trenell of Newcastle University's MoveLab and engineers at Philips' Cambridge laboratories. It was sponsored by an EPSRC (Engineering Physical Sciences Research Council) CASE studentship (Collaborative Awards in Science and Engineering) which was in-part funded by Philips. When the project was conceived Philips were interested in opportunities to develop technologies for people with dementia that would build on the organisation's competencies in activity and safety monitoring, personal coaching and chronic disease management. Meanwhile, MoveLab, with experts in health psychology and physical activity, was leading the field in physical activity monitoring for chronic disease management and wanted to expand its expertise into physical activity for cognitive health.

Although the collaboration with Philips meant that the primary motivation for this research was the development of digital technologies, Philips did not have a specific technology in mind. Instead, they wanted the research to provide insights into the needs of people with dementia and the opportunities for technologies to improve health. They were also open to suggestions of technology-led services, particularly those that allowed people with dementia to monitor and manage their health in collaboration with healthcare professionals. The implications of this focus on technology driven design solutions is considered further in the discussion chapter.

Despite their interest in developing technologies to support physical activity in dementia, neither collaborating team had expertise in dementia. Therefore, my first objective was to establish whether physical activity could be beneficial for people with dementia. An initial scoping review indicated that physical activity could have a number of benefits, including potentially improving cognitive function and the capacity to perform daily activities (an updated version of the evidence regarding the benefits of physical activity can be found in the following chapter). Evidence of the potential benefits of physical activity, and the lack of alternative treatments, led me to focus the research on facilitating physical activity.

The literature also indicated that engaging in physical activity as early as possible in the progression of cognitive impairment may have the greatest impact on cognition. Consequently, I suggested to Philips that the research should focus on addressing the needs of people in the early stages of dementia and be expanded to include people with MCI, which they were amenable to. As people with early dementia and MCI are likely to live at home and have different needs from those living in care, this led me to focus the research on people with later life cognitive impairment living in the community.

Despite evidence of the benefits of physical activity, it was unclear from the literature what type of activity should be promoted for optimal health benefits. There were, however, indications that, rather than bouts of effortful exercise, low levels of physical activity may be most effective at improving cognitive function and be particularly appropriate for people with later life cognitive impairment, who tend to be inactive. A review of qualitative literature on physical activity behaviours, also indicated that older adults tend to be disinclined to undertake effortful exercise, instead associating physical activity with purposeful activities and being motivated to maintain their independence and sense of contribution. In addition, people with later life cognitive impairment were found to be keen to maintain their routines and independence. These findings, combined with arguments discussed earlier, about the importance of a holistic approach to physical activity promotion, led me to consider ways that technologies might facilitate active lives, rather than supporting exercise, or physical activity per se.

As a result of these initial findings, the aim of the research was adjusted to:

- Identify opportunities for digital technologies to support people with later life cognitive impairment to live physically active lives, to support health and wellbeing.

In order to understand the needs of people with later life cognitive impairment, I first conducted a review of qualitative literature on the factors effecting physical activity participation. Due to the limitations of the small amount of available evidence (described in the following chapter) I considered it important to start the research by understanding the active lives of people with later life cognitive impairment as well as the barriers, motivators and facilitators of physical activity. This led to my initial research questions:

1. What are the everyday experiences of physical activity for people with later life cognitive impairment?
    a. What are the barriers and motivators of physical activity?
    b. Do people with later life cognitive impairment use any strategies to maintain physically active lives?
    c. Are there any facilitators that can help people with later life cognitive impairment to maintain physically active lives?

My initial literature review also identified a lack of research into the ways in which technology might support people with later life cognitive impairment living in the community to engage in physical activity, and led to the second research question:

2. How might digital technologies enable people with later life cognitive impairment to maintain or increase their physical activity levels?

Exploring the literature on technology for people with later life cognitive impairment revealed that they are rarely consulted during the design process, so this research also sought to understand:

3. How might design research methods be employed to involve people with later life cognitive impairment in a human-centred design process?

Human-centred design is a cyclical process in which users' needs are first established before concepts are generated, which are then evaluated and repeatedly refined to respond to users' needs. A human-centred design process was chosen for this enquiry as it allowed me to engage people with later life cognitive impairment in a manner that would not be overly demanding. It also allowed me to draw on the expertise of physical activity specialists, engineers and designers from Philips and Newcastle University's MoveLab to generate concepts for technologies which could then be evaluated by people with later life cognitive impairment. The reasons for choosing a human-centred design approach are described alongside my methods, in Chapter 3.

I initially planned to undertake several, iterative cycles of design and user feedback, however, only three stages of user research, design and evaluation were feasible within the time available. For the first, user-research stage I created a diary-probe, in which 15 people with later life cognitive impairment were asked to record their daily activities and reflect on various aspects of their active lives (see appendix A and appendix H). After completing the diary-probe, I interviewed participants about their responses to gather further information about the barriers, motivators and facilitators of physical activity. In the second, design stage of the research, concepts for technologies to support physical activity were generated by healthcare-research, design and engineering professionals from Philips and Newcastle University's

MoveLab in a series of design workshops. In the third and final stage, participants from the first stage of the research were invited to critique the concepts in focus groups. A detailed description of the methods can be found in Chapter 3.

During the first stage of the research, it became apparent that people with MCI and dementia had different physical activity support needs and I decided that it was necessary to focus on the needs of one group in the design stage. When I discussed this with Philips they preferred to focus on people with dementia, rather than those with MCI whose needs were found to be similar to those of the wider older adult population. Therefore, the second and third stages of the research were concerned with the development of technologies for people with dementia.

Although the research focused on the development of digital technologies to support physical activity, reactions from participants with dementia and their partners in the final stage of the research, led me to question the appropriateness of this emphasis, as I examine in the discussion chapter.

1.6. Thesis overview

The following chapter provides a review of the literature that informed this investigation. I start by examining evidence regarding the benefits of physical activity for people with later life cognitive impairment. Next, I review research into the barriers, motivators and facilitators to physical activity for people with later life cognitive impairment and older adults more broadly. I also review literature on the design of technologies to support physical activity in people with later life cognitive impairment. To close the chapter, I describe how the literature review gave rise to the research questions.

In chapter three I discuss the rationale for my choice of methodology and methods. This chapter details the three stages of the research as well as the recruitment and data-analysis processes.

Chapters four, five and six report findings from the first stage of the research. Chapter four describes how factors other than cognitive impairment underpinned the physical activity choices and behaviours of participants. In chapter five I focus on the barriers to physical activity associated with cognitive impairment. Chapter six describes how participants with later life cognitive impairment and their partners managed cognitive changes to maintain active lives. At the end of this chapter, I summarise the findings of the first stage of the research and describe the implications for the following stages.

In chapter seven, the findings and outcomes of the design workshops, undertaken in the second stage of the research, are reported. As well as describing the concepts generated in the workshops, chapter seven examines the concept generation process and the ways in which workshop contributors responded to the experiences of participants with later life cognitive impairment. Chapter eight presents the findings of focus groups, undertaken in stage three, in which participants with dementia and their partners critiqued concepts for technologies to support physical activity derived from those generated in the design workshops.

Findings from across the three stages of the research are drawn together and discussed in chapter nine, along with the implications for the design of technologies to support physical activity. Here I also reflect on the research process and its limitations. In chapter ten I summarise the contributions of this thesis and make recommendations for future design and research activities.

Chapter 2. Literature review

2.1. Introduction

This literature review examines the following questions:

- Is physical activity beneficial for people with later life cognitive impairment? If so, how and what type of physical activity would be most beneficial?
- What are the barriers, motivators and facilitators to engaging in physical activity for people with later life cognitive impairment and older adults more broadly?
- What is known about the design of technologies to support people with later life cognitive impairment to engage in physical activity?

After explaining my review method in section 2.2, I examine the literature relating to each of these research questions in turn. In section 2.6 I draw together and synthesise the literature, considering the evidence for the value of physical activity and the roles that technology could play, before describing how the literature informed my choice of research questions in section 2.7.

2.2. Review method

In this literature review I present a narrative synthesis of evidence from a series of systematic searches designed to answer the above questions. Since the review drew on literature from a range of fields, a narrative approach was considered appropriate, as it enables the researcher to integrate literature from diverse disciplines (Greenhalgh, Thorne and Malterud, 2018). Using a narrative approach allowed me to carefully select, present and discuss work of relevance to this enquiry (Jones, 2004; Jesson, Matheson and Lacey, 2011; Greenhalgh, Thorne and

Malterud, 2018). Data extraction tables were used to facilitate the analysis and synthesis of findings.

Although methods for appraising the quality of research for qualitative synthesis have been proposed, their use in constructivist enquiries such as this is controversial and the use of rigid checklists to appraise validity is considered inappropriate (Murphy *et al.*, 1998). A formal quality appraisal was, therefore, not conducted, however, the strengths and limitations of studies are considered and discussed.

2.3. The benefits of physical activity

The objectives of this first stage of the literature review were to identify whether physical activity might be beneficial for people with later life cognitive impairment and, if so, what type of physical activity intervention could confer the greatest benefits.

Numerous physical activity intervention studies have examined the health benefits of physical activity for people with dementia and MCI and several systematic reviews have attempted to synthesise the findings of these studies. Since there were already several systematic reviews, it was considered unnecessary to conduct a review of primary studies. Instead, for the first section of this review I chose to conduct an umbrella review of systematic reviews conducted in the past five years (January 2015-December 2020).

2.3.1. Method

Reviews were identified through a Web of Science database search for articles with the terms *Physical* activ** or *exercise* in their titles as well as the terms *Dementia* or *Alzheimer** or *mild cognitive* and either the term *review* or *meta*.

To be included reviews had to be systematic reviews, with or without meta-analysis, that investigated the clinical benefits of physical activity and included primary studies with participants with mild-moderate dementia or MCI, with some or all participants living in the community. The primary studies reviewed could appraise any form of physical activity, however, reviews which examined the effects of physical activity combined with another intervention (e.g. cognitive and physical activity) were excluded. Protocols were excluded as well as articles which were not full papers.

Review characteristics and outcomes of interest were transferred to a data extraction table for analysis. Clinical outcomes of interest were cognition, ability to perform activities of daily living (ADL), depression, behavioural symptoms, neuropsychiatric symptoms, quality of life and physical health. Findings regarding characteristics of effective interventions were also extracted, including the length, frequency, duration and type of physical activity.

2.3.2. Results

71 records were identified, of which 27 unique papers were eligible for inclusion. Eight papers reviewed the benefits of physical activity for people with MCI and 20 for people with dementia, of which 10 focused on Alzheimer’s disease. Cognitive function was the outcome of interest in most reviews. Other outcomes analysed included capacity to perform activities of daily living (ADL), depression, behavioural, neuropsychiatric and other psychological symptoms.

Interventions included aerobic and resistance exercise as well as strength, balance and flexibility training. A variety of types of exercise were trialled including walking, dancing, tai-chi and stretches. The length of exercise sessions and the duration of the programmes varied greatly, as well as exercise intensity. Some interventions were individual, home-based programmes while others were delivered to groups. To illustrate the diversity of exercise interventions: in Park and Cohen's (2019) study people with dementia undertook chair based yoga for 45 minutes, twice weekly for eight weeks; in Cammisuli, Innocenti and Fusi's (2018) intervention, people with dementia were asked to perform four hours of group-based exercise (including rowing machine exercises, outdoor Nordic walking and dancing) on two days a week for 12 weeks; Song et al. (2018) asked participants with MCI to walk for 50 minutes, three times a week for six months. Most reviews did not focus on a specific type of physical activity, however, several attempted to identify the most effective types of physical activity and other characteristics of effective interventions.

The findings reported in this section are intended to provide an overview of the evidence regarding the benefits of physical activity for people with dementia and MCI and to identify what types of physical activity might be usefully supported by technology. First, I will discuss the literature on the potential benefits of physical activity for people with dementia and the types of physical activity that might confer the greatest benefits. Then, I will focus on physical activity for people with MCI.

Physical activity for people with dementia

Of the twelve papers which reviewed the effects of physical activity on global cognition in dementia, five meta-analyses reported statistically significant effects on cognition when compared to controls (Ströhle *et al.*, 2015; Groot *et al.*, 2016; Lee, Park and Park, 2016; Du *et al.*, 2018; Jia *et al.*, 2019) and four systematic reviews concluded that physical activity could improve cognitive function (Hernandez *et al.*, 2015; Cammisuli, Innocenti and Fusi, 2018; Gomaa *et al.*, 2018; Guitar *et al.*, 2018) However, one systematic review reported mixed results (Park and Cohen, 2019) and two meta-analyses did not find a statistically significant effect of physical activity on cognition (Forbes *et al.*, 2015; Li *et al.*, 2019), although Li *et al*. found a significant effect in studies with participants under 80.

Notably, two meta-analytical reviews concluded that physical activity may have a comparable or greater effect on cognition in dementia than current drug treatments (Ströhle *et al.*, 2015; Groot *et al.*, 2016) and several reviews concluded that physical activity offers an effective, low-cost alternative or adjunct to current drug treatments with less potential for adverse side effects (Ströhle *et al.*, 2015; Groot *et al.*, 2016; Du *et al.*, 2018; Guitar *et al.*, 2018).

In four of five meta-analyses examining improvements in activities of daily living significant differences were found in people with dementia who undertook exercise, compared to controls who did not (Forbes *et al.*, 2015; Groot *et al.*, 2016; Lee, Park and Park, 2016; Lam *et al.*, 2018).

One paper assessed the effect of physical activity on various physical health outcomes in dementia (Lam *et al.*, 2018), finding significant effects on strength, flexibility, step-length, balance, mobility, walking speed, and walking endurance. Another study which aggregated various aspects of physical capacity (including walking speed, flexibility, balance and agility) also found a statistically significant effect, concluding that physical activity interventions were very effective in improving physical capacity (Lee, Park and Park, 2016). In contrast, the findings of another review, which specifically investigated the effectiveness of home-based exercise programmes was less positive, with only two of five studies reporting significant improvements in mobility (Brown and Yoward, 2019). However, all five of these programmes were found to significantly improve functional independence, which is a combined measure of physical, social and psychological function.

The potential for physical activity to improve mental health is less clear. Two meta-analyses found significant effects on depression, however, while Lee, Park and Park, (2016) reported a medium effect, de Souto Barreto *et al.*, 2015 cautioned that the small effect they found may not be clinically relevant and a third, more recent meta-analysis did not find a significant effect (Li *et al.*, 2019). These mixed results are reflected in the conclusions of systematic reviews (Hernandez *et al.*, 2015; Gomaa *et al.*, 2018; Park and Cohen, 2019; Veronese *et al.*, 2019).

Other behavioural and psychiatric symptoms have received less attention, however, there are indications that physical activity could reduce apathy, agitation, eating disorders, neuropsychiatric disturbances, agitation and sundowning symptoms (de

Souto Barreto *et al.*, 2015; Hernandez *et al.*, 2015; Veronese *et al.*, 2019). Veronese et al. also identified three studies in which physical activity led to improvements in sleep.

Regarding improvements in quality of life, Ojagbemi and Akin-Ojagbemi (2019) found a small but non-significant effect, noting that trials tended to be small, pilot studies, potentially with insufficient power to produce significant results. They also highlighted that quality of life was not the primary outcome measured in any of the studies, indicating that investigators had other objectives when designing their physical activity programmes.

Although there is evidence of potential benefits of physical activity in several areas, the outcomes of primary studies are not consistent, which can be explained, in part at least, by the diversity of intervention designs. Several studies have attempted to identify the characteristics of effective interventions, however, their results are largely inconclusive. Guitar *et al.* (2018) found significant improvements in executive function across exercise modalities (aerobic, resistance and combined exercise interventions) whereas Groot *et al.* (2016) found that aerobic exercise was necessary for cognitive benefits. In order to improve specific physical functions, such as strength, mobility and flexibility, Lam et al. (2018) concluded that exercises that target particular deficits are most effective.

Counterintuitively, the findings of two reviews indicated that smaller amounts of physical activity may have a greater impact on cognition. Groot *et al.* found that interventions prescribing less than 150 minutes of physical activity per week were more effective than those prescribing more, with even the shortest interventions, of only 40-45 minutes, having a positive effect. Jia et al. (2019) also found that shorter length interventions (30 minutes or less) and lower frequency interventions (3 sessions or less per week) tended to be more effective. Jia et al. did, however, find that participating in physical activity interventions for longer periods (over 16 weeks) had a greater effect on cognition.

The types, levels, intensity and duration of physical activity interventions for other health benefits were unclear (Hernandez *et al.*, 2015; Lam *et al.*, 2018; Ojagbemi and Akin-Ojagbemi, 2019; Veronese *et al.*, 2019).

Regarding the people with dementia most likely to benefit from physical activity, there were indications that physical activity may be particularly beneficial for cognitive function in those with Alzheimer's type dementia (Ströhle *et al.*, 2015; Du *et al.*, 2018; Jia *et al.*, 2019), potentially having the greatest effect in the mild-moderate stages (Cammisuli, Innocenti and Fusi, 2018). The results of one review indicated that the cognitive benefits of physical activity may be greater for those under 80 (Li *et al.*, 2019). For improvements in physical function, however, people with moderate dementia were found to benefit most from exercise programmes, perhaps as a result of increased physical deconditioning and therefore greater potential for improvements (Lam *et al.*, 2018).

Physical activity for people with MCI

There was consistent evidence across three meta-analyses and two systematic reviews that physical activity can have a positive effect on global cognition in MCI (Ströhle *et al.*, 2015; Cai and Abrahamson, 2016; Cammisuli, Innocenti and Fusi, 2018; Song *et al.*, 2018; Wang *et al.*, 2019). Importantly, in Ströhle et al.'s (2015) comparative review physical activity was found to have a greater effect on cognition than drug treatments. Loprinzi *et al.'s* (2019) meta-analysis also revealed a significant effect on both short- and long-term memory in people with MCI, however, Song et al. did not find a significant effect on memory or executive function.

The potential for other health outcomes in MCI has received relatively little attention. Two reviews failed to find effects on depression across four primary studies (Song *et al.*, 2018; Zhang *et al.*, 2019). Significant improvements in quality of life were only found in one of three primary studies identified by Song et al. (2018) and Lam et al. (2018). In the effective study people with MCI participated in social walking activities. Regarding physical function, Lipardo et al. (2017) identified two studies in which physical activity significantly improved walking speed but not balance.

As in dementia, the characteristics of effective interventions were unclear. Song et al.'s (2018) findings suggest that aerobic exercise may have a greater effect on cognition than resistance exercise. However, Wang et al. (2019) found aerobic and resistance exercise had similar effects on cognition and, Loprinzi et al. (2019) did not find that exercise modality moderated effects on memory. Regarding styles of exercise, mind-body exercises (including dance and traditional Chinese exercise) were found to have a positive effect (Wang *et al.*, 2019) however a meta-analysis of Chinese-exercise interventions did not find significant improvements on cognitive function (Zhang *et al.*, 2019). Altogether, there is insufficient evidence to conclude that any particular type of physical activity confers greater health benefits for people with MCI.

2.3.3. Discussion

This review has found strong evidence that physical activity can have a positive effect on cognitive function in people with MCI and good evidence of a positive effect on cognition in dementia. This review has also found that physical activity can have a positive effect on people with dementia's capacity to perform activities of daily living as well as their functional independence and various aspects of physical capacity. Physical activity may also improve certain psychiatric and behavioural symptoms in people with dementia.

Importantly, for both dementia and MCI, there is evidence that physical activity may have a similar or greater effect on cognition than currently available drug treatments. Drug treatments intended to improve cognitive function in MCI have been found to be ineffective (Ströhle *et al.*, 2015; Fink *et al.*, 2018) and for people in the early stages of dementia drug treatments have only small, short-term effects, which may be outweighed by adverse side-effects (Gill *et al.*, 2009; Buckley and Salpeter, 2015; Ströhle *et al.*, 2015; McShane *et al.*, 2019). Consequently, non-pharmacological therapies are of great interest for both conditions. Several authors propose promoting physical activity as a cost-effective alternative, with little side-effects and greater potential benefits for health and wellbeing (de Souto Barreto *et al.*, 2015; Ströhle *et al.*, 2015; Groot *et al.*, 2016; Du *et al.*, 2018; Loprinzi *et al.*, 2019; Veronese *et al.*, 2019). These findings suggest that technologies that support people with later life cognitive impairment to engage in physical activity are likely to be of value to individuals with later life cognitive impairment as well as healthcare providers looking for cost-effective treatments.

However, there is a lack of evidence that physical activity can improve quality of life or reduce in depression in people with dementia or MCI. If people with later life cognitive impairment are to independently sustain engagement in physical activity outside of research studies, it must be a positive experience. By focusing on functional outcomes, interventions studies may have overlooked factors that contribute to quality of life, such as relationships, self-esteem and the ability to undertake meaningful activities (Ready and Ott, 2003). Considering how physical activity can improve quality of life may improve engagement.

Regarding the stage at which to target physical activity interventions, the evidence indicates that physical activity may have greater effects on cognition in the early stages of cognitive decline and among those who are younger. Several studies recommend promoting physical activity to people in the early stages of dementia, who are more likely to be physically capable and able to establish long-term exercise routines (Cammisuli, Innocenti and Fusi, 2018; Du *et al.*, 2018; Guitar *et al.*, 2018). These findings support the focus of this research on people with MCI and those in the early stages of dementia.

The types of physical activity interventions required for optimal health benefits are, however, unclear. Although one review concluded that aerobic activity is necessary for cognitive benefits, there is also evidence that resistance activity may have equivalent effects. The distinction between exercise modalities may be misleading and unnecessary, since resistance exercise can lead to similar physiological responses to aerobic exercise, if undertaken at sufficient intensity. Rather than focusing on a particular exercise modality, it has been recommended that people be encouraged to engage in physical activity that suits their lifestyles and resources, to maximise the likelihood of engagement (Fisher and Steele, 2014). Rather than focusing on promoting a particular form of physical activity, these findings indicated a need to identify the types of physical activity that are appropriate for and acceptable to people with later life cognitive impairment.

Regarding the amount of physical activity required for cognitive benefits, although the World Health Organisation recommends at least 150 minutes of physical activity per week, there are indications that lower levels of physical activity may have a greater impact on cognition in dementia. One explanation for this effect is that strenuous exercise programmes may be tiring or overly demanding for people with dementia, who tend to be highly sedentary (van Alphen *et al.*, 2016; Hartman *et al.*, 2018). Elsewhere it has been recommended that interventions aimed at people with dementia promote frequent, light intensity activities to break up periods of sedentariness, which is in itself associated with impaired cognitive performance (Falck, Davis and Liu-Ambrose, 2017; Hartman *et al.*, 2018). Together these findings indicate an opportunity for technologies that facilitate low-intensity physical activity, to reduce sedentariness and improve cognition, particularly for people with dementia. However, further research into the active lives of people with later life cognitive impairment is needed to identify the most appropriate forms of physical activity.

Sustained engagement in physical activity programmes appears to increase effects on cognition in dementia. Technologies may be particularly useful in enabling people with later life cognitive impairment to maintain physical activity routines, if they help them to schedule activities and then provide prompts or reminders. As will be discussed in section 2.5, technologies that make physical activity fun and incorporate elements of competition may also promote sustained engagement.

Despite the extent of research into the efficacy of exercise interventions, it has been highlighted that relatively little research has been conducted to understand the types of interventions that are acceptable to people with later life cognitive impairment (Ströhle et al., 2015; Groot et al., 2016). Hernandez *et al.* (2015) identified a need for interventions to address individuals' goals and needs, focusing on enhancing quality of life, while Forbes *et al* (2015) suggested that physical activity interventions should match the needs, preferences and capabilities of people with dementia.

Together the findings of this review suggest that technologies that support physical activity may be beneficial for people with later life cognitive impairment. However, the needs and interests of people with later life cognitive impairment must be established in order to develop physical activity interventions that are appropriate, appealing and improve people's quality of life, alongside their health.

2.4. Barriers, motivators and facilitators of physical activity

In this section of the review, I examine literature on the barriers, motivators and facilitators of physical activity. As there has been limited research into the specific experiences of people with later life cognitive impairment, I first turn to the much larger body of research into the factors affecting physical activity participation among older adults in general. Then, I focus on the barriers, motivators and facilitators to physical activity for people with dementia and MCI. Finally, I consider what remains to be understood about the factors affecting physical activity participation among people with later life cognitive impairment.

2.4.1. *Factors affecting physical activity among older adults*

Given the extensive research into the barriers, motivators and facilitators of physical activity for older adults, in this section I draw on recent reviews, conducted from January 2015 to September 2019. Reviews were located by searching the Web of Science database, using a search for the terms *older people** or *older adult** and *physical activit** or *exercise** and *review* in the titles and the terms *barrier** or *motivator** or *facilitator** or *experience** in the topic fields. Studies were excluded if they were not full papers, were not systematic, did not report the experiences of older people, reviewed the effects of specific interventions or the experiences of specific groups (for instance those in care or with specific health conditions).

Four of 18 papers were eligible for inclusion. The references of these reviews were examined for further relevant papers and one additional review was identified. The final sample included four systematic reviews (Franco *et al.*, 2015; Devereux-Fitzgerald *et al.*, 2016; McGowan *et al.*, 2017; Morgan *et al.*, 2019) and one review of reviews (Olanrewaju *et al.*, 2016).

The reviews took a range of approaches. Franco *et al.*'s (2015) thematic synthesis of 132 primary studies provides an overview of factors affecting physical activity participation. Devereux-Fitzgerald *et al.* (2016) and McGowan *et al.* (2017) conducted meta-syntheses of 14 and 10 studies respectively, examining the acceptability of physical activity for older adults. Morgan *et al's.* 2019 meta-ethnography of 37 primary studies examined the factors influencing physical activity participation among older adults. In a review of reviews, Olanrewaju *et al.* (2016) conducted a narrative synthesis of the barriers and facilitators of physical activity identified in nine qualitative reviews (two reviews included here and seven conducted before 2015). Primary studies were predominantly conducted in high-income countries.

In this section of the review, I consider how the factors effecting physical activity participation in older adults might inform the development of technologies to support physical activity among people with later life cognitive impairment.

Health problems, physical limitations, pain and fatigue are commonly reported barriers to physical activity among older adults (Franco *et al.*, 2015; Devereux-Fitzgerald *et al.*, 2016; Olanrewaju *et al.*, 2016; McGowan *et al.*, 2017). Beliefs about physical health also appear to influence behaviour, with some older adults believing that physical health problems necessitate sedentary behaviour, although others recognise that physical activity can attenuate chronic health conditions (Franco *et al.*, 2015). These findings indicate a need to address a range of health-related barriers, beyond those associated with cognitive impairment, in the design of technologies to support physical activity.

The majority of exercise intervention studies reviewed in the previous section involved people with later life cognitive impairment in some form of structured exercise programme. However, negative attitudes and beliefs about exercise found among older adults suggest that engaging people with later life cognitive impairment in such programmes may be difficult. Negative attitudes include scepticism and aversion towards physically demanding exercise, as well as lack of confidence, apprehension about meeting others and self-consciousness. Other barriers include competing priorities, inaccessibility of public transport and an inability or unwillingness to pay for exercise programmes (Franco *et al.*, 2015; Devereux-Fitzgerald *et al.*, 2016; McGowan *et al.*, 2017; Morgan *et al.*, 2019). Although exercise trials have been successful in recruiting participants with later life cognitive impairment, their willingness to participate in the studies suggests that they may have been more inclined to engage in physical activity than the wider older adult population. In order to engage those who are averse to structured or effortful exercise, and as a result likely to benefit most from interventions to support physical activity, promoting low-intensity physical activity may be most appropriate.

This approach is supported by evidence that lower levels of physical activity can be sufficient for cognitive improvements among people with dementia.

Societal attitudes towards ageing have also been found to influence physical activity behaviours (McGowan *et al.*, 2017; Morgan *et al.*, 2019), with many considering physical activity incompatible with ageing, of little value or unnecessary in later life (Franco *et al.*, 2015; Devereux-Fitzgerald *et al.*, 2016; Olanrewaju *et al.*, 2016). On the other hand, Morgan *et al.* suggest that defying negative social attitudes towards ageing can motivate activity, and bolster self-esteem in defiance of the losses associated with ageing. These findings suggest that technologies to support physical activity must accommodate or adjust to people's perceptions about appropriate physical activity choices and behaviours.

Although in the last section of this review a number of health benefits of physical activity for people with later life cognitive impairment were identified, research with older adults has found that they tend not to be motivated by the long-term health benefits of physical activity. Instead, short-term priorities, including maintaining independence and self-worth, feeling useful and being valued have been found to be greater motivators (Franco *et al.*, 2015; McGowan *et al.*, 2017; Morgan *et al.*, 2019). Physical activity can, in itself, support these priorities, enhancing self-esteem and self-identity, providing a sense of role, purpose and structure in older adults' lives (Morgan *et al.*, 2019). For people with later life cognitive impairment, physical activity may also support independence through improvements in cognition and the capacity to perform everyday activities. Conveying the potential for short-term benefits and helping people with later life cognitive impairment to identify activities that support their priorities may enhance engagement in physical activity.

Rather than seeing value in physical activity in and of itself, older adults often associate physical activity with getting out and about or consider it a by-product of purposeful activities (McGowan *et al.*, 2017; Morgan *et al.*, 2019). These attitudes are reflected in a study which found walking to be the predominant form of physical activity undertaken by older adults in the UK, closely followed by household activities, including housework, gardening and DIY (Scholes and Mindell, 2013). Given the apparent prioritisation of purposeful activity, technologies might encourage and enable older adults to engage in constructive activities with a physical element, such as gardening. Technologies could also promote and support active travel to perform purposeful activities, for example encouraging people to walk to shops. However, environmental factors, such as adverse weather and the safety of local neighbourhoods would need to be considered (Franco *et al.*, 2015; Olanrewaju *et al.*, 2016; McGowan *et al.*, 2017).

Social interaction has also been found to be an important motivator of structured exercise, such as exercise classes, as well as unstructured, everyday physical activities, for instance walking to a social club (Franco *et al.*, 2015; Devereux-Fitzgerald *et al.*, 2016; Olanrewaju *et al.*, 2016; Morgan *et al.*, 2019). On the other hand, lack of companionship or social support have been identified as barriers to physical activity (Olanrewaju *et al.*, 2016; McGowan *et al.*, 2017), although solitary activity may be valued by some (Morgan *et al.*, 2019). The prevalence of social themes across the literature indicates a need to consider the importance of social and shared activity when designing technologies to support physical activity.

While these reviews tend to homogenise older adults, portraying a group largely disinterested in physical activity, there were indications that a minority of older adults do in fact actively choose to engage in physical activity (Franco *et al.*, 2015; McGowan *et al.*, 2017). For some, physical activity is associated with feelings of fun and joy, as well as sensory stimulation, mental activity and mental health (Morgan *et al.*, 2019). Those who had been active earlier in their lives were found to be inclined to maintain active habits, motivated to conserve their identities as active individuals or to revisit activities from their youth (Franco *et al.*, 2015; McGowan *et al.*, 2017; Morgan *et al.*, 2019). Franco *et al.* (2015) found that those who had never taken part in regular physical activity were reluctant to begin in later life. However, it is not impossible to change course, with positive first-hand experiences of physical activity having the power to change attitudes and improve self-efficacy (i.e. the confidence in one's ability to change a behaviour (Abraham *et al.*, 2008)), which can be a barrier to physical activity (Devereux-Fitzgerald *et al.*, 2016; Olanrewaju *et al.*, 2016).

Taken together these reviews indicate that older adults' attitudes towards physical activity vary greatly. Costello *et al.* (2011) found that individuals' attitudes reflected their activity levels, with inactive older adults being motivated by purposeful activities whereas those who were already active enjoyed exercise for its own sake. These findings suggest that interventions to support physical activity need to either accommodate the differing priorities of older adults, or otherwise be targeted at individuals with similar motivations. Rather than supporting those who are already physically active, targeting individuals who are relatively inactive is likely to produce the greatest health benefits, as discussed in the introduction (Sparling *et al.*, 2015; Silva *et al.*, 2017). For these individuals, interventions may be most effective if they enable people to maintain a purposeful and fulfilled life. For older adults with later life cognitive impairment, maintaining independence, contribution and purpose can become increasingly challenging and, as such, technologies that support these priorities, may be even more important. This approach aligns with my previous conclusion that interventions to support physical activity need to improve quality of life, including supporting self-esteem and the ability to undertake meaningful activities.

Although it is useful to understand the experiences of older adults, the onset of cognitive impairment may alter people's attitudes, needs and priorities and therefore a more detailed investigation into the specific experiences of people with dementia and MCI is also necessary.

2.4.2. Factors affecting physical activity for people with dementia

In this section I examine the barriers, motivators and facilitators to engaging in physical activity for people with dementia. The review is based on a search of the Web of Science database (from inception to September 2019) for papers with titles including the terms *Alzheimer** or *dementia*, and either "*physical activit**" or *exercise** and at least one of the following terms: *barrier** or *motivator** or *facilitator** or *experience**. Studies were excluded if they did not report the experiences of people with dementia, were conducted only with institutionalised people, only included people with severe dementia or were not full papers.

Four of the 13 papers identified were deemed eligible. One was a qualitative review of barriers, motivators and facilitators of physical activity for people with dementia (van Alphen, Hortobágyi and van Heuvelen, 2016). The references of this review were searched for relevant studies, leading to a further, primary, qualitative study being identified for inclusion as well as a review of factors correlating with physical activity participation, which complemented the qualitative research.

Across the four primary, qualitative studies a total of thirty-three people with mild-moderate dementia were interviewed about their experiences of physical activity (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Most studies focused on Alzheimer's disease, only McDuff and Phinney included a mix of dementias. All studies were interview based, although Cedervall and Åberg (2010) also conducted observations of two men with Alzheimer's performing physical activity. One study was conducted in England (Malthouse and Fox, 2014), two in Sweden (Cedervall and Åberg, 2010; Cedervall, Torres and Åberg, 2015) and one in Canada (McDuff and Phinney, 2015). Participants were community-dwelling, except for two who lived in assisted living facilities. The majority of participants had a spouse or partner, only four participants were described as living alone. Spouses or family members participated in all studies, although only in some cases in McDuff and Phinney's study.

Across these studies accounts of participation in formal exercise or sport were rare (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015) and attitudes towards physical activity participation were mixed. On one hand, Malthouse and Fox described participants who were disinterested in formal or effortful exercise, reflecting findings in the older adult population. On the other, Cedervall, Torres and Åberg (2015) found that their participants generally held positive attitudes towards physical activity, although few mentioned ambitions to increase their activity levels, even those who considered themselves insufficiently active. This positivity may reflect the fact that the study was conducted in Sweden, where adults are relatively active (Townsend *et al.*, 2015), or that participants in this study had volunteered to take part in an exercise intervention study, so may have been less averse to physical activity than the wider population. Despite the potential skew towards more active individuals, these findings suggest that, like their peers, people with dementia hold a range of different attitudes towards physical activity and as such technologies may need to be targeted or adaptable to different interests and attitudes.

Walking was the predominant form of physical activity discussed across all studies (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Walking was found to provide an alternative form of occupation when other activities had become challenging, and could be incorporated into people's daily routines (McDuff and Phinney, 2015). It was described as providing a sense of wellbeing, freedom and escape from the challenges of cognitive impairment into a physical realm where capabilities were unimpaired and individuals could, instead, take pleasure in automatic, simple, physical movement (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Walking was also a necessity for some people with dementia when they were no longer able to drive (McDuff and Phinney, 2015). The apparent benefits and necessity of walking for people with dementia suggests that technologies to support physical activity might focus on promoting walking.

Outdoor physical activity, including walking, made people with dementia feel refreshed, relaxed, calmer and alleviated fatigue (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Being in the natural environment and getting fresh air was also appreciated (Cedervall and Åberg, 2010; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Although these studies indicate that technologies to support walking outdoors, particularly in nature, may be valued by people with dementia, it should be noted that these responses are largely drawn from studies conducted in Sweden which, as well as having highly active older adults, has among the best access to green spaces in Europe (Poelman, 2016). It has already been noted that environmental factors, including the accessibility of local spaces may be a barrier to walking for older adults, and in McDuff and Phinney's (2015) Canadian study some participants described their outdoor activities being restricted by inaccessible walkways and lack of transport to the countryside. If technologies are to promote walking or other outdoor activity, the availability of safe and attractive outdoor spaces, as well as other environmental barriers, need to be considered.

Although several studies indicated that participants with dementia were confident about walking, some reported that impaired orientation or fears about getting lost could prevent them from going out alone or limit them to familiar routes (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015). Partners appeared to be particularly anxious about people with dementia walking out alone, although it was unclear to what extent this effected the behaviours of people with dementia (Cedervall and Åberg, 2010; Malthouse and Fox, 2014). One commonplace technology, the mobile phone, was already used by some people with dementia and their partners to provide reassurance when they went out alone (Cedervall and Åberg, 2010; Cedervall, Torres and Åberg, 2015). The design of mobile phone applications and other, specialised devices to support wayfinding has received research attention, as discussed in the following section.

Although purposeful activity has been found to be valued by older adults, for those with dementia, difficulties performing everyday activities were associated with loss of confidence and anxiety, which could reduce people's inclination to undertake activities (Cedervall, Torres and Åberg, 2015). The safety concerns of people with dementia or their relatives could also restrict their activities (Cedervall and Åberg, 2010; McDuff and Phinney, 2015). Perhaps as a result of these difficulties and restrictions, Malthouse and Fox (2014) noted that participants with dementia had become less active in the home. This may help to explain findings that people with dementia are less active than their peers (van Alphen *et al.*, 2016; Hartman *et al.*, 2018) and indicate an opportunity for technologies to support everyday activities in order to increase the physical activity levels of people with dementia.

Similar to findings in the wider older adult population, some studies also identified tiredness or lack of energy as being barriers to activity, although it was often unclear whether this was related to dementia or other aspects of ill-health and ageing (Cedervall and Åberg, 2010; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). McDuff and Phinney associated loss of energy with loss of enthusiasm and motivation, possible indicators of apathy or depression, which are common in dementia (Mortby, Maercker and Forstmeier, 2012). Further research to establish how loss of motivation affects physical activity in dementia, and how it might be overcome may provide important insights for the design of technologies to support physical activity.

As might be expected, some of the barriers found in the wider older adult population were also reported by people with dementia, including physical health problems and environmental factors, although reports tend to be focused on barriers related to cognitive impairment (Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Similar to their peers, motivators included social interaction and the health benefits of physical activity (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). These findings indicate that barriers and motivators other than those associated with cognitive impairment need to be considered in the design of technologies to support physical activity.

Familiarity and routine were also found to be important motivators and facilitators of physical activity (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). People with dementia were found to struggle to adapt to new activities or routines and, as such, were inclined to continue with activities they had previously enjoyed or to simplify their activity routines (Malthouse and Fox, 2014; McDuff and Phinney, 2015). These findings suggest that, rather than attempting to engage people with dementia in unfamiliar forms of physical activity, technologies should support familiar activities and enable people with later life cognitive impairment to incorporate physical activity in their existing routines. Further understanding of the daily lives and activity choices of people with later life cognitive impairment would help to inform the design of technologies that enable people to incorporate familiar forms of physical activity into their routines.

As found in the wider older adult population, the social component of an active life outside the home was valued by people with dementia (Malthouse and Fox, 2014; McDuff and Phinney, 2015). In some instances the support of others was necessary when performing physical activities, particularly walking (Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Activities undertaken with others in a similar situation and with sympathetic activity leaders were reported as being more enjoyable and accessible. However, difficulties coping with social situations and a lack of understanding from others could make activities outside the home difficult (Malthouse and Fox, 2014). Perhaps reflecting the challenges associated with social activities and increased reliance on caregivers, McDuff and Phinney found that walking alone was valued by some, in contrast to reports of the value of social activity. These findings suggest an opportunity for technologies that enable people with dementia to connect with others, to share and facilitate physical activity, however technologies that support independent activity may also be valued.

The partners of people with dementia were found to be facilitators of physical activity (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; McDuff and Phinney, 2015). However, lack of time, energy or ill health could limit partners' capacity to provide support (Malthouse and Fox, 2014), and maintaining a supportive disposition could also be challenging for caregivers (Cedervall and Åberg, 2010). There were also indications that caregivers' anxieties about people with dementia walking out alone, or performing tasks considered unsafe could restrict people with dementia's activities (Malthouse and Fox, 2014; McDuff and Phinney, 2015). These findings suggest that partners can have both a positive and negative effect on people with dementia's engagement in physical activity. While, on the one hand, technologies might encourage partners and other caregivers to help people with dementia to undertake physical activities, supporting people with dementia to be independently active may reduce demands on caregivers' time and energy. However, caregivers' anxieties about the safety of people with dementia undertaking activities independently may have to be allayed. Further understanding the relationship between people with dementia and those that support them will help to inform the design of technologies that address the needs and concerns of both parties.

A systematic review of quantitative studies by Stubbs *et al.* (2014) also sheds light on factors associated with physical activity among people with dementia. As might be expected, faster walking pace was associated with higher physical activity levels. Although the qualitative literature suggests that walking can be a positive, simple, activity for people with dementia, Stubbs *et al's* finding highlights a need to consider the different physical capabilities of people with dementia in the design of technologies to support physical activity.

Surprisingly, Stubbs *et al.* did not find that cognitive impairment was associated with physical activity levels. The authors suggest that this could be due to caregivers helping people with dementia to maintain physically active lives, as identified in the qualitative studies (Cedervall and Åberg, 2010; Malthouse and Fox, 2014). Another explanation indicated by the qualitative research is that people with dementia do more walking to compensate for loss of capacity in other areas (Cedervall and Åberg, 2010; Cedervall, Torres and Åberg, 2015). Together these findings suggest that cognitive barriers to physical activity might be overcome by caregivers' support or by identifying alternative activities, such as walking, that are not excessively demanding for individuals with dementia.

In contrast to their findings on cognitive function, Stubbs *et al.* did identify a link between physical activity levels and the capacity to perform activities of daily living, which may be explained, in part at least, by people with dementia's descriptions of feeling disinclined to undertake activities due to anxieties about their capabilities (Cedervall, Torres and Åberg, 2015). Stubbs *et al.* also found that apathy was associated with inactivity in people with dementia, reflecting reports of loss of energy or motivation to undertake activities in qualitative studies (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). As discussed earlier, reducing sedentariness in people with dementia may be particularly valuable, and therefore understanding the degree to which apathy and difficulties performing everyday activities lead to inactivity may help to inform the design of technologies to support physically active lifestyles.

Together these studies begin to form a picture of the barriers, motivators and facilitators to physical activity for people with dementia but there are limitations to this body of work. A major limitation of the qualitative research in this area is that participants were likely to be healthier or more active than the wider population as they were also participating in physical activity or drug trials or, in the case of one study, had been selected because of their interest in physical activity (Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Previous studies have also largely focused on people with Alzheimer's disease, who have been found to be more active than those with other types of dementia (van Alphen *et al.*, 2016). Due to these limitations, further research into the physical activity experiences of a broader range of people with dementia is warranted.

A further limitation of the qualitative, interview studies is that they tend to have focused on physical activities such as walking, cycling or exercise, rather than prompting discussion about people's activity levels throughout the day. There were, however, indications that difficulties performing everyday activities and impaired motivation could lead to inactivity, which may partially explain why people with dementia are more inactive than their peers. Due to the focus on physical activity, participants in previous studies may not have considered the barriers to everyday activity worthy of discussion. One study did ask people with dementia to talk about *"activities that were important in their daily lives"* (McDuff and Phinney, 2015, p 2-3), however, they only analysed interview transcripts where participants talked about physical activity and, in doing so, did not provide an overall picture of the barriers to activity in the daily lives of people with dementia. Further understanding the factors leading to inactivity is likely be valuable when designing technologies to support physical activity in dementia, since, as discussed earlier, averting sedentariness may be particularly important.

Although some barriers to physical activity found in the wider older adult population were noted, they were not prevalent in these reports, with the emphasis being on barriers associated with cognitive impairment. It is unclear whether people with dementia did not experience the same barriers as other older adults or whether interviewees were more inclined to talk about those associated with dementia, perhaps because of the emphasis of the studies. For example, physical health problems received limited attention, despite being a common barrier to physical activity among older adults more broadly. Gaining an overall picture of the factors effecting physical activity participation for people with later life cognitive impairment is likely to improve the effectiveness of interventions.

Routines have been identified as a possible facilitator of physical activity for people with dementia, however, the reflective interview approach employed in previous studies may have limited insights into participants' daily lives and routines (Clarke and Keady, 2001), since even those without memory problems may forget or omit routine, everyday and apparently inconsequential events when they are interviewed (Milligan, Bingley and Gatrell, 2005). Although one study combined interview with observation, they were only brief periods of observation of two individuals undertaking physical activities (Cedervall and Åberg, 2010). Longer observations to capture people's activities throughout a day would be intrusive and likely to influence people's behaviours. These findings and limitations influenced my decision to develop a diary-probe to allow people with dementia to record and reflect on their daily activities to improve our understanding of the everyday barriers to physical activity for people with dementia, which I describe in detail in the following chapter.

2.4.3. Factors affecting physical activity among people with MCI

An initial search for literature on the physical activity experiences of people with MCI (similar to the one undertaken for dementia) failed to identify any papers, so the search was expanded to include terms related to exercise intervention trials. The Web of Science database was searched for papers with the terms *barrier** or *motivator** or *facilitator** or *experience** or *feasibility* or *adherence*, and *"physical activit**" or *exercise** in the title and the term *"mild cognitive impairment"* in a topic field, published between January 2000 and December 2019. Studies were excluded if they did not report the barriers, motivators or facilitators of physical activity for people with MCI or were not full papers.

Only two of the 11 papers identified were suitable for inclusion. One studied the adherence of people with MCI to an exercise programme conducted in The Netherlands (Tak *et al.*, 2012). The other, investigated the feasibility of using step counting devices to increase the physical activity levels of people with MCI, in New England, USA (Richeson and Croteau, 2017).

Tak *et al.* (2012) interviewed 138 people with MCI about the barriers to engagement in a year-long, twice-weekly programme of either moderate-intensity walking or low-intensity physical activity. Across both programmes physical limitations were the main reasons why participants dropped out. Other barriers included lack of time, conflicting activities, cost, location, disinclination to exercise, and lack of social contact or support. Dislike of the exercise programme, and inappropriate exercise intensity also effected adherence, with the authors noting that future interventions should adapt to individuals' capabilities and preferences. These findings reflect barriers to physical activity found in the wider older adult population. Interestingly cognitive impairment was not reported as a barrier.

Richeson and Croteau (2017) interviewed ten people with MCI after they had used either a pedometer or a FitBit™ wearable activity monitor, for two weeks. Participants described being motivated to exercise to improve their cognitive function, maintain independence and improve health. Feedback from the step-counters, and competing with others through the devices, provided further motivation for participants to increase their daily steps. Participants also described using strategies to increase their step-counts, including finding opportunities and places to walk to (for example walking to the shops or to visit a friend) and finding walking companions. The strategies used by participants reflect findings among older adults that purposeful activity can be a motivator and that social aspects of physical activity are also important. The study did not report barriers to engaging in physical activity, only to using the technologies provided.

Participants in Richeson and Croteau's (2017) study were positive about using the activity monitoring devices, although they did note ergonomic and usability issues, including forgetting to put the devices on and wanting written instructions as a reminder of how to use the device. It should, however, be noted that the sample was small, and participants were self-selecting, based on their interest in taking part in a walking programme using an activity monitor.

Although it is difficult to draw conclusions about the factors affecting physical activity participation among people with MCI from these two very different studies, findings suggest that the barriers, motivators and facilitators of physical activity for people with MCI may be similar to those identified in the wider older adult population. As in the dementia studies, participants may have been fitter and more inclined to exercise than the wider population as they were expected to undertake physical activity as part of the trials. In addition, participants may be more motivated to engage in physical activity and provide positive feedback in order to please researchers.

These studies provide some preliminary insights into the factors effecting physical activity participation among people with MCI, however, in order to design technologies to support physical activity, a greater understanding of the barriers, motivators and facilitators of physical activity experienced by people with MCI is required.

2.5. What role can technology play in supporting physical activity?

The development and deployment of technologies for people with later life cognitive impairment, in particular those with dementia, has tended to focus on safety, and caregiver reassurance, with relatively little attention paid to enabling recreational activity or improving people's quality of life (Evans *et al.*, 2015; Gibson *et al.*, 2016; Holthe *et al.*, 2018). A review by Gibson *et al.* (2016) also found that there were more assistive technologies intended for caregivers to monitor, access or restrict a person with dementia than to be used by people with dementia themselves. Presumptions about the inability of people with later life cognitive impairment to use new technologies, may have contributed to the deficit in technologies to support these individuals directly. However, research demonstrates that people with MCI and dementia can and do use digital technologies (Meiland *et al.*, 2012, 2017; Hedman, Lindqvist and Nygård, 2016) and that they are able to learn to use new devices (Lekeu 2002; Lee, 2013; Meiland, 2012; Nygard, 2008). People with later life cognitive impairment have also expressed positive attitudes towards adopting new technologies (Gibson *et al.*, 2015; Hedman, Lindqvist and Nygård, 2016; Meiland *et al.*, 2017).

This section of the review focuses on the literature relating to the design of technologies to support people with later life cognitive impairment to engage in physical activity.

2.5.1. Method

A search was conducted to identify literature relating to the design or use of technology intended to enable people with later life cognitive impairment to live physically active lives. Having found that people with dementia in particular value walking, but that navigation may be a barrier to this form of physical activity, I expanded my search to identify literature related to navigation or wayfinding.

The Association of Computing Machinery’s (ACM) Guide to Computing Literature and the Web of Science were searched from 2000 to 2019 for papers containing the terms *“mild cognitive”* or *dementia* or *Alzheimer**, as well as the terms "*physical activity*" or *exercis** or *walk** or *navigation** or *wayfinding* or *fitness* or *recreation**, and terms related to technology including *technolog** OR *digital** OR *mobile** OR *tablet** OR *computer**. Papers were excluded if they did not consider the design or use of technology to support physical activity for or by people with mild-moderate dementia or MCI living in the community. Papers were included if they described devices intended to help people with later life cognitive impairment with navigation but excluded if they were solely concerned with tracking people's location. Protocols and abstracts were also excluded. References from the remaining papers were examined for further relevant papers.

2.5.2. Results

Thirty-two eligible papers were identified. Over half were from health and ageing journals and described trials which examined the potential for exercise technologies to facilitate improvements in physical and cognitive health. Around a quarter of the papers explored the design of technologies to support physical activity and were predominantly found in technology journals or technology conference proceedings. The remainder were reviews, either investigating the use and usability of technologies intended for people with later life cognitive impairment or the efficacy of exercise technologies. Here I summarise the relevant findings from the two different perspectives found in the literature, before considering how research to date informs this enquiry.

Fourteen papers described trials of either existing technologies, such as motion-sensing game consoles (e.g. Nintendo Wii) (Hughes *et al.*, 2014; Liao *et al.*, 2019), or novel technologies, including several systems which combined stationary exercise bikes with computerised route-finding games (Anderson-Hanley, Barcelos, *et al.*, 2018; Anderson-Hanley, Stark, *et al.*, 2018; Wall *et al.*, 2018; Karssemeijer, Aaronson, *et al.*, 2019; Karssemeijer, Bossers, *et al.*, 2019). Most systems incorporated some element of virtual reality or gamification (i.e. incorporation of game-like features) for example asking users to ride a specified route through a virtual town while pedalling an exercise bike (Hughes *et al.*, 2014; Anderson-Hanley, Barcelos, *et al.*, 2018; Anderson-Hanley, Stark, *et al.*, 2018; Wall *et al.*, 2018; Wiloth *et al.*, 2018; Karssemeijer, Aaronson, *et al.*, 2019; Karssemeijer, Bossers, *et al.*, 2019; Liao *et al.*, 2019).

Most of these technology-based exercise programmes were found to be beneficial, improving cognition, gait, balance and reducing frailty (Anderson-Hanley, Barcelos, *et al.*, 2018; Anderson-Hanley, Stark, *et al.*, 2018; van Santen *et al.*, 2018; Wall *et al.*, 2018; Wiloth *et al.*, 2018; Karssemeijer, Aaronson, *et al.*, 2019; Liao *et al.*, 2019). Several studies reported that participants enjoyed the programmes (Padala *et al.*, 2012; Dal Bello-Haas *et al.*, 2014; Hughes *et al.*, 2014; Bourrelier *et al.*, 2016). One attributed unexpectedly high adherence to the playful nature of their game-based exercise programme (Wiloth *et al.*, 2018) and another found higher levels of motivation and engagement among exergaming participants (Karssemeijer, Aaronson, *et al.*, 2019). Another fall-prevention programme which did not include gamification reported only a moderate level of enjoyment and adherence (Taylor *et al.*, 2019). Taken together these findings suggest that exergaming technologies may be particularly motivating and enjoyable for people with later life cognitive impairment. Although, several studies found that gaming elements have to be stimulating and adapt to individuals' competencies or else they can either be too difficult or too easy and boring (Anderson-Hanley, Barcelos, *et al.*, 2018; Anderson-Hanley, Stark, *et al.*, 2018; Wall *et al.*, 2018).

The findings of these studies suggest that exercise technologies are likely to be acceptable to people with later life cognitive impairment. However, few studies directly sought participants' feedback on the design or usability of the technologies, and none reported whether participants would choose to use the technologies outside trial settings. Although most of the studies were conducted in community or research settings, one study found that requiring people to travel to use exercise equipment limited participation, suggesting that home-based technologies may be most acceptable (Anderson-Hanley, Barcelos, *et al.*, 2018). None of the studies described involving people with later life cognitive impairment in the design of the technologies or consulting them about their needs and interests. Consequently, despite indicating that technologies could facilitate physical activity and lead to health benefits, these studies provided little information about the types of technologies that might be appropriate for widespread adoption.

Of the seven papers concerned with the design of technologies, only one was directly intended to support exercise, using a humanoid robot to demonstrate seated dance movements. Unfortunately, the authors did not describe anyone with later life cognitive impairment being consulted in the products' development or evaluation, making it hard to assess whether it would be useful, usable or desirable (Schrum, Park and Howard, 2019).

The focus of the remaining studies was on the design of navigation aids or 'safe walking' technologies, predominantly for people with dementia (Robinson *et al.*, 2009; Grierson *et al.*, 2011; Lindsay *et al.*, 2012; Holbø, Bøthun and Dahl, 2013; McCabe and Innes, 2013; Poppinga, Heuten and Boll, 2014). Several of these studies consulted people with dementia about their needs and some of their findings are of relevance to the design of technologies to support physical activity. First, it was found that people with dementia want technologies that support independence and freedom, enabling them to maintain control of their lives (Lindsay *et al.*, 2012; Holbø, Bøthun and Dahl, 2013; McCabe and Innes, 2013). Second, technologies must fit with people with dementia's routines (Lindsay *et al.*, 2012; Holbø, Bøthun and Dahl, 2013). Third, the needs of people with dementia were found to be diverse: in addition to the different forms and manifestations of dementia, people with dementia were found to have a range of fitness levels, personal preferences and values in relation to physical activity, as well as living in different environments which could affect how safe they felt performing outdoor activities (Lindsay *et al.*, 2012; Holbø, Bøthun and Dahl, 2013; McCabe and Innes, 2013).

2.5.3. *Discussion*

These design studies provide some relevant insights into the needs of people with later life cognitive impairment; however, they were not focused on the development of technologies to support physical activity. Further research is required to understand the various needs and preferences of people with later life cognitive impairment, the ways in which technologies to support physical activity might be integrated with people's existing routines and how they might support independence.

Across these studies, various methods were used to include people with dementia in the design process, including focus groups and participatory design activities. They demonstrate that people with dementia can be involved in the design process and that their contribution is valuable. However, the studies also highlighted some of the challenges of involving people with later life cognitive impairment in the design process, which will be considered further in the following chapter, where I discuss my selection of methods.

This section of the review has revealed a paucity of knowledge regarding the design of technologies to support people with later life cognitive impairment to maintain physically active lives. Although exercise technologies have been found to be usable and acceptable in trial settings, it is unclear how they might be integrated into the everyday lives of people with later life cognitive impairment. There is also evidence to suggest that people with dementia may be interested in technologies that support independence, so long as they fit with their routines, however, the degree to which these findings translate to the design of technologies to support physical activity is unclear.

2.6. Discussion

In this section I draw together and discuss the findings of this review to demonstrate the value of this enquiry into the design of technologies to support physical activity.

I consider what types of physical activity might be supported by technologies and what remains to be understood in order to develop technologies that meet the needs of people with later life cognitive impairment. Finally, I describe how the literature transformed the research questions.

2.6.1. Does the evidence warrant the design of technologies to support physical activity?

There is mounting evidence that physical activity can improve cognition in people with dementia and MCI, in addition to wider physical health benefits. Physical activity has also been found to improve people with dementia's functional independence and their capacity to perform activities of daily living. Importantly, there is evidence that physical activity may be more effective than current drug treatments at improving cognition in MCI and dementia. Consequently, physical activity has been advocated as an alternative or adjunct to current drug treatments.

With potentially greater benefits and less likelihood of negative side-effects, interventions that support physical activity may be more appealing to individuals with later life cognitive impairment than drug treatments. If technologies can support physical activity and have a greater impact on cognition at a lower cost, they may also be of particular interest to healthcare providers. However, research to-date has focused on the efficacy of physical activity rather than examining how people with later life cognitive impairment might be practically supported to increase their physical activity levels, outside of research trials. There is evidence that technologies may provide a particularly engaging way to support people with later life cognitive impairment to improve their physical activity levels, however, this review has highlighted a need for further research to identify the most appropriate and acceptable technologies.

Despite potential cognitive and functional benefits, there is a lack of evidence that physical activity can improve mood or quality of life. Without perceived improvements in wellbeing, people with MCI and dementia are unlikely to sustain engagement in physical activity. Building on the recommendations of previous researchers, I decided to focus my research on identifying ways in which technologies might support physical activities that align with the goals of people with later life cognitive impairment, with the overriding aim of improving quality of life.

2.6.2. What types of activity should be supported?

No particular type of physical activity has been identified as providing optimal cognitive benefits. It has, however, been identified that there is a lack of research into the types of physical activity that are most acceptable to people with later life cognitive impairment. Rather than designing a technology around a specific form of physical activity, the findings of this review suggested a need to first establish which types of physical activity are acceptable to people with later life cognitive impairment.

There is evidence that low levels of physical activity may be effective at improving cognitive function in people with dementia. It has been argued that interventions aimed at people with dementia, as well as older adults more broadly, should aim to reduce sedentariness by promoting physical activity throughout the day, rather than bouts of strenuous exercise. This approach complements findings that older adults tend to be averse to formal or strenuous physical activity. Together these findings indicated a need to identify ways to encourage and enable people with later life cognitive impairment to be more active throughout their daily lives.

Maintaining independence and contribution is important to older adults, who tend to associate physical activity with purposeful occupation. However, such activities may become difficult, particularly for people with dementia, and loss of capacity or motivation to engage in everyday activities may contribute to sedentariness. Independent activity may also be curtailed by the concerns of individuals with cognitive impairment or their caregivers. Rather than promoting exercise per se, these findings indicate a need for technologies that support independence and avert sedentariness by helping people to maintain valued purposeful activities.

Walking has been identified as a major source of physical activity for older adults and has been found to be particularly valued by people with dementia, providing a sense of freedom and pleasure in physical movement. However, the degree to which people with later life cognitive impairment are able or comfortable to walk out alone is unclear. Perhaps in response, people with dementia have been found to be interested in technologies which support independent walking. On the other hand, there are also indications that social aspects of walking are valued by people with dementia. The findings of this review suggest an opportunity for technologies that support people with later life cognitive impairment to walk out, either independently or with others. However, to develop effective technologies, there is a need for further understanding of the motivators and barriers to walking.

For people with dementia, routines have been found to be an important factor in maintaining an active life. However, to date, there has been little exploration of the everyday physical activity routines of people with later life cognitive impairment. It has also been found that people with dementia want technologies to fit with their routines. To inform the development of technologies to support physical activity, there is a need for further research to understand the daily routines of people with later life cognitive impairment.

2.6.3. What roles could technology play?

The findings of this review indicate that people with later life cognitive impairment are interested in technologies that support independence and their ability to maintain control of their lives. In line with these priorities, several potential opportunities for technologies to support physical activity have been identified. Technologies that enable people to engage in purposeful, physically active tasks throughout their day may be particular useful in increasing the activity levels of those who are largely sedentary and disinclined to engage in formal or effortful exercise. Technologies that help people with later life cognitive impairment to walk out independently or with others may also be valued. For those who are interested in more structured exercise, exergaming may be appealing.

Research with people with dementia suggests that technologies that support physical activity are likely to be more acceptable and useful if they fit with or support people's existing routines. These findings led me to focus on understanding the active lives of people with later life cognitive impairment including the barriers motivators and facilitators of everyday physical activity that might be addressed by technologies.

2.7. Research questions

In this section I describe how my review of existing literature informed the study aims and led to the questions for empirical research.

The initial research brief was to explore the potential for technology to help people with dementia, particularly around physical activity. Evidence that physical activity can have cognitive and wider health benefits, potentially greater than those offered by current drug treatments, led me to focus the research on physical activity. Indications that early engagement in physical activity may have the greatest impact, meant that I also chose to include people with MCI in the research while excluding those with advanced dementia, who were likely to have very different needs.

My initial intention was to use the literature review to identify a specific type of physical activity on which to base technology development. However, no one type of physical activity appeared to be preferable for health. Instead, the literature indicated a need for further research into the preferences of people with later life cognitive impairment as well as the ways in which physical activity might be integrated into people's lifestyles and routines.

Existing research into the factors effecting physical activity participation among people with later life cognitive impairment was limited, and the interview approach used in previous studies did not provide a full picture of the active lives of people with later life cognitive impairment. Therefore, the research was broken down into two stages, first to examine the everyday physical activity experiences of people with later life cognitive impairment and then to design technologies in response. This led to the following research questions:

1. What are the everyday experiences of physical activity for people with later life cognitive impairment?
    a. What are the barriers and motivators of physical activity?
    b. Do people with later life cognitive impairment use any strategies to maintain physically active lives?
    c. Are there any facilitators that support activity?
2. How might digital technologies enable people with later life cognitive impairment to maintain or increase their physical activity levels?

In order to develop technologies that responded to the needs of people with later life cognitive impairment I chose to employ design research methods within a human-centred design process. While there is growing recognition that people with later life cognitive impairment should be included in the design process, evidence regarding the best way to do this is limited (Span *et al.*, 2013; Meiland *et al.*, 2017). Consequently, to further knowledge about appropriate methods, this research also sought to understand:

3. How might design research methods be employed to include people with later life cognitive impairment in a human-centred design process?

In the following chapter I explain my decision to take a human-centred approach and describe the design research methods used.

Chapter 3. Methods

3.1. Introduction

In this chapter I describe the methods used to address the research questions. I start in section 3.2 by explaining my decision to use a human-centred design methodology. Then, in section 3.3 I provide an overview of the three-stage human-centred design research process undertaken for this enquiry. The sampling and recruitment of participants is detailed in section 3.4. In section 3.5 I discuss two, important ethical considerations of this research: gaining informed consent and discussing sensitive topics.

Subsequent sections detail the methods and procedure for each of the three research stages. In section 3.6 I describe the first stage of the research in which diary-probe led interviews were used to explore participants' everyday experiences of physical activity. Section 3.7 provides details of the data analysis process. Section 3.8 describes the second stage of the research, in which teams of researchers, engineers and designers generated concepts for technologies to support physical activity in design workshops. Section 3.9 describes the focus groups undertaken in the third stage of the research to gain participants' critique of technologies to support physical activity.

3.2. Methodology

The marginalisation of people with dementia from research and their exclusion from the development of products and services that affect them has been widely criticised (Bond and Corner, 2001; Clarke and Keady, 2001; Hellström *et al.*, 2007; Robinson *et al.*, 2009; Span *et al.*, 2013; Meiland *et al.*, 2017). It is increasingly recognized that people with dementia can make valuable contributions to research and design and that they should be consulted to ensure that products and services reflect their needs and interests (Hellström *et al.*, 2007; Meiland *et al.*, 2017; Novek and Wilkinson, 2017). From a research perspective it is recommended that studies be carefully and sensitively designed to ensure that people with cognitive impairment can make meaningful and effective contributions (Clarke and Keady, 2001; Novek and Wilkinson, 2017). In this section I consider appropriate methodologies for including people with later life cognitive impairment in design-research.

It is generally accepted that engaging with users during the design process is likely to produce more usable, acceptable and satisfying outcomes (Kujala, 2003; International Organization for Standardization, 2010; Steen, 2011). However, different design methodologies involve users to varying degrees. In human-centred design, users tend to be passive subjects of research, who might be interviewed or observed by a researcher who then reports their findings to a design team in order to inform the design process. On the other hand, in participatory or co-design approaches, users and other stakeholders are directly involved in design activities, collaborating with designers to generate concepts, make design decisions and develop prototypes (Sanders and Stappers, 2008; Sanders, Brandt and Binder, 2010; Steen, 2011).

By involving users directly in participatory or co-design, not only are users able to guide the design process towards solutions that address their needs, power can shift from designers to users, making these processes emancipatory, particularly for marginalised groups (Sanders and Stappers, 2008; Steen, 2011). Reflecting on these potential benefits, I initially considered undertaking co-design with people with later life cognitive impairment. However, previous studies have identified potential barriers to this approach with people with dementia.

In their reflections on several years of participatory designing with people with dementia, Hendriks *et al.* (2014) described how people with dementia could become frustrated when they were asked to make choices, had limited capacity to take initiative and found it difficult to deal with abstract concepts and visual methods of communication. Lindsay *et al.* (2012) also described difficulties engaging participants with dementia in abstract thinking and criticism. Mayer and Zach (2013) found that participants with dementia had difficulty describing their experiences and needs, suggesting that individuals with dementia were, at times, unaware or unwilling to discuss the problems that they faced. They also found that fluctuating moods and limited attention-span effected people with dementia's capacity to participate in co-design activities. Hendriks *et al.* (2014) concluded that participatory design can be unappealing and even stressful for people with dementia.

Attempts to address the challenges of involving people with cognitive impairment in the design process have had practical and ethical consequences. Some studies have excluded people with more severe forms of cognitive impairment from design activities (Lindsay *et al.*, 2012; Mayer and Zach, 2013). In Lindsay *et al.*'s 'modified' participatory approach, after starting exploratory research with sixteen people with dementia, they chose to focus on designing for two participants with mild impairments, excluding other participants considered less capable of engaging in design activities. By focusing only on those with dementia who are able to contribute directly to the design process, the needs of people with more severe cognitive impairment may be overlooked.

As in Lindsay *et al*'s study, Holbø, Bøthun and Dahl (2013) and Wallace, Wright *et al.* (2013) chose to work with individuals with dementia to develop tailored design solutions, thereby avoiding potential difficulties of undertaking co-design with groups of people with dementia, including the challenges of thinking abstractly about the needs of others (Lindsay *et al.*, 2012). This approach may limit the transferability of design solutions to the wider population. This limitation is not exclusive to design for people with dementia, it has been noted that participatory design can become overly focused on the needs of those who are able or available to participate, thereby failing to address the diverse needs of a population (Bratteteig and Wagner, 2016).

Although several studies describe themselves as participatory or co-design, the extent to which people with dementia actually participated in designing artefacts or made design decisions is often limited or unclear. In some studies design-research methods, such as design probes, were used to collect information about the needs, interests and experiences of people with dementia, which were then used by designers to generate concepts, rather than involving people with dementia directly in design activities (Mayer and Zach, 2013; Wallace, Wright, *et al.*, 2013). Although Lindsay et al. (2012) appeared to include people with dementia to the greatest extent, a significant amount of the design work appeared to be conducted by a team of designers who had little or no interaction with participants with dementia. Although described as a 'modified' participatory method, their approach appeared to be closer to human-centred design.

Together these findings suggest that participating in design activities may be difficult for people with dementia, could lead to frustration and potentially be upsetting. The wellbeing of participants must be the primary consideration in study design. Requiring people with dementia to participate directly in design activities could also prevent those with more severe impairments from contributing. For the purposes of this investigation, the potential benefits of participatory and co-design approaches had, therefore, to be carefully considered.

The aims of the research also had to be considered in my choice of methodology. While previous studies have worked with individuals with dementia to develop bespoke design responses, this approach was not considered suitable in this study, which sought to identify more broadly relevant, commercially viable technologies. Therefore, I needed to select a method which would allow me to work with several people with later life cognitive impairment, in order to identify common needs and preferences.

Reflecting on the potential ethical and practical limitations of co-designing with people with later life cognitive impairment, I decided that a human-centred approach would be more appropriate as it would allow a range of people with different degrees of cognitive impairment to participate and express their needs and preferences without having to participate directly in demanding design activities. Human-centred design is an iterative, cyclical process. It typically begins with a research stage, in which user requirements are investigated, and the context in which a product might be used is explored. Design solutions are generated in response to user requirements and then evaluated or tested by users to inform subsequent cycles of product development until a satisfactory solution is achieved.

Building on the previous successful use of design-research methods to involve people with dementia in the design process, I chose to employ design probes in this enquiry. As well as providing a rich understanding of users' perspectives, wishes and desires, design probes can support a degree of participatory engagement as participants become active contributors in the research process, able to reflect upon and curate their responses. Probes can also support dialogue, allowing participants to lead discussions, as experts in their own experience, potentially overcoming imbalances of power with researchers (Wherton *et al.*, 2012). The adaptation of the design-probe method to this research is described in section 3.6.

Having chosen to take a human-centred approach, I intended to undertake several cycles of design and user evaluation, hoping that users' feedback would inform the design process and lead to relevant solutions. However, time constraints meant that I was only able to complete one phase of design and evaluation (the ramifications of which are discussed in Chapter 9). The final process is described in the following section and shown in Figure *3.1*. I then go on to describe the choice of methods for each stage of the research in the remainder of this chapter.

3.3. Research process overview

The research was divided into three stages, as illustrated in Figure *3.1*. The first, user-research stage aimed to address the initial research questions:

1. What are the everyday experiences of physical activity for people with later life cognitive impairment?
    a. What are the barriers and motivators of physical activity?
    b. Do people with later life cognitive impairment use any strategies to maintain physically active lives?
    c. Are there any facilitators that support activity?

These questions were explored through diary-probe led interviews with fifteen people with later life cognitive impairment and their spouses. The reason for choosing to combine design-probe, diary and interview methods are described in section 3.6. The sampling choices and recruitment process are discussed in section 3.4.

Stages two and three of the research aimed to address the second research question:

2. How might digital technologies enable people with later life cognitive impairment to maintain or increase their physical activity levels?

In the second stage of the research concepts for technologies to support physical activity were generated. The concepts were developed in three design workshops, which engaged the expertise of design, engineering and health-research professionals from Philips and Newcastle University’s MoveLab. Findings from the first stage of the research were communicated to workshop contributors using quotes and personas. This choice of methods and the workshop process is described in section 3.8.

In the third stage, participants were asked to evaluate concepts for technologies to support physical activity in focus groups, as described in section 3.9.

Thematic analysis was used to analyse data from each stage of the research and is described in section 3.7.

By applying and examining the utility of various design-research methods, I also sought to address the third research question:

3. How might design research methods be employed to include people with later life cognitive impairment in a human-centred design process?

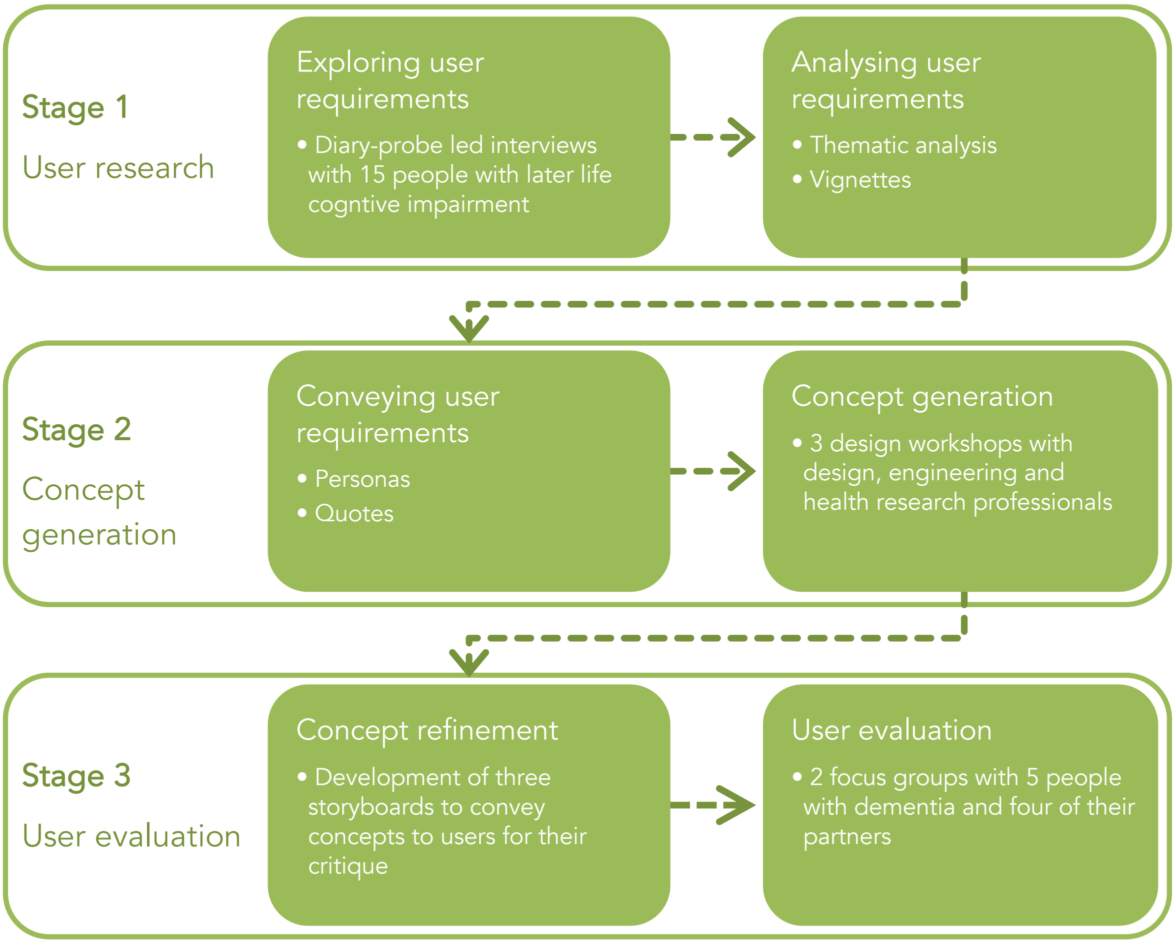

Figure 3.1: Research and design process

3.4. Sampling and recruitment

In this section I start by explaining my sampling approach, after which, I outline the recruitment process and inclusion criteria. The decision to include partners (or other family members or friends) in the research is also discussed before the final sample is described.

3.4.1. Sampling in human-centred design and qualitative research

Although qualitative research methods are commonly used in human-centred design, there is little guidance about appropriate sample sizes specific to human-centred design. One approach in qualitative research is to recruit until data saturation is achieved, i.e. when new data does not add to the findings (Mason, 2010; Boddy, 2016). This approach makes predicting sample sizes difficult. Guidelines suggest anywhere between 12 and 40 participants may be required, depending on the heterogeneity of the sample (Boddy, 2016). However, it is also recognised that the quantity of data has to be balanced against the time and resources available for meaningful analysis (Sandelowski, 2007; Boddy, 2016). With this guidance in mind, I aimed to recruit between 12 and 20 people with later life cognitive impairment to the initial research stage. The intention was to recruit until sufficient data was collected to inform subsequent stages of the design process.

Previous researchers have found that recruiting participants with dementia can be challenging (Cridland *et al.*, 2016). Consequently, a convenience sampling strategy was employed in this research, although a balance between participants with MCI and dementia was sought to ensure that both groups were represented in this study.

3.4.2. Recruitment process

People with mild dementia and MCI were recruited from VoiceNorth (a Newcastle University-based organisation that engages older adults in research) and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) who held a database of National Health Service (NHS) patients interested in participating in research. Potential participants were initially contacted by phone or email. Those who were interested in the research were sent a letter of invitation (appendix C) and an information sheet, (appendix D) which asked them to call me if they wanted to take part in the research. As well as answering any questions they had, during this call I asked a series of screening questions to ascertain whether individuals met the following inclusion criteria:

1. Self-reported diagnosis of a progressive form of dementia or MCI.
2. Able to converse in English.
3. Community dwelling (i.e. not living in residential care facilities).
4. Not participating in other research.
5. Age 18 or over.
6. Capable of meaningful participation in interviews or focus groups.
7. Able to give consent.

A more detailed description of the recruitment process can be found in appendix B.

For those with dementia, the intention was to only recruit those with mild dementia. However, testing people's cognition (for example using the Mini Mental State Examination) was considered inappropriate and potentially upsetting. Instead, participants were selected based on their capacity to discuss their condition, to take part in the research and provide consent. This was established during an initial screening call and introductory interviews (described in more detail in appendix B). In addition, DeNDRoN were able to select potential participants whose most recent cognitive assessment indicated that their dementia was mild, however these were not always current. Consequently, although participants with dementia could not definitively be said to have 'mild' dementia, they were assessed to have a level of cognitive impairment typical of people in the early stage of dementia.

In the initial screening call I gave participants with cognitive impairment the option to invite a partner, family member or friend to participate in the research. The decision to offer participants the opportunity to invite partners is discussed below. If this individual was willing to participate then they were also screened against the inclusion criteria provided in appendix B.

Participants were initially invited to the first stage of the research only, as I did not want participation to appear too onerous. However, at the end of the first stage of the research participants were asked if they would like to participate in future stages of the research. After the first stage of the research, I decided to focus on the needs of people with dementia and, as such, only participants with dementia and their partners were invited to the final stage of the research (this decision is described in detail in section 6.9). Interested participants were sent a letter of invitation and information sheet describing the focus groups.

3.4.3. Including partners

The inclusion of partners and other caregivers had to be approached with caution. Historically, caregivers have been used as proxies, with their perspectives being seen as more valid than those of people with dementia (Hellström *et al.*, 2007; Ablitt, Jones and Muers, 2009). Aside from the moral implications of prioritising caregivers views, caregivers have been found to be poor at judging the capabilities of people with dementia and their feelings about living with cognitive impairment (Cotrell and Schulz, 1993; Zanetti *et al.*, 1999; Loewenstein *et al.*, 2001). Basing the design of products and services on caregivers accounts is also problematic as they may have different or even conflicting priorities and interests (Hawkey *et al.*, 2005).

There were, however, several potential benefits to including partners and other caregivers in this research. People with later life cognitive impairment may feel more comfortable participating in research with a familiar individual present (Cotrell and Schulz, 1993). Caregivers may also help people with later life cognitive impairment to recollect events or articulate themselves (Mason and Wilkinson, 2002; Lindsay, 2012) and their contribution may provide further insights into the experiences of people with later life cognitive impairment (Clarke and Keady, 2001; Hellström *et al.*, 2007).

Clarke and Keady (2001) also argue that the role of caregivers should not be neglected as the adjustment to living with dementia is a process of family as well as personal adaptation. In this study, understanding the perspectives of partners and other caregivers was particularly important since previous research indicated that partners can effect each other's physical activity behaviours, and that the partners of people with later life cognitive impairment may facilitate activity (Hellström, 2005; Cedervall and Åberg, 2010; Dean and Wilcock, 2012; Li, Cardinal and Acock, 2013; Cobb *et al.*, 2016). Given the interconnectedness of people's active lives, insights into the needs and interests of a partner (or other close relation) had the potential to improve the effectiveness of technologies to support physical activity.

Considering these issues, I decided to give participants with later life cognitive impairment the option to invite a partner, close family member or friend to participate in the research, if they wanted. However, where partners were invited to participate I took steps to avoid caregivers' voices becoming prevalent, ensuring that I sought responses from participants with cognitive impairment, rather than relying on caregivers' accounts (Lindsay, 2012) as well as attempting to verify caregivers own comments with people with later life cognitive impairment (McDuff and Phinney, 2015).

3.4.4. Final sample

15 participants with later life cognitive impairment were recruited (4 from VoiceNorth and 11 through DeNDRoN) to the first, diary-probe led interview stage of the research. The sample size was limited by both time constraints and the availability of participants through these routes.

Participants with MCI were more readily available than those with dementia. Consequently, of the first eight recruits, seven had MCI. To ensure a balanced sample, in the later stages, recruitment shifted towards people with dementia. In addition, as the interviews were analysed it became increasingly apparent that the focus of the research should be on people with dementia, so the recruitment strategy shifted to exclusively enrolling people with dementia. This semi-purposive sampling led to a final sample of seven people with MCI and eight people with dementia for the first stage of the research.

All participants lived in the North East of England. Some participants lived in cities while others lived in suburbs, towns or country villages. Participants with cognitive impairment ranged in age from 56 to 83 with a mean age of 74. Seven were female and eight were male. Two participants were single and the remaining 13 lived with a spouse. Four participants with MCI and seven with dementia chose to take part with their spouses. Further demographic details about the participants can be found in section 4.2.

At the end of the first stage of the research, all of the participants expressed an interest in continued participation. However, only those with dementia and their partners were invited back, as the research focused on designing for people with dementia after the first stage. For the focus groups (in the third stage of the research), five people with dementia and four of their spouses responded to my invitation and were able participate.

3.5. Ethical considerations

This research was conducted with the approval of the NHS National Research Ethics Service Committee South West - Exeter. To gain this approval, the ethical conduct of the research had to be carefully considered. Two issues of particular concern in this study were gaining informed consent and discussing sensitive topics.

3.5.1. Informed consent

The law in England and Wales, requires that research participants give their informed consent to intrusive research, including that which involves the collection of personal data (*Mental Capacity Act 2005*; Dobson, 2008). Although the cognitive capacity to make informed decisions is fundamental to consent, a diagnosis of dementia or mild cognitive impairment does not preclude an individual from providing informed consent (Dewing, 2002; McKeown *et al.*, 2009; Cridland *et al.*, 2016). What's more, the Mental Capacity Act 2005 states that assumptions must not be made about a person's capacity to consent based on their age, condition or behaviour and that *"all practicable steps" (Mental Capacity Act 2005, p9)* should be taken to enable people to make an informed choice. Several strategies are advised to maximise the capacity of people with cognitive impairment to give informed consent, including: tailoring information and consent forms, having face-to-face preliminary meetings and verbally explaining information sheets (Dewing, 2002; Cridland *et al.*, 2016). In the remainder of this section, I detail how this research was designed to support informed consent.

Following the recommendations of people with dementia (The Dementia Engagement and Empowerment Project, 2013; truthfulkindness, 2014), the information sheets and consent forms (see appendices D and E) were designed to be easy to read and understand. Adaptations included using plain English in short sentences with one piece of information per sentence. Text was presented in a 12 point, sans-serif font, on a contrasting background. Images were added to aid understanding and recall. Photographic images were used rather than icons, as abstract images can be confusing for people with dementia. The information sheets and consent forms were reviewed by a staff member at the Alzheimer's Society to assess their clarity. Participants were sent paper copies of the information letter in advance of any meetings. A larger print and audio version were also offered.

The judgement of participants capacity to consent was a staged process. First, the letter asked participants to call or email me if they were interested in participating and to provide an initial indication that they had understood the information sheet. Next, at the initial phone call[2], potential participants were asked a series of

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[2] Participants were given an opportunity to answer the questions at another time if it was not convenient during their initial call.

questions to ascertain their capacity to communicate and their understanding of the information provided about the research (see screening questions and example screening form in appendices F and G). If potential participants were still interested and appeared likely to be able to give consent, a further meeting was arranged at a time and place they felt comfortable meeting.

At our first meeting, further discussion with potential participants about the research was used to assess their comprehension of the information sheet. Where necessary, prompts were used to establish capacity to provide informed consent (see appendix I). For instance, I might ask potential participants if they had any questions about the research to see whether their response was relevant to the study. If participants demonstrated capacity, then I showed them the consent form and offered to read it with them. If they preferred to read it themselves then I made it clear that there was plenty of time to read and complete the form, finding another activity to busy myself with (such as setting up the audio recorder) so that they did not feel under pressure. Although none of the participants in this study were deemed incapable, the contingency if a participant did not appear to have capacity was to explain that, unfortunately I did not feel that the research activities were suitable for them this point. Participants with MCI, dementia and their partners were treated equally.

As well as seeking consent at the outset of the research, as recommended in dementia research and qualitative research more widely (Dewing, 2007; McKeown *et al.*, 2009; Wiles, 2012; Cridland *et al.*, 2016) ongoing consent was sought. At subsequent interviews and focus groups participants' consent was re-sought, their capacity assessed, and a new consent form completed. As recommended when conducting research with people with dementia (Hubbard, Downs and Tester, 2001; Dewing, 2007; Novek and Wilkinson, 2017) I was also alert to any signs of distress or reluctance to participate. Participants were also made aware that they could withdraw from the research at any point, without giving a reason.

3.5.2. *Discussing sensitive topics*

Although the enquiry focused on physical activity in everyday life, the research activities were likely to prompt reflection on the disabling effects of cognitive impairment and possibly on future decline. The potential for psychological harm resulting from this research was addressed in a number of ways. First, potential participants were informed, in the information sheet, that they would be asked about their experiences of having memory problems and that this could be upsetting (see appendix D). Participants were, however, informed that they would not be obliged to talk about anything they were uncomfortable with and could withdraw at any point. Second, as discussed previously, care was taken to attend to signs of distress or reluctance to answer any questions. Should this happen, the protocol determined that I should reiterate that the participant did not have to talk about anything that they did not want to and that they could withdraw. Third, since negative emotions may have emerged following engagement in the research, the contact details of appropriate support services were provided in the information sheet.

In addition, while the research targeted people with a diagnosis of MCI or dementia, since diagnostic terms vary, suitable and sensitive terminology had to be used that would not cause unnecessary distress. A person with dementia can be diagnosed with Alzheimer's disease and be unaware that it is a form of dementia or may not even recall their diagnosis. Previous research has also highlighted that people with cognitive impairment may be uncomfortable with the diagnostic label they have received (Pratt, 2001; Bartlett and Martin, 2002; Novek and Wilkinson, 2017). As a result, following the guidance of previous researchers, I chose to use the catchall term 'memory problems', in information materials and at the outset in interactions with participants (Pratt, 2001; Bartlett and Martin, 2002; Hellström *et al.*, 2007). However, if in conversation participants used a specific term, such as dementia, to describe their condition and appeared comfortable doing so, then I followed their lead.

3.6. Stage one: Diary-probe led interviews

The aim of the first stage of the research was to explore the everyday experiences of physical activity for people with later life cognitive impairment, to identify barriers and motivators to engaging in physical activity, as well as the strategies and facilitators that enabled people to maintain physically active lives. In this section I describe the rationale for my choice of methods before describing the novel diary-probe used in this study and the conduct of follow-up interviews.

3.6.1. Rationale for a diary-probe approach

Previous research into people with later life cognitive impairment's experiences of physical activity has tended to employ interviews, to gather participants' retrospective accounts and reflections, with limited exploration of the wider context of physical activity as it is interwoven into everyday routines (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). A limitation of using interviews, in this context, was that they are a poor method for finding out what people do, particularly the unremarkable, everyday experiences which I sought to explore through this investigation (Bryman, 2012; Green and Thorogood, 2013). Furthermore, interviews can be challenging for people with dementia due to memory problems and communication difficulties (Clarke and Keady, 2001; Cridland *et al.*, 2016). One alternative would have been to observe people's everyday activities; however, this was considered excessively intrusive. In addition, observation can change people's behaviours, and, for those with cognitive impairment who may experience difficulties performing everyday tasks, being observed could make them feel particularly uncomfortable (Bryman, 2012).

Another option was to ask people to record their daily activities in a diary. Diaries offer several advantages over interviews: they can capture participants' experiences over a period of time (Green and Thorogood, 2013), mitigate memory loss and reduce retrospective distortions or generalisations (Alaszewski, 2006). Milligan, Bingley and Gatrell (2005) found diaries to be useful in health research for revealing taken-for-granted aspects of people's daily lives. Bartlett (2012) successfully used diaries in a study with people with dementia. Participants were given the option to provide written, photo and/or audio diary entries. Bartlett found that all three methods captured useful contextual information about people's lives and that the recording process stimulated reflection. Bartlett combined the diaries with follow-up interviews, which she found valuable and recommended for future research. This positive example indicated that combining diary keeping with interviews could provide contextual information about participants' everyday lives as well as enabling people with cognitive impairment to express themselves, reflect on their experiences and facilitate recall.

In a human-centred design context, design probes are used to gather insights into users' experiences. Typically, a design probe is a collection of engaging artefacts (e.g. cameras, maps, diaries) packaged together and given to participants to allow them to capture aspects of their lives. Derived from 'cultural probes'—originally conceived as a subjective method for capturing fragmentary insights into people's lives to provide inspiration to design teams—probes have been appropriated as an ethnographic tool, used to gather insights into users' lives to both inform and inspire the design process (Gaver, Dunne and Pacenti, 1999; Gaver, 2004; Mattelmäki, 2006; Wherton *et al.*, 2012).

Design probes offer a number of potential benefits over conventional qualitative research methods. Compared to observation, probes are an unobtrusive way to gain a rich understanding of users' experiences as well as their associated thoughts and feelings. Probes can be particularly valuable in capturing taken-for-granted aspects of everyday life, with visual tools, such as disposable cameras, also capturing the context in which people perform everyday activities. Unlike in interviews, by completing design probes, participants are actively involved in the research process as they collect and curate materials that document and explore their actions and experiences (Mattelmäki, 2006; Wherton *et al.*, 2012). As with the combined diary-interview method, probes may be augmented by follow-up interviews. Using participant-curated probes to ground interview discussions can transfer the power balance from the researcher towards the participant (Wherton *et al.*, 2012). Furthermore, probes can include participatory elements, which allow participants to reflect on their experiences to imagine the types of products or services that might be valuable to them (Mattelmäki, 2006).

Probes have been successfully employed in dementia research by Wallace, Wright *et al.* (2013), who reported that their probes supported reflection and recall as well as facilitating dialogue between the researcher and participant. In their work with older people, Wherton *et al.* (2012) also found probes to be a useful way to gain insights into participants' day-to-day activities, including subtle, idiosyncratic aspects of people's experiences that might otherwise have been overlooked in interviews. They found that reviewing photographs and other materials, generated as part of the probes, reduced formality, allowing participants to set the agenda and lead interview conversations. Probes were also found to be useful memory aids, helping participants to recall key events and routines.

The experiences of previous researchers suggested that both diary and design probe methods offered benefits for this enquiry. Combining aspects of diaries and probes provided the potential to not only address the aims of this stage of the research but to expand upon previous research, which has tended to rely on interview accounts. However, the limitations and challenges of using diary and probe methods also had to be considered.

The ways and extents to which participants engage in probe and diary-keeping can vary. Participants' motivation may wain, and fatigue or boredom can occur in longer studies. Written diaries rely on the literacy of participants. In addition, the disruption to participants' lives must be considered as well as the emotional impact of recording and reflecting on difficult issues in one's life (Elliott, 1997; Meth, 2003; Jacelon and Imperio, 2005; Alaszewski, 2006; Mackrill, 2008; Bartlett, 2012; Wherton *et al.*, 2012).

To address these limitations, previous researchers have offered participants a variety of methods of recording their experiences, including written, audio and visual recording. They have provided face-to-face explanations as well as written instructions about how to complete diaries and probes. Both diary and probe studies are often followed by interviews, which allows for the inclusion of individuals who provide limited or no responses to the diaries or probes (Jacelon and Imperio, 2005; Alaszewski, 2006; Mackrill, 2008; Bartlett, 2012; Wherton *et al.*, 2012). Jacelon and Imperio (2005) recommend that diary studies last for two weeks at most, and that participants are telephoned during the diary keeping period to improve completion. The experiences and advice of previous researchers were taken into consideration in the design and delivery of the diary-probe.

3.6.2. Diary-probe design

Building on findings outlined in the previous section I chose to develop a hybrid diary-probe, to engage people with later life cognitive impairment in recording and reflecting on their everyday experiences of physical activity. The final diary-probe can be found in appendix H. A six-day diary was chosen so that a variety of weekday and weekend activities were recorded without overburdening participants. As well as the diary activities, participants were asked to complete some more probing activities. For example, on day three, the diary invited participants to illustrate common journeys on a series of maps, starting with a map of their local area (centred around participants homes) and gradually zooming to larger geographical areas. The primary intention of this map activity was to understand people's travel and transport choices, including how far they normally walked; however, it was also hoped that the exercise would prompt participants to discuss their motivations for engaging in activities outside the home.

In another probe activity participants were asked to colour the outline of a mannequin in red for ‘troublesome bits’ and yellow for ‘good bits’ in order to investigate the relationship between physical- and cognitive-health related barriers to physical activity.

Several activities during the week suggested that participants might take photographs using a digital Polaroid camera that was provided with the diary-probe. It was hoped that providing opportunities for visual recording would offer those who were less confident about writing an alternative method of communication, as well as providing visual insights into the context of people’s active lives. The digital Polaroid allowed participants to print their photographs and stick them into the diaries so that they could be discussed in the follow-up interviews. I provided step-by-step instructions for using the camera within the diary booklet.

On the final day of diary keeping participants were asked to imagine something that would make a difference to their lives and were given a blank space to fill with a picture, sketch of description. The intention of this exercise was to give participants an opportunity to tell me about something that they would find useful, with the hope that they may reflect on their diary keeping to envisage a product or service to support physical activity.

For each activity, I limited the space for responses so that participants did not feel overwhelmed by the task or unsure about the extent of the response required, as advised by Wallace, McCarthy, *et al.* (2013). However, I also included two blank pages at the end of the diary so that participants could expand upon their responses if they wished.

The diary-probe and Polaroid cameras were packaged in a gift bag along with pens, pencils and sticky notes for completing the different activities. The diaries were personalised, with participants' names on the front and the maps activity was centred on individuals' homes. This combination of personalisation and gift-like presentation has been recommended in the design of probes, to signify respect towards research participants (Mattelmäki, 2006). It was hoped that the design of the diary and the mixture of different activities would motivate participants' engagement.

Although a paper version of the diary was produced, I anticipated that some participants may require alternative formats and was prepared to allow participants to make digital or audio records, depending on individual circumstances.

3.6.3. Semi-structured interviews

I conducted two semi-structured interviews with participants, before and after they completed the diary. At the first interview, I presented the diary-probe to participants. After following the consent process described in section 3.5.1., I asked participants some questions about themselves (see appendix I for the interview guide) before describing each of the activities in the diary and answering participants' questions about the research. I also explained how to use the camera. At the end of the interview, I arranged the follow-up interview, for the subsequent week in most cases[3]. The initial interviews lasted around 50 minutes. During the week of diary keeping, I phoned participants to check that they were happy with the diary activities and still wanted to meet for the follow-up interview. As well as responding to any questions the participants had, this call was intended to prompt participants, in case they had not been completing the diary.

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[3] In one case a participant was due to go on holiday the following week, so a later appointment was arranged. Unfortunately, she then forgot to complete the diary, so the appointment was rearranged so that she could complete the diary.

The second interview was primarily guided by participants' diary responses, although a topic guide was created to ensure that issues of relevance to the research were covered in the discussion (see appendix J). For example, if we were discussing the maps activity, I might first ask a participant about the places they had marked on the maps, then I might enquire why they went there, how they got there and who they went with. The topic guide was sometimes modified to explore issues raised in the first interviews, for example if participants had mentioned an active hobby. These second interviews lasted around two hours on average.

Although it has been recommended that interviews be conducted at the homes of individuals with dementia (Cotrell and Schulz, 1993; Clarke and Keady, 2001), to allow for individuals' personal preferences I gave them the option to be interviewed at home or another place they felt comfortable, as recommended by Novek and Wilkinson (2017). Thirteen participants with cognitive impairment chose to be interviewed in their homes. Two participants preferred to be interviewed at Newcastle University.

Each interview was audio recorded for transcription and analysis. Audio recording was chosen over video recording as video was considered to be unnecessarily intrusive and potentially off-putting to participants. Audio recording devices can be discrete, whereas video capture requires a device to be set up and pointed at the interviewee, which may make them overly conscious of being recorded. Analysis of visual cues and body language was also beyond the scope of the research and, as such, video recording was considered unnecessary. As I did not have a justification for videoing the interviews, I considered it inappropriate and therefore unlikely to be acceptable to the ethics committee, as I would be collecting unnecessary visual data from potentially vulnerable participants while they were discussing highly personal, sensitive issues, in their homes. As I was conducting the interviews, I was able to note relevant visual cues. It was also hoped that any visual materials that participants felt were relevant to their active lives (for example physical barriers to activity around the home) would be included in the diary probe, at the participants discretion.

3.7. Data analysis

A thematic approach to data analysis was chosen for this study. Widely used in qualitative research, thematic analysis allows researchers to identify common patterns or themes in a data set (Braun and Clarke, 2006; Guest, MacQueen and Namey, 2011). Thematic analysis was considered appropriate for this enquiry as it has been successfully used to explore users' behaviours in previous design research studies, including diary and focus group studies, and has proved valuable in informing the design of new technologies (Brown and Stockman, 2013). Less theoretically and technically complex than other approaches, thematic analysis is also considered particularly accessible to novice qualitative researchers.

Other methods such as interpretative phenomenological analysis (IPA) and grounded theory were discounted because they have specific objectives that were not relevant to this research.

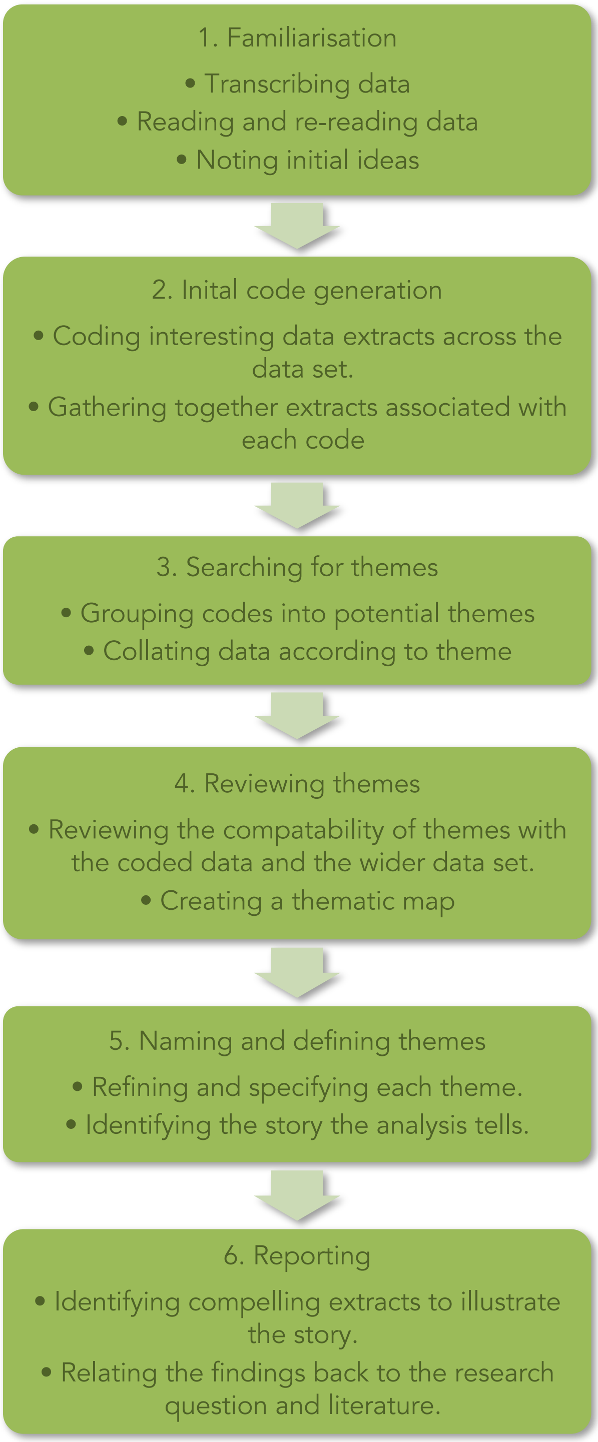

Figure 3.2: Thematic analysis process as prescribed by Braun and Clarke

In this research, the process of thematic analysis was informed by Braun and Clarke's (2006) method, as illustrated in Figure 3.2. Braun and Clarke describe two approaches to thematic analysis; an inductive, bottom-up approach, where themes arise from data and a deductive, top-down approach, in which data is analysed in relation to a predetermined theory or research questions. An inductive approach was chosen for this study because it corresponded with the principles of human-centred design, allowing findings to be driven by participants' accounts rather than by preconceived ideas or expectations about their needs or the design outcome. An inductive approach offered the potential for latent user needs, unexpected preferences or unforeseen challenges to be uncovered.

Data from all three stages of the research were analysed using thematic analysis. Interviews, focus groups and workshops were all audio recorded, with participants' consent. The audio was transcribed verbatim and anonymised before analysis. Although a professional agency was used to transcribe the scripts, I listened to recordings multiple times to familiarise myself with the data, to check transcript accuracy, anonymise the data and add comments about inflections or tone that effected meaning. The NVivo software program was used to facilitate coding. Participants' diaries were scanned and anonymised and used to support interpretation of the interview data but not coded themselves since the interviews elaborated on the diary responses. Mind mapping software was also used to facilitate the analytic process.

Although data analysis was guided by Braun and Clarke's linear method, in reality the process was iterative, as illustrated in Figure 3.3. This was particularly true in the first stage of the research where coding was conducted in parallel with data collection so that nascent themes could be further explored in future interviews. Consequently, familiarisation, coding and theme identification were conducted in a cyclical manner. In addition, throughout the analysis process, the original data was consulted to situate the coded extracts in the original conversations. This iterative analysis also occurred towards the end of the process, when my analytic writing led to a richer understanding of the themes and their relationships, leading me to reassess the thematic structure. Thematic mapping was also used throughout the analysis process to explore the relationship between coded fragments and themes.

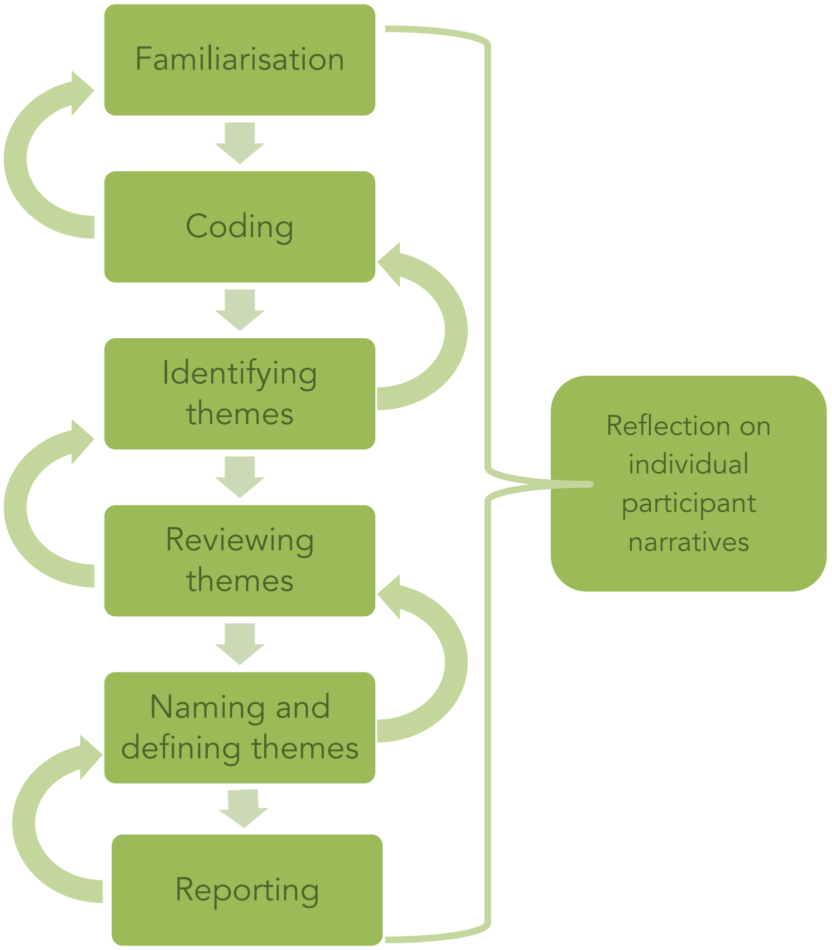

Figure 3.3 Illustration of the iterative data analysis process

Although I listened to the audio recordings, read transcripts thoroughly and continued to refer back to them throughout the analysis process, I found that the coding process fragmented the data and dissociated the coded quotes from the context of participants' experiences. This fragmentation meant that inter-related aspects of participants' experiences, arising at different points in the interviews, could be overlooked, preventing me from understanding individuals' experiences as a whole. In order to overcome this limitation, I created descriptive summaries, or vignettes of participants' experiences which helped me to comprehend the participants' stories. Examples of these vignettes can be found in appendix T.

Creating these vignettes allowed me to reflect on and draw together comments from across my interactions with each participant. It helped me to build a picture of people's lifestyles and daily routines, to identify the challenges they faced and the things that motivated them. Generating the vignettes provided an opportunity to reflect on participants' stories as a whole and to draw together fragments from across participants' interviews to elucidate an issue. For example, one participant repeatedly mentioned needing routine, which I initially attributed to coping with memory-loss, however, elsewhere he described how his life in the army had made him extremely regimented, indicating that his background may have played a role in his need for routine. These vignettes then informed my coding as I had a richer understanding of participants' accounts. These vignettes were also used as the basis for the development of the personas, used in the next stage of the research to convey the experiences of people with dementia.

3.8. Stage two: Design workshops

Initially, the objective of the second stage of the research was to develop technologies for people with later life cognitive impairment. However, findings from the first stage of the research suggested that the research should focus on the needs of people with dementia (this is discussed in chapter 6, section 6.9). Consequently, this second stage of the research sought to generate concepts for technologies to enable people with dementia to live physically active lives.

3.8.1. *Engaging professionals in design-workshops*

In order to generate innovative concepts that capitalised on cutting-edge technologies and techniques for health behaviour change, professionals from Philips and Newcastle University's MoveLab were invited to three design workshops. Across the two organizations I had the opportunity to recruit a range of experts, including health psychologists, physical activity specialists, designers and engineers.

As the professionals would be participating in the research voluntarily, I had to carefully consider how to optimise their input in a limited time period. In consultation with staff at Philips and MoveLab it was decided that a half-day design-workshop would be appropriate. To convey the needs of people with dementia and stimulate concept generation, in these brief workshops, I had to carefully select and design the workshop activities and support materials.

Most of the workshop contributors had not been involved in the research and were not necessarily knowledgeable about dementia. Therefore, I had to find a succinct way to describe the experiences of participants with dementia. I contemplated presenting workshop contributors with the results of my thematic analysis, however, I thought that they were too lengthy and that it may be difficult for workshop contributors to assimilate the experiences of participants with dementia in the fragmented form that resulted from my thematic analysis. Instead, I chose to use a modification of the 'personas' method, which provided a concise and engaging way to convey users' needs, behaviours and characteristics. The personas were based on the experiences of two participants with dementia from the first stage of the research. A description of the personas method and the reasons for choosing these participants is provided in the following section.

I chose to send the personas to the professionals in advance of the workshops so that they could begin to familiarise themselves with the individuals described in the personas and reflect on ways to address their needs. It was hoped that this would mean that they would be primed and prepared for the workshops, having already started to think about the needs of people with dementia. Each workshop participant received one persona only and, in the workshops they worked in teams to design for that individual, since attempting to consider the divergent needs of both personas in the time available was considered unfeasible.

Due to the time limitations, I developed a series of design activities that would focus the teams on responding to the persona’s needs rather than considering technical details about how the products or services they conceived might work. This included asking teams to list the barriers, motivators and facilitators of physical activity for the persona they were designing for on a worksheet, shown in Figure 3.8, before generating concepts for products or services. Once they had selected a concept to develop, I asked teams to illustrate how their persona would use the concept on a storyboard (shown in Figure 3.9). This method was chosen because I wanted teams to consider how the individual with dementia would use their product or service, rather than deliberating on technical or functional details. These, I felt, could be resolved once the utility of the concepts proposed had been determined. To ensure that teams focused on designing products and services that addressed the persona’s goals, I also suggested that they started by considering the final frame of their storyboard, where the persona experienced the outcome or benefit of the proposed product or service.

To ensure that workshops ran on time and contributors knew what they were expected to do, I produced worksheets which described the aims of each exercise and its anticipated duration (as shown in Figure 3.8). I also provided a written schedule and described the individual activities verbally.

In the following sections I provide further details of my choice of methods and the process of running the workshops.

3.8.2. Conveying user requirements

As noted in the previous sections, during the analysis of the interviews it became apparent that thematic analysis led to a fragmentation the data, removing participants' comments from the context of their experiences. I felt that the amalgamation of accounts generated by the thematic analysis would not adequately convey the context of people's experiences of living with dementia to workshop contributors. In addition, I was concerned that a lengthy report would not be engaging. Consequently, instead of presenting the workshop contributors with the outcomes of the thematic analysis, I wanted to find a way to succinctly present a rich and coherent account of participants' experiences.

Various methods have been proposed to communicate the needs of users to design teams. Scenarios, for example, describe a typical users' goals and experiences as well as the context of their interaction with a proposed technology, normally through a fictional, written story (Nardi, 1992; Maguire, 2001; Rosson and Carroll, 2001; Nielsen, 2002). Alternatively, 'problem scenarios' can be used to describe users' interactions with existing technologies (Rosson and Carroll, 2001). Scenarios were not appropriate for this stage of the research as it was not clear what type of technology or service should be proposed and I had not observed participants using an existing product or service.

Blythe (2004) proposed 'pastiche scenarios' to stimulate reflection on conceptual issues in the early, exploratory stages of a design enquiry (Blythe and Dearden, 2009). Rather than portraying real users, pastiche scenarios envisage famous fictional characters undertaking tasks, for example, Dickens' Scrooge buying a bus pass (Blythe and Dearden, 2009). Pastiche scenarios were not considered appropriate for this stage of the research as the intention was to generate concepts that responded to the needs of real users. In addition, there are few realistic, and widely recognisable representations of people with dementia that could be drawn upon to create such scenarios.

As well as focusing on users' interactions with technologies, rather than on the user as a whole, scenarios have been criticised for generating one-dimensional, unengaging and unbelievable users (Nielsen, 2002). Cooper (1999) proposed the use of 'personas' to provide rich descriptions of users, with an emphasis on their goals and motivations. Personas have been widely adopted and adapted since their conception as a software development tool in the late nineties (Cooper, 1999), however, they are typically a fictional representation of an archetypal user. Biographical information about this imagined user, along with details such as their motivations, their requirements, their likes and dislikes is normally presented alongside a representative portrait (Pruitt and Adlin, 2010). This information is intended to communicate users' needs, to inform the design process (Miaskiewicz and Kozar, 2011).

Miaskiewicz and Kozar (2011) identified numerous potential benefits of personas, including bringing the user to life, challenging designers' assumptions and helping to overcome disconnections between designers and users. Describing a character with a name and a face, rather than providing designers with a list of user requirements, is considered to be a more engaging and efficient way of communicating user needs, which may also foster empathy and encourage the designer to consider their decisions from the user's perspective (Miaskiewicz and Kozar, 2011). Given these potential benefits, personas appeared to be a useful tool to capture the attention of the design workshop contributors and inform them about the experiences of people with dementia. However, personas have also been criticised for stereotyping users (Turner and Turner, 2011), being based on supposition and lacking the detail necessary to fully convey users' needs (Guo and Razikin, 2015). In response, rather than concocting imagined users, I chose to ground the personas in the rich data from interviews with people with dementia and their spouses.

3.8.3. Modified persona method

Part of Cooper's (1999) rationale for the persona method was to avoid developing products that attempt to address the varied needs and interests of all potential users and in doing so satisfy no one. In this investigation, the challenge of satisfying a diverse user group became evident when, in the first stage of the research, it became apparent that the physical activity levels, lifestyles and activity preferences of people with dementia varied greatly and that, as such, a single product or service was unlikely to meet the needs of all people with dementia. However, my findings suggested that there were two distinct groups whose needs might be addressed with separate interventions: first, those who were highly sedentary and second, those who were sufficiently physically active but might benefit from support to maintain independence. Consequently, I decided to create two personas, one to represent each of these groups.

The conventional persona method requires the creation of a fictional, archetypal persona to represent the requirements of a set of users (Cooper, 1999). Even when personas are grounded in data, they are often an amalgamation of characteristics and behavioural patterns, derived from a group of research participants (Pruitt and Adlin, 2010; Faily and Flechais, 2011). Such synthesis of user characteristics has been criticised for generating unrealistic and unbelievable representations of users (Guo and Razikin, 2015). In this study, even having divided participants with dementia into two groups, those who were more active and those who were less active, it did not seem appropriate to attempt to fuse the experiences of participants within these groups. This detailed investigation revealed the complexity of experience and the interrelated factors that affect people's physical activity behaviours and choices. Therefore, I decided that the personas should be direct descriptions of two individuals rather than a synthetic amalgamation of participants' experiences and characteristics. It was also hoped that by using the biographies of real individuals the personas would be more compelling to workshop contributors.

I was able to base the personas on vignettes, created during the interview analysis, which summarised participants' experiences (as described in section 3.7). The personas described several aspects of participants' lives, including their physical activity levels and choices, their memory condition and their daily activities. The descriptions were built around participants' own quotes, in order to convey the individual's experiences accurately and to emphasise to workshop contributors that the personas described real people. Rather than producing a list of attributes (as often employed in personas) a descriptive style was used to make the accounts more engaging and compelling, as recommended by Tedjasaputra, Sari and Strom (2004). As in conventional personas, a portrait photo was included on the personas, however, to protect participants' anonymity, a naturalistic photo of a similar individual was sourced[4].

Visual presentation was carefully considered to encourage contributors to read the personas in advance of the workshops. Information was broken down onto separate cards, as shown in Figure 3.4, so that they could be easily read and spread out in the workshops for quick reference. The personas were sent to workshop contributors along with a letter asking them to read the persona cards before the workshops and explaining that the personas described the experiences of real individuals. All the persona cards can be found in the appendix, sections K and L.

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[4] All images were available for use under the Creative Commons license.

Figure 3.4: Persona cards and letter of invitation.

The personas were tweaked slightly after the first workshop in which a contributor made a comment that indicated that they held a stereotypical view of the lifestyles of older people, making a presumption that they would not be interested in the types of hobbies that younger people enjoy. Consequently, for later workshops I chose to include images on the persona cards that hinted at the people with dementia's younger lives. For instance, on one, I included a picture of a young couple on their wedding day, as shown in Figure 3.5. It was hoped that these additional images might connect the designers to a sense of an individual, like themselves or others they knew, just somewhat older.

Brian Routledge Psuedonym

Memory condition: Dementia

Age: 72

Married to Linda (70)

Brian and Linda live on the outskirts of a rural town in the North of England. They have good bus access to their local town as well as the city, touristic villages, countryside and beaches.

Photo for illustration only.

'Alnwick gardens' by Chris Booth is licensed under CC BY-SA 2.0 (creativecommons.org/licenses/by-sa/2.0/), image cropped and border added, original available at flickr.com/photos/monkeypuzzle/475932395/

Health conditions

Slight arthritis in his knees but other than this and his dementia he is in very good health.

"We hadn't seen Graham for a while. When he came, poor Brian didn't know who he was and they'd been very close friends. He was was your best man, wasn't he? That was hard." Linda

"It was really hard." Brian

Regular activities

Daily 3.5 mile early morning walk.

Visiting local beauty spots and gardens.

Trips to stately homes and museums with the couple's close friends.

Walking to the shops in town or taking the bus to the city.

Gardening.

Interests

Walking in local countryside.

Wood carving and painting.

Used to be an avid reader but cannot read now due to dementia.

Photo for illustration only

'002-4' by Andrea Ariel is licensed under CC BY-SA 2.0 (creativecommons.org/licenses/by-sa/2.0/), image cropped and border added, original available at flickr.com/photos/andreanako/5911348294/

Figure 3.5: First page of the persona for Brian (originally A5).

3.8.4. Affinity diagrams

In addition to the personas, I wanted to sensitise workshop contributors to the wider experiences of participants from the first stage of the research. I also wanted to begin the workshops with an activity that would get the team members' working together and communicating. Therefore, before the teams started designing, I asked them to undertake an affinity diagram exercise. Affinity diagrams are a tool used by design teams to analyse research data, in which interview quotes are organised into groups, much like the themes in a thematic analysis (Holtzblatt and Beyer, 1993). Kouprie and Visser (2009) suggest that discussing such information within a design team can lead to enhanced understanding. The affinity diagram exercise was chosen as an interactive and engaging way for workshop contributors to explore the experiences of people with dementia.

Within the limited time available in the workshops, it was not possible for contributors to read all the interview data. Therefore, salient quotes were selected that represented core themes identified in the first stage of the research and transferred to A7 cards (see Figure 3.6 and appendix N) so that they could be arrange them into themes. Each team was given around 30 quote cards.

Figure 3.6: Examples of the quote cards used in the affinity diagram exercise, originally A7 cards.

3.8.5. *Design workshop process*

Three design workshops were held, one at Newcastle University, another at Philips Research's offices in Cambridge, UK and a third at Philips head office in Eindhoven, Holland. Each workshop lasted around three hours; a schedule of activities can be found in appendix R.

To begin the workshops, I gave an introductory presentation including basic information about dementia, a description of my research, the workshop aims and schedule. Contributors then worked in teams to complete the affinity diagram exercise described above. Next, teams were guided through a series of concept generation and development exercises, during which they were asked to design specifically for the persona that they and their teammates had been sent before the workshops.

In the first workshop the contributors were first asked to describe ‘a day in the life’ of their persona on the worksheet shown in Figure 3.7. The intention of using a ‘day in the life’ activity in the workshops was to encourage contributors to consider the daily routines of their persona and when they might engage in physical activity. However, contributors to the first workshop told me that they did not have enough information to complete the exercise, instead finding themselves inventing the person’s day, which they did not think was appropriate or helpful. Therefore, in the remaining workshops the teams were first asked to identify the barriers, motivators and enablers to physical activity for the persona and write them on an A3 worksheet, shown in Figure 3.8. In the second workshop this appeared to be a more successful activity, prompting contributors to share their recall of the information on the persona cards, so this alternative task was kept.

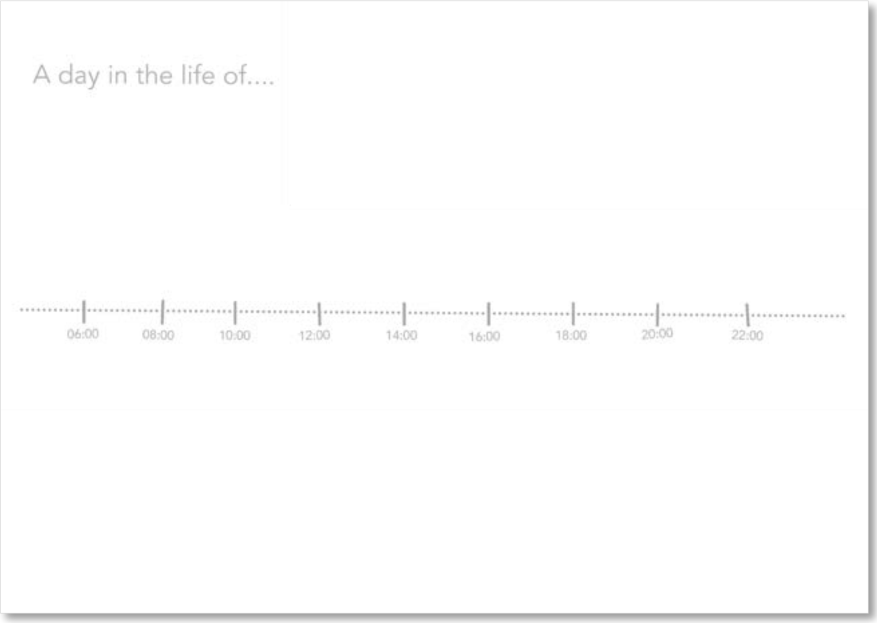

Figure 3.7: ‘A day in the life’ worksheet, originally A3.

Next, teams were asked to generate as many ideas as they could for products and services that might help their persona to be more physically active. Although the primary objective of the research was to identify opportunities for technologies to support physical activity, at this stage I wanted concept generation to be open minded, so I did not specify that their concepts should be technologies.

The teams were then asked to select and develop a concept. To structure the concept development activities, teams were given an A1 storyboarding worksheet, with frames like a comic strip, on which to describe their designs (see Figure 3.9). Storyboards were chosen to encourage the teams to consider how their persona would use the product or service they envisioned rather than focusing on technical details (Holtzblatt, 2009; Stickdorn and Schneider, 2012). Teams were provided with A5 sheets of paper, representing the frames of a comic strip, to sketch and develop their ideas. The intention was that these 'frames' could be changed and rearranged, to aid concept development, before being stuck onto the storyboard. As well as the

Barriers, motivators and enablers: 15 minutes
Aim – identify the barriers, motivators and enablers to physical activity for your group's persona.
Equipment – persona cards, worksheet, pens, sticky notes.

Figure 3.8: 'Barriers motivators and enablers' worksheet, originally A3.

blank frames, the teams were given A5 frames marked ‘before’, on which they could describe the user’s current situation and a frame marked ‘after’ on which they could illustrate the objective of their intervention. On the remaining blank frames, the teams were asked to illustrate how the persona would engage with their product or service, to create a story, taking them from ‘before’ to the outcome of their intervention in the ‘after’ frame. At the end of the workshop, teams were asked to present their concepts to the rest of the group.

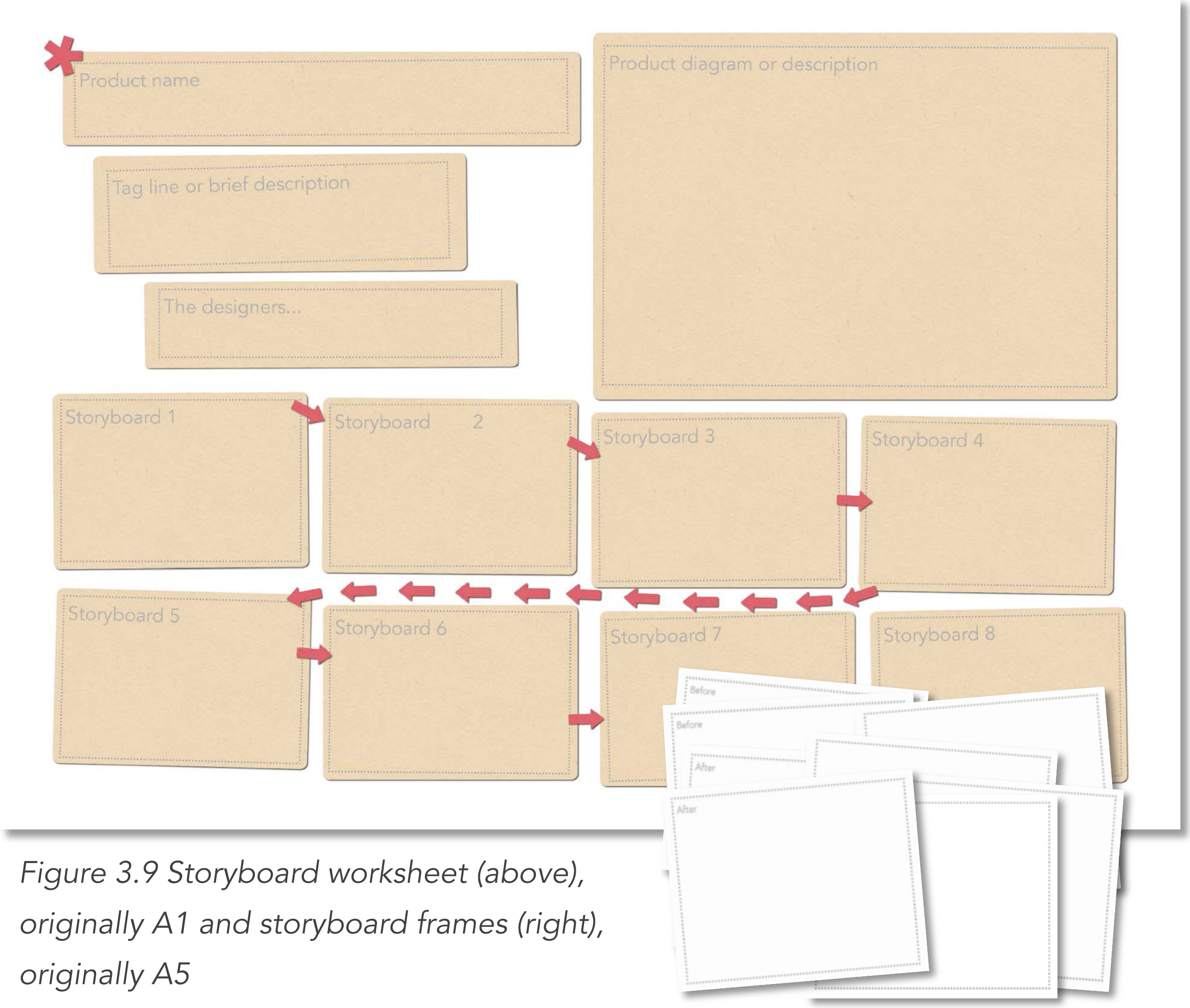

Figure 3.9 Storyboard worksheet (above), originally A1 and storyboard frames (right), originally A5

3.8.6. Recruitment and running of the workshops

Six members of Newcastle University’s MoveLab attended the first workshop, including researchers with specialisms in health psychology, physiotherapy, exercise physiology and interaction design. Initially the six contributors worked in two groups, however two left after the affinity diagram activity leaving four to work on the design tasks. Seven staff from Philips Research, Cambridge attended the second workshop, including electrical and electronic engineers and interns who studied computer science, software engineering and electrical engineering. Nine members of Philips Design and Research participated in the third workshop including an interaction designer, people researchers[5] and research scientists with interests in software development, psychology and engineering.

Although the primary objective of the workshops was to generate concepts that could be presented back to participants with dementia and their spouses in the final stage of the research, a secondary objective was to understand the utility of the methods used. The first workshop was not audio recorded since I had not considered analysing the process in detail and it was hoped the material outcomes, along with my own notes, would provide sufficient evidence of the process. However, it became apparent that there was an opportunity for richer data collection and so the second and third workshops were audio recorded and transcribed in order that the workshop process could be analysed in more detail.

Audio rather than video recording was chosen as video recording was considered excessively intrusive, with the potential to make contributors self-conscious and limiting their creativity. The active nature of the design workshops, with both table-based and wall-based activities, discussions and presentations, also meant that multiple video cameras would have been required to capture all of the activity and to avoid shots being blocked as contributors moved around the room. Collation and analysis of multiple camera feeds would have been too time-consuming and unnecessarily elaborate for the intended analysis. Video recording may have provided some additional insights into the design activities; however, it was felt that the combination of audio recordings, materials created in the workshops and my

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[5] An alternative term for user researchers.

own notes would provide sufficient data for the level analysis required at this stage of the research.

3.9. Stage three: Focus groups

The primary objective of the final stage of the research was to get feedback from participants with dementia and their spouses on the workshop concepts. To do this, the workshop concepts were refined and presented to participants for their critique as storyboards in two focus groups. It was also hoped that participants might envisage new ideas or suggestions for improvements to the solutions proposed. In addition, this re-engagement with participants offered an opportunity to review and verify some of the themes raised in the interviews.

To begin this section, I consider alternative approaches to conveying concepts for user feedback and my rationale for selecting storyboards, after which I describe the workshop process.

3.9.1. Conveying design concepts

Presenting initial concepts to users offers an opportunity, not only for their feedback, but to prompt critical appraisal and creative responses. However, conveying nascent design ideas to users can be challenging, when it is unclear exactly how a product will function or what it will look like. Developing and producing prototypes can be expensive and time-consuming and may be counter-productive if users are drawn to critiquing technical or aesthetic details when the designer actually wants users to appraise the underlying concept (Briggs *et al.*, 2012).

A variety of methods have been proposed to describe early design concepts to users without providing specific details, to stimulate critical and creative responses. Briggs *et al.*'s (2012) 'invisible design' employs purposefully ambiguous films that show characters discussing and engaging with a product which is out of shot so that a physical manifestation of the product is never shown. Briggs *et al.* presented a series of ‘invisible design’ films to older adults and found that their method prompted participants to reflect upon what the products ‘would’, ‘should’ or ‘could’ do. However, the degree of feedback depended on the ambiguity of the products’ description; films were most successful when the device’s function was described in detail, whereas more ambiguous descriptions were frustrating, with participants requesting clearer descriptions.

Vines, Blythe, Lindsay *et al.* (2012) developed a method called ‘questionable concepts’, in which several fantastical ideas for future banking technologies were presented to older adults to provoke creative criticism. The authors reported that participants were indeed highly critical, however, their criticism tended to focus on their aversion to new technologies, rather than prompting generative discussions about more practical or desirable alternatives. In a later stage of the same project, older adults were enthusiastic when presented with tangible, physical prototypes of technologies that they had been dismissive of when the same concepts were described to them verbally (Vines, Blythe, Dunphy, *et al.*, 2012). Vines et al.’s experiences suggest that older adults may be wary of intangible or abstract descriptions of technologies and more positive if they are able to interact with realistic prototypes. This may reflect older adults’ concerns about usability and the potential to become excluded by the imposition of new technologies. More realistic, advanced prototypes may help to allay fears about the accessibility of new technologies.

In a further degree of abstraction, ‘design fiction’ places speculative, fantasy products into fictional worlds to promote discussion about possible future technologies and their implications (Lindley and Coulton, 2015; Ahmadpour *et al.*, 2019). Reflecting Vines *et al.'s* experiences, Ahmadpour *et al.* (2019) advised caution when considering design fiction with older adults, since, rather than being a playful way to promote future-thinking, they warned that the method may exacerbate older people’s fears about the technological future and the challenges it might present.

Together the findings of these studies suggest that presenting ill-defined, provocative or abstract technology concepts to older adults can lead to negative responses, potentially eliciting anxieties about new technologies. Across these studies, participants appeared unwilling or unable to engage in the level of abstract thinking that the researchers and designers hoped for (although all of the studies highlight creative responses from some participants). Elsewhere it has also been identified that people with dementia find it particularly difficult to engage in abstract thinking (Lindsay, 2012; Hendriks *et al.*, 2014). Lindsay (2012) reported that people with dementia struggled to imagine future technologies or to discuss abstract or intangible design concepts, however, physical products and storyboards illustrating product features were found to facilitate discussions.

Together the findings of these studies suggest that more ambiguous and provocative methods may not be particularly fruitful when working with people with later life cognitive impairment. In order to convey the concepts generated in the design workshops to participants with dementia and their partners, a more concrete and realistic approach appeared to be preferable. The concepts generated in the design workshops were not sufficiently defined to create physical prototypes, however, building on Lindsay's (2012) successful use of storyboards it appeared appropriate to use this format to present concepts to people with dementia and their partners. Similar to the ‘invisible design’ method, storyboards offered a way to describe the intended function of the concepts, without being specific about technical or aesthetic details which might dominate discussions if they were overtly represented. Storyboards also offered a way to describe potential product features that I wanted to promote discussion about.

A potential weakness of storyboards was the possibility that people with dementia would not understand graphic representations. Films could have been used instead of paper-based storyboards; however, this was not feasible with the time and resources available. A photo storyboard was also considered; however, this would also have required recruitment of actors and the identification of locations suitable to set the scenes. Instead, I chose to convey the concepts in illustrated storyboards, using a realistic, rather than a sketchy or cartoonish style.

Although the concepts generated in the workshops were already in a storyboard format, they required further refinement for presentation to focus group participants, a process which is described in Chapter 8. The final concepts were illustrated on three A0 storyboards for presentation to focus group participants.

3.9.2. Focus groups

Focus groups can be used to gather users' feedback on design concepts or prototypes. Focus groups typically include between five and twelve people. Their particular utility is in the interaction of participants. By discussing, reflecting and building upon each other's comments focus groups can generate new insights and innovative solutions (Langford and McDonagh, 2003). Focus or discussion groups have proved suitable for engaging people with dementia in the design process (Hanson *et al.*, 2007; Robinson *et al.*, 2009) and can provide a supportive environment for people with dementia to recollect and share their experiences (Bamford and Bruce, 2002). However, small groups are recommended when working with people with dementia (Robinson *et al.*, 2009).

Recommendations on the appropriate length of focus groups vary greatly, from one to three hours or more (Kitzinger, 1995; Langford and McDonagh, 2003). For this research, I considered twenty minutes sufficient to discuss each of the three concepts and so allowed an hour and a half for the focus groups, to include introductions, consent and a short break.

Participants with dementia from the first stage of the research and, where relevant, their partners were invited to participate in two focus groups. Five people with dementia and four of their partners agreed to take part.

After completing the consent process and introductions, I described the purpose of the focus groups. I asked participants to be critical of the concepts and suggest their own ideas and improvements, while being respectful of others' opinions. I presented the storyboards, asking for comments after I described each concept. Where necessary I prompted participants to discuss issues that had arisen in the first stage of the research which I hoped to gain further insight into, detailed in the topic guide in appendix S. At the end of the workshop participants were asked to select their preferred concept or features.

Focus groups were audio recorded (with participants' consent) for transcription and thematic analysis. Video recording can be useful in focus groups where participants undertake interactive or visual design activities, however, based on my previous experiences of video recording focus groups I considered it unnecessary for the largely conversational activities anticipated in these particular focus groups. As discussed previously, ethical and practical considerations also influenced my decision to audio record the focus groups.

A detailed description of the focus group process can be found in appendix R.

3.10. Summary

In this chapter I have explained my decision to use a human-centred design methodology and incorporate design research methods in order to address the research questions. I have also described the practical and ethical considerations taken to sensitively include people with later life cognitive impairment in the design process. The process of recruitment, data collection and analysis has also been detailed. Reflections on the strengths and weaknesses of my choice of methods can be found in the discussion chapter.

In the following chapters, findings from the three stages of the research are presented, starting with findings on the lived experience of physical activity, from my diary-probe led interviews with people with late life cognitive impairment.

Chapter 4. Stage one: Underlying barriers and motivators of physical activity

4.1. Introduction

In this and the following two chapters I present findings from the first stage of the research, in which fifteen people with later life cognitive impairment shared their experiences of physical activity. These chapters address the initial objectives of the investigation, which were to explore the everyday experiences of physical activity for people with later life cognitive impairment and to identify any motivators and barriers to physical activity as well as any facilitators or strategies that supported participants' active lives.

Although the research focus was on cognitive impairment, for most participants cognitive changes were not the predominant factors affecting their physical activity choices or levels. Instead, a range of underlying barriers and motivators to engaging in physical activity were revealed, which I will describe in this first findings chapter. In the following chapters I focus on the barriers to physical activity associated with cognitive impairment (chapter 5), and then on the strategies to facilitate physical activity (chapter 6).

To begin this chapter, in section 4.2, I introduce the research participants. In section 4.3, I describe the variety of physical activity undertaken by participants. Then, in sections 4.4 and 4.5 I consider the two most commonly cited barriers to physical activity—health and ageing. In section 4.6, I describe the ways in which identity and personal values appeared to influence participants' activity choices and behaviours. In section 4.7, I report some of the external and environmental factors that effected participants' active lives, before summarising the findings presented in this chapter in section 4.8.

Pseudonyms are used to protect the anonymity of participants and anyone else mentioned in their quotes. The acronym PWMCI is used for participants with mild cognitive impairment and PWD for participants with dementia.

4.2. Participants

The following table provides key demographic details for the participants recruited to stage one.

Pseudo-nym	**Age**	**Gender**	**Memory condition**	**Relationship status (partner's pseudonym)**	**Interview setting**	**Home location**
Brian	71	Male	Dementia	Married (Linda)	Interviewed at home with partner	Suburb of a large rural town
June	77	Female	Mixed vascular dementia and Alzheimer's disease	Married (Pete)	Interviewed at home with partner	Suburban estate
Heather	69	Female	Alzheimer's disease	Married (George)	Interviewed at home with partner	Rural village
Anthony	70	Male	Dementia with Lewy Bodies	Married (Sue)	Interviewed at home with partner	Rural town
Gerald	83	Male	Alzheimer's disease	Married (Marjorie)	Interviewed at home with partner	Rural town

Larry	68	Male	Alzheimer's disease	Married (Jean)	Interviewed at home with partner	Suburb of a coastal town
Esther	80	Female	Mixed vascular dementia and Alzheimer's disease	Married (John)	Interviewed at home with partner	City suburb
Lynn	78	Female	Alzheimer's disease	Single	Interviewed alone at a university meeting room	City suburb
Janet	76	Female	MCI	Married	Interviewed alone at her home	Rural town centre
Pat	71	Male	MCI	Married (Mildred)	Interviewed at home with partner	Suburb of a coastal town
Tom	80	Male	MCI	Married (Tess)	Interviewed at home with partner	Town suburb
Malcolm	73	Male	MCI	Single	Interviewed alone at a university meeting room	City central
Norman	81	Male	MCI	Married (Frances)	Interviewed at home with partner	City suburb
Sheila	56	Female	MCI	Married (Robert)	Interviewed at home with partner	Town suburb
Brenda	77	Female	MCI	Married	Interviewed alone at her home	Village

4.3. Physical activity in daily life

Participants enjoyed a wide range of activities with a physical component, from shopping to scuba diving, and described a range of motivations to engage in physical activity, which I will outline in this section.

Sport, exercise and recreational walking

Few participants undertook formal sport or exercise. Malcolm (PWMCI) went to the "*gym, four mornings a week*" and Janet (PWMCI) led a "*gentle*" exercise class for older adults. Pat (PWMCI) and his wife Margaret were the only participants who played sport. Pat played crown green bowls several times a week as well as regularly going ten-pin bowling or playing pétanque with his wife and friends. He was also hoping to get back to playing golf, having recently sustained a shoulder injury. Another couple, Larry (PWD) and Jean, had enjoyed scuba diving but had recently stopped as she was no longer able to manoeuvre the heavy equipment.

Walking was the most common form of physical activity, with several participants regularly walking in parks, country gardens or local countryside, particularly those who lived in more rural locations. Brian (PWD), the most prolific walker, walked out most days. In his diary he described a walk on the beach:

> "Beach walk to Amble and back, we saw a heron and wonderful views of Coquet Island and breaking waves, with no other person in sight. Fantastic feeling." (Extract from Brian's diary, completed jointly by Brian and his wife[6])

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[6] Brian's (PWD) wife, Linda, wrote in his diary because Brian had difficulties writing. She described the meticulous process by which she documented Brian's thoughts:

> Linda I took a long time on some days, didn't it?
> Brain Yes.

Like Brian, most participants who walked out regularly would walk with their partners, however, one participant Janet (PWMCI) went out with a walking group:

> "I'm going to do tomorrow about five or six miles I suppose and then we have lunch in the pub." (Janet, PWMCI)

Purposeful activity

Although several participants walked out for recreation, walking out for a purpose, for instance to buy a newspaper, was the commonest form of physical activity described by participants. For Lynn (PWD), walking had to be purposeful:

> "I can't just go for a walk. I've got to have some reason." (Lynn, PWD)

Several participants found reasons to walk out on most days, for example Gerald's (PWD) wife Marjorie described how they would *"walk nearly every day… even if it's only to the shops and library"* (Marjorie, partner). However, it was often unclear whether the primary motivation for walking was the end goal (for instance going to the shops), the exercise participants gained from walking out or simply a need to get out of the house. For example, Norman's (PWMCI) wife, Frances, suggested that the objective of his daily walk was to buy a newspaper, whereas Norman implied that the purpose of his trip was the walk itself:

Frances	He goes out nearly every day.
Norman	Nearly every day.
Frances	'Cause he goes out for a paper.
Norman	I go just for a walk.

Linda	[…] because I had to know […] what Brian wanted to put down, and we chose the times when we could both sit together to talk about it and then I understood exactly what you wanted to put down.
Brian	Yes

Comments such as these indicate that having a reason to walk out every day can help to motivate physical activity.

The preference for purposeful activity was also reflected in the popularity of gardening, with over half of the participants indicating that they took pleasure in tending to their gardens. Several participants described their gardens requiring regular attention and Lynn (PWD) suggested that the sense of being needed by her plants kept her active:

> "Gardening is me main occupation. And I can feel meself when I'm in the garden… People need you. Plants need you. Especially plants in pots which would die if I didn't get out and see to them […] They do keep you on your toes." (Lynn, PWD)

Lynn also described how caring for others motivated many of her activities. She reflected that supporting her daughter and grandson might have kept her active:

> "It's all because of Joe and his mum that I want to stay on the ball. You know, I think if he hadn't been born, I quite possibly would've just sat and vegetated. But I'm needed." (Lynn, PWD)

Like Lynn, several participants regularly cared for their grandchildren. For Heather (PWD) and her husband George, their most active days seemed to be those they spent with their three grandsons:

George	We go to the beaches a lot.
Heather	Yeah. When the children are here.
George	Yes.
George	Which is most weekends […]
Heather	Yes.
George	[…] We'll be so shattered the next day, we'll do nothing.

As well as their grandchildren, Heather and George's dog provided a motivation to walk, as George described it "*forces you to get out*" (George, partner).

Friends and social activity were also motivators for some. For example, Malcolm described the social aspects of his visit to the fish market:

> "About once a month, I generally take my friend with me, because fish at the Fish Quay is about half the price of the supermarket fish. And it's a lot nicer and it's time out, go and watch the world go by. Talk to people, you get people going along the pier with their dogs and that, and playing on the beach and that, and stuff like that. So, apart from the economic side of going down there, I buy fish for the old lady who lives upstairs from me. It's entertainment and it fills in time. I enjoy it."
> (Malcolm, PWMCI)

Malcolm's comments highlight how purposeful activity may provide a reason to walk out, but that it provides many other benefits, including social activity, time out of the house, occupation and the entertainment of seeing the world go by.

Hobby and interest groups could also be a source of physical activity, for example Anthony (PWD) went to a weekly gardening club, as shown in the extract from his diary in Figure 4.1. Other hobbies were less demanding but still had a physical element, for example, several participants sang in choirs. Some participants also described walking to participate in regular activities or clubs in their local communities.

Figure 4.1: Extract from Anthony's (PWD) diary, including an image of him at the gardening club he attended. The text accompanying the image reads "My gardening friends, with head gardener".

Physical activity levels

In addition to the variety of different physical activities undertaken, participants' physical activity levels varied greatly. Brian (PWD) and his wife Linda were perhaps the most physically active participants, as Linda explained, *"on a very small week I would think 35 miles would be the least that I would walk […] without us going out for […] a big walk"* (Linda, partner). In addition, Brian would walk three to four miles on his own each morning. Like Brian and Linda, Anthony (PWD) and his wife Sue walked out in the countryside most days and Sue said, *"I reckon we walk more than, say, an average thirty-year-old [...] You're talking a good three, four miles"* (Sue, partner). Although walking was not the focus of her activities, Janet (PWMCI) was one of the busiest participants; she had several active hobbies and often walked into her local town to take part in activities:

> "Sunday I was singing … Monday I help volunteer in the hospice shop […] Tuesday can be a meeting, sometimes not. Wednesday I'm out walking mostly […] Thursday can be anything, usually something with the two of us doing something. Friday, I teach an exercise class […] Always go to a rugby match on Saturday […] Sunday it'll be garden, allotment or whatever we're doing […] I like to have something to participate in every day." (Janet, PWMCI)

Conversely, some participants were very inactive, rarely walking out of the house and spending much of their days watching television. For example, when I asked June (PWD) if she walked anywhere, she responded jovially, *"I walk to the end of the drive!"* (June, PWD) indicating that the furthest she walked was to the car. Later June added, *"Sometimes I find I don't do anything […] I watch a lot of television actually"* (June, PWD). Similarly, Brenda (PWMCI) rarely walked out, finding herself unable to walk a quarter of a mile without getting out of breath. She was frustrated at not being able to garden for more than half an hour and remarked regretfully, *"I don't find very much to do. I'm a lazy lump […] I just put the television on and that was it"* (Brenda, PWMCI).

Physical activity levels did not appear to be related to participants' degree of cognitive impairment. Several of the most active participants had dementia, including some that described the most severe cognitive impairment, such as Brian (PWD). In contrast, some participants with MCI as well as others with dementia were among the least active participants. This suggests that factors other than cognitive impairment may have played a more fundamental role in determining participants' physical activity levels, as will be explored in the following sections.

4.4. Health as a barrier to physical activity

Health issues were most often raised by the 'body and mind' activity in the diaries, in which participants were asked to colour an outline of a figure to illustrate 'good bits' and 'troublesome bits'. This section describes how participants perceived their health problems affecting their physical activity choices and levels as well as the ways they sought to overcome them.

Physical health problems

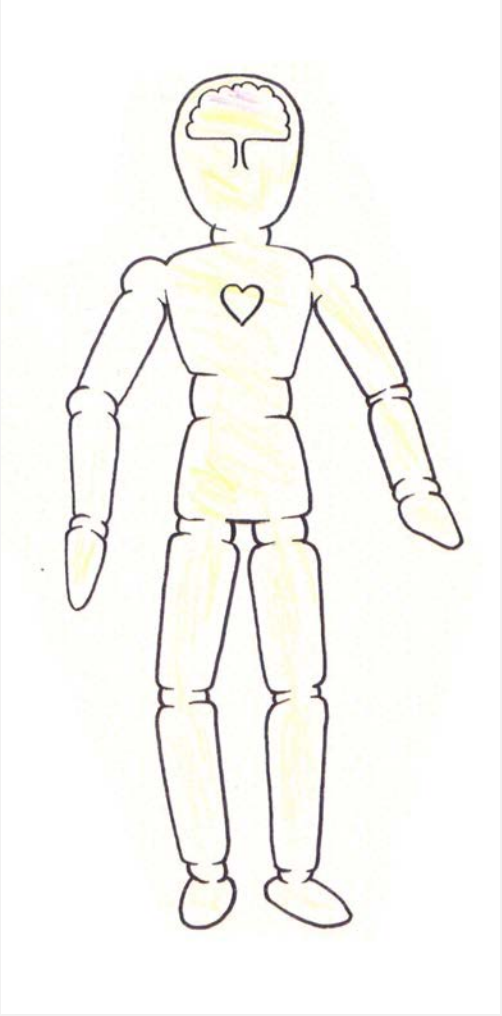
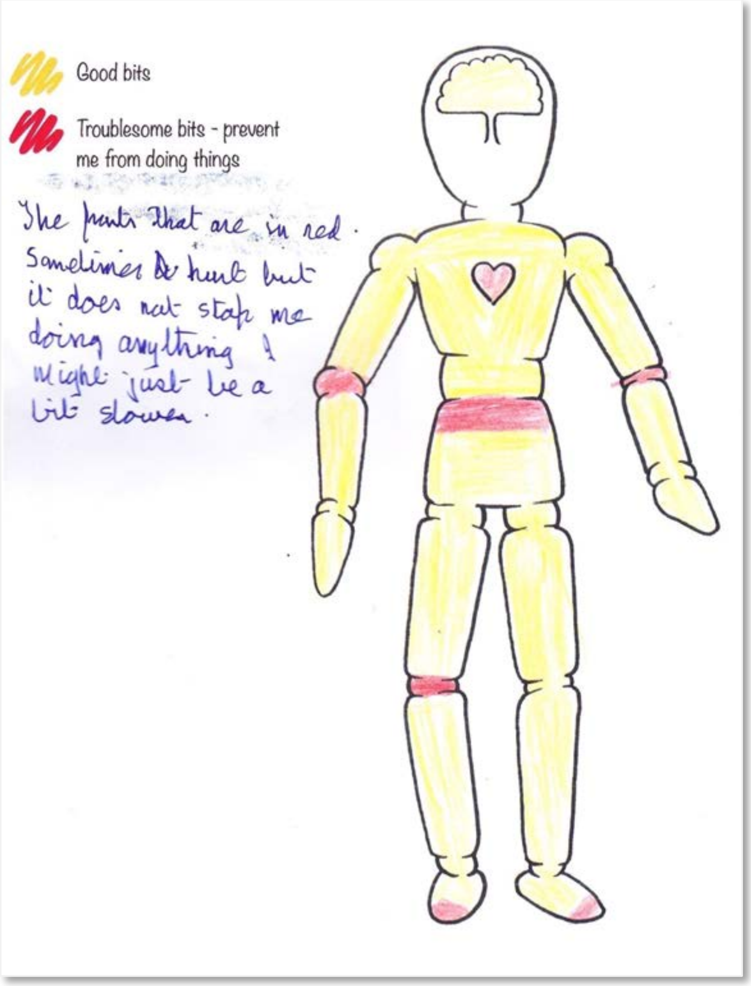


Figure 4.2: The 'body and mind' exercise from Janet's (PWMCI) diary. Participants were asked to colour the mannequins in yellow for 'good bits' and red for 'troublesome bits'.

All participants with cognitive impairment reported at least one health problem, other than MCI or dementia. However, the number of health problems and their impact on participants' physical activities varied greatly. At one extreme, Janet (PWMCI) described the least health impairments, explaining that she was *"very lucky"* since at seventy-six she had *"no aches or pains"* and so had coloured her mannequin in yellow for 'good bits', with a hint of pink on the brain *"for forgetting"* (see Figure 4.2). Like Janet (PWMCI), several participants reported that health problems did not impact on their physical activity choices or levels. For others, although their health problems did not stop them from being active, they did curtail the pace or extent of their activities. For example, Pat (PWMCI) wrote in his diary:

> "The parts that are in red sometimes hurt but it does not stop me doing anything I might just be a bit slower." (Pat, PWMCI, as shown in Figure 4.3)

A more detailed description of the impact of Pat's health problems on his activity choices can be found in appendix T.



The parts that are in red sometimes do hurt but it does not stop me doing anything I might just be a bit slower.

Figure 4.3: The 'body and mind' exercise from Pat's (PWMCI) diary. Text reads: "The parts that are in red sometimes hurt but it does not stop me doing anything I might just be a bit slower".

Several participants reported multiple health problems. These participants tended to be among the least active. Brenda (PWMCI), for example, described having arthritis, joint stiffness and having blocked tear ducts, as illustrated in Figure 4.4. She also found that shortness of breath made it difficult to walk around a quarter of a mile to her friend's house:

> "It takes me an age. 'Cause I've got to keep – pfhhhw, stopping and having a [break] and then I could go on again. I would love to be [able to walk] 'cause I used to walk a lot." (Brenda, PWMCI)

Brenda explained that being overweight caused shortness of breath, which was exacerbated by the medication that she took. This also made gardening, one of her preferred forms of physical activity, more difficult:

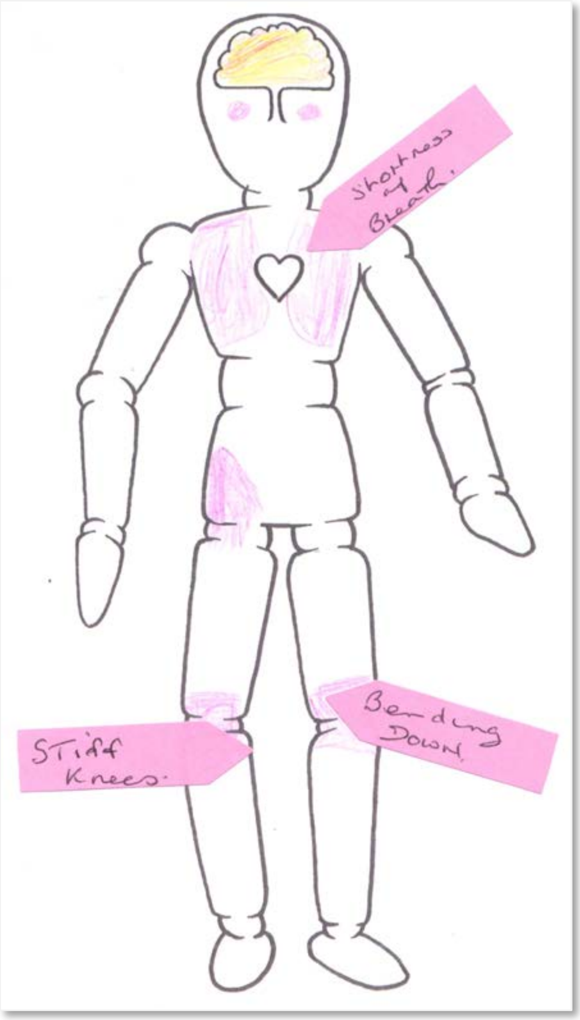


Figure 4.4: The 'body and mind' exercise from Brenda's (PWMCI) diary. Labels read "shortness of breath", "stiff knees" and "bending down".

> "I'm really bothered about it […] It's just the fact I've got too much weight. […] They say it's the medication I'm on makes losing weight exceptionally hard. [...] I find it difficult trying to bend down now 'cause this ((pointing to her stomach)) gets in the road[7] […] I find my knees won't bend when I'm trying to get down. And if I do get down, I can't get back up again. You know, it's me knees are stiff." (Brenda, PWMCI)

As well as problems with bending, she described how she was easily tired:

> "I've loved doing gardening […] I want to do something with the garden we've got now. And I go

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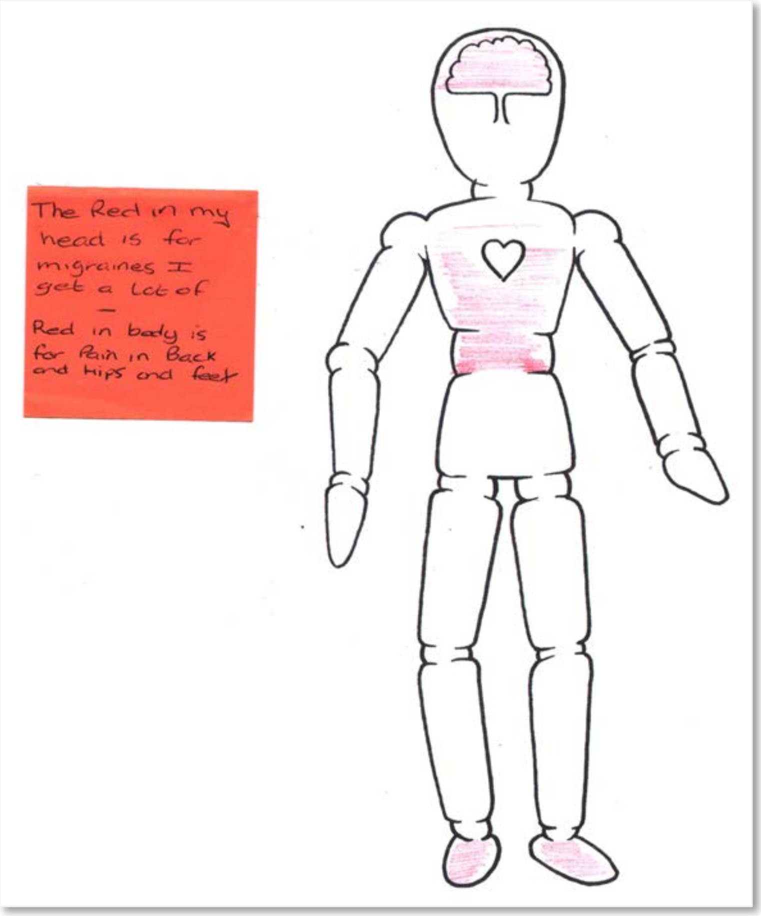
[7] 'Gets in the road' is a colloquialism meaning something gets in the way.

> out […], do it for about, well, half an hour and that's it […] I just get tired and I just say 'no good. I'll have to come and sit down'." (Brenda, PWMCI)

For Brenda, a combination of health problems made physical activity more difficult, which, in turn, contributed to a lack of energy and difficulties losing weight, creating a downward spiral of physical deconditioning.

Physical and cognitive barriers combined

Like Brenda, other participants indicated that multiple health conditions, in combination with cognitive changes, had led to a progressive decline in activity levels. Sheila (PWMCI) was the most severe example, reporting a series of health problems that had aggregated over many years. She was the only participant to colour the mannequin in the 'body and mind' exercise only in red for 'troublesome bits', with no areas marked yellow for 'good bits', as shown in Figure 4.5. Sheila described how back, shoulder, hip and feet problems, as well as asthma made walking difficult. These health problems, combined with long-term depression, migraines and more



The Red in my
head is for
migraines I
get a lot of
—
Red in body is
for Pain in Back
and Hips and feet

Figure 4.5: The 'body and mind' exercise from Sheila's (PWMCI) diary. Note reads "The Red in my head is for migraines I get a lot of – Red in body is for pain in back and hips and feet."

recently, memory problems, made Sheila feel trapped in a vicious cycle of decline:

> "It's worse now than it's ever been. I'd say since I was diagnosed with memory problems, I just seem to be going downwards. And I thought once I got this sorted out, I'd start to pick myself up, but it's not working that way [...] I don't walk very far, no, because I get too breathless. [...] It's just going in a vicious circle really." (Sheila, PWMCI)

As a result, Sheila (PWMCI) described *"getting a lot slower"*. June (PWD) also said that she had slowed down and her husband Pete indicated that, although this had started when June had developed a thrombosis in her leg, it was perpetuated by her dementia.

Esther's (PWD) mobility problems also seemed to have started when she developed a blood clot in her leg, which led to her using a walking stick. Subsequently, trapped nerves had led her to use a wheelchair, until they were operated on a few weeks before we met. However, it seemed that this series of health problems had affected her mobility and may have been further aggravated by the onset of dementia, as Esther and her husband John discussed:

John	It started, September last year […]
Esther	Trapped nerves in the spine. […]
John	…it took 'til what? August, July for the operation […]
Interviewer	And how did that affect you […]?
Esther	Terrible because it was painful to go out, you know?
John	And then of course on the top of all that …
Esther	It's when I started to use me walking stick because, you know, you …
John	Oh, you used a walking stick long before that […] when you had your leg problem.
Esther	Oh yeah, off and on. Off and on, not …

John Oh, aye. And then of course, to make matters worse of course, the dementia set in as well.

For June, Esther and Sheila, cognitive impairment appeared to have exacerbated their existing poor health, slowing them down and, as Sheila articulated, producing a vicious cycle of physical inactivity. These three women were also the most sedentary participants, spending most of their days sitting. These accounts highlight that physical and cognitive health problems should not be considered in isolation.

Overcoming health problems

Some participants were able to continue engaging in physical activity despite multiple health problems, adapting activities to suit their capabilities where necessary. For example, Norman (PWMCI) was determined to stay active, despite multiple health problems, as shown in Figure 4.6, exclaiming, *"I'm not going to curl up and die. Not yet."* (Norman, PWMCI). Previously a sporty and active individual, Norman found that his health problems limited his mobility and stopped him from

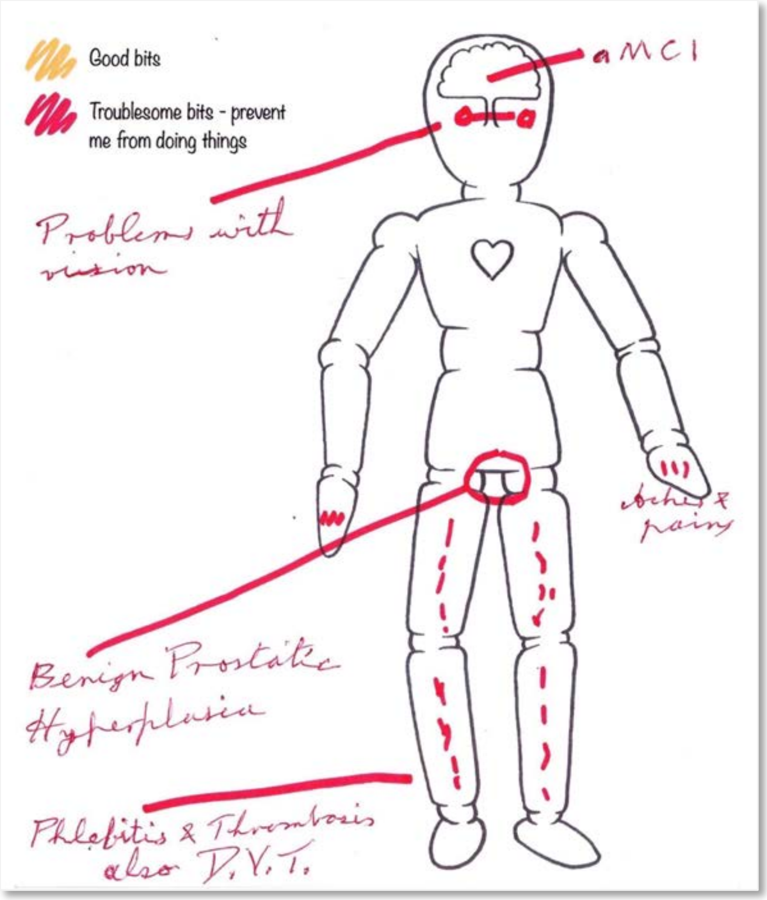


Figure 4.6: The 'body and mind' exercise from Norman's (PWMCI) diary. Text reads: "aMCI" (referring to amnestic MCI) "Problems with vision", "Aches & pains","Benign Prostatic Hyperplasia" and "Phlebitis & Thrombosis, also D.V.T."

participating in the physical activities he enjoyed. Despite this he seemed determined to walk out every day. When asked whether he had to push himself to keep walking he responded, *"Oh yeah. That's why I go out. I mean I try to go out every day. Just for a walk"* (Norman, PWMCI).

Malcolm (PWMCI) also had multiple health problems, as shown in Figure 4.7, including arthritis in his knees and pain in his spine, which made walking difficult. However, in Malcolm's case health problems had actually triggered a more active lifestyle. Malcolm described how poor health choices after leaving the army had landed him in hospital, where he was advised to do some exercise:

> "In the Army, we used to use the gym every day. I would go for a five-mile run at night, every night, and sometimes twice a day […] I left the Army and I reverted to type, beer swilling Geordie, no exercise, fish and chips and things like that. And it caught up with me. I was in hospital for a few days and then they wouldn't let me go until I had signed the pledge about doing exercise and altering my diet, which I did."(Malcolm, PWMCI)

Subsequently Malcolm attended NHS funded physical training sessions, after which he had continued to go to the "*gym four mornings a week*" (Malcolm, PWMCI), a routine he now enjoyed:

> "It's great. And I can people-watch as well. You can listen to the conversations that go on around you, you can see the different types of people who go there and what they do. And I enjoy it." (Malcolm, PWMCI)

Malcolm's knee problems limited his capacity to walk but the low-impact equipment at the gym did enable him to exercise:

> “I don’t do anything like on the treadmill which involves my legs bouncing up and down off the ground. I do nearly everything sitting down, like the rowing machine, the skiing machine.”

Further details of Malcolm’s fluctuating enthusiasm for exercise can be found in a summary of Malcolm’s interview in appendix T.

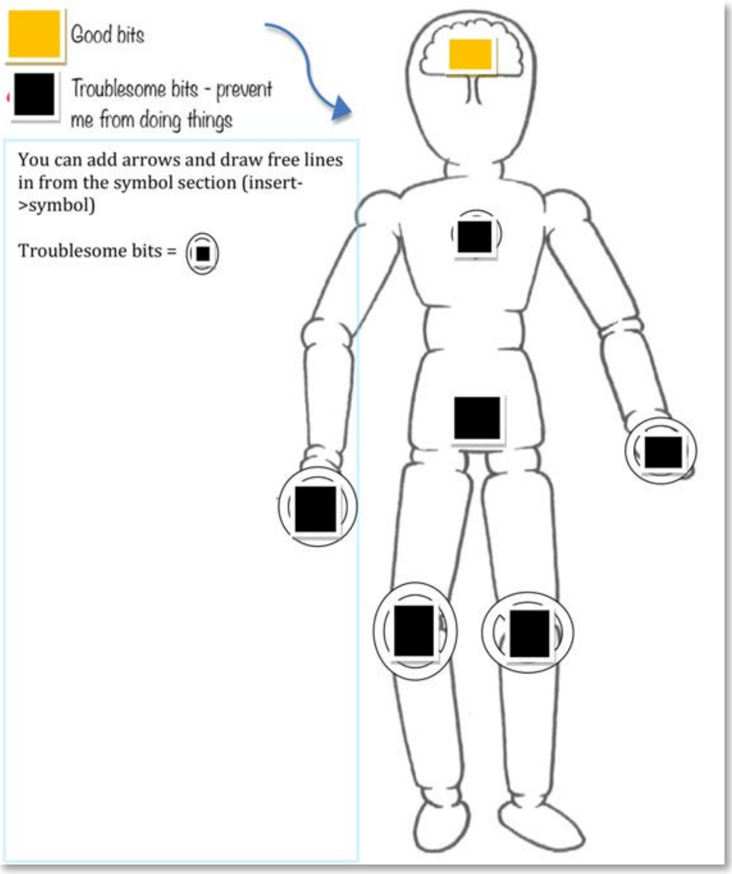


Figure 4.7: The 'body and mind' exercise from Malcolm’s (PWMCI) diary. Malcolm completed his diary in Microsoft Word because his arthritis made writing difficult, so he marked the troublesome bits in black and the good bits in yellow.

Mood

In addition to physical health problems, some participants indicated that mood affected their interest in engaging in activity. In the most striking instance, Sheila (PWMCI) described how several years of severe depression, had led her physical health to "*go downhill*" (Sheila, PWMCI). Because of on-going depression, her husband, Robert, described how he had to persuade her to leave the house:

> “She was getting herself down and I says, ‘alright we'll have a ride to the beach’, just to try and get her out […] because she was down in the dumps, you know.” (Robert, partner)

Lynn (PWD) also volunteered, "*I do have depression*" and went on to suggest that low mood occasionally affected her motivation to go out:

> "Sometimes if something goes really wrong […] then I might have what they call […] a duvet day […] I think- well, why not? I've got nothing to do. I may as well just slob around for a day [...] But it doesn't happen very often [...] You know, it's probably medication that keeps me going." (Lynn, PWD)

4.5. Impact of ageing on physical activity

In addition to specific health problems several participants talked about the impact of ageing on their physical activity choices or levels. In this section I include participants' ages to illustrate that participants' experiences and attitudes towards ageing did not necessarily relate to their chronological ages.

Physical changes

Some participants talked resignedly about physical decline as an inevitable part of ageing:

> "I am old. Bits drop off you. You deteriorate. It's part of the natural process of ageing." (Malcolm, PWMCI, 73)

Others described their energy levels having depleted as they got older. Tom (PWMCI, 80) described his energy levels limiting his activities:

> "You don't have enough time or enough energy to do all the stuff in the garden that we want." (Thomas, 80, PWMCI)

On the other hand, Larry (PWMCI, 69) felt that his stamina had increased, although his strength had decreased:

> "I think you tend to have more stamina [...] you lose your strength to a certain extent [...] but the stamina, you can go longer sort of thing." (Larry, 69, PWD)

For Lynn (PWD, 78) diminished strength impacted on her gardening:

> "The [plant] pots are a nuisance and I know I'm getting less able to lift them around." (Lynn, PWD, 78)

Despite several participants attributing physical changes to ageing, some noted that the physical experience of ageing was not congruent with chronological age or activity levels. For example, Sheila (PWMCI, 56), the youngest and one of the least active participants, remarked that her multiple health problems made her feel older than her years:

> “As I'm getting older and older, I'm getting a lot slower, although I'm not really old […] It just seems it's making me old before me time.” (Sheila, PWMCI, 56)

On the other hand, some of the oldest participants, Gerald (PWD 80) and Norman (PWMCI 81) were among the most active. Esther (PWD, 82), who was largely inactive, illustrated the disparity between the activity levels of people of the same age when she described with incredulity the activity levels of her childhood friend:

> "If you see an elderly lady running […] She runs from down here; she goes right up round there ((pointing out of the window)) … and she’s [...] same age as me. ((Chuckles.)) Can you believe it? […] And she never stops. She runs. She … does all sorts of things [at church]. She bakes […] Everything!” (Esther, PWD, 82)

Attitudes and motivations

Like Esther, some participants were astonished by the amount of physical activity some of their contemporaries undertook, while others derided those who prematurely adopting ageing stereotypes:

> "I live beside older people. And they are *old* […] in my head I'm not seventy-nine. I'm seventy-nine next month! [...] The old people that I live near to, that I should be associating with, bore the pants off me" (Lynn, PWD, 78)

Like Lynn, several participants described not feeling their age. Some suggested that maintaining motivation was an important factor in sustaining an active later life. For example, Malcolm (PWMCI, 78) described the importance of finding something to keep him motivated in retirement:

> "When I retired I realised I needed a reason to get out of bed in a morning and I needed a reason to keep me out of the pub. I needed to do something." (Malcolm, PWMCI, 78)

In contrast, Esther's (PWD, 82) husband John (80) intimated that, decades into their retirement, they had lost motivation to go out for anything other than shopping:

> "You get to the stage where you're, 'what's the point'? [...] What's the point of going out? [...] If you don't want anything, why go out?" (John, partner, 80)

These comments reflect earlier accounts of the importance of purposeful activity and occupation in motivating people to get out of the house.

4.6. Identity and personal values

As touched upon earlier, participants held a range of different attitudes towards physical activity. These appeared to be related to individuals' identities and personal values, which I will discuss in this section.

Active identities

Many of the participants reminisced about their active lives, with some describing their sporting pursuits and others reflecting on their active lives in the home or at work. Norman (PWMCI), for example, described his sporting endeavours as a representative of the Civil Service swimming team:

> Norman I did […] competitions against the RAF, the Army and the Navy […] I turned up to take part in an event and I found the man on my left was the world champion […] never got near the man. But it was good fun. […] My grandfather used to insist that every one of his grandchildren had to be able to swim before they went to the beach with him. So, I learnt to swim in one day […]
>
> Frances When he was working […] he used to just go to the swimming baths at lunchtime.
>
> Norman Oh yes […] three or four times during the [week] and when I was doing that, I was going weight training the other two days a week […] 'cause I was swimming to race.

Figure 4.8 Image from Brian's (PWD) diary of a photograph of him looking out over the countryside.

Brian (PWD), who had been an avid long-distance walker, often referred to the times when he had led walking groups. When asked to take a picture of his favourite thing in the room, Brian selected a picture of himself on a walk, looking out over the local countryside (see Figure 4.8). When we discussed the places that he liked to walk he reflected:

> "That's my place […] It's a wonderful place and there's hardly anybody goes." (Brian, PWD)

Further description of the importance of walking and being in nature for Brian can be found in vignette 4 in appendix T.

Brenda (PWMCI) described, with a sense of pride, the produce she had generated on the smallholding that she had maintained at her family home:

> "I had a massive strawberry bed and I had raspberries and blackcurrants and— you name it, I had them. And I used to bottle fruit and make wine. Anything that I could get out of me garden I did. And I had hens." (Brenda, PWMCI)

Vignettes such as these were common and provided a sense of individuals' active identities, the types of activities that were important to them and defined them. Many participants strove to maintain their active identities. Some, like Brenda, were disappointed that they were no longer able to engage in activities that were important to them. These accounts indicate that individuals' physical activity choices are embedded in their identities.

Perceived value of physical activity

For some participants maintaining an active life appeared to be an imperative. For example, Norman (PWMCI) was determined to stay active even though his health limited him to short walks (as described in section 4.4). However, not everyone considered physical activity something to strive for. For example, when I asked June (PWD) whether she was bothered about not being active, she responded:

> “Not really. I'm active when I want to be […] I'm not active just 'cause I've got to be active.” (June, PWD)

John (partner) and Esther (PWD) mocked their friends for exercising:

John	They're never in! Every day they go out […] Janet, when we first knew her, she was what I would, what I'll term, that she was nice, rounded.
Esther	((Chuckles)).
John	But I don't know why- where she got this thing from, but she went on a diet. Oh, she went to -
Esther	Seriously, she went to a class, she went swimming
John	[…] Exercise, exercise, exercise. To lose this weight […]
Esther	They've got to go out every day.
John	Out of obsession for exercise.

Although some participants expressed strong opinions about the value of physical activity, one participant illustrated that attitudes can change: Malcolm went from taking no exercise to attending the gym four times a week, although it took a health-scare and a visit to hospital to change his behaviour (as described in section 4.4). However, he was happy with his new lifestyle:

> “I like exercise. I like going in and doing it.” (Malcolm, PWMCI)

4.7. External and environmental factors

Participants identified a number of external and environmental factors that dictated their activity choices. However, a barrier to physical activity for one participant could be a motivation for another, as illustrated in the following examples.

Weather

With the majority of physical activity being undertaken outdoors, many described the weather impacting on physical activity. For example, Tom (PWMCI) and his wife indicated that the weather would determine whether they went for a walk:

Tom	On an afternoon like this, for example, we might very well go out for a bit. But, er-
Tess	It just depends what's to do and what the weather's like.
Tom	That's right, yes.

Similarly, Pat (PWMCI) and his wife Mildred said they were more likely to walk or use public transport instead of the car if the weather was good. However, the threshold at which participants considered the weather acceptable for walking varied greatly. Anthony (PWD) and his wife Sue were not easily deterred from walking and described, with enthusiasm, their walks, ascending the hill to their home in the snow, rain and even blizzards:

Sue	There was one day coming up in this blizzard-
Anthony	((Chuckles.))
Sue	-with backpacks with shopping. And I just wanted to lie down in the snow and he wouldn't let me.
Anthony	She says - *'lie down, I wanna die. You'll have to go on.'*
Sue	Yeah, we do this play thing where we sometimes sing a little jolly song going up the hill to get your pace going.
Anthony	Yes.

Sue	And we talk about base camp and summit. You know, it is, it's like climbing Everest at times.

Unlike Anthony and Sue, some participants indicated that they were more likely to be sedentary in the winter months. For example, Pat (PWMCI), a keen gardener, said that the winter weather stopped him from doing things outdoors:

Patrick	Bad day is if it's chucking down with rain.
Interviewer	That stops you from doing a lot of the things…?
Patrick	Yeah, doing things. That right, yeah […] makes a big difference.
Mildred	But the sun comes out, Pat goes out.
Patrick	In the winter, you know, you're all wrapped up. I think it's a miserable time.

Transport

Transport options also affected participants' physical activity levels. For some, the convenience of taking the car deterred them from walking. As Larry (PWD) described: *"The car's too easy"* (Larry, PWD). Pat's (PWMCI) wife Mildred also remarked that the car was the *"lazy"* (Mildred, partner) option. On the other hand, access to a car enabled Malcolm (PWMCI) to exercise, since, although joint problems meant he could not walk very far, he could drive to the gym to do low-impact, seated exercise.

Cost

Some participants remarked that the cost of activities was a barrier. Anthony (PWD), for example, had stopped going to the gym because of the cost. Like Malcolm, Esther (PWD) had received physical training at her local gym through the National Health Service, however, the on-going cost of gym membership had been a barrier, as her husband said that he was not willing to pay for it. Conversely Malcolm

(PWMCI) suggested that, for him, the on-going membership fee was, in fact a motivator:

> “I pay £19 a month for a ticket now and I hate wasting the £19 […] When the hospital kicks you out they send you for a specific training regime at the leisure centre and that lasts a month. After […] that month, you have got to pay. But you only pay half price or something for six months, then it goes up to the full price […] and by that time I was paying by Direct Debit!” (Malcolm, PWMCI)

Time and commitments

Some participants described how other activities and commitments competed for their time, for example Lynn (PWD) described how she had stopped going to an NHS exercise session because it clashed with her childcare responsibilities:

> “I went to the gym for me knees […] I fell out with [the physiotherapist] because she wouldn’t accept that I had to come home- that I had to leave early to pick Joe up. […] And she just shouted at me in front of the class. […] I walked out of the class and I never went back.” (Lynn, PWD)

4.8. Chapter summary

As illustrated in section 4.3, participants’ physical activity levels varied greatly but, notably, did not appear to be related to the degree of cognitive impairment, with some participants with MCI being highly sedentary and others with dementia being very active. Instead, the findings in this chapter indicate that a range of other factors underpinned participants’ physical activity choices and levels. Most participants described physical health problems and, or age-related physical changes and some also reported mental health problems. However, the degree to which these impacted on participants’ active lives differed. Those with multiple ailments tended to be the least physically active. Some experienced a vicious cycle of deconditioning and inactivity, resulting from a combination of physical, mental and cognitive health problems. Others developed strategies to maintain an active life, despite apparently similar limitations.

Psychosocial factors appeared to underpin participants' activity choices and affect their motivation to maintain an active life. For some, physical activity formed a part of their identity—as sportsmen or outdoor enthusiasts—which drove them to maintain an active life. For others, their active self-identity was embedded in homemaking or community. In these cases, although physical activity was not the primary motivation, there remained a desire to maintain an active life. Individuals' perceptions of the value of physical activity also varied; for some maintaining a physically active life was essential, while others considered it a needless pursuit.

As well as needing to overcome the physical changes associated with ageing, some participants indicated that staying motivated to get out and do things in retirement was important to maintaining a physically active lifestyle. Social attitudes towards physical activity in later life were also found to influence people's disposition towards physical activity.

Walking was the most commonly mentioned form of physical activity with few participants partaking in formal sport or exercise. Although a few participants walked out for recreation, for most, walking was incidental to everyday activities. Having a purpose or goal, such as shopping or visiting a local attraction, appeared to be an important motivator to get out and walk. Gardening was another example of a purposeful activity enjoyed by many of the participants. The findings in this chapter indicate that exercise was not a priority for most participants and that, instead, the majority of physical activity was interwoven with everyday and purposeful activities.

A range of environmental barriers to physical activity were also mentioned. However, the extent to which these factors stopped participants from engaging in activity varied greatly and in some instances a barrier for one participant was a motivator to engage in physical activity for another.

Together these findings highlight that, aside from their experiences of cognitive impairment, a complex combination of personal, social and environmental factors influenced participants' physical activity choices and levels. These factors are discussed further in relation to the wider literature in chapter 9, where I also consider the implications of these findings.

Chapter 5. Stage one: The impact of cognitive changes on an active life

5.1. Introduction

Having identified the importance of purposeful activities as motivators of physical activity in the previous chapter, here I explore the extent to which cognitive changes affected participants' ability to perform the everyday activities that contribute to a physically active life.

Cognitive impairment affected different aspects of participants' active lives, including their travel and transport choices, described in section 5.2, as well as the everyday activities participants undertook outside the home, discussed in section 5.3. The impacts of cognitive impairment on hobbies and interests and how this affected participants' sense of mastery and roles in their communities is explored in section 5.4. The challenges associated with household activities and how these led to increasing sedentariness for some are discussed in section 5.5. Diminished motivation also appeared to be a barrier to activity for some, as described in 5.6.

Cognitive changes were found to effect participants' active lives to different degrees. Most participants with MCI did not indicate that cognitive changes had restricted their active lives, although they sometimes caused frustration. Similarly, for some participants with dementia cognitive changes seemed to have had little or no effect on their active lives. However, for those with more severe dementia, cognitive changes appeared to have a significant effect. Consequently, the narratives of participants with more severe dementia are prevalent in this chapter.

5.2. Getting out and about

The impact of cognitive impairment on participants' active lives was most apparent when it affected their capacity to get out and about independently. This section describes participants' difficulties and concerns about walking, driving and using public transport, predominantly experienced by those with dementia.

Walking out independently

Participants in couples tended to walk out with their spouses. Those with MCI who were physically able also walked out on their own, whereas participants with dementia who walked out tended to walk with spouses other than on familiar, regularly walked routes. Brian (PWD), for example, normally walked out with his wife or occasionally with his friends, except when he took a regular morning walk. Brian had previously been a long-distance walker and had led walking groups through the Northumberland countryside. Now, when he walked out on his own each morning, he always took the same route so that his wife Linda knew where he would be:

Linda	It's best to stick to the routine, isn't it?
Brian	Uh huh, because Linda knows how long it's going to take, so if there isn't any— Linda will come out, and she knows where I'm coming to.
Linda	Hopefully. [Laughter]. With her heart in her mouth!

Linda's final comment suggested that she was anxious about Brian walking out on his own, even on this routine walk. Brian, on the other hand, remarked *"I'll not get lost"* (Brian, PWD). Elsewhere in our discussion Brian expressed confidence about finding his way when walking, in contrast to his wife.

Like Brian, Anthony (PWD) enjoyed walking and considered himself to have "*a good memory for routes*" (Anthony, PWD). However, Anthony and his wife Sue's descriptions of their normal routines suggested that they always walked out together. When I asked them whether this was the case Anthony responded:

Anthony	Yes. Unless I let you go down first and I meet you later.

Sue	Yes. If I've gone down to the hairdressers and then I'll say *'do you want me to come home or do you want to walk down the hill to meet me?'*
Anthony	Yeah. I do that… And I'll come down, pick you up at the [Ukulele club]
Sue	[…] As I come out, I'll ring you up and say *'right, I'm finished now and I'm coming up […] walk down and meet me'.*

Similarly, Gerald's (PWD) wife Marjorie said, *"we walk everywhere […] we always – we go together*", although later it emerged that Gerald walked on his own to the weekly choir meeting, he had been attending for several years. Like Anthony and Brian, Gerald appeared to be confident about finding his way to his choir meeting although there was some confusion about the building he went to:

Gerald	I know my way there.
Interviewer	[…] whereabouts is choir?
Gerald	In the, erm – what's it called? Community centre […]
Marjorie	No- the first school. It's not [the community centre]. It's the first school. The little first school, when you go through past the police station […]
Gerald	Go past the police station then turn left.
Marjorie	[…] yeah […]
Gerald	It's not a school […] it's a leisure centre.
Marjorie	No. […] That's when we go to the U3A[8] […]
Gerald	And that's where I'll— choir practice is.
Marjorie	No. No, it isn't. It's at the first school […]
Gerald	Oh that's right. Sorry, yes, we go …

---

[8] U3A or University of the Third Age is an organization in which groups of retired people meet to organise and share in educational and other leisure activities.

Marjorie	Yeah?
Gerald	Yeah […]
Interviewer	Is that weekly then, the choir?
Gerald	Hmm. Wednesday evenings […]
Interviewer	And how long have you been a member of the choir?
Gerald	Oh pretty well since we came here, isn’t it?

Despite being some of the most prolific walkers in the study, Brian, Anthony and Gerald walked out with their wives other than on familiar routes. Despite this, none of the men described problems with walking out alone, or any instances when they had faced difficulties. Instead, they expressed confidence about finding their way. On the other hand, their wives appeared to be inclined to accompany their husbands due to concerns about them walking out alone. The effect of partners’ concerns on independence is explored further in the following chapter.

Although Brian, Anthony and Gerald’s experiences were similar, they were not shared by all participants with dementia. Most others rarely walked out, tending to travel by car instead. Although, one other participant Lynn (PWD), who lived alone, did regularly walk out on her own, including on trips to unfamiliar places. More details of Lynn’s travel choices can be found in appendix T, section 3.

Driving

Driving was an area in which the impact of cognitive changes was particularly apparent. All of the participants with dementia who drove had experienced difficulties or had concerns about driving. As a result, some no longer drove. June (PWD) and her husband discussed the safety and navigation concerns that had led her to forfeit her driving license:

June	I stopped driving. I returned my driving licence to the DVLA… because I didn't want to run anybody over [...] or damage any-

Pete And you didn't want to get lost 'cause you thought you wouldn't know where you were going to and …
June Yeah

Similarly, Esther (PWD) had voluntarily relinquished her driving license prior to being diagnosed with dementia, when she had been told she had MCI. Gerald (PWD), on the other hand, considered himself capable of driving despite his wife explaining that his license had been revoked on his doctor's advice.

Some participants with dementia continued driving, despite experiencing difficulties with navigation. For Anthony (PWD) these difficulties were severe enough for him to restrict his driving to familiar journeys:

Anthony I don't go to strange places […] I can't do going straight to a place where I've never been before. 'Cause you've got to take all the information of what's- where am I gonna go. When I know the route, no problem.
Sue (Partner) […] He doesn't even like it if they've suddenly put on […] traffic lights or something, temporary ones […]
Anthony Oh no, that's – oh, no!
Sue Cos I was quite shocked. I think we went to take some things to the tip and were just driving round….
Anthony Oh it was horrible. Didn't like that, no.
Sue […] you suddenly went 'I don't know where to go' because they had traffic lights on.
Anthony They put them in a different place.

As a result, Anthony's wife was concerned about him driving on his own and accompanied him whenever he drove. Heather (PWD) and her husband George also recounted an instance when Heather had problems navigating due to a change in the road layout:

George	We only had that once and that was about a month or so ago, and Heather was in town, and she came home […] and they blocked the A1 off.
Heather	Hmm. Terrible, terrible.
George	So she did have quite fun getting home.
Heather	Hmm. Yes. It was horrendous.
George	Yeah. So, it took an awful long time.
Heather	Yes.
George	Because the way she went, I don't know.
Heather	I don't think I know which- I didn't know where I went.
George	No. But she got here in the end.

Despite this experience, Heather was still confident about finding her way to the shops in her village and continued to drive there on her own. Larry (PWD) also described forgetting where familiar places were, however, he also continued to drive on his own, using a satellite navigation system to assist him when his wife was not accompanying him:

Jean $^{\text{(Partner)}}$	Sometimes he'll say, *'remind us where this place is?'* ((Chuckles))
Larry	((Chuckles)) Well, yes, lately I've been doing that a lot.
Jean	Uh-huh. Or *'when I'm taking the boys to school this morning, do I turn left, do I turn right here?'*
Larry	Yes, I know.
Jean	[…] He forgets things like that.
Interviewer	Right, okay. So that hasn't affected your driving at all?
Larry	No. Just as bad as ever. ((Laughter)).
Jean	No. He's got a sat nav if I'm not in.
Larry	Aye.
Interviewer	[…] So that's helpful? [...]

> Larry Oh, brilliant, aye.

Unlike participants with dementia only one participant with MCI, Pat (PWMCI), described a single instance when he had felt disoriented when driving:

> “I drove out here, down to the bottom of the road […] and I had to stop. I didn’t know where I was, basically, or where I was going. Literally for that, you know, I had to stop. And I had to ask Mildred I said, *‘where are we going?’ You know?”* (Pat, PWMCI)

Despite this experience Pat continued to drive on his own. Further details of Pat’s travel and transport choices can be found in appendix T, vignette 2.

Public transport

Pat (PWMCI) also regularly used public transport. During the week of diary keeping, he went on a trip to get the Polaroid camera which I had provided with the diary fixed. His wife had gone out in the car, so he used public transport, taking at least four journeys in his hunt for a camera repair shop:

> “I found… [that the Polaroid camera] wasn't working. I knew there wasn't a photo or a camera shop in [my town] so I thought, well, I'll go across the ferry to [another town] and went over there and sort of walked around […] There wasn't a shop there, so I thought - well I'll come back and go to [the city…] and there was a great camera shop.” (Pat, PWMCI)

Like Pat, several participants with MCI regularly travelled by public transport. On the other hand, only one participant with dementia, Lynn (PWD), spoke confidently about using public transport on her own:

> “The Metro’s right outside me door. So, wherever I’m going, I hop out there and I think ‘right, where does that get me to?’ You know? […] I manage fine.” (Lynn, PWD)

Unlike Lynn, who had relied on public transport all her life, several participants with dementia had started using public transport more often since they stopped or reduced their driving, although they tended to travel with their spouses. For some cognitive changes also made public transport difficult to use. Brian (PWD), for example, had stopped driving and instead travelled by bus several times a week with his wife. When I asked Brian if he ever travelled on his own, he responded:

Brian	No.
Linda	Yes.
Brian	Have I?
Linda	If you go for a walk with Graham, and, or you might get a bus back with Sidney?
Brian	Right, yes, possibly.
Linda	And always back. And you would get on the bus and use your bus pass by yourself. Uh-huh, yes.
Interviewer	[…] And how do you find getting off at the right stop? […]
Brian	[…] I suppose, the places I go to are places I know, so […] I would know when I was going to stop […]
Linda	It's always on the way back so it's always the same stop, isn't it?

For Anthony (PWD) on the other hand, using public transport was not an attractive alternative to driving, since, despite having formerly taken long-distance bus trips to football matches, a combination of perceptual changes and travel sickness, which appeared to be related to his dementia, now made bus travel difficult:

Anthony	I don't like buses.
Sue $^{\text{(partner)}}$	He feels sick and I think it's the scenery going past.
Anthony	Hmm-hmm.
Anthony	Don't like travelling in buses, which is unfortunate.

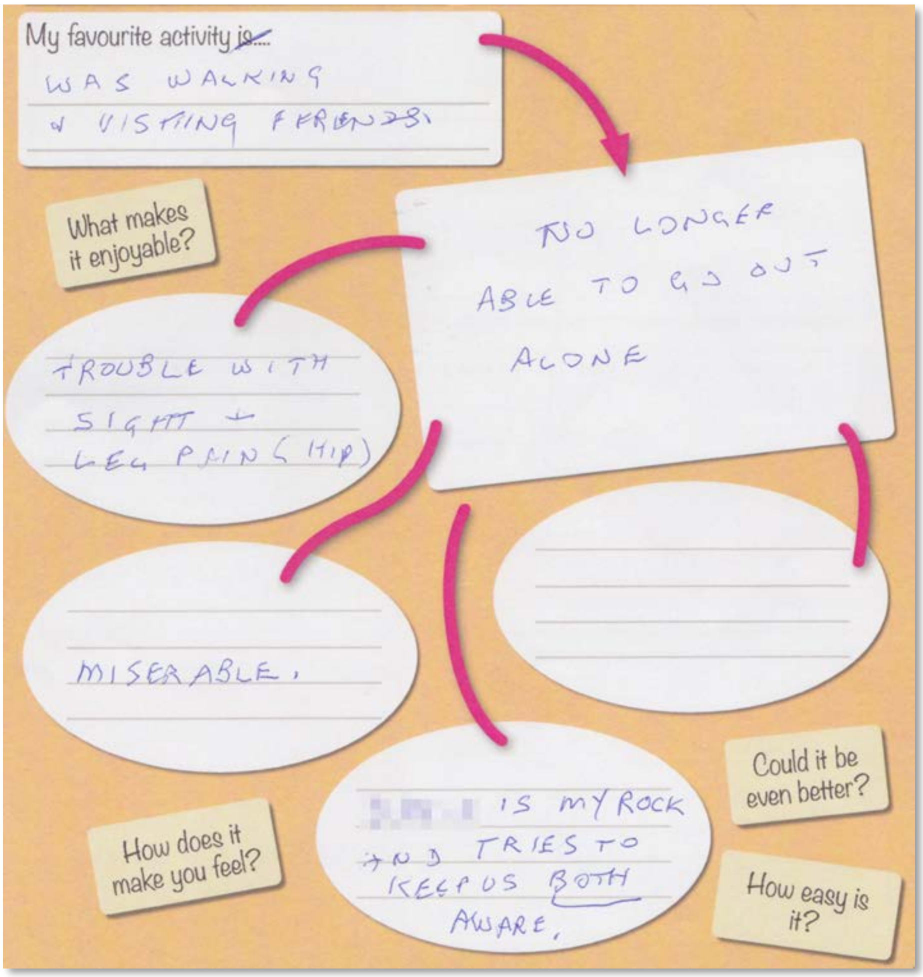
Impact of restricted travel

In some cases, no longer being able to drive forced participants to walk. Gerald's (PWD) wife Marjorie described how "*we walk everywhere*" including walking into the nearby town to shop rather than taking the car to the supermarket. Similarly, Brian (PWD) and his wife Linda would take the bus and walk to the shops:

> "We tend to shop in shorter spells. So, we'd shop every other day perhaps." (Linda, partner)

However, travel difficulties could also impact on participants' ability to undertake activities that they valued. For example, Esther (PWD) noted in her diary that no longer being able to go out alone prevented her from visiting friends, one of her favourite activities (see Figure 5.1). In the interview she elaborated on the comments in her diary:

> "You see [in the past] I would've just thought, well, I'll get the bus and go and visit so and so. Or even when I had the car, me friend in […] that other part of Gateshead, I'll just go and visit. But of course, no car, then not getting out and walking. And, so I just, I don't go anywhere." (Esther, PWD)



My favourite activity ~~is...~~
WAS WALKING
& VISITING FRIENDS.

NO LONGER
ABLE TO GO OUT
ALONE

What makes it enjoyable?

TROUBLE WITH
SIGHT +
LEG PAIN (HIP)

MISERABLE.

How does it make you feel?

[redacted] IS MY ROCK
AND TRIES TO
KEEP US BOTH
AWARE.

Could it be even better?

How easy is it?

Figure 5.1 'Hobbies and interests' page from Esther's diary

For Brian (PWD) and his wife Linda, giving up their car meant that they could no longer manage their allotment:

Linda	Brian stopped driving in two thousand and thirteen, […] Brian worries about me driving with the car and so we gave it a shot for twenty fourteen to use the bus pass... So, we got rid of the car, didn’t we? […] Tell Lizzie about the allotment.
Brian	Oh, we had an allotment. And we used to go with the car, but after that we just used to use the bus […]
Linda	But when you’ve got an allotment, you need to go quite regularly.

5.3. Everyday activities outside the home

Several participants described difficulties performing everyday activities outside the home, although this effected their active lives to differing degrees. For most participants with MCI memory aids, such as shopping lists, enabled them to continue undertaking activities independently. However, for several participants with dementia cognitive changes had become a significant barrier, necessitating assistance from others.

Memory problems

Malcolm (PWMCI) described how he would sometimes find himself wondering *"Why have I gone out?"*, explaining how he would go *"out of the house, go up the car park, get into my car, drive up the road, then turn around and come back because I had forgotten something"* (Malcolm, PWMCI). However, Malcolm compensated for his memory loss by making lists and lining up items he had to remember to take out. Similarly, Pat (PWMCI) described forgetting items he went out for and using a list to compensate. The use of strategies to manage memory problems is discussed further in the following chapter, and further details of Pat and Malcolm's coping strategies can be found in the vignettes in appendix T.

Pat (PWMCI) also described how he often lost his wallet when he went out:

> "Frequently lost [my wallet] …] I think that's about the fifth time […] I just forget about it. […] Left it in the pub one day and two hundred pound in it. […] We got in the car and drove off, up the road. And I thought *'where's me wallet?'*" (Pat, PWMCI)

Despite these experiences, both Pat (PWMCI) and Malcolm (PWMCI) regularly went out alone. Most other participants with MCI and some with dementia did not talk about memory problems or other cognitive changes effecting activities outside the home. However, for several participants with dementia various facets of dementia made everyday activities outside the home challenging.

Sensory and perceptual difficulties

For some participants with dementia sensory and perceptual difficulties made public spaces challenging. Anthony (PWD), for example, struggled in busy and noisy environments, such as cafes and restaurants. Anthony's distress was clear to see when, at one point in the interview, he mimicked a scenario in a coffee shop including making the sounds of crashing crockery and the coffee machine erupting, *"Clang! Bash! Tssshhhh!"* (Anthony, PWD) while placing his hands over his ears to express his discomfort. Similarly, when visiting the supermarket, his wife explained if "*it's noisy you'll go and stand outside"* (Sue, partner). In addition, Anthony experienced difficulties with balance and spatial awareness, typical of his condition: dementia with Lewy bodies. As a result, escalators became difficult to negotiate, as Anthony exclaimed *"I hate escalators! I never used to. Never a problem before"* (Anthony, PWD). These problems limited the places that the couple could visit.

For Brian (PWD), changes in visual perception caused difficulties, for example when discussing a trip to a restaurant he described how, *"if there is a sharp piece of glass or whatever, and [a light] really hits it […] it startles me"* (Brian, PWD). Brian also had difficulty recognising faces, including his own, which in one instance caused him to become confused in a public toilet:

> "I'll tell you a funny one […] about the thing in the loo [...] I turned around and there was this person […] and so I said, *'You go first'*, and there was nothing said and so I moved and nothing was said and […] this went on for a little while, the person moving and then stopping. Me moving and then stopping and we weren't going anywhere. And a chap came in and he says, *'that's a* […] *mirror'*. I said, *'Honestly?'* […] and […] I suddenly realised." (Brian, PWD)

Money and payment devices

Handling money was problematic for some participants with dementia. For example, Brian (PWD) explained, *"I can't work out the money"* (Brian, PWD). June (PWD) also found banknotes difficult to differentiate but was still able to use her credit card:

June	Cards no problem. But when it comes to–
Pete	You always remember your PIN number, don't you?
June	I always rememb— [...] I don't forget that. But what I do get is when it comes to pay […] the notes confuse me.

Brian (PWD) and Anthony (PWD) also experienced difficulties using payment devices outside the home. Brian's wife described a stressful experience when Brian tried to use a public toilet that required payment at a turnstile:

> "We've been to the Lake District on a bus tour, you know, and that was absolutely horrendous. Because it's a very busy place and they have turnstiles and you have to put money in to the gents' toilet and I have to sort of be on the edge and saying, you've got to put the money in there and turn it, but how do you get back out again." (Linda, partner)

Anthony (PWD) became frustrated when he was asked by a member of staff to use the self-checkout at the newsagent, as illustrated by his wife, Sue, in the diary (Figure 5.2). In Sue's description of her illustration, she commented that it was

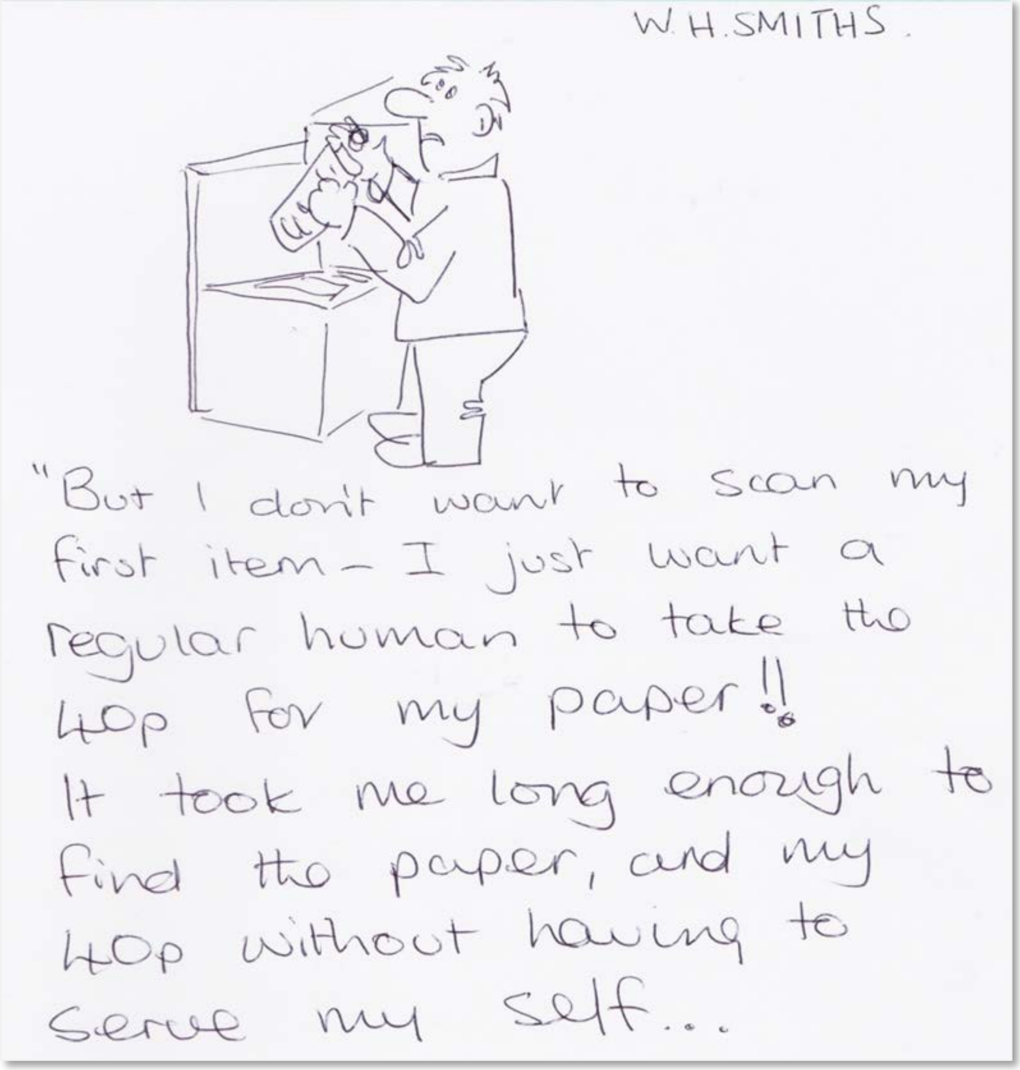


Figure 5.2: An illustration of Anthony trying to buy a newspaper. Drawn by Anthony's (PWD) wife Sue in Anthony's diary.

challenging enough for Anthony to find the newspaper and the correct change to pay for it, without having to try to use the self-checkout.

Social interactions

The challenges of going out to public places could be exacerbated by worries about social interactions. For example, June's (PWD) husband described a negative experience she had when shopping:

> "We were in Primark [...] June went up to pay [...] and she got confused with her money. And the woman who was serving […] I think she wanted a five-pound off you, and you were giving her fifty pence or something

> like that. And she said to June *'oh you're trying to get away with it.'* Now she probably wasn't meaning it in a nasty way. Irene heard her as she was approaching. She said *'listen you- don't you dare talk to my friend like that. She has dementia.'*" (Pete, partner)

As Pete indicated, other's lack of understanding could result in challenging experiences for people with dementia. Some participants suggested that seeking other's understanding could be beneficial. For example, due to his difficulties with facial recognition, Brian (PWD) decided it was best to explain his situation to others. However, despite finding that most people were sympathetic, he indicated that he still found social interactions difficult:

Brian	One of my students stopped me the other day and […] I told him what the problem was, you know, which was okay, he understood, and he continued with what was happening and things like that.
Linda (partner)	People are lovely, aren't they?
Brian	The majority of people. Well, I've never had a problem with anybody, I suppose, in that sense. And they just— If I haven't seen them within, say a week or two, maybe more than two weeks possibly, I'll not know who they are. I just can't work it out at all, and things, and some of them couldn't understand, but didn't say anything. And so, until one lad turned round and said something, he said, *'Have I upset you?'* and I said, *'No'* I said, *'it's a problem I've got, that I don't—.'* And from then on, most people were okay with it.
Linda	If you explain it to people, it's good, isn't it?
Brian	But it does make it difficult.

One participant with MCI also described how he faced situations when he had to explain his memory loss to others to avoid appearing rude:

> “I don’t remember names. I remember faces. […] I’ve been perfectly open about it. So, if somebody comes up and speaks to me, I say ‘*I know your face, but I don’t know who you are.*’” (Norman, PWMCI)

Despite this, Norman (PWMCI) continued attending his regular social activities, including trade-union meetings, on his own. For Brian (PWD), on the other hand, the severity of his memory loss meant that he needed his wife’s support even when he spent time with friends:

Linda (partner)	We haven’t seen Graham for quite some time, and then when he came, and you know I said to Brian, *‘Oh it’ll be lovely for you to go on this walk with somebody different’*. And poor Brian, he didn’t know who he was, and they’d been very close friends. You were his best man, weren’t you? Yeah, that was hard.
Brian	It was really hard.
Linda	But we went together. I went too, but I just let them walk and I was looking at the flowers.

Unlike Norman (PWMCI) and Brian (PWD), who were willing to disclose their diagnosis, Anthony (PWD) did not want to reveal his condition to others, which made him shy away from social interactions. For example, Anthony enjoyed going for a pint, but did not want people in the pub to know about his problems:

> “You know from the way— in the pub, the way that they talk about— You wouldn't tell. So, I didn't— wouldn't tell people what my problem was.” (Anthony, PWD)

5.4. Hobbies, interests and communities

Most participants had hobbies and interests, of which many spoke with enthusiasm or pride. For several participants with dementia, however, memory problems had stopped them from participating in their hobbies and interests, leading to loss of community, status and skills.

Loss of mastery

Anthony (PWD) was a keen photographer. His wife spoke with pride about her husband's skill and the "*thousands upon thousands of photographs*" (Sue, partner) they had in the house. In contrast to his wife's enthusiasm Anthony became uncharacteristically withdrawn when we discussed his photography. Anthony could no longer use Photoshop to edit his photographs because he had been unable to learn to use an upgraded version of the software on a new computer. His wife described how, despite still being a competent photographer, not being able to use the software meant that Anthony had lost the satisfaction of completing his artistic process:

Sue	The level of doing things was he used to— I had some old photographs, which were damaged, and he would scan them in […] and repair them. […] So, it was a high, high level of—
Anthony	Now I haven't got a […] computer. ((In a sad, whining voice))
Interviewer	[…] But you can still take the photographs?
Anthony	((Quietly)) It's not the same.
Sue	[…] And doing artwork with them. You used to make them into oil paintings and watercolours. And—
Anthony	Hmm […]

Sue	You know [if] it’s sunset and he’ll look out and that’s it, he’s gone. Or, you know, a cluster of roses and it’s been raining and […] the raindrops are still there, and straight in. And his shots are always superb […]
Anthony	But they’re just stuck in the camera […]
Sue	Its part of the process […] and you lose that satisfaction of taking it through to the end.
Anthony	Hmm

This conversation, along with Anthony’s reluctance to discuss his photography, suggested that, although Anthony was still a competent photographer, not being able to complete his artwork to his high standard, was a severe disappointment to him.

Like Anthony, Brian’s (PWD) mastery of his long-held hobby had been eroded by dementia. As a keen walker, Brian used to lead groups of walkers on long hikes, however, he was no longer able remember routes:

> "It would have been places we hadn't been before and there's fields across and different things […] and once I'd set it up, I knew exactly what it was the next time and things like that. But that's disappeared. And that's the hard part." (Brian, PWD)

Similarly, dementia prevented Gerald (PWD) from participating in the amateur dramatics performances that he had once starred in. Having been withdrawn through most of the interview, Gerald’s voice lifted when he told me about his reputation as an actor within this community:

> “My main hobby for a long time was acting […] I had a reputation for learning a part quickly. And, in fact, I quite often got invited to other groups when they wanted to fill a part […] because I could learn a part very quickly. And of course, *I was a very good actor* ((in a theatrical

> voice)), as you can tell! […] It's long in the past now […] I used to enjoy the acting." (Gerald, PWD)

Loss of role in a community

Gerald indicated that no longer acting meant that he had lost his role in the amateur dramatics community that he had played a significant part in for many years. Similarly, June (PWD) experienced a loss of status at her Masons' group. As a member of the Masons, June had scaled the ranks within the organisation, however, when her health problems prevented her from moving up to the next rank, she was relegated to a subordinate position, as her husband Pete explained:

> Pete She was Inner Guard and […] you quite enjoyed that I think. Did you?
> June Yeah.
> Pete […] And June had said *'I don't think I'll be able to do Deacon'* […] She told them about her Alzheimer's and what have you. So, they dropped her off the ladder all together and they put her back as Steward. But you hated being a (Steward). A Steward makes the teas in June's place and puts the sandwiches out […] And you didn't like that, did you?
> June No, no.
> Pete And I said, *'tell them you can't do Steward.'* And we did. And they said, *'well okay, you know, if you could just maybe sell the raffle tickets or something like that'*.

While some hobbies were lost, others were maintained, adapted or even replaced by new activities; Anthony (PWD) continued to garden and had joined a gardening club since developing dementia; Gerald (PWD) continued to sing in a choir and still attended U3A group meetings with his wife; Brian (PWD) continued walking, although to a much lesser degree than he had previously and with his wife's assistance. The ways in which people with dementia modified and maintained activities, with the support of their partners, are explored in the next chapter.

5.5. Household activities

As well as difficulties performing activities outside the home, several participants noted that cognitive changes impacted on their ability to undertake everyday activities in and around the home. As with activities outside the home, the extent of individual's impairments varied, with some participants with milder cognitive impairment describing frustrations, while others with more severe dementia appeared to be limited in their capacity to perform everyday chores. This section describes the implications of these limitations on participants' activity levels and their sense of contribution to the household.

Misplaced items

When performing tasks around the home, several participants described losing things or not knowing where items belonged. Malcolm (PWMCI) described how he would put things in the wrong place:

> "Go to put something into the microwave and I put it into the fridge by mistake and half an hour later […] I say, '*where did that bloody fish go?*'" (Malcolm, PWMCI)

Other participants with MCI also mentioned mislaying items, for example Janet (PWMCI) would lose her handbag and Pat (PWMCI) expressed frustration at losing his keys. Further examples of these frustrations can be found in vignettes 1 and 2 in appendix T. While for participants with MCI memory lapses caused irritation, some participants with dementia described how memory loss led to the termination of activities. For example, Esther (PWD) explained how she found it difficult to perform tasks in the kitchen:

> "It was obviously my kitchen all our lives [...] But [now] I think [...] *'well where does that live again?'* [...] I do dishes and put them – *'where do I put that again? Oh yes, there.'* Or I want something, and I'll say, *'where will I find that?'* And then, you know, I'll sort of think and think and then maybe get it and maybe think *'oh I'll do something else instead.'*"
> (Esther, PWD)

Esther's description suggests that despite her efforts to "*think and think*" where things were, not being able to find things led her to give up on household tasks. Similarly, Anthony (PWD) experienced difficulties remembering where he had put things:

> "Kindle needed charging. Found charger. Misplaced Kindle. Lost charger again." (Taken from Anthony's diary, completed jointly by Anthony and Sue)

Later in our discussion, Anthony's wife explained that he had also had difficulty finding a place to charge his Kindle, not realising that he could unplug other devices. Consequently, charging his Kindle turned into a "*big task*" (Sue, partner), which Anthony eventually had to ask for help with, despite being determined to do things for himself. Anthony remarked on his "*frustration*" (Anthony, PWD) when faced with such difficulties.

Planning and executing tasks

Participants with dementia and their spouses indicated that cognitive changes also made planning and carrying out household tasks difficult. For example, June's (PWD) husband described how she had difficulties with meal preparation:

> "You get your timing wrong. You'll do something, but haven't done that or, you know, you'll say *'oh I didn't do this, I didn't do—'*. So, I'll, in the main, do it now." (Pete, partner)

Esther (PWD) and Anthony's (PWD) spouses had also taken control of the cooking. June's (PWD) husband also suggested that she would forget what she planned to do, which stopped her from performing relatively simple tasks such as making a cup of tea:

> "She'll say, *'do you want a cup of tea'* when I'm in the garden, I say *'yes'*. An hour goes by [...] I'll think *'where's that cup of tea?'* and I'll come, and I'll say. She says '*what are you talking about? Oh, I forgot to put the kettle on.*'" (Pete, partner)

On 'bad days', Anthony (PWD) also struggled to make a cup of coffee. He described his experience of not being able to remember what he was doing:

Anthony	You think - *'I'm gonna do this.'* Then you think *'and I'm gonna— I'm gonna— oh, I was going to— I was going to, er …'* and you think '*well I'll try to think back where I was*' and it then pfffhh – it's all gone, then…
Sue	And he says it's just like smoke that dissipates and then it's gone. Everything's gone.
Anthony	It starts off and goes tsshhhww. It's gone. You just give up.

Not all participants with dementia indicated that cognitive changes affected their ability to undertake everyday activities and even those who experienced difficulties continued to do some activities in the home, although for most their contribution was limited to some degree. Anthony (PWD), for example, no longer organised meal preparation but contributed to the cooking, did the gardening, vacuuming and washing up. Similarly, although Esther (PWD) no longer did the gardening and cooking, two activities she had previously

Figure 5.3: Picture of Esther (PWD) hanging out washing, taken from her diary

enjoyed, she did do the washing (see Figure 5.3) and ironing and emptied the dishwasher. Among the participants with dementia June (PWD) and Gerald (PWD) were the least active in the home only occasionally contributing to household activities.

Valuing household activity

Some participants with dementia expressed satisfaction at being able to contribute to household activities. For example, in Brian's diary, beside a picture of him vacuuming (Figure 5.4), his wife had written on his behalf:

> "I vacuum each day this gives me confidence that I can do this task independently and it gives me a sense of a worthwhile contribution to the household tasks." (Extract from Brian's (PWD) diary)

Figure 5.4 Image taken from Brian's (PWD) diary of him vacuuming

Brian subsequently corroborated this in the interview, adding that he took pleasure in the task:

Brian	It's my duty to [vacuum] the whole of the house in the morning, every morning […] *We're* doing it.
Linda	We share every, all the tasks.
Brian	It's good fun as well, doing it, in a sense […]

Washing-up was Anthony's (PWD) responsibility. In his diary there was a picture of him standing at the sink (Figure 5.5) and a comment saying, "*Anthony cleans and washes dishes. ALWAYS!*"[9]. In response to this diary entry Anthony remarked:

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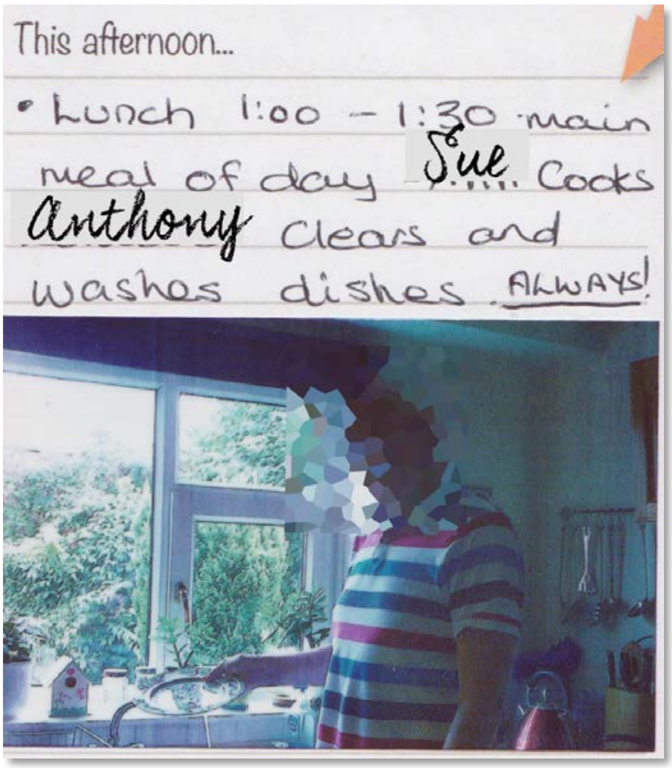
[9] Anthony's (PWD) wife, Sue wrote in his diary due as he had difficulties writing. The couple described the process by which they made the diary entries:

Anthony	That's my job.
Sue	And, you like – you -
Anthony	I like doing it.



This afternoon...
• Lunch 1:00 – 1:30 main meal of day Sue Cooks Anthony Clears and washes dishes. ALWAYS!

Figure 5.5: Extract from Anthony's diary. Text reads: "Lunch 1:00 - 1:20 main meal of day. Sue cooks Anthony clears and washes dishes. <u>ALWAYS!</u>"

Anthony (PWD) and Brian's (PWD) comments suggest that they valued these routine household tasks. However, other participants with dementia indicated that they felt excluded from household chores. For example, June (PWD) said that she was no longer *"allowed"* (June, PWD) to participate in household activities. Esther (PWD) also described how her husband had *"taken over"* the cooking, an activity which she had previously taken pride in. Despite this, Esther (PWD) expressed conflicting feelings about not being able to contribute to the cooking:

> "Sometimes it's really acceptable, you know I think *'that's great. I can just sit here and watch the telly'*. Then you think *'I'm just being put out to grass here. I can't do anything.'*" (Esther, PWD)

Sue	You would – we would talk about it and you would give me…
Anthony	Talk over it and say what- how much do we need to put on in here.
Sue	So – and then I would just write in the necessaries.

Taken together, the accounts in this section suggest that maintaining responsibilities in the home can be valued by people with dementia whereas no longer being able to contribute can lead to feelings of worthlessness. Some of the comments indicate that partners play a role in restricting or maintaining activities, a factor which is discussed in the following chapter. For both Anthony (PWD) and Brian (PWD), routines seemed to be an important factor facilitating sustained engagement in household activities, which is also explored in the next chapter.

Loss of occupation

Reduced engagement in household activities, hobbies and interests, left some people with dementia bereft of activity for much of the day. Gerald found himself at a loss for occupation, commenting that *"it's a bit difficult to find things to do*" (Gerald, PWD). Similarly, when I inquired how June kept herself occupied during the day, she responded, "*Sometimes I find I don't do anything*" (June, PWD). While her husband prepared the meals Esther (PWD) described how she would *"get sat here and watch the telly instead. And me head going…"* and then gesticulated while making a noise to indicate her brain turning to mush. Like Esther, June often spent most of the day watching television and emphasised, *"I watch a lot of television actually"* (June, PWD). June's husband commented that watching television would send June to sleep resulting in her *"sleeping more and more during the day"* (Pete, partner). Together these reports indicate that no longer being able to perform everyday household activities led to sedentariness for several participants with dementia.

5.6. Loss of motivation

In previous sections of this chapter, I described how dementia eroded several participants' capacity to perform valued activities, leading to feelings of disappointment, frustration and worthlessness. These experiences alone might understandably lead to loss of motivation. However, participants reported several additional factors that may have contributed to loss of motivation.

Loss of initiative

Some participants with dementia and their partners indicated that the ability to make plans and initiate tasks was affected by dementia, as Esther (PWD) described:

> "It's there all the time. You can't—. You're not aware of yourself, in yourself, of what you want to do." (Esther, PWD)

Several spouses indicated that their partner with dementia had to be prompted to do things or, as in the following example, described being surprised when their partner had initiated an activity without prompting:

> "Good god she's made the bed. ((Chuckles.)) I'm in the wrong house!" (Pete, partner)

Such comments suggest that dementia impaired some participants' initiative and that this could lead to inactivity unless their spouses prompted them to do things.

Fluctuations

For some participants with dementia, their levels of initiative and their capacity to perform tasks fluctuated. For example, on the day June (PWD) made the bed she also surprised her husband by spontaneously starting to prepare the evening meal, which she attributed to having had *"a good day that day"* (June, PWD). In contrast June reported *"sometimes I find I don't do anything"* (June, PWD). Anthony (PWD) also experienced fluctuations in his condition, although they were more marked, which is typical of his type of dementia: dementia with Lewy bodies. Anthony's wife, Sue, described how fluctuations in cognition prevented him from performing tasks:

Sue	You wouldn't believe the difference between—
Anthony	The good man and bad man.

Sue	Good man is how we see him today […] bad man is - can’t tolerate anything and really can’t access- process – even to go and make a cup of coffee.

Anthony also described fluctuations in his motivation and the need for encouragement to engage in activities on ‘bad days’:

Anthony	Some days are good, and some days is bad days.
Sue	Yeah. Sometimes I have to chivvy you on.
Anthony	Yes. I need that prod, don’t I?

However, on other days Anthony felt too tired to engage in any activities, finding that he had to *“hide under the quilt.”* (Anthony, PWD). His wife suggested that fluctuations in his cognition were caused by *“mental tiredness*” (Sue, partner), which could be triggered by *“a very busy day”*. Anthony added that he could not *“recharge quickly.”* (Anthony, PWD). These fluctuations made it difficult for the couple to plan ahead:

Sue	It’s very hard to plan things […] We’ve had various things that we’ve literally had to say we can’t go. […] It’s hard. You know, we’ve had reunion dos, all sorts of things.
Anthony	Hmm-hmm.
Sue	And it’s just *‘sorry but in a bad place and can’t do it today’.*

Perhaps in anticipation of fluctuations in capacity, June (PWD) suggested that she preferred activities that she was not obliged to do. For instance, when asked whether she enjoyed going out with her husband in the car she replied:

> "Yeah, especially if it's not—, if it's nothing that has got to be done. I don't have to go, you know? It's not something that's gonna make a big difference […] if I don't go, but there again, if I want to go, that's there." (June, PWD)

Reluctance to engage in activities

Although June (PWD) was happy to go out in the car she was not interested in walking out, as she explained:

> "I was supposed to go for a walk yesterday with Irene and she came round to take me for a walk ((chuckles)) and I managed to talk her out of it [...] I couldn't put my mind to it. I couldn't – it just wasn't – I wasn't in the right feel, you know?" (June, PWD)

Her husband remarked that June's aversion to walking developed relatively recently:

> "We did go walking last year along the river, but you found that you didn't want to do it." (Pete, partner)

June's response to Pete's comment suggested that she felt that she should walk:

> "I know. I should get back on to that." (June, PWD)

June used to be active and outgoing. She led a keep-fit group for many years and described herself as tenacious: *"I don't give in very easily"* (June, PWD). It therefore seemed uncharacteristic that June did not want to walk out.

Similarly, Anthony (PWD) had been an active individual, a runner, "*prolific walker*" (Sue, partner) and gym member. Anthony had stopped running and going to the gym, but unlike June, still walked out with his wife most days. However, despite describing walking as *"good therapy"* (Anthony, PWD), when asked whether he would walk out without his wife's encouragement he responded with a chuckle, *"I wouldn't"* (Anthony, PWD). His wife went on to describe how she sometimes had to be *"quite bullying"* (Sue, partner) to get Anthony to take a walk. Together these comments suggest that Anthony (PWD) and June (PWD) were disinclined or reluctant to engage in activities, despite having previously been busy, active people who enjoyed and saw value in physical pursuits.

Low mood

When participants described how dementia had limited their engagement in activities they valued, they often conveyed feelings of disappointment, worthlessness, frustration and loss of identity, as illustrated previously in this chapter. Anthony (PWD) appeared to be particularly devastated by his loss of capacity and explained how he felt when he was not able to do something:

Anthony	You come across something you can't do because it doesn't work and then you feel bleurgh.
Sue	And that sets you down.

Anthony's wife went on to convey the extent of Anthony's despondency:

> "He can be as low as '*I want you to put me in a home.*'" (Sue, partner)[10]

Other participants with dementia whose activities had been limited by their cognition did not convey such anguish as Anthony (PWD). Some even described the positive aspects of being cared for, for example, when Gerald (PWD) was asked how he felt about not being able to do things he reflected:

> "I don't think – it's not worried me much. I mean, a bit disappointing that you can't do things but, erm… I'm well looked after." (Gerald, PWD)

Apathy

As well as being reluctant to engage in activities, some conversations with participants with dementia and their spouses indicated that they were not averse to

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[10] The effect of low mood and depression on physical activity was also raised in the previous chapter. Unlike Anthony, the participants in the previous chapter did not attribute their depression to cognitive changes and suggested that it had begun before the onset of cognitive impairment. However, it is recognised that mood and cognitive changes may be interrelated.

activity but had merely become disinterested or apathetic towards activities they had previously enjoyed. For example, as Gerald (PWD) reflected:

> "[I] don't do much. […] It's not really bothered me much […] I enjoy it when we go out […] But I'm not much concerned about it if I don't go out." (Gerald, PWD)

Later, however, when asked whether he had lost motivation, he was insistent that he would rather go out than do nothing:

Gerald	Oh no, certainly not […]
Marjorie	No, you do like to go to the shops, don't you?
Gerald	Quite so, yes. Yes, I'd rather go out to the shops than just sit and do nothing.

As such, it was unclear whether Gerald experienced apathy or whether he was just relaxed about whether he went out or not. However, elsewhere in the interview Gerald's comments indicated that he may have experienced apathy:

> "Well, I suppose I don't do enough but I've lost interest in a lot of things." (Gerald, PWD)

Similarly, Esther (PWD), a proud homemaker, appeared to have lost motivation to engage in cooking and gardening, activities she had previously enjoyed. When asked what stopped her from gardening she replied:

> "Oh, I can't be bothered." (Esther, PWD)

Gerald and Esther's feelings of disinterest may be signs of apathy, a common symptom of dementia characterised by disinterest or indifference. However, they could also be symptomatic of depression, in which loss of interest can also occur, although typically alongside negative feelings (Mortby, Maercker and Forstmeier, 2012) which were not evident in Gerald and Esther's comments.

5.7. Chapter summary

In this chapter the impact of cognitive impairment on participants' active lives has been explored. The experiences of a few participants with more severe dementia dominate this section as they experienced most difficulties. Conversely, several participants with MCI are not represented in this chapter since they did not report that cognitive changes affected their active lifestyles. A few participants with MCI and some others with less severe dementia did report some cognitive challenges but did not suggest that they prevented them from engaging in activities. However, for the participants with dementia whose experiences are most prevalent in this section, cognitive changes impacted on their active lives to the extent that it limited their activity choices and levels. These findings indicate that cognitive changes begin to become a barrier to an active life during the early stages of dementia. It should be noted, however, that there was not a clear demarcation between the capabilities of participants with MCI and mild dementia and that the ways and extents to which cognitive changes affected participants' active lives was highly individual, dependent on the manifestation of cognitive impairment in the individual as well as on individuals' personalities and personal circumstances.

For most participants with dementia, difficulties getting out and about were a barrier to an independent, active life, preventing some from undertaking valued activities and leading to increased reliance on others. Although no longer driving meant that some participants with dementia walked out regularly, possibly leading to increased physical activity, independent activity was limited as these participants normally walked out with their spouses. It was, however, unclear whether this was initiated by the individuals with dementia—who actually expressed confidence about finding their way—or their spouses, who appeared concerned about their partners with dementia walking out alone.

Dementia could also affect engagement in everyday activities outside the home, which may have contributed to the tendency for some people with dementia to go out with their spouses. However, this was not the case for all participants with dementia. Some participants with MCI described having to use strategies to manage their memory problems although they did not indicate that cognitive changes stopped them from undertaking activities independently. Together these findings suggest that, in MCI and early dementia, independent activities may be maintained but as dementia progresses, cognitive impairment can become a barrier to independent activity outside the home. This is an important consideration since everyday activities were found to make an important contribution to participants' active lives, as described in the previous chapter.

Several participants with dementia also found that they were no longer able to undertake valued hobbies, leading to loss of identity, occupation and status in their communities. For others, household activities such as cooking and gardening were valued, however, for some these activities had also become challenging. For several participants with MCI and some with mild dementia, memory problems made everyday activities in the home somewhat more difficult, which could lead to frustration but did not appear to prevent them from doing things. However, for several participants with more severe dementia, difficulties initiating and undertaking everyday activities had become a barrier to an active life in the home. Despite this, most participants with dementia maintained some level of involvement in household activities and some expressed their satisfaction at being able to contribute to the household. The extent to which participants with dementia continued their engagement in hobbies and interests as well as household activities may have been mediated by spousal support, which is explored in the next chapter.

Loss of motivation was a recurrent theme in the accounts of several participants with dementia. A number of factors were found to contribute to loss of motivation, including loss of initiative, fluctuations in cognition and apathy. In addition, some participants described their frustration at lost skills or capacity, which may have led to disinclination to engage in activities. For one participant in particular this may have also contributed to low mood. The reasons why participants' motivation to engage in activities had diminished was often unclear, with one or more factors potentially contributing. In response, partners often described having to prompt or encourage their spouses to undertake activities. Partners' contributions to motivating and supporting active lifestyles are discussed in the following chapter.

The cumulative impact of dementia on participants' ability and motivation to undertake everyday activities, hobbies and interests, led to loss of occupation for several participants with dementia, which appeared to contribute to sedentariness. It should be noted that some of these participants also had physical health problems, which may have contributed to their sedentariness, as discussed in the previous chapter. Other participants with dementia were, however, able to maintain an active, although somewhat altered life, with the support of their spouses, which is explored in the following chapter.

In conclusion, cognitive impairment did not appear to have a significant impact on the active lives of most people with MCI and some with milder dementia, however, for others with more severe dementia, cognitive changes became a barrier to an active life. For these participants, cognitive changes led to loss of hobbies, interests, communities and roles and could impact on everyday activities. In addition, some participants with dementia experienced loss of motivation. This combination of factors could lead to reduced engagement in physical activity outside as well as inside the home and appeared to contribute to sedentariness.

These findings indicate that interventions to support people with MCI to engage in physical activity should focus on barriers other than cognitive impairment described in the previous chapter, since cognitive impairment did not appear to be a significant barrier to a physically active life. Meanwhile, interventions to support people with dementia might look to address difficulties performing everyday activities and loss of motivation. These ideas are discussed further in my discussion in chapter 9. First, however, in the following chapter I describe the strategies employed by participants to manage cognitive changes and maintain an active life.

Chapter 6. Stage one: Managing cognitive changes to maintain an active lifestyle

6.1. Introduction

The previous chapter described how cognitive changes affected participants' active lives, in particular their everyday activities. In this chapter I explore the strategies used by participants and their partners to overcome these difficulties.

Strategies used by participants included routines and familiarity, described in section 6.2, and memory aids, described in section 6.3. Some participants suggested that engaging in activity could help to manage cognition and mood, which will be explored in section 6.4. The second half of the chapter focuses on partnership and partners' roles in supporting activity. Section 6.5 describes the role of partnership in an active life, with the degree to which partners supported or restricted activity being explored in 6.6. Section 6.7 reveals both negative and positive consequences of increased dependence on partners.

In section 6.8 I summarise this chapter, before drawing together the findings from across the first stage of this research in section 6.9, where I also describe how my findings affected subsequent stages of the investigation.

6.2. Routines and familiarity

In this section I explore the ways in which participants used routine and familiar activities to help them to maintain activities outside and inside the home.

Regular activities

Malcolm (PWMCI) was an advocate of routine and recommended that other people with MCI should "Have a routine, get a routine" (Malcolm (PWMCI). When asked whether he always stuck to his routine he responded:

> "Yes. Routine gives me confidence." (Malcolm, PWMCI)

However, the degree to which routine was instilled in Malcolm due to his career in the army was unclear, as described in appendix T, vignette 1.

Janet (PWMCI) also stressed the importance of her weekly routine:

> “There's a pattern to the week, and I would find that if there wasn't a pattern to the week, I would find that quite difficult.” (Janet, PWMCI)

During the interview Janet confidently listed her busy schedule of regular activities (see section 4.3), but irregular activities were more difficult to recall. When we came across a photograph of a pub meal, stuck in her diary on a Tuesday, she was confused, as it did not fit her expected pattern of the week, which normally included a pub meal on a Wednesday. However, when we turned the page, we saw another picture and a note that reminded her that she had been for this meal with her son, an unusual event that she had not remembered:

Janet	That's the Rat Inn. Now why would I be at The Rat on Tuesday? Tut. Hmm.
Interviewer	That's normally a walking day?
Janet	It would be- it would be a Wednesday. Oh, well not a walking day [...] It's not my cooking so it must be [a meal] out somewhere […] can we turn over?
Interviewer	Yes. Oh.
Janet	Okay. […] The Rat. ((Janet sees a note in her diary that says that she went to The Rat Inn as well as a picture of her son)) That's - Yes. Tim is our eldest, yes […] So that's why.

The contrast between Janet’s confidence about her regular activities and those that were unscheduled, suggested that Janet relied on the anchor points of her routine to support her memory. Throughout the interview Janet indicated that her short-term memory was poor. Despite this she continued, with apparent confidence, to attend a number of activities in the local community on her own. Routine may have helped Janet to remember her scheduled activities and maintain her independent, active lifestyle.

Routine and familiarity also appeared to be important to Brian (PWD) and Gerald (PWD). As described in the previous chapter, every morning Brian went for a long walk on his own along the same route and at the same time. His wife commented that "*it's best to stick to the routine*" (Linda, partner). Other than this routine, familiar walk, Brian went out with his wife. Similarly, Gerald (PWD) usually walked out with his wife except when he took the familiar walk to his weekly choir meeting which he had attended for many years. It was unclear, however, whether routine and familiarity were necessary for Brian and Gerald to remember their routes, or whether the familiarity gave their wives the confidence to let them walk unaccompanied.

Daily chores

As mentioned in the previous chapter, some participants valued household routines. Brian (PWD), for example, vacuumed the house *"in the morning, every morning"* (Brian, PWD) and Anthony (PWD), always washed the dishes. His wife emphasised that this included washing up on Christmas Day:

> "Even Christmas Day – even if we've had people for Christmas dinner, family have been [and they say] '*I can just [do the dishes]*', [then I say] '*no, please just leave it.*'" (Sue, partner)

Sue's emphasis on allowing Anthony to do the washing every day, indicates that maintaining this routine was essential for Anthony. As described in the previous chapter, Brian and Anthony suggested that maintaining these routine chores gave them a sense of confidence, contribution, independence and pleasure.

6.3. Memory aids

As well as developing routines, several participants used memory aids, such as lists and diaries, to facilitate an active life. This section explores participants' use of memory aids as well as partners' contributions to their use.

Lists and prompts

Malcolm (PWMCI) described using lists to remind him what he was doing each day:

> "Because of the way I am and the way my life's going, I rely a lot on things like this […] Before I go to bed at night […] I write myself a list of what I'm doing the next day [...] so that when I get out of bed the next morning [...] I see this list and that refurbishes what's going on in there and off I go." (Malcolm, PWMCI)

Tom (PWMCI) also used lists to remind him about daily tasks, which was apparently a habit he had developed around the time his memory problems started:

Tom	((Reading from diary)) *'In a.m., routine chores, list ticking.'* Because I have a list of things that I do every day or every other day […] It's a physical list, you know? […] Emptying the dustbins in the kitchen, the waste paper baskets. […] It's in the kitchen where we have breakfast [...] We've done it for quite a long time.
Tess	Only a couple of years. It's since you started having this memory thing that you had to have a list.
Tom	Yeah, yeah. Probably. That's right.

Like Tom, Malcolm (PWMCI) recalled that he had started making lists around the time his memory problems began:

> “It's about three years ago […] Before that [...] I didn't need lists; I could do everything in my head […] I don't know. I don't even know how it started. Perhaps I just did it automatically, made a list.” (Malcolm, PWMCI)

Several participants described using lists when they went out shopping, although it was often unclear whether this was a new habit. Pat (PWMCI) used a shopping list but commented that he would often forget to refer to it. Despite this Pat continued to go out shopping on his own and when I asked him whether his memory problems had affected his shopping he responded:

> “No, I don’t think so […] I make a little list. Nine times out of ten I forget one of them on there because I look at it […] put it in my pocket, I then forget about it […]. No, but no, no, it's not too bad” (Pat, PWMCI)

Like Pat, Tom (PWMCI) and Malcolm (PWMCI) also highlighted the importance of being able to see their lists, as they explained that they needed to place them in a prominent position, on a kitchen or bedside table, where they would see them. Further description of Pat and Malcolm’s use of memory aids can be found in appendix T.

Diaries and appointment reminders

Several participants also used diaries and some used digital reminders. Malcolm (PWMCI), for example, used his smart phone to remind him about forthcoming appointments:

> "This will bleep when it's half an hour, an hour before I'm supposed to be doing something." (Malcolm, PWMCI)

Pat (PWMCI) also used the diary on his smart phone to provide reminders. Larry (PWD) on the other hand preferred a paper diary, as his wife Jean described:

Jean	He keeps a diary. […] Every day he writes in that.
Interviewer	You write what you've done or what you're doing?
Larry	Mainly what I've done [...]
Jean	And obviously he uses it if there's a doctor's appointment coming up or whatever. He'll put it in.
Larry	Yeah.
Jean	'Cause Larry will forget if he's got appointments [...] Where Larry goes, that goes.

Although Larry appeared fastidious about keeping his diary, when I asked him whether he remembered to use it he responded jovially:

> “I've got a special way of remembering. Jean tells me! ((Chuckles)). I'm not too bad as it happens actually.” (Larry, PWD)

Partners’ encouragement and support

As Larry suggested, partners often played a role in instigating, encouraging or facilitating the use of memory aids. For example, Pat’s (PWMCI) wife Mildred indicated that she had encouraged Pat to use a paper diary to record appointments, but that this had not been successful. Subsequently he received a smart phone from his son which had been more useful:

> "When [the memory problems] […] first start[ed] […] we tried with a small diary for him but he couldn't get into the habit of putting it in that […] When he got this [smart phone], he could do it with this” (Mildred, partner)

Janet (PWMCI) also described how her husband encouraged her to use strategies to support her memory, although she was disinclined to do so. Referring to a letter from her doctor Janet (PWMCI) said:

Janet This is my husband being - '*encouraging to make lists that she's planned to do each day*.'

Interviewer And how do you find that? Does…?

Janet *I don't do it* ((whispered, as if being naughty.))

Despite her husbands' efforts Janet said she preferred to continue, "*relying on my mind*" (Janet, PWMCI) as she felt that she should *"keep it active"*, or else, *"I think if you stop […] doing things then it's going to deteriorate"* (Janet, PWMCI).

Although, unlike Janet, several participants with MCI described using memory aids themselves, among participants with dementia only Larry talked about using a memory aid himself, instead spouses tended to describe using memory aids to remind individuals with dementia to do things. For example, Anthony's (PWD) wife Sue explained how she wrote the schedule for the next three days on a planner, which she displayed in the kitchen:

> "I've done that from the very start. I do it as a daily planner. And I never do more than three days at a time. So that the structure of the day is on the board." (Sue, partner)

When asked whether he found the planner useful Anthony (PWD) responded:

> "Oh yeah. Oh, it's ideal for me." (Anthony, PWD)

Like Sue, Gerald's (PWD) wife Marjorie described how she put things on a 'memory board', and crossed days off their calendar, although Gerald did not see the need for a diary, apparently relying on his memory for routine activities instead. When I asked if he used a diary, he responded:

Gerald No. I just— 'cause there aren't that many of them. There's only choir on Wednesday and the …

Marjorie […] We've got, a calendar. But we've got a memory board and I put things on there…

Gerald Hmm

Marjorie …that we've to do within the next day or to remind us that we've got to do. Like phoning for a prescription and collecting prescription. I put it on the memory board because it's a bit more obvious than the calendar. […] I cross off each day as well […] on the calendar.

June's (PWD) husband Pete had a slightly different approach, writing the week's events in a notebook, which he placed beside June's chair:

Peter I've started a little jotter there. And I've tried to put in all the highlights of what's happening each week, you know? […] I try to scribble them out […] as you done them.

Interviewer So you can go to this during the day?

June Uh-huh.

Interviewer Do you remember that this is here, on the side?

June Uh-huh. Yeah. […] He writes all this out for me and nobody else. And I know it's there, so I know ((referring to the diary)) I mean - Beth is the baby who's two-year-old. Now her birthday was on Tuesday […] but she's having a birthday party down here on Saturday.

Despite partners' efforts to encourage their spouses with memory problems to use memory aids, it appeared that the individuals with memory problems would tend to rely on their partners for prompts and reminders instead. For example, when I asked June (PWD) whether she was ever unsure what she would be doing in the day ahead, she responded:

June I generally ask him […] what we're doing.

Pete She does.

Janet (PWMCI) also suggested that she could rely on her husband to remind her if her memory failed her:

> "I've got him to remind me." (Janet, PWMCI)

On the other hand, the only participant who did not have any family support, Malcolm (PWMCI) was the participant who described employing the most memory aids and strategies. He remarked that he had to plan ahead as he had nobody to rely on, to prompt or remind him:

> "As long as I keep my system, like writing notes, that's a great, if I lose that system, or I stop planning ahead, I think it will be a disaster area, because I live by myself, and I have no family, and there's no nobody coming to see me, that's where the problem will come." (Malcolm, PWMCI)

Although participants with MCI who lived with spouses often received their support, they also tended to describe a degree of independence in the management of their memory problem. On the other hand, participants with dementia who lived with a partner tended to appear more reliant on their spouses to use memory aids. This divergence in self-management capacity indicates a shift from independent management of memory problems in MCI to dependence on spouses to support an active life in the early stages of dementia.

6.4. The benefits of activity

As well as using memory aids and routines to overcome cognitive barriers to an active life, there were indications that activity itself could be used as a strategy to manage cognition and mood. Anthony (PWD) was a vocal advocate of physical activity and described walking as *"about the best therapy"*. Anthony's wife Sue described how they used daily walks as a strategy to alleviate the 'mental tiredness' that Anthony often experienced:

Sue	We have a strategy to get out of it ‘cause …
Anthony	Yeah
Sue	I’ve learnt that mental tiredness has nothing to do with physical [tiredness…]
Anthony	Hmm ((of agreement))
Sue	[…] even though you don’t want to, I’ll say *‘do you think we could manage a little walk?’*
Anthony	Yes. Walking’s good therapy.
Sue	And it is like a magic spell, and you will walk and then at some point you’ll say *‘it’s lifted now. I’m fine.’*

Although other couples did not talk about using physical activity as a strategy to support cognition or mood, some did remark that being generally active was beneficial. For example, Heather’s (PWD) husband George reflected that an active day with their grandchildren could improve Heather’s memory:

George	I think you find that when you’ve been with the boys …
Heather	Hmm-hmm ((in agreement))
George	You find yourself being more active, don’t you?
Heather	Yeah.
George	Your mind being more active and memory being better, don’t you?
Heather	Hmm-hmm ((in agreement))
George	I think it’s fair to say that we might be shattered and complain miserably about the buggers …
Heather	[Chuckles].
George	But I think you’re better, aren’t you? When we’ve got the boys and we’re doing things and—
Heather	Yes, yes.

Similarly, reflecting on the objectives of the research, June's (PWD) husband Pete remarked that an active day, doing household chores and spending time with friends, had a positive effect:

> "You had a busy day yesterday and you were really upbeat […] So what you're saying is there is evidence of that—if you're busy and what have you, you feel different, you feel better—and you did yesterday." (Pete, partner)

6.5. Partnership and shared activity

In this study 13 of the 15 participants with cognitive impairment lived with a partner, a relatively large proportion compared to around 60% of older adults who live in couples in the UK (Office for National Statistics, 2013). This section explores the role of partnership in participants' active lives and examines how living with dementia led to increasingly shared lives.

Shared activity

The couples in this research did a range of activities together. When participants walked out, they often went out with their spouses to go for a meal, a drink, or just travelling to the shops together, as one couple described:

Jean (partner)	We walk along to the [Metro station].
Larry (PWD)	Hmm.
Jean	It's about a mile or so […] and we'd walk back obviously. And then we walk around Newcastle. So, we keep ourselves pretty fit […] we usually go to Chinatown, have a meal and then we can come back on the Metro to North Shields and get the ferry over.
Larry	Ferry crossing […]
Jean	Just a day out […] Sometimes I'll shop, if I want anything.

Some couples also walked together for recreation, for example Tom (PWMCI) and his wife Tess regularly walked at the gardens of a local country estate:

> Tess	We probably go once a week or once a fortnight. Watch all the different plants coming out.
>
> Tom	Because there's quite a variety of walks for, you know, a mile or two miles maximum that you can do.

Shared activities meant that the health or fitness of one partner could impact on the others choice or level of activity. For example, Tess had arthritis, which had recently restricted her walking. When I asked whether this prevented Tom from walking the longer routes that they used to walk together they responded:

> Tess	Yeah, well you don't, do you?
>
> Tom	I don't […] But I probably should […]
>
> Tess	Occasionally you'll go off a bit further than I do.
>
> Tom	Occasionally I'll go, yes.

On the other hand, although Anthony (PWD) enjoyed a long walk, his wife Sue found walking the same distances challenging:

> Anthony	You know […] the recent long [walks] through the parks? It was agony for afterwards, wasn't it? But it- you feel better for it.
>
> Sue	You so enjoyed that.
>
> Anthony	Yeah.
>
> Sue	I didn't! ((Jovially)) […] I felt that we'd walked past my limit.

Some couples also shared sporting hobbies. For example, Larry (PWD) and his wife Jean had enjoyed scuba diving together for many years although they had recently stopped because Jean was not strong enough. Another couple, Pat (PWMCI) and Mildred also shared an active hobby:

> “[Bowling] was very much a joint thing. We’ve been in it for years together.” (Mildred, partner)

Several couples also enjoyed gardening together, particularly Tom (PWMCI) and his wife Tess who shared an interest in cultivating antique roses.

Couples’ descriptions of their shared active lives indicated that physical activity is often a shared pursuit and that partnership plays a role in people’s physical activity choices and levels. The value of companionship in an active life was highlighted by one participant who lived on her own, who remarked that she would not want to walk out on her own recreationally:

> “I spend a lot of time on my own and I’m, you know, okay in my own company […] but a walk on my own for no reason, nah-nah.” (Lynn, PWD)

As well as active pursuits, the couples in this research described sharing many other activities, such as going to the cinema or doing the grocery shopping, as well as activities inside the home. As a result, some described how they spent most of their time together:

> “I would think, you know, seventy, eighty per cent of the time we do, you know, things together basically.” (Pat, PWMCI)

> “We are mostly together” (Janet, PWMCI)

Increasingly shared lives

Although couples described sharing a considerable amount of their daily routines, most also had their own interests and spent some time apart. However, several participants with dementia and their spouses suggested that their lives had become increasingly shared. For example, Anthony’s (PWD) wife reflected:

> "It's just been a natural progression. We did things together, other than the football. And when you were at your football, you know, I'd maybe meet up with Sarah." (Sue, partner)

Similarly, when I asked Brian (PWD) and his wife Linda whether they had ended up doing things together Linda responded:

> "Of course it is. It always has been, but yes, more so now, yeah." (Linda, partner)

Although Linda and Sue suggested that they did more things with their husbands, they also stressed that they had always shared many aspects of their lives with their partners, as did another participant with dementia:

> "Everything's done together […] It hasn't just been because I've got Alzheimer's, it's before then." (June, PWD)

Although June suggested that she had always done things with her husband, they both described activities that they had previously done separately. Like these couples, several of the participants with dementia and their spouses indicated that their lives had become increasingly shared. In the rest of this section, I explore the ways in which the active lives of couples with a spouse with dementia came together and why.

Supporting activity outside the home

For those couples living with dementia, their lives became increasingly shared as spouses helped their partners with dementia to get out and about and perform activities outside the home. For instance, some participants with dementia relied on their partners for transport, as Esther's (PWD) husband John described:

> "It doesn't matter where Esther goes, I'll have to take her" (John, partner).

Partners also reported assisting their partners with tasks when they went out. For instance, when Anthony (PWD) had to sign a new contract for his mobile phone his wife guided him through the process:

Sue	The phones are in your name.
Anthony	Yeah […]
Sue	And [the sales assistant] was talking to you but I knew a lot of it [wasn’t going in] because she was talking very fast and there was background noises and things.
Anthony	Yeah, it was going— ((imitates the noisy environment))
Sue	((Sighs)) Yes. She would say things like, you know, ‘can you sign here? Fill there. Print your name.’ […] And I’d be sliding my hand underneath and going ‘just print your name. Just sign your name.’
Anthony	Yeah.
Sue	[…] I was aware that she wasn’t aware. And he was becoming stressed over it.

Anthony later implied that it was necessary to have a good partner as he would not want to go out alone:

Sue	Would you want to go out on your own?
Anthony	Err [sighs] – probably not.
Sue	You see, we do things like joined at the hip. We don’t go—
Anthony	You’ve got to have a good partner.

Concerns about separation

In addition to responding to their partners’ needs, there were indications that the partners of participants with dementia were anxious about them going out or being on their own and that this may have led to increasingly shared lives. For instance, although Anthony (PWD) continued to drive locally his wife always accompanied him because she was concerned about his capabilities. In addition, she normally accompanied Anthony when he walked out. Several partners indicated concerns about their spouse with dementia walking out alone and accompanied them on all but familiar journeys, as described in the previous chapter.

Some partners limited their time away from home, as they were worried about their spouses with dementia becoming confused or anxious when they were away. For example, June's (PWD) husband enjoyed running but was worried about being out too long:

> "I try not to be more than forty, forty-five minutes […] but sometimes June forgets how long I've been out and when I come back she's concern[ed], she's '*you've been a long time.*' […] And of course you do get confused 'cause […] sometimes she thinks I'm in the garden when I'm actually out for a run." (Pete, partner)

Like Pete, Anthony's (PWD) wife, Sue, was concerned about him getting anxious when he was on his own. Consequently, she limited her trips away from home and described how she would make sure Anthony had everything he needed before she went out, as well as texting him while she was away:

> "If we're separated, he gets anxious. […] I send him constant texts the whole time I'm there. […] And he'll be here [on the sofa] 'til I get home with the kittens and the TV and his coffees made and everything's there [for him]." (Sue, partner)

It was not clear from the interviews whether participants with dementia shared the same concerns about being left alone as their spouses. As described in the previous chapter, several participants with dementia expressed confidence about walking out alone, whereas their partners appeared concerned. Consequently, it was unclear, at times, what precipitated the shift towards more shared lives, whether it was the needs of participants with dementia, the concerns of their spouses or a combination of factors.

6.6. Modifying and maintaining activities

As noted in the previous chapter, several participants with dementia experienced difficulties undertaking everyday activities, hobbies and interests. This section explores the ways and extents to which spouses supported their partners to maintain these activities.

Supporting hobbies and interests

Some spouses made significant efforts to enable their partners with dementia to continue doing activities they enjoyed. For example, one spouse, Linda, had given up her own interests to support her husband Brian (PWD) in his hobby of walking, an activity that had not previously interested her. She described how much she now walked each week:

Linda	I would think thirty-five miles would be the least that I would walk […] without us going out for a walk, a big walk, yes. So, yes, I do go with Brian now.
Interviewer	But before that wasn't so much your hobby.
Linda	No! No thank you! No. […] I like quilting and things, craft things. […] when Brian would be going on a walk with his friends, I would perhaps go on a course. That was nice.
Interviewer	Now you find that?
Linda	We do things together.
Brian	Oh yeah, you'll see in here, we do lots of things together.

As well as accompanying him on walks, Linda indicated that she put a lot of effort into finding activities to keep Brian entertained:

> “I was trying to think of different activities that you wanted to do, some painting or something. […] We used to play dominoes quite a lot […] I thought yesterday we might […] have a game, but it didn’t work very well, did it? […] I wanted you to bake […] but you didn’t fancy doing that…” (Linda, partner).

Similarly, Sue (partner) and Anthony (PWD) walked out together on most days as they felt it helped Anthony to manage his dementia, although, unlike Brian and Linda, this couple had previously shared this hobby. Like Linda, Sue described having to encourage Anthony to be active at times. She also made efforts to keep Anthony engaged in social and community activities, getting him involved in new groups and classes. On the other hand, Gerald’s (PWD) wife Marjorie appeared to prioritise maintaining Gerald’s existing interests over new activities. She reflected on how they had decided to continue attending their longstanding U3A group rather than joining local activities for people with dementia, which Gerald considered to be more interesting:

Marjorie	You want to stay in everyday situations. That’s why the priority for me is U3A […] Because we—you can—and they’re very good at the U3A, that we can continue being members, you see?
Gerald	Hmm.
Marjorie	So that’s more important than doing things that are associated with memory problems to a certain extent […] Don’t you think that? You think the U3A’s?
Gerald	Oh yes […] its regular and, erm…
Marjorie	Yeah. And our friends are there, aren’t they?
Gerald	And more interesting.

Modifying and adapting activities

Some activities were modified or adapted to make them manageable. For example, previously a keen cook, Anthony (PWD) became the sous chef:

Sue	If we’re cooking, you know, you’ll say ‘*can I help?*’ ‘cause you love cooking.
Anthony	Hmm-hmm ((in agreement))
Sue	And you’re good at chopping and slicing and dicing and keeping the pans turned.

At times, Sue described having to provide clear instructions to enable Anthony to complete a task:

Sue	Changing beds – and that is a very difficult task for Anthony…
Anthony	Ho-ho!
Sue	…to put on a duvet
Anthony	Trying to pull the cover on. I think *‘oh no.’*
Sue	And I’ll say that I’m really good at explaining things from working with special needs children.
Anthony	Hmm-hmm. Hmm ((in agreement))
Sue	And we do it step by step. I know not to give too much information or to give consecutive information.
Anthony	Oh no, no. That’s—
Sue	Even if it’s just three or two steps.
Anthony	It’s vital.
Sue	It’s got to be one step at a time until we’ve accomplished that.

Sue felt that she drew on her skills as a teacher to find ways to adapt activities to suit Anthony’s needs and suggested that perseverance was vital:

> "If you can't do something one way then you try to look straight away to find how to do it another way. Not *'oh well we can't do it. Never mind.'*" (Sue, partner)

Similarly, Brian's (PWD) wife Linda, also a retired teacher, suggested that it was necessary to adapt activities to suit her husband's changing needs, although she indicated that this was not always easy:

> "I think it's being flexible and being able to twist and turn on a sixpence so that if something's not working, we'll always find a way to make it work or to change it slightly. And that's one of the things that I think you have to be." (Linda, partner)

Notably, Linda and Sue both spoke in the plural, indicating a joint effort with their husbands to modify and maintain activities. However, the couples' discussions suggested that the women played a substantial part in supporting their husbands. For example, when I suggested that Anthony (PWD) and his wife Sue had successfully adjusted their lives, Anthony responded:

> "That's all down to my good friend in the corner there ((referring to his wife)). Keeps me going, don't you darling." (Anthony, PWD)

Similarly, Brian remarked to his wife:

> "I rely so much on you." (Brian, PWD)

June's (PWD) husband Pete also endeavoured to maintain her engagement with the Masons (of which she was a longstanding member) driving her to the meetings each week and endeavouring to keep her involved in the associated social events. In addition, Pete looked for other ways to get June (PWD) out of the house. However, he remarked that this was time consuming for him:

> "I [used to] say '*I'm going to the garden centre*' [...] and I would be there and back in half an hour. 'Cause I would just go […] but now June always

> goes with me, 'cause it gets her out the house. […] What was a twenty-minute job now turns into three hours ((chuckles)). But it takes her out of the house, and we'll have a look around. And look at various things. And I do, you know, try to involve her and I'll make sure that she comes down and looks at the gardening stuff and what have you." (Pete, partner)

Prompting and encouraging activity

Despite partners describing attempts to support activity, loss of motivation was common among participants with dementia, as highlighted in the previous chapter, and this appeared to be a disappointment to some spouses. For example, Heather's (PWD) husband George was frustrated that she no longer joined in activities when they were on holiday, remarking "*she doesn't participate in anything!*" (George, partner). June's (PWD) husband expressed disappointment that she would no longer even sit in the garden while he worked, preferring to stay indoors and watch television, although she had contributed to the garden in the past. Despite this, Pete described encouraging June to engage in the design of the garden:

> "You come out the garden with me 'cause I'll say, *'come down, have a look at this rockery* […] *Do you think I should put this here*?'" (Pete, partner)

Persuading a partner to participate was not always easy though. For example, although Anthony (PWD) enjoyed walking he was sometimes reluctant to go out and, as a result, his wife Sue sometimes needed to do more than just encourage him to go for a walk:

> "Sometimes I can be quite bullying. I'll say *'look, we're going for a walk. You're gonna feel much better*" (Sue, partner)

However good the tactics and persistent the encouragement, sometimes engaging a partner in activities was unsuccessful, as Brian's (PWD) wife Linda reflected:

> “Sometimes it can be difficult, you know, I’ll suggest things but if he doesn’t want to do it, there isn’t any point." (Linda, partner)

Although some partners, like Sue and Linda, were persistent in their efforts to motivate their partners to engage in activity, others seemed to be more inclined to take-over certain activities.

Taking over

Esther’s (PWD) husband John appeared more inclined than others to take over household activities and did not seem to have even considered supporting Esther to engage in activities that she had once valued. For example, although they had both taken pleasure in developing their garden, John now did all of the gardening, and when I asked him whether he encouraged Esther to help he said, *“I’ve never thought, actually”* (John, partner). Esther also enjoyed cooking, and, during the interview, they laughed about times when Esther had tried to teach John to cook. However, unlike Sue’s (partner) earlier description of sharing the cooking tasks with her husband, Esther remarked that John had “*taken over*” (Esther, PWD) the cooking. When asked whether he ever involved Esther in meal preparation he replied, *“Not really. Keep her out the way”* (John, partner). Later John reiterated that he preferred Esther not to help with the cooking:

> John Occasionally you’ll wander in the kitchen and sit.
> Esther Yes. Oh, I do.
> John *‘Can I help?’* And I say *‘no, just …*
> Esther Yeah, I go in *‘can I help? Can I do that?’*
> John *…sit and just- just sit and watch.’*

Elsewhere, John indicated that he did not see the value of engaging Esther in activities she enjoyed despite wanting her to be more physically active:

> Esther The only thing I would like to do that I'm not doing […] would be cooking.
>
> John I'm not worried about the cooking. I'd rather you be on your feet. I mean there was once last week […] I says, *'get up, walk around the table, will you? And come back and sit down again.'* It was just to get you out of the chair.
>
> Esther But if you've got nothing to get out of the chair for, you just seem to just…

This discussion suggests that Esther felt disinclined to be active as she could no longer do the things that she enjoyed, and that her husband did not realise that he had demotivated her by taking over these tasks.

Echoing Esther's comment about being taken over, June (PWD) remarked that her husband, Pete, had *"stopped me doing housework"* and that she was *"not allowed"* to do the cooking. However, unlike Esther's husband, Pete refuted June's claims that he stopped his wife from doing things, instead stating that he did not want to stop her from doing things:

> "Maybe one day I'm gonna have to, but at the minute I won't take that off June […] If we go in a shop, like, buy a loaf of bread, you know, June'll get [it] […] Now some people would, I guess, in my situa- or our situation, would say *'I'll do that.'* But I don't want to do that." (Pete, partner)

Even though Pete's comments indicated that he had not actively or intentionally stopped June from engaging in activities, elsewhere in the interview his reactions did suggest that he could become frustrated when June did not do things the way he expected, which may have led to her feeling restricted. For example, he spoke with mild frustration about hearing June repeatedly press the buttons on their new washing machine when she did not realise that the wash was about to start:

> "I can hear you pressing it sometimes and I think *'will you stop pressing it? It will click in.'*" (Pete, partner)

Such remarks from Pete suggest that he may have found it harder to avoid taking-over than he professed in his comment about the shopping. Furthermore, such admonishments alongside his desire to control the domestic space may have made June feel excluded. There was a sense throughout the interview that June was seeking Pete's approval for her actions, for example she spoke about being allowed to use the remote control:

> June: Oh, I'm allowed to use it now?!
> Peter ((Sighs)) Well…
> June I can use it. I'm not doing— I'm doing good?

Like Pete's earlier comment about taking over the shopping tasks, Sue (partner) remarked that the partners of people with dementia might be inclined to take over activities:

> "I don't just take on this *'I do everything because you can't do anything.'*" (Sue, partner)

Although, like Pete, she seemed keen to avoid taking tasks away from her husband, she also made a remark about his approach to washing up that suggested that it was sometimes difficult to stop herself from taking over:

> "Gets me irritated seeing everything everywhere in the kitchen… So, I have to come out of the way. [...] You have that sort of mind-set to step back […] and say right, *'you get on with it.'*" (Sue, partner)

Pete (partner) and Sue's (partner) comments indicate that, despite their good intentions, it was difficult at times to prevent themselves from taking control of activities when they felt frustrated or irritated with their partners. As with the comments throughout this section, there is evidence that partners can find it challenging to support a partner with dementia to maintain an active life and that the degree of partners' support varies greatly. While some partners went to great efforts to support activities that were meaningful for their partner with dementia, others saw little value in encouraging their partners to engage in activities or had different priorities about what activities were valuable.

6.7. Dependence and independence

The previous two sections have illustrated the role partners played in supporting participants with dementia to maintain active lifestyles. Some couples indicated that their lives had become increasingly shared as a result of one spouse developing dementia but stressed that this was a natural extension of their shared lives. However, despite these positive portrayals of couples adjusting to dementia, there were some indications that increasing interdependence came with challenges for both partners, which will be explored in this section.

Increasing demands

Several of the partners of participants with dementia indicated that they faced additional responsibilities, for example Larry's (PWD) wife Jean remarked:

> "I do a lot more than I ever did before in the sense of, well I have to do things that Larry can't do." (Jean, partner).

These increasing responsibilities encroached on partners' time for their own activities:

> "I'm not running as much as I did. Basically, because I'm doing more now at home." (Pete, partner)

Some partners also described how their efforts to keep their partner with dementia engaged in activities took up much of their time, for example as Brian's (PWD) wife Linda remarked, "*I don't have a lot of time*". In addition, partners' concerns about leaving their spouse with dementia on their own restricted their movements. For example, Pete (partner) recalled his concern when he had to wait to be seen at the hospital:

> "I was there about three hours and I was getting really worried because June was on her own. It was the early stages. In fact, I don't think you'd been diagnosed then but you weren't well. And I said [to the nurse] '*look, I've got to get out of here*'" (Pete, partner)

In response to their increased responsibilities, some partners commented on the need for time to oneself to maintain health and wellbeing, as Sue (partner) remarked:

> "The hairdresser's and manicurist's lovely. And you get a head massage and they really do a pampering session and that's my one sort of thing, every six, seven weeks […] because you need it, you need that." (Sue, partner)

Similarly, although Pete (partner) felt restricted in his time and ability to leave his wife alone to go for a run, he suggested that maintaining his health was important to him:

> "I like to try to keep fit. Keep my health up […] for two reasons. A, I want to keep healthy and B, I want to keep healthy so I can look after June. I feel that if I'm, er, got some degree of fitness then I can take care of her better, you know? (Pete, partner)

Increased reliance

Some participants with dementia expressed disappointment at their increased reliance on their partners. For example, Esther (PWD) described feeling *"put out to grass"* when she was not allowed to contribute to the household. She also felt that her freedom was limited as she relied on her husband to drive her places, as described in section 5.3. For Anthony (PWD), having to ask for help was frustrating, as he and his wife Sue described:

Sue	This is a normal thing where he's wanting to do something and I'll say, *'do you want me to do it?' 'No, I want to do it myself.' 'Fine.'* And that's exactly what happened. He had the Kindle. *'Where's my charger? Don't tell me. I'll find it.'*
Anthony	((Mimicking a snappy voice)) *'I'll find it.'* And then I've come back ((mimicking an exasperated voice)) *'I can't find it.'*

For Brian (PWD), reliance on his wife meant that he could no longer treat her, which he regretted:

> "If I want to buy Linda a birthday present and stuff like that I used to be able to do it, now I can't do it because I can't work out the money and different things like that, so that makes it really difficult." (Brian, PWD)

Caring and being cared for

Although increased dependence had negative consequences, some participants with dementia and their spouses indicated mixed feelings about their situations. For example, although Esther (PWD) indicated disappointment at no longer being needed, she also said that having her husband do the cooking could be *"really acceptable"* as she could *"just sit and watch the telly"*. Gerald (PWD) expressed a similar mix of disappointment about not being able to contribute alongside acceptance and gratitude for being *"well looked after"*. On the other hand, having resigned from her job to support her husband, Sue (partner) remarked that she missed working as a teacher but found a new vocation in her caring role:

Sue	I think when I had to give up teaching, I missed that …
Anthony	Planning thing.
Sue	That planning and being a bit of a …

Anthony	Yeah.
Sue	I think all teachers are a bit of control freaks. And so rather than lose it altogether […] I just put it in a different direction, and you were it.

These final comments indicate that while independence is valued, being cared for and caring for a partner can have positive facets.

6.8. Chapter summary

Reinforcing the motivation for this enquiry, several participants described the benefits of being physically active and occupied for both cognition and mood. Participants experiences suggest that averting sedentariness and helping people with dementia to maintain active daily lives may help to improve cognition and mood, further increasing people's capacity and inclination to engage in activities.

This chapter revealed several strategies employed by participants with later life cognitive impairment to maintain active lives. Several participants with MCI and dementia indicated that routines provided confidence, bolstered memory and helped them to maintain active, independent lives. For some participants with dementia, routine and familiarity appeared to facilitate independent walking, although it was unclear whether this helped participants with dementia directly, or whether it gave their partners the confidence to let them walk out alone. For some participants with dementia, routines also appeared to facilitate engagement in valued household activities, providing a sense of independence as well as contribution to the home. The findings in this chapter suggest that establishing and maintaining routines may help people with MCI and dementia to maintain independent, active lives.

For several participants with MCI and dementia, memory aids appeared to facilitate an active life, providing reminders about events, appointments and tasks to complete. Some participants preferred mobile-phone-based reminders, while others used paper diaries and calendars. Some were disinclined to use memory aids and most participants in couples indicated that they relied on their partners to provide reminders, to varying extents. Partners often supported the use of memory aids and, notably, among couples with a spouse with dementia it tended to be the spouses that used diaries, lists and calendars, to prompt individuals with dementia, rather than the participants with dementia using these tools themselves. It was unclear why this was the case or whether memory aids were actually helpful for people with dementia, even if they had to be prompted to use them. The divergence in approaches to self-management indicates a shift from independent management in MCI to dependence on a spouse to plan and prompt activities in the mild-moderate stages of dementia.

As demonstrated throughout the findings, partnership was a significant aspect of most participants' active lives. The shared nature of physical activity meant that the capabilities and needs of one partner could affect the activity levels of another. Although most couples shared a significant portion of their regular physical activity, for several couples with dementia the extent of their shared activities had increased. At times it was unclear whether this was because participants with dementia requested assistance from their spouses or because spouses were concerned about their partners with dementia doing things on their own. However, most partners of participants with dementia supported their spouses to maintain active lives, to greater or lesser degrees. The most active participants with dementia were those whose spouses described the greatest efforts to support their active lives, with less active participants tending to have partners who appeared more inclined to take over.

Although this chapter has highlighted the role of partners in supporting an active life, particularly for those with dementia, it has also revealed that increasingly shared lives can have negative consequences for both partners. Some partners highlighted the impact of caregiving on the time and freedom to attend to their own health and wellbeing. On the other hand, participants with dementia reported loss of independence, self-worth and role in their relationships. Despite these negatives, some participants also identified that being cared for and taking-care-of a spouse could be a positive experience.

6.9. Implications of the findings from stage one

In this section I describe how findings from across the first stage of the research informed the following, design stage of this investigation.

As noted in Chapter 5, most participants with MCI did not indicate that cognitive changes were a significant barrier to an active life. Although some employed strategies such as memory aids and routines to facilitate everyday activities, most reported successfully maintaining an independent active life. Rather than cognitive impairment, participants with MCI indicated that other barriers to physical activity, particularly physical health problems, were prevalent. These findings suggested that physical activity interventions aimed at the wider older adult population might be suitable for people with MCI. Consequently, in consultation with the research partners at Philips, I decided that the following stages of the research should focus on designing technologies specifically for people with dementia. However, the implications for the design of physical activity interventions for people with MCI will be considered further in my discussion in chapter 9.

Having decided to focus on the needs of people with dementia, I had intended to use the findings of my thematic analysis to generate a design brief for the development of a technology to support physical activity. However, while my analysis identified some common themes among participants' experiences, the needs of people with dementia were not homogeneous, with cognitive impairment impacting on people's active lives in different ways and to different extents, in addition to a range of other factors—including physical health, social and environmental circumstances—that influenced people's physical activity behaviours.

However, two distinct groups of potential users, with broadly similar needs emerged. First, there were those who were relatively active but whose independent activity was now limited. For this group, I thought that interventions to facilitate independent walking and alleviate spouses' concerns could be beneficial. Second, there were some participants who were largely sedentary, apparently as a result of a combination of physical health problems, cognitive impairment and loss of occupation. I thought that this group could benefit from interventions to help them to engage in purposeful and valued everyday activities in order to reduce sedentariness and increase quality of life. Rather than attempting to create a universal intervention, I decided that it would be valuable to consider the design of technologies to support these users separately.

As the thematic analysis synthesised the experiences of people with later life cognitive impairment, I did not think it would be a suitable way to convey the needs of these distinct user groups to design teams, in the second stage of the research. In addition, the thematic analysis fragmented the experiences of participants with dementia and failed to convey the complex and interwoven factors that affect people's activity choices. Therefore, rather than using the results of the thematic analysis to inform concept generation, I decided to generate personas to convey participants' experiences to the design teams. I based these personas on the vignettes created earlier in the data analysis process, as described in section 3.8.3.

Rather than trying to amalgamate the experiences of participants into generic personas I chose to base the personas on two individual participants who could represent the two needs-profiles that I had identified. It was also hoped that by using the biographies of real individuals the personas would be more compelling to workshop contributors, since, as described in the methods chapter synthesising user characteristics has been criticised for creating unbelievable and unrealistic personas. In addition, following my close engagement with participants it did not seem appropriate to homogenise their unique experiences or the interrelated factors that contributed to their activity choices and behaviours. Further details about the design of the personas and how they were used to stimulate concept generation can be found in chapter 3. The personas themselves can be found in appendices K and L.

Chapter 7. Stage two: Generating design concepts to support physically active lifestyles

7.1. Introduction

The findings from the first stage of the research, presented in the preceding three chapters, indicated that, for participants with MCI, factors other than cognitive impairment were the predominant barriers to physical activity and that, consequently, physical activity interventions aimed at the wider older adult population might be suitable for people with MCI. However, for most participants with dementia, cognitive impairment made independent physical activity difficult. Therefore, in the second stage of the research I chose to focus on the needs of people with dementia.

The aim of this stage of the research was to generate concepts for products and services to enable people with dementia to live physically active lifestyles. The intention was to produce concepts that could be presented to people with dementia for their critique. To capitalise on current knowledge of technologies and techniques to facilitate health behaviour change, three design workshops were arranged at Philips and Newcastle University's MoveLab. Workshop contributors included physical activity specialists, health psychologists, designers and engineers.

The findings from the first stage of the research were conveyed to workshop contributors using personas and quote cards, which I describe in section 7.2. Next, in section 7.3 I reflect on the ways in which workshop contributors used information about the participants with dementia to inform concept generation. In section 7.4 I present the concepts generated in the workshops. This chapter will conclude in section 7.5, by discussing the effectiveness of the workshop process and the degree to which it responded to participants' experiences.

7.2. Personas and quote cards

Personas were the main tool used to convey participants' experiences of living with dementia to workshop contributors. My rationale for choosing personas is described in the methods in section 3.8, as well as the persona generation process. Unlike most conventional personas, these personas were directly based on two participants from the first stage of the research (the reasons for this are also detailed in section 3.8). These participants were selected as they represented the different needs and levels of physical activity among participants with dementia. The first persona was based on the participant given the pseudonym June. June was selected to represent participants who were largely sedentary. For this group physical health problems and motivational barriers needed to be addressed in the design process. The second persona was based on Brian, who was selected to represent participants who were relatively fit and active. Brian walked out regularly but was mostly accompanied by his wife who expressed concerns about him walking out alone. By using this persona, it was anticipated that the workshop contributors would explore ways to support independent walking.

The personas included detailed descriptions of the participants' lives as well as direct quotes from the individuals and their partners. Information was divided onto separate cards describing different facets of their lives, as shown in Figure 7.1. Both sets of persona cards started with a card which provided biographical details. Other cards described the participants' health, walking routines, daily activities, memory condition, travel and transport choices, activity levels, technology use and their history and interest in activity. All the persona cards for Brian and June can be found in appendices K and L.

Figure 7.1: Persona cards for June

The persona cards were sent to workshop contributors in advance of the workshops to allow them time to read about the personas before the workshops. They then provided the basis for concept generation in the workshops.

In addition to using the personas, for the first workshop exercise, contributors were provided with a series of quotes from participants on individual cards, which they were asked to categorise in an affinity diagram. An example of an affinity diagram completed in the workshops is shown in Figure 7.2. Further details about the personas and affinity diagram exercises can be found in the methods chapter, sections 3.8.3 and 3.8.4.

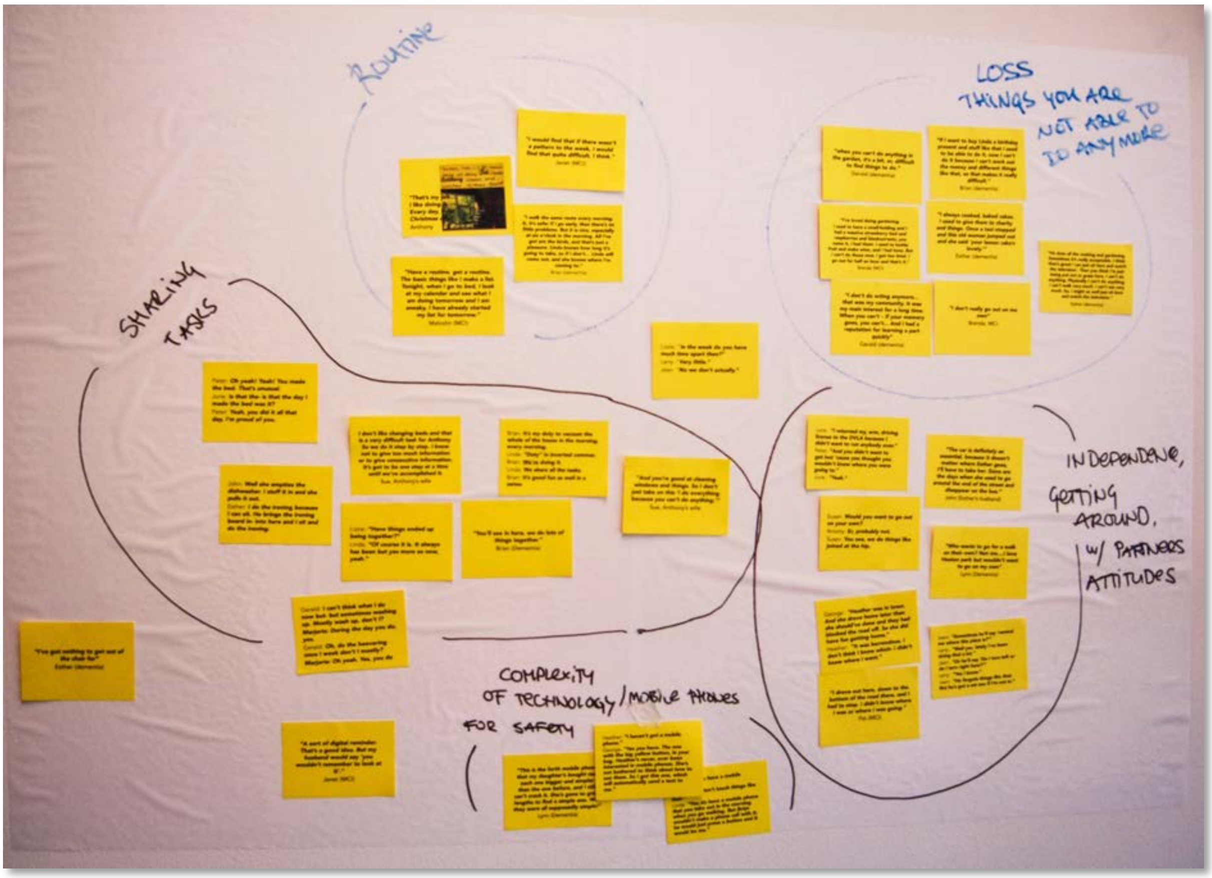


Figure 7.2: Affinity diagram

7.3. Reflections on the design workshop process

This section will present findings on the design workshop process, focusing on how the contributors engaged with the workshop activities and materials provided. Each of the three workshops consisted of a series of structured activities, intended to help workshop contributors to generate concepts for products and services to support their personas to engage in physical activity. Contributors worked in teams of three to five individuals and were asked to design for either Brian or June. For a detailed description of the workshop process, see section 3.8.5 of the methods chapter.

In the first part of this analysis contributors' interpretation of the information about people with dementia will be explored. Next, in section 7.3.2, the extent to which contributors empathised with the personas will be considered. The process by which teams generated, selected and developed their concepts will be described in section 7.3.3.

The first workshop, held at Newcastle University, was documented through the materials generated by contributors during the workshop activities. During this workshop, it became clear that contributors' discussions provided valuable insights into their design process. Consequently, subsequent workshops were audio recorded and transcribed for analysis and are, therefore, predominant in this report.

In the transcripts the workshop contributors' names were replaced by a unique letter to protect their anonymity. The workshop at Newcastle University will be referred to as workshop one, the Philips workshop held in the UK as workshop two and the workshop held at Philips in Eindhoven, Holland, as workshop three. I have labelled my own comments as those of the 'moderator'.

7.3.1. Interpretation and analysis

Workshop contributors' understanding and interpretation of the information in the personas and on the quote cards was fundamental to the success of the workshops. This section considers the extent to which workshop contributors engaged with and interpreted this information.

Understanding and misinterpretation

On the whole, workshop contributors appeared to comprehend the information and quotes provided in the personas and on the quote cards. They tended to share similar interpretations of the information and quotes provided and their interpretations were mostly in accord with my own. Occasionally, however, contributors made comments that suggested that they had misread or misconstrued the information provided. When this happened, contributors were often corrected by their teammates. For example, when discussing the barriers to activity experienced by June, when one contributor stated that June was overweight his teammate questioned his assertion:

C She's overweight [...]

A It doesn't say that they are overweight it just says that they have got too much weight on. Like we're not overweight but we'd still like to lose weight.

B Yeah. Okay.

[Workshop two, team one]

In some instances, the quotes provided were ambiguous. For instance, one quote was misinterpreted because the full context of the interview conversation had not been provided. During the interview with June and her husband Pete, he said, *"you have this habit of hiding things"* (Pete, partner) as he searched for June's mobile phone down the side of the sofa. However, without this context, some workshop contributors inferred that the quote meant that June was hiding the symptoms of her dementia:

S ((Reading from a quote card)) This 'habit of hiding things.'

Q […] aren't they going to be in the same group as this? – 'He does put things in obscure places' […]

R No, but hiding things is like hiding dementia.

P Yeah, I guess but it could be both, but—

R Yeah, maybe that's interpretation.

P I think it's about hiding symptoms...

[Workshop three, team two]

Another quote that was misunderstood out of context said: *"who wants to go for a walk on their own? Not me… I love [the park], I couldn't go on my own."* (Lynn, PWD). The workshop contributor who read this quote card immediately presumed that the person with dementia was not able to walk out alone because she could not remember the route:

M I've got one about making a walk, but she can't. I think she can't remember how the walk goes. She doesn't want to go on her own.

J So that's here.

L Something now she can't do anymore.

[Workshop three, team one]

The team did not have enough information to understand that this individual had been confident about travelling alone and that her comment referred to her dislike of walking alone. This team's interpretations appeared to be guided by their assumptions about the lives of people with dementia. Conversations such as this suggest that contributors came to the workshops with preconceived ideas about people with dementia and that this affected their interpretation of the information provided.

Analysis and reflection

Occasionally team members' interpretations of the quote cards differed, leading teams to discuss their meaning, as in the following example:

Q He's encouraging her to make list. […] She doesn't do it. It's about memory, right?

P Yeah, but it's also a little bit here I think - still the spouse.

Q Is this kind of… stops? Is this about independence?

P Yes […] because the spouse is giving her tasks, but she says, *'I don't really do it'*, so it's about the spouse taking over.

[Workshop three, team two]

Some contributors in this team were particularly contemplative and considered the underlying reasons why people with dementia and their spouses made certain comments. Certain contributors offered more nuanced interpretations of the quotes than their colleagues. For example, when the participants in workshop two, team one presented the themes that they identified in the affinity diagram exercise, contributor 'C', suggested that becoming dependent on a spouse probably had a positive impact on spousal relationships (as, indeed, some quotes suggested). However, earlier in their discussion I had overheard another member of the team, ‘A’, inferring from the quotes that some spouses may have fostered dependence. When I prompted her, she described her interpretation:

> C The fourth group we have was around the relationship between the person with dementia and their partner […] Doing things together. Being dependent on each other. Working together. Working as a team. So probably strengthening the relationship between the person with dementia and their carer [...]
>
> Moderator [A] you said something about […] relying… or other people taking over or something before?
>
> A Yeah, like, well, I think that comes under doing things together. Independence. Where [the partner] may not feel comfortable [with the person with dementia] doing things, so therefore [the person with dementia becomes] just automatically dependent on the other person.
>
> C But there were some adaptations that they had come up with like being able to iron sitting down rather than having to iron standing up. So, allowing the person with dementia to continue to perform some of these ADLs[11].
>
> [Workshop two, team one]

Despite ‘A’ highlighting the potential impact of caregivers taking over and controlling tasks, ‘C’ continued presenting a care-centric view of the scenarios, in which people with dementia are ‘allowed’ to continue performing daily activities by those around them. It was interesting to see these different perspectives within the team, particularly as it later emerged that ‘C’ was a carer, which may have influenced his point of view.

---

[11] Activities of daily living

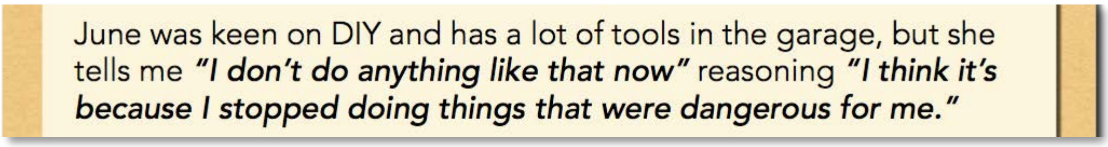
In addition to influencing their teammates interpretations, some contributors' comments enriched my own understanding of the data. For example, one of the contributors suggested that the persona, June, might be experiencing apathy, something I had not previously considered:

P 'Sometimes I find I don't do anything' I think it's a little bit here but—
[…]
R It's also a symptom, like apathy.

This finding suggests that having a variety of perspectives can enrich the analysis of research data and enhance the design process.

Ambiguity

Sometimes, ambiguities in the data compelled teams to discuss why the person with dementia might have said or done something. For example, June's persona card described how she had stopped doing the DIY (do it yourself) (see Figure 7.3).



June was keen on DIY and has a lot of tools in the garage, but she tells me ***"I don't do anything like that now"*** reasoning ***"I think it's because I stopped doing things that were dangerous for me."***

Figure 7.3: Excerpt from the persona card for June.

One of the workshop contributors speculated that June's comment contained an inference that she was prevented from doing DIY:

R She liked to do those do-it-yourself things, but the barrier is kind of fear of safety, confidence or, erm, because she used tools and they are dangerous right? […]
Q That's part of the confidence, right?
R Yeah, but I felt in the quote— I felt it was also her husband saying 'this is dangerous' or something or maybe I've interpreted it too much. I'm not sure.

[Workshop three, team two]

This interpretation may have been informed by another quote included on the persona card in which June said that her husband had *"stopped me doing housework"*. However, as indicated in the quote above, 'R' was nervous about making an incorrect inference. Another team also wondered why June did not want to walk out anymore. This was unclear from the interviews with June and, as such, I had left it open to interpretation in the persona description:

> C Why does she not want to walk along the river anymore? […] She enjoys walking by the river, but she doesn't walk by the river so there must be a barrier in here somewhere. […]
> A Lack of motivation?
> B 'I wasn't in the right feel'.
> A Yeah. Depression?
> C Hmm?
> B Maybe lack of confidence as well, because of other things.
> A Hmm
> B But that's being presumptuous as opposed to actually... written.
> A Knowing.

Like 'R' in the other team, 'B' expressed concerns about making assumptions. Together, these discussions reveal that interpreting the partial and, at times, ambiguous information in the personas was a challenge for the workshop contributors.

7.3.2. Empathy and othering

By fostering empathy, personas have been purported to encourage designers to step into users' shoes (Cooper, 1999; Pruitt and Adlin, 2010). In this section I will consider how workshop contributors related to the personas and whether they elicited empathy.

Relating to and empathising with personas

Reading the quotes and information in the personas, workshop contributors sometimes reflected on their own experiences or the experiences of those close to them. For example, one of the workshop contributors reflected on her grandfather’s experience:

> “Must be terrifying. My grandfather, he had Alzheimer's and one night he didn't know who the person lying in bed next to him was.” (K, workshop three, team one.)

Another participant tried to compare his experience of caring for his children with that of caring for a partner with dementia:

> “…you don't have time for yourself any more [...] it's also important to have time for yourself [...] in fact you should— I think of my own kids when they were younger, then you also have to hire a babysitter so that you can go out […] Otherwise you are so homebound that, then you both go down.” (J, workshop three, team two)

Some workshop contributors’ comments indicated that they were attempting to empathise with the personas. For example, one of the contributors imagined how June’s experiences would cause her to lose confidence:

> P Loss of confidence
> F Definitely, yeah. I can imagine that one.
> R And confidence or belief in one's self, it's also…
> F Yes, there are so many ways that that could happen or little things that would affect.
> [Workshop three, team two]

In a previous workshop, the same participant made another comment that implied that he experienced a sense of empathy:

> “What it feels like is just – big barrier is just the weight of everything… piling up.” (F, workshop two, team two)

However, relating to the individuals described in the personas was not always easy, as one team found when they were deciding whether shopping could be classified as a motivation to be active:

> Q Have you put shopping as a motivator? She goes out for shopping. Garden centres and shopping.
> P Is that a motivator? Shopping?!
> R Yeah, why not? She likes to buy bags, right?
> F For some people it is, yeah. I disagree!
> P It's more activity.
> R June likes buying handbags!
> Q She likes bags!
> F If June does, it's valid. Fair enough.
> [Workshop three, team two]

Othering and stereotyping

While some workshop contributors’ comments indicated a degree of empathy with the personas, a few made comments that suggested that they did not relate to the personas but rather saw them as ‘other’:

> “It's okay because these people do forget, so even if you do repeat it, it doesn't matter so much.” (Q, workshop three, team two.)

Some contributors also referred to stereotypical perceptions of older people’s lifestyles or capabilities. For example, when talking about a new technology one contributor suggested:

> “That would be difficult for an old person” (H, workshop two, team two.)

This comment was particularly inappropriate since it was made by a contributor in a group designing for June, whose persona stated that she enjoyed using technology and finding out how it worked. Another contributor started to assume that June had probably not been on holiday very often compared to "*us*", despite the persona card describing how June and her husband enjoyed going on holidays and cruises:

> "I mean like for us maybe we go more frequently on vacation compared to June who might have done it a couple of times in her life. I don't know, do they say how often? Maybe that's really something that she, yeah, talks more often about than doing it. I'm not sure, the data doesn't really tell it." (R, workshop three, team two.)

Comments such as these suggest that, despite the detailed information in the personas, workshop contributors tended to revert to underlying, perhaps subconsciously held, stereotypical perspectives of older people and those with dementia. Although some comments suggest a degree of sensitivity and empathy towards the personas, other instances of othering and stereotyping indicate that the personas had mixed success in eliciting empathy.

7.3.3. Concept generation and development

This section will consider the process of concept generation and development and explore whether the workshop activities and materials effectively supported the design process. Although the following sections differentiate the stages of concept generation, selection and development, these stages often overlapped.

Concept generation

Workshop contributors were asked to come up with concepts on their own, before sharing them with the rest of their team. These concepts were mostly driven by information on the persona cards. Most contributors attempted to address the motivators and barriers to physical activity for the individual that they were asked to design for. For example, one contributor suggested a service for June:

> “An activity group for people living with dementia. So, because in the past she's […] led dance groups or exercise groups it would be good for her to do the same again but especially for people with dementia.” (C, workshop two, team one.)

Others took a more technology-centric approach, looking for ways to apply existing technologies to the challenges faced by the personas:

> “A very, very simple navigation system for walking. So, TomTom for walking.” (J, workshop three, team one.)

In some instances, the technology seemed to have been considered before its applicability, as in the following example:

> H So I was generally just thinking about like Fitbit. If you just gave her some sort of goal progress […]
>
> G Yeah. But she did say she doesn't like walking, like, she doesn't like physical activities just for the sake of physical activity so that might not be motivating.

Concept selection and development

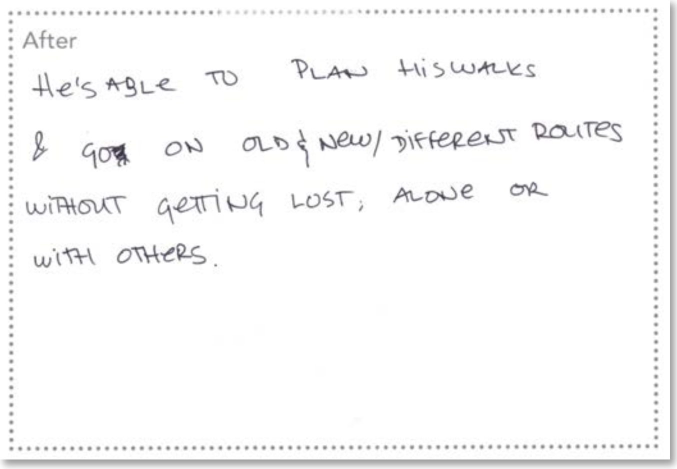
After they had shared and discussed their individual concepts, the teams were asked to select a concept to develop using a storyboarding worksheet, as described in section 3.8.5 and shown in Figure 3.9. Teams were asked to start by writing the aim of their product or service on the storyboard worksheet marked ‘after’, to represent the outcome of their interventions and then consider the stages by which the persona would use their product and service to achieve the outcome.

First the teams discussed their individual ideas, dismissing concepts that were not relevant to the persona (as illustrated by the previous quote) as well as concepts that were similar to existing products and those that did not directly support physical activity. Several teams looked for synergies between concepts and most combined several ideas to form the concept they went on to develop.

There was a limited amount of critical appraisal of the concepts during the selection process. In contrast to the other teams, however, a member of one team critiqued the utility of all of her team's concepts:

> "In all of these concepts the person needs to remember that there's something that can help them, but they might not remember that […] they can press the button, that they can look at the navigation [aid] or that there's an audio book…" (K, workshop three, team one.)

Having dismissed their initial ideas, this team's process then diverged from the other teams' approaches to concept selection. Using the storyboard worksheet marked 'after' they reconsidered the needs and desires of their persona (see Figure 7.4), leading them to re-envision one of their initial concepts, a navigation aid, so that it reflected their persona's interests:



After

He's ABLE TO PLAN HIS WALKS & GO ON OLD & NEW/ DIFFERENT ROUTES WITHOUT GETTING LOST; ALONE OR WITH OTHERS.

Figure 7.4: 'After' storyboard sheet for team one, workshop three.

> K Maybe, based on this he's able to live independently or as independently as possible and, I mean we could be more specific, like he's able to plan his walks […]

J We could also combine these and then say the desired state is that he should be able to make, not always make the same route but also different routes, without getting lost.

[Workshop three, team one]

Other than this team, the proposed process of generating an ‘after’ scenario or aim for the concept development process was not adopted. Instead, teams tended to work in a chronological fashion, starting with the ‘before’ scenario (describing their personas current situation) and only considering the ‘after’ scenario when they had completed the illustration of their concepts. For example, having started the first scene of their storyboard, one team had to decide how their social networking service would work as they considered what to draw in the second scene of their storyboard:

F What are you doing again?

H The Grandma’s watching TV while the grandkids watch TV (Figure 7.5).

F On the next one, are they actually meeting up now?

[…]

G What are we saying that, er, Mum of those grandchildren contacts Grandma?

H Erm.

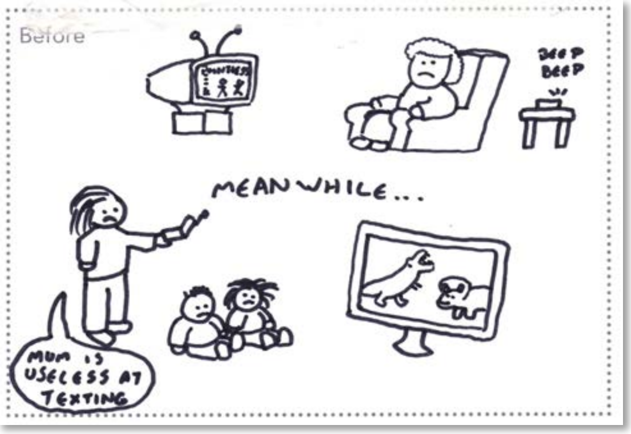


Figure 7.5: First storyboard scene, team two, workshop two.

F Well they're all on the network, aren't they?

G But how is the thing initiated? […] How do they meet up?

F That's a good point.

G Someone has to start initiation, so is that Mum on that picture of those kids that looks on the Facebook overlay and thinks *'Mum is just watching tele'*? But how do they know that Mum is just watching tele?

[…]

G Ah, maybe the thing then pops. Ah, yeah, yeah, yeah. She's watching the TV, right, and then screen turns into this overlay Facebook page.

[Workshop two, team two]

Despite working towards an outcome, rather than considering the outcome of their product or service at the outset, the teams were able to use the storyboarding activity to describe their concepts and there were some indications that the storyboarding process made teams think about the ways in which users would engage with their concepts, rather than focusing on the mechanics of the technology or service proposed. However, time limitations meant the teams' first draft of their storyboards were the final concepts that they presented, with limited refinement occurring.

7.4. Design concept outcomes

In the final stage of the workshops, teams were asked to present their storyboards. The teams' storyboards, along with a paraphrased version of the descriptions given in their final presentations are provided below.

7.4.1. Holi-DAY

The Holiday concept generated in workshop three by team two is shown in Figure 7.6.

Figure 7.6: Holi-DAY concept storyboard. Text reads: 'Holi-DAY'. 'Bring 'active' holiday to home'. 'Motivated by fun holiday activities'. 'Bringing holiday home'. 'Every week she can have 1 day "off" to experience a holiday'. 'Different countries and activities'. Sticky note reads 'Local cuisine, language, activities that link to what she did during holidays'.

Paraphrased concept description:

Holi-DAY gives June an active holiday at home. The concept was inspired by a quote from June's husband that said: *'When we go on holiday she's like a spring lamb.'* To which June responded: *'I'm much better I can walk better, and I do everything better you're under no stress, no strain, nothing.'*

Holi-DAY gives you one day a week when you can get out of the house and enjoy activities you would enjoy on your holiday.

The story starts with June sitting at home on the couch watching TV (Figure 7.7). Pete suggests she should take a walk, but June says, *'Hey, I'm not active just 'cause I've got to be. Don't tell me what to do, I am enjoying watching this right now.'* June does not like to be told what to do, she wants to make her own choices in her own time.

June enjoys planning activities with Pete because it makes her feel confident about what is happening and makes her feel connected. June loves to go on holiday and reminisce about her holidays. Pete introduces June to the Holi-DAY calendar app (Figure 7.8). This could be a physical calendar, or an app. Pete explains that they can plan their weekly 'Holi-DAYs', when they can take a break together in the local area. She says 'okay, that sounds fun' and they plan their 'Holi-DAY' for next Monday.

Figure 7.7: Scene one of the 'Holi-day' concept storyboard. Text reads 'I'm not active just because I've got to be'.

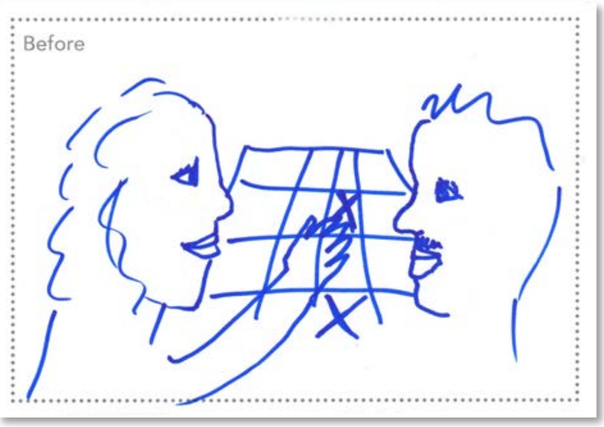


Figure 7.8: Scene two of the 'Holi-day' concept storyboard.

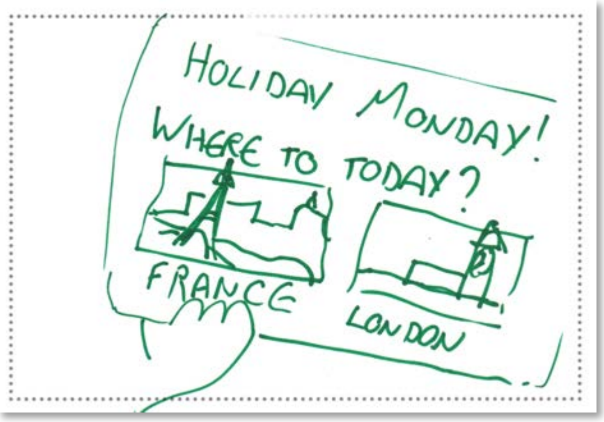


Figure 7.9: Scene three of the 'Holi-day' concept storyboard. Text reads 'Holiday Monday! Where today?' 'France.' 'London.'

It is Monday, so when June opens the 'Holi-DAY' app, she can choose where she wants to go based on places she has enjoyed visiting (Figure 7.9). She chooses to do something French today, so she is presented with different activities that she can do: eat French cuisine at the local French cafe, shop for French food at the market, go sightseeing, review holiday photos, or meet others who went to France (Figure 7.8). If June has a good day she will say, *'I'm feeling active, so I would like to go out'*.

Figure 7.8 Scene four of the 'Holi-day' concept storyboard.
Text reads 'Choose yourself or random button.' 'Local cuisine.' 'Activities' 'Sightseeing.' 'Photo review.' 'Meet others who went to the place too.' 'Shopping.'

Often, people with dementia have issues with choice making. If June is having a bad day it can be difficult for her to make a choice so there is a random choice option (Figure 7.8). If she selects it then the wheel will turn and make a suggestion for her.

Today June chooses to go sight-seeing because she used to enjoy looking at churches and learning about history when she was in France. Instead, today, she goes for a walk in Newcastle and looks at the local church (Figure 7.9).

Figure 7.9: Scene five of the 'Holi-day' concept storyboard.
Text reads 'I liked going for sightseeing, enjoy looking at churches & learning about history!'.

In the app, June can write a log of what she did and what she enjoyed. This will create a memory bank for June to read about in the future. She can keep a diary of her ‘Holi-DAYs’ or she can just write short notes or take photos (Figure 7.10).

In the final scene (Figure 7.11) June asks Pete ‘When can we plan our next Holi-DAY?’ As she likes to be with her grandchildren, she hopes that they will be motivated to do something with her too.

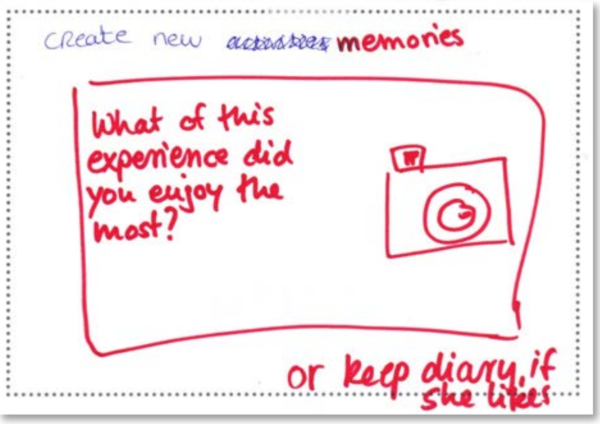


Figure 7.10: Scene six of the ‘Holi-day’ concept storyboard. Text reads ‘create new memories.’ ‘What of this experience did you enjoy the most’, ‘or keep diary if she likes.’

Figure 7.11: Scene seven of the ‘Holi-day’ concept storyboard. Text reads ‘create new memories.’ ‘What of this experience did you enjoy the most’, ‘or keep diary if she likes.’

7.4.2. Breadcrumbs

The ‘Breadcrumbs’ concept generated in workshop three by team one, is shown in Figure 7.12.

Paraphrased concept description:

Brian is a keen walker and explorer who enjoys being outdoors in nature. However, since he developed dementia, he always walks the same route so that his wife does not worry where he is and whether he will get home safely. Brian’s ability to plan and create has also diminished so he struggles to decide what to do.

Figure 7.12: Breadcrumbs concept storyboard

Brian tells his wife he is going for a walk and she says, '*okay let's plan it*' (Figure 7.13) The Breadcrumbs system helps Brian and his wife to plan the activity, the route and the duration.

Figure 7.13: Scene one of the Breadcrumbs concept storyboard Text reads: "I'm going for a walk." "Great let's plan it!" "Adaptive threshold. Duration. General Direction."

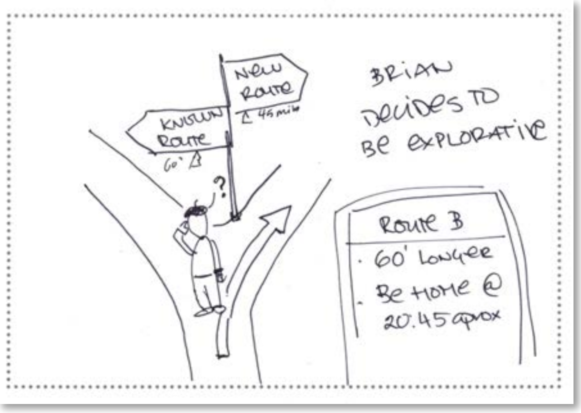


Figure 7.14: Scene two of the Breadcrumbs concept storyboard Text reads: "Brian decides to be explorative." "Known route." "New Route." "Route B, 60' longer, be home @ 20:45 aprox"

Now Brian's wife can be notified of his whereabouts. She used to stay at home waiting for Brian to come back and she worried about him returning safely. Now they have Breadcrumbs she can go out and do her own thing while Brian goes out for his walk.

Figure 7.15: Scene three of the Breadcrumbs concept storyboard.

Text reads: "How is your tiredness level?" "You should start walking back!" "Alerts & notifications in emergencies"

Brian starts his walk and then he comes to a turning point (Figure 7.14). Although he has a planned route, there is also another path and he can see beautiful daffodils in that direction. Because he is an explorer Brian decides to take this the new route. The Breadcrumbs device can let him know how long it will take him to get home with his new route.

Brian can walk freely, going where he pleases. The device monitors his tiredness and the estimated distance it will take to walk back home (Figure 7.15). If he has walked too far or for too long the system will alert him. It can also suggest a route home if Brian is not sure how to get back.

Figure 7.16: Scene four of the
Text reads: "Later @ home…" "Brian sees and shares the route w[ith] his wife. He publishes it for other walkers to follow."

Today Brian agreed with his wife that he will return for dinner in two hours so after one hour his Breadcrumbs device says, *'please consider turning around and walking back.'*

Later, when Brian is at home with his wife, he can share where he went and what happened on his trip (Figure 7.16). He can save his route for another time or he can publish it online. This way he can find other walkers around who can join him next time, just like he used to do when he planned walks for his walking group.

7.4.3. Phit

The ‘Phit’ concept, generated by the first team in the second workshop is shown in Figure 7.17.

Figure 7.17: Phit concept storyboard

Paraphrased concept description:

Our product is called Phit. It is inspired by the popular TV game show, ‘It’s a Knockout’, which was like a school sports day for adults. June is a bit unhappy. She lacks confidence to go out and become active on her own. This makes her husband, Pete, stressed, so he decides to get June this new product called Phit, which is a tablet and a watch (Figure 7.18). The product designs exercise obstacle courses. It is like a coaching app that rewards users when they do activities.

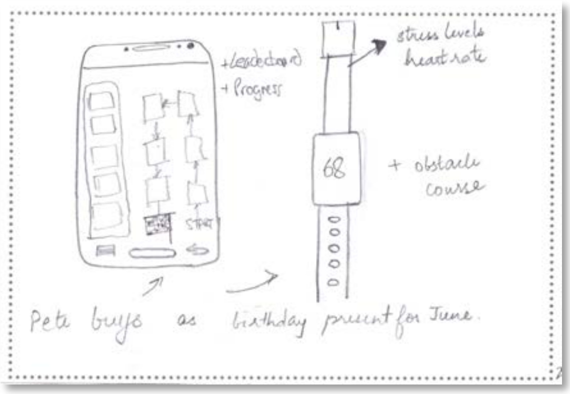


Figure 7.18: Second scene from the Phit concept storyboard

Text reads: "Leaderboard." "Progress." "Stress levels" "Heart rate" "Obstacle course" "Pete buys as birthday present for June"

The app allows June to choose an obstacle course or build custom courses. She can start with a simple pre-built obstacle course and it builds in complexity (Figure 7.19). She can select games that she might have played in her childhood for example skipping and hopscotch.

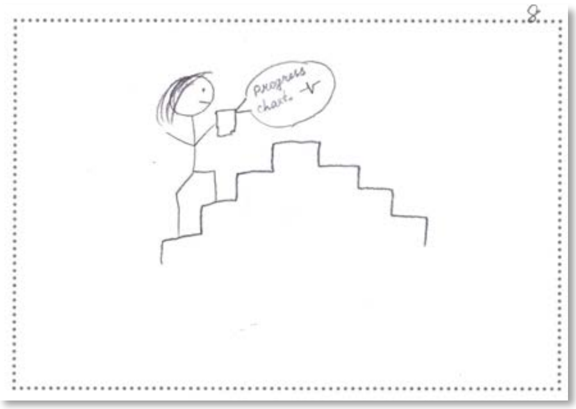


Figure 7.19: Eighth scene from the Phit concept storyboard

Text reads: "Progress chart"

The Phit pack comes with starter obstacles but then she could extend the kit with harder obstacles, such as the skipping rope as she becomes fitter. The product can be used indoors and outdoors. As June gets better, she can customise her own obstacle courses. When she does well the app rewards her. The app is linked with supermarkets, which provide reward vouchers to motivate users to be more physically active. The device can also send data to June's doctor to tell her about June's activity levels.

Pete realises that June has gained confidence, so he decides to tell the world about Phit. When lots of people have Phit they can do the obstacle courses together and come together as a community. Pete tells the family and they come and join in as well.

7.4.4. SimpleBook

The SimpleBook concept was generated by the first team in the second workshop (Figure 7.20).

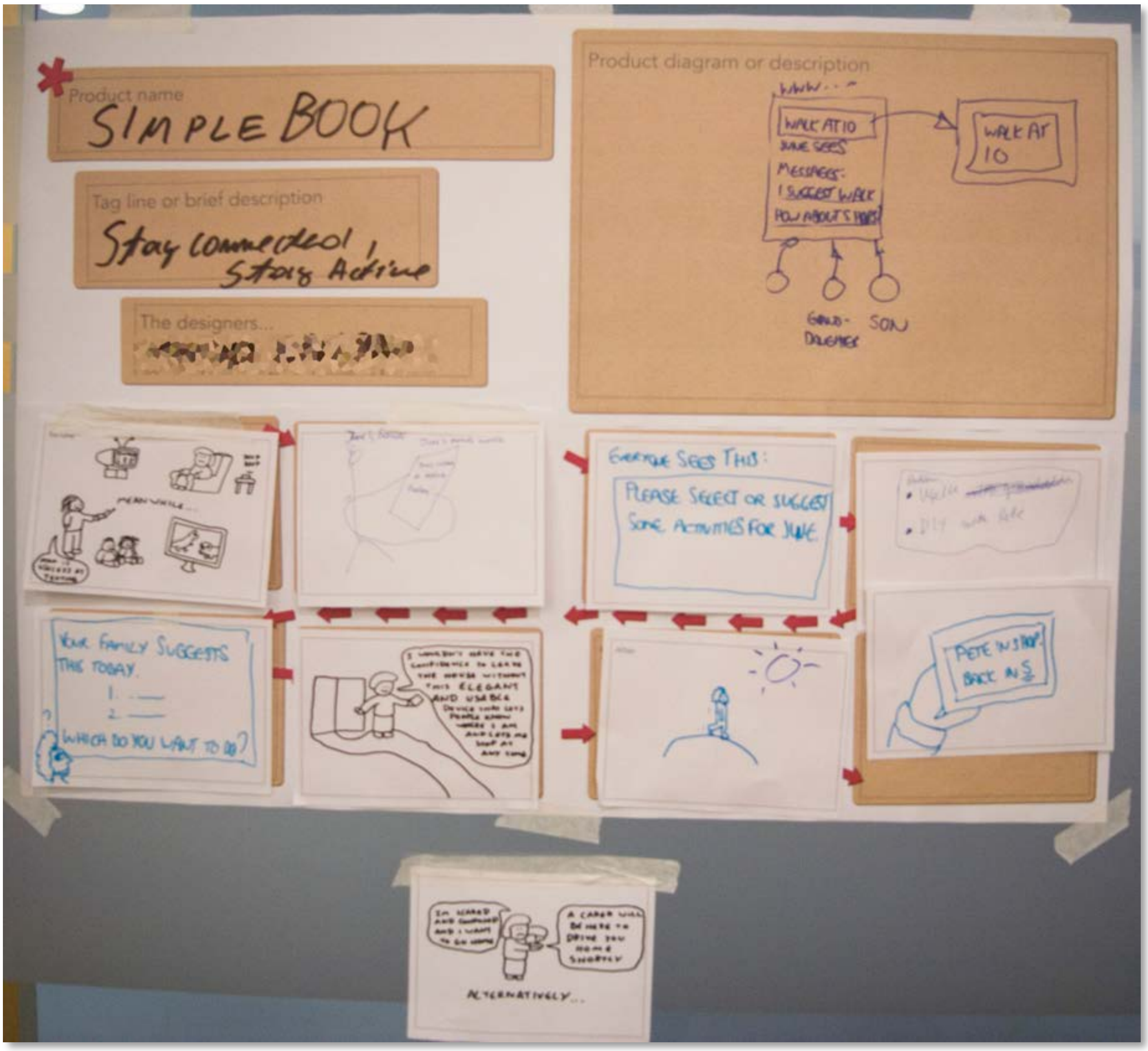


Figure 7.20: Simplebook concept

Paraphrased concept description:

June often struggles to do things on her own, to choose to do things and lacks the confidence to go out alone. We wanted to motivate June to leave the house. So, there are two parts to the product; first we wanted her to be able to coordinate activities with her family and second, we wanted her to feel confident to go out on her own.

SimpleBook is a simple version of Facebook that allows June and her family to plan to do things. By using the SimpleBook activity-planning tool June can make independent decisions while her family support her in being active. It also allows June's family to interact with her more easily.

June's daughter gets a notification asking her to suggest an activity for June. On her smart phone it says, *'please select or suggest some activities for June'*. On June's smart TV (or phone or other device) she can see different options for activities suggested by her daughter. A message comes up with suggested options for example '*go for a walk*' or *'go swimming with the grandchildren'*. June can then make her own decision as to what she would like to do.

In addition to selecting activities, SimpleBook allows family members to post messages to keep June connected to what is going on. Because June gets confused about what's happening, people can send posts to her device or smart TV. For example, her husband Pete could send a post saying *'running late, back in 5 minutes'*.

We wanted to overcome the problem that June gets confused when there is lots of text on the screen, on programmes like Facebook. So SimpleBook will make it much easier for her to stay connected with her family and friends with a clear and simple user interface.

The second part of the proposal is a device that June can carry with her all the time and particularly when she goes out of the house. June was worried about going for a walk alone because she was worried about something going wrong or not being able to get back home easily. Now June feels confident to go outside and have that walk because she can stop at any time and say, *'I don't feel happy any more'* and the device will allow her to call for help or a lift home. It could call a family member, someone from a network of local carers or a special dementia taxi service. This would provide an extra safety net for June to feel confident when going out alone.

7.4.5. Spark

The Spark concept, shown in Figure 7.21 was created by Newcastle University's MoveLab. Unlike the other concepts, the presentation of this concept was not audio recorded so the description is in my own words.

Figure 7.21: Spark concept storyboard. Text reads: Spark. Sedentary + Physical Activity + Resources + Knowledge. Lighting the flame of activity.

In the first scene June is sleeping on the sofa while her husband, Pete, looks on, worried. In the second scene Pete visits her doctor who asks, *'how's it going'*, Pete describes his concerns to her doctor. June's doctor thinks that she needs some help to get active, so she refers June to a healthcare professional. In scene three, the healthcare professional visits June and her husband at home to talk to them about physical activity. They have an informal chat and he provides them with information about the benefits of physical activity (scenes four, top right and five, bottom left). He also tells June about a programme that she can participate in to help her to get active. June signs up and a physical activity specialist then visits June at home to guide her through a personalised exercise programme to help her to build her strength and balance so that she can walk out confidently (scene six, bottom, centre). He also helps June to set activity goals. The final scene shows June and her husband enjoying a walk together. They have pedometers to track their steps and help them to increase their physical activity levels further.

7.5. Summary

In this chapter I have analysed the ways in which workshop contributors engaged with information about the experiences of people with dementia and the degree to which this enabled them to create relevant concepts for products and services to support physical activity. The workshop contributors engaged well with the activities, understood what was expected of them and worked together effectively in their teams. Contributors were enthusiastic and seemed absorbed in the activities, sometimes to the extent that it was difficult to move them on to the next task, which impacted on the time available for later activities. Despite this, one contributor remarked that the workshops had encouraged focused thinking.

The information in the personas and quote cards appeared to be understood in the most part, and teams often referred to the personas during their design activities. Where the meaning of quotes was unclear, teams were often able to discuss and decipher their meaning. The different perspectives, personal experiences and professional knowledge within the teams seemed to enhance their interpretation. Occasionally contributors' interpretations also provided new insights, enhancing my own understanding of the data. Some workshop contributors were more inclined to analyse the meaning behind quotes, leading to more nuanced interpretations.

The capacity of the personas and quotes to convey the experiences of people with dementia was, however, limited, for several reasons. First, the quotes from participants with dementia were sometimes unclear outside the context of the interviews, leading workshop contributors to make assumptions, which sometimes drew on inappropriate, stereotypical views of older people with dementia. Second, because the quotes and information in the personas was sometimes ambiguous (genuinely reflecting the incomplete interview findings), workshop contributors occasionally found that they had to interpret the information provided. This led some to express concerns about misinterpreting the meanings of people with dementia and their partners. Finally, although some participants expressed empathy towards the personas, others seemed to be less empathetic, with some using language that indicated that they saw the older people with dementia described in the personas as ‘other’. These findings indicate that, even these detailed personas, provided insufficient information and were open to interpretation and misrepresentation.

The primary objective of the design workshops was to produce concepts for products and services to support physical activity. Although the contributors engaged well with activities, generating novel ideas, there was limited time for development and refinement of their initial concepts. In addition, none of the workshop activities required them to critique their ideas; in fact, to encourage concept generation they were initially encouraged to suspend criticism. This arguably led to naïve final concepts.

Concepts generated in the design workshops were intended to be presented back to participants with dementia and their spouses for their feedback. However, I felt that the concepts needed some refinement and clearer illustration before they could be presented. In the following chapter I will describe how the concepts were refined before reporting the reactions of participants with dementia and their partners to the products and services proposed.

Chapter 8. Stage three: Appraising concepts with people with dementia

8.1. Introduction

In the third stage of the research, concepts generated in the design workshops were refined and presented back to participants with dementia and their spouses for their critique in two focus groups. As well as asking participants to evaluate these concepts, this stage of the research aimed to further understand the needs of people with dementia and their partners by re-examining key themes from the first stage of the research.

Before they were presented to focus group participants, the rapidly generated design workshop concepts were refined and more clearly illustrated, as described in section 8.2. Next in section 8.3., I outline the recruitment and running of the focus groups. Findings from the focus groups are then arranged into four overarching themes; independent activity (8.4.1); intrusiveness and autonomy (8.4.2); prompts, reminders and support (8.4.3); and finally critiquing technology and valuing human intervention (8.4.4). The findings from this final stage of the research are then summarised in section 8.5.

8.2. Focus group storyboards

To clearly communicate the ideas generated in the design workshops to participants with dementia and their spouses I decided that the roughly sketched concepts had to be refined and more clearly illustrated. To communicate the concepts succinctly in the one-and-a-half-hour focus groups, I decided that the five workshop concepts should be amalgamated into three more coherent storyboards. In doing so I also hoped to draw out and emphasise features that responded to the key findings from the first stage of the research, to trigger discussions that would develop the research enquiry. The following three sections describe how features from the five design-workshop concepts were selected and combined to generate three storyboards.

8.2.1. Storyboard one

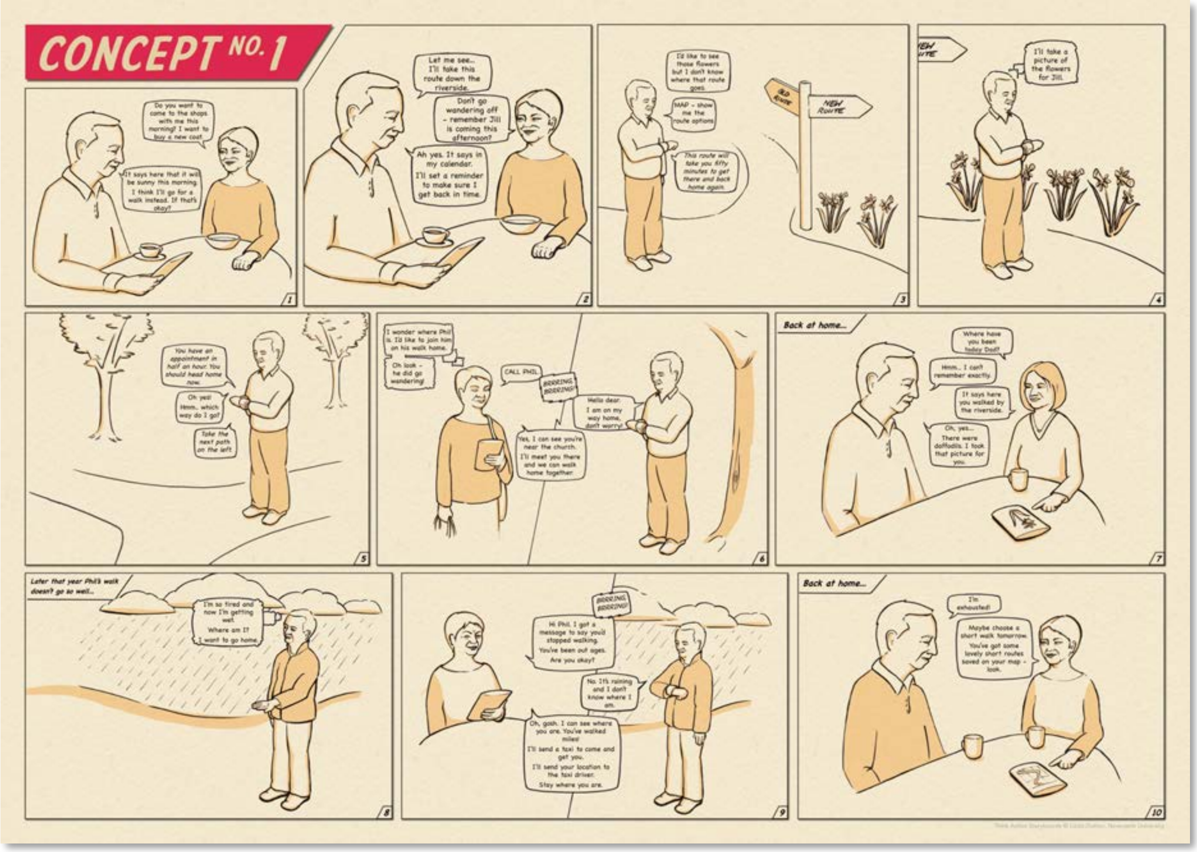


Figure 8.1: First focus group storyboard

The first storyboard (Figure 8.1) was composed to respond to the finding in the first stage of the research that several participants with dementia no longer walked out independently. It built on a design workshop concept called Breadcrumbs (see section 7.4.2), which proposed a watch-based navigation device that could guide a person with dementia, prompting them to walk home if they were out for a long time as well as informing their partner about their location. An element from the SimpleBook concept (7.4.4), which allowed people with dementia to call for help or a lift home was also added to this storyboard to gauge participants' reactions to this feature.

In the first stage of the research, it was unclear what prevented participants with dementia from walking unfamiliar routes on their own. While there were indications that navigation difficulties potentially limited independent travel (although mostly in relation to driving), there were also indications that partners' anxieties could be a greater inhibitor. Presenting the breadcrumbs concept to focus group participants offered an opportunity to explore whether difficulties with navigation stopped people from walking out alone and whether a navigation device would be useful. It was also hoped that the storyboard would reveal whether partners' anxieties were influential, and whether a tracking device could alleviate these anxieties. Although the tracking aspect of the concept was intended to help people with dementia and their partners, ethical concerns have previously been raised about prioritising caregivers' needs at the expense of the privacy of people with dementia (Robinson, Hutchings, Corner, *et al.*, 2007; Holbø, Bøthun and Dahl, 2013; Meiland *et al.*, 2017). Presenting this concept to people with dementia and their partners offered an opportunity to explore this contentious issue further.

The storyboard shows a man planning a walk using a tablet-computer shaped device. During his walk he decides to deviate from his route and asks his smart watch device how long this alternative route will take him. He is also able to use this device to take a picture of something of interest on his walk. During his walk, the smart watch reminds him that he has planned to meet his daughter in half an hour, so he asks the watch which way he should go to get home and it provides directions. His wife is able to check the man's location and she calls him on his watch to suggest that they walk home together. When they get home, the man's daughter visits, and he is able to share the picture he took on his walk. In the final row of images, the storyboard presents a different scenario, in which the man has found himself lost in a storm. The device alerts his wife that he has stopped walking and she calls him to suggest that she orders a taxi to collect him. She uses his location information to direct the taxi to him.

A detailed description of the scenes in this and the other storyboards can be found in appendix U.

8.2.2. Storyboard two

Figure 8.2: Second focus group storyboard

The first stage of the research highlighted that physical health problems can contribute to inactivity in dementia. To explore whether a home-based exercise programme might help people to improve their physical activity levels and increase their confidence to walk out, features from the design workshop concepts Phit and Spark (described in sections 7.4.3 and 7.4.5) were amalgamated in the second storyboard. The Spark concept proposed a professionally led personal training service and the Phit concept was an exergaming technology. Exergaming has been found to be acceptable to people with later life cognitive impairment (Wiloth *et al.*, 2018; Karssemeijer, Bossers, *et al.*, 2019) and tailored exercises and professional instruction has also been found to be valued (Franco *et al.*, 2015; Anderson-Hanley, Barcelos, *et al.*, 2018; Anderson-Hanley, Stark, *et al.*, 2018; Wall *et al.*, 2018; Morgan *et al.*, 2019). I therefore decided to incorporate both professional and digital features to gauge participants' acceptance of these different approaches to supporting physical activity and to see whether a combined approach would be acceptable. A remote monitoring feature was also included to assess participants' reactions to receiving remote support and to their activity levels being monitored by their healthcare provider.

The storyboard (Figure 8.2) shows a woman receiving a visit from an occupational therapist to arrange a tailored exercise programme. The occupational therapist demonstrates the exercises before attaching a device to her television which includes a motion-sensing camera, which will guide her through the exercises in future and provide feedback to tell her whether she is doing them right. The storyboard describes the woman receiving reminders to exercise through her television and getting positive feedback when she does them. When the woman stops exercising for a few days, she receives a phone-call from the occupational therapist to ask if she has a problem. The occupational therapist is able to help the woman to address a problem with her medication, and she is able to get back to exercising. Next she is shown having fun doing the exercises with her granddaughter and later feeling confident to take a walk in the park.

8.2.3. Storyboard three

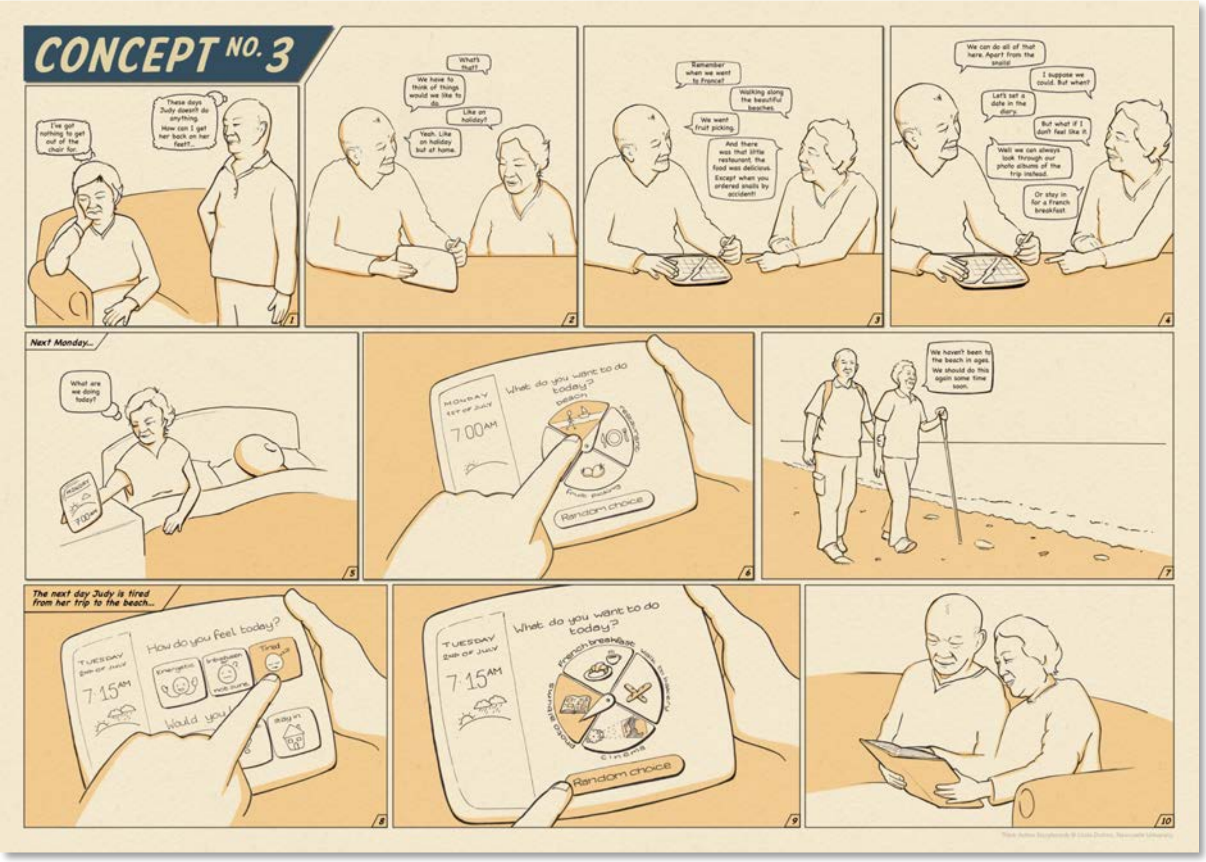


Figure 8.3: Third focus group storyboard

In the first stage of the research loss of motivation and occupation were found to contribute to sedentariness among participants with dementia. There were indications that loss of initiative and apathy contributed to loss of motivation. One of the design workshop groups generated a concept called Holi-DAY that attempted to overcome loss of motivation, occupation and initiative (see section 7.4.1) using a digital planner that would allow people with dementia to plan activities. This concept was selected and modified for presentation to participants in the focus groups as it provided an opportunity to discuss loss of motivation and explore whether digital tools might stimulate people with dementia to engage in activities.

The storyboard (Figure 8.3) shows a couple using a tablet computer like device to identify activities that they enjoy doing. When she wakes up the next day, the device helps the woman to choose what she will do from the activities that she enjoys. The device asks her questions about how she is feeling to help her to decide what to do. If she cannot decide what to do, she is able to press a button to choose a random activity.

8.3. Recruitment and running of the focus groups

The three storyboards were presented to participants with dementia and their spouses for critique in two focus groups, each lasting an hour and a half. I displayed the storyboards to participants on A1 boards, revealing and explaining one concept at a time, seeking participants' feedback after each concept had been described. Further details of the methods and recruitment process can be found in sections 3.4 and 3.9 of the methods chapter.

Five people with dementia and four of their spouses took part in the focus groups. The first group included the participant given the pseudonym Gerald (PWD) and his wife Marjorie alongside Anthony (PWD) and his wife Sue. The second focus group included Lynn (PWD); June (PWD) and her husband Pete; Esther (PWD) and her husband John. In the following sections the acronyms 'FG1' and 'FG2' are used for focus groups one and two.

8.4. Focus groups findings

Participants in both focus groups responded readily to the storyboards. Around twenty minutes of discussion followed the presentation of each concept. Participants' reactions indicated that they comprehended the concepts described by the storyboards. Conversation flowed easily, and participants worked together well, building on each other's comments and sharing their experiences.

All participants contributed to the focus groups, although partners tended to dominate the conversations. In the first focus group, one partner in particular, Sue, was dominant and tended to lead discussions. In the same focus group, Gerald (PWD) rarely spoke, unless directly addressed, although he seemed to follow the conversation, muttering occasionally to signal his agreement or interest in the other participants' comments.

Several themes from the first stage of the research were reiterated in the focus groups, including those relating to independent activity; occupation and agency; and the utility of memory aids. In addition, participants' reactions to the concepts generated several new themes around intrusiveness and autonomy; usability and utility; technology and human intervention. The following sections explore these key themes.

8.4.1. Independent activity

The first key theme—independent activity—was prominent in discussions about the first storyboard, described in 8.2.1. Reactions to this concept highlighted issues associated with getting out and about with dementia, including the different perspectives of people with dementia and their spouses about people with dementia going out alone.

Out and about

Two partners in the first focus group thought that the navigation aid presented in the first storyboard could support people with dementia to be more independent:

Sue	It's giving you that independence of not being next to someone, of not having to rely totally on their physical presence there.
Marjorie (FG1)	Yeah.

As well as providing independence for people with dementia, Sue (partner, FG1) and Marjorie (partner, FG1) agreed that the first concept could provide independence for the partners of people with dementia:

Sue It's be nice to give some independence back.
Marjorie Yes. Yes. I think that's the thing.
Sue And I think that's what a device like that would give.
Marjorie Yeah. Yes.
Interviewer Independence?
Sue Independence for both.
Marjorie Yes.
(FG1)

Sue (partner, FG1) and Marjorie (partner, FG1) were both enthusiastic about the first concept, but it was unclear whether it was the benefits for people with dementia or their carers that prompted this enthusiasm. Notably, their enthusiasm was not echoed by their partners.

Other responses suggested that navigation was not the only factor that prevented people with dementia from walking out alone. Esther (PWD, FG2) indicated that she had experienced confusion when she went out:

> "Going out and doing something. Oh yeah! I was! I was about on my own and doing things. But you think *'what do I do now?'* You know? *'Where am I going?'*" (Esther, PWD, FG2)

Similarly, Anthony (PWD, FG1) and his wife Sue's (partner, FG1) discussion indicated that confusion had stopped him from going to the shops on his own:

Sue You used to enjoy going down to [get] the paper and the odd bit of shopping…
Anthony Hmm-hmm ((in agreement))
Sue You really enjoyed that.
Anthony Hmm ((in agreement))
Sue It became too confusing and you would often go down there then come back with—

Anthony (FG1) Come back without— the wrong thing or nothing at all.

These comments extend findings from the first stage of the research, in which the outdoor environment and interactions outside the home were found to present various challenges for participants with dementia (see section 5.3). Together these findings indicate that technologies to support independent walking must consider challenges beyond navigation.

Partners' fears

Unlike Sue (partner, FG1) and Marjorie's (partner, FG1) ideas about supporting mutual independence, the most common response to the concept was that it could alleviate partners' concerns about leaving their spouses with dementia alone, rather than promoting independence for individuals with dementia, as was intended. In both focus groups partners described the anxiety they felt when they did not know where their partner with dementia was, as John (partner, FG2) described:

> "On the odd occasion we go shopping I'll say, *'I'm going there.' 'I'll see you there.'* And if she's not there, my immediate panic - *'where is she?'*" (John, partner, FG2)

Apparently as a result of these anxieties, all four partners of people with dementia indicated that they liked the idea of being able to locate their spouses:

> "I like the second device that the carer had so that she could locate where her husband had gone." (Sue, partner, FG1)

> "I often say *'I'm gonna put a tracker on you.'* so the […] concept's a good idea." (Pete, partner, FG2)

Despite partners expressing concerns about losing their spouse with dementia, nobody mentioned any instances when the individuals with dementia had actually got lost, as in the first stage of the research. However, one partner did indicate that fears about future incidents may have contributed to his anxiety:

> "June never goes out on her own but if she did [...] I mean, I might go out, say, for a run along the river [...]. There might come a stage where she thinks *'well where is he? I'll go and find him.'*" (Pete, partner, FG2)

In reaction to Pete's comment, June (PWD, FG2) was adamant that she would not leave the house on her own:

> "I wouldn't […] I wouldn't go out." (June, PWD, FG2)

Like June, none of the participants with dementia expressed concerns about getting lost and, unlike their spouses, none suggested that the device proposed in the first storyboard would be useful to them, although most did not state that they disliked the concept either. Gerald (PWD, FG1) did, however, say that he did not think that the product would be of use to him, despite his wife perceiving a need:

> Marjorie ^{Partner} Don't you think it'd be useful?
>
> Gerald Well perhaps it may come to that. I can't say I've had any problems.
>
> (FG1)

Unlike partners' preoccupation with losing the individuals with dementia, Gerald (PWD, FG1) was dismissive, indicating that this was not a present concern for him. The only participant with dementia who lived on her own, appeared to hold a pragmatic attitude to getting lost, suggesting that the first concept was *"a brilliant idea"* for other people but not for her:

> "[My daughters] don't have time to track me. If I get lost, I get lost." (Lynn, PWD, FG2)

As in the first stage of the research, we can see a disparity between the attitudes of people with dementia and the anxieties of their partners, which may contribute to the curtailment of independent activity. It is interesting that one of the most independently active individuals with dementia lived on her own, and therefore may be less restricted by the concerns of others, forced to be pragmatic. However, it should also be noted that this participant appeared to be least effected by dementia and described having been diagnosed as being 'in the grey area' between MCI and dementia.

Partners' independence

The partners of participants with dementia also talked about the impact of dementia on their own lives. Partners in the second focus group, in particular, were more forthcoming than they had been in the interviews:

> John $^{\text{Partner}}$ Up 'til two years ago, we were two people. Esther looked after her stuff and I did my stuff. But now I have to combine mine to fit her in. So, my activities are limited […] My life's completely changed […] I had a garden, I walked. But now I have to do everything. I have to cook and clean…
>
> Pete $^{\text{Partner}}$ That's right. […] I had a life. I used to go out running thirty miles a week. […] We're devoting everything to our wives.
>
> (FG2)

Sue (partner), who had been positive about her caring role in the interviews, also released her exasperation in the focus groups. When her husband Anthony (PWD) left the focus group briefly, after having made some jovially contrary, sarcastic comments, she commented:

> "Count yourself lucky you don't have it twenty-four seven. It's been a long week." (Sue, partner, FG1)

This comment contrasts with Sue’s positive description of the couple being *“joined at the hip […] we don’t get bored with each other”* (Sue, partner, interview), in the first stage of the research

These findings extend those from the first stage of the research, in which couples indicated that their lives had become increasingly shared. However, unlike findings from the first stage, in which some partners talked positively about the convergence of their lives, these more negative comments suggest that partners may also mourn their own independence.

8.4.2. Intrusiveness and autonomy

The concepts raised concerns about intrusiveness and autonomy. The first concept highlighted that carers tracking people with dementia could lead to unacceptable privacy infringements, whereas the second concept roused fears about the intrusion of healthcare providers. However, participants’ views on the acceptability of these intrusions differed.

Tracking and being tracked

In relation to the first concept, participants with dementia and their partners indicated different attitudes toward tracking technology. The aim of the concept was to support independent walking but the spouses of participants with dementia were most enthusiastic about the feature that allowed partners to locate their spouses, as described in the previous section. One partner’s immediate response to the concept was:

> "It sounds to me like it's like a tracker, which is a good idea. I’m just thinking […] you know when people are on remand or whatever; they put this tag on. The tracker. It’s kinda like that, you know? But it’s a good idea.” (Pete, partner, FG2)

Despite the negative connotation of the criminal tracker, when I asked Pete (partner, FG2) whether *he* would want to be tracked he responded:

> "I don't think it's an issue [...] Not as far as I'm concerned." (Pete, partner, FG2)

However, Pete's wife June (PWD, FG2) was more reticent when asked how she felt about being tracked:

> "Depends on the tracker. What type- what style of tracker." (June, PWD, FG2)

Unfortunately, June did not explain whether the tracking process or the aesthetics of the tracker (i.e., that it was not styled like a criminal tag) was important to her. Anthony (PWD, FG1), on the other hand, was somewhat more critical, suggesting that being tracked could stop people doing things their partners disapproved of:

> "You can't sneak into the pub for a quick one" (Anthony, PWD, FG1)

When I mentioned Anthony's concern to the second group, Lynn (PWD, FG2) remarked that you could simply *"switch it off"* and then June (PWD, FG2) suggested that the device could show "*a blank*" rather than the user's exact location.

Unlike participants with dementia, who appeared to want some degree of privacy, Sue (partner, FG1) felt that being watched was a reasonable trade-off for independence:

> "I know it is very sort of – somebody's watching you all the time – but it's, at least it's giving you that independence." (Sue, partner, FG1)

As described in the previous section, there was a disparity in attitudes between people with dementia and their partners, with the partners being more enthusiastic about the idea of tracking than the individuals with dementia. The presentation of the concept may have influenced the responses since the storyboard showed the person with dementia being located by his wife and not the other way around. It would have been interesting to hear partners' reactions if the concept had shown the person with dementia tracking their partners' location.

Communication

Although discussions initially focused on tracking, some participants saw the device described in the first concept as a tool to facilitate communication. Marjorie (partner, FG1) said that she liked the *"partnership"* aspect of the concept and went on to discuss with Anthony (PWD) how the device could provide two-way communication:

Marjorie	I think the two-way […]
Anthony	Hmm. You can communicate.
Marjorie	You can communicate, yes.
Anthony	'Where are you?' 'I don't know' 'What can you see'.
(FG1)	

Lynn (PWD) also saw the concept as a way of staying in touch, rather than as a tracker:

> "I wouldn't have called it a tracker […] I think ... it's just, well, keeping in touch." (Lynn, PWD, FG2)

These comments suggest a more positive interpretation of the concept as a supportive device that could allow people to stay in touch, perhaps reassuring partners and allowing people with dementia to seek help if necessary.

Privacy and autonomy

The second concept elicited fears about the intrusion of healthcare services on people's privacy and autonomy. Participants in the first focus group were scathing, suggesting that the television-based system was too *"intrusive"* (Sue, partner, FG1), with one participant referring to it as *"Big Brother" (*Anthony, PWD, FG1). Marjorie (partner, FG1) remarked that the device could start passing judgement on people, telling them *"you are watching too much tele!"*. Meanwhile, Sue (partner, FG1) was concerned that people should have the freedom to choose when and whether they exercised:

> Sue It sounded a bit intrusive at times…
> Anthony (PWD) Hmm.
> Sue …as to well, why aren't you doing it? So yes, I think it's good but it's a bit like, you know, we've all been given exercises at times, we've all been say, for physiotherapy or something. And sometimes you feel like doing it and sometimes...
> Anthony Sometimes you don't.
> Sue Really you don't.
> (FG1)

When the first group's reservations about intrusiveness were mentioned to the second focus group, they were more relaxed. Pete (partner, FG2) and John (partner, FG2) responded by highlighting the preponderance of monitoring technologies:

> Pete CCT all over the shop.
> John Yeah.
> Pete It doesn't bother us at all.
> John I mean you have them in lifts now. Have them all over the place.
> (FG2)

Likewise, June (PWD, FG2) was dismissive of Anthony's suggestion that the system was like 'Big Brother' saying:

> "Oh, no such thing." (June, PWD, FG2)

Lynn's (PWD, FG2) view was that individuals were free to *"make a choice"* whether and when their activities were monitored. However, later, Lynn indicated that this apparent freedom of choice could have implications, since when asked if she would be happy for her doctor to monitor her activities, she responded:

Lynn	Well they kind of need to really, don't they?
June (PWD)	Hmm-hmm. Yeah.
Lynn	Whether you want to or not [...] if you want people to make sure you're okay, you're gonna be open to these kind of things.

Lynn's comment suggested that being monitored is something one has to accept in order to be looked after, not quite the free choice that she initially portrayed.

8.4.3. Prompts, reminders and support

During the interviews it became clear that loss of motivation, as well as difficulties planning, initiating and performing household tasks, could lead to inactivity for people with dementia. In this section, the ways in which partners support activities in the home is discussed as well as the potential for memory aids to prompt and remind people to engage in activity.

Occupational activity and partners' support

Building on findings from the first stage of the research, the desire among people with dementia to maintain a role in the home and the importance of spousal support emerged in the focus groups. For example, Esther (PWD, FG2) remarked on her former capacity to *"run the house, go to work the whole lot"* (Esther PWD, FG2) and went on to express remorse that she could no longer do things herself:

> "So, everybody's very good about the dementia but you still can't help feeling […] I want to do it myself." (Esther PWD, FG2)

These comments reflect those in the interviews, which revealed that Esther's engagement in household activities had become limited since her husband had taken over several activities that she had previously valued. In the interviews it appeared that Esther's husband was frustrated about her inactivity but saw little value in trying to engage her in household tasks. Interestingly, during the focus group Esther (PWD, FG2) remarked that an occupational therapist had visited her. Her husband went on to describe the occupational therapist's advice:

> "The programme [that the occupational therapist] was running was trying to motivate dementia people. To make them work. And so much so that there was one thing that [the occupational therapist] suggested, which we do, and that is, occasionally I'll say to Esther *'you do the lunch.'*
> (John, partner, FG2)

Despite having received advice from an occupational therapist, John's account of his efforts to engage Esther in household activity contrasted with other partners' approaches. For example, John's comment implied that he would instruct Esther to prepare the lunch on her own, while Sue (partner, FG1) emphasised the importance of sharing tasks such as cooking, to support and involve a partner with dementia:

> "I think one of the important things is not to take over completely but involved and to share things […] still keeping, you know, your partner involved in what you're doing." (Sue, partner, FG1)

Sue (partner, FG1) also alluded to the importance of routines for her husband, describing how Anthony would *"do set things that you like to do in the morning"* (Sue, partner, FG1). On the other hand, John suggested that he only *"occasionally"* told Esther to prepare the lunch, rather than helping Esther to establish a routine. In comparison with Sue and other partners' descriptions of the ways in which they supported their spouses to maintain an active life in the home, John's support appeared to remain limited, despite the occupational therapist's visit.

It should be noted, however, that even Sue (partner, FG1), who advocated supporting autonomy, made comments that suggested it could be challenging for spouses not to take over everyday tasks:

> "When you bring the shopping back, like, you don't want to find […] a tub of ice cream in the fridge two days later." (Sue, partner, FG1)

Furthermore, despite emphasising the importance of sharing tasks, she talked in way that indicated that she took control, allowing her husband to participate, rather than supporting his agency:

> "I'll have certain things that Anthony will do. He'll chop things, peel things while I'm doing something else." (Sue, partner, FG1)

This contrasts with Anthony's (PWD) determination in the interviews to do things without his wife's assistance and with Esther's earlier comment that she wanted to be able to *"do it myself"* (Esther, PWD, FG2). Together these findings suggest that even the most determined partners can find it difficult to enable people with dementia to maintain a role in the home.

Memory aids and prompts

The use of planners and calendars as memory aids was discussed in the interview findings, in section 6.3. Among couples where a spouse had dementia, partners appeared to instigate and sustain the use of these memory aids while participants with dementia had little input. This was an issue I wanted to explore further in the focus groups since the viability of an intervention to prompt people with dementia to engage in physical activity may depend on their capacity and inclination to engage with such tools.

The third storyboard provided an opportunity to better understand the utility of memory aids for people with dementia. The concept was designed in response to information about the lives of June (PWD) and her husband Pete who described writing the week's activities in a notepad for his wife during the interviews. When they went on a cruise, he had also used notecards to inform June what they would be doing each day.

In the focus groups Pete immediately noted that the device was similar to his own strategies, although, it seemed that, since the interviews, Pete had adapted the cards he had used on their cruise into an everyday memory aid for June:

> "This is a bit like the card I put beside the bed on a night for June. And I write out 'Friday', the date and coming to here. You know? So, she knows what day it is, she knows the date, she knows to get up and get dressed because we're going out. […] I put it there every night. And then the next morning she knows." (Pete, partner, FG2)

It is interesting that Pete’s own system had evolved in a similar way to the concept presented, although in low-tech fashion.

Like Pete and June, all of the couples in the research used some sort of daily activity reminder. Gerald’s (PWD, FG1) wife Marjorie wrote the following days’ appointments onto a whiteboard. When asked whether he used the whiteboard Gerald’s initial reaction was that he neither wrote on, nor read the planner, but he quickly adjusted his response, perhaps to satisfy his wife Marjorie, who thought he should use it:

Interviewer	Do you put anything on the whiteboard Gerald?
Marjorie	No.
Gerald	No.
Interviewer	No. Do you read the whiteboard?
Gerald	No… Oh, oh, well I suppose.
Marjorie	You ought to.

This conversation prompted Anthony (PWD, FG1) and Sue (partner, FG1) to discuss how they used their own whiteboard:

Sue	You look.
Anthony	I look [...] To remind me what we're doing.
Sue	Well sometimes if I've reminded you more than once this is what we're doing,
Anthony	Yes.
Sue	I'll then say, *'go and have a look on the whiteboard or go and have a look on the calendar and tell me what we're doing'*, because as much as I might repeat things, it doesn't go in. But sometimes if I put it in a different way so that he's got to physically go read it and see and then report back to me—.

(FG1)

Although Anthony said that he voluntarily checked the planner, Sue's comments suggested that she had to actively encourage and reinforce Anthony's use of the whiteboard. Sue indicated that Anthony would sometimes ask her several times before she told him to refer to the planner, echoing comments from the interviews that suggested that it was easier for people with memory problems to rely on their partners than use memory aids. Similarly, during the focus group, Marjorie suggested that Gerald would normally ask her what they would be doing each day rather than checking their whiteboard or calendar.

Reflecting on the utility of the activity-planning device in the third concept, Sue commented:

> "I think sometimes, especially with people living on their own, is they sit down, and they generally can't remember what it is that they're wanting to do, or when to do it and that's when they rely on someone to say *'it's*

> *such and such a day. You’re going to do this. You’re going to do that.’”* (Sue, partner, FG1)

Sue’s suggestion reflects findings from the first stage of the research that indicated that loss of initiative affected some participants with dementia and could lead to inactivity. Sue’s comment also suggests that people with dementia may lack the initiative to engage with planners, digital or otherwise. However, in contrast to her initial scepticism about people with dementia being able to be prompted by technology, Sue indicated that her husband Anthony did respond to prompts she sent to his mobile phone:

> "If there's been a family emergency and I've had to go […] away […] I have to remind you at the moment by texting, *'you need to have a drink now.'* [...] *'Lunch is in the fridge. It's made.'* Because otherwise if I went away and came back then, no, he won't have drunk anything, he won't have eaten anything.” (Sue, partner, FG1)

Furthermore, in contrast to Sue’s doubts about the utility of the third concept for people who lived alone, the participant who did live on her own, Lynn (PWD, FG2) thought the device would be useful. Lynn explained that her own paper calendar was problematic because she would *“forget to put things on”*, that she would *“stick things on and they fall off”* and consequently she found that she would *“muddle through every day”*. As a result, Lynn thought that the device in the third storyboard could be useful for her, so long as it was with her at all times:

> "That would be good. Tie it round me neck. [...] It has to be with me at all times" (Lynn, PWD, FG2)

Presumably, Lynn wanted the device to be close-by so that reminders were not missed and so that she would remember to record appointments, unlike on her paper calendar. However, Lynn was the only participant with dementia who suggested that the device presented in the third storyboard would be useful. This could be because Lynn did not have a partner to rely on. As discussed in section 6.3, people with cognitive impairment who live alone may be more inclined to adopt strategies to maintain independence. Another explanation could be that, because Lynn’s dementia was apparently less advanced than the other participants’, she was more confident about using technologies and strategies to support her memory.

8.4.4. Critiquing technology and valuing human intervention

In both focus groups and in relation to all three concepts, participants raised concerns about technology, suggesting low-tech solutions or preferring human interventions. This section considers participants’ critique of the technologies proposed.

Learning and usability

Several participants emphasised the need for technology to be simple to use for people with dementia as well as for other older users:

> "She needs simplicity. Not just for people with Alzheimer's or dementia. Just general. Certainly, with the older generation." (Pete, partner, FG2)

Learning to use technologies was a major concern, with several participants describing difficulties using new devices. Most commented that they were not good with technology and some expressed aversion to new technologies:

> “I think the more technical things they give you, the more you go - *‘I don’t want to know.’*” (Sue, partner, FG1)

Several participants expressed concerns about people with dementia being able to use the technologies proposed. For example, in response to the navigation device presented in the first storyboard one participant remarked:

> “Frankly, by the time I’m gonna get lost when I’m out, I wouldn’t be able to use the darn thing either. I don’t think I’d be able to handle it […] But, I'm not good at technology in the first place” (Lynn, PWD, FG2)

Esther’s (PWD, FG2) husband John thought that his wife would not be able to learn to use the devices, pointing out that *"Esther can no longer use her mobile phone or anything"* (John, partner, FG2). Although a comment from Esther suggested that she was able to learn to use technology, as she described how she had learnt to use a new function on their home phone. Since the interviews Anthony (PWD, FG1) had also been learning to use the self-service checkout, something he had been frustrated with in the interviews:

Sue (P)	You've even got it. You're almost there now with using the self-service for when you're getting your paper.
Anthony	Yeah.
Sue (FG1)	Because we've stood and done it so many times.

Unfortunately, learning to use the mobile phone he had acquired since the interview was proving more challenging for Anthony, even with his wife’s assistance:

Sue	We haven't managed to get our heads round your mobile phone yet.
Anthony	No, I haven't been able to get my—
Sue (FG1)	But no, even for myself.

These comments suggest that, while it is possible for people with dementia to learn to use technologies, learning can be difficult and may stop people from adopting new technologies.

Preference for low technology solutions

Several participants felt that the design solutions proposed were too focused on digital technology:

Sue (P) Unfortunately you're talking at the present of an age group that are not as technically savvy as the people who are wanting to put this in place.
Anthony$^{(PWD)}$ Yes.
Marjorie (P) Exactly.
(FG1)

Emphasising this preference, both groups suggested low-tech alternatives. For example, participants in the first focus group discussed whether a paper booklet would be preferable to the activity planning device proposed in the third storyboard:

Sue How much emphasis would people want to put on a device as against something coming through their door once a month to tell them what's on in their location?
Marjorie Yeah, I suppose that's true […] I would rather read something than press buttons quite honestly.
(FG1)

Similarly, the second focus group felt that an identity bracelet would be sufficient, rather than the navigation device:

Lynn (PWD) I would have an identity bracelet with my name, address and phone number and next of kin on it.
John (P) Yeah.
Lynn You know, that's [chuckles] – that would be my lot.
Esther (PWD)Yeah [...]

Lynn	Not knocking this at all but, you know, that would be the basic, wouldn't it?
John	With memory problems I think you've got to keep it simple
Esther	Simple, yeah
(FG2)	

Even Lynn (PWD, FG2), who was the most positive of the participants about technology, highlighted the need for designers to understand users' needs:

Lynn	The only snag with these magic devices is that these people designing them have to stay in touch with the likes of us, to find out what we can cope with and what we can't.
Pete (P)	Good point. Good point, that.
Lynn	They're wasting their time otherwise. If they're designing that for people like us, they've got to stay in touch with us.
(FG2)	

Preference for human intervention

As well as favouring low-tech solutions, some participants expressed a preference for human interventions. The second storyboard in particular, which showed an occupational therapist visiting the character to plan an exercise programme, prompted discussions about the value of human intervention:

Marjorie	I think the very first section with the physio coming is wonderful.
Sue	Yes.
Marjorie	Because you very often […] get people who say, *'I'm waiting.'* [for therapy, when] they've had a stroke or something. […] That would be absolutely great from that point of view.

> (FG1)

Like Marjorie, a number of participants lamented the lack of healthcare practitioners. Lynn (PWD, FG2), however, highlighted that technologies could help to fill the gap in resources. When asked whether she would prefer visits from an occupational therapist, rather than the technology proposed she responded:

> "Well, that's not gonna happen. So, it's the next best thing, isn't it?"
> (Lynn, dementia, FG2)

For Sue (partner) though, it was important that technology should not replace human companionship:

> "I think that's what's missing in our society is human intervention. And […] it doesn't matter what gadgets you put in place, you're not gonna replace that human companionship. And the reassurance that comes with it." (Sue, partner, FG1)

8.5. Chapter summary

This chapter has presented the responses of people with dementia and their partners to a series of concepts for products and services to support physical activity, arranged into four overarching themes which both answer and question the research aims.

The first theme brought together issues relating to independent activity and was particularly prevalent in responses to the first storyboard. Participants with dementia did not appear interested in the navigation aid proposed, and did not express concerns about getting lost, indicating that navigation was not a barrier to independent activity outside the home. Instead, confusion about what one was doing appeared to be a greater barrier. In contrast to the responses of participants with dementia, partners were enthusiastic about the concept, however, their focus was on its potential to alleviate fears about losing their partners, rather than helping them to walk out independently. The disparity in attitudes towards independent activity reflects findings from the first stage of the research, although the degree to which partners' anxieties led to loss of independence for participants with dementia remained unclear. Some comments suggested that confusion may be a bigger factor effecting people with dementia's tendency to do things alone than difficulties with navigation.

The second key theme related to the intrusion of monitoring technologies. The tracking feature of the navigation concept was well received by partners but some participants with dementia expressed concerns about the loss of privacy and freedom that would result from being tracked. The monitoring of physical activity levels by health service providers, proposed in the second storyboard, was contentious, with some participants being vehemently opposed and others considering monitoring a normal, acceptable part of modern life. Participants responses highlighted the potential for health monitoring technologies to erode individuals' freedom to choose how or whether they manage their own health. One participant's comment also highlighted the potential for monitoring to become a prerequisite for the receipt of healthcare.

In the third theme, the utility of prompts and reminders were considered as well as the role of partners in initiating and supporting activity. Questions remain as to the value of paper-based calendars and diaries, since memory loss or loss of initiative appeared to prevent some participants with dementia from using such memory aids and instead relying on partners to provide reminders. There were indications that digital technologies could overcome the limitations of passive, paper-based tools and dependence on partners by providing visual or auditory reminders.

Extending evidence from the interviews, occupation was found to be important to people with dementia. The focus groups provided further insights into the different ways and extents to which partners supported occupation, as well as the challenges of enabling a partner with dementia to maintain an active life.

The final theme drew together participants' critique of technological interventions. Participants expressed little interest in the technologies proposed and raised concerns about people with dementia learning to use new technology. They were concerned about the usability of technology and emphasised the value of human interaction. Participants indicated that low-tech or even no-tech solutions would be preferable to the devices presented.

These findings, along with those from the first stage of the research are explored further in the following, discussion chapter.

Chapter 9. Discussion

9.1. Introduction

In this chapter I draw together and discuss key findings from across the study. In light of participants' preference for human-centred and low-tech interventions, here I consider how my findings could inform the development of technologies and services to support people with later life cognitive impairment to live physically active lives.

In section 9.2 I focus on the first research question and discuss how my findings regarding everyday physical activity might inform the development of physical activity interventions. In section 9.2.1, I consider the types of physical activity that would be most appropriate for people with later life cognitive impairment in general, before focusing on the specific needs of people with MCI, in section 9.2.2 and then those of people with dementia in section 9.2.3. In sections 9.2.4 and 9.2.5, I discuss the need to consider the role of partners and partnership in the design of technologies and services to support physical activity among people with dementia.

Section 9.3 examines the second research question, discussing how technologies might enable people with dementia to maintain or increase their physical activity levels and whether digital technologies are appropriate.

In response to the final research question, section 9.4 considers the extent to which the design-research methods used in this enquiry supported the inclusion of people with later life cognitive impairment in human-centred design. Here I also reflect on the extent to which the interdisciplinary nature of the work enriched but also constrained the design process.

In section 9.5 I summarise the contribution of this research and consider the implications for the design of technologies and services to support people with later life cognitive impairment to live physically active lives. Finally, in section 9.6 I discuss the limitations of this enquiry and how they might be addressed in future research.

9.2. Supporting everyday activity

In this section I start by discussing how my findings extend arguments for the development of interventions that promote and support purposeful, everyday activity. Next, I consider the extent to which the barriers to physical activity for people with MCI were revealed through this enquiry and how their needs might be addressed. In the remainder of this section, I focus on the needs of people with dementia, considering the potential benefits of supporting everyday activities inside and outside the home and the need to overcome loss of motivation. Finally, I discuss the role of partners in people with dementia's active lives, and the extent to which their concerns should be taken into account when designing interventions to support physical activity.

9.2.1. Benefits of physical activity and appropriate interventions

In the first part of my literature review (section 2.3), I identified a range of health benefits of physical activity for people with later life cognitive impairment, and, importantly, that physical activity may have a greater effect on cognition than current drug treatments with fewer unwanted side-effects (Ströhle *et al.*, 2015; Groot *et al.*, 2016). Participants in this research attested to the benefits of physical activity, describing how being active could improve cognition and mood.

However, despite substantial research into the benefits of physical activity, my literature review highlighted a lack of understanding of the types of interventions that might be acceptable to people with later life cognitive impairment. Clearly, increasing acceptability is important for improving engagement in physical activity and long-term adherence. In addition, the available evidence failed to demonstrate that physical activity can improve quality of life, which may be explained by a research-focus on modifiable health outcomes, rather than on factors that contribute to a fulfilled life. It has been suggested that failures to increase the physical activity levels of older adults, may be due to promoting the health benefits of exercise, rather than considering how physical activity can address older adults' goals and aspirations (Morgan *et al.*, 2019). Similarly, I argue that, supporting people with later life cognitive impairment to engage in physical activity that fits with their priorities and interests will increase levels of engagement.

The physical activity choices and motivations of participants in this research, described in chapter 4, reflected those found among their peers, and corresponded with older adults' preference for productive activities which contribute to individuals' sense of identity, roles and independence (Olanrewaju *et al.*, 2016; McGowan *et al.*, 2017; Morgan *et al.*, 2019). Building on research with older adults more broadly, the findings of this study suggest that interventions that help people with later life cognitive impairment to engage in physically active, purposeful tasks and encourage them to incorporate physical activity in their everyday routines may be more appealing than formal exercise programmes.

Evidence suggests that low levels of physical activity may be sufficient for cognitive improvements in people with later life cognitive impairment (Groot *et al.*, 2016; Jia *et al.*, 2019). This may be because people with later life cognitive impairment tend to be relatively inactive and therefore likely to benefit from moderate increases in physical activity, whereas higher activity levels may be overly demanding, both physically and cognitively. These findings suggest that interventions should aim for small improvements in people with later life cognitive impairments' physical activity levels. In support of this approach, it has been argued that small increases in activity throughout the day, associated with everyday and lifestyle activities, may be more effective at reducing sedentariness among older adults more broadly and consequently have greater overall health benefits (Sparling *et al.*, 2015; McGowan *et al.*, 2017). Bringing together findings on the most acceptable and effective types of physical activity suggests a need for technologies that support people with later life cognitive impairment to engage in physically-active everyday tasks in order to increase activity levels throughout the day and avert sedentariness.

It should be noted, however, that while the sedentary lifestyles of several participants in this research reflected generalised reports of inactivity among people with later life cognitive impairment, participants' activity levels varied greatly. The most active individuals enjoyed exercise or walking for fitness and recreation, reflecting findings that a minority of active older adults do enjoy physical activity for its own sake (Costello *et al.*, 2011). These finding suggest that technologies to support physical activity need to accommodate a range of activity levels and interests, as recommended for the wider older adult population (Zubala *et al.*, 2017).

Unlike previous studies, which have tended to focus on cognitive barriers to physical activity, this research emphasises that the underlying motivators and barriers to physical activity experienced by people with later life cognitive impairment are often shared with their peers, and that these underlying factors may have a greater influence on people's physical activity choices and levels than cognitive impairment. The findings of this research highlight a need for interventions to provide people with later life cognitive impairment with tools to identify and overcome a range of barriers to physical activity, not just those associated with cognitive changes, as recommended for older adults in general (Zubala *et al.*, 2017).

Given the diversity of activity levels found among participants in this research, as well as the range of personal barriers and motivators, a one-size-fits-all intervention appears unlikely to be appropriate for everyone with later life cognitive impairment. Instead, targeting a specific group or groups who would benefit most from interventions to support physical activity is likely to be more effective. I recommend that the priority should be to reduce sedentariness among people with later life cognitive impairment who are moderately inactive. For this group, technologies and services that encourage and enable people to embed physical activity into everyday and purposeful activities are likely to be most engaging, as recommended for inactive older adults in general (Costello *et al.*, 2011; McGowan *et al.*, 2017). For those who are highly inactive, the challenges associated with physical activity may be greater and more complex, as illustrated in section 4.4. In such cases tailored, individual support is likely to be necessary.

Technologies and services to support physical activity should also consider physical activity as a shared pursuit. The role of partners and partnership in an active life was a recurrent theme of this research (see section 6.5 in particular), reflecting McGowan *et al.'s* (2017) conclusion that older adults tend to be disinclined to undertake physical activity without a companion. Interventions aimed at people with later life cognitive impairment might include features targeted at couples, for example, encouraging people to plan shared walks or set shared activity goals. For those without partners (or with partners who are unable or unwilling to engage in physical activity) technologies or services might encourage people to undertake physical activity with friends and family or, alternatively, connect with community groups, as Devereux-Fitzgerald *et al.* (2016) recommend for older adults in general.

Together these findings indicate an opportunity for technologies and services to support people with later life cognitive impairment to engage in everyday activities with a physical component, such as gardening or housework, or to incorporate physical activity in their daily routines, for example by taking a daily walk to the shops. Incorporating a social or shared element may also increase the likelihood of engagement in physical activity. In the following sections I will consider the extent to which cognitive impairment may be a barrier to such activities and how this might be addressed, first for people with MCI and then for those with dementia.

9.2.2. Engaging people with MCI in physical activity

Since, in the first stage of this research, cognitive changes did not appear to be a barrier to physical activity for most participants with MCI, I concluded that technologies aimed at the wider older adult population would be suitable for people with MCI. However, emerging research suggests that MCI may have subtle impacts on people's activity levels that were not apparent in this study. Recent research has found that everyday activities, such as shopping and driving are consistently impaired in MCI, although typically to a lesser degree than in dementia (Jekel *et al*., 2015; Lindbergh, Dishman and Miller, 2016). Other studies have found that people with MCI tend to withdraw from social and leisure activities (Parikh *et al*., 2016) and that concerns about getting lost or performing tasks outside the home can restrict their activities (Frank *et al*., 2006; Lindqvist *et al*., 2016). These studies suggest that MCI can, in fact, limit people's active lives, and that interventions aimed at the wider older adult population may not be suitable for people with MCI, or that they would need to be adapted to suit their needs.

Barriers identified in previous research may not have been apparent in this study as participants were asked to reflect on their current activities rather than on any difficulties they experienced as a result of cognitive changes. Participants in previous, focus group research may also have been more forthcoming as they were able to share and compare their experiences with others. Another explanation may be that cognitive impairment was less severe for participants in this study. There was also evidence that participants with MCI adopted strategies to overcome cognitive changes (as described in section 6.3), consequently they may not have considered cognitive changes to be a barrier to activity.

Strategies used by participants with MCI in this research may provide clues for the adaptation of technologies to support physical activity. For instance, technologies might help people to set new routines and provide reminders to engage in physical activities. Since previous research also suggests that confidence can be undermined by cognitive changes (Frank *et al*., 2006), technologies might incorporate features that improve people's confidence to engage in physical activity, for example by providing positive feedback or by connecting people with others in a similar situation.

Despite the potential challenges faced by people with MCI, they should not be overlooked as targets for technologies or services to support physical activity. Previous research has identified that people with cognitive impairment are keen to continue mastering new activities (Lindqvist *et al.*, 2016) and, in contrast to reports of withdrawal (Parikh *et al.*, 2016), Morgan, Garand and Lingler (2012) found that a diagnosis of MCI can trigger engagement in activities that support health and wellbeing. As there are currently no effective drug treatments, people with MCI may be particularly keen to engage in physical activity to improve their cognitive function.

Given the limited research into physical activity interventions for people with MCI, further research is warranted to understand the barriers to physical activity for this group, particularly those associated with the everyday activities that contribute to an active life. In addition, further design-research with people with MCI is recommended to identify whether technologies might be developed to help them to overcome these barriers.

9.2.3. Supporting people with dementia to live active lives

For individuals with dementia, the findings of this research suggest that difficulties performing everyday activities may not only contribute to inactivity, but also have a detrimental effect on quality of life. As with older adults more broadly, the findings of this research suggest that people with dementia are concerned with maintaining their independence as well as their contribution to their households and communities (see chapter 5). Together these findings lead me to conclude that, rather than promoting exercise per se, interventions aimed at people with dementia should focus on supporting valued everyday activities, to reduce sedentariness and provide people with dementia with occupation and a sense of contribution.

In this section I discuss three ways in which products or services might support people with dementia to live more active lives: by facilitating household activities, supporting activities outside the home and overcoming loss of motivation.

Supporting household activity

The findings of this research suggest that helping people with dementia and their carers to develop strategies that enable them to maintain engagement in household activities may help to reduce sedentariness (see chapter 6 and section 8.4.3). There were also indications that enabling people with dementia to perform activities independently would be valued by both people with dementia and their partners (see sections 6.7 and 8.4.1).

There have been efforts to develop technologies to support independent household activities, by prompting and guiding people through simple tasks such as making a cup of tea or handwashing (Dishman, 2004; Mihailidis *et al.*, 2008; Witte Bewernitz *et al.*, 2009; Evans *et al.*, 2015; Boyd *et al.*, 2017; Lancioni *et al.*, 2017; Braley *et al.*, 2018). However, research in this area is nascent and several challenges remain, including guiding people through more complex tasks, accommodating the differing capabilities of people with dementia and adapting to individuals' home environments (Mihailidis *et al.*, 2008; Seelye *et al.*, 2012; Evans *et al.*, 2015; Lancioni *et al.*, 2017).

Rather than a technological approach, self-management or occupational therapy services may be more appropriate for increasing people with dementia's engagement in household activities. Self-management programmes have been found to help people with dementia to develop strategies to cope with memory loss by bringing them together to discuss and share strategies (Graff *et al.*, 2006; Laakkonen *et al.*, 2013; Martin *et al.*, 2015; Sprange *et al.*, 2015; Quinn *et al.*, 2016). Occupational therapists can also enable people with dementia to implement strategies to maintain everyday activities as well as educating carers so that they can better support people with dementia (Laver *et al.*, 2017).

Digital technologies might be developed to complement such services, for instance providing online information about strategies to maintain everyday activities and tools to help people to put strategies into practice, for instance online planners. Smart phones might be particularly useful for scheduling and prompting activities, as will be discussed in the following section. Connecting people with others living with or caring for someone with dementia, for instance through online forums, might also help people to support each other in identifying and maintaining strategies. Although online services might be more appealing and offer additional benefits for some, low-tech solutions such as paper-based information booklets may be more appropriate for others, and so a mixed media approach may be most suitable. The appropriateness of technological approaches will be discussed further in section 9.3.

Overcoming loss of motivation

As well as difficulties performing everyday activities, loss of motivation appeared to contribute to inactivity among participants in this study (see section 5.6), a factor that has received limited attention in previous research (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015; McDuff and Phinney, 2015). Findings from this enquiry extend previous research by illustrating that a number of different factors can contribute to diminished motivation and inactivity in dementia and may need to be addressed individually.

Loss of initiative is common in mild dementia (Cook, Fay and Rockwood, 2008), and appeared to contribute to inactivity for some participants with dementia in this study. Participants' attempts to use passive, written prompts (such as diaries and calendars), appeared to be of limited value in overcoming loss of initiative (see sections 6.3 and 8.4.3), reflecting the findings of previous studies (Holthe, Hagen and Bjørneby, 1996; Cahill *et al.*, 2007). Digital technologies may offer more effective solutions, for example by using eye-catching moving graphics to attract attention and remind people to undertake tasks. Although some such products are already available, including tablet-computer based prompting applications, a review by King and Dwan in 2017 identified a need for further research and development to ensure that these devices are effective and accommodate the diverse needs and capabilities of people with dementia.

Separate from loss of initiative, loss of competency, was found to contribute to diminished motivation among participants with dementia who described feelings of disappointment, frustration, worthlessness and low mood, extending findings from previous studies (Phinney, Dahlke and Purves, 2013; Malthouse and Fox, 2014). Feelings of worthlessness and depression are common in the early stages of dementia and are associated with withdrawal and loss of motivation (Mortby, Maercker and Forstmeier, 2012; Cipriani *et al.*, 2015). Together these findings suggest a need to address the emotional impact of diminishing capabilities, in order to restore people's motivation. As mentioned in the previous section, self-management interventions might help people with dementia to address the emotional impact of loss of capabilities by discussing their experiences with others in a similar situation.

There were also indications that apathy, disinterest or indifference towards activities that participants had previously enjoyed, could lead to inactivity. Previous qualitative studies have alluded to the effects of apathy on people with dementia's activity levels, but not labelled it as such. For example, Phinney, Dahlke and Purves (2013) reported that the two men in their study "*no longer felt like participating in activities in the ways they once did*" (p356) and McDuff and Phinney (2015) described participants being *"less interested"* (p4) in activities. Apathy is a common but under recognised symptom of dementia (Mortby, 2013; Goris, Ansel and Schutte, 2016) which is associated with deconditioning, impairment in activities of daily living and more rapid functional decline (Forstmeier and Maercker, 2015; Goris, Ansel and

Schutte, 2016). In quantitative studies, increased levels of apathy have been linked with reduced physical activity (Kuhlmei *et al.*, 2013; Stubbs *et al.*, 2014).

Approved treatments for apathy are lacking (Theleritis *et al.*, 2018), however, non-pharmacological treatments such as cognitive stimulation, music therapy and multi-sensory stimulation have been found to reduce apathy in people with dementia who live in care (Goris, Ansel and Schutte, 2016). The findings of this research indicate a need for interventions to reduce apathy in people with dementia living in the community, to reduce sedentariness. Building on the approaches used in care and nursing homes, digital technologies might be developed to provide visual, audio and cognitive stimulation to alleviate apathy. Enabling people to maintain involvement in daily activities, may in itself help to reduce apathy.

The varied experiences of participants in this, and previous research, suggest that the factors leading to loss of motivation differ between individuals and that, as such, interventions to support physical activity need to help people with dementia and those that support them to identify and address the specific motivational barriers that they face.

Supporting activities outside the home

Travelling to perform everyday activities, particularly on foot or by public transport, has been identified as making an important contribution to older adults' physical activity levels (Davis *et al.*, 2011). For participants with dementia in this study, the extent of physical activity outside the home varied greatly (as described in section 5.2). Even for those who were more active, however, difficulties associated with travel and transport were common and could lead to a sense loss of freedom and independence as activities were restricted and partners were increasingly involved in their journeys, as found in of previous studies (Duggan *et al.*, 2008; Brittain *et al.*, 2010; Caddell and Clare, 2011). Enabling people with dementia to get out and about independently may facilitate physical activity and improve quality of life.

For several participants who walked out regularly, trips tended to be accompanied by a spouse, so that independence was limited, reflecting reports in Cedervall, Torres and Åberg's (2015) study. Whereas in previous studies, the fears of people with dementia about getting lost have been identified as restricting independent walking (Brittain *et al.*, 2010; Cedervall, Torres and Åberg, 2015; van Alphen, Hortobágyi and van Heuvelen, 2016), in this study none of the participants with dementia expressed concerns about finding their way. Rather it appeared that spouses' concerns led them to accompany their partners (see sections 6.5 and 8.4.1), a potential barrier to independent activity which has been noted in previous studies (Brittain *et al.*, 2010; Cedervall and Åberg, 2010). The role of partners' concerns in limiting independent walking is considered further in section 9.2.5.

Rather than concerns about getting lost, findings from the focus groups and interviews suggested that difficulties undertaking tasks and engaging with technologies outside the home may be greater barriers to independent activity for people with dementia (see section 8.4.1 and 5.3). Previous studies have found that such difficulties can leave people with dementia feeling anxious and vulnerable, undermining their confidence to go out alone (Duggan *et al.*, 2008; Brittain *et al.*, 2010; Brorsson *et al.*, 2011). This may help to explain why participants with dementia in this research tended to go out with their spouses, even if they considered themselves capable of finding their way on their own.

The findings of this research suggest that technologies and services that support independent activity outside the home would be valued by people with dementia. However, technology development to-date has largely focused on the design of navigation aids (Evans *et al.*, 2015). The findings of this research indicate that navigation is not the primary barrier to independent activity outside the home for people with dementia. Instead, these findings suggest a need to find ways to enable people with dementia to undertake activities outside the home.

Improving the accessibility of public transport, spaces, services and technologies may play an important role in enabling people with dementia to maintain independent active lives. There may be opportunities to develop technologies and services to support this. These do not have to be sophisticated, for instance, as one participant in this study identified, a bus pass can provide increased independence if it allows people with dementia to use a bus without handling money. Future collaborations between service providers, designers, technologists and, importantly, people with dementia, could provide joined-up solutions to the challenges faced by individuals with dementia when getting out and about.

9.2.4. Partnership and independence in dementia

This thesis extends our understanding of the role of partnership in the active lives of people with dementia. Participants' reports of increasingly shared lives (section 6.5) reflect Hellström (2005) and Hellström, Nolan and Lundh's (2007) descriptions of the gradual coming-together of couples' lives. Interview and focus group findings, also indicated the importance of partners' prompts, encouragement and support (see sections 6.6 and 8.4.3), extending findings from previous studies (Hellström, 2005; Hellström, Nolan and Lundh, 2007; Phinney, Chaudhury and O'connor, 2007; Vikstrom *et al.*, 2008; Phinney, Dahlke and Purves, 2013; McDuff and Phinney, 2015).

As described in section 6.6, some spouses indicated that they put a great deal of effort into sustaining their spouse with dementia's identity, agency and sense of contribution, extending Hellström, Nolan and Lundh's (2007) findings. Similar to the findings of Hellström, Nolan and Lundh, (2007) and Vikstrom *et al.*, (2008), the most actively supportive partners in this study tended to talk about the things '*we*' do, rather than emphasising their own efforts to support their partners with dementia. Together, these findings indicate that some couples consider managing dementia to be a shared endeavour, strengthening Hellström, Nolan and Lundh's argument that couplehood[12] may be equally, if not more, important than personhood in dementia. In line with Hellström, Nolan and Lundh's call for relationship-centred care, the present research suggests that interventions to support physical activity should take account of the needs of couples living with dementia who want to work together to overcome barriers to activity and to sustain shared, active lives.

It should be noted, however, that not all relationships in this study appeared to be as collaborative as Hellström, Nolan and Lundh's work suggests and that, as such, a couple-focused model may not be appropriate for all. Unlike previous research, which has presented a largely positive picture of partners in respect to supporting activity, this research indicates that some partners take-over activities leaving people with dementia feeling redundant or prohibited from engaging in everyday activities (see sections 6.6 and 8.4.3). Even partners who expressed determination to be supportive, indicated that avoiding taking-over was not easy, a finding which illustrates Steeman *et al.'s* (2007) assertion that it is a *"major challenge"* (p128) for caregivers to support an individual with dementia to feel valued. There were some indications that the differing approaches of partners may, in part at least, be a result of their different caregiving skills and experience; knowledge about dementia and attitudes towards supporting physical activity and occupation (see sections 6.6 and 8.4.4), suggesting a need for caregiver education and support.

The apparent positive relationship between the efforts of partners and the activity levels of participants with dementia in this study, indicates that partners may play a significant role in supporting and sustaining active lifestyles. Although the findings of this study partially support Stubbs *et al.'s* (2014) hypothesis that caregivers enable people with dementia to maintain physically active lives, in some instances in this

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[12] Couplehood has been described as the sense of belonging that a partner has within their relationship or the extent to which they feel married (Molyneaux *et al.*, 2012)

research, partners appeared to prevent people with dementia from undertaking everyday activities and thereby foster sedentariness.

Although partners have been identified as potential facilitators of activity, there were also indications that increased dependence could have negative consequences for both partners (see sections 6.7 and 8.4.1), extending Malthouse and Fox's (2014) findings. Consequently, although shared activity may be valued and spousal support beneficial, facilitating independent activity, where possible, may also be important. As discussed earlier in this chapter, technologies may enable people with dementia to perform activities independently and reduce the need for partners to provide prompts and guidance. These might be coupled with self-management programmes and occupational therapy to help people with dementia and their caregivers to identify ways to maintain some independence (Graff *et al.*, 2006; Quinn *et al.*, 2016).

There were also indications that partners' anxieties about participants with dementia performing activities safely could be a source of restricted independence, particularly in relation to them walking out alone. Partners' fears appeared to outweigh those of their spouses with dementia, reflecting reports in earlier studies (Duggan *et al.*, 2008; Cedervall and Åberg, 2010; Phinney, Dahlke and Purves, 2013). Some have concluded that caregivers fears can restrict the activity choices of people with dementia (Brittain *et al.*, 2010; Holbø, Bøthun and Dahl, 2013; Lindqvist *et al.*, 2016). Together these findings suggest that the anxieties of spouses and other caregivers may need to be assuaged to enable people with dementia to engage in independent physical activity. This issue was highlighted in participants' responses to one of the technologies proposed to the focus groups, as I will discuss in the following section.

Together the findings of this research have highlighted the importance of considering the relationship between people with dementia and their partners when designing interventions to support active lives, including recognising the importance of couplehood and supporting caregivers in their roles as facilitators while enabling people to maintain a degree of independence.

9.2.5. Attitudes to independent walking

Previous studies have reported that fears about getting lost can stop people with dementia from walking out alone (Cedervall and Åberg, 2010; Malthouse and Fox, 2014; Cedervall, Torres and Åberg, 2015), however, participants with dementia in this study appeared unconcerned about this and expressed little interest when presented with a concept intended to support wayfinding and independent walking (see sections 5.2 and 8.4.1). In contrast their partners were enthusiastic about the concept and were prompted to describe their own fears about losing the individuals with dementia, although no-one mentioned any incidence of individuals with dementia actually getting lost (section 8.4.1). The disparity between the attitudes of people with dementia and their partners reflects those found in studies investigating the design of navigation and safe walking technologies (Lindsay *et al.*, 2012; Holbø, Bøthun and Dahl, 2013; McCabe and Innes, 2013) and indicates that the preponderance of research into navigation technologies may be driven by caregivers fears, rather than the priorities of individuals with dementia.

The enthusiasm of the caregiving partners about tracking people with dementia, described in section 8.4.2, reflects reports by Robinson *et al.* (2007). However, in contrast to caregivers in Robinson *et al.*'s study, who recognised a need to balance their own safety concerns with the autonomy of individuals with dementia, partners in this study expressed little interest in enabling their spouses with dementia to find their own way or compunction about tracking them, despite participants with dementia expressing concerns about the potential for tracking devices to limit freedom. These findings suggest that tracking technologies may erode the privacy and freedom of individuals with dementia and, furthermore, that tracking technologies may foster power imbalances between those living with dementia and their caregivers.

Brittain *et al*., (2010) warn that the proliferation of tracking technologies may reproduce and reinforce beliefs that people with dementia are unsafe when walking out alone and unable to make rationale choices about risks. However, the different roles and perspectives of caregivers and people with dementia in relation to risk should also be considered. While those with dementia may feel that the benefits of independent activity outweigh any potential dangers, as participants in Cedervall, Torres and Åberg's (2015) study suggested, caregiving partners find themselves in a position of responsibility and consequently face the dilemma of balancing their partners' safety and autonomy (Vikstrom *et al*., 2008). Such reactions point to a need to address partners' fears, even if they are different from those of individuals with dementia. Since Holbø, Bøthun and Dahl (2013) found that people with dementia were willing to accept tracking to alleviate caregivers' fears, tracking technologies that accommodate their concerns may be acceptable to people with dementia if they also enable independent activity.

Together these findings highlight opportunities and drawbacks that need to be considered in the development of technologies intended to support independent walking. As suggested by some participants in this study, there may be ways to balance privacy and safety (see section 8.4.2), for instance by allowing people with dementia and their partners to specify areas where they would normally walk and only informing partners if a person with dementia walks outside the boundary (Teipel *et al*., 2016). In addition, as proposed by participants in Holbø, Bøthun and Dahl's (2013) study, technologies should allow individuals with dementia to help themselves first, for example enabling them to find their own way home if lost, rather than automatically informing a caregiver.

My findings in this area raise complex, ethical dilemmas surrounding navigation and tracking technologies. They highlight a potential conflict between the fears of caregivers and the autonomy and privacy of people with dementia. A key concern raised in this discussion is whether tracking technologies may validate and even contribute to the potentially exaggerated fears of caregivers. On the other hand, alleviating these fears may help to increase the independence of people with dementia, providing them with more opportunities for physical activity outside the home.

9.3. Appropriateness of digital technologies

In this section I discuss my findings in relation to the second research question, which asked how digital technologies might enable people with later life cognitive impairment to maintain or increase their physical activity levels. Based in a commercial partnership with Philips, this research was driven by an interest in digital technologies to support physical activity. However, having identified several opportunities for technologies to support physical activity, the reactions of participants with dementia and their partners to the technologies proposed highlighted several factors that must be carefully considered before contemplating technology development.

Despite attempting to make the interactional elements of the concepts presented to focus groups vague or hidden, usability and the capability of people with dementia to learn to use new technologies were prominent concerns, as described in section 8.4.4. These apprehensions may have stemmed from previous negative experiences of using digital technologies, as few commercially available technologies have been specifically designed to meet the needs of people with dementia (Meiland *et al.*, 2017). It should also be noted that concerns were predominantly voiced by partners and should therefore be considered in light of evidence that caregivers tend to underestimate the capabilities of people with dementia (Zanetti *et al.*, 1999; Martyr and Clare, 2018). Since I was not able to present participants with prototypes which they could interact with, it is difficult to assess whether, with careful design, the technologies proposed could be accessible for people with mild dementia.

Reflecting evidence in the literature, some participants with dementia and their partners described occasions when they had learned to use new technologies, although there were indications that the learning process could be challenging, leading to frustration, and that caregivers' support was often required (Lekeu *et al.*, 2002; Nygård, 2008; Malinowsky *et al.*, 2010; Lee *et al.*, 2013; Rosenberg and Nygård, 2014; Thorpe *et al.*, 2016; Meiland *et al.*, 2017). Despite these challenges, previous research has found that people with dementia are often enthusiastic about adopting technologies that support independence (Holbø, Bøthun and Dahl, 2013; Gibson *et al.*, 2015; Meiland *et al.*, 2017). Consequently, the potential for technology to address the needs of people with dementia should not be overlooked, although usability issues must be carefully considered.

In addition, in focus groups, participants expressed reluctance towards adopting new technologies (8.4.4), which was somewhat surprising since during interviews, several participants excitedly discussed recently acquired digital technologies, such as smart phones. Participants may have been averse to the devices proposed because they were aimed at people with dementia rather than being fashionable consumer products (Meiland *et al.*, 2017). Yusif, Soar and Hafeez-Baig (2016) found that the stigma associated with assistive technologies can make them unattractive to older adults. Together these findings indicate that the design and marketing of technologies intended for people with dementia must be carefully considered as this may impact desirability and adoption. Technologies to support physical activity might be more successful if they are designed and marketed as general health promoting technologies, rather than assistive devices specifically for people with dementia. Alternatively, assistive applications might be incorporated into devices that have an existing appeal, for instance applications could be discretely downloaded onto smartphones or tablets.

Activity monitoring was another, potentially unappealing aspect of some of the technologies proposed, although reactions varied (see section 8.4.2). While there were some strongly adverse reactions to activity monitoring by healthcare providers, echoing findings from telecare research (Percival and Hanson, 2006; Vines *et al.*, 2013), others considered monitoring a benign part of modern life. A similar dichotomy in older adults attitudes to monitoring-technologies has been reported in previous studies (Robinson, Hutchings, Dickinson, *et al.*, 2007; Thomas *et al.*, 2013). Although older adults attitudes may vary, the potential for privacy concerns, indicates a need for technologies that engender trust if they are to be widely accepted (Thomas *et al.*, 2013).

Perhaps unsurprisingly, given increasing expectations on patients to take responsibility for maintaining their health (Hansson, 2018), participants also raised concerns about the potential for activity-monitoring technologies to limit individuals' autonomy to choose whether or not to adopt healthy behaviours (8.4.2). Participants' reservations about intrusions on their privacy and liberty reflect prominent ethical concerns (Mittelstadt *et al.*, 2014) and should be considered in the design of technologies that monitor health behaviours.

These negative reactions to the concepts proposed and the expressed preference for low-tech solutions (see section 8.4.4) indicates a need to consider whether digital solutions are desirable or useful for people with dementia. As Brittain *et al.* (2010) suggest, technologies may represent an imposition that, rather than facilitating activity, could become a barrier, disrupting established and familiar routines that are important to people with dementia. Participants' responses to the technologies proposed raise questions about the emphasis in this and wider research on developing digital technologies for people with dementia. These findings highlight a need for designers to consider whether low-tech or no-tech solutions might be more effective, acceptable and accessible (Baumer and Silberman, 2011).

Focus group participants also expressed a preference for human interventions (see section 8.4.4), echoing wider ethical concerns about the replacement of important, relational aspects of human care by remote monitoring technologies (Oppenauer *et al.*, 2007; Holbø, Bøthun and Dahl, 2013). Increasing healthcare demands mean that digital assistive technologies are often seen as a tool to reduce costs and free-up limited human resources (Dahl *et al.*, 2013), however, the reactions of participants in this study suggest that technologies should enhance human-centred services, rather than aiming simply to provide cheap alternatives to human interaction (McCreadie and Tinker, 2005; Oppenauer *et al.*, 2007).

In summary, although this investigation was focused on the opportunities for digital technology to support physical activity, the reactions of participants with dementia and their partners in the focus groups suggest that digital technologies should be proposed with caution. Digital technologies should only be offered where they provide benefits over alternative low-tech or no-tech solutions and they should be an adjunct to human care, not a replacement. If digital technologies are appropriate, they must be accessible to people with dementia, easy to learn and use. They should also be attractive to people with dementia and not stigmatising. In the case where monitoring technologies may be beneficial for people with dementia, they must also consider the privacy and autonomy of users.

9.4. Methods and process

In the methods section I explained my decision to employ a human-centred design approach to include people with later life cognitive impairment in the design process as informants and evaluators, rather than expecting them to participate directly in design activities. I chose to use diary-probes to include people with later life cognitive impairment in the initial research stage and then used personas to convey their experiences to design teams. In this section I evaluate the utility of these methods and consider the degree to which the interdisciplinary nature of this research effected the design process.

9.4.1. Diary-probe

By providing participants with the opportunity to record their everyday experiences, the diary-probe successfully produced novel insights into the context of physical activity in participants' everyday lives and routines. Participants' records of their daily routines highlighted periods of inactivity and led to discussions about the impact of loss of motivation and occupation in dementia, which have received little attention in previous interview research. The probe exercises in the diary were particularly valuable in providing new insights into the factors effecting physical activity. For example, the 'body and mind' exercise allowed participants to illustrate the comparative impact of cognitive and other health problems, which has received limited consideration in other studies. Building on evidence of the potential benefits of diary-interview and probe methods (discussed in section 3.6), these findings suggest that an integrated diary-probe can help people to convey everyday and muted aspects of their lives, which may be overlooked in interview studies.

Several participants made positive comments about the diary's design, particularly the customised elements, and some expressed delight at its presentation, along with the stationary, in the gift bag:

> "It was wonderfully designed." (Lynn, PWD)
>
> "Oh, I love it ((excitedly)) I've even got my address here" (Janet, PWMCI)
>
> "I get to take the bag home?... Oh God, they're going to be dead envious." (Malcolm, PWMCI)

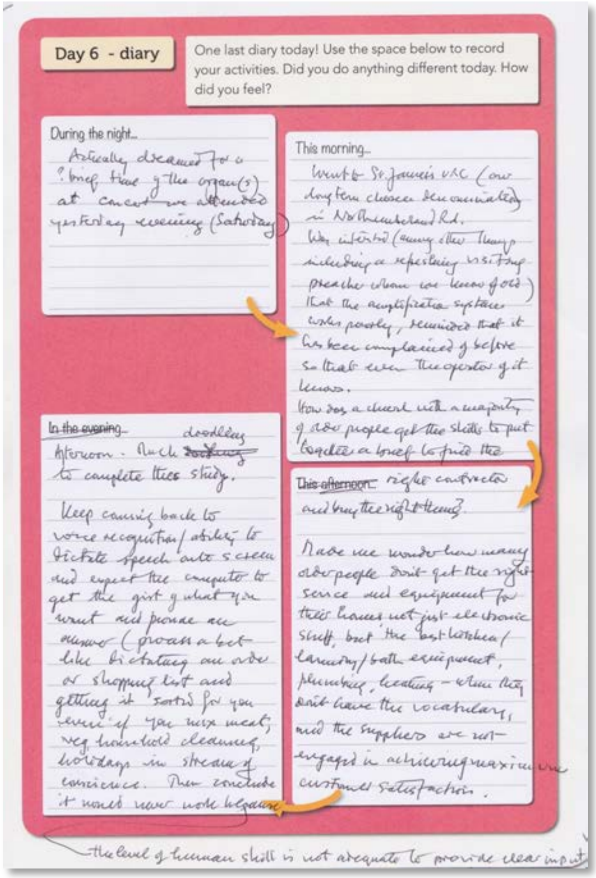
One participant remarked that she felt obliged to reciprocate the effort that had been put into the diary:

> "There's quite a lot of thought that Lizzie's put into this and we need to really think about things." (Linda, partner)

Such reactions support the notion that attractive, customised probes are appreciated and can encourage investment in probe completion (Mattelmäki, 2006; Wallace, McCarthy, *et al.*, 2013). However, although all participants responded to the diary, the extent of participants' responses varied, as found in previous diary studies (Alaszewski, 2006; Mackrill, 2008; Bartlett, 2012). In this study most participants wrote something in response to all of the exercises with only two of the participants failing to complete exercises in the later part of the diary-probe. Some participants wrote extensively, extending beyond the deliberately bounded spaces for responses, as in the example shown in Figure 9.1, while others provided limited responses, as shown in Figure 9.2. Several participants went on to use the notes pages at the back of the diary to add further reflections and comments. All participants included photos, some added just a couple while others inserted images throughout the diary. The variety of participants' responses reflects reports of previous diary studies. Even when participants' responses were limited, the structure of the diary-probe provided a useful basis for interview discussions.

Elements of the diary-probe intended to stimulate reflection were particularly valuable. For example, on one day of diary keeping participants were prompted to consider "Did anything please you", to which Pat (PWMCI) replied:

> "Seeing the people at the Alzheimer's club enjoying themselves." (Pat, PWMCI)



Day 6 - diary

One last diary today! Use the space below to record your activities. Did you do anything different today. How did you feel?

During the night...
Actually dreamed for a ?brief time of the organ(s) at concert we attended yesterday evening (Saturday)

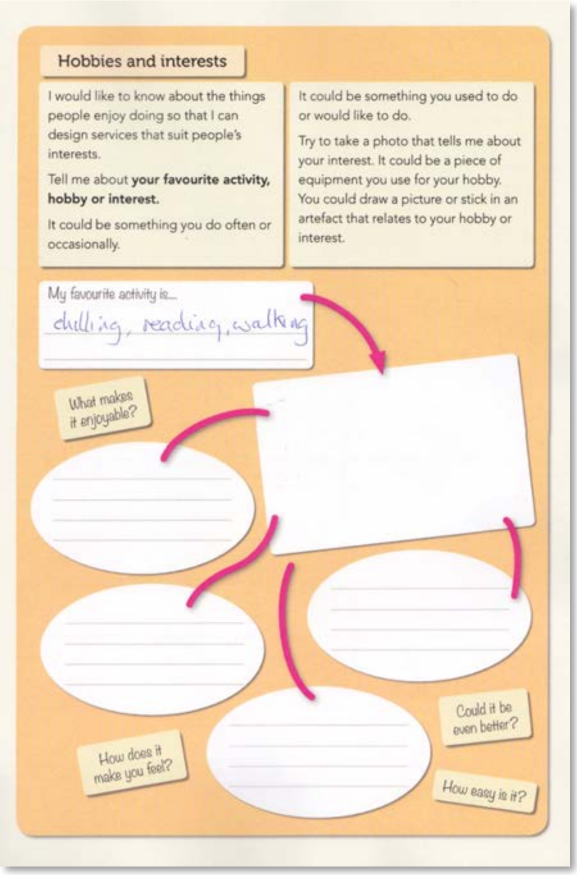
This morning...
Went to St James's URC (our long term chosen denomination) in Northumberland Rd. Was irritated (among other things including a refreshing visiting preacher whom we know of old) that the amplification system works poorly, reminded that it has been complained of before so that even the operator of it knows.
How does a church with a majority of older people get the skills to put together a brief to find the right contractor and buy the right thing?

~~In the evening...~~
Afternoon - Much ~~[illegible]~~ doodling to complete this study.

Keep coming back to voice recognition/ability to dictate speech onto screen and expect the computer to get the gist of what you want and produce an answer (process a bit like dictating an order or shopping list and getting it sorted for you even if you mix meat, veg, household cleaning, holidays in stream of conscience. Then conclude it would never work because the level of human skill is not adequate to provide clear input

~~This afternoon...~~
Made me wonder how many older people don't get the right service and equipment for their homes not just electronic stuff, but the best kitchen/laundry/bath equipment, plumbing, heating - when they don't have the vocabulary, and the suppliers are not engaged in achieving maximum customer satisfaction.

Figure 9.1: Example of an extensive response to the diary-probe.



Hobbies and interests

I would like to know about the things people enjoy doing so that I can design services that suit people's interests.

Tell me about **your favourite activity, hobby or interest.**

It could be something you do often or occasionally.

It could be something you used to do or would like to do.

Try to take a photo that tells me about your interest. It could be a piece of equipment you use for your hobby. You could draw a picture or stick in an artefact that relates to your hobby or interest.

My favourite activity is...
chilling, reading, walking

Figure 9.2: Example of a scantly completed diary-probe exercise.

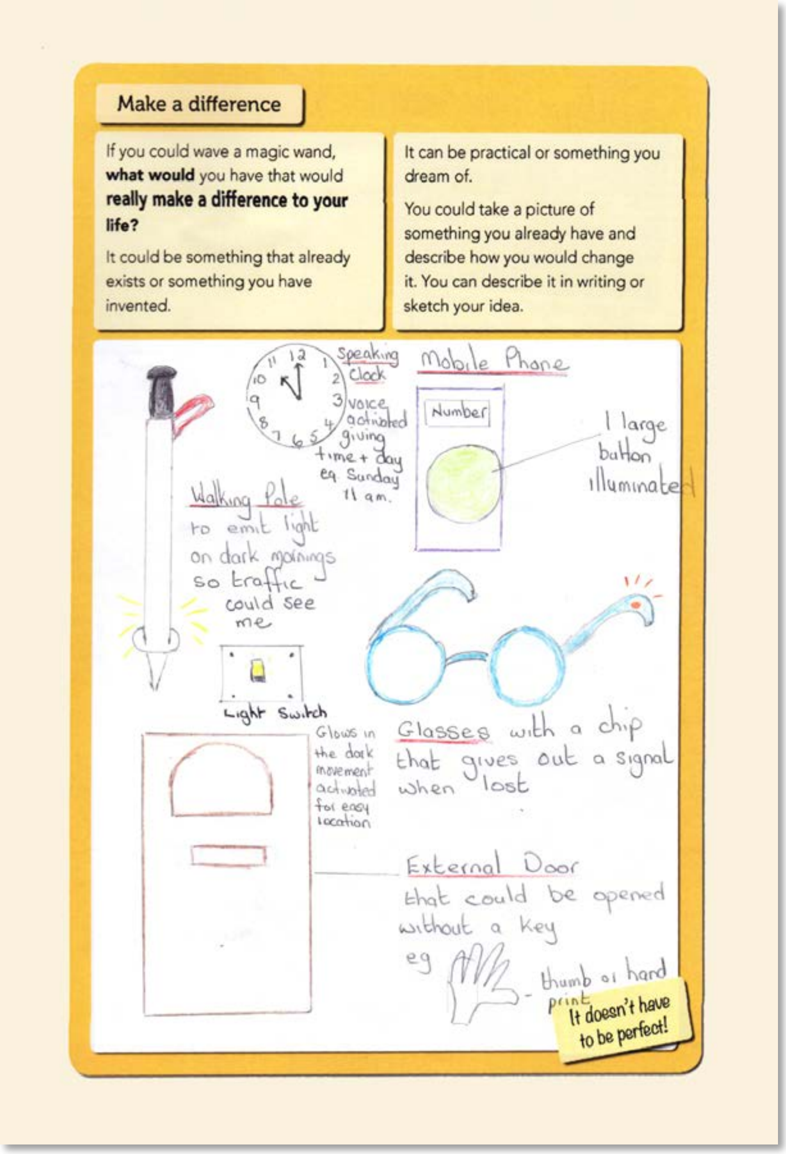
Elsewhere, participants provided unsolicited reflections, for example, on the notes page at the end of the diary, Brenda wrote:

> "Having recorded the things I do in a week. I have just realised what a boring and uninteresting life I now lead." (Brenda, PWMCI)

Other participants talked about how the diary-probe had prompted reflection. Marjorie (partner) suggested that the diary-probe *"provided food for thought"* and Linda (partner) described how the diary-probe had prompted *"a lot of reflective thinking"*. These comments suggest that, as well as providing a method of recording activities, the diary-probe method can enable people to reflect on their experiences, potentially improving their ability to communicate their needs to inform the design process. This study does, however, also highlight that reflection on one's life through diary keeping can lead to undesirable revelations, as previously noted by Meth (2003) and Bartlett (2012).

The final diary exercise was intended to support an element of participatory design, by asking participants to think of something that would help them. I had hoped that, having reflected on their active lives during diary keeping, participants might have their own ideas about products or services that could help them to be more active, although I was not prescriptive as I wanted to be open to any suggestions that participants had. Participants were asked to either sketch their idea, write about it or take a picture of something they already had and describe how they would change it. In four of the diaries, participants suggested products or technologies, although only one suggested products to support physical activity, as shown in Figure 9.3 (the others related to housework, storage or electric cars). Three participants chose to draw their ideas, including two partners who drew on behalf of participants with dementia, as in the example in Figure 9.3. The remainder of the participants either wrote about personal desires (such as winning the lottery, having better health or being closer to family) or did not complete the activity. Overall, this particular activity was not successful in enabling participants to contribute their own ideas, indicating that people with later life cognitive impairment in particular need more support from researchers and designers to engage in the design process and generate their own design ideas, as in the co-design process described by Sanders and Stappers (2008).

Although all participants responded to the diary to some extent, the written format was not accessible to all participants with dementia. Three of the eight participants with dementia had difficulty writing and so their partners wrote in the diaries on their behalf. Although the participants in these couples described working together to complete the diary-probe, having a partner record their thoughts may have limited their freedom of expression. These findings suggest that, if diaries or probes are used with people with dementia in future research, then alternative recording options should be made available, for instance audio or video recording. Despite this limitation, the diary-probe proved useful in guiding the subsequent interviews with participants with dementia, prompting discussion about everyday experiences of physical activity and revealing novel insights into participants' active lives.



Make a difference

If you could wave a magic wand, **what would** you have that would **really make a difference to your life?**

It could be something that already exists or something you have invented.

It can be practical or something you dream of.

You could take a picture of something you already have and describe how you would change it. You can describe it in writing or sketch your idea.

Speaking Clock voice activated giving time + day eg Sunday 11 am.

Mobile Phone

1 large button illuminated

Walking Pole to emit light on dark mornings so traffic could see me

Light Switch Glows in the dark movement activated for easy location

Glasses with a chip that gives out a signal when lost

External Door that could be opened without a key eg - thumb or hand print

It doesn't have to be perfect!

Figure 9.3: Example response to the 'make a difference' diary exercise

Overall, the effectiveness of the diary-probe as a tool for including people with later life cognitive impairment in the human-centred design process was limited. It facilitated recall and reflection and allowed people with later life cognitive impairment to express their experiences, however, the written format was inappropriate for some people with dementia and led to a reliance on partners which may have limited their freedom to express themselves fully (discussed further in section 9.6). Despite providing rich insights into participants' lives, the information gathered remained insufficient to guide the design process towards relevant solutions.

9.4.2. Personas

Personas were chosen to communicate the needs and experiences of people with dementia to workshop contributors. They were successful in helping to focus workshop contributors attention on the target user and their goals, as suggested in the literature (Miaskiewicz and Kozar, 2011). However, despite the extensive descriptions provided in the personas, the information was not sufficient to fully inform the design process, indicating a need to involve people with dementia more closely in the design process in order to develop products that address their needs.

As well as informing the design process, personas have been purported to foster empathy in designers, enabling them to step into users' shoes (Cooper, 1999; Pruitt and Adlin, 2010; Miaskiewicz and Kozar, 2011). In this study, there were instances when the personas appeared to evoke empathy in workshop contributors. However, some contributors' comments suggested that they saw the personas as 'other'. Stereotypical representations occasionally arose, particularly when the personas provided partial or ambiguous information, indicating that, despite being based on in-depth empirical data, the personas still provided a limited picture of the lives of people with dementia which were open to misinterpretation. These findings suggest that, even when personas are extensive and grounded in empirical data, they are subject to othering, cognitive bias and stereotyping, reflecting previous critiques of personas (Turner and Turner, 2011; Marsden and Haag, 2016).

9.4.3. *Interdisciplinary design and research*

By working cross-disciplinarily, this research benefited from the perspectives of different fields. However, differing priorities across the literature influenced the course of this research. At the outset the research was focused on evidence from the physical activity and exercise science literatures, where dementia and MCI tend to be considered from a biomedical perspective, and the dominant aims are to reduce or eliminate cognitive impairment. However, literature examining the experiences of people with dementia suggested that the priorities of people with later life cognitive impairment may not be aligned with those of the biomedical scientists. This led me to shift from a biomedical focus on physical activity as a mechanism to treat the symptoms of later life cognitive impairment, to examine the needs, interests and priorities of people with later life cognitive impairment.

The scope and course of this research was influenced by the commercial interests of the industrial partner. In the initial stages of the research this meant that I focused on supporting physical activity however, it became apparent that people with dementia in particular may be more interested in maintaining everyday activities. The research was also focused on developing novel digital technologies, although it emerged that participants were averse to high-tech solutions. On reflection, it would have been prudent to start the research by asking people with later life cognitive impairment whether they would be interested in technologies to support physical activity.

A major challenge of this research has been to establish a target user group. Much of the literature attempts to draw conclusions about people with dementia or MCI as unified cohorts, yet they are diverse in their interests and priorities. It became apparent that trying to address the varied needs, attitudes and capabilities of people with dementia or MCI with a single product or service was unlikely to be successful. However, by homogenising individuals with MCI and dementia, the literature provided little information about potential segments, within these broad diagnostic categories, that might have similar needs in relation to physical activity. Furthermore, as in previous qualitative research in this field, my choice of thematic analysis tended to homogenise participants' needs and experiences. By using personas as representatives of a sub-group of potential users, I hoped to address this limitation, however personas presented their own limitations, as discussed earlier.

Working with physical activity specialists, health psychologists, designers and engineers in the concept development stage of the research was valuable as it provided a range of insights and generated a range of initial ideas for products and services to support physical activity. However, the brevity of the workshops and the limitations of the personas (discussed in the previous section) meant that the outcomes were somewhat naïve and under-developed. It would have been preferable to have a team of specialists involved in several, iterative stages of design, evaluation and development, ideally working closely with people with later life cognitive impairment, to develop more considered design solutions. However, this was not feasible with the time and resources available.

My initial intention was to undertake several cycles of human-centred design, involving people with later life cognitive impairment in the design process by presenting them with concepts and responding to their feedback. However, starting with an initial stage of in-depth user research and thematic analysis, limited the time available for iterative design development. The thematic approach to data analysis, considered appropriate for rigorous analysis in social-science disciplines, also limited the degree to which the complexities of individuals' experiences could be conveyed to designers. This experience suggests that methods traditionally used in social sciences may not be appropriate for informing the design process. While participatory and co-design approaches can be employed to overcome the disconnect between users and designers, and potentially offer a more rapid route to concept development, they may not be appropriate for people with dementia, and may limit the generalisability of outcomes (as discussed in my methods chapter). The limitations of my approach highlight a need for further research into ways to involve people with later life cognitive impairment in the design process.

Overall, the methods and approach taken in this enquiry provided novel insights into the needs and experiences of people with later life cognitive impairment but failed to generate appropriate design responses. In part, this was due to the focus on technological solutions. In addition, a closer relationship between a dedicated design team and people with later life cognitive impairment, who are able to work together through several iterations of concept generation and development, may be required to generate appropriate design solutions in future.

9.5. Contributions and implications

With 15 participants this is one of the largest qualitative studies to have investigated people with later life cognitive impairment's experiences of physical activity. The novel diary-probe led interview approach undertaken in this research has led to several contributions to our understanding of people with later life cognitive impairments' experiences, providing evidence to corroborate previous findings as well as new insights and perspectives.

The research has contributed to our comprehension of the diversity of people with later life cognitive impairments' active lives, demonstrating that individuals hold different motivations and attitudes towards physical activity. Where previous qualitative studies have tended to focus on barriers related to cognitive impairment, this research has highlighted that people with later life cognitive impairment face a variety of barriers to physical activity other than cognitive impairment, including physical health problems, environmental and psychosocial factors. Consequently, a need has been identified for interventions to enable people with later life cognitive impairment to identify and overcome these underlying barriers. The findings of this research also suggest that accommodating the range of activity levels and support needs of people with later life cognitive impairment is unlikely to be achieved through a single solution. Instead, I propose that efforts should be focused on reducing sedentariness among those who are moderately inactive, since this is likely to have the greatest impact on health and wellbeing.

The use of diary-probes provided novel insights into the contribution of everyday and purposeful activities to an active and fulfilled life for people with later life cognitive impairment. The findings of this research indicate that promoting purposeful activity and encouraging people to embed physical activity in their everyday routines may be an effective way to increase physical activity levels. This thesis has also drawn attention to the importance of social and relational aspects of physical activity: accordingly, interventions to support physical activity should consider ways to facilitate shared activity.

This is the first qualitative study found to have investigated people with MCI's everyday experiences of physical activity. Although this research did not find cognitive changes to be a significant barrier to physical activity, concurrent research suggests that MCI may affect people's confidence and capacity to perform everyday activities. Since everyday activities have been found to make a significant contribution to a physically active life, I recommend further research be undertaken to understand how difficulties performing such activities might affect the physical activity levels of people with MCI and how any barriers might be addressed. Although some tentative suggestions for technologies have been made in this discussion, further design research is recommended to investigate the potential for technologies and services to support people with MCI to live more physically active lifestyles.

This research extends our understanding of the barriers to physical activity associated with dementia. Unlike previous research, which has tended to focus on physical activity events, such as walking or exercise, the diary-probe approach used in this study revealed that dementia can impact on the everyday activities which, not only contribute to people's physical activity levels but also to quality of life. The findings of this thesis indicate that difficulties performing household activities in particular can contribute to sedentariness in dementia, a relationship that has previously received limited consideration. Consequently, an opportunity has been identified for technologies and services to support people with dementia to maintain everyday activities, in order to improve quality of life and reduce sedentariness. Self-management and occupational therapy services may enable people with dementia and their carers to identify strategies to overcome the barriers to performing everyday activities. These might be complemented by technology-based information and services to help people to maintain activity routines and connect with others facing similar challenges, although a mixed-media approach should be considered in order to include those who are not interested in, able to access or use digital services. Technologies that guide people with dementia through everyday activities may also be useful in the future, however further development is required before such technologies can provide seamless support.

This research has also provided insights into the impact of motivational impairment on the active lives of people with dementia, a factor that has received little consideration in similar studies. The findings of this research indicate that interventions to support physical activity need to provide tools to help people to overcome various aspects of loss of motivation, including loss of initiative, apathy and low mood. Occupational therapy or self-management approaches may again be useful for helping people to overcome loss of motivation. Technologies might also usefully motivate engagement in everyday activities, for example providing stimulation or reminders to prompt engagement in routine household tasks.

Although there has been significant design and research interest in navigation aids to support independent walking, this research suggests that navigation is not a primary concern for people with mild dementia. Instead, the findings of this research suggest that difficulties associated with everyday activities outside the home may be a greater barrier to independent physical activity. There may be opportunities for technologies to enable people with dementia to perform everyday activities outside the home, such as shopping or using public transport. However, this research also indicates a need to improve the accessibility of public spaces, services, transport and technologies, to ensure that people with dementia can remain independently active in their communities for as long as possible.

As well as identifying a range of barriers to activity, the diversity of experiences presented in this thesis highlight the differing ways and extents to which dementia can impact on people's active lives. Consequently, technologies and services must accommodate and adapt to the highly individual and changing needs of people with dementia.

This thesis has also developed our understanding of partners' roles in the active lives of people with dementia, identifying both supportive and restrictive behaviours and a need to support both independent and shared activity. The findings of this research indicate a need to provide partners with information and support to implement strategies to enable people with dementia to maintain active lives. This research also supports previous findings that partners can be excessively protective of people with dementia, restricting independent activity. This may be exacerbated by the introduction of technologies that pander to caregivers' concerns, such as activity monitoring technologies. As such, while this thesis has identified opportunities for technologies to support independent activity, it has also highlighted a need to consider the relationship between people with dementia and their partners to ensure that technologies do not unnecessarily curb the freedom of people with dementia.

Although this research has identified opportunities for technologies to support physical activity it has also highlighted several barriers to technology use by people with dementia that should be taken into consideration. Building on previous research, this study reiterates the need to ensure that technologies are attractive and not stigmatising as well as being easy to learn and use. Given the challenges associated with learning to use new technologies, designers should consider low-tech or no-tech solutions, which may be equally useful and more accessible to people with dementia.

This research also extends previous findings regarding privacy and autonomy concerns relating to monitoring technologies aimed at older adults. Despite intending to enable people to increase their physical activity levels, should they wish, the research highlighted the potential for health behaviour monitoring technologies to limit people's freedom to choose whether or not to undertake health promoting activities. This research has also highlighted that valued aspects of human care and support should not be overlooked in the focus on technology, instead designers should consider how technologies can enhance care services. Rather than taking a technology-centric approach this research indicates a need to consider how human-centred services might be enhanced by technologies, without impinging on individuals' freedom of choice and privacy.

This research also contributes to our understanding of the strengths and limitations of design research methods when designing with and for people with later life cognitive impairment. The use of a hybrid diary-probe was successful in providing insights into participants' everyday lives and prompting reflection, leading to novel insights which may not have emerged through interviews alone. However, the written approach was not suitable for all participants with dementia, some of whom needed their spouses to write on their behalves potentially limiting their freedom of expression.

This thesis also contributes to our understanding of the efficacy of personas as a tool for communicating the experiences of people with dementia to designers. Although there was some evidence to support assertions that personas can inform the design process and foster empathy in designers, there were also examples of othering and stereotyping. The findings of this research suggest that, even when personas provide rich descriptions, based directly on empirical data, they are still open to misrepresentation or misunderstanding by designers. Consequently, this research highlights a need for closer collaboration between designers and people with dementia, throughout the design process, in order that products and services reflect their needs and interests.

9.6. Limitations

Although this is one of the largest investigations into the lived experience of physical activity for people with later life cognitive impairment, the sample size may still be insufficient, particularly given the heterogeneity of participants' experiences. The findings of this research confirmed many of the themes identified in previous research on the lived experience of dementia, suggesting a degree of convergence. However, there were also emergent themes relating to occupation, sedentariness and motivation in dementia that would benefit from further investigation. This study has also provided initial insights into the experiences of physical activity for people with MCI. However, given the disparities with concurrent research with people with MCI, a need for further research has been identified to understand the barriers to physical activity for this group, especially those related to everyday activity.

The diversity of the sample was limited, with all participants recruited from the North East of England. A convenience sampling strategy was used with no consideration given to cultural or ethnic diversity. Since ethnic factors have been found to influence people's attitudes towards physical activity (Wright, 2014; Franco *et al.*, 2015) future research should aim to recruit more diverse samples. This is a limitation across this area of research, which has been focused on a handful of countries, with no express consideration given to sample diversity. To develop broad-reaching, internationally relevant products and services, future research should investigate the extent to which the findings of this and previous research extend to other communities.

A major limitation of the convenience sample recruited for this research was that only two participants lived on their own, compared to around 40% of the UK older adult population (Office for National Statistics, 2013). Since one of the key findings of this research is that partners play an important role in the active lives of people with later life cognitive impairment, lack of insight into the experiences of people living on their own is a significant limitation. Neglecting the experiences this group may overlook important insights into the coping strategies that help them to maintain their independence. This disparity is, unfortunately, reflective of the majority of research in this area (van Alphen, Hortobágyi and van Heuvelen, 2016). It is imperative that future research seeks the experiences of people living on their own to ensure that the needs of this group are addressed.

The diary-probe used in this study may have been off-putting to potential participants who were unable to write or who were concerned about writing (as discussed in section 9.4.1). This barrier to participation may have contributed to the lack of single participants in this research, who did not have someone to write on their behalf, as was the case in some instances in this study.

Including partners in interviews and focus groups also presented limitations. There were some indications that the joint interviews may have prevented participants from expressing themselves fully, as in some cases spouses were more forthright when their partner with dementia left the room. In addition, differentiating the opinions of individuals within a couple was difficult as they often discussed their responses to my question between them or spoke on each other's behalfs. These limitations are evident in the findings presented in section 5.2, where it was unclear what stopped individuals with dementia from walking out alone. The joint focus groups were also problematic since the speed and fluency of partners' responses meant that they dominated the conversations. I would recommend that people with later life cognitive impairment be encouraged to participate in interviews and focus groups on their own, where possible, so that they have the space and freedom to voice their opinions, although individuals’ comfort when participating in research alone, with unfamiliar researchers should also be considered.

Chapter 10. Conclusions

10.1. Introduction

In this final chapter I provide recommendations for future research, before summarising the conclusions of this thesis.

10.2. Recommendations for future work

For people with dementia, this research suggests a need to develop interventions that support everyday activities, overcome loss of motivation and support independence. Rather than developing exercise programmes and technologies I suggest that future research should focus on the development of self-management or occupational therapy services that provide people with dementia and their caregivers with strategies to maintain engagement in everyday activities and overcome loss of motivation. Assistive technologies could be developed to complement these services, for instance providing information, prompts, reminders and guidance. However, they must be carefully designed, with the input of people with dementia, to ensure usability, acceptability and appropriate levels of privacy. In addition, I recommend that further research and design be conducted to improve the accessibility of public services and spaces, to enable people with dementia, in particular, to maintain independent activities outside the home.

I also suggest that further research be conducted to understand the barriers to performing everyday, physically active tasks for people with MCI. The potential for technologies to support people with MCI to overcome barriers to physical activity warrants further investigation, although as with technologies aimed at people with dementia, careful design with the input of users is necessary.

I recommend that future research continues to explore the development of methods to involve people with later life cognitive impairment in the design process. Future work should also seek to include more of those people with later life cognitive impairment who live alone to ensure that interventions meet their needs. In addition, cultural and ethnic diversity should be considered in recruitment strategies to ensure that products and services are inclusive and widely relevant.

10.3. Conclusions

Despite a great deal of interest in the potential for exercise interventions to ameliorate cognitive impairment and other symptoms of dementia and MCI, little consideration has been given to the priorities of people with later life cognitive impairment. This thesis provides novel insights into the activity choices and priorities of people with later life cognitive impairment. As a result of my findings, I propose that, rather than considering exercise as merely a tool to improve clinical health outcomes, interventions should be focused on supporting people with later life cognitive impairment to engage in physically active, purposeful tasks that contribute to an active and fulfilled life.

This research has contributed insights into the diversity of activity levels among people with later life cognitive impairment and the numerous underlying barriers, motivators and facilitators to engaging in physical activity. My findings suggest that a one-size-fits-all solution is unlikely to be appropriate. Consequently, I propose that interventions should be targeted at those who are relatively inactive, who may benefit most from interventions that encourage and enable them to incorporate physical activity into everyday tasks and routines. Even if interventions are targeted towards defined groups, my findings suggest that interventions must also accommodate individual situations, needs and priorities.

This research has also delivered insights into the roles of partners in the active lives of people with later life cognitive impairment, as companions and facilitators, but also contrastingly as potential inhibitors of independent activity. My findings highlight a need to consider the roles of partners in the design of interventions to support physical activity.

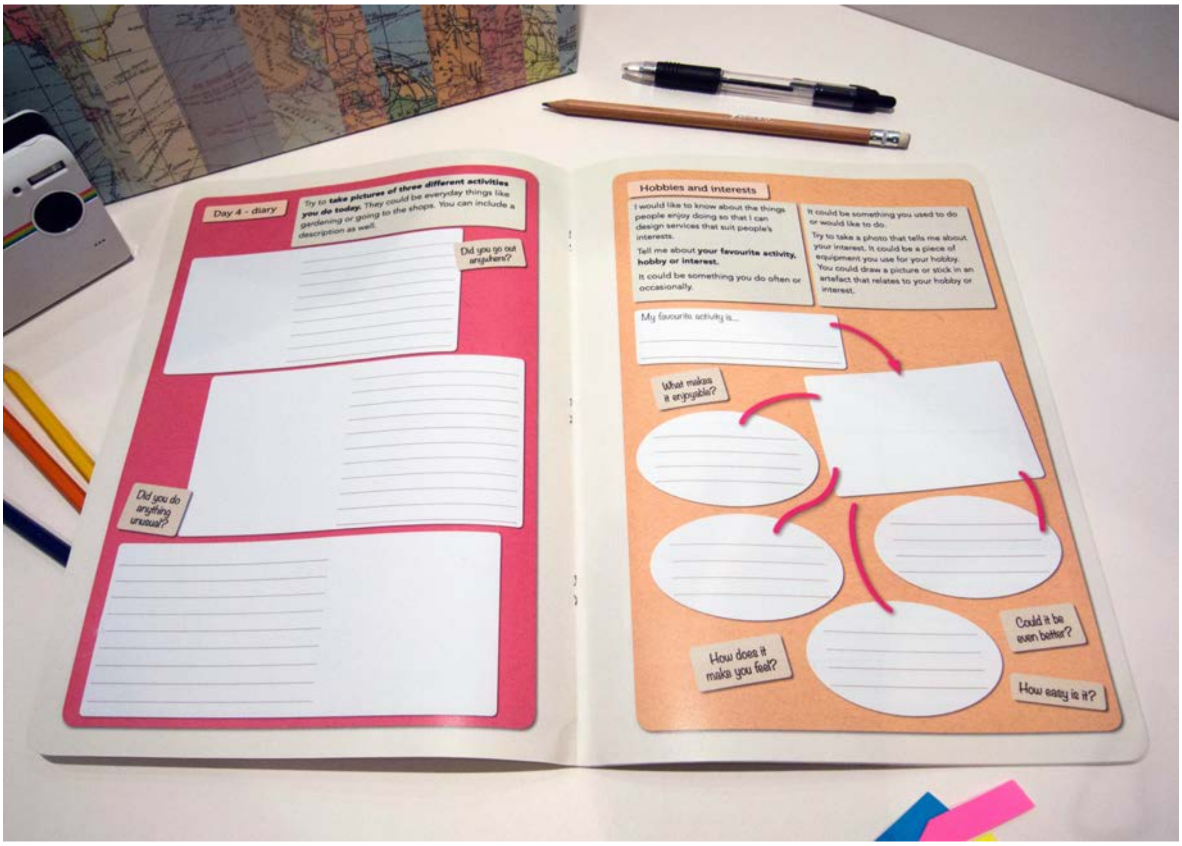
There has also been interest in the potential for technologies to support physical activity, however, the findings of this research question a technological approach to supporting physical activity for people with dementia. Instead, my findings indicate a need to improve the design of public services and spaces as well as providing support services to people with dementia, such as occupational therapy and self-management interventions, to enable them to maintain active lives. While there may be opportunities for technologies to support everyday activities and independence, the findings of this research emphasise a need to first establish whether technological solutions are the most appropriate approach and, if so, to ensure that technologies are usable and acceptable.

In order to develop services and products that reflect people's needs, priorities and interests, this research has highlighted a need to carefully consider how people with later life cognitive impairment can be closely involved throughout the design process.

It is hoped that the findings of this thesis will provide the groundwork for the development of services and products to enable people with later life cognitive impairment to maintain their health and wellbeing by supporting activities that people value.

Chapter 11. Appendices

A. Diary probe images



Day 4 - diary

Try to **take pictures of three different activities you do today.** They could be everyday things like gardening or going to the shops. You can include a description as well.

Did you go out anywhere?

Did you do anything unusual?

Hobbies and interests

I would like to know about the things people enjoy doing so that I can design services that suit people's interests.

Tell me about **your favourite activity, hobby or interest.**

It could be something you do often or occasionally.

It could be something you used to do or would like to do.

Try to take a photo that tells me about your interest. It could be a piece of equipment you use for your hobby. You could draw a picture or stick in an artefact that relates to your hobby or interest.

My favourite activity is...

What makes it enjoyable?

How does it make you feel?

Could it be even better?

How easy is it?

B. Recruitment process and inclusion criteria

People with mild dementia and MCI were recruited to the first stage of the research and then re-recruited to provide feedback in focus groups in the third stage. Two organisations were used for recruitment. Initial participants were recruited through VoiceNorth, an organisation based at Newcastle University that engages members of the public interested in volunteering for research. The remaining participants were recruited through the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), part of the National Institute for Health Research. Their database included a range of National Health Service (NHS) patients interested in participating in research and was therefore considered likely to be more representative than other potential recruitment routes, such as dementia support groups, which may have resulted in a more socially active and outgoing sample.

Recruitment through VoiceNorth was via an email invite to their mailing list. Interested individuals were asked to call or email me so that I could post an information sheet and a letter of invitation. If, having read about the study, they were still interested or had any questions they were invited to call or email me. To identify whether interested individuals met the inclusion criteria, screening was conducted over the phone. The inclusion criteria for participants with cognitive impairment were as follows:

8. Self-reported diagnosis of a progressive form of dementia or MCI.
9. Able to converse in English.
10. Community dwelling (i.e. not living in residential care facilities).
11. Not participating in other research.
12. Age 18 or over.
13. Capable of meaningful participation in interviews or focus groups.
14. Able to give consent.
15. Participation not deemed likely to significantly impact on health (e.g. causing fatigue, or distress).

Recruitment partners at DeNDRoN (part of the National Health Service) had access to patients' medical records and were therefore able select potential participants that were likely to meet these criteria[13]. Suitable patients were called by DeNDRoN staff to ask whether they would be interested in participating in the research. If so, a letter of invitation and an information sheet was sent, with a request to call or email me if they were interested in participating.

DeNDRoN were able to refer to participants medical records to find out whether they had dementia or MCI, however, participants recruited through VoiceNorth were self-selecting. To ascertain whether potential participants had a diagnosis of dementia or MCI I asked people to describe their memory problems, rather than asking people directly about their diagnosis and potentially causing distress. If they did not declare their diagnosis, I then asked whether they had spoken to a doctor about their memory problems to ascertain whether they had received a diagnosis of MCI or dementia.

Participants' capacity to meaningfully participate and give consent was established during the initial screening call and at the introductory interview. During the screening call potential participants' capacity to talk about their memory condition and about themselves was assessed (see appendix F for screening questions). Their comprehension of the information provided in the information sheet was also established. If potential participants met the first five criteria (above) and were likely to meet the latter three, then an introductory meeting was arranged, either at participants' homes or a place they felt comfortable meeting. This meeting provided an opportunity to confirm whether participants were meaningfully able to participate and give consent and that their participation was not likely to be detrimental to them. The consent process is detailed in the following section.

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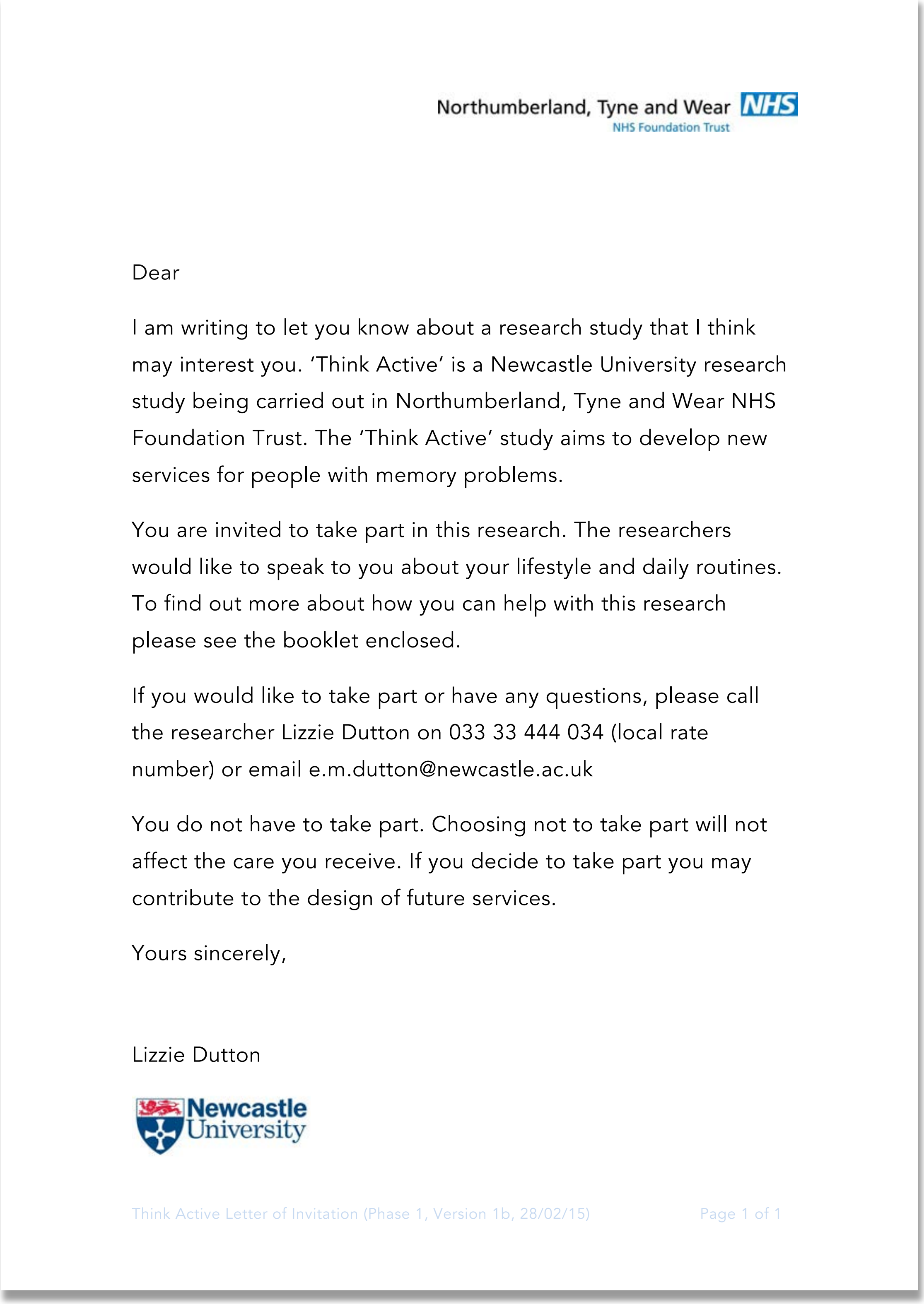
[13] DeNDRoN were not able to share patient's medical details with me.

During the screening call, interested participants were asked whether they would like their partner or another family member to participate in the research with them. Eleven individuals chose to participate with their spouse. Spouses were also asked whether they were interested in participating and were screened according to the following criteria:

1. Family member, close friend or carer.
2. Capable of meaningfully participating in interviews or focus groups.
3. Able to converse in English.
4. Able to give consent.
5. Not taking part in other research.
6. Aged 18 or over.

At the outset of the research participants were only invited to the first stage of the research so as not to overwhelm them. At the end the first stage participants were asked whether they would like to be invited to the third stage of the research, should their participation be useful. All participants agreed. Following the first stage, the research became focused on people with dementia. Consequently, only participants with dementia and their partners were re-invited to the focus groups in stage three. An information sheet (with details about the focus groups) and a letter inviting them to participate was posted to participants with dementia and, where relevant, their partners.

C. Example letter of invitation



Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Dear

I am writing to let you know about a research study that I think may interest you. 'Think Active' is a Newcastle University research study being carried out in Northumberland, Tyne and Wear NHS Foundation Trust. The 'Think Active' study aims to develop new services for people with memory problems.

You are invited to take part in this research. The researchers would like to speak to you about your lifestyle and daily routines. To find out more about how you can help with this research please see the booklet enclosed.

If you would like to take part or have any questions, please call the researcher Lizzie Dutton on 033 33 444 034 (local rate number) or email e.m.dutton@newcastle.ac.uk

You do not have to take part. Choosing not to take part will not affect the care you receive. If you decide to take part you may contribute to the design of future services.

Yours sincerely,

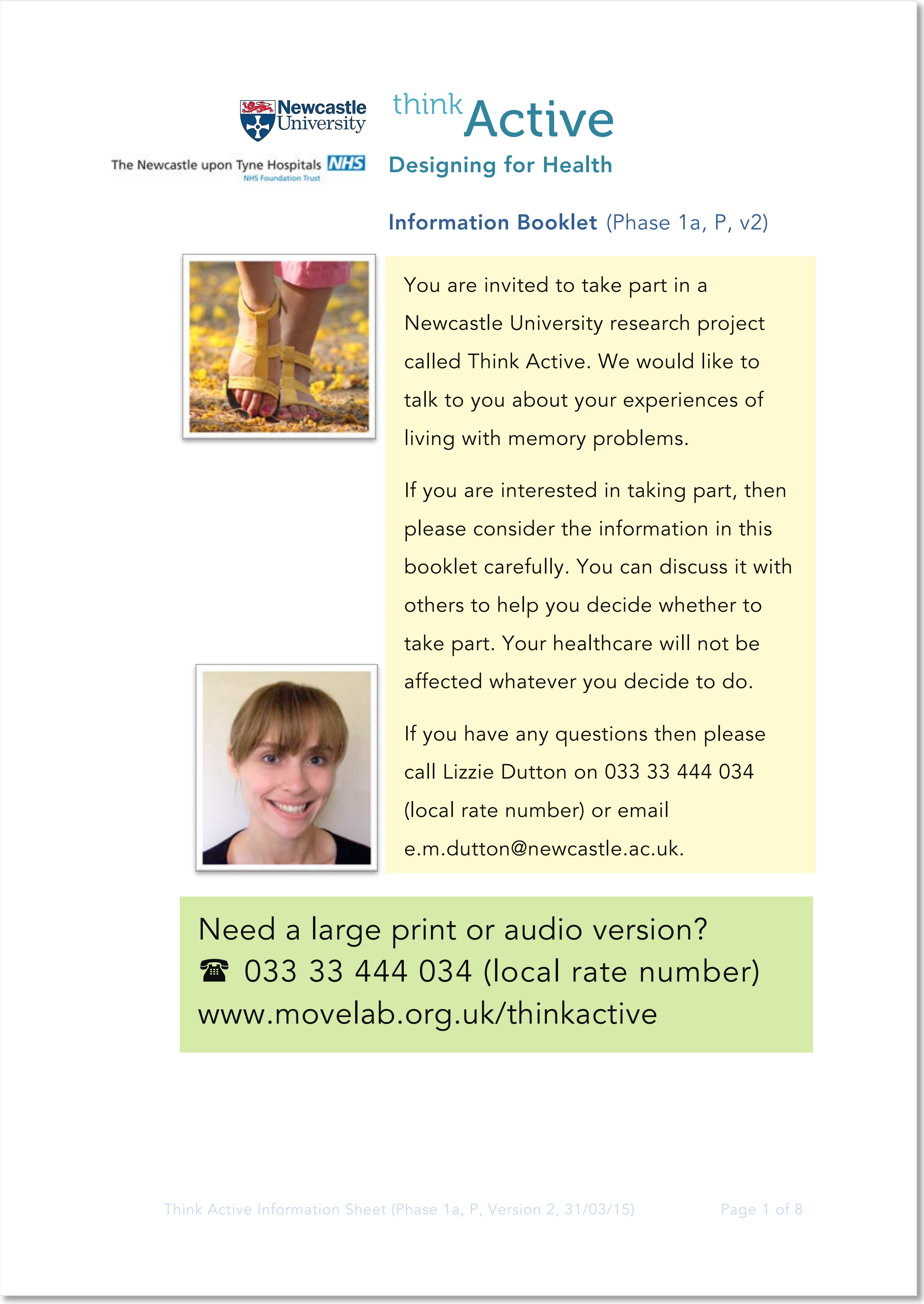
Lizzie Dutton

Newcastle University

Think Active Letter of Invitation (Phase 1, Version 1b, 28/02/15) Page 1 of 1

D. Example information sheet

The following document is an example of one of the information sheets used in the first stage of the research for participants with later life cognitive impairment. The text in the information sheet was amended for partners interested in participating. For the second stage of the research the information on pages 3 and 4, in the section 'what do I have to do' was also modified.



Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

think Active

Designing for Health

Information Booklet (Phase 1a, P, v2)

You are invited to take part in a Newcastle University research project called Think Active. We would like to talk to you about your experiences of living with memory problems.

If you are interested in taking part, then please consider the information in this booklet carefully. You can discuss it with others to help you decide whether to take part. Your healthcare will not be affected whatever you decide to do.

If you have any questions then please call Lizzie Dutton on 033 33 444 034 (local rate number) or email e.m.dutton@newcastle.ac.uk.

Need a large print or audio version?
☎ 033 33 444 034 (local rate number)
www.movelab.org.uk/thinkactive

What is this research about?

Researchers have found that being physically active is beneficial for people with memory problems. Physical activity includes everyday things like gardening, shopping, walking or swimming.

The aim of the Think Active research project is to design new services that help people to be physically active.

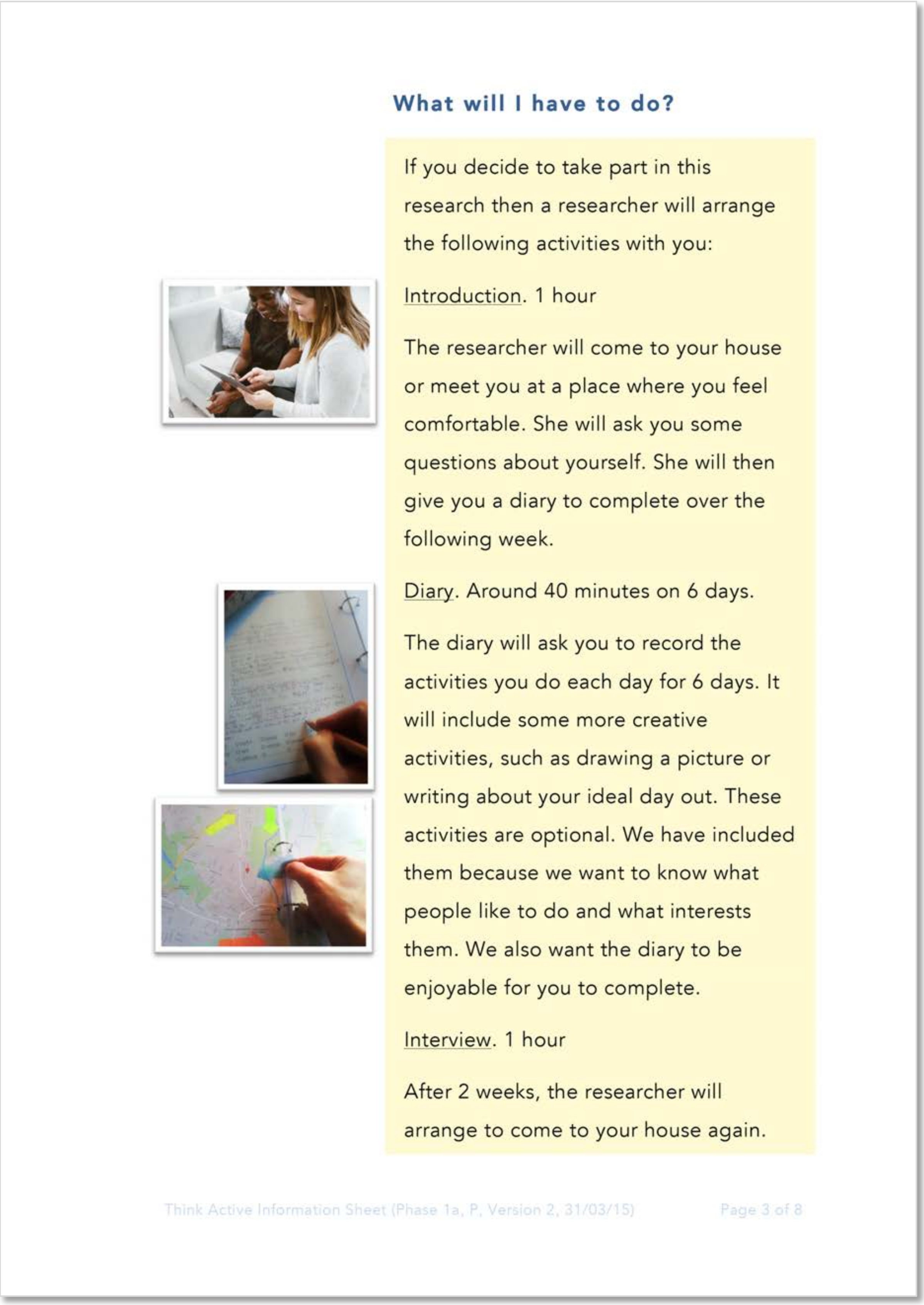
Up to 84 participants will take part in this research.

Can you help us?

If you have a diagnosed memory problem then we would like to talk with you.

We are keen to know about the activities you enjoy doing. We want to know if memory problems affect your activities. By sharing your experiences you will help us to design new services.

If you live with someone they can also take part, if you both agree to this.



What will I have to do?

If you decide to take part in this research then a researcher will arrange the following activities with you:

Introduction. 1 hour

The researcher will come to your house or meet you at a place where you feel comfortable. She will ask you some questions about yourself. She will then give you a diary to complete over the following week.

Diary. Around 40 minutes on 6 days.

The diary will ask you to record the activities you do each day for 6 days. It will include some more creative activities, such as drawing a picture or writing about your ideal day out. These activities are optional. We have included them because we want to know what people like to do and what interests them. We also want the diary to be enjoyable for you to complete.

Interview. 1 hour

After 2 weeks, the researcher will arrange to come to your house again.

She will ask you about the events and ideas that you recorded in the diary. She will also ask you about your experiences of physical activity in general.

All of these activities are voluntary.

Will the research benefit me?

It is unlikely that taking part will help you directly. However, many people enjoy talking to researchers about their experiences. Your ideas will help us to create new products and services for people with memory problems.

To thank you for your time we will give you £50 worth of shopping vouchers after the second interview.

Are there any risks?

The researcher will ask you about your experiences of having memory problems. Some people may find this upsetting. But, you do not have to talk about anything you are not comfortable with. You can also stop taking part at any time.

How can I take part?

To take part or to find out more, please call Lizzie Dutton on 033 33 444 034 (local rate number).

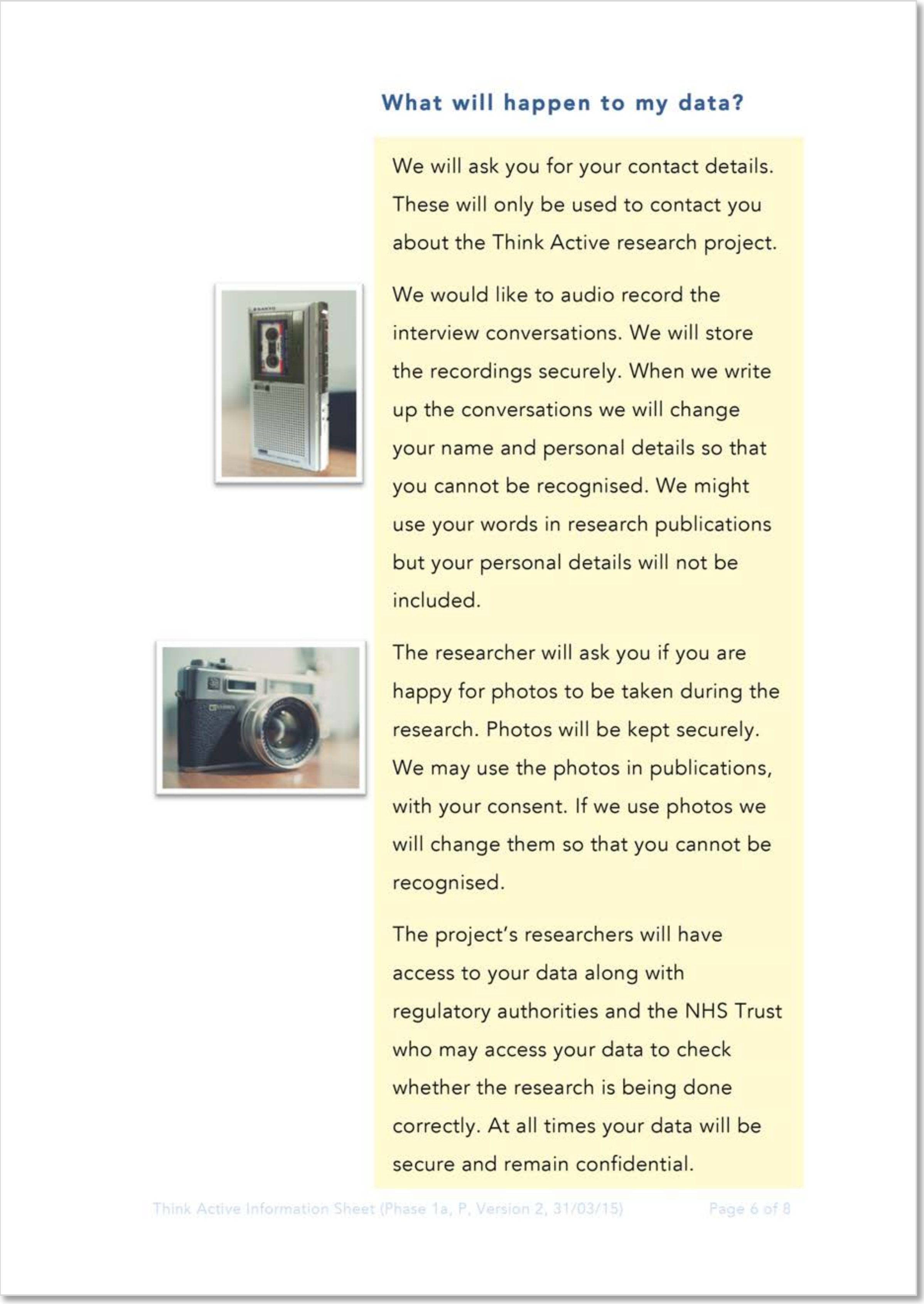
You can ask the researcher questions. She will also ask you some questions. We may not be able to interview everybody.

If you want to take part then the researcher will arrange a time to come to your home or a place you would like to meet.

When you meet the researcher she will discuss a consent form with you. It will be your decision whether or not to take part.

You can withdraw from the research at any point. You do not have to give a reason. You will not be penalised for withdrawing. It will not affect any care you receive.

If we think that the research is not suitable for you at any point then you may be withdrawn.



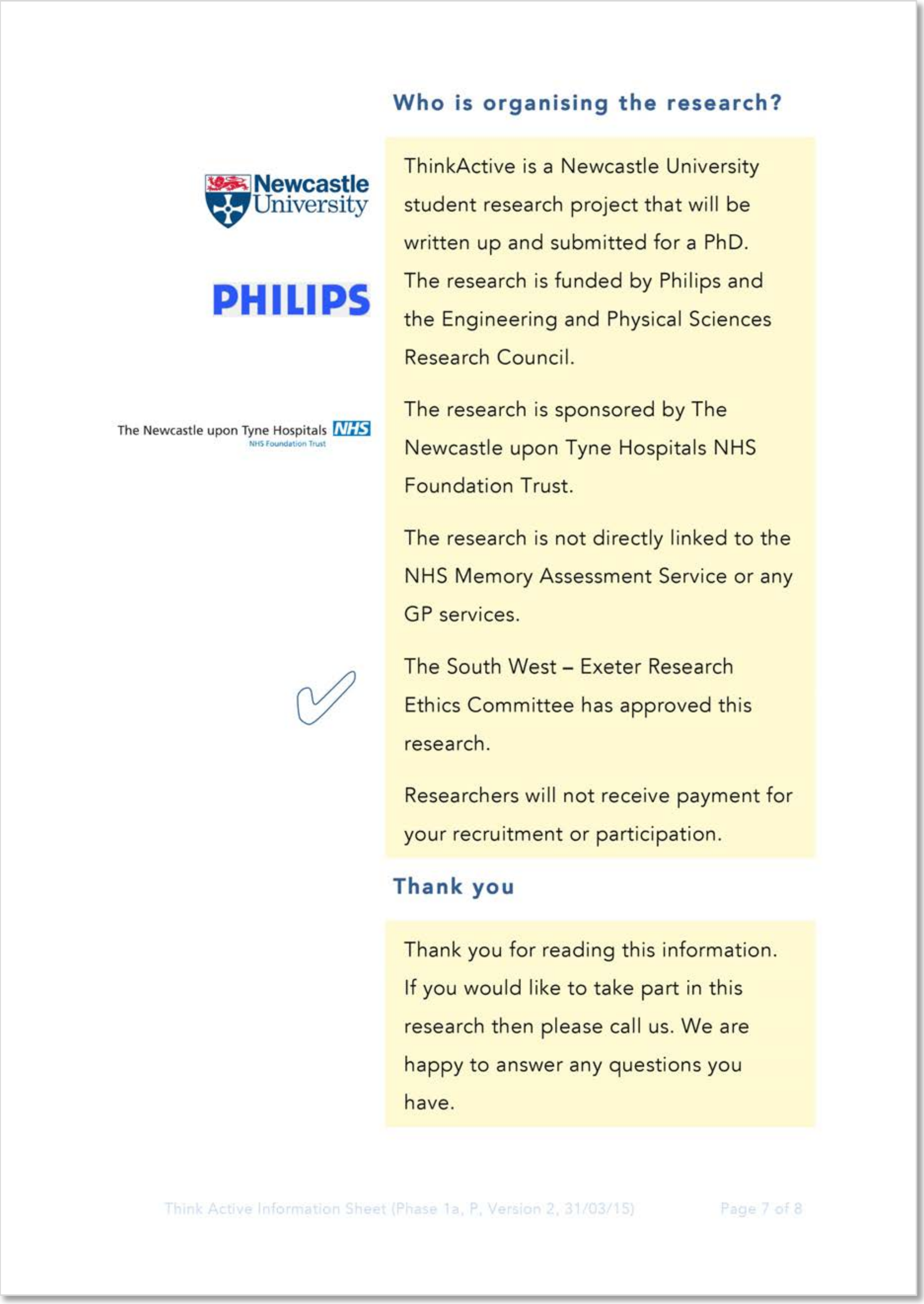
What will happen to my data?

We will ask you for your contact details. These will only be used to contact you about the Think Active research project.

We would like to audio record the interview conversations. We will store the recordings securely. When we write up the conversations we will change your name and personal details so that you cannot be recognised. We might use your words in research publications but your personal details will not be included.

The researcher will ask you if you are happy for photos to be taken during the research. Photos will be kept securely. We may use the photos in publications, with your consent. If we use photos we will change them so that you cannot be recognised.

The project's researchers will have access to your data along with regulatory authorities and the NHS Trust who may access your data to check whether the research is being done correctly. At all times your data will be secure and remain confidential.



Who is organising the research?

ThinkActive is a Newcastle University student research project that will be written up and submitted for a PhD. The research is funded by Philips and the Engineering and Physical Sciences Research Council.

The research is sponsored by The Newcastle upon Tyne Hospitals NHS Foundation Trust.

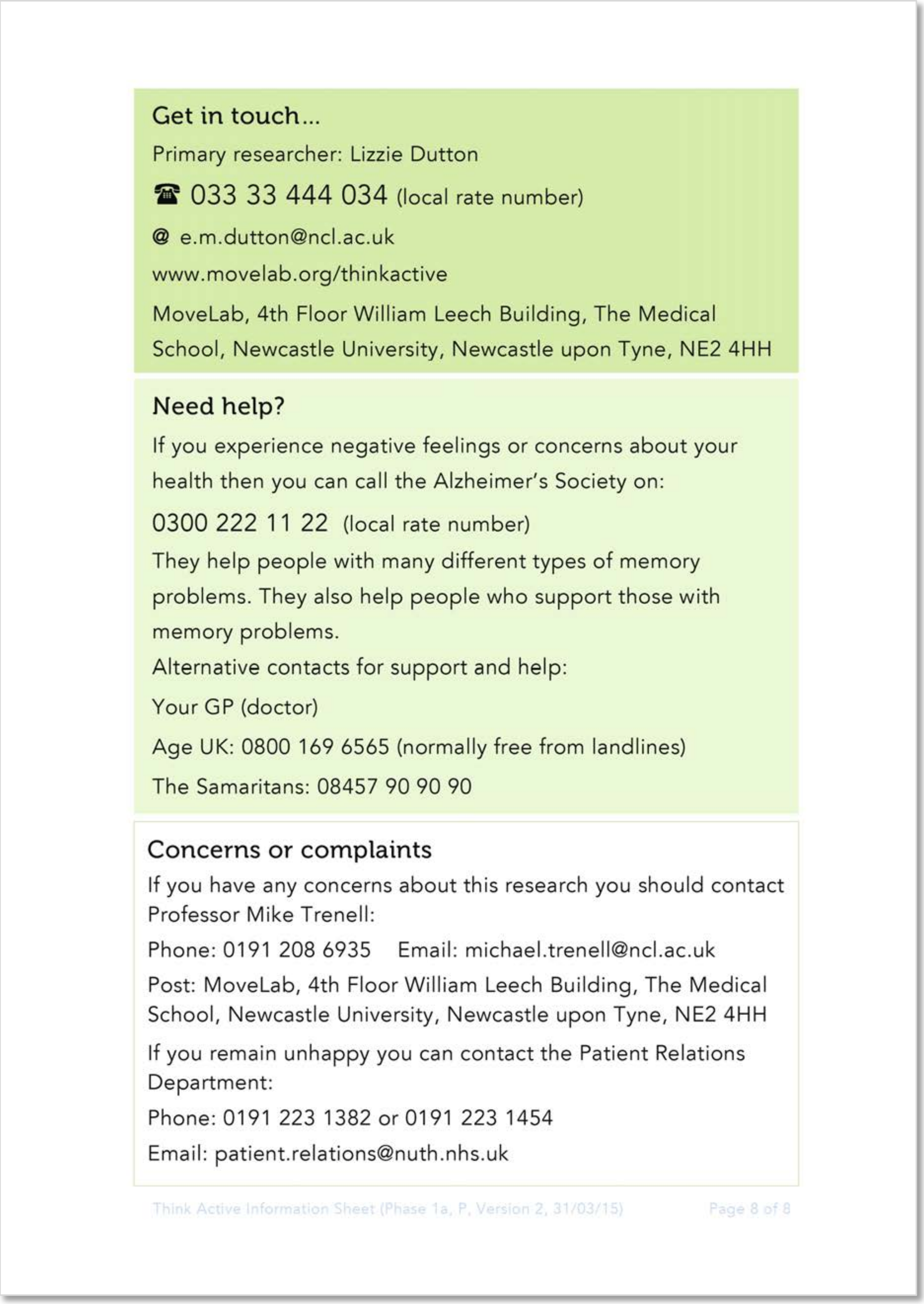
The research is not directly linked to the NHS Memory Assessment Service or any GP services.

The South West – Exeter Research Ethics Committee has approved this research.

Researchers will not receive payment for your recruitment or participation.

Thank you

Thank you for reading this information. If you would like to take part in this research then please call us. We are happy to answer any questions you have.



Get in touch...

Primary researcher: Lizzie Dutton

☎ 033 33 444 034 (local rate number)

@ e.m.dutton@ncl.ac.uk

www.movelab.org/thinkactive

MoveLab, 4th Floor William Leech Building, The Medical
School, Newcastle University, Newcastle upon Tyne, NE2 4HH

Need help?

If you experience negative feelings or concerns about your health then you can call the Alzheimer's Society on:

0300 222 11 22 (local rate number)

They help people with many different types of memory problems. They also help people who support those with memory problems.

Alternative contacts for support and help:

Your GP (doctor)

Age UK: 0800 169 6565 (normally free from landlines)

The Samaritans: 08457 90 90 90

Concerns or complaints

If you have any concerns about this research you should contact Professor Mike Trenell:

Phone: 0191 208 6935 Email: michael.trenell@ncl.ac.uk

Post: MoveLab, 4th Floor William Leech Building, The Medical
School, Newcastle University, Newcastle upon Tyne, NE2 4HH

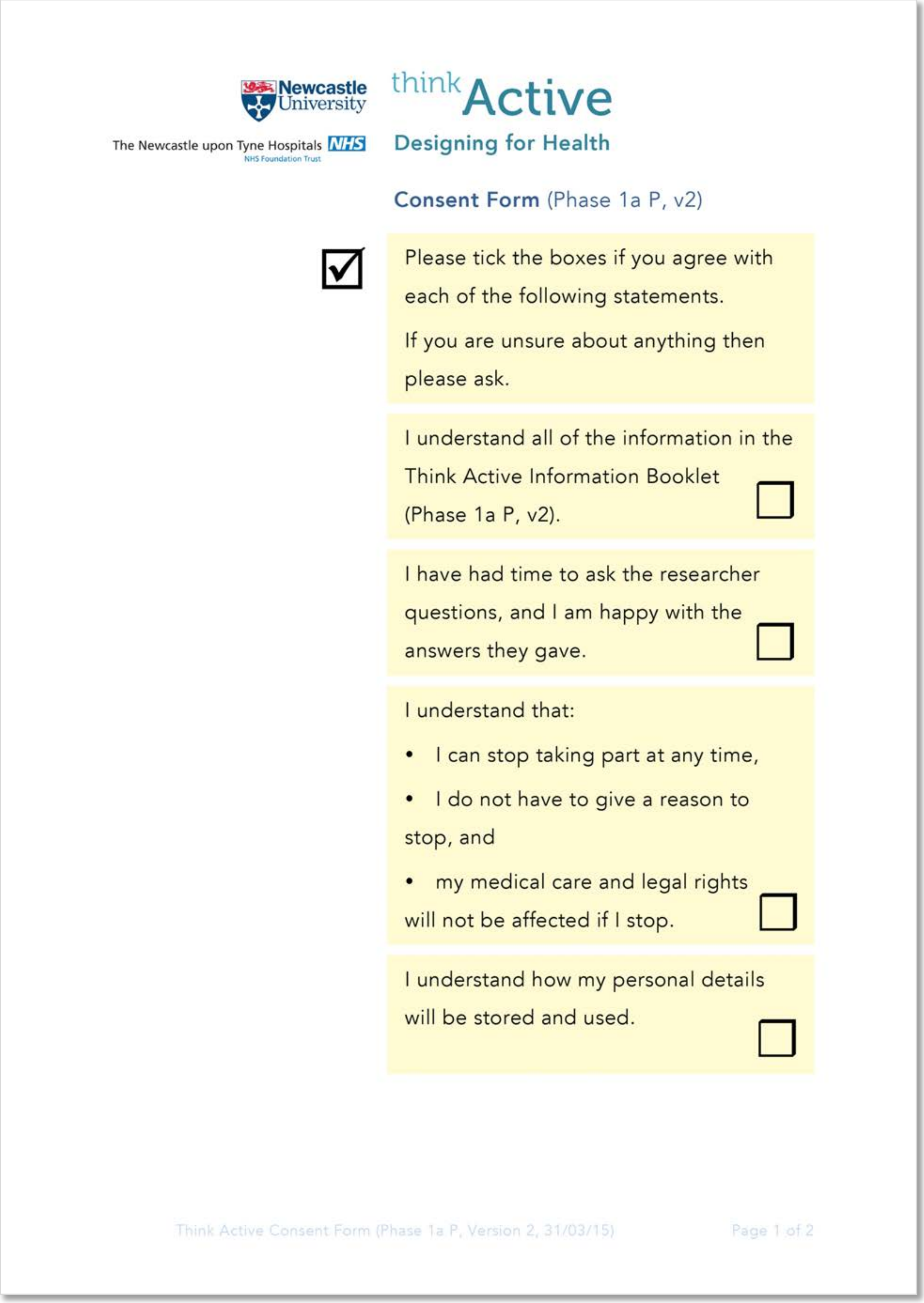
If you remain unhappy you can contact the Patient Relations Department:

Phone: 0191 223 1382 or 0191 223 1454

Email: patient.relations@nuth.nhs.uk

E. Example consent form

The following is an example of the consent form used in the interviews. The consent form for the focus groups differed only in the information about the phase of the research and the associated information sheets.



Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

think Active

Designing for Health

Consent Form (Phase 1a P, v2)

☑ Please tick the boxes if you agree with each of the following statements.

If you are unsure about anything then please ask.

I understand all of the information in the Think Active Information Booklet (Phase 1a P, v2). ☐

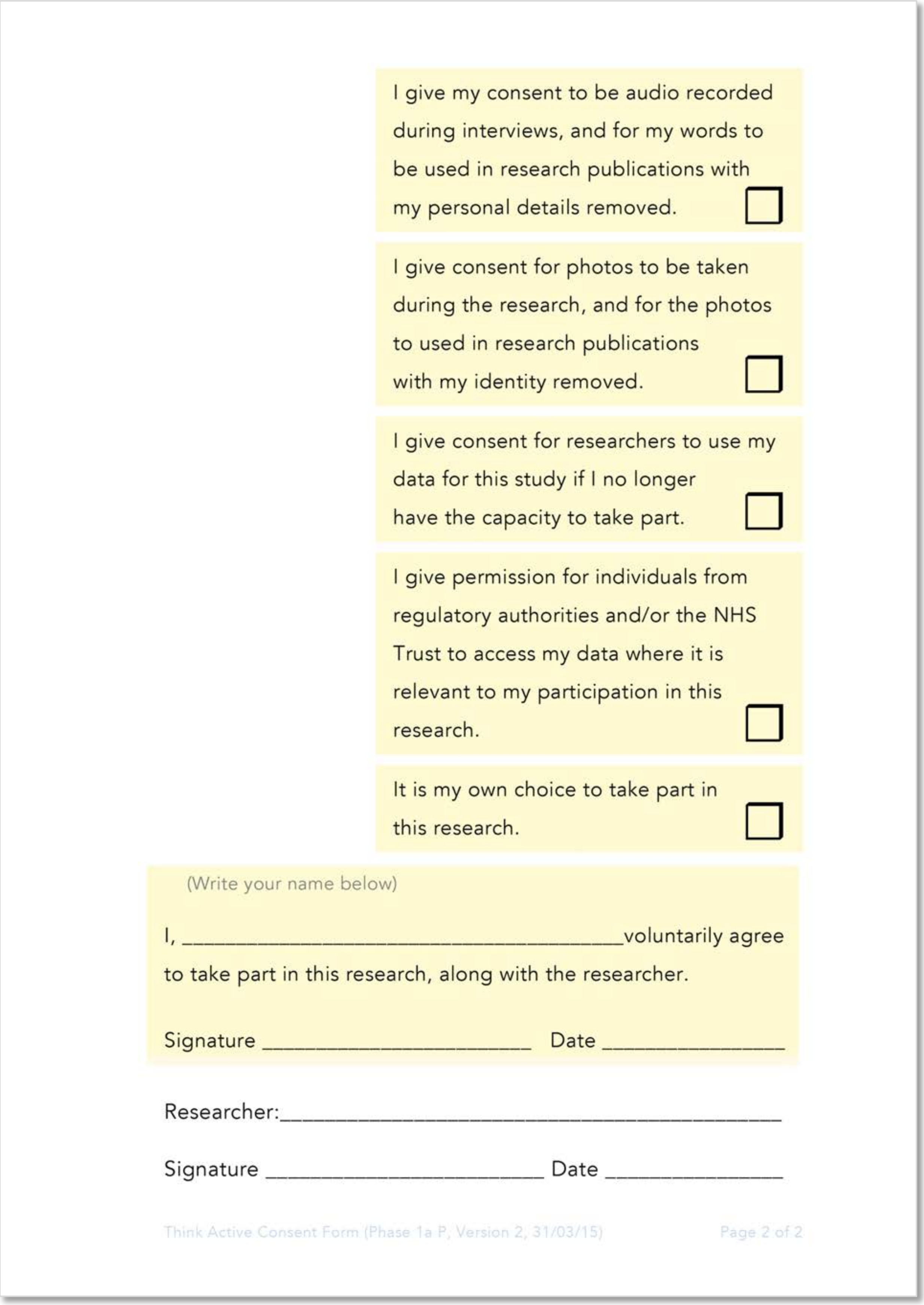
I have had time to ask the researcher questions, and I am happy with the answers they gave. ☐

I understand that:

- I can stop taking part at any time,
- I do not have to give a reason to stop, and
- my medical care and legal rights will not be affected if I stop. ☐

I understand how my personal details will be stored and used. ☐

Think Active Consent Form (Phase 1a P, Version 2, 31/03/15) Page 1 of 2



I give my consent to be audio recorded during interviews, and for my words to be used in research publications with my personal details removed. ☐

I give consent for photos to be taken during the research, and for the photos to used in research publications with my identity removed. ☐

I give consent for researchers to use my data for this study if I no longer have the capacity to take part. ☐

I give permission for individuals from regulatory authorities and/or the NHS Trust to access my data where it is relevant to my participation in this research. ☐

It is my own choice to take part in this research. ☐

(Write your name below)

I, ____voluntarily agree to take part in this research, along with the researcher.

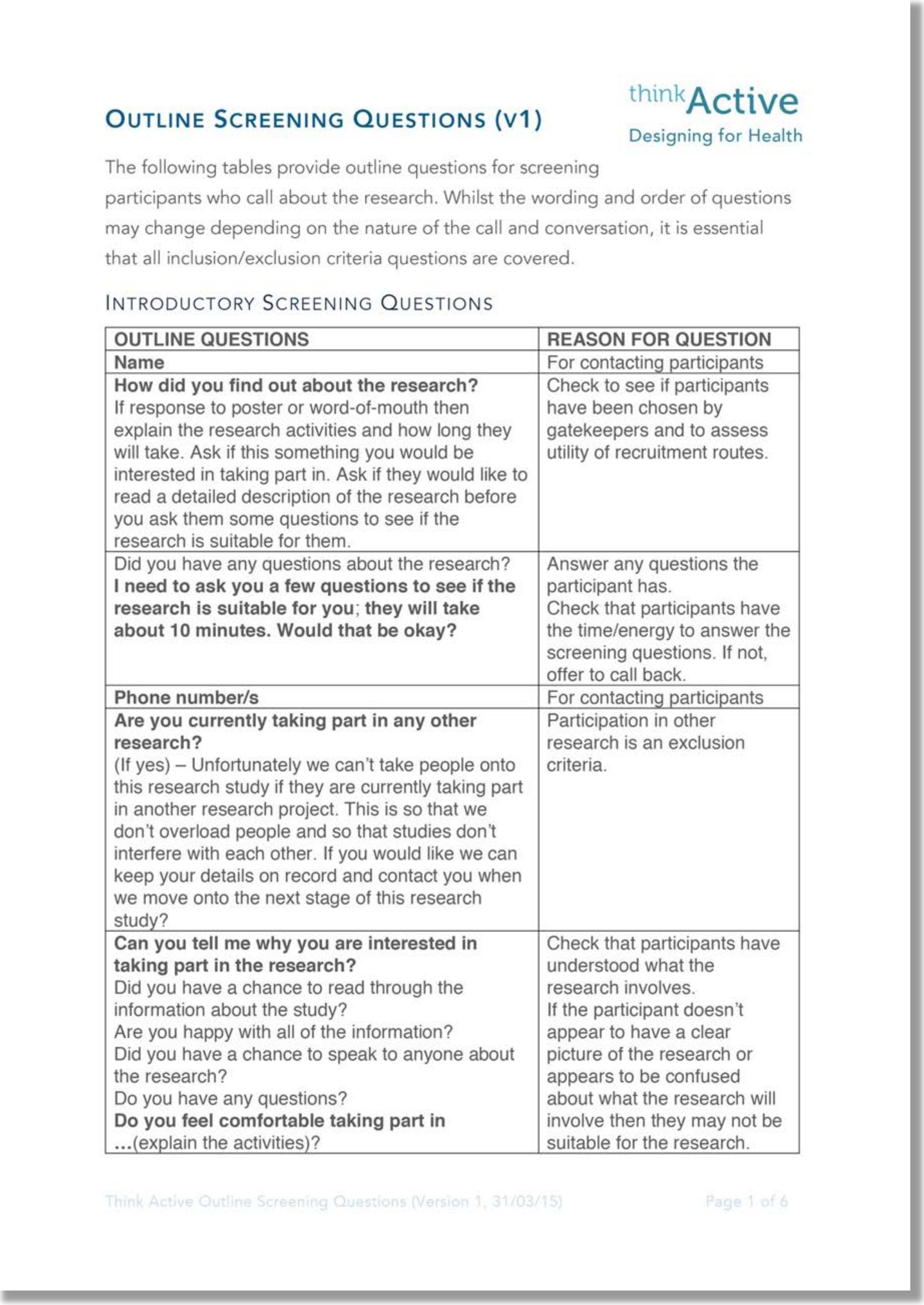
Signature ________________________ Date ________________

Researcher:____

Signature _________________________ Date ________________

Think Active Consent Form (Phase 1a P, Version 2, 31/03/15) Page 2 of 2

F. Screening questions



thinkActive
Designing for Health

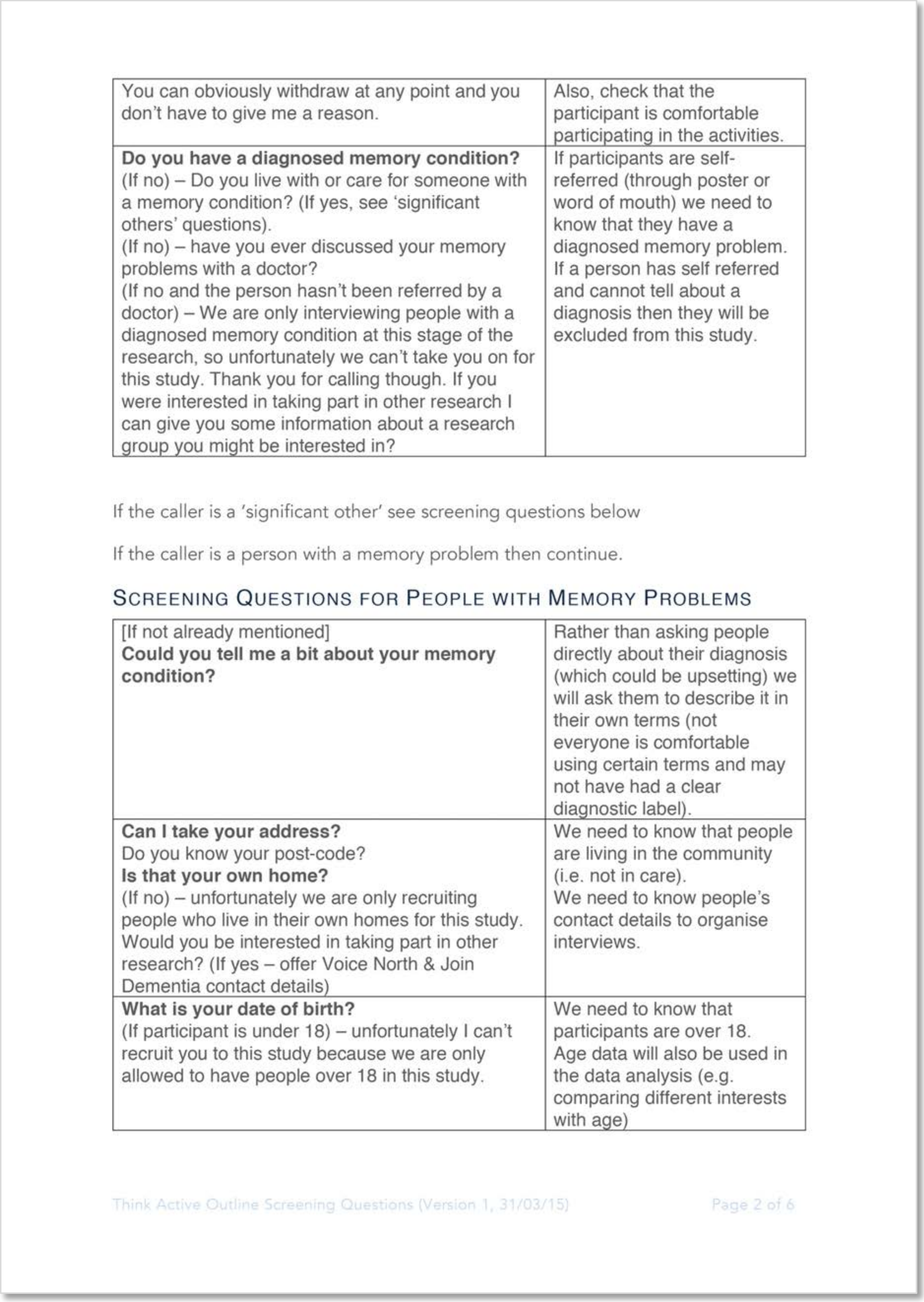
OUTLINE SCREENING QUESTIONS (V1)

The following tables provide outline questions for screening participants who call about the research. Whilst the wording and order of questions may change depending on the nature of the call and conversation, it is essential that all inclusion/exclusion criteria questions are covered.

INTRODUCTORY SCREENING QUESTIONS

OUTLINE QUESTIONS	REASON FOR QUESTION
Name	For contacting participants
How did you find out about the research? If response to poster or word-of-mouth then explain the research activities and how long they will take. Ask if this something you would be interested in taking part in. Ask if they would like to read a detailed description of the research before you ask them some questions to see if the research is suitable for them.	Check to see if participants have been chosen by gatekeepers and to assess utility of recruitment routes.
Did you have any questions about the research? **I need to ask you a few questions to see if the research is suitable for you**; **they will take about 10 minutes. Would that be okay?**	Answer any questions the participant has. Check that participants have the time/energy to answer the screening questions. If not, offer to call back.
Phone number/s	For contacting participants
Are you currently taking part in any other research? (If yes) – Unfortunately we can't take people onto this research study if they are currently taking part in another research project. This is so that we don't overload people and so that studies don't interfere with each other. If you would like we can keep your details on record and contact you when we move onto the next stage of this research study?	Participation in other research is an exclusion criteria.
Can you tell me why you are interested in taking part in the research? Did you have a chance to read through the information about the study? Are you happy with all of the information? Did you have a chance to speak to anyone about the research? Do you have any questions? **Do you feel comfortable taking part in …**(explain the activities)?	Check that participants have understood what the research involves. If the participant doesn't appear to have a clear picture of the research or appears to be confused about what the research will involve then they may not be suitable for the research.

Think Active Outline Screening Questions (Version 1, 31/03/15) Page 1 of 6



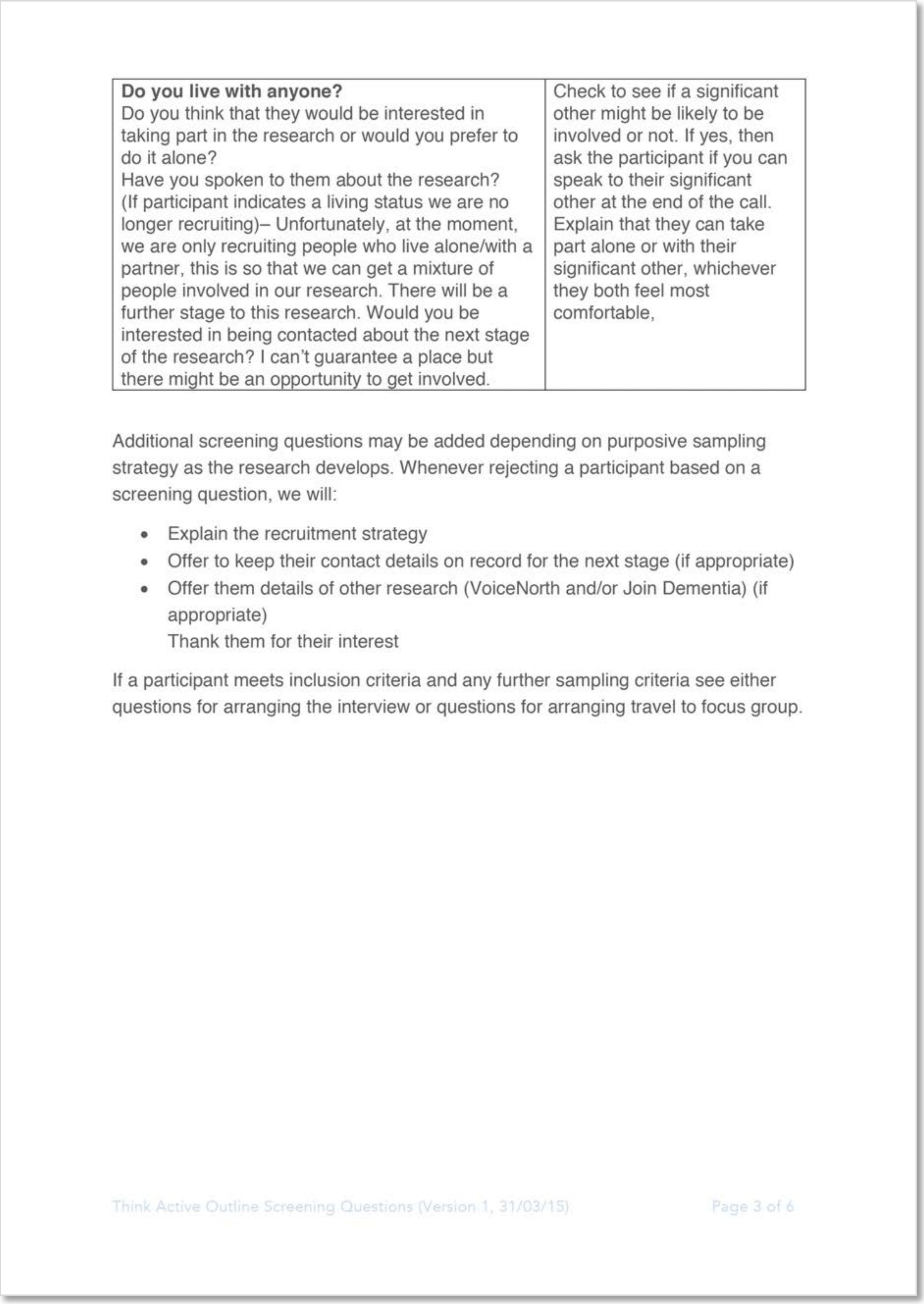
You can obviously withdraw at any point and you don't have to give me a reason.	Also, check that the participant is comfortable participating in the activities.
Do you have a diagnosed memory condition? (If no) – Do you live with or care for someone with a memory condition? (If yes, see 'significant others' questions). (If no) – have you ever discussed your memory problems with a doctor? (If no and the person hasn't been referred by a doctor) – We are only interviewing people with a diagnosed memory condition at this stage of the research, so unfortunately we can't take you on for this study. Thank you for calling though. If you were interested in taking part in other research I can give you some information about a research group you might be interested in?	If participants are self-referred (through poster or word of mouth) we need to know that they have a diagnosed memory problem. If a person has self referred and cannot tell about a diagnosis then they will be excluded from this study.

If the caller is a 'significant other' see screening questions below

If the caller is a person with a memory problem then continue.

SCREENING QUESTIONS FOR PEOPLE WITH MEMORY PROBLEMS

[If not already mentioned] **Could you tell me a bit about your memory condition?**	Rather than asking people directly about their diagnosis (which could be upsetting) we will ask them to describe it in their own terms (not everyone is comfortable using certain terms and may not have had a clear diagnostic label).
Can I take your address? Do you know your post-code? **Is that your own home?** (If no) – unfortunately we are only recruiting people who live in their own homes for this study. Would you be interested in taking part in other research? (If yes – offer Voice North & Join Dementia contact details)	We need to know that people are living in the community (i.e. not in care). We need to know people's contact details to organise interviews.
What is your date of birth? (If participant is under 18) – unfortunately I can't recruit you to this study because we are only allowed to have people over 18 in this study.	We need to know that participants are over 18. Age data will also be used in the data analysis (e.g. comparing different interests with age)

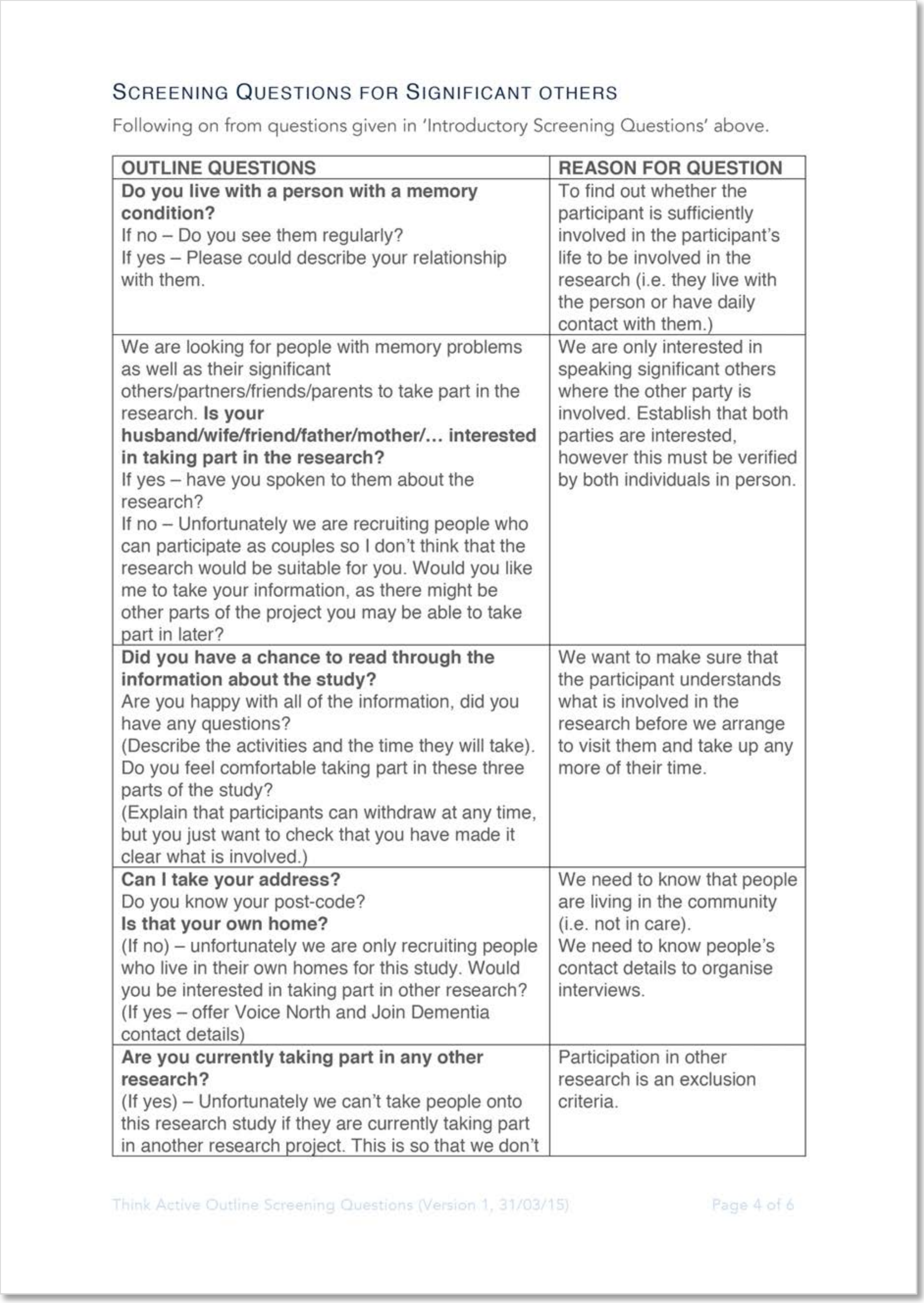


Do you live with anyone? Do you think that they would be interested in taking part in the research or would you prefer to do it alone? Have you spoken to them about the research? (If participant indicates a living status we are no longer recruiting)– Unfortunately, at the moment, we are only recruiting people who live alone/with a partner, this is so that we can get a mixture of people involved in our research. There will be a further stage to this research. Would you be interested in being contacted about the next stage of the research? I can't guarantee a place but there might be an opportunity to get involved.	Check to see if a significant other might be likely to be involved or not. If yes, then ask the participant if you can speak to their significant other at the end of the call. Explain that they can take part alone or with their significant other, whichever they both feel most comfortable,

Additional screening questions may be added depending on purposive sampling strategy as the research develops. Whenever rejecting a participant based on a screening question, we will:

- Explain the recruitment strategy
- Offer to keep their contact details on record for the next stage (if appropriate)
- Offer them details of other research (VoiceNorth and/or Join Dementia) (if appropriate)
  Thank them for their interest

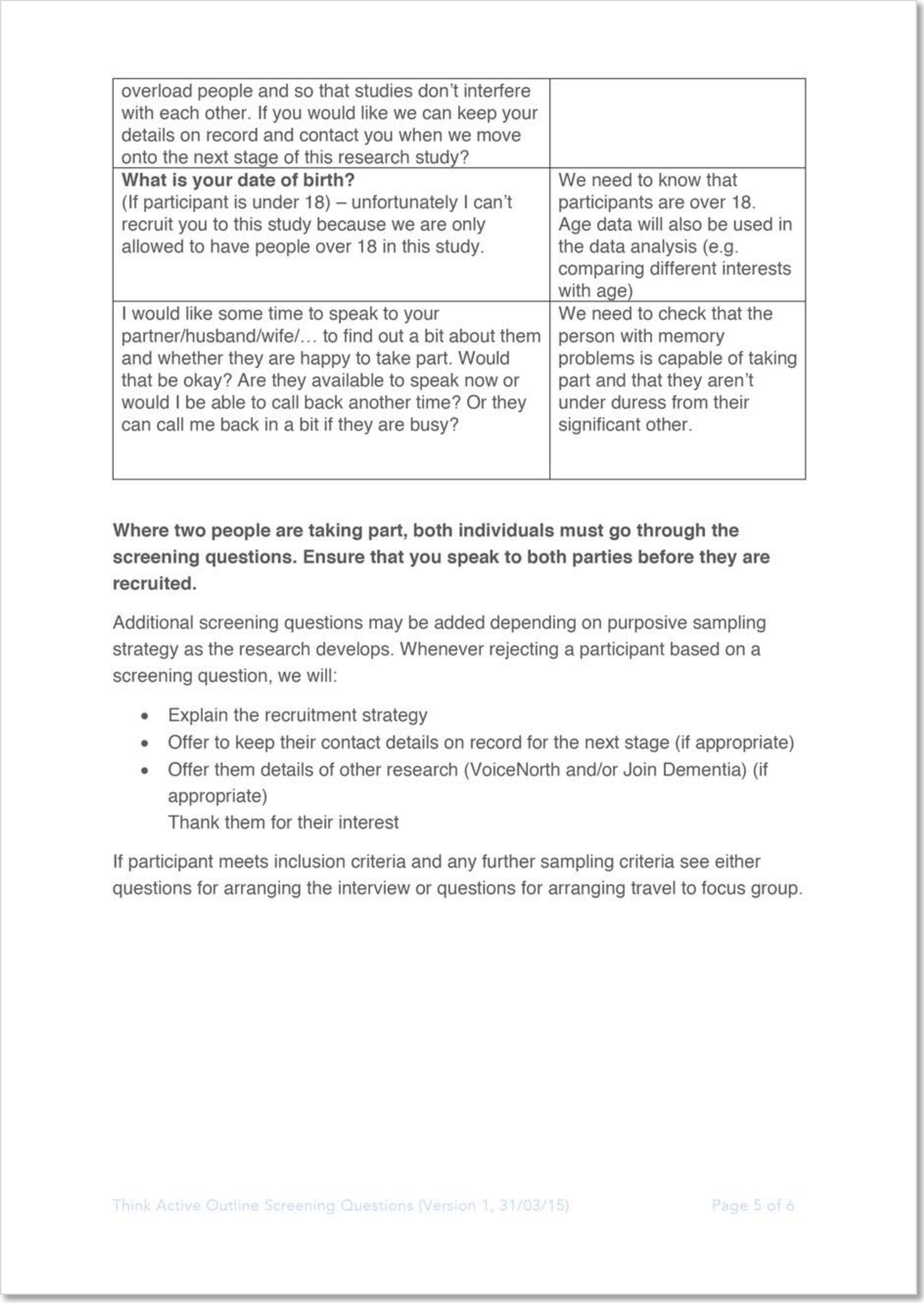
If a participant meets inclusion criteria and any further sampling criteria see either questions for arranging the interview or questions for arranging travel to focus group.



SCREENING QUESTIONS FOR SIGNIFICANT OTHERS

Following on from questions given in 'Introductory Screening Questions' above.

OUTLINE QUESTIONS	REASON FOR QUESTION
Do you live with a person with a memory condition? If no – Do you see them regularly? If yes – Please could describe your relationship with them.	To find out whether the participant is sufficiently involved in the participant's life to be involved in the research (i.e. they live with the person or have daily contact with them.)
We are looking for people with memory problems as well as their significant others/partners/friends/parents to take part in the research. **Is your husband/wife/friend/father/mother/… interested in taking part in the research?** If yes – have you spoken to them about the research? If no – Unfortunately we are recruiting people who can participate as couples so I don't think that the research would be suitable for you. Would you like me to take your information, as there might be other parts of the project you may be able to take part in later?	We are only interested in speaking significant others where the other party is involved. Establish that both parties are interested, however this must be verified by both individuals in person.
Did you have a chance to read through the information about the study? Are you happy with all of the information, did you have any questions? (Describe the activities and the time they will take). Do you feel comfortable taking part in these three parts of the study? (Explain that participants can withdraw at any time, but you just want to check that you have made it clear what is involved.)	We want to make sure that the participant understands what is involved in the research before we arrange to visit them and take up any more of their time.
Can I take your address? Do you know your post-code? **Is that your own home?** (If no) – unfortunately we are only recruiting people who live in their own homes for this study. Would you be interested in taking part in other research? (If yes – offer Voice North and Join Dementia contact details)	We need to know that people are living in the community (i.e. not in care). We need to know people's contact details to organise interviews.
Are you currently taking part in any other research? (If yes) – Unfortunately we can't take people onto this research study if they are currently taking part in another research project. This is so that we don't	Participation in other research is an exclusion criteria.



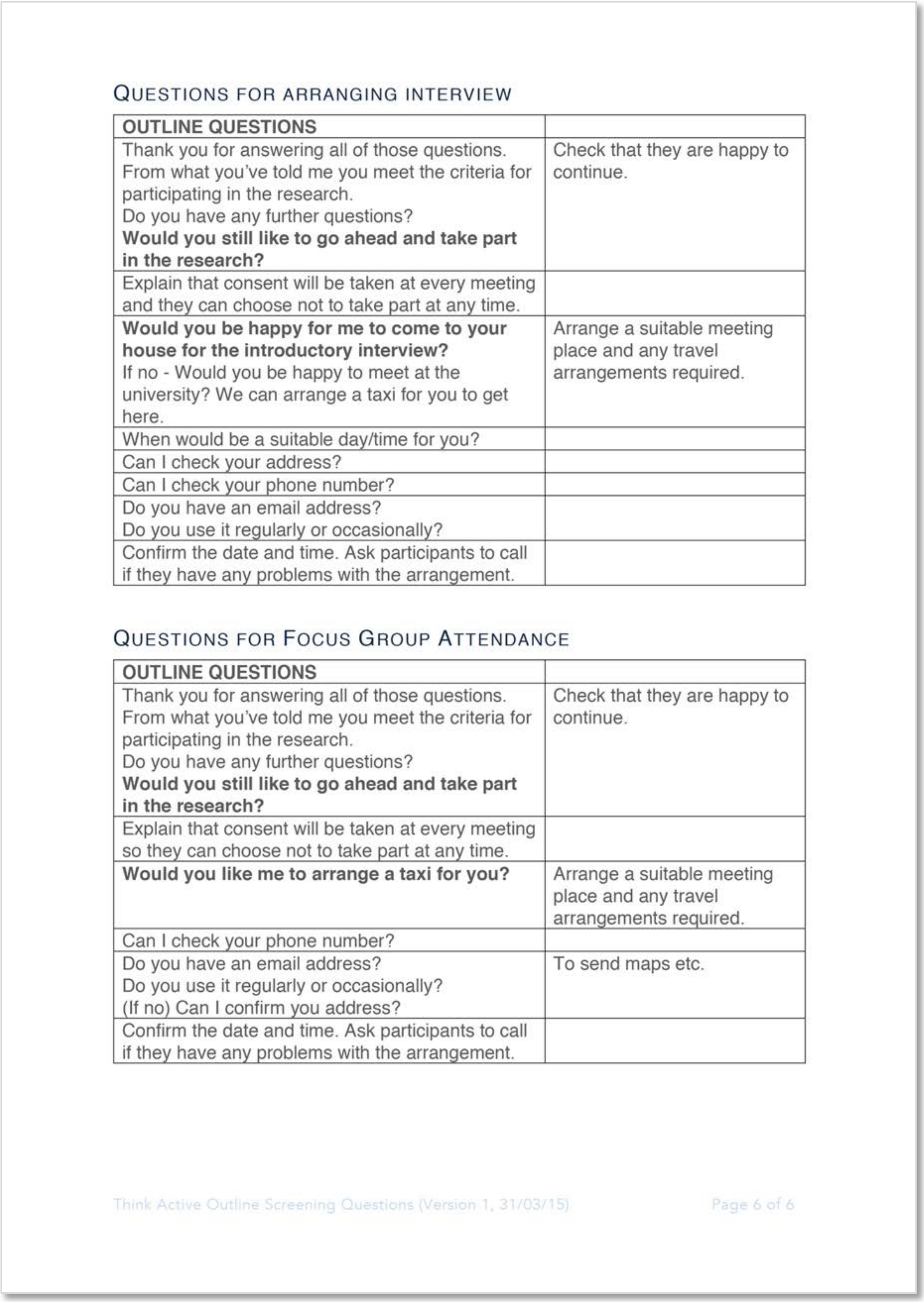
overload people and so that studies don't interfere with each other. If you would like we can keep your details on record and contact you when we move onto the next stage of this research study?	
What is your date of birth? (If participant is under 18) – unfortunately I can't recruit you to this study because we are only allowed to have people over 18 in this study.	We need to know that participants are over 18. Age data will also be used in the data analysis (e.g. comparing different interests with age)
I would like some time to speak to your partner/husband/wife/… to find out a bit about them and whether they are happy to take part. Would that be okay? Are they available to speak now or would I be able to call back another time? Or they can call me back in a bit if they are busy?	We need to check that the person with memory problems is capable of taking part and that they aren't under duress from their significant other.

Where two people are taking part, both individuals must go through the screening questions. Ensure that you speak to both parties before they are recruited.

Additional screening questions may be added depending on purposive sampling strategy as the research develops. Whenever rejecting a participant based on a screening question, we will:

- Explain the recruitment strategy
- Offer to keep their contact details on record for the next stage (if appropriate)
- Offer them details of other research (VoiceNorth and/or Join Dementia) (if appropriate)
  Thank them for their interest

If participant meets inclusion criteria and any further sampling criteria see either questions for arranging the interview or questions for arranging travel to focus group.



Questions for arranging interview

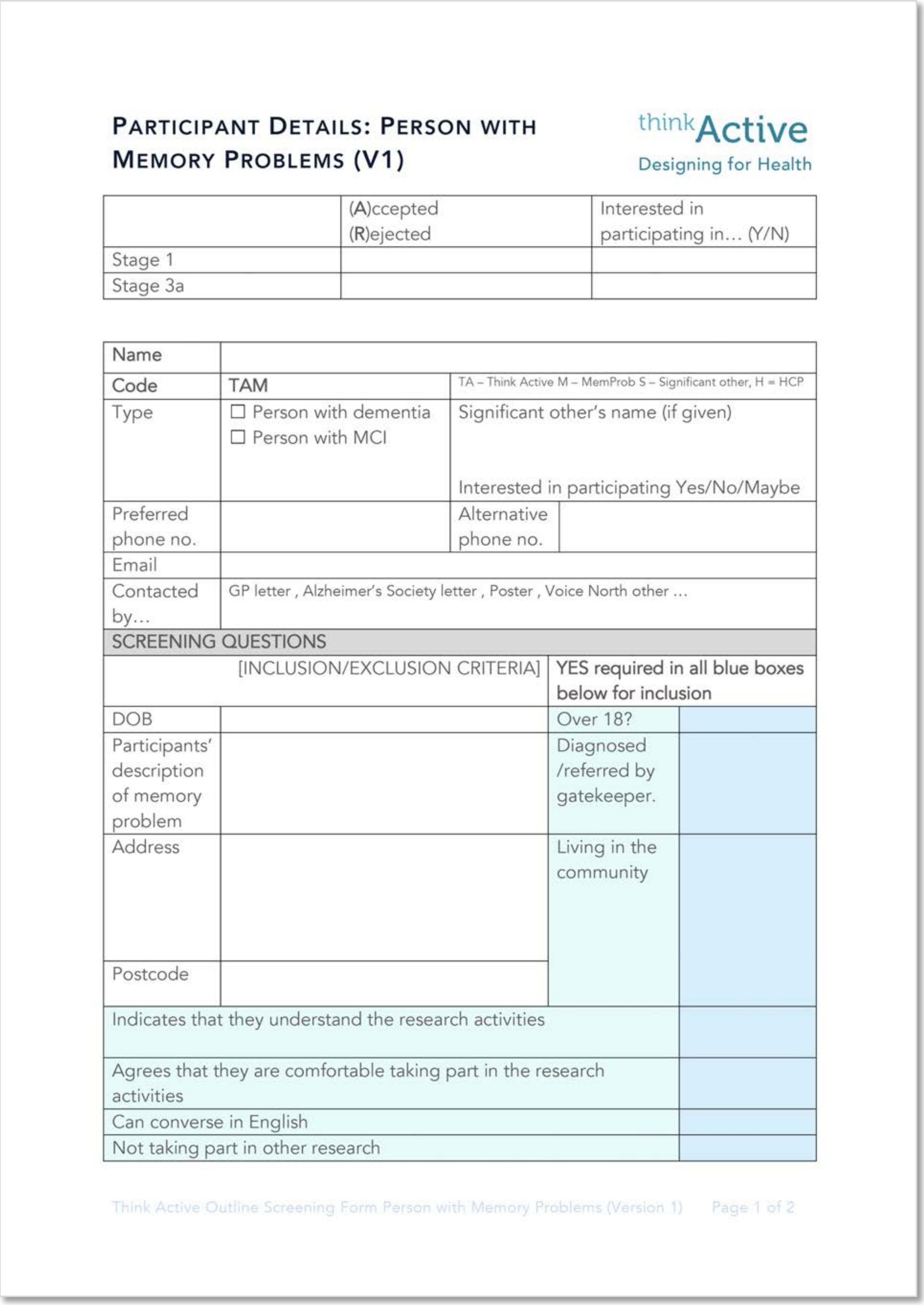
OUTLINE QUESTIONS	
Thank you for answering all of those questions. From what you've told me you meet the criteria for participating in the research. Do you have any further questions? **Would you still like to go ahead and take part in the research?**	Check that they are happy to continue.
Explain that consent will be taken at every meeting and they can choose not to take part at any time.	
Would you be happy for me to come to your house for the introductory interview? If no - Would you be happy to meet at the university? We can arrange a taxi for you to get here.	Arrange a suitable meeting place and any travel arrangements required.
When would be a suitable day/time for you?	
Can I check your address?	
Can I check your phone number?	
Do you have an email address? Do you use it regularly or occasionally?	
Confirm the date and time. Ask participants to call if they have any problems with the arrangement.	

Questions for Focus Group Attendance

OUTLINE QUESTIONS	
Thank you for answering all of those questions. From what you've told me you meet the criteria for participating in the research. Do you have any further questions? **Would you still like to go ahead and take part in the research?**	Check that they are happy to continue.
Explain that consent will be taken at every meeting so they can choose not to take part at any time.	
Would you like me to arrange a taxi for you?	Arrange a suitable meeting place and any travel arrangements required.
Can I check your phone number?	
Do you have an email address? Do you use it regularly or occasionally? (If no) Can I confirm you address?	To send maps etc.
Confirm the date and time. Ask participants to call if they have any problems with the arrangement.	

G. Example screening form

The following is an example of a screening form for potential participants with memory problems. A slightly different form was used to record the screening of partners/caregivers.



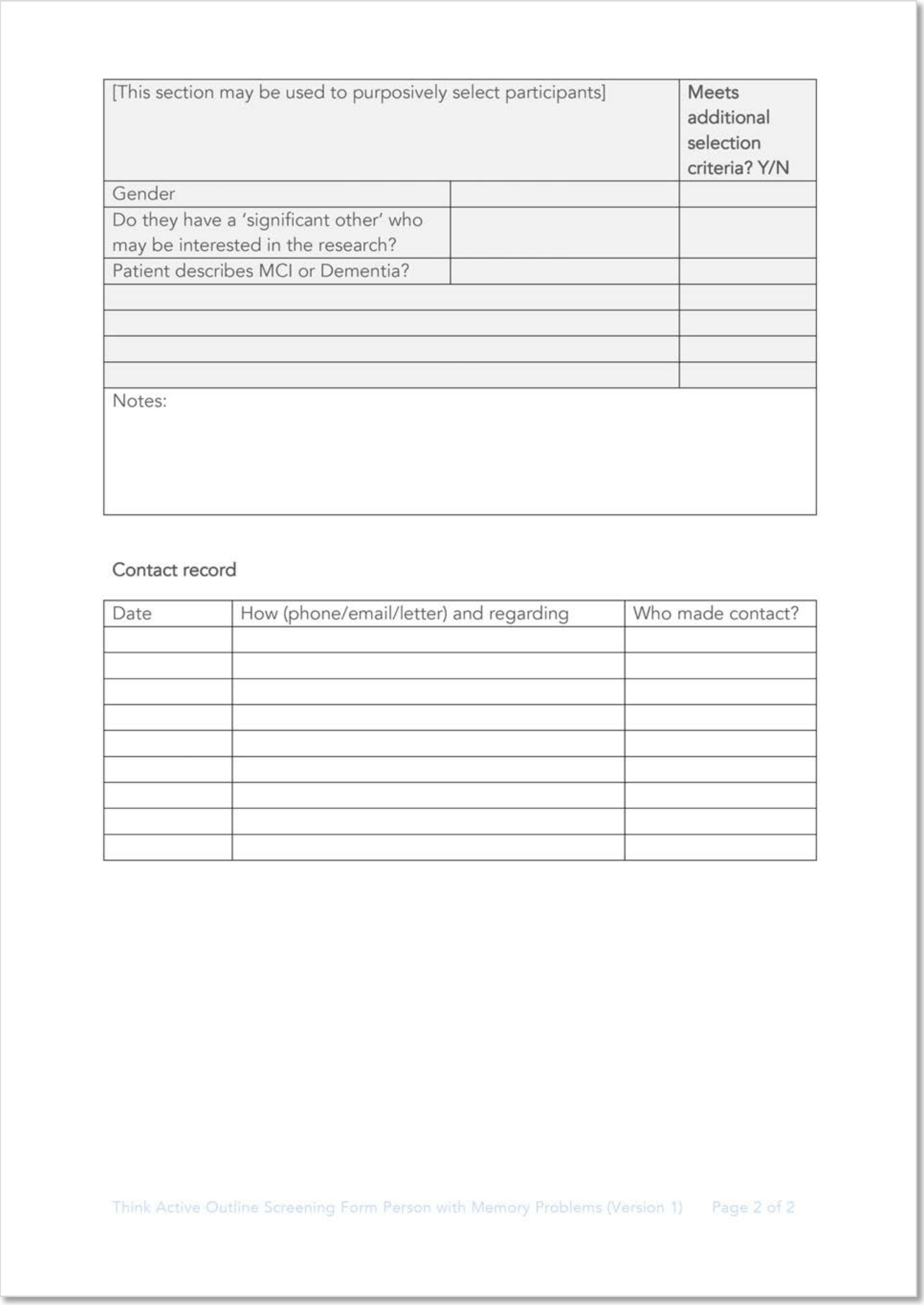
PARTICIPANT DETAILS: PERSON WITH MEMORY PROBLEMS (V1)

thinkActive
Designing for Health

	(A)ccepted (R)ejected	Interested in participating in… (Y/N)
Stage 1		
Stage 3a		

Name				
Code	TAM	TA – Think Active M – MemProb S – Significant other, H = HCP		
Type	☐ Person with dementia ☐ Person with MCI	Significant other's name (if given) Interested in participating Yes/No/Maybe		
Preferred phone no.		Alternative phone no.		
Email				
Contacted by…	GP letter , Alzheimer's Society letter , Poster , Voice North other …			
SCREENING QUESTIONS				
	[INCLUSION/EXCLUSION CRITERIA]		**YES required in all blue boxes below for inclusion**	
DOB			Over 18?	
Participants' description of memory problem			Diagnosed /referred by gatekeeper.	
Address			Living in the community	
Postcode				
Indicates that they understand the research activities				
Agrees that they are comfortable taking part in the research activities				
Can converse in English				
Not taking part in other research				

Think Active Outline Screening Form Person with Memory Problems (Version 1) Page 1 of 2



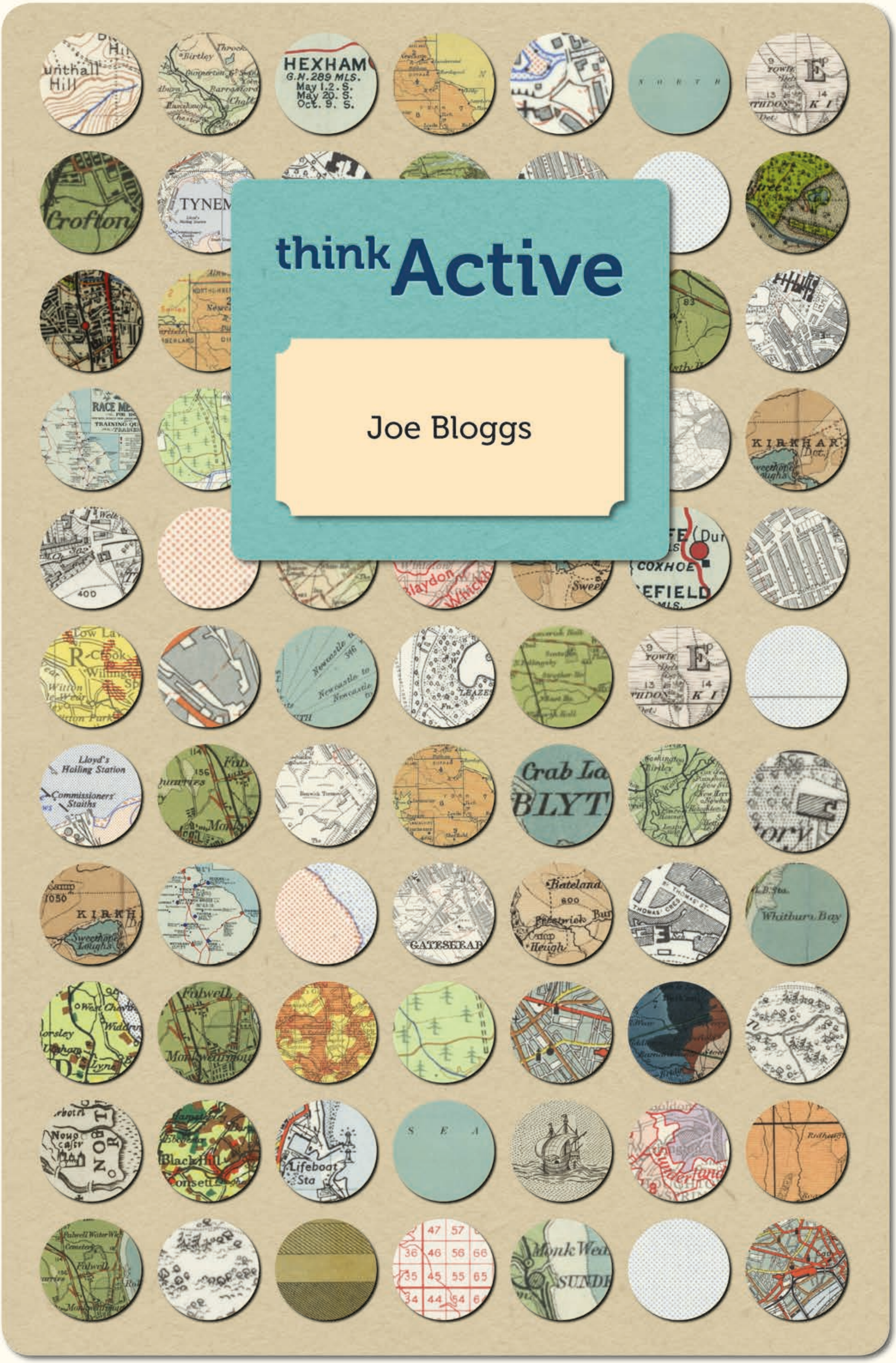
[This section may be used to purposively select participants]		**Meets additional selection criteria? Y/N**
Gender		
Do they have a 'significant other' who may be interested in the research?		
Patient describes MCI or Dementia?		
Notes:		

Contact record

Date	How (phone/email/letter) and regarding	Who made contact?

H. Example diary probe

The diary probes, shown on the following pages, were personalised with each participants’ name on the front page. The maps were also adapted for each participant so that they centred on the participant’s home location.



think Active

Joe Bloggs

Guide

Thank you for agreeing to be a part of the Think Active research study. I hope you enjoy taking part.

I need your help so that I can understand different aspects of people's lives. I want to know about the normal things people do as well as the unusual things. I want to know about the things people enjoy doing. I would also like to find out what stops people from doing the things they want to do. This information will help me to design services that will help people to be more active.

In this booklet you will find a series of activities that I would like you to try.

Some days there are diary pages. Some days have an extra activity. You do not have to do them in the order I have given you.

If you find an activity confusing or difficult then please let me know so I can change it.

I would like to talk to you about the things you record in the diary when I return for a second meeting. However, you do not have to talk about anything you do not want to.

If you have a question then please call me on:

033 33 444 034 (local rate number).

I will be happy to answer any questions you have.

There are no wrong answers to any of the questions!

Camera practice

Try out the camera.

Why not take a picture of your favourite thing in the room.

Try printing the picture and sticking it here.

You can try taking more pictures and sticking them in the spaces below.

Have fun with the camera!

Try to put the camera on charge when you're not using it.

Take lots of pictures!

I want you to enjoy using the camera. If you get stuck then you can give me a call.

Don't worry about breaking it. I would like to use it again but I understand accidents can happen.

Diary pages

Please use the diary pages to record the activities you do over the next few days.

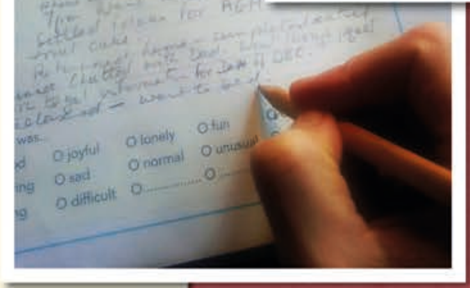
You can use the pages however you like. You could:

- Write things down throughout the day.
- Write at the end of the day.
- Take photos of things you do during the day and stick them in.
- Sketch or doodle.
- Collect things during the day and stick them into the diary.

What you tell me is your choice entirely. You might include:

- **The places you go.**
- **Who you go with.**
- **The people you meet.**
- **How you felt.**

I have asked you to fill in the diary because I want to know about the different things people do and why they do them. This will help me to design products for people in the future.



Day 1 - diary

I want to know about people's daily routines.

List the main things you do or did today. You can add photos too.

During the night...

This morning...

What did you do today?

Was today a 'normal' day?

In the evening...

This afternoon...

Think Active Co-design Diary V2 3 August 2015

Day 2 - Diary

Today I would like you **write about the things you do and describe how you felt** during the day. What did you enjoy? What did you dislike? Through this exercise I want to find out what motivates people to do different things.

During the night...

In the morning...

Did anything make you smile?

Did anything frustrate you?

This afternoon...

In the evening...

Body and mind

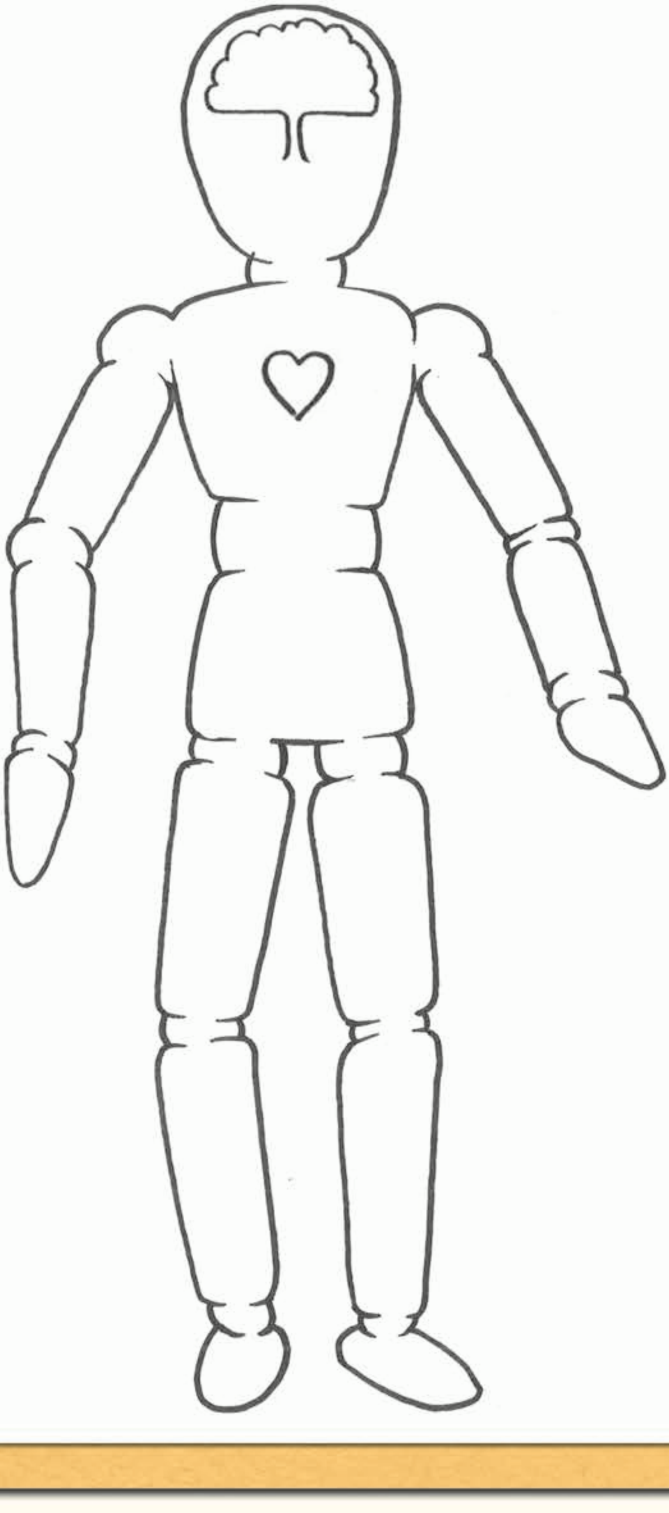
I want to know how your health effects the things you do.

Colour the parts of your body you feel positive about in yellow. If some parts of your body make doing things difficult then colour them in red.

For example someone might colour the hands red if sore joints stop them from doing things. They might colour their head yellow if they are good at crosswords.

🟨 Good bits

🟥 Troublesome bits - make doing some things difficult



Day 3 - Out and about

I would like to know about the different places people go. I will use this information so that I can design services that suit different people's lifestyles.

On the following pages I have included different scales of maps, starting with a map close to your home and then zooming out.

Use the pens and sticky notes to **mark different places you go onto the maps.** Tell me about the things you do everyday as well as things you do occasionally.

You don't have to use all of the maps.

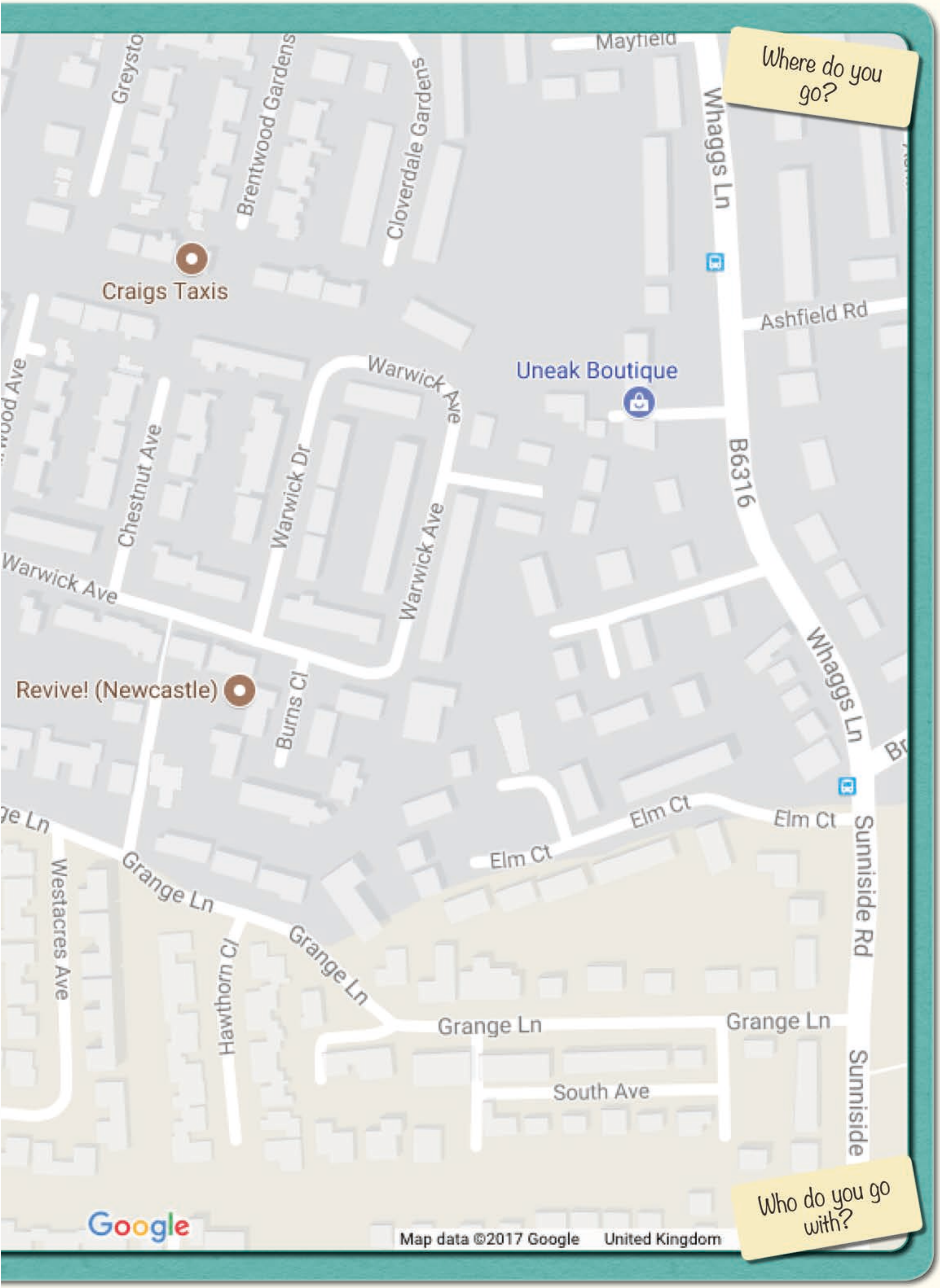
You could add notes about:

- **Where you go,**
- **Why you go there,**
- **With whom and**
- **How often.**

You can **stick in photos** of the places you go and people you meet during the week.

You can mark the routes you take.

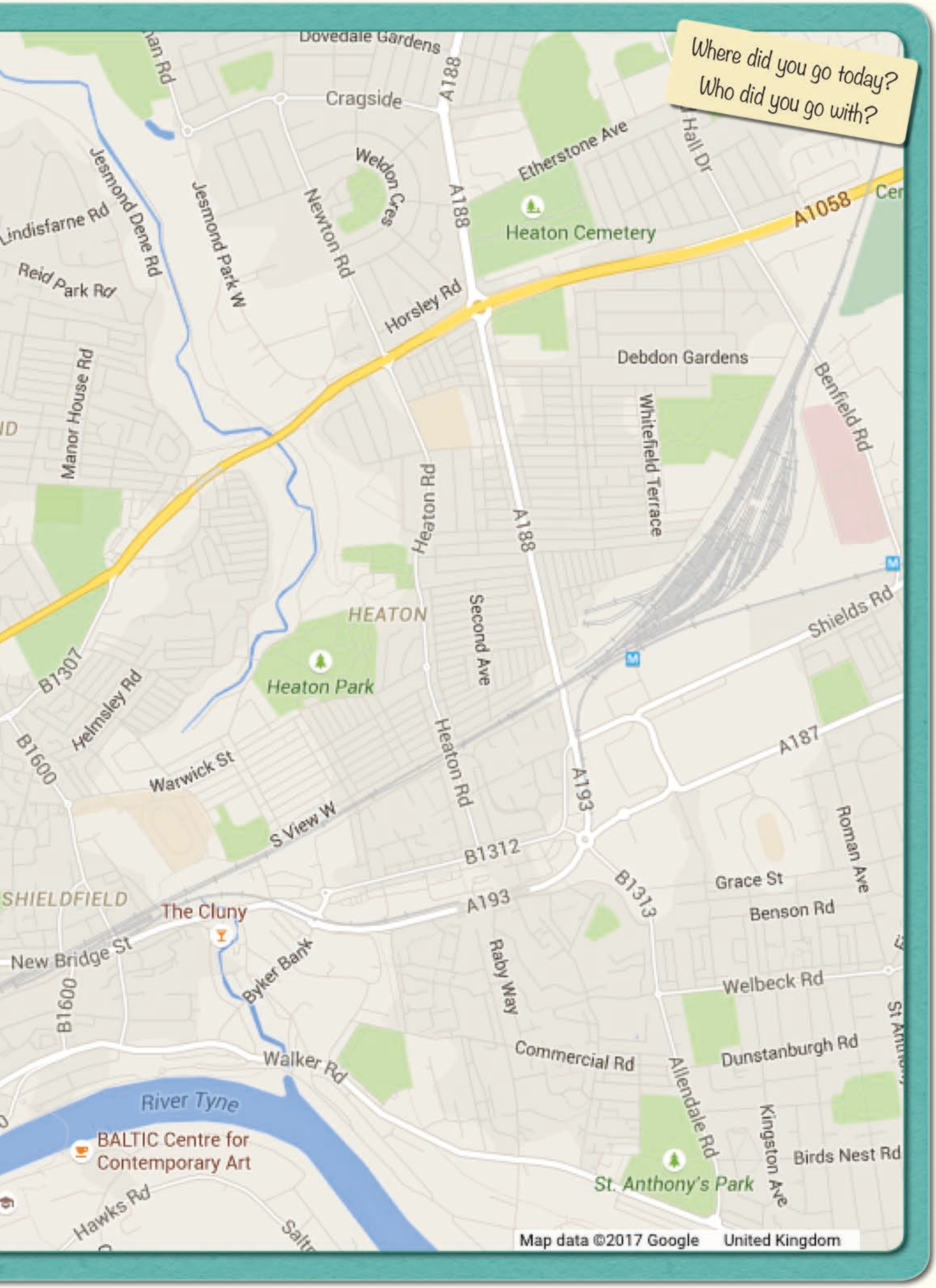
You could even include places you would like to go.



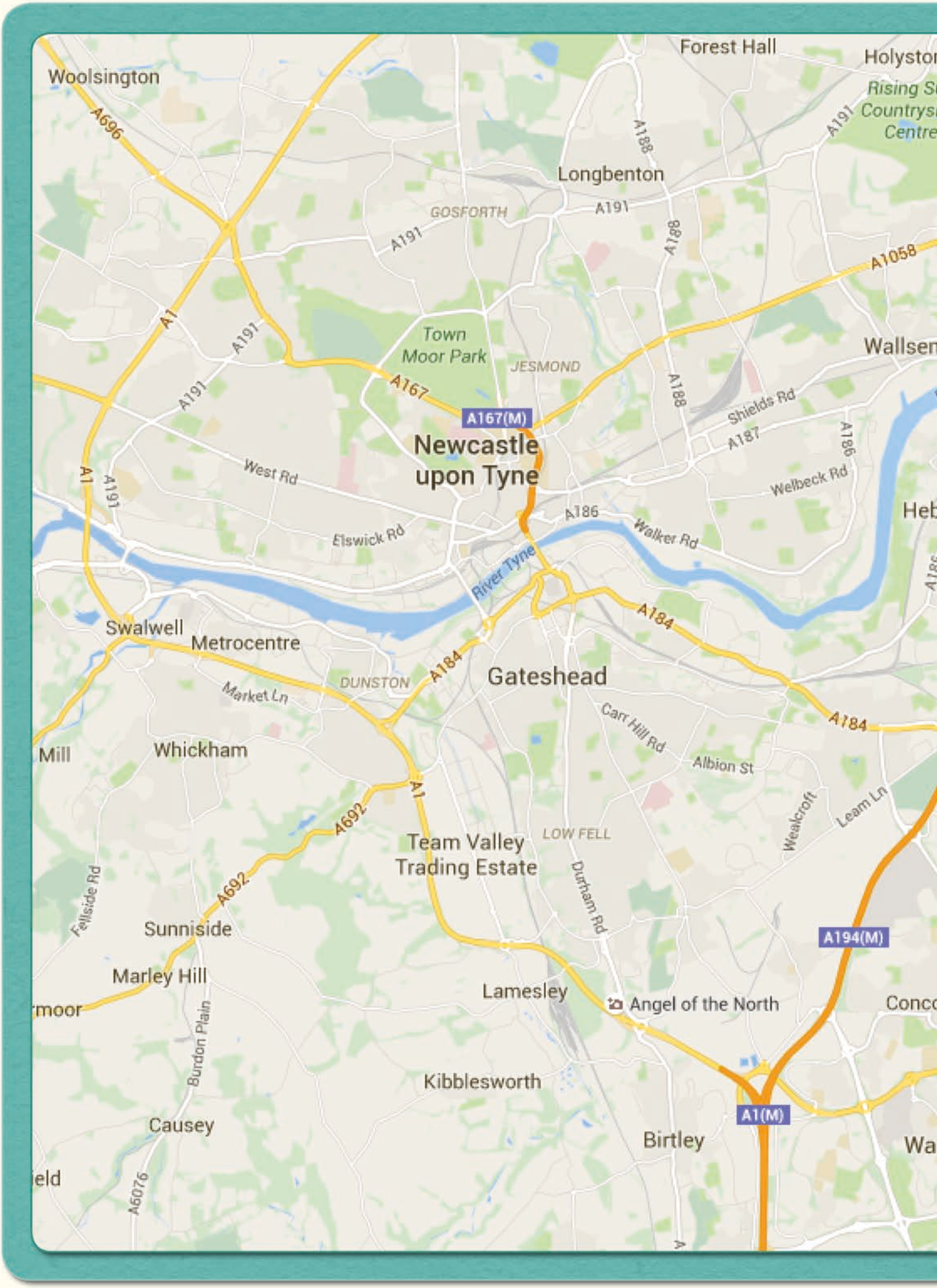
Where do you go?

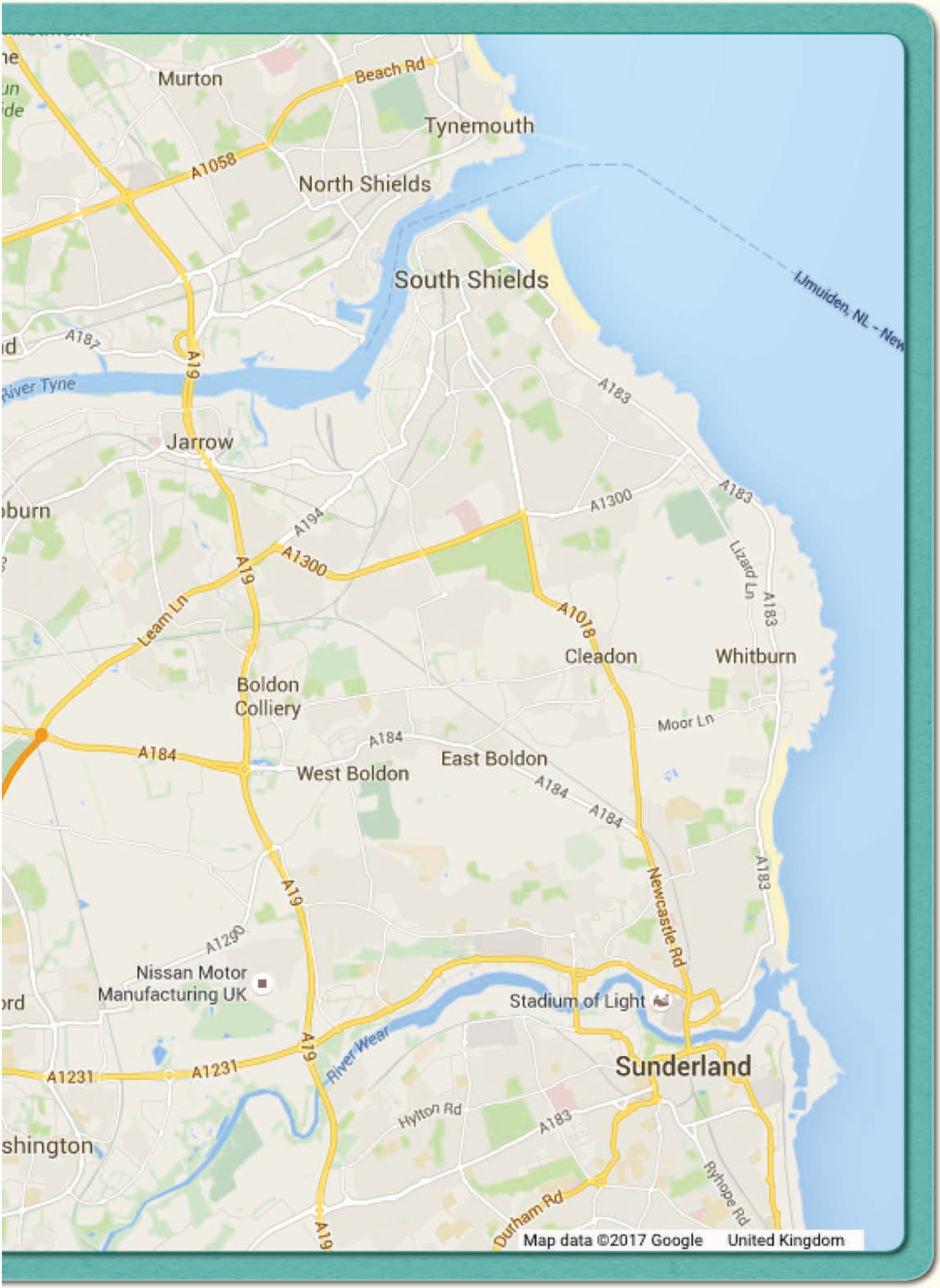
Who do you go with?


Wyndham
Kenton Ave
The Drive
Moorfield
Dukes Moor Park
Montagu Ave
Westfield
Moor (North)
Grandstand Rd
Town Moor Park
Highbury
Brentwood Ave
Forsyth Rd
JESMON
Moor (Central)
A167
Great N Rd
Hunters Moor
Clayton Rd
Exhibition Park
Claremont Rd
Hunter's Rd
Ponteland Rd
Moor (South)
Richardson Rd
Newcastle University Robinson Library
Newcastle upon Tyne
A167(M)
Sidney Grove
Brighton Grove
Croydon Rd
Barrack Rd
Arthurs Hill
Stanhope St
St. James' Park
intu Eldon Square
Pitt St
LEAZES
Pilgrim St
Dunholme Rd
Bentinck Rd
Westgate Rd
St James' Blvd
O2 Academy Newcastle
Elswick Rd
Neville St
Sage Gateshead



Where did you go today?
Who did you go with?


Woolsington
A696
Forest Hall
Holystor
Rising S
Countrys
Centre
A191
A188
Longbenton
GOSFORTH
A191
A191
A188
A1058
A1
A191
Town
Moor Park
JESMOND
A167
A191
A188
Wallsen
Shields Rd
A167(M)
A187
A186
Newcastle
upon Tyne
A1
A191
West Rd
Welbeck Rd
A186
Walker Rd
Heb
Elswick Rd
River Tyne
A184
Swalwell
Metrocentre
DUNSTON
A184
Gateshead
Market Ln
Carr Hill Rd
A184
Mill
Whickham
Albion St
A1
A692
Leam Ln
Wealcroft
LOW FELL
Team Valley
Trading Estate
Fellside Rd
A692
Durham Rd
Sunniside
A194(M)
Marley Hill
Lamesley
Angel of the North
Conco
rmoor
Burdon Plain
Kibblesworth
A1(M)
Causey
Birtley
Wa
ield
A6076


Murton
Beach Rd
Tynemouth
A1058
North Shields
South Shields
IJmuiden, NL - New
A187
A19
River Tyne
A183
Jarrow
A1300
A183
A194
A1300
A19
Lizard Ln
A183
Leam Ln
A1018
Cleadon
Whitburn
Boldon
Colliery
Moor Ln
A184
A184
East Boldon
West Boldon
A184
A184
A19
Newcastle Rd
A183
A1290
Nissan Motor
Manufacturing UK
Stadium of Light
A1231
A1231
A19
River Wear
Sunderland
Hylton Rd
A183
Ryhope Rd
Durham Rd
A19
Map data ©2017 Google
United Kingdom

Day 4 - diary

Try to **take pictures of three different activities you do today.** They could be everyday things like gardening or going to the shops. You can include a description as well.

Did you go out anywhere?

Did you do anything unusual?

Hobbies and interests

I would like to know about the things people enjoy doing so that I can design services that suit people's interests.

Tell me about **your favourite activity, hobby or interest.**

It could be something you do often or occasionally.

It could be something you used to do or would like to do.

Try to take a photo that tells me about your interest. It could be a piece of equipment you use for your hobby. You could draw a picture or stick in an artefact that relates to your hobby or interest.

My favourite activity is....

What makes it enjoyable?

How does it make you feel?

Could it be even better?

How easy is it?

Day 5 - diary

I want to know about the types of technology that people use.

Take a picture, draw or describe **three devices or pieces of technology you use today.**

Everyday essentials

I would like to know about the technologies people find helpful and unhelpful.

Take a picture of **an object, device or technology you wouldn't be without.** You can include a description below.

Take or draw a picture of **an object, device or technology that makes your life difficult.** Perhaps there is something you find challenging or frustrating. You can add notes below.

Day 6 - diary

Was anything challenging today?

I would like to know about the problems people face.

Take a picture, draw or describe up to two things that you found difficult or challenging today.

Does your memory make anything difficult to do?

Does your health make anything challenging?

Make a difference

If you could wave a magic wand, what would you have that would help you?

It could be something that already exists or something you have invented. It can be practical or fanciful.

Use the space below to draw or describe a device or service that would help you.

Or you could take a picture of something and explain how you would improve it.

Sketch your idea here:

It doesn't have to be perfect!

Add notes about your idea

Description:

Your notes

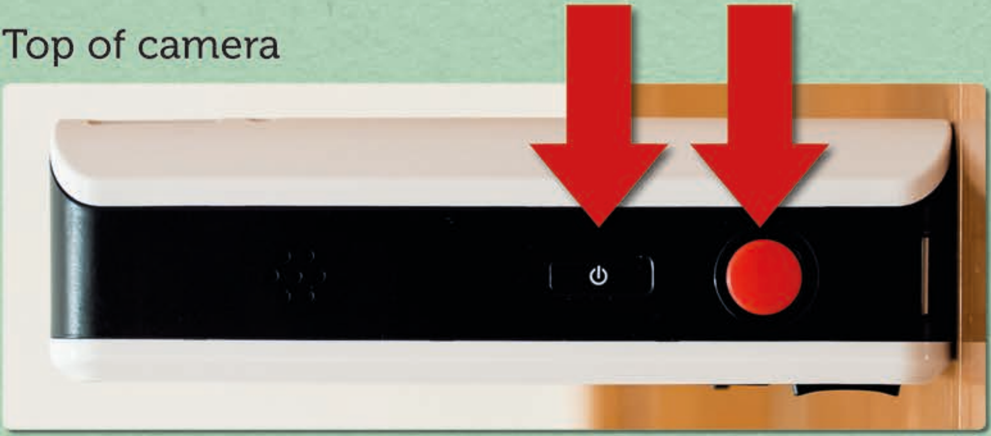
Space for sketches and doodles

Take a picture

1. Press the 'on' button

4. When the picture you want to take is on the screen, press the red button

Top of camera



Back of camera

2. Slide the slider to the right to the camera symbol

3. A picture should appear on the screen.

Point the camera at the thing you want to photograph

If you have any problems then please call :

033 33 444 034

Charging

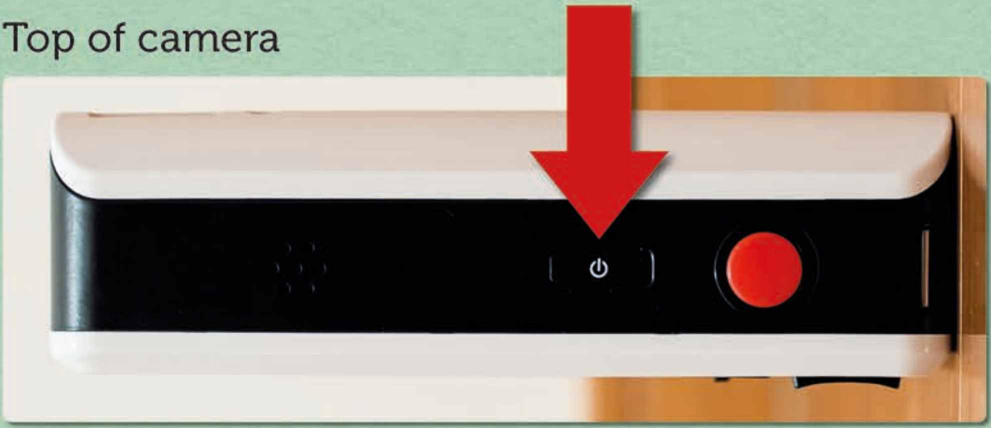
1. Plug the charger into the side of the camera.

2. Leave to charge.

View your pictures

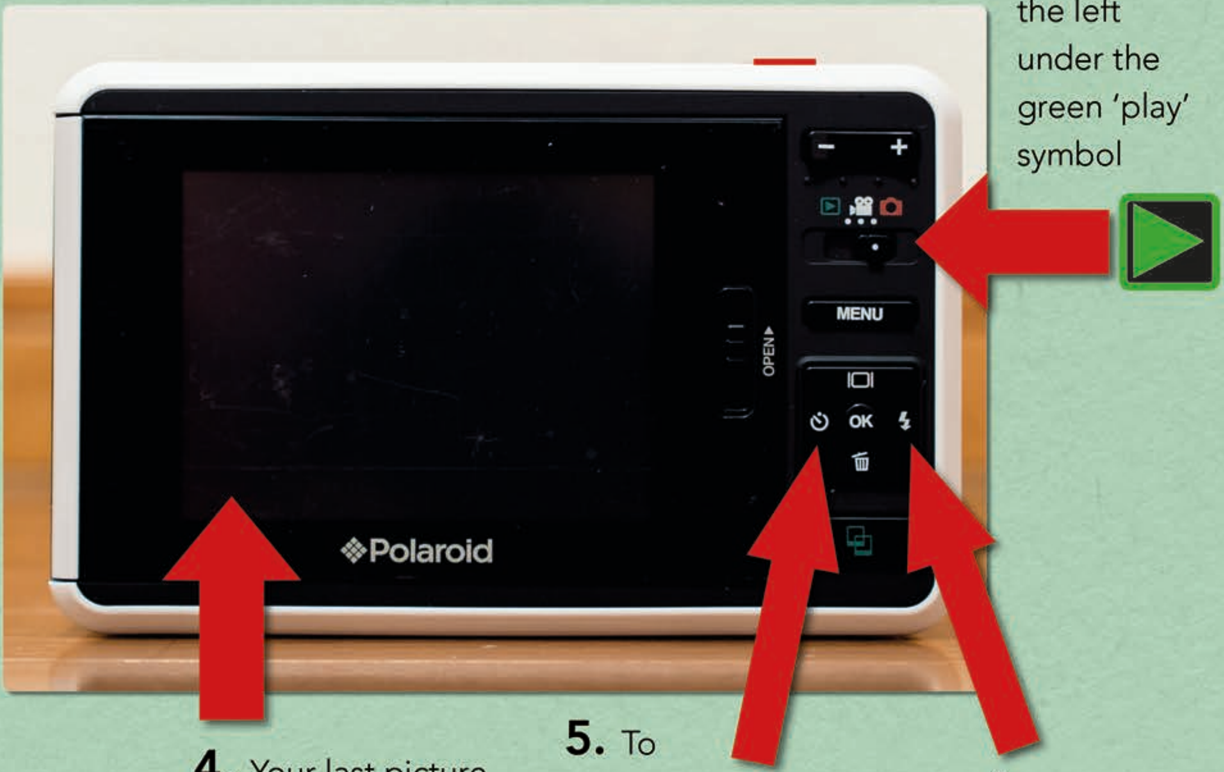
1. Press the 'on' button

Top of camera



2. Move slider to the left under the green 'play' symbol

Back of camera



4. Your last picture will appear on the screen.

5. To see previous pictures press on the left side of the square

6. To see more recent pictures press the right side of the square button

Print a picture

1. Follow the previous instructions for 'view your pictures' to select the picture you want to print.

Back of camera

3. Press the OK button if you are happy to print.

2. When the picture you want to print is on the screen press the bottom button.

(If you have changed your mind press the bottom button to exit.)

4. When this green menu pops up press the top button on the square keypad to select "print"

5. Press the OK button to print.

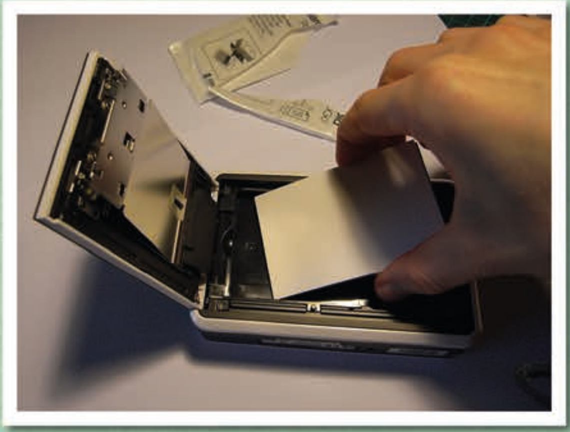
Fill with paper

If you get a message that says 'NO PAPER' you need to put another pack of printer paper in.

NO PAPER
LOAD PAPER TO CONTINUE

1. Press the bottom button

2. Slide this button upwards to open the back of the camera.



3. Open a new pack of paper.

4. Put the paper in the back of the camera with the blue side facing down. The shiny side of the paper should be facing you. Shuffle the paper into the draw so it is all aligned.

Do not put the blue page on the top! The bar code must be facing down.

5. Press down the lid.

DO NOT BLOCK PAPER FEED.
CORRECTION CARD EXITING.

6. You will now get a message saying 'do not block paper feed'. After a few seconds the blue piece of paper will come out of the camera. You can throw this away.

7. You can now print another picture using the previous instructions.

If you have any problems
then please call :

033 33 444 034

Our next meeting

I will visit you again on

....

at

....

I will ask you some questions about the things you have written in the diary. You will not have to talk about anything you do not feel comfortable discussing.

Got a question?

Please call me if you have any questions or would like to rearrange our meeting.

Lizzie Dutton

033 33 444 034

(local rate number)

e.m.dutton@ncl.ac.uk

Help and advice

If you experience negative feelings or concerns about your health then you can call the Alzheimer's Society on:

0300 222 11 22

(Local rate number)

They help people with many different types of memory problems. They also help people who support those with memory problems.

Alternative contacts for support and help:

Your GP (doctor)

Age UK: 0800 169 6565 (normally free from landlines)

The Samaritans: 08457 90 90 90

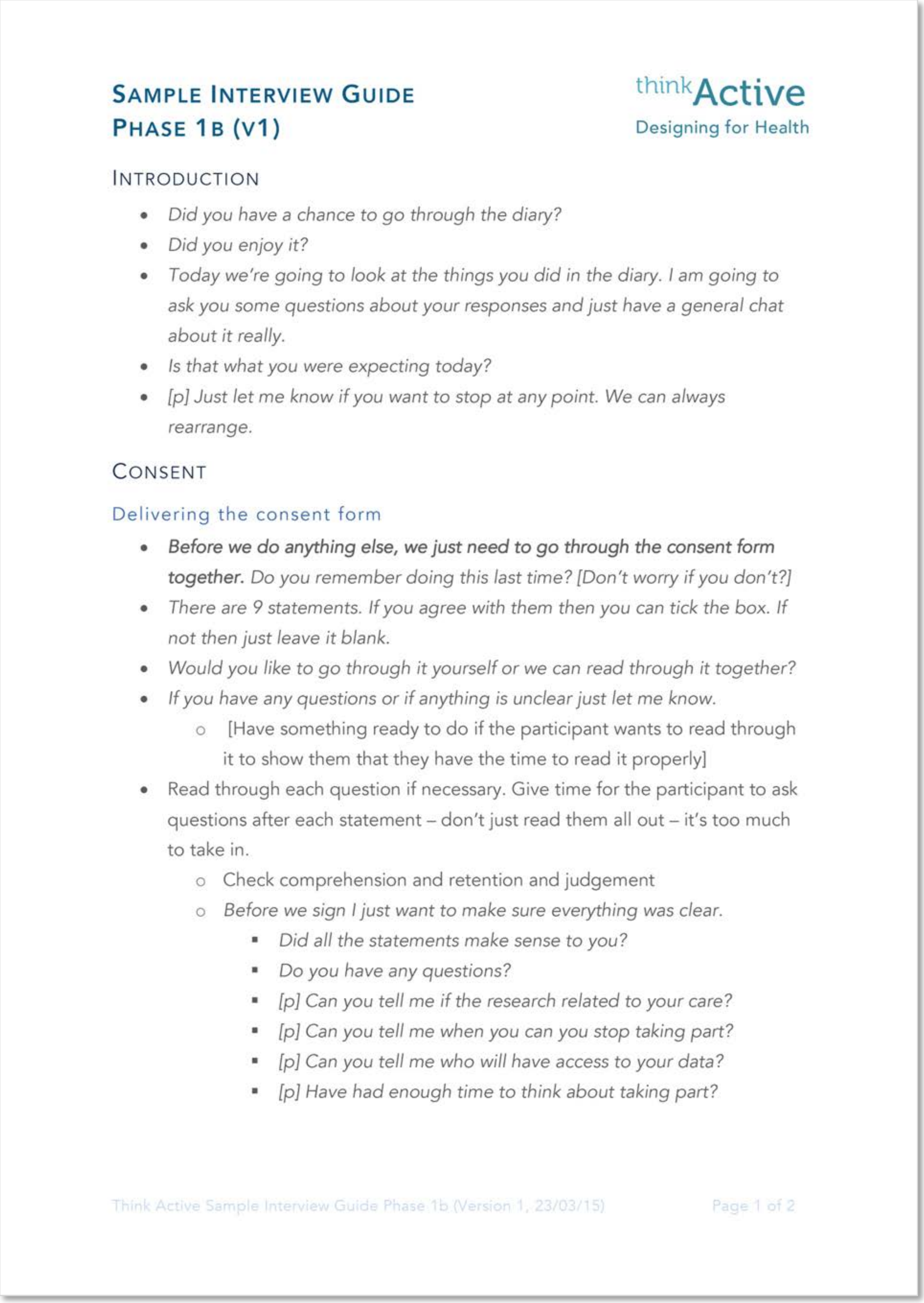
If you have any concerns about this research you should contact Professor

Research conduct

Mike Trenell on 0191 208 6935, email michael.trenell@newcastle.ac.uk or post to MoveLab, 4th Floor William Leech Building, The Medical School, Newcastle University, Newcastle upon Tyne, NE2 4HH.

If you remain unhappy you can contact the Patient Relations Department on 0191 223 1382 or 0191 223 1454

I. First interview guide



SAMPLE INTERVIEW GUIDE
PHASE 1B (V1)

thinkActive
Designing for Health

INTRODUCTION

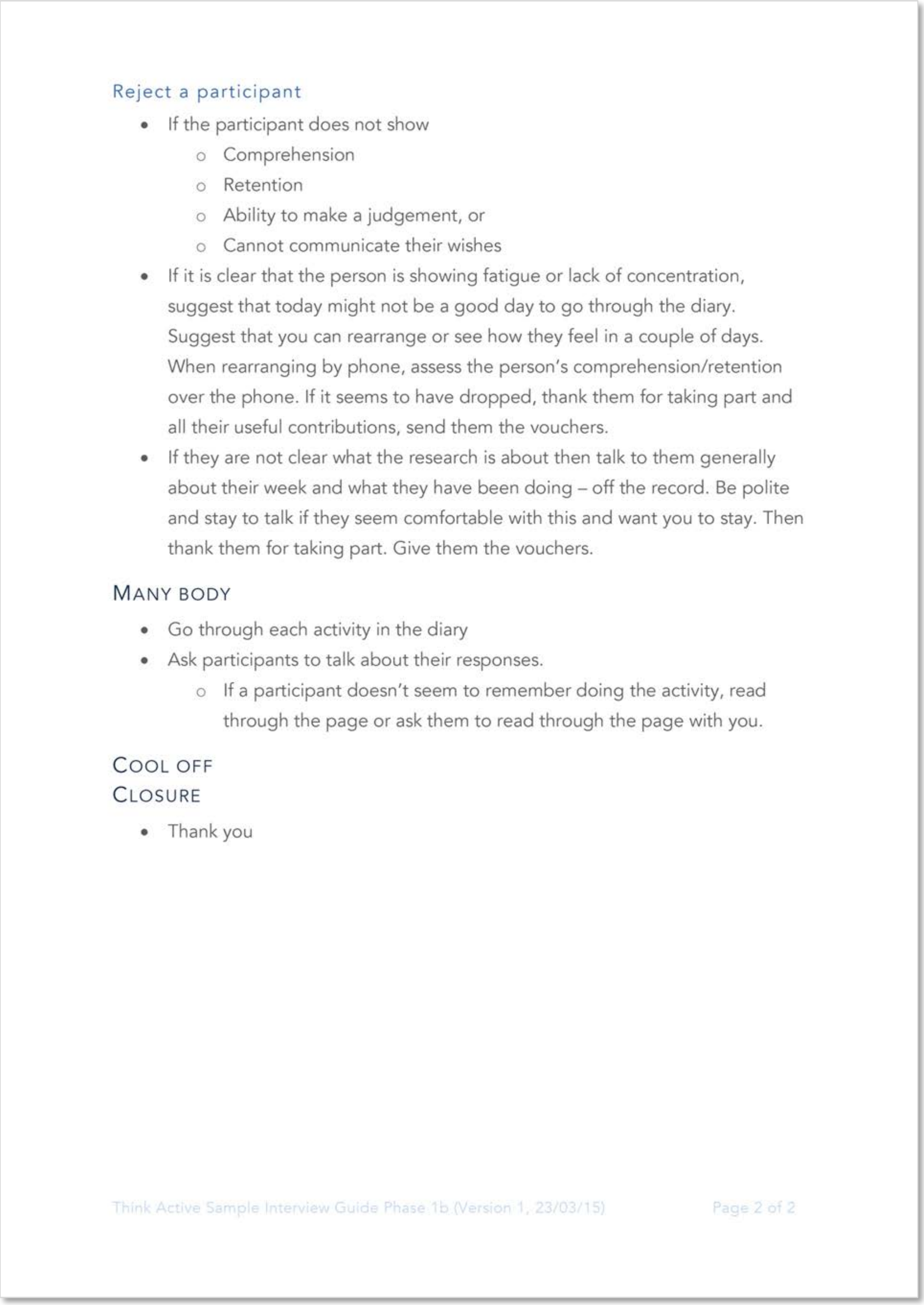
- *Did you have a chance to go through the diary?*
- *Did you enjoy it?*
- *Today we're going to look at the things you did in the diary. I am going to ask you some questions about your responses and just have a general chat about it really.*
- *Is that what you were expecting today?*
- *[p] Just let me know if you want to stop at any point. We can always rearrange.*

CONSENT

Delivering the consent form

- ***Before we do anything else, we just need to go through the consent form together.** Do you remember doing this last time? [Don't worry if you don't?]*
- *There are 9 statements. If you agree with them then you can tick the box. If not then just leave it blank.*
- *Would you like to go through it yourself or we can read through it together?*
- *If you have any questions or if anything is unclear just let me know.*
  - [Have something ready to do if the participant wants to read through it to show them that they have the time to read it properly]
- Read through each question if necessary. Give time for the participant to ask questions after each statement – don't just read them all out – it's too much to take in.
  - Check comprehension and retention and judgement
  - *Before we sign I just want to make sure everything was clear.*
    - *Did all the statements make sense to you?*
    - *Do you have any questions?*
    - *[p] Can you tell me if the research related to your care?*
    - *[p] Can you tell me when you can you stop taking part?*
    - *[p] Can you tell me who will have access to your data?*
    - *[p] Have had enough time to think about taking part?*

Think Active Sample Interview Guide Phase 1b (Version 1, 23/03/15) Page 1 of 2



Reject a participant

- If the participant does not show
  - Comprehension
  - Retention
  - Ability to make a judgement, or
  - Cannot communicate their wishes
- If it is clear that the person is showing fatigue or lack of concentration, suggest that today might not be a good day to go through the diary. Suggest that you can rearrange or see how they feel in a couple of days. When rearranging by phone, assess the person's comprehension/retention over the phone. If it seems to have dropped, thank them for taking part and all their useful contributions, send them the vouchers.
- If they are not clear what the research is about then talk to them generally about their week and what they have been doing – off the record. Be polite and stay to talk if they seem comfortable with this and want you to stay. Then thank them for taking part. Give them the vouchers.

MANY BODY

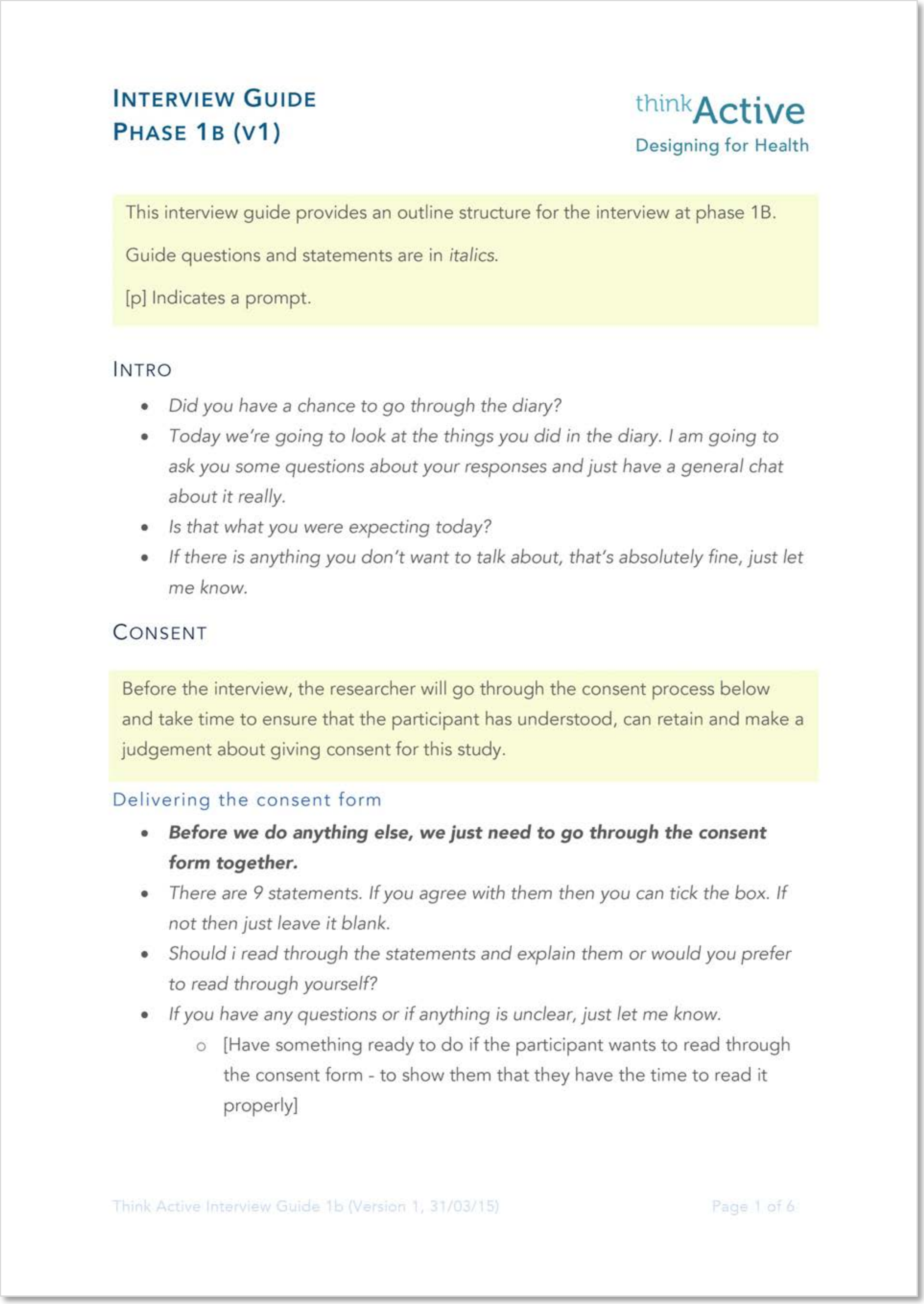
- Go through each activity in the diary
- Ask participants to talk about their responses.
  - If a participant doesn't seem to remember doing the activity, read through the page or ask them to read through the page with you.

COOL OFF

CLOSURE

- Thank you

J. Second interview guide



INTERVIEW GUIDE
PHASE 1B (V1)

thinkActive
Designing for Health

This interview guide provides an outline structure for the interview at phase 1B.

Guide questions and statements are in *italics*.

[p] Indicates a prompt.

INTRO

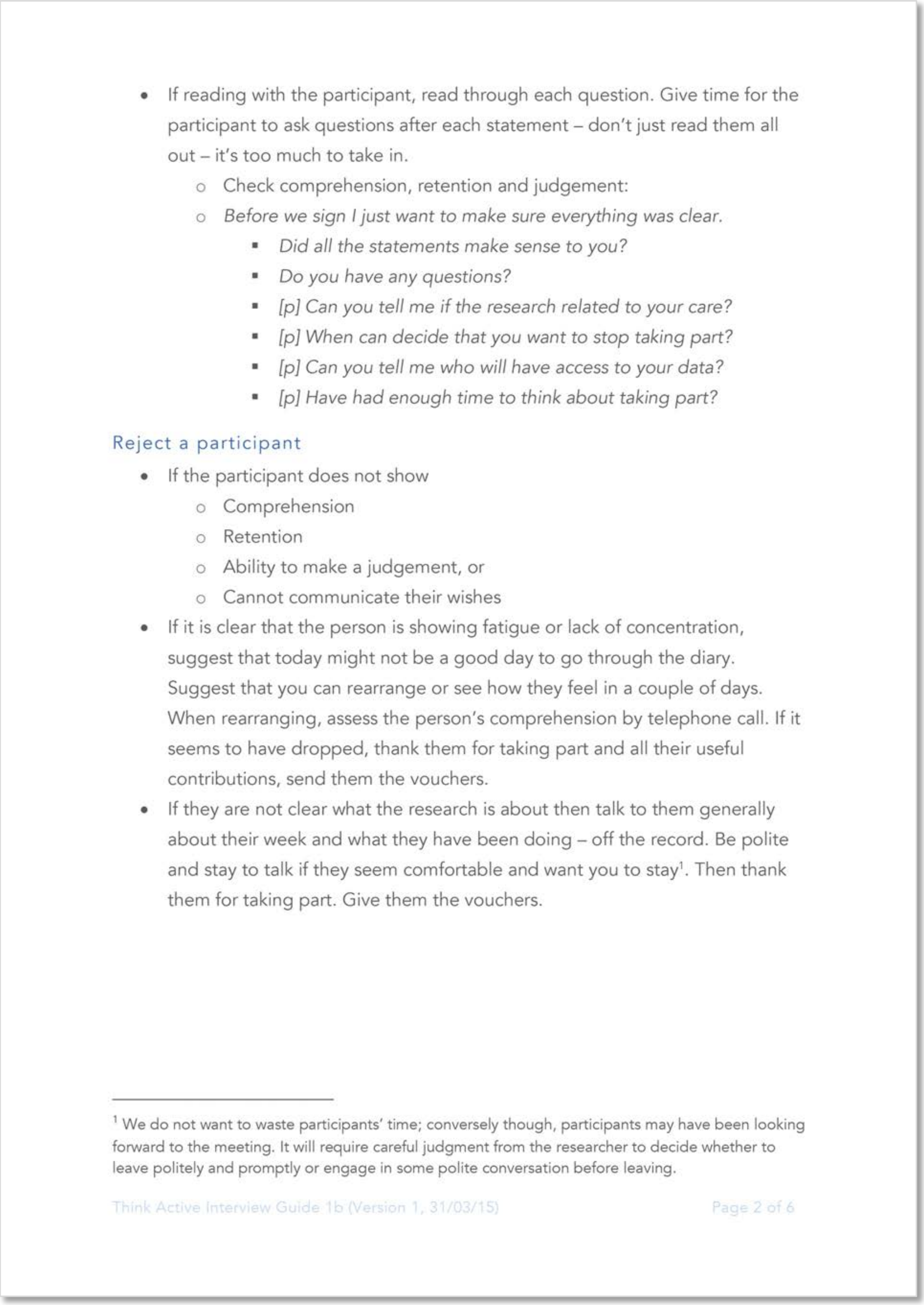
- *Did you have a chance to go through the diary?*
- *Today we're going to look at the things you did in the diary. I am going to ask you some questions about your responses and just have a general chat about it really.*
- *Is that what you were expecting today?*
- *If there is anything you don't want to talk about, that's absolutely fine, just let me know.*

CONSENT

Before the interview, the researcher will go through the consent process below and take time to ensure that the participant has understood, can retain and make a judgement about giving consent for this study.

Delivering the consent form

- ***Before we do anything else, we just need to go through the consent form together.***
- *There are 9 statements. If you agree with them then you can tick the box. If not then just leave it blank.*
- *Should i read through the statements and explain them or would you prefer to read through yourself?*
- *If you have any questions or if anything is unclear, just let me know.*
    - [Have something ready to do if the participant wants to read through the consent form - to show them that they have the time to read it properly]



- If reading with the participant, read through each question. Give time for the participant to ask questions after each statement – don't just read them all out – it's too much to take in.
    - Check comprehension, retention and judgement:
    - *Before we sign I just want to make sure everything was clear.*
        - *Did all the statements make sense to you?*
        - *Do you have any questions?*
        - *[p] Can you tell me if the research related to your care?*
        - *[p] When can decide that you want to stop taking part?*
        - *[p] Can you tell me who will have access to your data?*
        - *[p] Have had enough time to think about taking part?*

Reject a participant

- If the participant does not show
    - Comprehension
    - Retention
    - Ability to make a judgement, or
    - Cannot communicate their wishes
- If it is clear that the person is showing fatigue or lack of concentration, suggest that today might not be a good day to go through the diary. Suggest that you can rearrange or see how they feel in a couple of days. When rearranging, assess the person's comprehension by telephone call. If it seems to have dropped, thank them for taking part and all their useful contributions, send them the vouchers.
- If they are not clear what the research is about then talk to them generally about their week and what they have been doing – off the record. Be polite and stay to talk if they seem comfortable and want you to stay[1]. Then thank them for taking part. Give them the vouchers.

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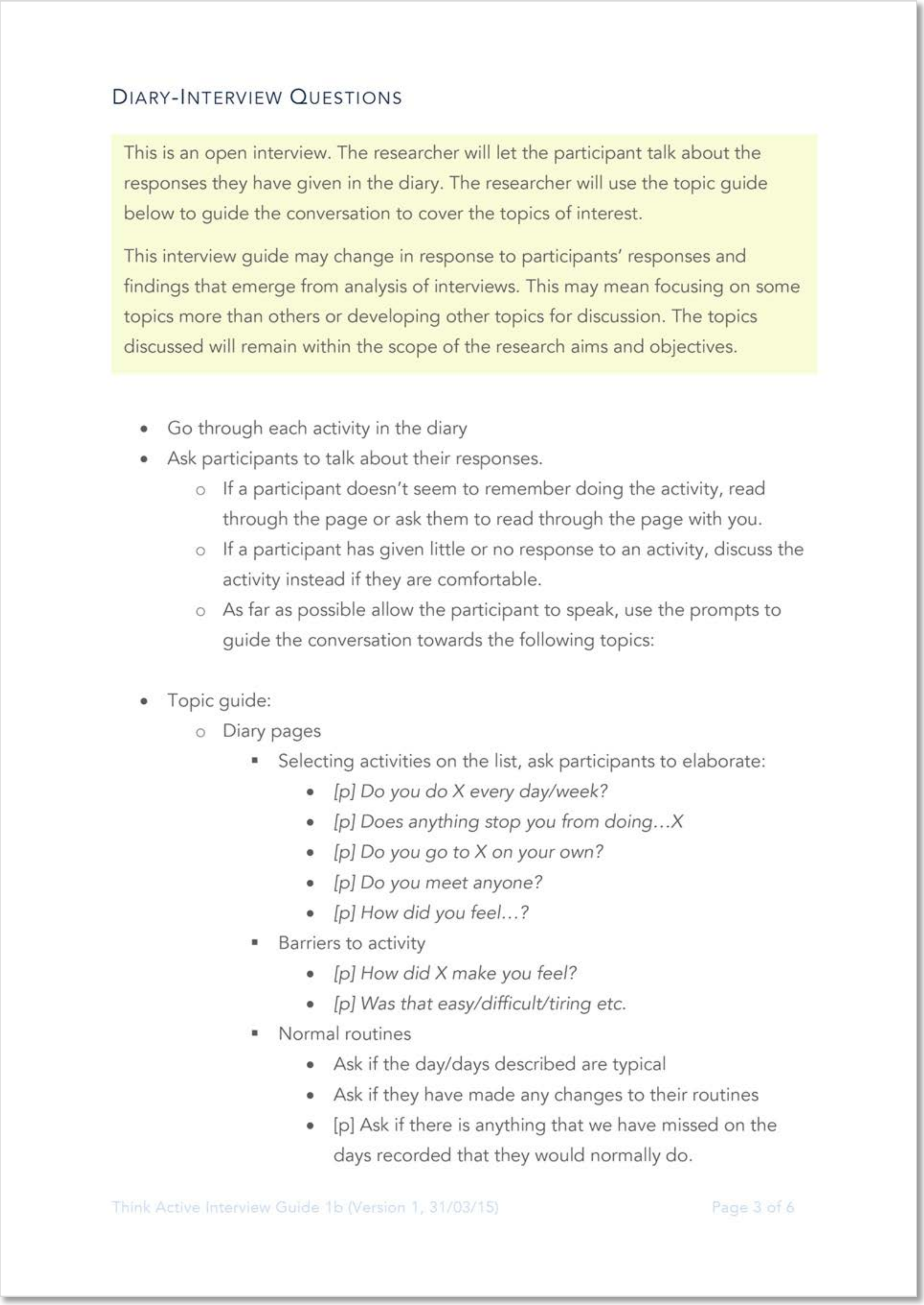
[1] We do not want to waste participants' time; conversely though, participants may have been looking forward to the meeting. It will require careful judgment from the researcher to decide whether to leave politely and promptly or engage in some polite conversation before leaving.



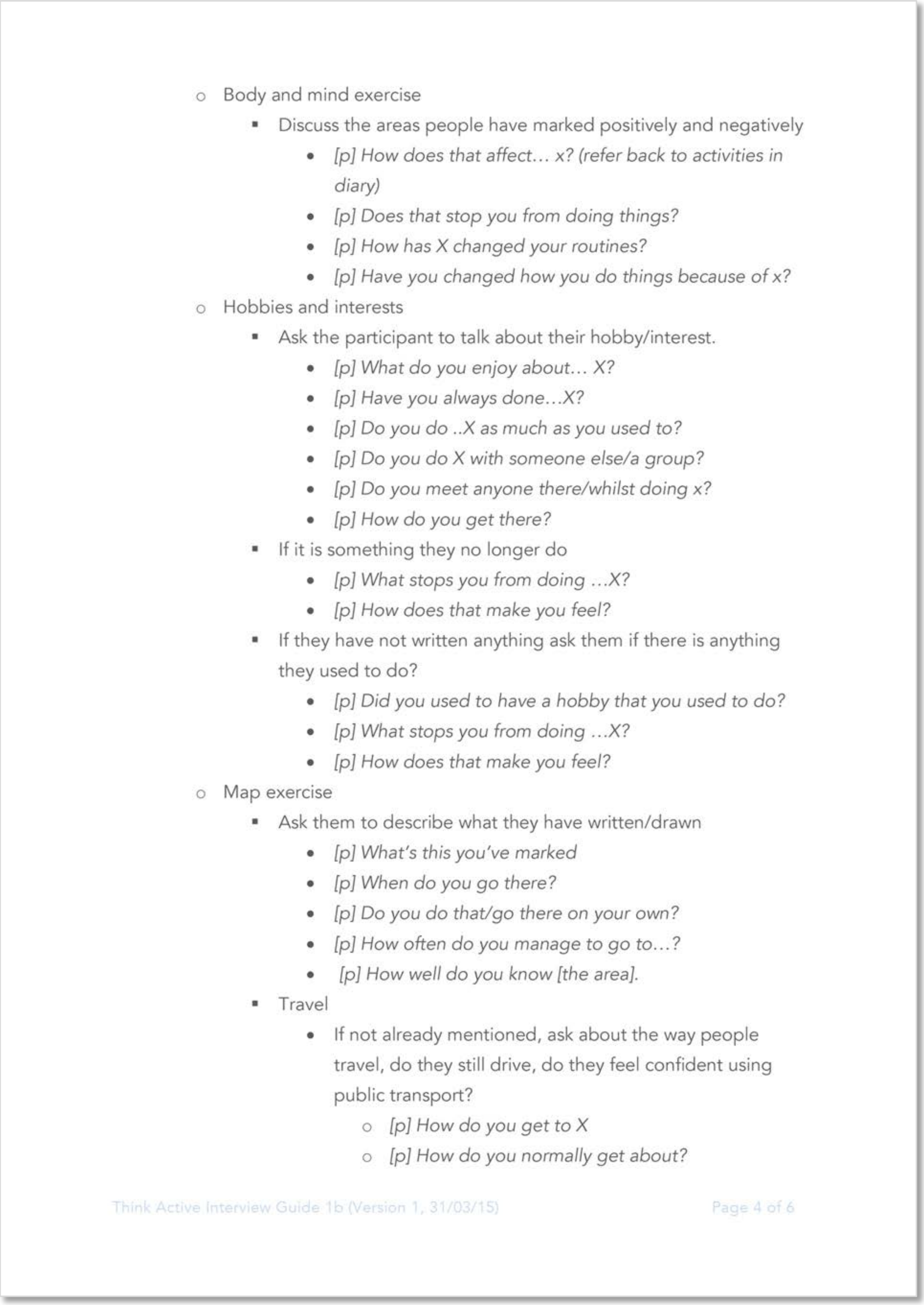
DIARY-INTERVIEW QUESTIONS

This is an open interview. The researcher will let the participant talk about the responses they have given in the diary. The researcher will use the topic guide below to guide the conversation to cover the topics of interest.

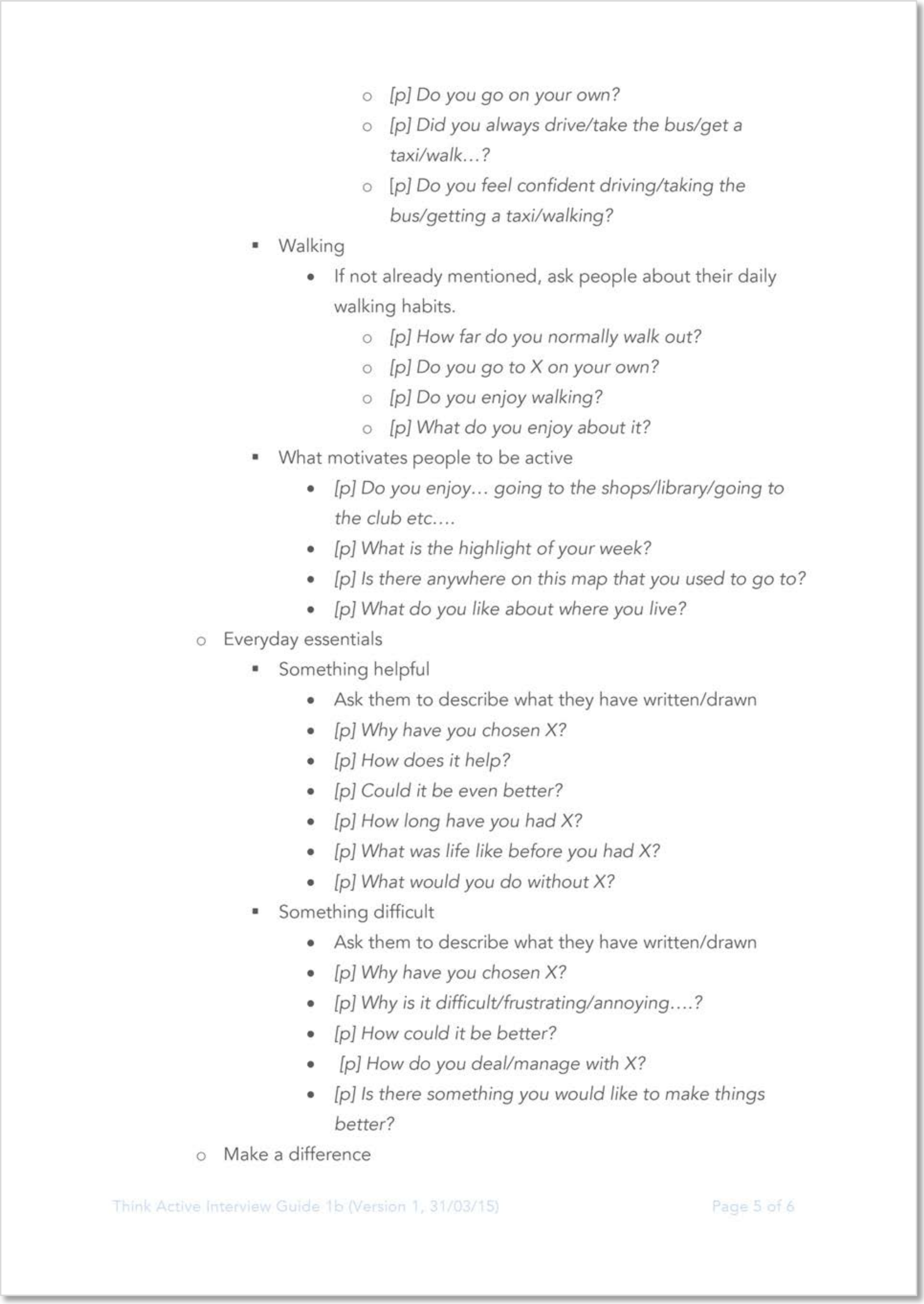
This interview guide may change in response to participants' responses and findings that emerge from analysis of interviews. This may mean focusing on some topics more than others or developing other topics for discussion. The topics discussed will remain within the scope of the research aims and objectives.

- Go through each activity in the diary
- Ask participants to talk about their responses.
  - If a participant doesn't seem to remember doing the activity, read through the page or ask them to read through the page with you.
  - If a participant has given little or no response to an activity, discuss the activity instead if they are comfortable.
  - As far as possible allow the participant to speak, use the prompts to guide the conversation towards the following topics:

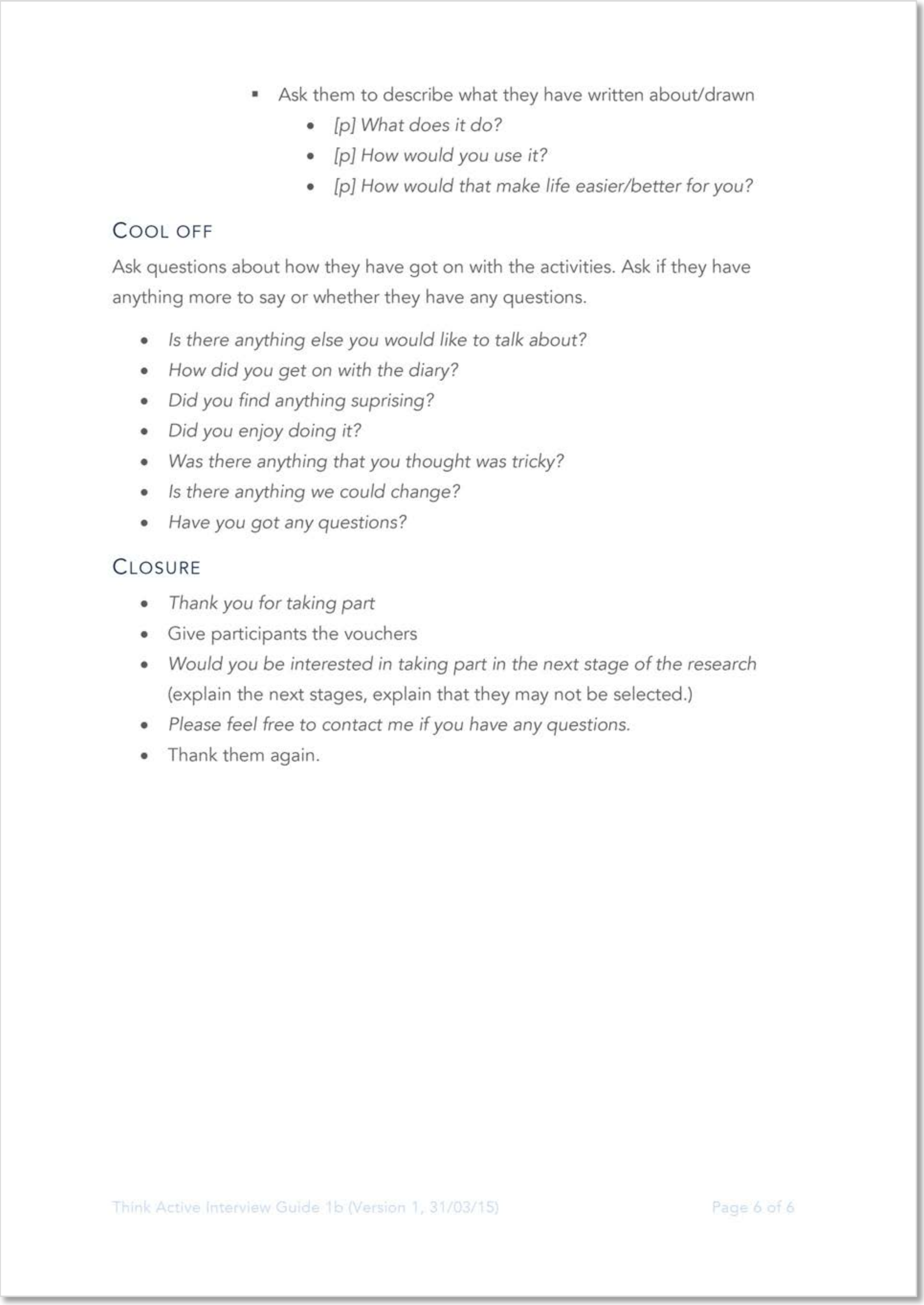
- Topic guide:
  - Diary pages
    - Selecting activities on the list, ask participants to elaborate:
      - [p] *Do you do X every day/week?*
      - [p] *Does anything stop you from doing…X*
      - [p] *Do you go to X on your own?*
      - [p] *Do you meet anyone?*
      - [p] *How did you feel…?*
    - Barriers to activity
      - [p] *How did X make you feel?*
      - [p] *Was that easy/difficult/tiring etc.*
    - Normal routines
      - Ask if the day/days described are typical
      - Ask if they have made any changes to their routines
      - [p] Ask if there is anything that we have missed on the days recorded that they would normally do.



- Body and mind exercise
  - Discuss the areas people have marked positively and negatively
    - *[p] How does that affect… x? (refer back to activities in diary)*
    - *[p] Does that stop you from doing things?*
    - *[p] How has X changed your routines?*
    - *[p] Have you changed how you do things because of x?*
- Hobbies and interests
  - Ask the participant to talk about their hobby/interest.
    - *[p] What do you enjoy about… X?*
    - *[p] Have you always done…X?*
    - *[p] Do you do ..X as much as you used to?*
    - *[p] Do you do X with someone else/a group?*
    - *[p] Do you meet anyone there/whilst doing x?*
    - *[p] How do you get there?*
  - If it is something they no longer do
    - *[p] What stops you from doing …X?*
    - *[p] How does that make you feel?*
  - If they have not written anything ask them if there is anything they used to do?
    - *[p] Did you used to have a hobby that you used to do?*
    - *[p] What stops you from doing …X?*
    - *[p] How does that make you feel?*
- Map exercise
  - Ask them to describe what they have written/drawn
    - *[p] What's this you've marked*
    - *[p] When do you go there?*
    - *[p] Do you do that/go there on your own?*
    - *[p] How often do you manage to go to…?*
    - *[p] How well do you know [the area].*
  - Travel
    - If not already mentioned, ask about the way people travel, do they still drive, do they feel confident using public transport?
      - *[p] How do you get to X*
      - *[p] How do you normally get about?*



      - *[p] Do you go on your own?*
      - *[p] Did you always drive/take the bus/get a taxi/walk…?*
      - *[p] Do you feel confident driving/taking the bus/getting a taxi/walking?*
  - Walking
    - If not already mentioned, ask people about their daily walking habits.
      - *[p] How far do you normally walk out?*
      - *[p] Do you go to X on your own?*
      - *[p] Do you enjoy walking?*
      - *[p] What do you enjoy about it?*
  - What motivates people to be active
    - *[p] Do you enjoy… going to the shops/library/going to the club etc.…*
    - *[p] What is the highlight of your week?*
    - *[p] Is there anywhere on this map that you used to go to?*
    - *[p] What do you like about where you live?*
- Everyday essentials
  - Something helpful
    - Ask them to describe what they have written/drawn
    - *[p] Why have you chosen X?*
    - *[p] How does it help?*
    - *[p] Could it be even better?*
    - *[p] How long have you had X?*
    - *[p] What was life like before you had X?*
    - *[p] What would you do without X?*
  - Something difficult
    - Ask them to describe what they have written/drawn
    - *[p] Why have you chosen X?*
    - *[p] Why is it difficult/frustrating/annoying….?*
    - *[p] How could it be better?*
    - *[p] How do you deal/manage with X?*
    - *[p] Is there something you would like to make things better?*
- Make a difference



  - Ask them to describe what they have written about/drawn
    - *[p] What does it do?*
    - *[p] How would you use it?*
    - *[p] How would that make life easier/better for you?*

COOL OFF

Ask questions about how they have got on with the activities. Ask if they have anything more to say or whether they have any questions.

- *Is there anything else you would like to talk about?*
- *How did you get on with the diary?*
- *Did you find anything suprising?*
- *Did you enjoy doing it?*
- *Was there anything that you thought was tricky?*
- *Is there anything we could change?*
- *Have you got any questions?*

CLOSURE

- *Thank you for taking part*
- Give participants the vouchers
- *Would you be interested in taking part in the next stage of the research* (explain the next stages, explain that they may not be selected.)
- *Please feel free to contact me if you have any questions.*
- Thank them again.

K. Persona: June

June Jackson

Psuedonym

Memory condition: Alzheimer's disease

Age: 77

Married to Pete (69)

Lives on a quiet suburban housing estate in North East England with Pete and Milly the cat. There are some local shops. There are country and riverside walks nearby.

Health conditions

Recent deep vein thrombosis.

Regular activities

Goes out about every other day with husband Pete to shops, garden centres etc.

Visits from family members.

Interests

Enjoys shopping and buying clothes and particularly handbags.

Enjoys TV quizzes and word puzzles.

Used to enjoy DIY.

Enjoys spending time with grandchildren when they visit.

Used to do gardening with Pete.

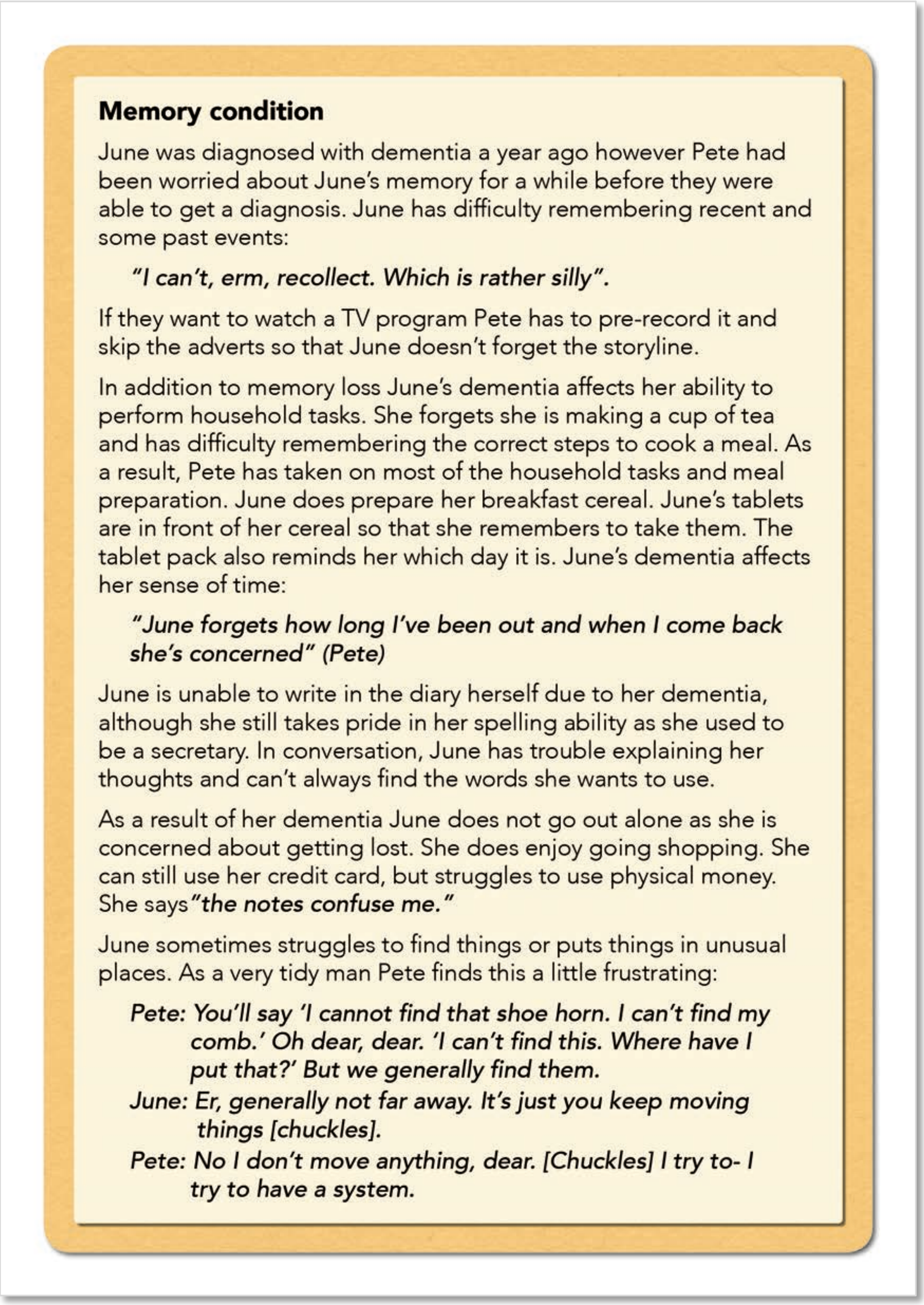
Ran a keep fit group for many years before retiring.

'Mom' by Adam is licensed under CC BY-SA 2.0 (creativecommons.org/licenses/by-sa/2.0), image cropped and border added, original available at flickr.com/photos/azadam/118015111

'Grandma' by fiddlesticks23 is licensed under CC BY 2.0 (creativecommons.org/licenses/by/2.0), image cropped and border added, original available at flickr.com/photos/ross_fullerton/4371506288

You like to see the kids. You'll enjoy tonight 'cause the girls'll be there and grandson and great-grandaughter. (Pete)

'Grandma and Gramps' by fiddlesticks23 is licensed under CC BY 2.0 (creativecommons.org/licenses/by/2.0), border added, original available at flickr.com/photos/ross_fullerton/4370759189



Memory condition

June was diagnosed with dementia a year ago however Pete had been worried about June's memory for a while before they were able to get a diagnosis. June has difficulty remembering recent and some past events:

> ***"I can't, erm, recollect. Which is rather silly".***

If they want to watch a TV program Pete has to pre-record it and skip the adverts so that June doesn't forget the storyline.

In addition to memory loss June's dementia affects her ability to perform household tasks. She forgets she is making a cup of tea and has difficulty remembering the correct steps to cook a meal. As a result, Pete has taken on most of the household tasks and meal preparation. June does prepare her breakfast cereal. June's tablets are in front of her cereal so that she remembers to take them. The tablet pack also reminds her which day it is. June's dementia affects her sense of time:

> ***"June forgets how long I've been out and when I come back she's concerned" (Pete)***

June is unable to write in the diary herself due to her dementia, although she still takes pride in her spelling ability as she used to be a secretary. In conversation, June has trouble explaining her thoughts and can't always find the words she wants to use.

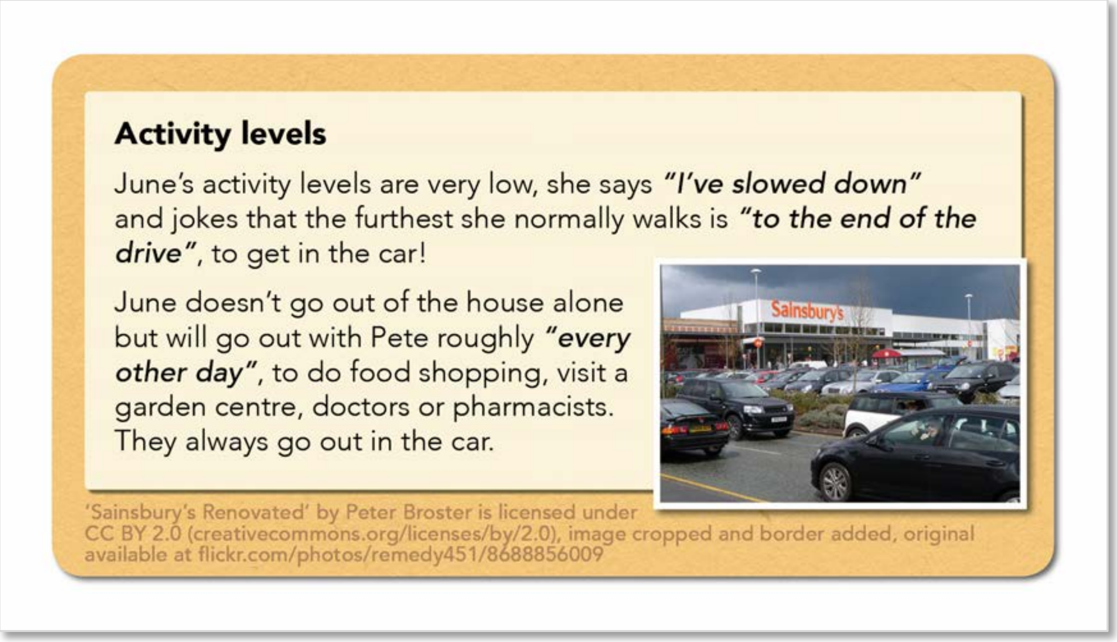
As a result of her dementia June does not go out alone as she is concerned about getting lost. She does enjoy going shopping. She can still use her credit card, but struggles to use physical money. She says ***"the notes confuse me."***

June sometimes struggles to find things or puts things in unusual places. As a very tidy man Pete finds this a little frustrating:

> ***Pete: You'll say 'I cannot find that shoe horn. I can't find my comb.' Oh dear, dear. 'I can't find this. Where have I put that?' But we generally find them.***
>
> ***June: Er, generally not far away. It's just you keep moving things [chuckles].***
>
> ***Pete: No I don't move anything, dear. [Chuckles] I try to- I try to have a system.***

Travel and transport

June chose to give up her driving license because she was worried about being dangerous as well as getting lost. June and Pete go everywhere by car. June is reliant on Pete or other family members to provide transport.

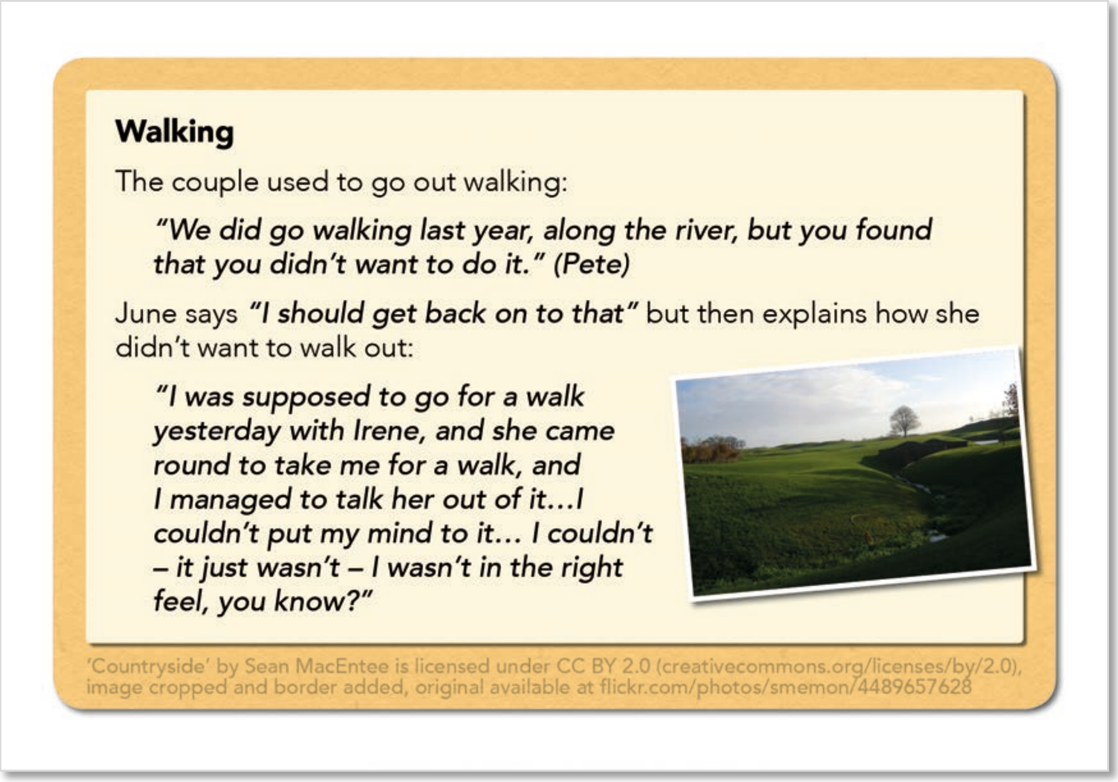


Activity levels

June's activity levels are very low, she says ***"I've slowed down"*** and jokes that the furthest she normally walks is ***"to the end of the drive"***, to get in the car!

June doesn't go out of the house alone but will go out with Pete roughly ***"every other day"***, to do food shopping, visit a garden centre, doctors or pharmacists. They always go out in the car.

'Sainsbury's Renovated' by Peter Broster is licensed under CC BY 2.0 (creativecommons.org/licenses/by/2.0), image cropped and border added, original available at flickr.com/photos/remedy451/8688856009



Walking

The couple used to go out walking:

> ***"We did go walking last year, along the river, but you found that you didn't want to do it." (Pete)***

June says ***"I should get back on to that"*** but then explains how she didn't want to walk out:

> ***"I was supposed to go for a walk yesterday with Irene, and she came round to take me for a walk, and I managed to talk her out of it…I couldn't put my mind to it… I couldn't – it just wasn't – I wasn't in the right feel, you know?"***

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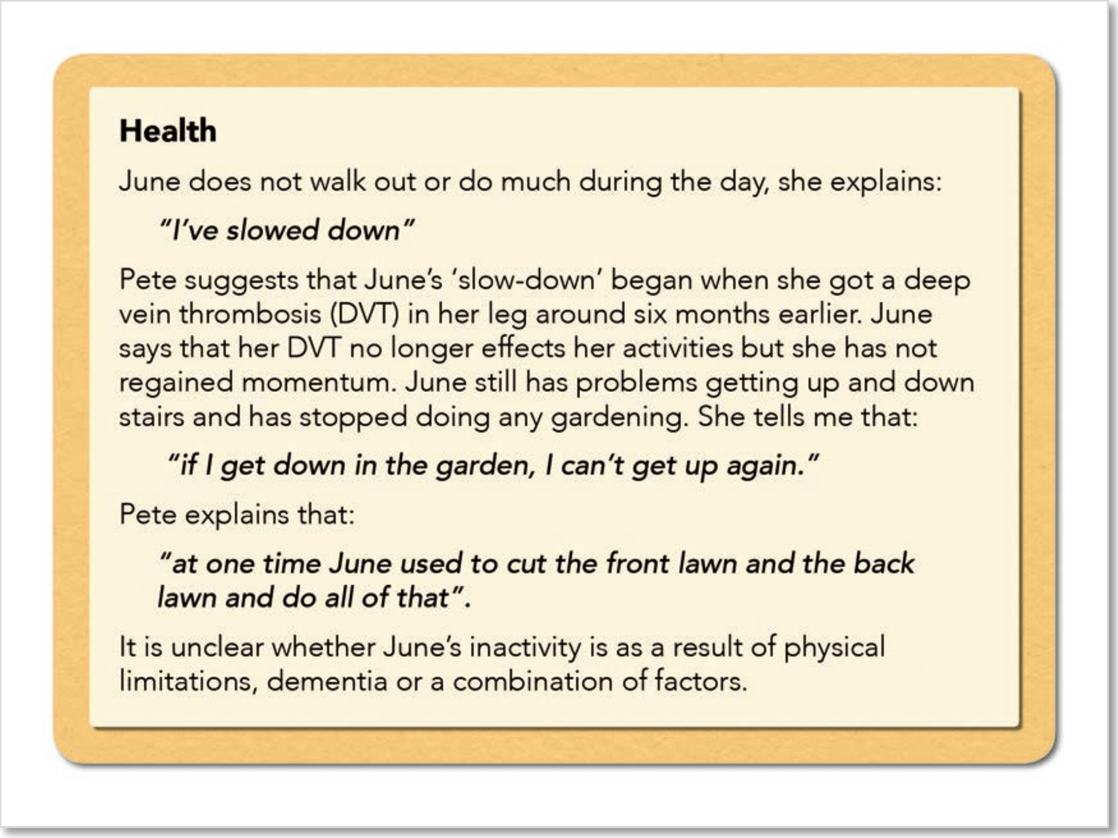


Health

June does not walk out or do much during the day, she explains:

> ***"I've slowed down"***

Pete suggests that June's 'slow-down' began when she got a deep vein thrombosis (DVT) in her leg around six months earlier. June says that her DVT no longer effects her activities but she has not regained momentum. June still has problems getting up and down stairs and has stopped doing any gardening. She tells me that:

> ***"if I get down in the garden, I can't get up again."***

Pete explains that:

> ***"at one time June used to cut the front lawn and the back lawn and do all of that".***

It is unclear whether June's inactivity is as a result of physical limitations, dementia or a combination of factors.

History of activity and interest in exercise

Pete is an active runner and keen cyclist but June is less interested in formal exercise. She explains,

> ***"I'm not active just because I've got to be active"***.

June was, however, previously involved in a dance-based keep-fit club. She was a member and then leader of the group for around 30 years but stopped taking part before she retired. Since retirement, the couple joined a gym for a couple of years but they don't reflect on this as a pleasurable experience.

Pete used to run up to thirty miles a week but is now limited to around ten miles. However he views gardening, and building his rockery as a form of exercise, which he does most days. His running time is limited as he doesn't want to leave June alone for longer than 45 minutes. When he does run, he will put a TV program on for June so that she doesn't worry where he is.

June is not worried about being inactive or staying in the house. When I ask June whether it bothers her not to be active. She says:

> ***"Not really. I'm active when I want to be."***

One motivation for exercise expressed by both Pete and June is the desire to lose weight. June says that she has ***"got far too much weight on"***.

June and Pete enjoy going on long-haul holidays and cruises. Pete remarks:

> ***"When we go on holiday she's like a spring lamb."***

June agrees:

> ***"I'm much better I can walk better and I do everything better"... "you're under no stress, no strain, nothing".***

June used to play exercise games on a Wii Fit but has now given it away. When I asked her whether she would be interested in a keep-fit DVD similar to the club she used to be part of she initially says ***"not really, no."*** But goes on to suggest that she might be interested if the DVD was an adjunct to her normal sessions.

Image: 'Batibou Beach, Dominica' by Matthias Ripp is licensed under CC BY 2.0 (creativecommons.org/licenses/by/2.0), image cropped and border added, original available at flickr.com/photos/56218409@N03/15238615085

Daily activities

When I ask June about her daily activities she says:

> ***"sometimes I find I don't do anything...I watch a lot of television actually".***

Pete thinks that this is causing her to sleep more during the day. Despite Pete spending a lot of time in the garden June does not go outside to join him.

June indicates that she feels like her activities are being restricted by her husband. She tells me:

> ***"He stopped me doing housework."***

However, Pete suggests that he does try to help June to maintain her independence. For example he says:

> ***"If we go in a shop to buy a loaf of bread June'll get that. Now some people in my, or our, situation, would say 'I'll do that.' But I don't want to do that."***

One day in the week of the diary June helps Pete to put some washing into the washing machine and hang it out to dry. She also has a visit from her sister and sits out in the garden. In the evening Pete is pleasantly surprised to find that June has decided to prepare some potatoes for their dinner. He remarks:

> ***"You had a busy day yesterday and you were really upbeat. If you're busy you feel different, you feel better."***

June was keen on DIY and has a lot of tools in the garage, but she tells me ***"I don't do anything like that now"*** reasoning ***"I think it's because I stopped doing things that were dangerous for me."***

June and Peter have a lot of family members living locally. June's granddaughters, and her sister Irene, visit regularly. Occasionally Pete will take June to Irene's house.

To help June to remember what is happening during the week Pete has started writing a list of activities and important reminders in a jotter which is placed beside the sofa where June normally sits.

Technology

Pete says that June has

> ***"Always liked technology. To mess about with things and see how they work."***

but June remarks

> ***"I don't mess about with them as much now."***

The couple recently purchased matching iPhones. They also both had iPads but June gave her's to her granddaughter. June shows me how her phone works but has difficulty doing anything beyond her normal routine calls. She can no longer send text messages. Pete expresses some frustration when he finds that June has turned on the Bluetooth on her phone:

> ***Pete: "You've got blooming Bluetooth on here again. I don't know how you do it."***
>
> ***June: "I don't know how you put Bluetooth on."***

June tries to search for something on Pete's iPad but struggles to remember which icon brings up the search function. When she does manage to search she seems to find the information on the web page overwhelming.

June also has difficulty recalling how to use their Sky box TV controller. They have a smart TV but Pete admits:

> ***"We've never done anything smart with it."***

The couple have a new washing machine which June also finds confusing as it doesn't operate how her old one did. It doesn't provide feedback on the stage of the cycle so June isn't sure whether it is working.

The couple get help with their gadgets from they granddaughters. Their granddaugther set up Siri voice activation software on June's phone to help her to use the phone but she does not use it. June says:

> ***"Technology can get so confusing."***

L. Persona: Brian

Brian Routledge

Psuedonym

Memory condition: Dementia

Age: 72

Married to Linda (70)

Brian and Linda live on the outskirts of a rural town in the North of England. They have good bus access to their local town as well as the city, touristic villages, countryside and beaches.

Health conditions

Slight arthritis in his knees but other than this and his dementia he is in very good health.

Regular activities

Daily 3.5 mile early morning walk.

Visiting local beauty spots and gardens.

Trips to stately homes and museums with the couple's close friends.

Walking to the shops in town or taking the bus to the city.

Gardening.

Interests

Walking in local countryside.

Wood carving and painting.

Used to be an avid reader but cannot read now due to dementia.

Photo for illustration only.

'Alnwick gardens' by Chris Booth is licensed under CC BY-SA 2.0 (creativecommons.org/licenses/by-sa/2.0/), image cropped and border added, original available at flickr.com/photos/monkeypuzzle/475932395/

"We hadn't seen Graham for a while. When he came, poor Brian didn't know who he was and they'd been very close friends. He was was your best man, wasn't he? That was hard." Linda

"It was really hard." Brian

Photo for illustration only

'002-4' by Andrea Ariel is licensed under CC BY-SA 2.0 (creativecommons.org/licenses/by-sa/2.0/), image cropped and border added, original available at flickr.com/photos/andreanako/5911348294/

Memory condition

Brian has mild-moderate dementia. He was diagnosed 3 years ago when he realised that he was having difficulty remembering who people were. Brian's dementia has caused him to have visual impairments. He struggles to read and to write even his own name. He also has problems with facial recognition. More recently he has had difficulty recognising numbers and he does not use money any more. Brian explains:

> ***"If I want to buy Linda a birthday present and stuff like that I used to be able to do it. Now I can't do it because I can't work out the money and different things like that, so that makes it really difficult."***

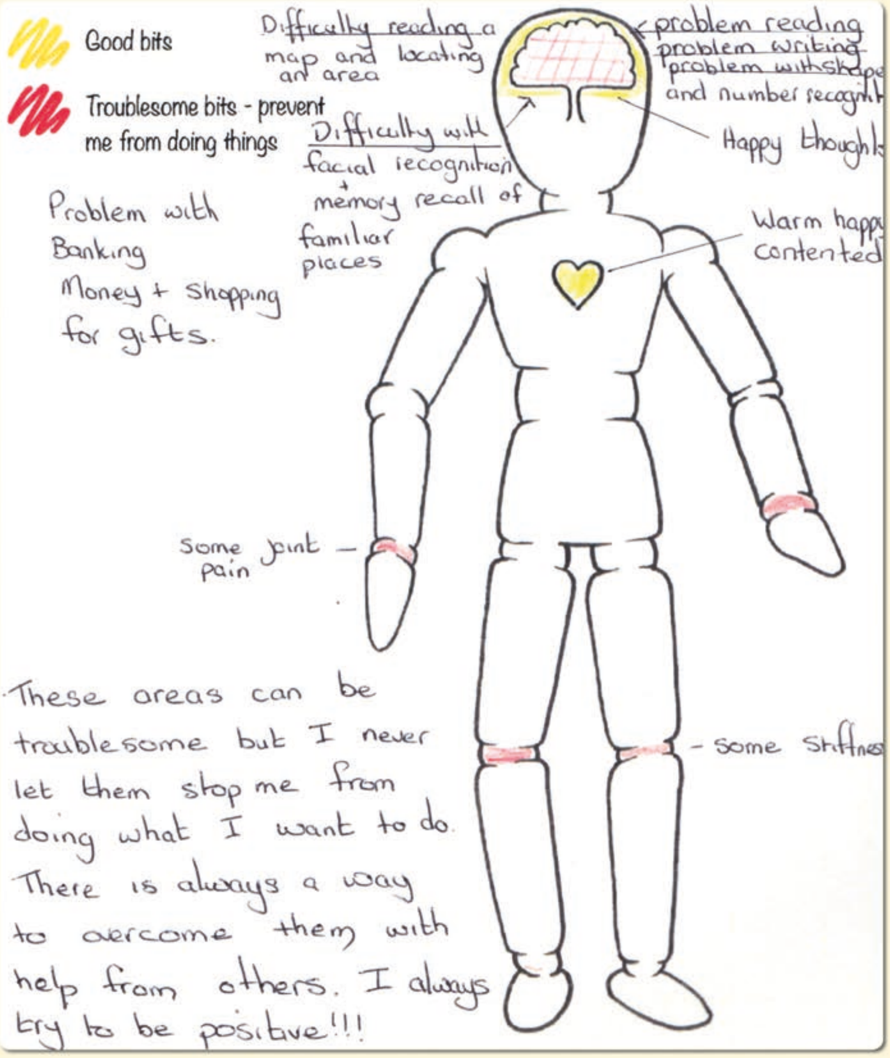
Brian finds it difficult to focus on the small buttons on devices (e.g. remote controls) and to use the door key. His visual problems can make public spaces difficult to negotiate:

> ***Brian: "I'll tell you a f- funny one. I was in the gents and I turned around and there was this person there and so I said, "You go first", and, erm there was nothing said and so I moved and nothing was said and this went on for a little while, the person moving and then stopping. Me moving and then stopping and we weren't going anywhere. And a chap came in and he says erm that's a... what was it?"***
>
> ***Linda: "A mirror."***
>
> ***Brian: "- that's it, a mirror" I said. "Honestly?" And it's then I suddenly realised."***

Brian is relatively fluent in conversation, particularly when recounting past anecdotes but he has difficulty recollecting more recent events and has some trouble recalling words.

Health

In the diary Brian was asked to colour the following mannequin to describe how his health effected his choice of activities. With Linda's help to write and colour the diagram, he completed it as follows:



These areas can be troublesome but I never let them stop me from doing what I want to do. There is always a way to overcome them with help from others. I always try to be positive!!!

Activity levels

Brian and Linda lead a very active lifestyle, walking over 30 miles each week. At 6 am, each morning Brian goes out for an additional 'training walk' of around 3.5 miles on his own. He does exactly the same route every day so that he does not get lost. The route is complex, along paved and unpaved roadsides, through an industrial estate and by a railway line. Because he follows the same route ever day, Linda knows where he is going and exactly when to expect Brian to get home.

I asked Brian if he had ever had any problems on his early morning walks? He responded:

> ***"No, none at all. None that I can find."***

I then asked him if he felt confident going on the walk, he replied emphatically ***"Oh yes."*** Brian goes on to explain that:

> ***"Linda knows how long it's going to take, so if there is a problem, Linda will come out, and she knows where I'm coming to."***

Linda responds:

> ***"Hopefully…. with her heart in her mouth".***

Her comment indicates that Linda is not so confident about Brian finding hiw way home safely.

Travel and transport

Brian stopped driving as a result of his dementia. The couple decided to sell their car and use public buses instead because Brian was anxious when Linda was driving. As they are over 65, the couple have a free bus pass. The free pass is of particular advantage to Brian:

> ***"Using my bus pass allows me to travel confidently without the need to carry cash. Money can be difficult to handle."***

Linda and Brian take the bus regularly, to go into the town centre, the city and the countryside. They go on day trips, travelling up to an hour and a half on buses to get to attractions, villages and beauty spots.

Instead of doing one big shop at a supermarket they now take the bus to the shops every couple of days. Linda gets a lift from her friend Jean when she needs a car to get to the supermarket for large items. However, she worries about leaving Brian at home alone as he sometimes decides to go for an extra walk. She tried to find a suitable mobile phone for Brian but it is not effective:

> ***"If I go shopping, sometimes Brian decides that he might like to do another little walk when I'm not here. He's got his mobile and that's my mobile number but it would be difficult for Brian to get down to my mobile number. We had to get something that had big buttons and hardly any buttons on it. And that's been a big problem, hasn't it? So it's never been used."***

History of activity and interest in exercise

Brian is a keen walker and used to be a long-distance walker who led walking expeditions. Brian comments on his affinity with the natural environment:

> ***"Yeah, that's my place... It's a wonderful place."***

In his diary Linda has written for him:

> ***"I appreciate nature and feel that I live as part of it."***

Linda now accompanies Brian on his walking trips away from home. When I asked her whether walking was always her hobby she responded animatedly:

> ***"No, no, thank you! No!... I like quilting and erm things, craft things.... When Brian would be going on a walk with his friends, I would perhaps go on a course. That was nice.... We do everything together now, don't we? .... We always have done, but more so now."***

At one point Linda indicates that walking has become a daily necessity for Brian which she would like to have an occasional break from:

> ***There's no stopping at six days a week... I do try and convince you of that but seven always hits."***

Interestingly, Linda may have become more active as a result of Brian's dementia which may have had a positive impact on her physical health. However, Linda downplays the impact of supporting Brian's choices on her own recreation time. However she indicates at one point that her life is very full supporting Brian, remarking:

> ***"I don't have a lot of time."***

Daily activities

The couple have always shared the household chores. Brian now contributes by vacuuming routinely, each morning after his walk. They discuss the importance of maintaining an independent role:

> ***Brian:**"Its my er duty to, er, do the whole of the house in the morning, every morning. It's good fun as well, in a sense."*
>
> ***Linda:** "you like to do it because that's your job, and you're contributing to doing things by yourself, isn't it?"*
>
> ***Brian:** "Uh, hu"*
>
> ***Linda:** "Independence."*

The couple also share the gardening. Brian said:

> *"Linda looks after the plants. The rockery itself… it's been going for a while, and I decided I wanted to change it, erm, and, er, so that's what I did."*

Brian enjoys wood carving and painting but he has not done it for a while. Linda tries to find activities for Brian to do during the day:

> ***Linda:** "Yesterday was hard because your foot was hurting and you couldn't walk, so you couldn't go out. I was trying to think of different activities that you wanted to do, some painting or something, but Brian didn't want to do that yesterday. We used to play dominoes with Brian's aunt quite a lot. I thought yesterday we might have a game. But it didn't work very well, did it?"*
>
> ***Brian:** "No, no. I was confused."*
>
> ***Linda:** "Yeah, you didn't like it so we just scrapped that."*

Instead the couple decided to watch a DVD. Linda later indicates that Brian can find it difficult to become engaged with activities:

> *"Sometimes it can be difficult. I'll suggest things but if he doesn't want to do it, there isn't any point. And I think they get ... as Brian said before, you have to have it in your head - what he would like to paint, or draw."*

Technology

Brian and Linda do not have a computer or internet in their home. Linda has a mobile phone but tells me that her friend disapproves of her not having a smart phone and her slowness at replying to texts. When I first ask Brian if he has a mobile phone he says:

> ***"I don't touch things like that."***

However, Linda corrects him:

> ***"You do have a mobile phone that you take out in the morning when you go walking."***

Linda recently experienced a problem trying to contact Brian on his mobile phone, she explained:

> ***"Brian went out on Sunday morning and he hurt his foot so he was late back. I didn't know what'd happened to him so I quickly got ready at half past six, pulled on a tracksuit to go and see if he was okay. I had to go back round your route to meet you, because you were late. I tried to call him and I couldn't get through, it was just a voicemail. His mobile phone was switched on but it's just totally not the right thing. I need something different that we've got."***

Whenever I mention technology Brian asserts that he is ***"not good with things like that"***. Device usability is affected by Brian's dementia, as described in his diary:

> ***"Remote control for television is very difficult to operate. Identifying the number, the buttons are so close together and so many of them. I would like to select channels independently!!"***

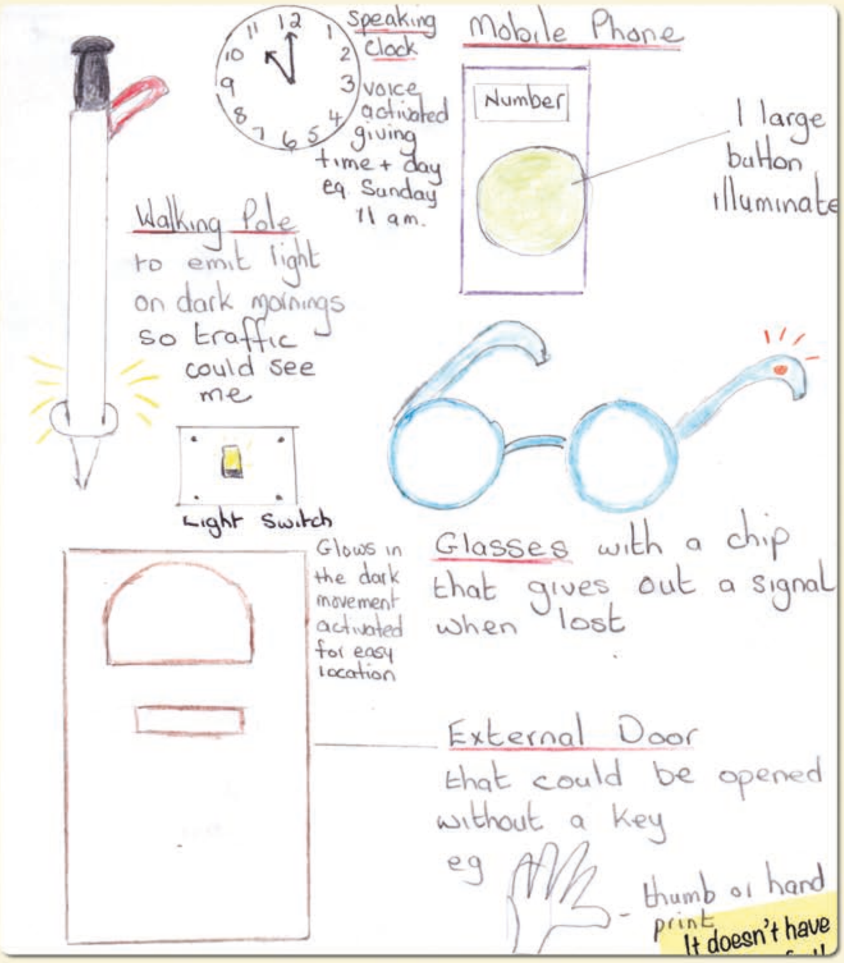
At the end of of discussion Linda reflects:

> ***"Doing this diary has brought about a huge amount of changes that we realise that we need to make, somehow, in our lives with technology."***

When I suggest a diffferent type of mobile phone Linda indicates her need for assistance in configuring technology for their needs:

> ***"If I went to the shop and spoke to them about this, would they set it up for us?"***

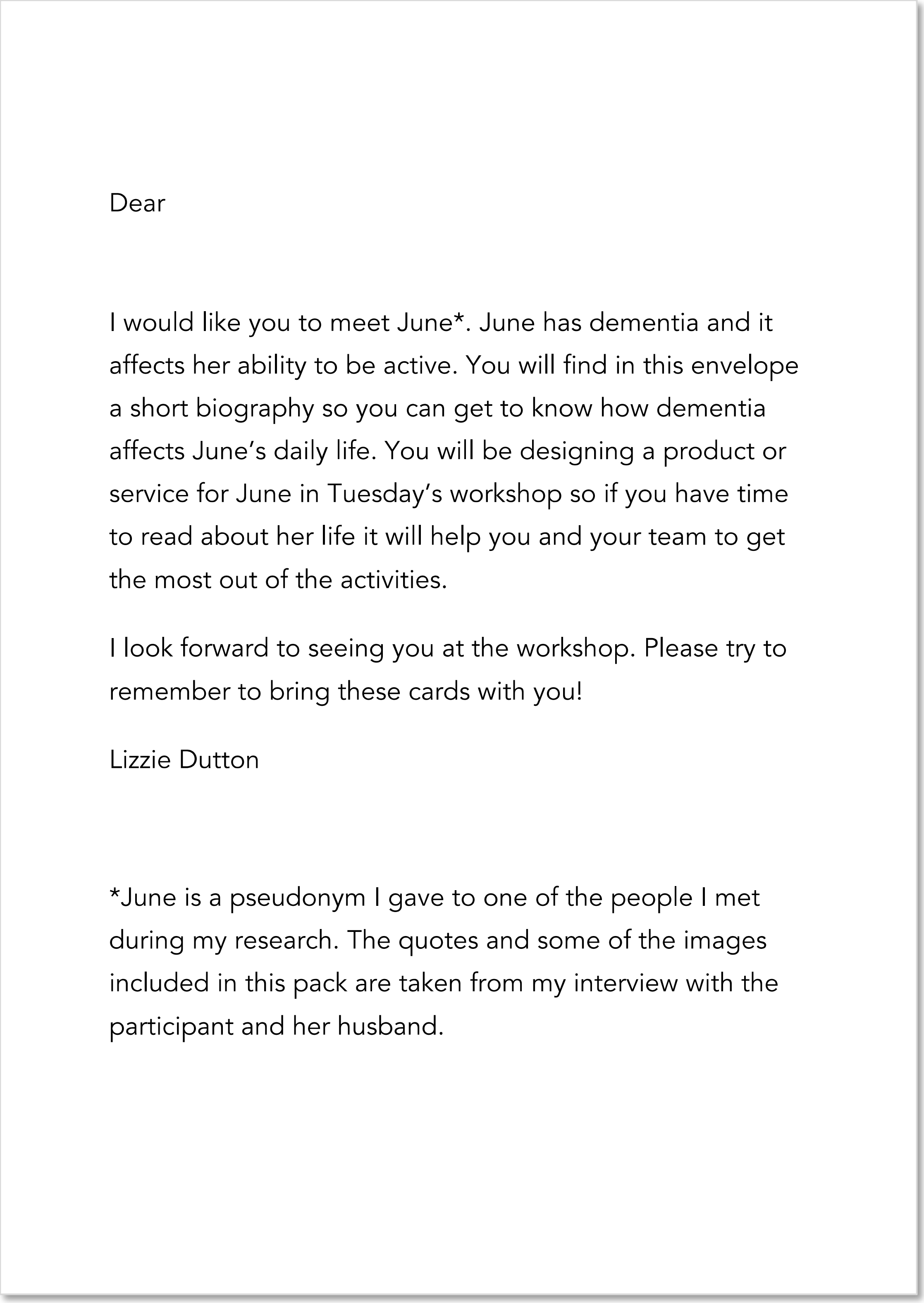
Technology In the diary Linda and Brian conceived the following ideas for devices to help Brian:



Linda expressed a need for technology to adapt to the changing needs of people with dementia:

> ***"It changes so quickly, something might work for a few weeks or a few days, and then it has to be changed to something else. So the investment in things, you have to think very carefully about. It has to cover long term, something that we could use now but that could be changed or used differently in the future."***

M. Letter accompanying persona cards



Dear

I would like you to meet June*. June has dementia and it affects her ability to be active. You will find in this envelope a short biography so you can get to know how dementia affects June's daily life. You will be designing a product or service for June in Tuesday's workshop so if you have time to read about her life it will help you and your team to get the most out of the activities.

I look forward to seeing you at the workshop. Please try to remember to bring these cards with you!

Lizzie Dutton

*June is a pseudonym I gave to one of the people I met during my research. The quotes and some of the images included in this pack are taken from my interview with the participant and her husband.

N. Quote cards

Examples of the quote cards used in the design workshops.

"When you've been with the grandkids you find yourself being more active, your mind being more active and memory being better, don't you?"
George (partner) speaking to Heather (dementia)

"I suppose I don't do enough but I've lost interest in a lot of things."
Gerald (dementia)

"You have this habit of hiding things"
Pete (partner) referring to June (dementia)

"I was with a friend yesterday and we'd spent quite a long time going round the place and halfway round I didn't know who he was. I didn't say anything until I got home and then Linda explained. It was a friend I'd known for years."
Brian (dementia)

Lizzie: "**In the week do you have much time apart then?**"
Larry: "**Very little.**"
Jean: "**No we don't actually.**"

"Someone can say something to me and- and thirty seconds later it's gone."

Anthony (dementia)

"I watch a lot of television actually."

June (dementia)

"You'll see in here, we do lots of things together."

Brian (dementia)

"I've got nothing to get out of the chair for"

Esther (dementia)

"I come down in the morning and I put the telly on and the programmes I watch are on until lunchtime. So I don't move until lunchtime."

Esther (dementia)

"he does put them in obscure places."

Sue (partner)

O. Barriers, motivators and enablers worksheet

Originally A3.

motivators

enablers

barriers

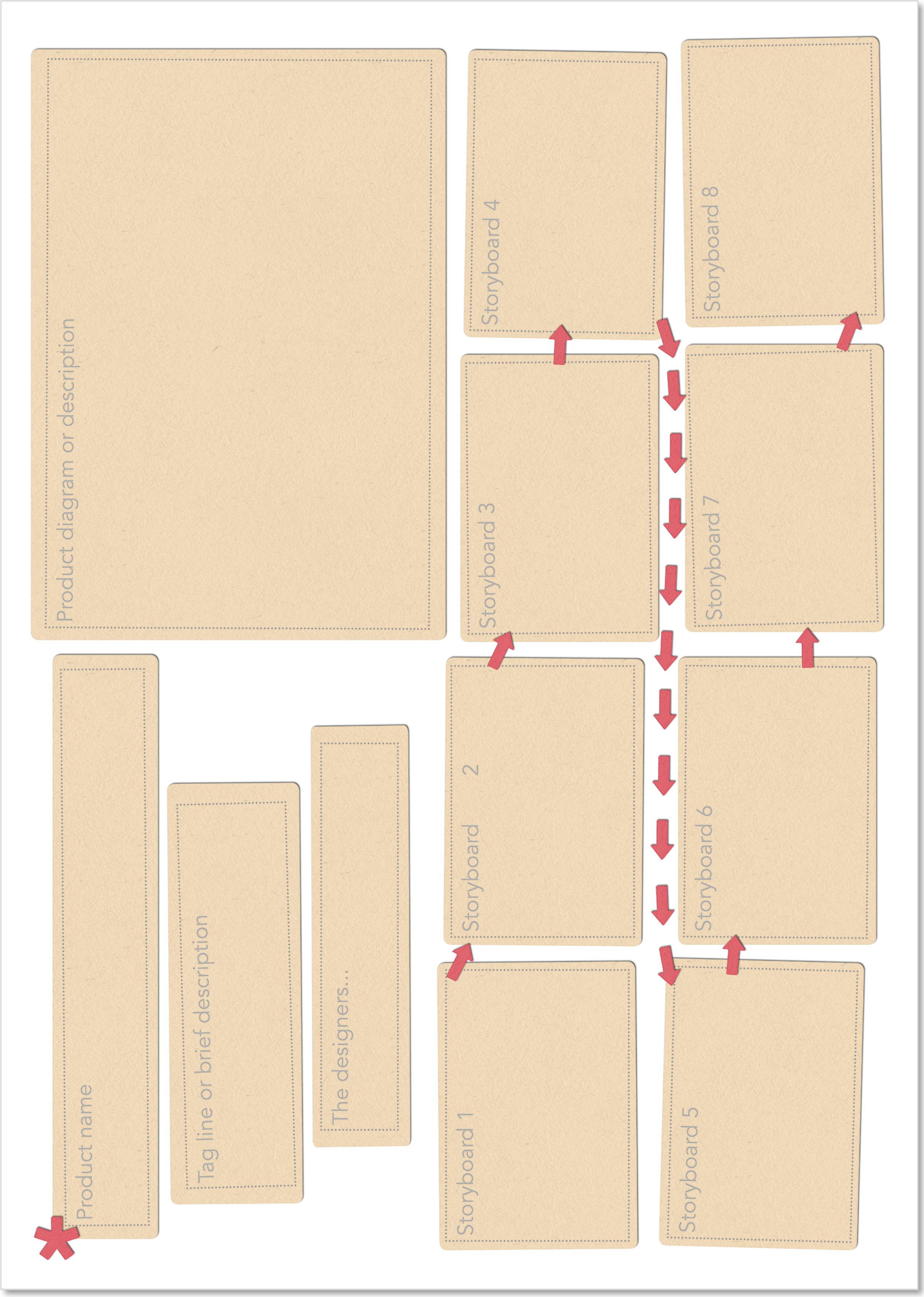
Barriers, motivators and enablers: 15 minutes

Aim – identify the barriers, motivators and enablers to physical activity for your group's persona.

Equipment – persona cards, worksheet, pens, sticky notes.

P. Storyboard worksheet

Originally A1.



Q. Design workshop schedule

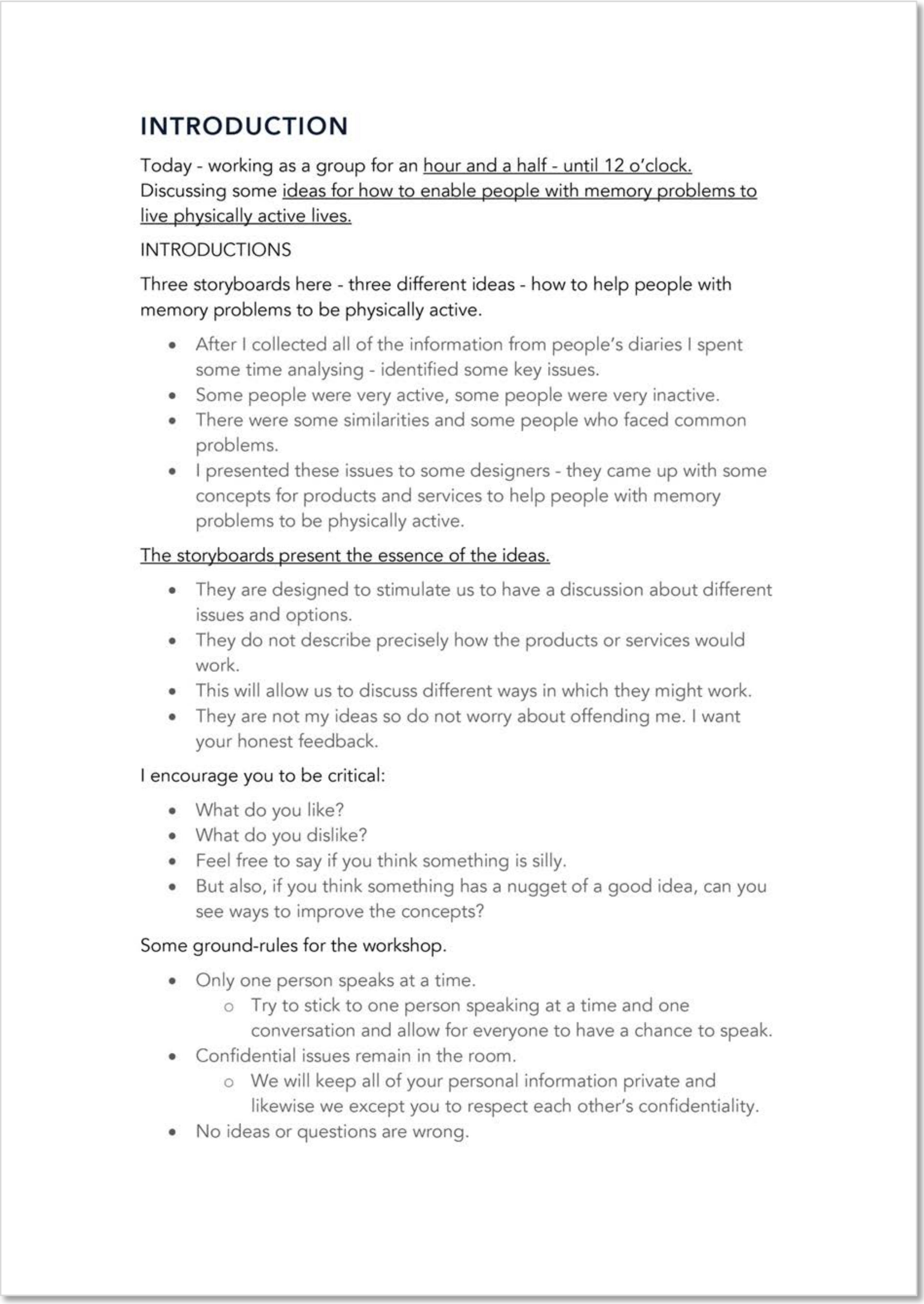
Arrival and introductions	30 minutes
Introductory presentation	30 minutes
Affinity diagram exercise	20 minutes
Day in the life/barriers and motivators activity	20 minutes
Individual concept generation	10 minutes
Break	15 minutes
Team concept selection	10 minutes
Concept development	45 minutes
Presentation	15 minutes

R. Focus group process

One focus group was held at Newcastle University for three people with dementia and two of their partners. Another was held at a meeting room local to two participants with dementia and their partners, who lived some distance from the University. Before the focus groups started, the consent process was completed. Next, I described the purpose of the focus groups to participants. I described how the concepts had been generated and explained what would happen in the focus groups. Participants were asked to be critical of the concepts and to make suggestions about how they would improve them. Participants were asked to abide by some ground-rules for the workshop, including respecting each other's points of view and taking turns to speak. I then presented the storyboards to the groups, asking for their comments after each concept was described.

As I presented each storyboard, I described the intention of the product or service. I also described key features, for instance *"the device has an emergency call button"*, before reading and describing the story presented on the storyboard. Before seeking their feedback, I asked participants if they needed any clarification. Where necessary I used prompts to initiate and guide participants' conversations. Once all three storyboards had been presented and discussed participants were asked to compare the concepts and select their preferred concepts or features.

S. Focus group topic guide



INTRODUCTION

Today - working as a group for an hour and a half - until 12 o'clock. Discussing some ideas for how to enable people with memory problems to live physically active lives.

INTRODUCTIONS

Three storyboards here - three different ideas - how to help people with memory problems to be physically active.

- After I collected all of the information from people's diaries I spent some time analysing - identified some key issues.
- Some people were very active, some people were very inactive.
- There were some similarities and some people who faced common problems.
- I presented these issues to some designers - they came up with some concepts for products and services to help people with memory problems to be physically active.

The storyboards present the essence of the ideas.

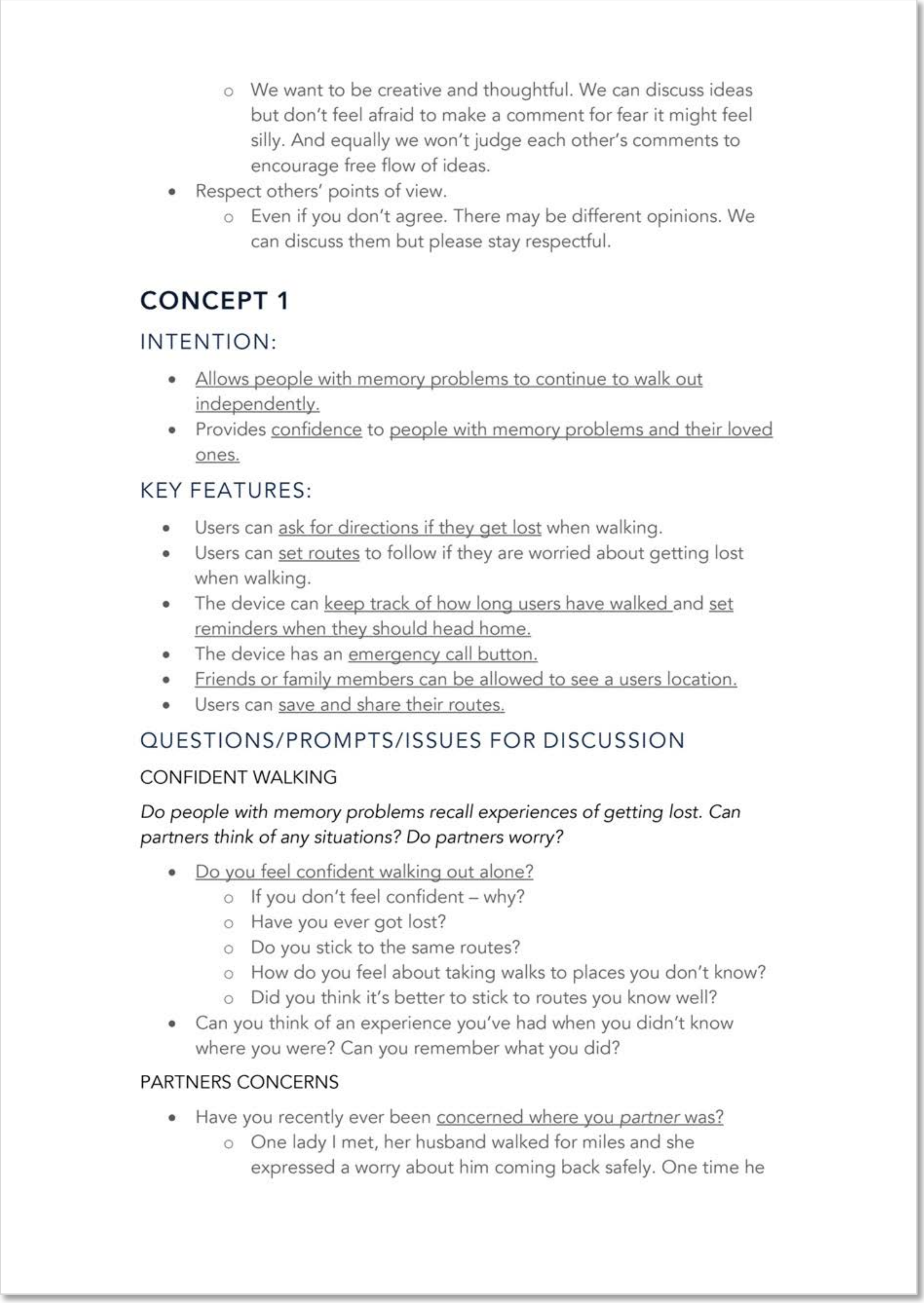
- They are designed to stimulate us to have a discussion about different issues and options.
- They do not describe precisely how the products or services would work.
- This will allow us to discuss different ways in which they might work.
- They are not my ideas so do not worry about offending me. I want your honest feedback.

I encourage you to be critical:

- What do you like?
- What do you dislike?
- Feel free to say if you think something is silly.
- But also, if you think something has a nugget of a good idea, can you see ways to improve the concepts?

Some ground-rules for the workshop.

- Only one person speaks at a time.
    - Try to stick to one person speaking at a time and one conversation and allow for everyone to have a chance to speak.
- Confidential issues remain in the room.
    - We will keep all of your personal information private and likewise we except you to respect each other's confidentiality.
- No ideas or questions are wrong.



  - We want to be creative and thoughtful. We can discuss ideas but don't feel afraid to make a comment for fear it might feel silly. And equally we won't judge each other's comments to encourage free flow of ideas.
- Respect others' points of view.
  - Even if you don't agree. There may be different opinions. We can discuss them but please stay respectful.

CONCEPT 1

INTENTION:

- Allows people with memory problems to continue to walk out independently.
- Provides confidence to people with memory problems and their loved ones.

KEY FEATURES:

- Users can ask for directions if they get lost when walking.
- Users can set routes to follow if they are worried about getting lost when walking.
- The device can keep track of how long users have walked and set reminders when they should head home.
- The device has an emergency call button.
- Friends or family members can be allowed to see a users location.
- Users can save and share their routes.

QUESTIONS/PROMPTS/ISSUES FOR DISCUSSION

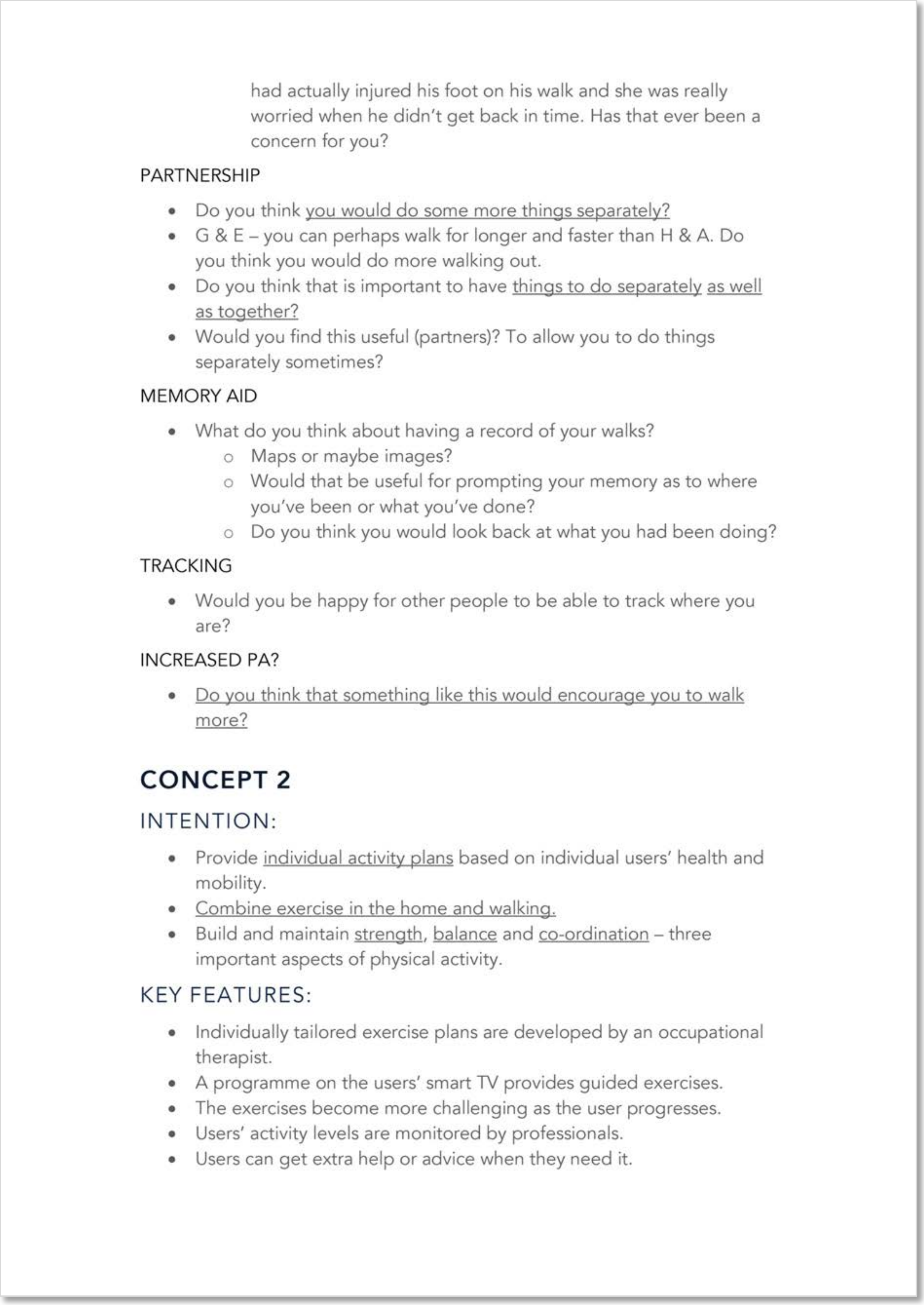
CONFIDENT WALKING

Do people with memory problems recall experiences of getting lost. Can partners think of any situations? Do partners worry?

- Do you feel confident walking out alone?
  - If you don't feel confident – why?
  - Have you ever got lost?
  - Do you stick to the same routes?
  - How do you feel about taking walks to places you don't know?
  - Did you think it's better to stick to routes you know well?
- Can you think of an experience you've had when you didn't know where you were? Can you remember what you did?

PARTNERS CONCERNS

- Have you recently ever been concerned where you *partner* was?
  - One lady I met, her husband walked for miles and she expressed a worry about him coming back safely. One time he



had actually injured his foot on his walk and she was really worried when he didn't get back in time. Has that ever been a concern for you?

PARTNERSHIP

- Do you think you would do some more things separately?
- G & E – you can perhaps walk for longer and faster than H & A. Do you think you would do more walking out.
- Do you think that is important to have things to do separately as well as together?
- Would you find this useful (partners)? To allow you to do things separately sometimes?

MEMORY AID

- What do you think about having a record of your walks?
    - Maps or maybe images?
    - Would that be useful for prompting your memory as to where you've been or what you've done?
    - Do you think you would look back at what you had been doing?

TRACKING

- Would you be happy for other people to be able to track where you are?

INCREASED PA?

- Do you think that something like this would encourage you to walk more?

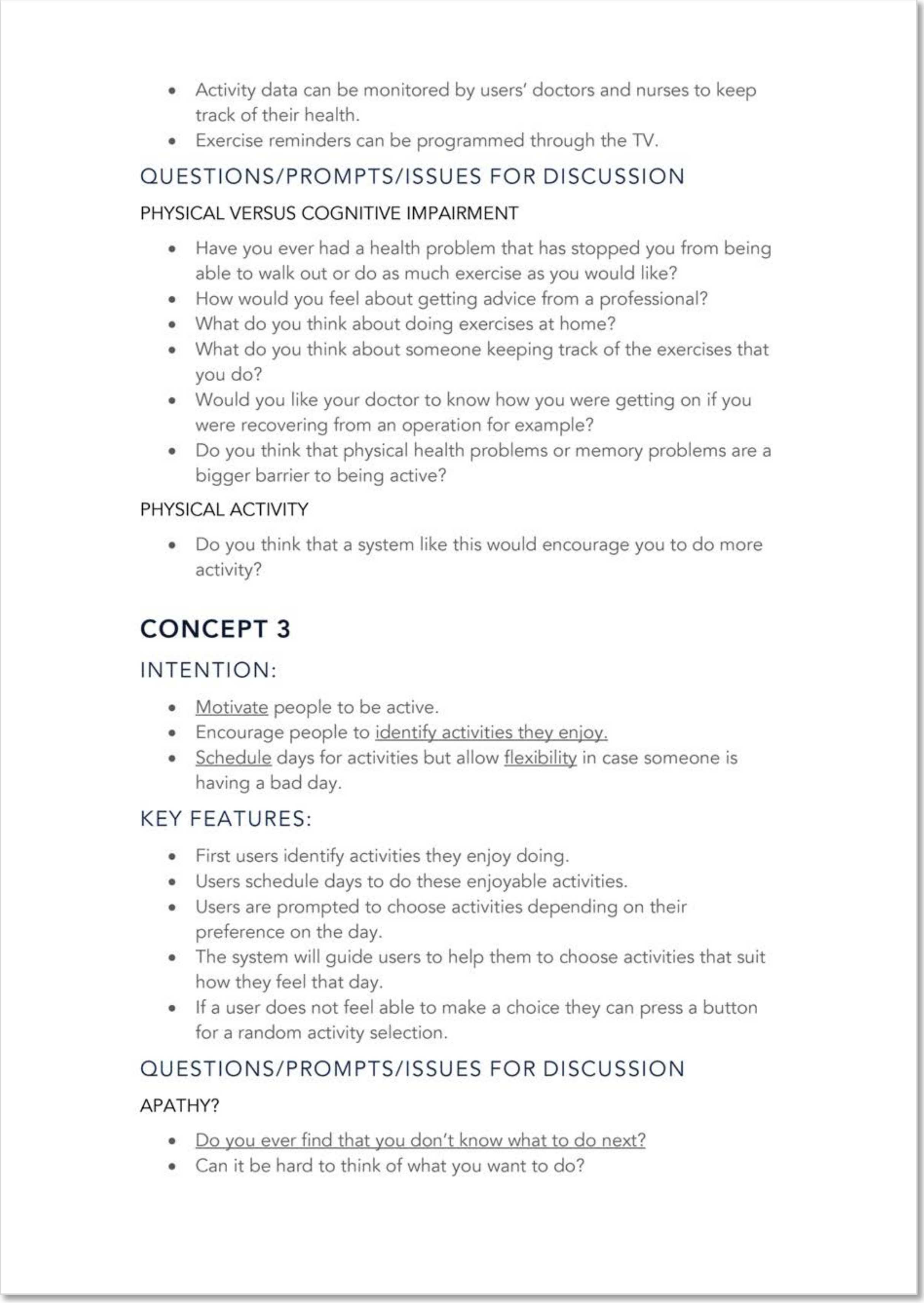
CONCEPT 2

INTENTION:

- Provide individual activity plans based on individual users' health and mobility.
- Combine exercise in the home and walking.
- Build and maintain strength, balance and co-ordination – three important aspects of physical activity.

KEY FEATURES:

- Individually tailored exercise plans are developed by an occupational therapist.
- A programme on the users' smart TV provides guided exercises.
- The exercises become more challenging as the user progresses.
- Users' activity levels are monitored by professionals.
- Users can get extra help or advice when they need it.



- Activity data can be monitored by users' doctors and nurses to keep track of their health.
- Exercise reminders can be programmed through the TV.

QUESTIONS/PROMPTS/ISSUES FOR DISCUSSION

PHYSICAL VERSUS COGNITIVE IMPAIRMENT

- Have you ever had a health problem that has stopped you from being able to walk out or do as much exercise as you would like?
- How would you feel about getting advice from a professional?
- What do you think about doing exercises at home?
- What do you think about someone keeping track of the exercises that you do?
- Would you like your doctor to know how you were getting on if you were recovering from an operation for example?
- Do you think that physical health problems or memory problems are a bigger barrier to being active?

PHYSICAL ACTIVITY

- Do you think that a system like this would encourage you to do more activity?

CONCEPT 3

INTENTION:

- Motivate people to be active.
- Encourage people to identify activities they enjoy.
- Schedule days for activities but allow flexibility in case someone is having a bad day.

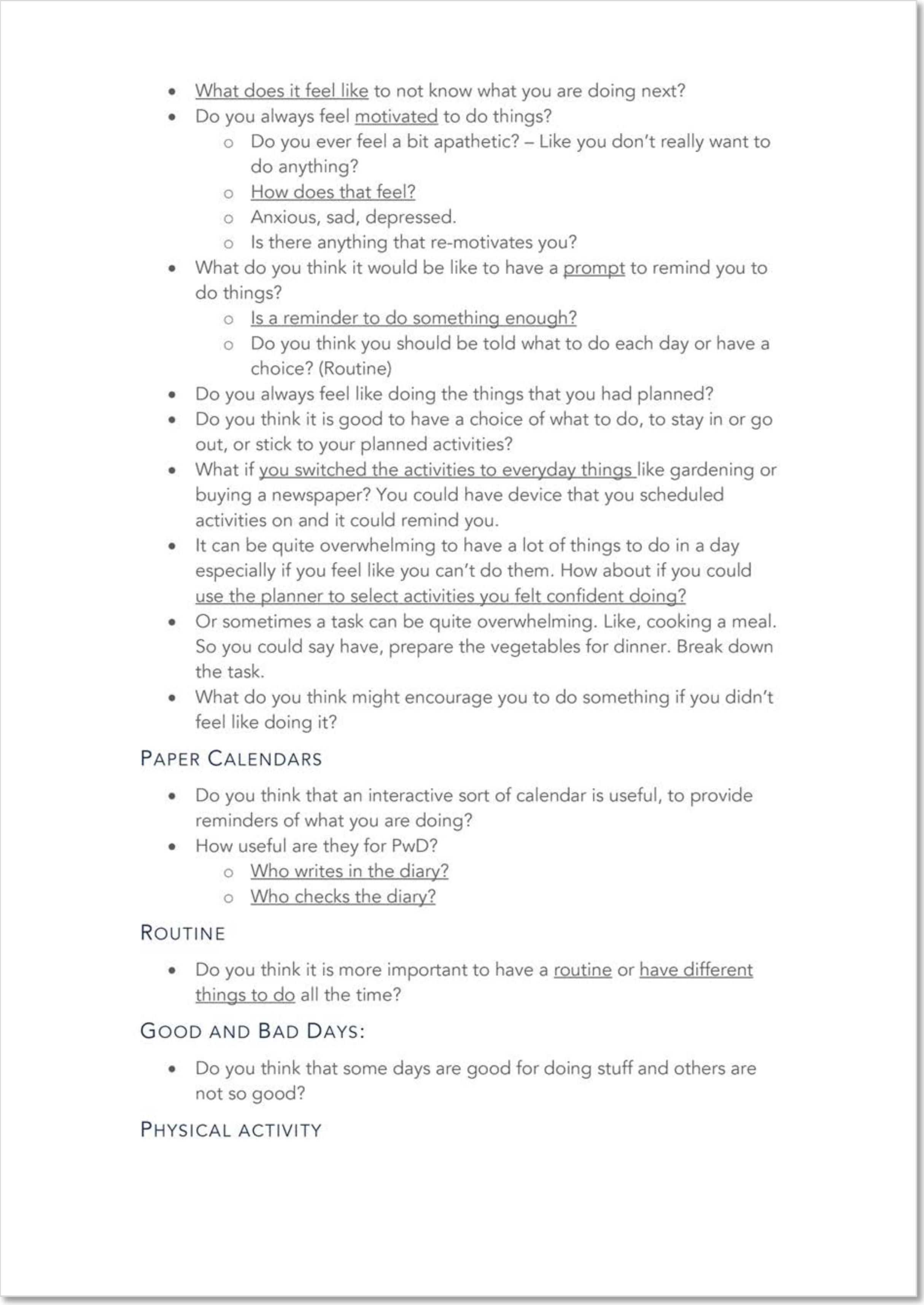
KEY FEATURES:

- First users identify activities they enjoy doing.
- Users schedule days to do these enjoyable activities.
- Users are prompted to choose activities depending on their preference on the day.
- The system will guide users to help them to choose activities that suit how they feel that day.
- If a user does not feel able to make a choice they can press a button for a random activity selection.

QUESTIONS/PROMPTS/ISSUES FOR DISCUSSION

APATHY?

- Do you ever find that you don't know what to do next?
- Can it be hard to think of what you want to do?



- What does it feel like to not know what you are doing next?
- Do you always feel motivated to do things?
    - Do you ever feel a bit apathetic? – Like you don't really want to do anything?
    - How does that feel?
    - Anxious, sad, depressed.
    - Is there anything that re-motivates you?
- What do you think it would be like to have a prompt to remind you to do things?
    - Is a reminder to do something enough?
    - Do you think you should be told what to do each day or have a choice? (Routine)
- Do you always feel like doing the things that you had planned?
- Do you think it is good to have a choice of what to do, to stay in or go out, or stick to your planned activities?
- What if you switched the activities to everyday things like gardening or buying a newspaper? You could have device that you scheduled activities on and it could remind you.
- It can be quite overwhelming to have a lot of things to do in a day especially if you feel like you can't do them. How about if you could use the planner to select activities you felt confident doing?
- Or sometimes a task can be quite overwhelming. Like, cooking a meal. So you could say have, prepare the vegetables for dinner. Break down the task.
- What do you think might encourage you to do something if you didn't feel like doing it?

PAPER CALENDARS

- Do you think that an interactive sort of calendar is useful, to provide reminders of what you are doing?
- How useful are they for PwD?
    - Who writes in the diary?
    - Who checks the diary?

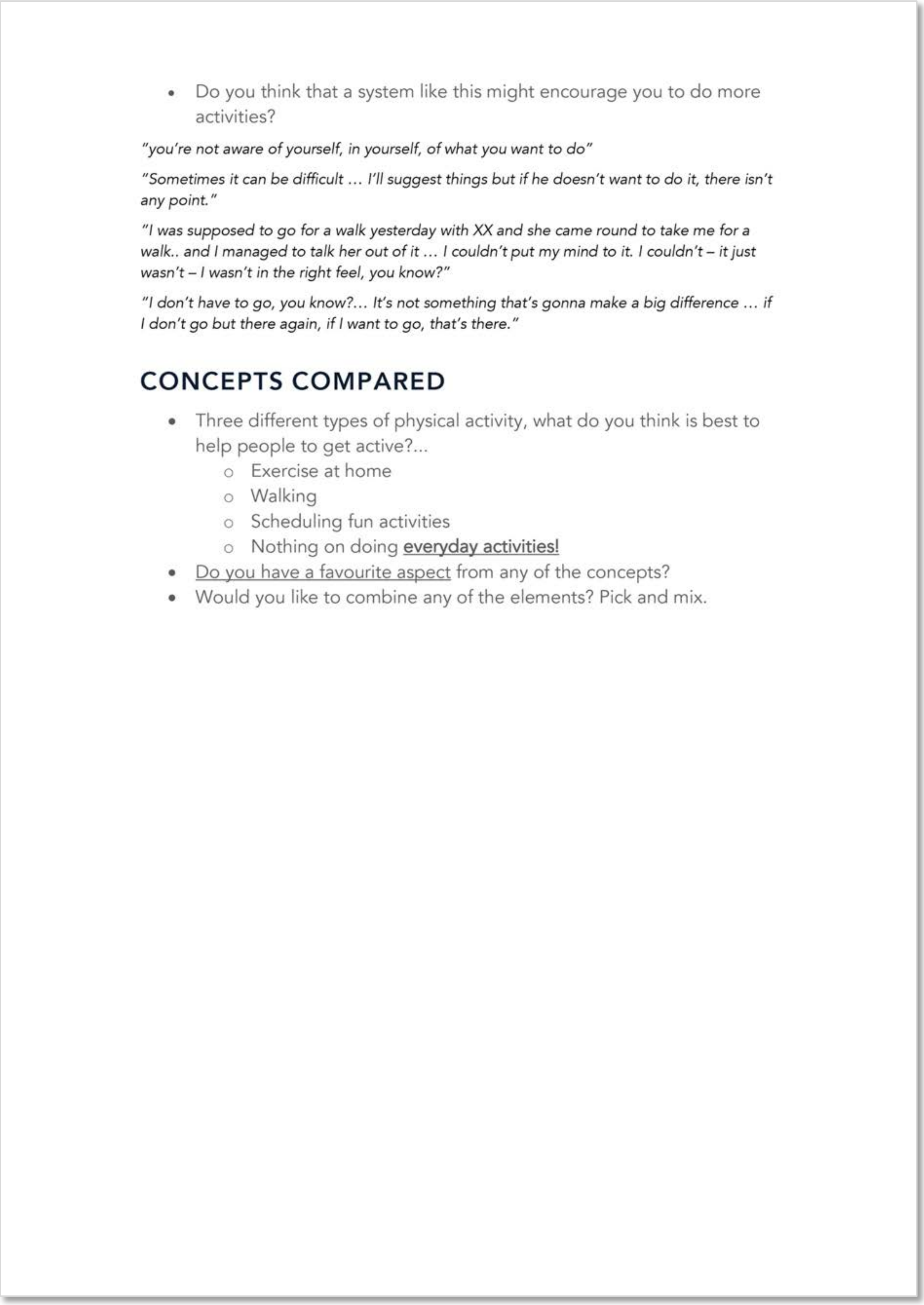
ROUTINE

- Do you think it is more important to have a routine or have different things to do all the time?

GOOD AND BAD DAYS:

- Do you think that some days are good for doing stuff and others are not so good?

PHYSICAL ACTIVITY



- Do you think that a system like this might encourage you to do more activities?

"you're not aware of yourself, in yourself, of what you want to do"

"Sometimes it can be difficult … I'll suggest things but if he doesn't want to do it, there isn't any point."

"I was supposed to go for a walk yesterday with XX and she came round to take me for a walk.. and I managed to talk her out of it … I couldn't put my mind to it. I couldn't – it just wasn't – I wasn't in the right feel, you know?"

"I don't have to go, you know?… It's not something that's gonna make a big difference … if I don't go but there again, if I want to go, that's there."

CONCEPTS COMPARED

- Three different types of physical activity, what do you think is best to help people to get active?...
    - Exercise at home
    - Walking
    - Scheduling fun activities
    - Nothing on doing **everyday activities!**
- Do you have a favourite aspect from any of the concepts?
- Would you like to combine any of the elements? Pick and mix.

T. Sample vignettes

1. Malcolm

Malcolm (pseudonym) is 73. He has a diagnosis of MCI (mild cognitive impairment). (His mother had dementia). He also has a *"benign tremor",* arthritis *and "a slight heart problem".* He lives alone in his flat in Gateshead and has no family. He lived with one girlfriend for six months, but it didn't work out, so he decided to sell his house and rent a flat. He has always been based in Gateshead, however his job in the army took him around the world.

Memory problems

Malcolm reports having had the memory problems that have led to his diagnosis of MCI for *"at least three years*". However, his memory problems are not obvious during our conversations. He is verbally fluent and very talkative. He doesn't repeat himself. At one point he did say - *'if I've told you before, tell me to shut up',* however, at the time I put this down to him enjoying telling stories rather than being conscious of repeating himself due to memory problems. Twice, in conversations about technology he referred to *'the thingy',* once in reference to a USB port, and another time, perhaps more markedly, in reference to his computer which he uses on a daily basis.

Malcolm talks about forgetting and not remembering throughout our conversations. He mentions forgetting an email that he had sent to me, forgetting to take things out of the house with him, forgetting what he was going out for. At one point he asks me for a new question *"because I have forgotten what you asked for"* but this was after a digression from the topic. At one point in our first conversation, he asks whether I want to know whether he is *"going crazy or not".* He describes an instance when he put some fish in the fridge instead of the microwave to cook and then couldn’t find it when he returned half an hour later. He indicates that he is frustrated by these kinds of behaviours, which he calls screw ups and stupid mistakes.

Malcolm indicates that his reading has also been affected however, it is unclear to what extent. At one point he says, *“I can’t concentrate on reading a book or a magazine”* but later says “I read the newspaper through the day”. When quizzed on this he says, *“I still read but not as much”* and *‘if I am reading something, like a newspaper, I know what I am reading but it doesn’t register. It doesn’t stick in my head.”* He also mentions that he can’t do crossword puzzles and brainteasers, he talks about not being able to see the logic. Despite this, he enjoys playing Scrabble online. After the interview Malcolm decided to email me with a reflection on this. He said:

“I now realise why I can play Scrabble but not do crosswords or these Brain Teasers. It’s because in a crossword or a Brain Teaser there is only one correct answer to each question. But in Scrabble there can be many answers - you can fit in any word with the correct spelling. It’s the multiple-choice kind of answer that makes it easy for me.”

This could be an interesting insight for the design of games for people with memory problems. Multiple answers or no wrong answer may make games more enjoyable.

The exact reason for seeking a diagnosis was unclear, Malcolm reports that after going to his GP about something (of which he is unsure), he was visited by a psychiatrist. Following this was asked to see a psychoanalyst who conducted a memory test with him. He then reports receiving a letter from the hospital with a diagnosis of MCI. He reports receiving a book, “*about ten or twelve pages in it, telling me how I could cope with this, what I could do about it, etc,”*. However, when he read the book he found *“that all the things in the book that were relevant to me, that I was already doing them. Like keeping a paper diary, like having a diary on the computer and all sorts - I was already doing everything that was in the book”.*

Coping strategies

Malcolm is keen to tell me about how he manages his life using lists, keeping to a routine and using his computer and mobile phone as memory aids. He tells me:

"Once I realised that I was starting to not remember things, I had to compensate for it. Like having the calendars, like writing things down that I would put onto there [points to mobile phone, and stuff like that."

He writes a list every day:

"I write myself a list of what I'm doing the next day … so that when I get out of bed the next morning, when I go to switch this computer on I see this list and that refurbishes what's going on in there and off I go."

He describes how he lines things up in the kitchen or the hallway, where he can see them, so that he doesn't forget to take them out with him. He says, *"if I don't have them in full view as I walk past them, I will forget them."*

Before the interview Malcolm sent me, a document entitled; *'Things I do to compensate.'* In it he says:

"I have a paper diary beside my main landline in the living room – I have a calendar on my phone – I have two calendars on my computer."

"Medication (I have a slight heart problem) – I have a date/time box beside the phone in the bedroom – this works quite well – I very rarely miss taking my pills."

He also explains that he uses paper notes - *"When I go out, I nearly always have a pen & paper with me"*. He also has a note-taking application on his mobile phone called Evernote but says *"I don't seem to use it much."*

Throughout the interview Malcolm talks about these coping strategies and talks a lot about routine - *"I like routine", "My whole life is routine"*. He says, "*routine gives* *me confidence"*. It is difficult to know why routine is so important to Malcolm. Even for a person coping with mild cognitive impairment he seems to advocate routine to an extreme. I wondered if the routines he described were more to do with his army training than a coping strategy for MCI, particularly after he said - *"I come out clockwork, after 22 years in the Army".* When I quizzed him on his list-making, he said that the list-making was something that had happened more recently. He said that he didn't used to need lists *"I could do everything in my head."*

"…as far as I can remember, about three years ago, things started to go, I don't know. I don't even know how it started. Perhaps I just did it automatically, made a list."

He admits that the routine and list making were part of his army life, but goes on to say that:

"when I left the Army, I didn't need lists. My life was simple, so everything I could do in my head as far as I remember, it wasn't until about three years ago that I reverted back to lists again."

Exercise

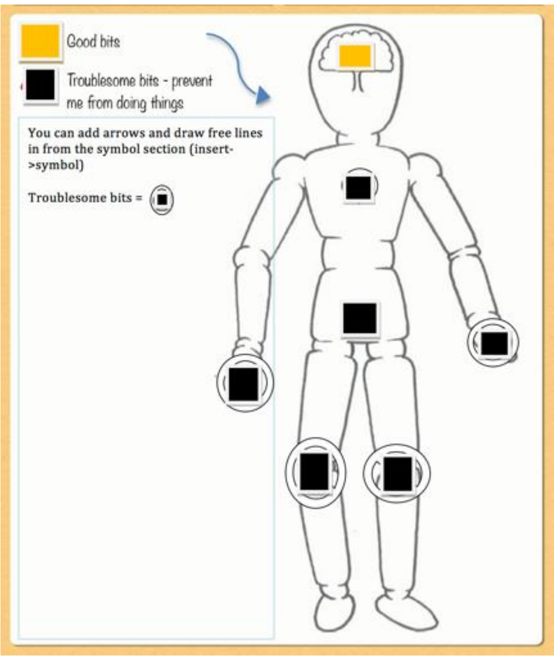
Malcolm is active and makes point of getting out and doing something every day. He goes to the gym from *'seven till eight 'o'clock'* in the morning on four days a week. At the gym he does circuit training to his 'own plan'.

Despite having been active in the army were he *"would go for a five-mile run. Every night and sometimes twice a day"*, after leaving the army he *"reverted to type, beer swilling Geordie, no exercise, fish and chips and things like that"*. This lifestyle *'caught up'* with him and ended in hospitalisation. The hospital referred him to the leisure centre for a specific training regime which lasted for a month. After that he only had to pay half price for the first 6 months, and attributes his continued attendance, in part to having signed up to a direct debit. As a result, he has been going to the gym for *'two, nearly three years.* He says that the gym is *'alright, it's great…I enjoy it.'* He likes to *'listen to the conversations that go on around you,'* and *'see the different types of people who go there, and what they do.'* He sees it as a *'social activity but I'm doing the exercise as well.'*

Whilst Malcolm is able to go to the gym four times a week, he has to drive to the gym because, if he walked the 1.5 miles to the gym he would be '*wrecked*' and have to '*come straight back again*'. This may be in part due to his arthritis, which prevents him from doing weight-bearing exercise, such as use the treadmill. He says, *'I do nearly everything sitting down, like the rowing machine, the skiing machine, because my feet are nailed to the floor for things like that.'* When we walked across the university building to the interview room, I noticed that he walked quite slowly and with a slightly unusual gait. However, in our interview he indicated that he was happy to walk around half a mile to local shops and the local restaurant.

On the diary page 'Body and Mind' Malcolm highlights the arthritis in his knees, back pain, a tremor in his hands and his heart as 'troublesome bits'. It is clear that his arthritis effects his ability to be physically active, although he compensates for this when he uses the gym. His tremor is problematic when writing. Arthritis appears to have the greatest effect on Malcolm's capacity to be active. He exercises for his heart but doesn't mention it being a problem that prevents him from being physically active.

Daily activity



Other than the gym, Malcolm doesn't mention any other forms of formal exercise. However, he does keep active. He uses the car for journeys to visit friends and do a supermarket shop. However, he uses the bus when travelling into Gateshead or Newcastle to save on the parking charge. He also uses the Metro (for which he has a reduced-price pass). He particularly enjoys travelling on the Metro where he can indulge his pleasure in people watching, watching the different and interesting people who get on the Metro.

During his week, Malcolm walked to local shops and the restaurant. Took the bus to Newcastle for the interviews. Drove to the gym, supermarket and to visit friends. Took his monthly drive to the Fish Quays. He went into Newcastle with his friend, got drunk and took a taxi home. He went on a more unusual trip to meet an acquaintance in Blyth which he drove to. In the list he sent prior to the interviews he mentioned that when he travels:

"I plan ahead – I make a route card – I do this on paper and on the computer – I sometimes put some details on my phone (but not often)."

However, this didn't come up again in the interview.

Malcolm presents as a very sociable person. He lives alone but obviously values contact with others. He tells me "*I'm a people watcher, I like to watch the world go by.*" As well as watching people he enjoys listening to their conversations, he mentions making impromptu conversation with strangers he meets. He also makes acquaintances around the world through playing Scrabble on Facebook. Despite mentioning a number of acquaintances that he connects with during the week he says he only has three friends.

The future

At the weekends he goes to see *"the old ladies"*. These women helped his mother at the end of her life, "*so*", he says "*I feel as if I'm doing a bit for them as well.*" One of these ladies has dementia. He reflects on her management of her memory problem. She doesn't remember she has a calendar, on which her family leave notes when they visit. He attributes her lack of use of the calendar to lack of practise - *"She's never had to practise it before, and she is struggling to practise it."* He goes on to reflect on his own use of routine as a buffer against future loss of memory. He says:

"So I've got this [routine] now, when I think I'm not too bad, and I have got my fingers crossed that if I live long enough and I get worse, then because I have got the routine, it it's embedded up there somewhere, the routine will keep going. I don't know."

The necessity of managing his condition is heightened for Malcolm by the fact that he has no family to look after him in the future:

"As long as I keep my system, like writing notes, that's a great, if I lose that system, or I stop planning ahead, I think it will be a disaster area. Because I live by myself, and I have no family, and there's no nobody coming to see me, that's where the problem will come."

Malcolm highlights the problem that he faces if his memory declines and he stops 'planning ahead'. For him there is no support system

> *"there's no nobody coming to see me, that's where the problem will come."*

Energy levels

Despite being very active, Malcolm finds a 30 minute 'power nap' beneficial in maintaining his energy levels during the day. He says that this is "*fairly new, that's about a year that I've started power naps.*" He indicates that it refreshes his brain power:

"I can think sharper, I can do anything I want to after I have had a power nap. "

Health maintenance

Malcolm actively manages his health. He mentions going to the dentist every six months. He goes to the gym four times a week for his heart problem. He is conscious of not eating too much. When he received his diagnosis of MCI, he looked for information on the internet:

"I googled it and I found out more about it, and more about it, and I just took everything from what google said."

Technology

My favourite activity is....

Downloading "Torrents" trying different hacked programmes from such sites as Kickass & Torrentz.

Grr! I couldn't move the photograph here ☹
I like working with my computer – it makes me think & keeps me alive!

What makes it enjoyable?

Alive!

How does it make you feel?

No- it's quite fast and powerful – it's me that's old & slow

Could it be even better?

75% easy
20% frustrating
5% difficult

How easy is it?

Malcolm is a confident computer user. He chooses using the computer as his hobby or interest in the diary. During the interview he mentions that he uses his computer to read the news, research holiday destinations, play games and for buying books on Amazon. He appears to be a proficient computer user who is confident enough to use torrents to download free software. He does however suggest that he finds using the computer *'75% easy, 20% frustrating, 5% difficult*', but, when questioned, he indicates that he enjoys the challenge of solving problems on his computer. He has linked the diary on his computer with one on his mobile phone which is a touchscreen smart phone.

Despite carrying the mobile phone as a diary, he says that *'people don't phone'* it, so when it rings, he doesn't recognise his ring tone. He can use his mobile as a phone and also send messages, but he doesn't use it to go on the internet, for;

"Two reasons. One I can't see the point of it, and I would hate to exceed my bandwidth and get charged lots of money for doing it, so I don't do it."

I asked him about using apps. He said, *"I can't see the point in them"* but then realised that he had one *'little notepad thing' (presumably the aforementioned Evernote which he said he doesn't seem to use much).* As we had already discussed playing scrabble online, I asked if he realised, he could download scrabble apps. He didn't seem keen on this idea:

"Why would I do that when I have got a computer with a big screen? Why would I [groans] with my shaky hands?"

I asked him how usable the keyboard on his mobile phone's touch screen was. He said he had previously owned a Blackberry with a full keyboard but that the touch screen *"didn't make any difference*, implying similar usability. On reflection, however, it is unclear how often Malcolm uses the mobile phone other than as a diary and whether it would be difficult for him to use it for complex or frequent tasks because of his tremor.

Despite using the computer on a daily basis, including playing Scrabble on Facebook Malcolm thinks:

"I'm not part of the computer world and the I can't relate to young people now. I can do what I want to do, I can experiment a little bit but I, how can you have a thousand friends?"

Whilst Malcolm is confident with the computer, he divulges that he doesn't know how to use his Virgin Box because it didn't come with instructions, that he can get frustrated when programming the microwave, and that he can't work the central heating:

"I've got the idiots guide for that and I still can't understand how it works, no. But never mind, so I just switch it off and on again, I don't use the timer."

It is interesting to note that someone who is so confident in one area of technology has difficulty with another.

2. Pat

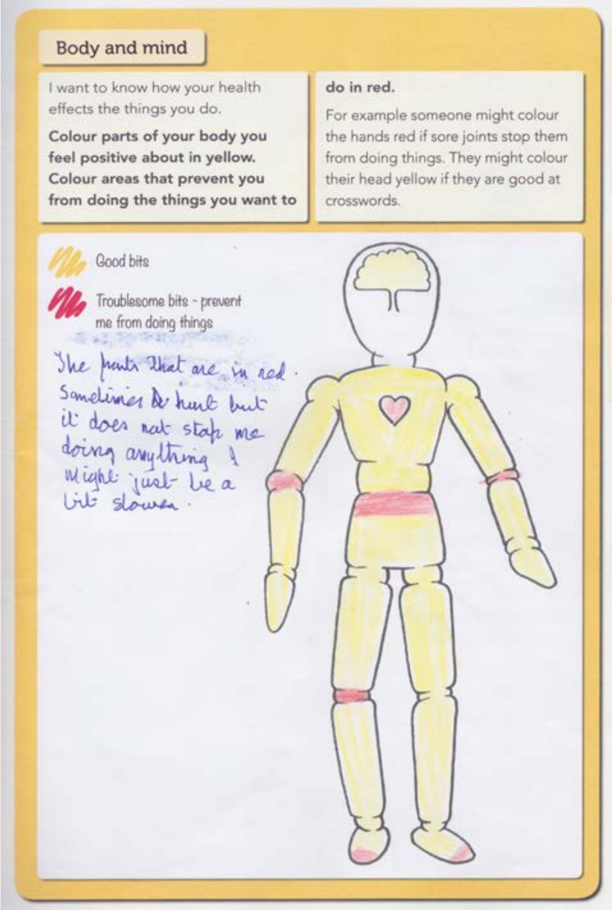
Pat lives with his wife Mildred in the suburbs of a seaside town. Pat is seventy-one and his wife is seventy. Pat was in the RAF as a radio engineer and on leaving the service went onto use his skills repairing hi-fis and televisions. Mildred did clerical work in the NHS. Pat had a heart attack in his early 60s and took retirement a year earlier than expected at around 64. They have lived around the UK and also in Singapore where Pat was stationed. They moved to their current seaside location eight years ago.

In addition to having a heart attack Pat has had DVTs on his lungs. Despite these cardiovascular health problems, Pat appears to be a youthful 71-year-old. When I ask him about his previous health and activity levels, he says, *"…if anybody was going to have a heart attack, it wasn't going to be me."* He goes on to say, "*I've always done sport*" and his wife comments "*he's very much an outside person*".

On the Body and Mind page of the diary Pat marks his arthritis and also his back problems. He says:

"The parts that are in red sometimes hurt but it does not stop me doing anything I might just be a bit slower" (Pat)

Pat marks his brain in yellow as a 'good bit'.



Body and mind

I want to know how your health effects the things you do.

Colour parts of your body you feel positive about in yellow. Colour areas that prevent you from doing the things you want to do in red.

For example someone might colour the hands red if sore joints stop them from doing things. They might colour their head yellow if they are good at crosswords.

🟨 Good bits

🟥 Troublesome bits - prevent me from doing things

The parts that are in red. Sometimes do hurt but it does not stop me doing anything I might just be a bit slower.

The couple's suburban location offers plenty of scope for activity. They can use their free bus passes to get into town, where they can shop and go to the cinema. They also mention using the metro and the ferry to take them further afield and to the nearby cities, although they admit to using the car to get into the city if they feel *"lazy" (Mildred)*. They live in walking-distance of several parks and coastal paths. They both drive and regularly visit friends around the country. The couple used to share the driving but Mildred remarks at one point *"we don't take turns anymore"*. There is no reason given for this change of circumstances. This is particularly remarkable since Pat has experienced a blank in his awareness of location whilst driving:

"I drove out here, down to the bottom of the road there…. And I had to stop. I didn't know where I was, basically… Or where- where- where I was going." (Pat)

This appears to be Pat's first experience of dislocation in a familiar place as Mildred says that is *"Only the first time it's happened."*

It seems that the biggest memory issue Pat currently faces is losing things. He has forgotten his wallet on a number of occasions. This also happened during the week of the diary. Thankfully, in this instance, a friend found the wallet. However, Pat described this event as stressful and Mildred said it should have been described as '*very stressful*'. The couple also describe an occasion when Pat put the house keys in an unusual place. Pat remarked that in the hunt for his keys *"I was getting really peed off" (Pat).* Mildred described him *"getting very angry with himself" (Mildred).* Pat says that *"It's only the occasional times that I really get frustrated with it."* He said that other memory problems, such as forgetting where he went on holiday was "*no real problem. I don't wind myself up with that.*" However:

"…when I lose something in here, I think or- or put it down, like I can't find it…. And I- I- it- and the more I walk round trying to look for it, I think, the more I get wound up about it." (Pat)

Mildred says that she has always done the household shopping alone which she drives to a supermarket for. However, Pat does do his own shopping trips, independently. When I asked if memory problems affect his shopping he says - "*No I don't think so" (Pat).* However, Mildred interjects - "*You do make a bit of a list if there's special things that he wants.*" Pat confirms, "*I make a little list*", but goes onto to suggest that he doesn't always remember that he has a list: *"Nine times out of ten I forget one of them on there because I look at it,… put it in my pocket, I then forget about it."* (Pat) It is unclear, in this aspect at least, how much memory problems effect Pat, more than the 'normal' memory changes of a 71-year-old.

Pat demonstrates his capacity for independent activity in an incident with the Polaroid camera. There was a problem with the camera, so Pat went out to try and find a camera shop to get some advice. After he couldn't find a camera shop in the local town, he took the ferry to a town across the river. They didn't have a shop in this town either, so he went back on the ferry and then took a bus or metro, to the nearest city where he found a camera shop. In total he took an 18-mile round trip using several buses (or possibly the metro) and a ferry. He didn't describe any difficulties on this trip.

Despite moving to the area only eight years ago, Pat and Mildred have amassed a substantial group of friends and have an active community life. Many of the couple's friends also participate in their primary hobby - bowling. Pat and Mildred both play pétanque twice a week and ten-pin bowling every other week. Pat also plays crown green bowls twice a week. Pat also has friends through golf. He hasn't played golf this year due to a shoulder injury however he plans to start again in the week following our discussion. In his diary Pat's explains the reason for finding golf enjoyable as: *"Just hitting the golf ball properly and getting the distance."* (Pat). Pat and Mildred also participate in local community activities, for example, during the week of the diary Pat helps run a stall at a local fair and goes to the Armed Forces Day parade.

Pat also chooses gardening as a favourite hobby, explaining that *"gardening is very relaxing"* (Pat). He has an immaculately kept garden and a greenhouse where he brings on cuttings. Pat mentions that a problem with his back causes pain if he does a lot of bending and digging. He wears a 'thing' round his waist which he says is helpful. He also has some arthritis in his knees and elbows but says *"there's nothing that really stops me doing anything" …" I just get on and do things".* (Pat).

Pats hobbies demonstrate an active life. He has participated in various sports throughout his life and has an adventurous outlook, noting in his diary that he *"would like to go gliding. Drive a very fast sports car".* (Pat) However, when I quiz Pat about the level of physicality to his current sporting hobbies, he admits that he doesn't often do things that are energetic enough to get him out of breath. Margaret mentions that they were previously part of a walking group and that they might go back to that.

Pat also enjoys relaxing hobbies, his bowling and gardening as well as completing jigsaws. However, Pat's determine nature comes across, even in his comments about jigsaws. He says, *"once I start one, I have to finish it as quick as possible." (Pat)* Mildred comments; *"that's been Pat all his life, you know? When he starts something, he has to finish it."* Pat's determination may have softened slightly more recently however as he indicates that he can now put something off until tomorrow:

Patrick:	I can sit here and think ‘well I’ve got to do that’
Mildred:	Oh, that’s now, yes. That’s now, yeah.
Patrick:	Yeah, ‘I’ve got to do that. Got to do that … Oh, I’ll do that tomorrow.’

Throughout the interview Pat and Mildred mention meeting friends and family for meals or a coffee. Pat says his ‘favourite place’ is a cafe that they visit. They can combine a visit to the cafe with a walk through the park or along the seafront. Every Sunday they go out with Mildred’s sister and brother-in-law for a drive and a Sunday lunch.

In addition to travelling with Pat’s work, the couple have taken holidays around the world and continue to do so (although they are now limited by travel insurance). They have just come back from Dubai and have holidays planned in Cracow and Prague for later in the year. They travel in the UK, *“on the national holidays a lot… for three or four days”* (Pat).

After leaving the RAF, Pat went on to work repairing hifis and TVs, however he admits that his skills are less relevant to today’s technology:

“I used to repair all the hifi equipments and televisions, er, when I … when I came out the Air Force. That was me trade…. But, er, now I’m … Not up with phones and things and …”

The couple both have iPhones. They have a laptop and iPad and have the internet at home. They use a sat-nav in the car and have a digital camera. Mildred seems to be the more confident of the two with technology. She uses the iPad to check emails and do shopping and has booked holidays online with the help of her son.

When I ask Pat what he does on the iPad and computer he says:

“Well, all I do is look at me email and- and delete most of the stuff”

However, Mildred reminds Pat that he has sold things on Gumtree. She goes on to clarify that in such situations *"Our son's always there to help" (Mildred).* Pat confirms this and suggests he need's his son's help *"Because I always… press the wrong button and other things happen" (Pat).* He says that *"I find that … very frustrating" (Pat*). Pat's ability to press the wrong button seems to be a family joke, as Mildred laughs and says, *"it's well known in the family that he … presses the wrong buttons."* Pat seems happy to ask for help though, as he goes on to explain that when he does something wrong, "*I have to ring Thomas",* their son. Despite some lack of confidence Pat does use his iPhone, which he has only had for three months, to make calls and as a diary. He says, *"I still have trouble with it"* and that it *"takes me a little while"*. Pat struggled with his son's previous attempt to upgrade him from a phone with buttons to touch-screen phone however using his son's old iPhone seems to be more successful. As yet he hasn't mastered the alarm on his iPhone and still uses his old phone to set his morning alarm. He doesn't yet use any apps on his iPhone, and he doesn't use maps or use the internet outside the home. Pat does, however, use internet banking on his computer with confidence, asserting *"that's pretty easy" (Pat).*

An interesting comment was made about the diary on the iPhone as a tool for coping with memory problems. Pat uses the diary in his mobile phone and a reminder for appointments, events and medicines. Mildred comments that: "*when they all first started to come about this, we tried with a small diary for him but he- he couldn't get into the habit of putting it in that,"* but now, with his iPhone *"When they- when he got this one, he could do it with this."* Despite not being particularly confident with his iPhone it is working better as a reminder tool than a written diary. Although once Pat also manually transfers his appointments to the kitchen calendar. Unfortunately, it isn't clear from our conversations why the iPhone works better than the written diary.

The couple's son seems to play a significant role in their use and purchase of technology. He lives locally and seems to be their main source of IT Support. Mildred suggests jokingly that *"If we didn't have him, we probably wouldn't let him* (referring to Pat) *push buttons".* She goes onto reflect what will happen when her son goes to work away, suggesting that she isn't sure how they will cope, until she thinks of their friend, who is also into IT.

The couple seem happy to use technology to an extent *"we just take out what we need and- and that's it really"* (Mildred) *"If we wanted to venture any further, well Tom's there and he would probably show us."* It is questionable how much of the couple's choice and use of technology has been guided, encouraged or even foisted on them by their son. Mildred did mention that Thomas encouraged his father to go on the Facebook. Pat did not seem to like people wanting to be friends with him. They also use FaceTime with their daughter and had used Skype before that.

They are not averse to learning new technology and have been on IT courses. Their son's teaching skills seem to leave something to be desired as he goes too fast for them. Mildred comments that their friends have the same problem with their children's impatience.

Pat often mentions the need for instructions in relation to technology. Pat thinks that having received their iPad without an instruction booklet is "ridiculous". Pat also keeps notes from his classes about how to complete different tasks on the iPad.

I asked the couple if they had every used the internet to research health issues. They said they had done so on one occasion to look at a new procedure they had read about in the newspaper. However, Mildred said:

"We wouldn't actually go in and look at things medically… I think ... the more you know, the worse it becomes"

3. Lynn

Lynn was seventy-eight when we met, although she said she did not feel it:

> "In my head I'm not seventy-nine." (Lynn, PWD)

Lynn lived alone, around two miles from the city centre, in the home she had moved to ten years previously. Lynn had separated from her husband when her children were young. One of Lynn's daughters lived locally and had a young son who Lynn was very close to. Lynn had helped to care for her grandson since he was a baby and had retired when her daughter returned to work. She continued to babysit at evenings, weekends and holidays.

Lynn was recruited for the research through the NHS. On her medical record she was recorded as having Alzheimer's disease; however, when we discussed her diagnosis, she reported that she had been told that she was 'in the grey area'.

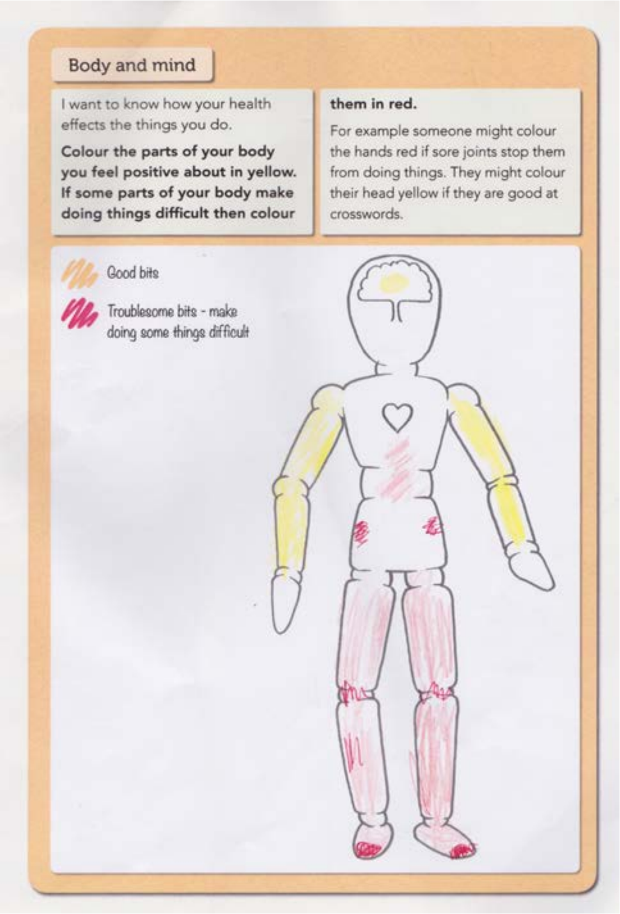
> "She sent me there first…. The Memory Clinic… and then tests and things to fill in and … they did an MRI… and it came back… and [the doctor at the Memory Clinic] she says, 'you're in the grey area.' That was the conclusion, all the test together - 'you're in the grey area.' … My whole point was to get the magic pills that I'd read about… a pill who could slow it down… And she says … 'you're so determined and you're so keen, I'm going to give you pills. Even though you're just in the grey area.'" (Lynn, PWD)

Of the participants with dementia, she reported the least cognitive difficulties, and less even than some of the participants with MCI. As a far as Lynn was concerned her dementia was having a limited impact on her day-to-day life:

> "It probably didn't stop me from going out…. I'm not that bad and I don't think I was even before the donezepil."

Other than occasional word finding difficulties and describing once getting lost in an unfamiliar place, Lynn did not describe her dementia causing her any problems. Only one comment in the diary mentioned cognitive difficulties:

> "I forget appointments, I forget to write them on calendar."



Body and mind

I want to know how your health effects the things you do.

Colour the parts of your body you feel positive about in yellow. If some parts of your body make doing things difficult then colour them in red.

For example someone might colour the hands red if sore joints stop them from doing things. They might colour their head yellow if they are good at crosswords.

For Lynn, it seemed that physical health problems were more of a barrier to activity than cognitive problems, as illustrated in her completion of the body and mind exercise, in which she coloured her brain in yellow for 'good bits'. Her 'troublesome bits' were her legs and her lungs.

Lynn had problems with her legs, which she felt was "*just part of old age*". As a result, she described how she had to use the handrails to "*pull meself up the stairs*" (Lynn, PWD). In addition, Lynn described problems with her knees, for which walking was preferable to sitting or 'pottering' around the house:

> "Sometimes, once you get into a rhythm of walking, it works. It works better for me… walking along the road than going around in me house. I sit down, takes me five minutes to get up…. Walking is easier than pottering."

Lynn also experienced falls and in a recent fall had broken her finger. Despite describing having daily sensations of instability, Lynn suggested that she had "*no choice*" but to carry on with her activities.

A year previous to our meeting, Lynn had had surgery to remove cancerous portion of her lung. Although she described initially being low on energy because she had "*not got enough puff*" Lynn took her grandson to school on the metro three weeks after her operation. When she was at the gym for her knee problem Lynn had spotted that there was a pulmonary rehab class, which she joined. As a result, she described how *"at one point I was going four times a week to the gym… twice a week for the pulmonary class and twice a week for the knees"* (Lynn, PWD).

"I probably have built up a lot" (Lynn, PWD). However, she did describe an instance when she was *"nearly lungless"* when walking along a long road, trying to find her hotel on a trip to London.

Lynn also revealed that she had depression, for which she took medication. Occasionally, Lynn said that if *"something goes really wrong… then I might have… a duvet day… but not very often"*. She went on to explain that sometimes she struggled to avoid these days, however:

> "Then I think well why not? I've got nothing to do. I may as well just slob around for a day. But it doesn't happen very often. But, you know, it's probably medication that keeps me going. And hopefully I have some incentive. Joe's my incentive. Well so many things."

Despite these health problems, Lynn was relatively active, going out most days or tending her garden. When I asked Lynn whether she had always had an active lifestyle, she responded that, for her, being active was "*only for necessity*", commenting that she *"would make a very good lady of leisure"* (Lynn, PWD). Lynn had not previously been involved sports or formal exercise, apart from her visits to the hospital gym. Her active life was driven by the needs of her family and her plants:

> "There's usually some little thing for me to do that day involving somebody in the family. But if not there's always something in the

> garden… People need you; plants need you. Especially plants in pots, which would die if I didn't get out and see to them… They're all things that … keep you on your toes."

Unlike the majority of participants, Lynn had never owned or driven a car. She was very comfortable travelling by public transport, which was very handily located:

> "The Metro's right outside me door. So, wherever I'm going, I hop out there and I think 'right, where does that get me to?' … I manage fine with this public system. I really do. It's great." (Lynn, PWD)

> "I go to …hospital… occasionally, which I have to get a bus for. So, I'll get Metro from home, into town… And then get a bus up the West Road for that." (Lynn, PWD)

Twice a week she went on the Metro to collect her grandson from school. She also regularly took the Metro into the city to shop. A month previous to our interview she had taken the train, alone to visit friends in London.

Like many participants Lynn enjoyed gardening. She selected it as her favourite activity in the diary described it as: *"me main occupation"*. In the diary she wrote that it made her feel "*positive and proud*" and in the interview she said, *"I can feel meself, when I'm in the garden."* Lynn used to have an allotment, which she gave up when her grandson was born. When I asked her whether it was something she would go back to, she said

> "It's too much hard work now. It's actual digging involved with an allotment."

During the time that I was meeting with Lynn, she was in the process of digging up the communal garden around her house and transferring her plants to make her life easier in the future so that she did not have to water her "*hundred and something pots*".

During the school holidays, Lynn described taking her grandson out:

> “During the holidays, him and I have gone places, parks and museums… We’ve done lots of things.” (Lynn, PWD)

She was keen to keep going and do things for her grandson, despite her physical difficulties. At one-point Lynn pushed herself too far:

> So, yeah … I hate to be beaten by anything. And I hate to say no to him. But I should have said no there.”

Lynn described herself as a “technophobe”, although she was not disinterested in technology. She had been to computer classes and she wanted to have access to the Internet and to be able to receive pictures of her family members around the world. However, Lynn had never had a computer and did not have the Internet at home as, she said: “*I can’t afford it*”. Also, her daughter had bought her several mobile phones, but she had not found one that was usable:

Lynn	This is the fourth mobile phone that my eldest daughter’s bought me. Each one bigger and simpler than the one before and I still can’t crack it.
Lizzie	Have you got it with you?
Lynn	No. That’s another thing… If I bring it with me, it runs out of juice. If I leave it at home charged up, I forget to bring it out.
Lizzie	… Is it like a touchscreen phone or has it got buttons?
Lynn	Buttons… She’s gone to great lengths to find a simple one.
Lizzie	…Did you have a more complicated one before…?
Lynn	Well they were all supposedly simple.

4. Brian

Brian and Linda (pseudonyms) are a couple who live in a town in Northumberland.

Brian has memory problems that presents as a form of mild-moderate dementia. He was diagnosed in 2012 when he realised that he was having difficulty remembering who people were. He has visual problems, particularly face recognition. Due to the visual aspects of his dementia Brian doesn't read and struggles to remember and write the letters that constitute his own name. He struggles with numbers (in a game of dominoes) and cannot handle money. He finds it difficult to use buttons on devices (e.g. remote controls) and the keys to open the door. Brain gave up driving. Brian is relatively fluent in conversation but has some trouble finding words and stumbles, umms and errs, substitutes words and occasionally seeks his wife's help. During the interview he demonstrates lack of recall for some recent events but can tell me about other recent events.

Because Brian can't read or write in the diary, Linda volunteers herself to write for him. It is apparent in the interview that Linda has put a lot of effort into enabling Brian to express his thoughts in the diary activity. At one point I praise Linda's drawings in the diary, but she quickly corrects me, asserting *"No, we did this together."*

Brian and Linda lead a very active lifestyle. Brian is a keen walker and has previously been a long-distance walker and lead walking groups. Early each morning (between 5 and 6am) Brian goes out on his own, for a 'training walk' of around 3-4 miles. He does exactly the same route every day. The route is complex, along paved and unpaved roadsides, through an industrial estate and by a railway line. Due to following the exact same route, Linda expects Brian home at the same time every day.

Safety

I asked Brian if he had ever had any problems when going on his early morning walks? Brian responded; *"No, none at all. None that I can find~ er no."* I then asked him if he felt confident going on the walk, he replied emphatically *"Oh yes."* Brian goes on to concede that *"because Linda knows how long it's going to take, so if there isn't any Linda will come out, and she knows where I'm coming to."* Linda responds, with, ironic laughter - *"hopefully…. With her heart in her mouth".*

Throughout the interview there are instances that indicate that Linda has organised their lives to provide Brian with a sense of self and independence. However, it is clear that this comes at a cost to her.

Transport

Brian stopped driving in December 2013. Whilst Linda reports that she is an experienced driver, she says that *"Brian worries about me driving with the car"*, and so they decided to stop using the car and use their bus passes instead. This change meant they had to give up their allotment, which they used to go to every day, as it was around 6 miles away.

Linda and Brian take the bus regularly, to go into the town centre, the nearest city and the local countryside. They take day trips, travelling up to an hour and a half on busses to get to attractions, villages and beauty spots across Northumberland.

Lacking a car means that they have changed their shopping routines, taking the bus to the shops, every couple of days. They do this together as Brian can't handle money so he can't do shopping. He seems happy to go along with Linda in a trip to town *"I don't have to do anything, apart from carrying and things" (Brian).* However, he does mention that he regrets no-longer being able to buy his wife presents.

Linda also has help from her friend Jean who will take her to the shops in car for large items.

Friends

Sarah and John are a very important part of Brian and Linda's lives -

> *"with Sarah and John we do things all four of us together, don't we?" (Linda)*

John appears to have been a keen walker with Brian, as he took a picture which Brian chose as his favourite object in the room. A picture John took of Brian on a walk in Northumberland.

Sarah and John go out to places with Brian and Linda several times a week

> *"it might be two or three days in a week. If the sun shines we'll go together" (Linda)*

Brian's friends Les and Stan have also accompanied him on longer walks. However, after an incident where Brian couldn't remember who Graham's was (despite him having being the best man at his wedding) Linda now accompanies Brian and Les for at least part of their walks together. His other walking partner, Stan is leaving the country for a year and Linda intimates that this is sad because Brian may not be able to remember Stan when he returns.

Activities

During the week of the diary Linda and Brian:

- Go to a museum with Sarah and John
- Take the bus and go on a coastal walk
- Do some gardening
- Go shopping in Newcastle (on the bus)

- Get a lift from a family member to visit his caravan and to take a walk on the beach.

Most of the activities that Brian and Linda mention in the interview are centred around walking. During the week they go to the beach and for a walk in the countryside. Brian becomes more animated when we talk about the coast and the countryside. He says at one point:

> *"If you've never been to the coastal area you're missing out"*

When I mention the Cheviots, a prominent range of hills in Northumberland, Brian asserts his affinity to the countryside:

> *"Yeah, that's my place … It's a wonderful place and there's hardly anybody goes." (Brian)*

Brian's other hobbies, woodcarving and landscape painting also reflect Brian's affinity with nature. Linda quotes Brian in the diary,

> *"I appreciate nature and feel that I live as part of it"*

However, it seems that Brian hasn't done painting or woodcarving recently. It is unclear, however, it may be that Brian's dementia is preventing him from resuming these hobbies.

Brian also contributes to the household chores by vacuuming every morning after his walk. Linda tells me that they have always shared the housework as they both used to work full time. However, this may be one of Brian's last remaining contributions to the household chores. Linda indicates the importance of maintaining an independent role within the relationship.

> *Linda: "you like to do it because that's your job…and contributing to doing things by yourself, isn't it?"*
>
> *Brian: "Uh, hu"*
>
> *Linda: "Independence."*

From the interviews it seems that much of the couple's activities are centred on maintaining Brian's previous activities and enabling him (although this may be because of the diary and my enquiry being focused on Brian). However, at one point I did ask Linda whether walking used to be her hobby. She retorted, laughing, *"No, no, thank you. No."* Linda enjoys craft activities and used to go on courses when Brian went on his walks. However, now she says "we do everything together". It appears that her hobbies and interests have taken a backseat in order to support Brian in an active and fulfilled life.

It seems that activity is important for Brian as he has always had an active hobby. However, there is also an indication that Brian may in fact find it difficult to be inactive. I quizzed Linda about this, when Brian happened to be out of the room I asked her whether Brian found it difficult to be inactive? She replied *"Yes"* emphatically. She then said, *"we try and find different things to do"* and *"it can be difficult … I'll suggest things but if he doesn't want to do it, there isn't any point."* It is unclear in the dialogue whether Brian find's it difficult to be inactive or whether Linda is determined to keep Brian active.

Exercise

The couples exercise levels are very high. At one point Linda mentions that the minimum amount of walking she does a week is 35 miles. Brian walks an extra 3-4 miles per day on top of whatever Linda walks.

In the mind and body activity the hands and knees are marked red where Brian has some arthritis. However, the arthritis is not mentioned as a barrier to activity throughout the rest of the conversation.

The main barrier to activity is marked as the brain area.

At one point in the week Brian is tired in the afternoon. However, when I asked whether this was due to over-exercise, Brian said it was *"nothing to do with the* *walking"* but said that a change had occurred in the last week which Linda noted was probably to do with some new medication Brian was taking.

Technology

Brian and Linda have not got a computer or internet in their home. They have a digital camera. Linda has a mobile phone but tells me that her friend disapproves of her not having a smart phone as well as of her slowness at replying to texts. Brian also has a mobile phone but when I asked whether he had a mobile phone he initially replied:

> *"I don't touch things like that" (Brian)*

However, Linda firmly corrects him;

> *"You do have a mobile phone that you can take out in the morning when you go walking." (Linda)*

Whenever I mention technology Brian asserts that he's *"not good with things like that".*

During the week of the diary Brian and Linda experience a mishap. On the last day of the diary Linda is waiting for Brian to return from his daily walk, but he doesn't return on time. Linda tries to call Brian's mobile it went straight to voicemail as they had set it up for outgoing calls only. As a result, Linda had to walk the opposite way round Brian's route and hope that she would find him. Thankfully, on this occasion, Brian had just slowed his pace and not deviated from the route. However, it was clear that Linda was concerned about what had happened.

As a result of their experiences and the activities they completed in the diary Linda remarks:

> *"I do have to say that doing this diary has brought about a huge amount of changes that we realise that we need to make, somehow, in our lives (1) with technology." (Linda)*

Later she says:

> *"We've got to go forward"*

On the design page, Linda and Brian have illustrated a number of ideas:

A 'one big button' mobile phone with built in tracking.

A glowing light switch (so that Brian can easily find the bathroom light in the night)

A glowing walking pole so that Brian can walk safely on country roads in the early hours of the morning.

A thumb print recognition door entry system so that Brian doesn't have to struggle with keys and there are no worries that the door is left open.

Spectacles with a locating buzzer, to help them to find spectacles when Brian changes between close and distance vision.

Despite tracking products being on the market. Linda and Brian had never come across any tracking devices. They had specifically sought out the mobile that Brian carries, Linda remarks that *"it's totally inadequate"* for their needs. She has pointed out the options she needs on her diagram - tracking for her to locate Brian and;

> *"…it would have to be only one button that Brian touched to get me." (Linda)*

When I tell them that there are products available to track, locate and set safe zones for walking they are very receptive. Brian even says at one point *"Yes. I think that's great idea"* which surprised me as he had not been very positive about using technology up until that point.

Not having the internet means that the range of assistive technology on the market is not readily available to Brian and Linda. When I mention that some of the technology that I have seen on the internet she says, *"I can get John to look on the internet"*. It also means that they cannot use the feature on their smart TV which would allow Brian to talk to the TV to change channels (eliminating the need for a new remote).

When I suggested getting a smart phone and adding an app Linda asked whether the Carphone Warehouse "*would they set it up or*"*.* The couples' technology literacy was relatively low so they would probably need assistance to help them to set up any devices that weren't specially designed for their needs.

Linda did highlight need for technology to be adaptive for the changing needs of people with memory problems:

"..because it changes so quickly … something might work for .. a few weeks .. or … a few days, and then it has to be changed to something else. So the investment in things, you have to think very carefully about, that it has to … cover long term, so that it would be something that we could use now but it would also be something that could be changed or used differently in the future." (Linda)

U. Storyboards

Storyboard 1

The storyboard describes how a character called Phil uses a tablet-computer-sized device to plan a walk and then refers to a smart-watch style device to guide his walk. His wife Jan also has a device, which she uses to locate Phil. The story starts with Phil and Jan planning their day (Figure 11.1). Jan asks Phil whether he wants to go shopping but Phil says he would prefer to go for a walk. Phil decides to go for a walk along the riverside (Figure 11.2). Jan reminds him that their daughter is visiting that afternoon and so Phil uses the device to set a reminder to return home from his walk in time.

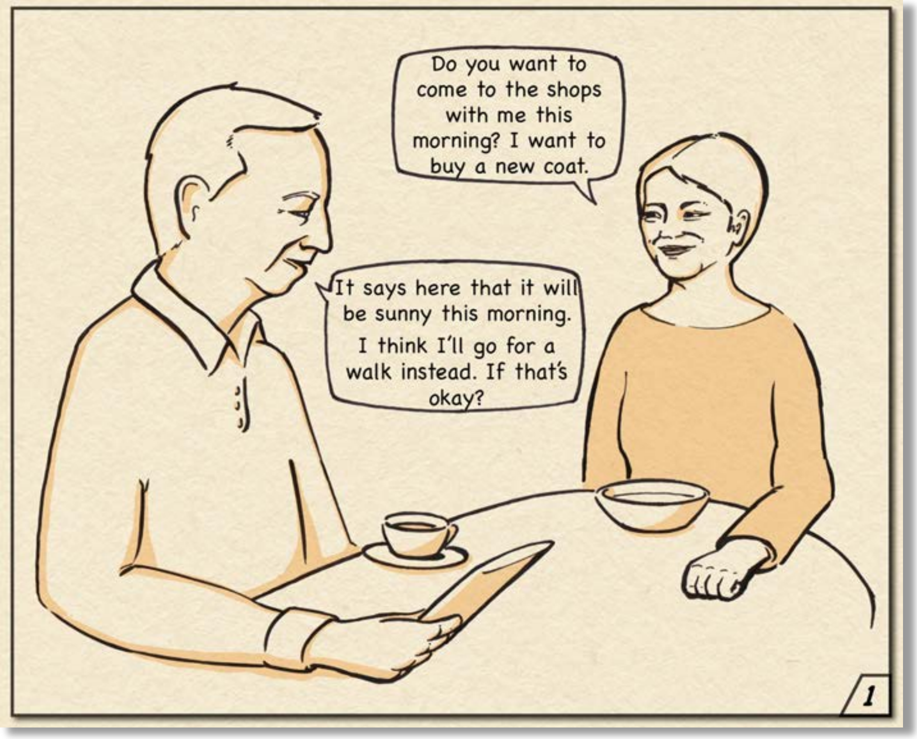
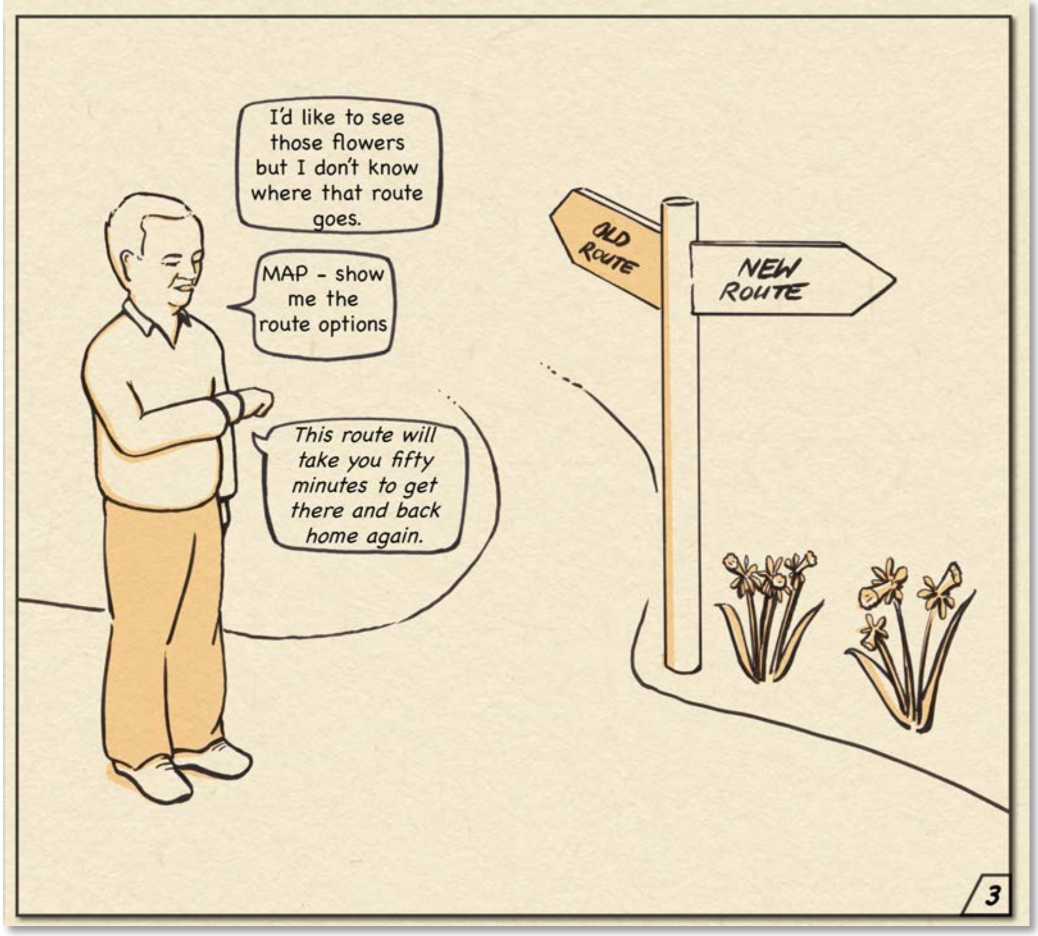


Figure 11.1: Storyboard one, scene one

In the next scene (Figure 11.3) Phil is on his walk and has come to a split in the path. He thinks he would like to take a different route from the one he had planned so he looks down at a wrist worn device and asks it to show him the route options. The device responds, telling him how long this new route will take. On the new route he uses the wrist worn device to take a picture of some daffodils so that he can show them to his daughter later (Figure 11.4).

Figure 11.2: Storyboard one, scene two.

Figure 11.3 (below): Storyboard one, scene three.



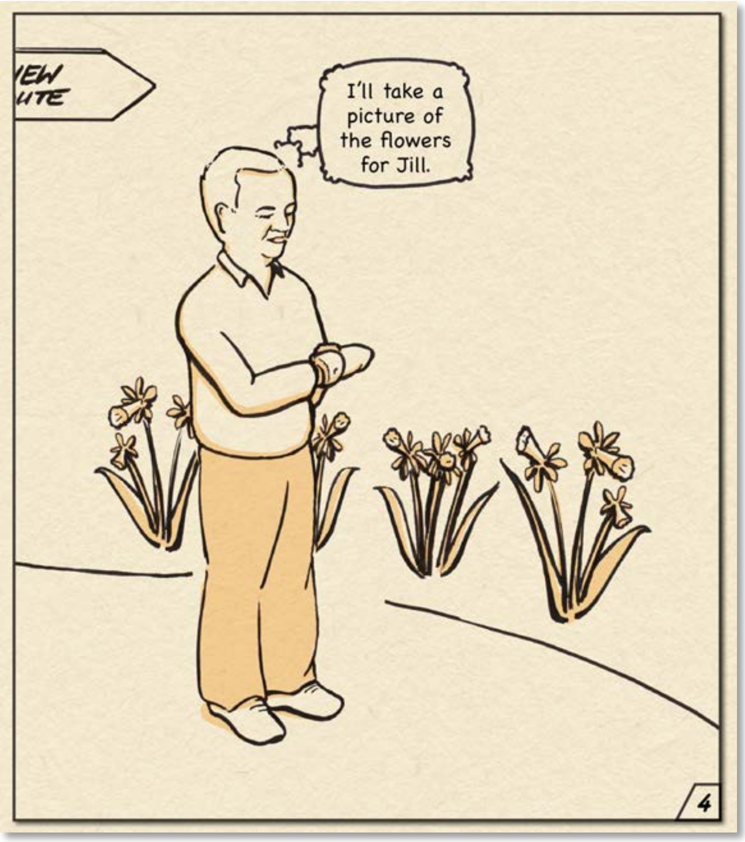


Figure 11.4: Storyboard one, scene four.

Sometime later (Figure 11.5), Phil's device prompts him to go home, reminding him of his appointment with his daughter, but he is not sure which way to go so he asks the device for directions.

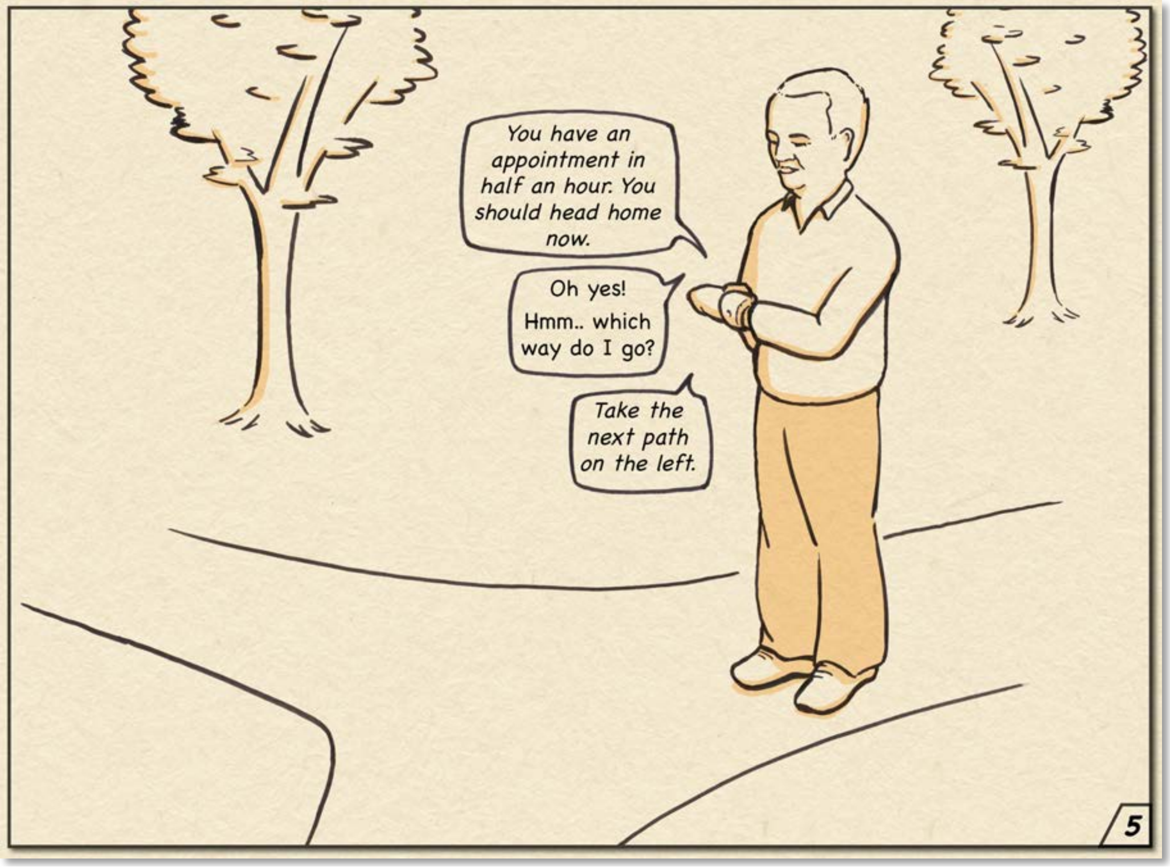


Figure 11.5: Storyboard one, scene five.

In the next scene (Figure 11.6) we see Jan out shopping, wondering where Phil is. She looks at a device to see Phil's location. She calls Phil on his wrist worn device and asks him to wait for her so that they can walk home together.

Figure 11.6: Storyboard one, scene six

Back at home, Phil is talking to his daughter about his day, but he cannot remember what he did (Figure 11.7). They look at the tablet device where his route information and photographs are displayed, and Phil is reminded of the picture he took of the daffodils.

Figure 11.7: Storyboard one, scene seven

On another trip, Phil has been out for a walk, but it has started raining, he is lost, and he wants to go home (Figure 11.8). Suddenly he hears a ringing from his wrist worn device: Jan is calling, she got a message on the tablet device to say that he had stopped walking so she decided to call him (Figure 11.9). Phil tells her that he is lost, and Jan uses his location information to order a taxi to collect him.

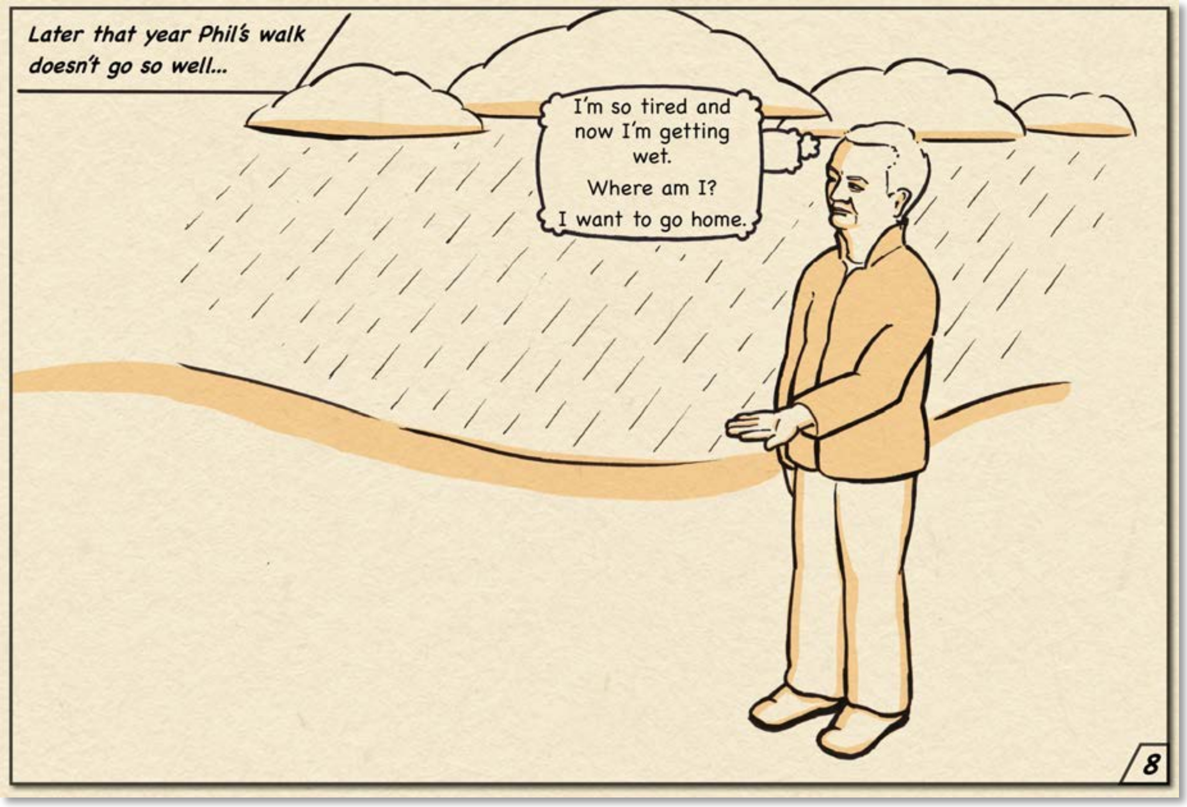


Figure 11.8: Storyboard one, scene eight.

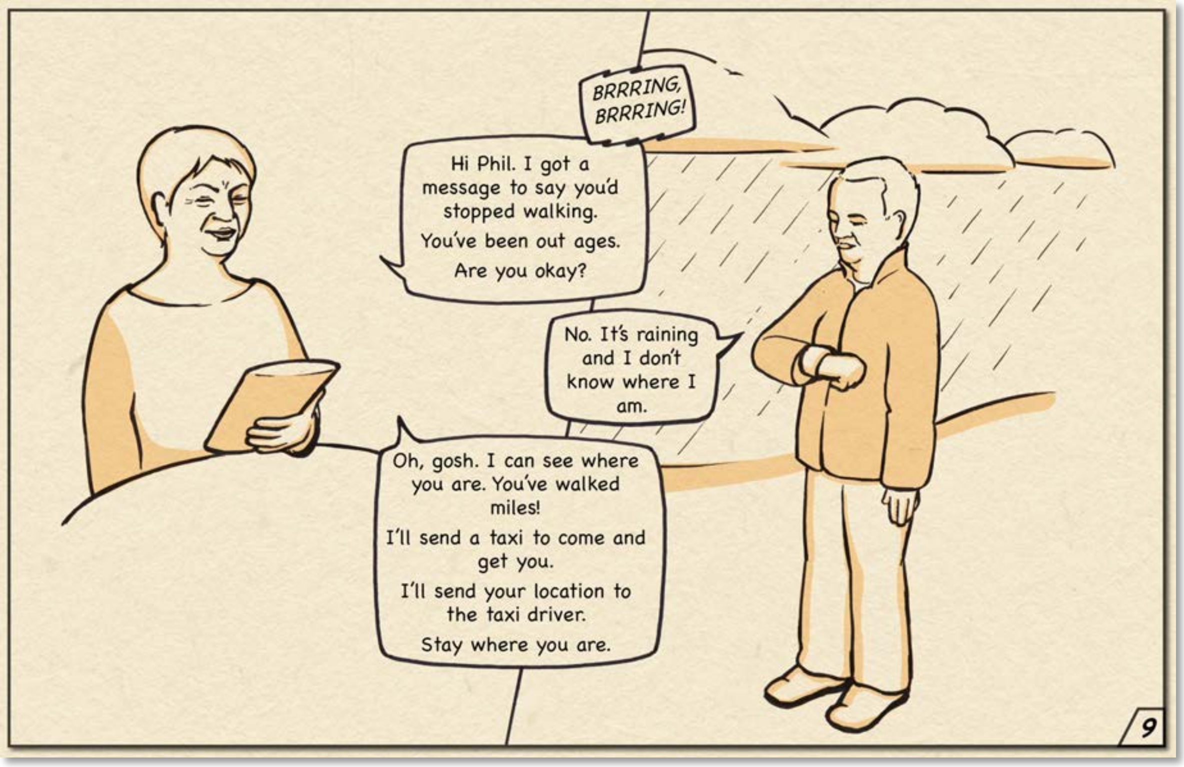


Figure 11.9: Storyboard one, scene nine.

In the final scene (Figure 11.10) Phil is back at home, feeling exhausted after getting lost. His wife suggests that tomorrow he should select a shorter route from the ones he has already saved on his device.

Figure 11.10: Storyboard one, scene ten.

Storyboard 2

For this concept the exemplar story, illustrated in the following storyboard frames, was based on a character called Carol. After Carol told her doctor that she rarely went out, he arranged for an occupational therapist to visit Carol at home. In the first scene the occupational therapist asks Carol what she enjoys doing to establish an activity goal for her to work towards (Figure 11.11).

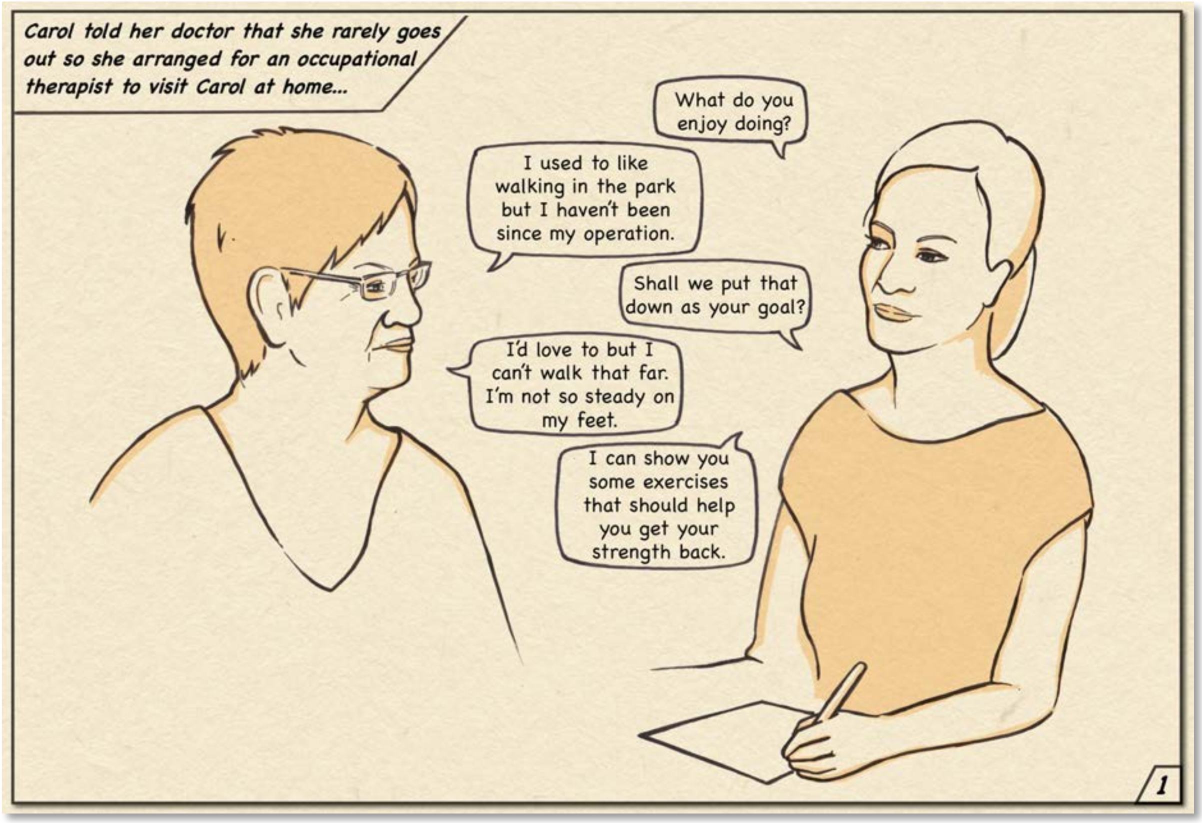


Figure 11.11: Storyboard two, scene one

Carol is not confident that she can get active again, so the occupational therapist shows Carol some exercises to help her get her strength back (Figure 11.12).

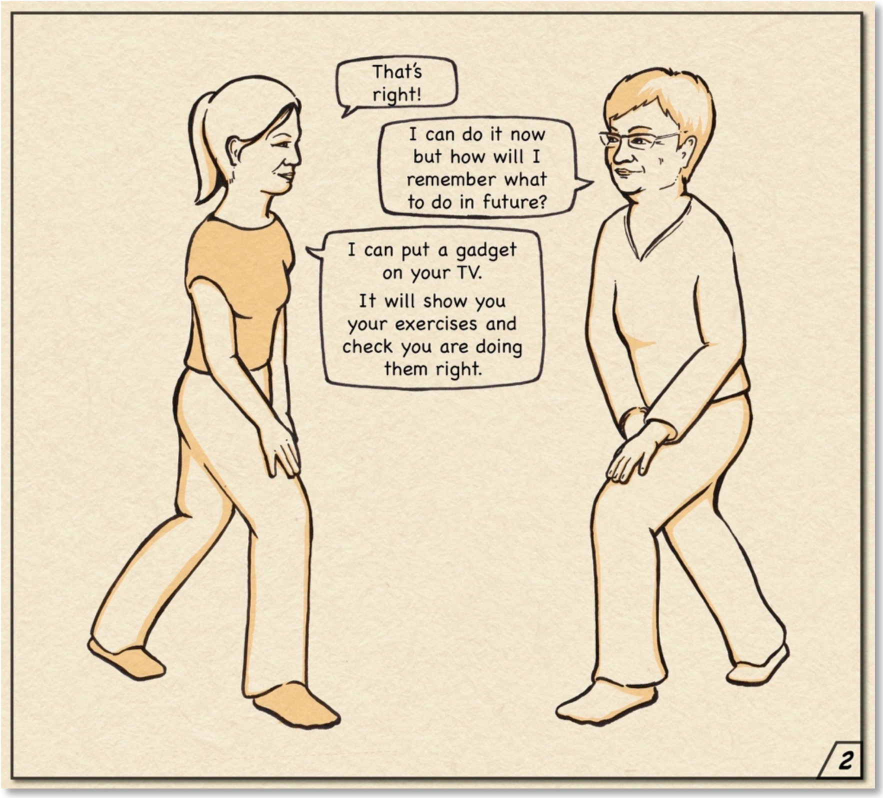


Figure 11.12: Storyboard two, scene two

Carol is worried that she will not remember how to do these exercises, so the occupational therapist connects a device to Carol's television that will remind her how and when to do the exercises. The next day, Carol receives a reminder on her TV, asking her whether she is ready for her exercise session (Figure 11.13).

Figure 11.13: Storyboard two, scene three

Carol follows the exercise instructions on her television, but she is worried whether she is doing the exercises right (Figure 11.14). The device on her television can detect Carol's stance and the character on her television screen reassures her that she is doing the exercise correctly. The character congratulates Carol when she has completed the first level of the exercise programme.

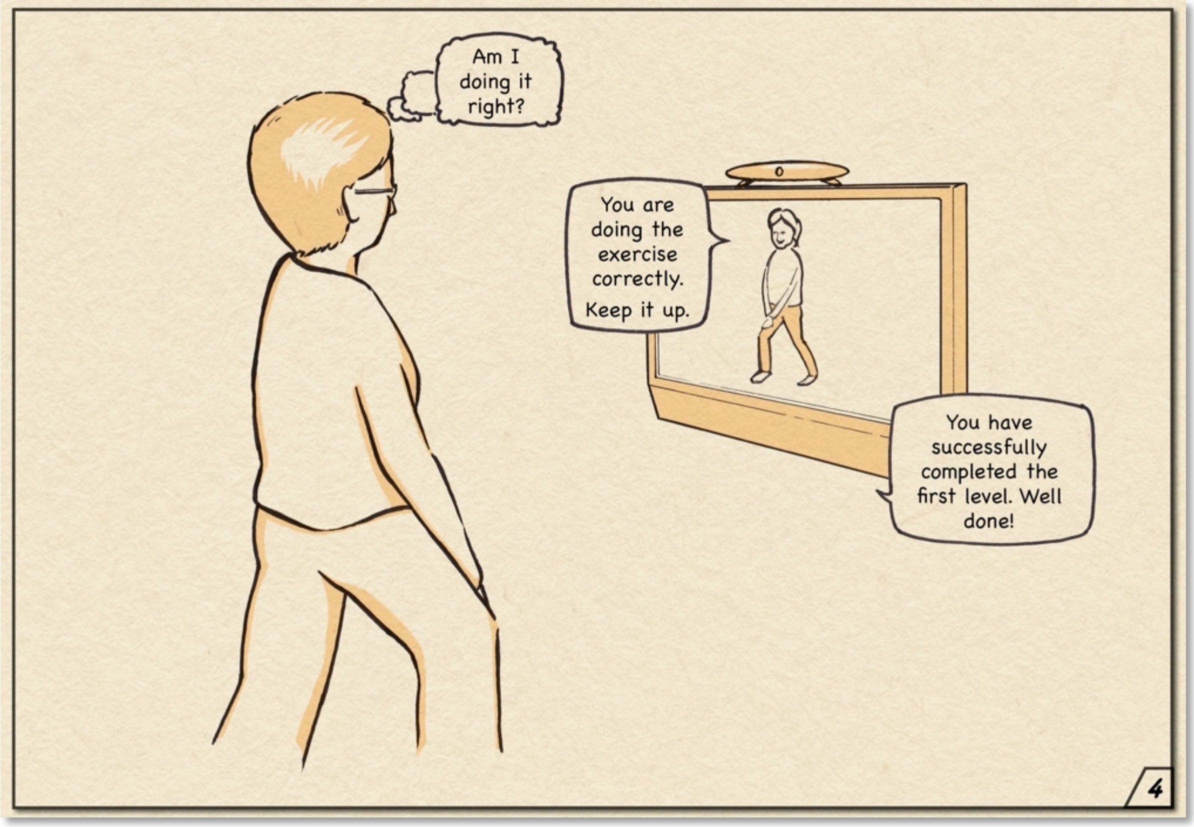


Figure 11.14: Storyboard two, scene four

Two weeks later (Figure 11.15) Carol has stopped doing her exercises. Her healthcare provider is alerted, and Carol receives a call to check that everything is okay. Carol tells the caller that she does not feel like doing anything, so an appointment is made for Carol to see her nurse.

After visiting the nurse, Carol changes her medication and feels able to exercise again. In the penultimate scene (Figure 11.16) Carol is following the exercises along with her granddaughter.

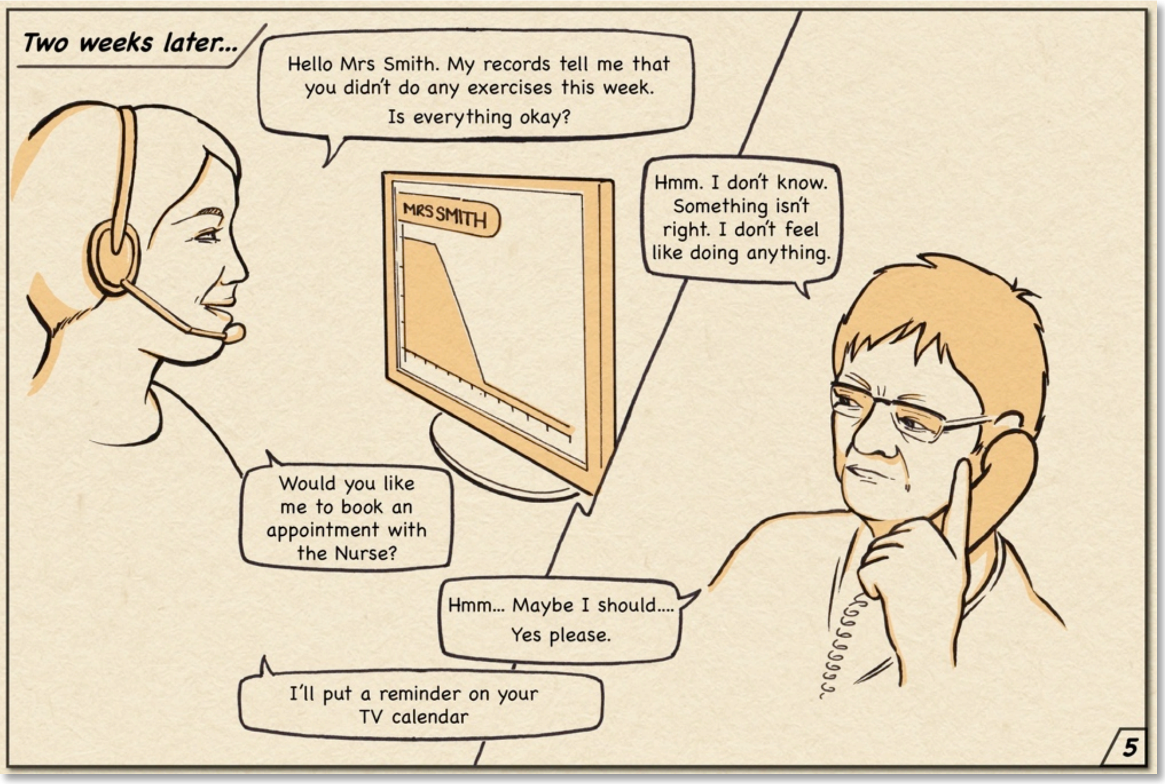


Figure 11.15: Storyboard two, scene five

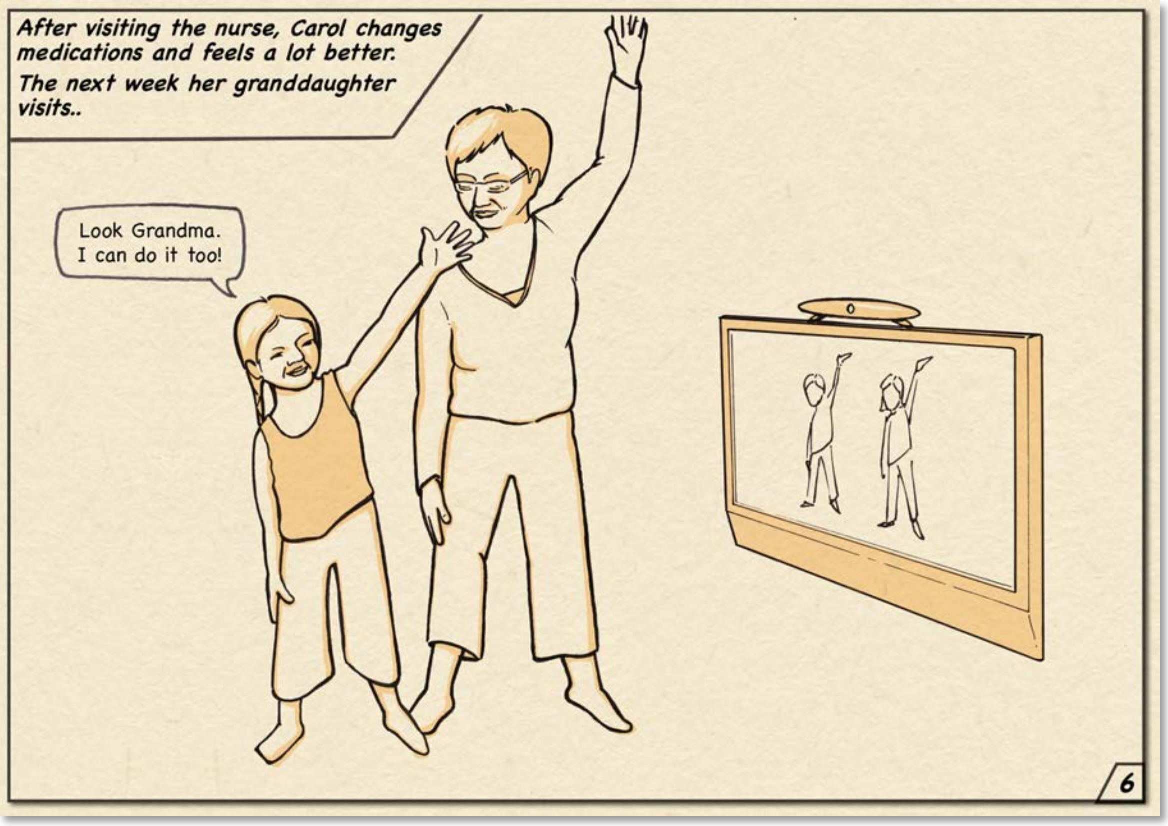


Figure 11.16: Storyboard two, scene six

After a month Carol reaches her goal to walk in the park. She is looking at a device in her hand and is impressed at how far she has been able to walk (Figure 11.17).

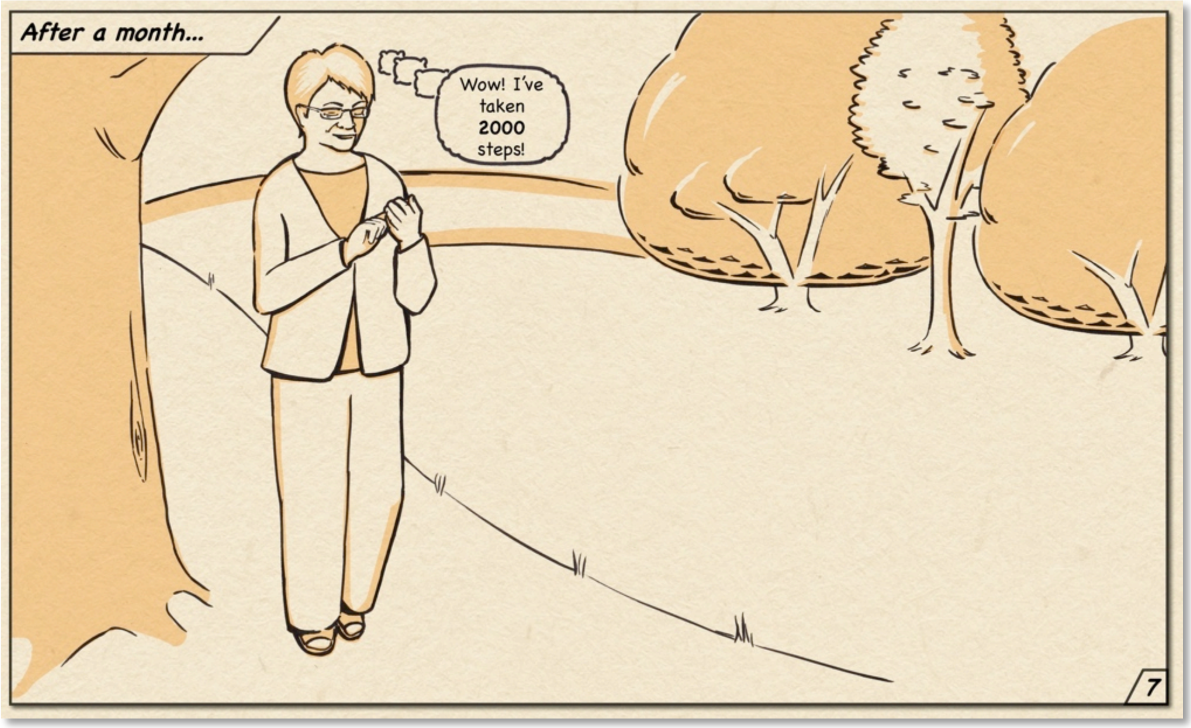


Figure 11.17: Storyboard two, scene seven

Storyboard 3

This concept was presented through a story about a couple called Judy and Ken. The first scene of the storyboard (Figure 11.18) shows Judy sitting on the sofa, feeling that she has nothing to get out of the chair for. Meanwhile Ken looks on wondering how he could help Judy to be more active.

In the next scene (Figure 11.19) Ken shows Judy an application on a tablet like device. He explains that they must think of things that they would like to do, like the activities they enjoy doing on holiday.

Figure 11.18: Storyboard three, scene one.

Figure 11.19: Storyboard three, scene two.

This prompts the couple to talk about things that they enjoyed doing on their holidays (Figure 11.20).

Ken suggests setting a date in the diary to do some activities, but Judy is unsure whether she will feel able when the day comes (Figure 11.21). Ken suggests that they can stay at home and look at photos of their holidays if Judy does not want to go out.

Figure 11.20: Storyboard three, scene three.

Figure 11.21: Storyboard three, scene four.

Next Monday morning (Figure 11.22) Judy wakes up and wonders what she has planned to do that day. She picks up the tablet device from her bedside.

Figure 11.22: Storyboard three, scene five.

The device displays a question, *"what do you want to do today?"* and shows pictures of four activity options Figure 11.23).

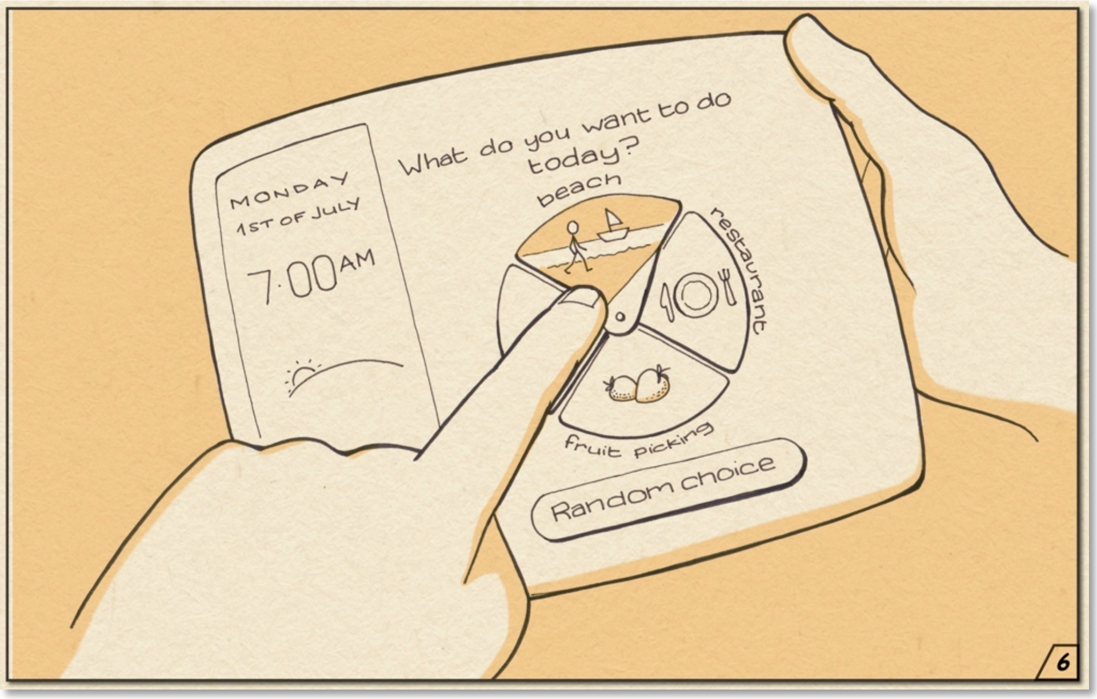


Figure 11.23: Storyboard three, scene six.

Judy chooses to go to the beach and in the next scene (Figure 11.24) we can see Judy and Ken enjoying a walk on the beach.

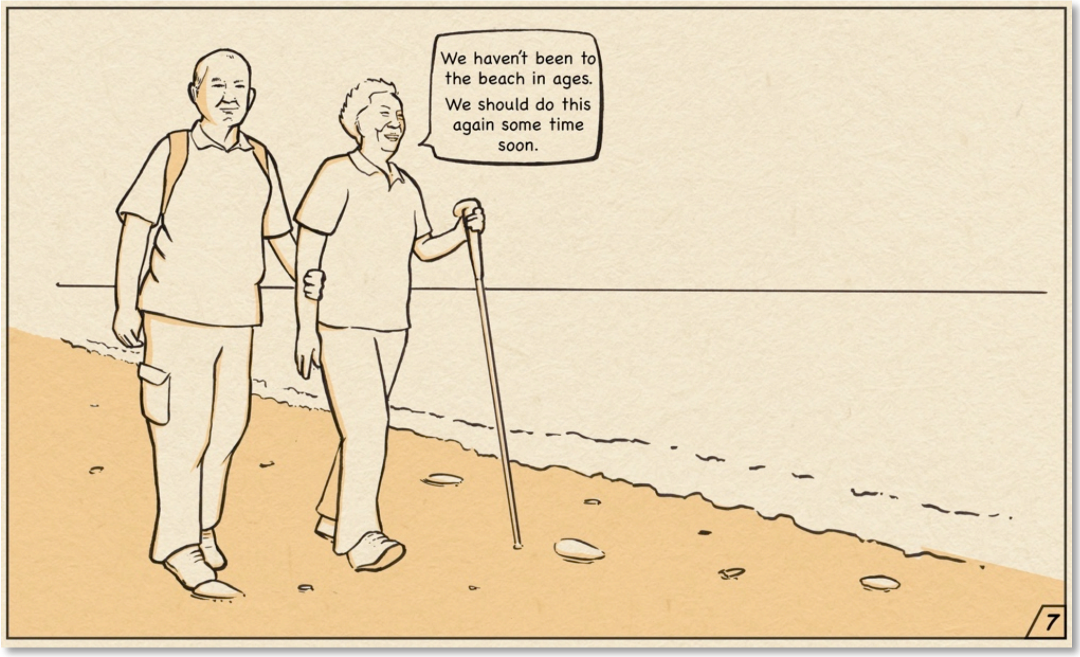


Figure 11.24: Storyboard three, scene seven.

The next day (Figure 11.25) Judy is using the device again. The device asks Judy *"how do you feel today?"* and Judy selects the option *"tired"*.

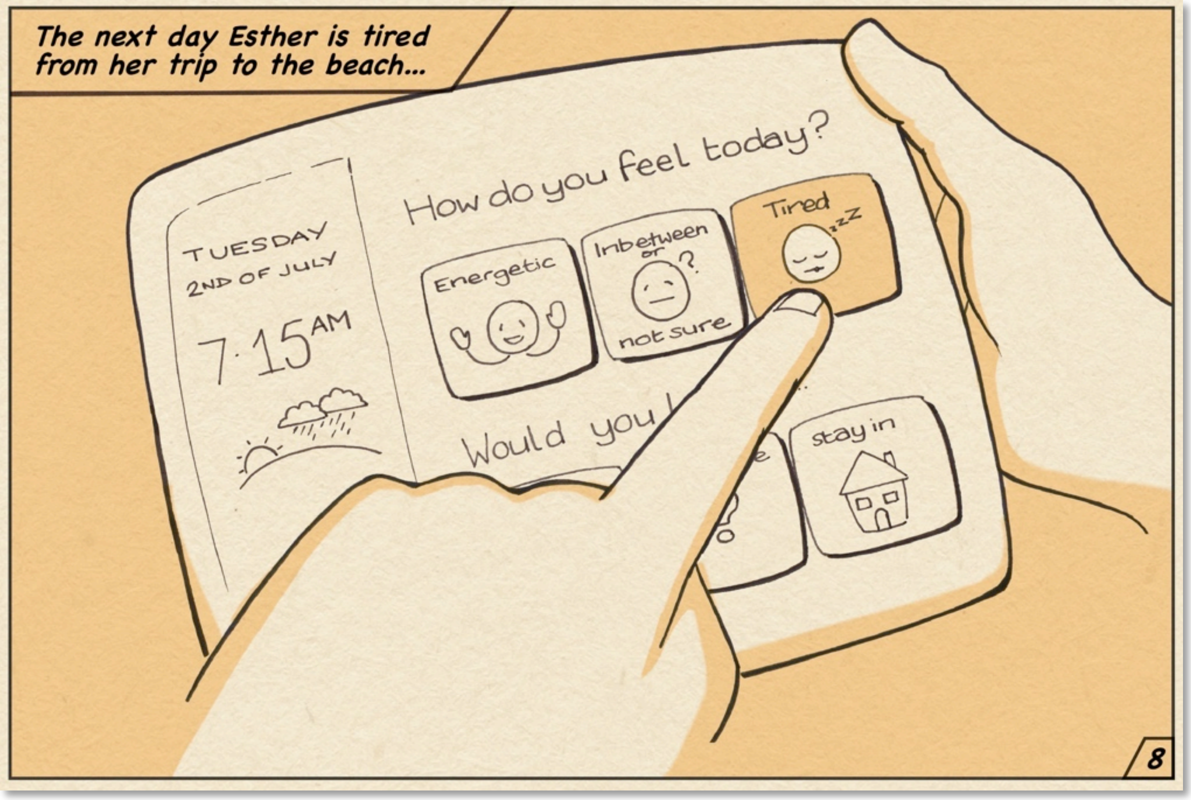


Figure 11.25: Storyboard three, scene eight.

In response, the device shows four sedentary activity options (Figure 11.26). Judy is not sure what she wants to do so she presses a button at the bottom of the screen that says, *"random choice"*. The central arrow spins round to point to *"photo albums"*.

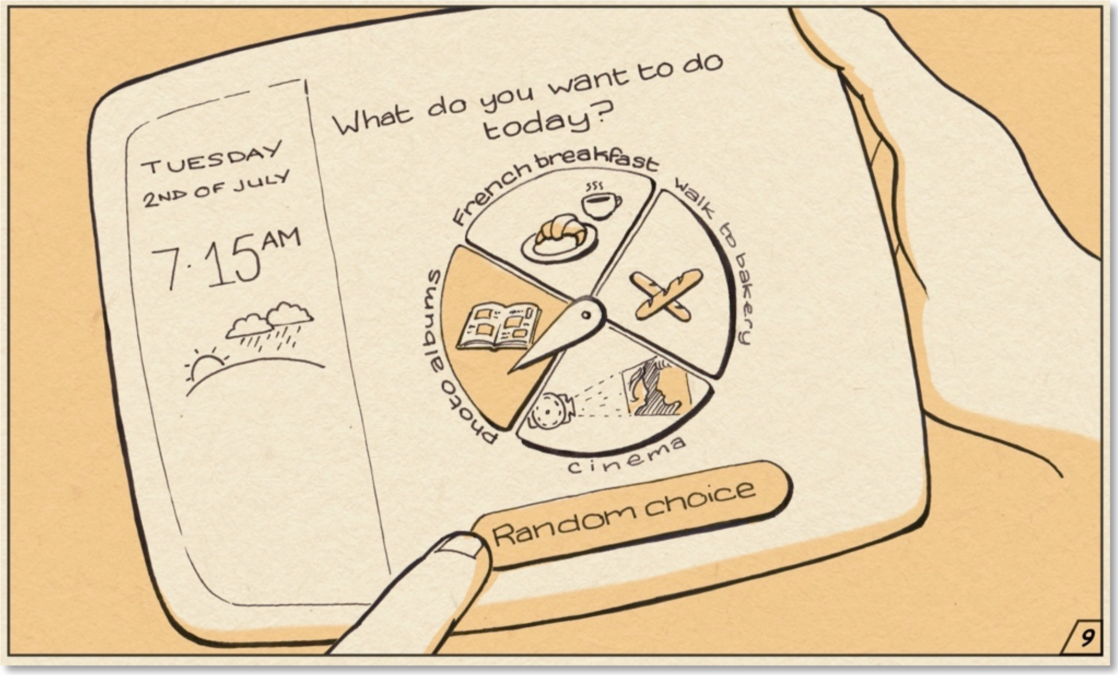


Figure 11.26: Storyboard three, scene nine.

In the final scene (Figure 11.27) Judy and Ken are sitting on the sofa enjoying looking at their photo album together.

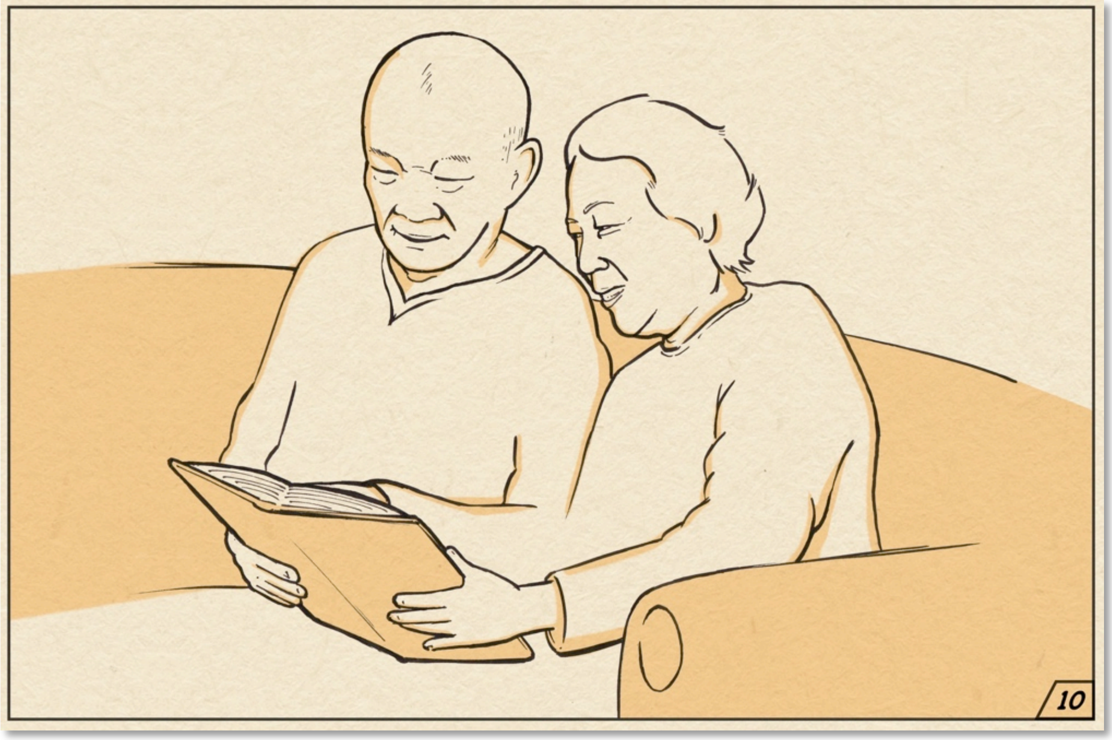


Figure 11.27: Storyboard three, scene ten.

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