

Engaging older adults and people with
dementia in the design of digital technologies

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A thesis submitted for the degree of
Doctor of Philosophy (PhD)
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19th July 2011

Abstract

Improvements in healthcare and nutrition have led to increased life expectancies for people around the world, and a growing need to support the larger numbers of older people living with chronic and age-related health conditions. Although the use of digital technologies is increasingly proposed for health and social care solutions, in practice the designers of these technologies are ill equipped to actively engage older people and in particular people with syndromes such as dementia. An examination of previous work on design for older people, and people with dementia, suggests that poor design arises from a gulf in knowledge and experience between the designers and their subjects. To address this divide the KITE participatory design method for engaging people with dementia in design is proposed. KITE facilitates engagement by structuring and scaffolding an empathic relationship between designers and their participants. The approach is elaborated and evaluated through an exercise to design a digital technology to help people with dementia have safe walking experiences. The analysis of this process leads to the formulation of the OASIS design method which is intended to apply to older people more generally. OASIS is evaluated and refined through a number of design studies for technologies to support healthy eating, day-to-day travelling needs and living safely within the community. Reflection on the application of the OASIS method highlights a number of key strategies that can be used to establish and maintain respectful, empathic, and productive participatory design relationships with older adults and people with dementia.

Acknowledgements

First, I would like to offer thanks to my supervisory team: to Prof. Patrick Olivier provided a constant drive to ask deeper questions about the thesis, while never allowing the importance of *doing* in research to be neglected and providing the opportunity to work in an amazing research environment; to Dr. Louise Robinson for contributing her considerable knowledge about dementia care, especially regarding the phenomenon of wandering and safe walking and; to Dr. Katie Britain for guiding me through the my first encounters with qualitative work and helping me understand how to go about approaching people with dementia and charitable organisations to broach the idea of taking part in this work.

I would like to thank staff at The Dementia Care Partnership and the volunteers at the North Shields branch of the Alzheimer's Society, the Tyneside branch of the Alzheimer's society and the Newcastle AgeUK group (formerly Age Concern Newcastle) for their openness to working with me to help me find participants throughout this process.

I would also like to thank all of the people that took the time to participate in my work in focus groups, workshops, prototyping sessions and trialling the devices that were built in this process. This thesis would not have been possible without their ideas or their willingness to engage in this process. The act of sharing their experiences gave me a radically different take on this work.

The people I was lucky enough to work with in Culture Lab were a great source of motivation, education and friendship.

Finally thanks to Mum, Dad and Emma.

Publications Arising from this Thesis

Cueing for Drooling in Parkinson's Disease 2011, Roisin McNaney, Stephen Lindsay, Karim Ladha, Cassim Ladha, Guy Schofield, Thomas Ploetz, Nils Hammerla, Daniel Jackson, Richard Walker, Nick Miller and Patrick Olivier in *Proceedings of the 2011 annual conference on Human factors in computing systems (CHI '11)* ACM, Vancouver-Canada, pp.619-622

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Design with Older Users and People with Dementia – Methodologies, Practical Lessons and Challenges 2010, Stephen Lindsay, Katie Britain, Louise Robinson, presented at *Senior-Friendly Technologies: Interaction Design for the Elderly at the 2010 annual conference on Human factors in computing systems (CHI'10)* ACM, Atlanta-USA

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Designing Technologies for People with Dementia 2007, Stephen Lindsay, Patrick Olivier, Louise Robinson and Andrew Monk, presented at *The ESRC funded Workshop on the Family And Communication Technologies (FACT'07)* Newcastle-England

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CHAPTER 1: INTRODUCTION

Designers are being confronted with an increasingly apparent challenge, an ageing population, which is the result of an increase in the average life expectancy of people throughout the world [143]. For example, the life expectancy in the United Kingdom (UK) is dramatically increasing, while birth rates remain almost constant [114,115]. The majority of caregivers are older adults [159]. Older adults in the UK now work for longer and retire later. Older adults are also a key part of the make-up of many voluntary organisations [146]. However, whilst increased life expectancy yields enormous benefits for the individual and society, the increase in the numbers of older people comes with an increase in the resources a society needs to provide to care for them. These demands arise from higher levels of incidence of age related diseases such as dementia [154] and other health problems that are a consequence of the normal ageing process [71].

Appropriately designed technology has the potential to address many of the needs of the ageing population, from the healthcare requirements of age-related illness [71], to social needs, such as addressing feelings of loneliness and social exclusion [87]. However, in practice, new technologies have been the cause of a number of problems that older people experience, rather than the solution. For example, the growing use of “Chip and PIN” technology and the rise of Internet shopping has resulted in plans to phase out the system of cheques in the UK. Consequently, it is widely anticipated that this will cause significant problems for the older members of society, many of whom still rely on cheques [7].

The social model of disability [117] proposes an explanation of why little attention is paid to the needs and lifestyles of older people, not only in relation to the design of digital technologies, but across a range of social and organisational contexts. The social model perspective recognises that someone with impaired health or cognitive function is in fact only transformed into someone with a disability through barriers that are created by the society around them. For example, a hearing-impaired man watching a film presentation with subtitles in a museum is *impaired* but not *disabled*. But if the museum fails to provide subtitles, he becomes disabled as a direct consequence of the actions or inactions of the technicians, curators, and managers of the museum. The disability is a consequence of a failure in design. Inappropriate design methodologies are a mechanism through which society disables people with impairments by ignoring them.

Eyesight, hearing, memory and physical coordination impairments are a common consequence of the ageing process [71]. However, placing undue emphasis on the functional characteristics that make older people different to younger people can distract designers from considering older people as complex individuals with their own sets of social and emotional needs and desires. As Keith and Whitney state “*an old person is not just the sum of their acquired impairments*” [79]. Also, designing digital technologies for older people is not simply a matter of addressing the immediate consequence of the most obvious impairments (e.g. lack of visual acuity, lack of manual dexterity). Designers must consider the very metaphors and cognitive models that underpin interaction techniques used in current digital technologies [124]. Even the seemingly most basic metaphors, such as the indirect manipulation of document icons using a mouse pointer, is far from intuitive to a user unfamiliar with WYSIWYG interaction techniques. Furthermore, older people do not form a homogenous group with respect to the level of their physical or cognitive function. In fact, as a collection of individuals, people above the age of 65 years old, comprise a group that is considerably more diverse than members of the general (younger) population [68]. As such, the experience of each individual older person is unique to them and shapes their expectations when they encounter a new technology in ways that an interaction designer does not necessarily account for [110]. This is in part a historical legacy of human-computer interaction (HCI), which originally framed the user as “information processor” with little consideration given to the different qualities of their experience of technology.

More recently, as computers have moved out of the workplace and into the home and wider world, new paradigms have arisen that prioritise experience-centred technology design methodologies [156] but the impact of this third wave of HCI has had little impact on the design of technologies for people with cognitive, perceptual and physical impairments. Of all of the age-related chronic conditions and impairments, probably the most significant, and most problematic, is dementia [154]. Dementia is an enormous, and growing, challenge to society as the prevalence of the disease is set to increase in line with the age profile of the general population. As a disease label the term *dementia* is still widely misunderstood. *Dementia* denotes a global decline in cognitive function; meaning all the mental faculties of a person with dementia can be impaired including memory, emotional control and reasoning. An individual with dementia can expect their condition to deteriorate over a period of time that can range from a few months to several years. Ultimately, the progression of dementia often leads to the loss of the ability to perform basic activities of daily living, such as preparing food or washing their clothes, forgetting personal information and details about loved ones, becoming aggressive towards other people, becoming lost or disoriented whilst outside, or eloping from home and becoming lost.

Dementia frequently goes undiagnosed for long periods of time after onset, and is dismissed as ‘senility’ (i.e. viewed as a normal aspect of growing old). However, in 2009 the Alzheimer’s Society estimated that the total number of people with dementia worldwide was *estimated* to be 35 million [58] and that the financial costs of caring for people with dementia globally was \$604 billion per year [154]. Traditionally the care of people with severe dementia wholly depended upon formal or informal caregivers (e.g. family member). The time and effort required from these caregivers is enormous, and

in the case of informal caregivers often go unnoticed and un-credited [121] as they themselves are forced to withdraw into the home. In addition to the care burden, informal carers experience the relational and personal emotional consequences of the progression of the syndrome first-hand; this often has a significant impact on the mental wellbeing of caregivers themselves resulting in a high incidence of stress and depression [125]. In the UK (and much of the world) the ratio of available caregivers to people with dementia is declining [121]. If the gulf between current design practice and the needs and experiences of people with dementia and their caregivers can be addressed, then digital technologies may in part provide a scalable solution to this shortfall.

1.1 THEORETICAL POSITIONING

Keates and Clarkson suggested that designers struggle to design for populations they have little in common with [78], and this phenomenon is widely acknowledged by experts in design for older people [56,67,111]. A person's experiences of ageing, declining health, and the onset of dementia, are complex and highly individual phenomena that are difficult for a designer to comprehend. Kitwood's Person Centred Care [81] proposals for dementia care is the basis for an approach to the design of digital technologies for people with dementia, and older people in general, that addresses this challenge. Kitwood proposed the Person Centred Care concept in order to address a similar set of problems that are endemic in healthcare institutions, and his approach successfully facilitated healthcare providers to become more attuned to the needs of the people with dementia that were cared for although the process remains ongoing [54]. Understanding the experience of dementia and respecting that it is real and valid for the person with dementia is central to the Person Centred Care process and this is referred to as acknowledging the individual with dementia's Personhood. This respect for Personhood is achieved through placing emphasis on the quality of the relationship between the professional caregiver and the person with dementia whom they care for.

A participatory design approach is proposed as a way to develop a relationship between the designer and the person with dementia that can emulate the Person Centre Care approach. This will improve the designer's incomplete understanding of the person with dementia's experiences. Participatory design originated in Scandinavia as a way to democratize the process of introducing new technologies into the workplace [32]. The democratization is an important aspect of the process that is leveraged to give people with dementia and older adults an equal voice in design. This democratisation shows respect for the person with dementia and helps create respect on the part of the designer for the experiences of the person with dementia. However, the participatory design approach is not without problems. The techniques are task or work oriented [80], can fit poorly with use within a social or non-work context [33] and make numerous assumptions about the cognitive ability of the people involved in the process that do not necessarily hold when working with people with dementia [157]. Previous work has attempted to address these issues by making these assumptions explicit and identifying the ways that people with cognitive deficits can be supported in the process [157].

It is the aim that, through extensive contact and interaction, it will be possible for designers to be imbued with insight into and a sympathetic disposition towards the experiences of older people or people with dementia and improve their designs as a result of this. Through a participatory design process, it will be possible for designers to gain a fuller understanding of participants' lives and tailor their solutions to them. This will in part be due to the large amount of contact time between designer and participants. Ultimately by using a participatory design approach to understand the experiences of people with dementia, it will be possible to create an opportunity for designers to respect their Personhood. The work that is conducted in this process teaches many lessons that can also be applied in other domains [136].

1.2 RESEARCH QUESTION, AIMS AND OBJECTIVES

The commitment to engaging with older people and people with dementia in an empathic design approach that aims to elicit their experiences through a respectful relationship, leads to the research question:

How can a design process be configured so that it engages older people and people with dementia in a way that is both sensitive to, and respectful of, their experiences?

To answer this research question, perform theoretically grounded but practice driven work to develop, test and refine an approach to including older adults in the design process will be performed. Meeting these aims will require the examination of the challenges that confront designers when working with older people and people with dementia, the underlying concepts of participatory design and the literature around conducting participatory work with older adults, people with dementia and the cognitively impaired. The participatory design approach will be created in light of these issues to circumvent them whilst empowering the participants, respecting their Personhood and creating an empathic relationship between them and the designers. This leads to the research objectives:

Objective 1: To review assistive technologies for people with dementia (and academic proposals for such technologies) and characterise the mechanisms and levels of engagement of users in their design.

Objective 2: Create a participatory design approach to support the design of technology for people with dementia and older users that facilitates their contribution to the design process.

Objective 3: To conduct authentic design activities with people with dementia and older people and through reflection on these activities refine the participatory design method.

Objective 4: To evaluate the method with respect to the nature and extent of the empathic engagement, and the impact this has on the outcome of the design activities.

1.3 THESIS OVERVIEW

In Chapter Two the prevalence of ageing and dementia and their impact on society is established. This begins with examination of the phenomenon of the ageing population and the impact that it has on the world, this leads into an examination of the UK specifically to understand the wider context that this work will take place in. Paired with this is an examination of the causes and consequences of dementia that will seek to begin to understand what specific challenges this syndrome poses for the individuals who live with it. There are many technologies designed with older people and people with dementia in mind so the review focuses upon the realm of assistive technologies developed to help people with dementia. This takes the form of an examination of previous designers' work which has sought to cater for people with dementia in which it is established that both commercial research solutions and research work has encountered certain issues and as a result produced low quality designs. The review then focuses on challenges to design for people with dementia and observes that the designs tend to be functionally oriented, that is to say they choose to place their emphasis on accounting for the functional deficits of the users rather than engaging with the felt lives of older people and people with dementia. The understanding of these challenges to design is built on with an examination of the concepts of Person Centred Care [81] and empathic relationships between users and designers [155]. The two concepts are shown to have certain similarities and an approach that might overcome the challenges to design realised through engagement with the target group (older people and people with dementia) is shown to realise both of these concepts core principles: participatory design. Participatory design approaches are particularly suitable because they demand that the participants work with the designers. However, there are numerous challenges to conducting participatory design with people with dementia and older people so previous work on the subject of design with people with dementia, older people and people with cognitive impairments is examined in an attempt to find techniques to circumvent or neutralise them.

Chapter Three outlines a specific participatory design approach based upon the previous work and the overarching aim of creating opportunity spaces in which empathic relationships between people with dementia and designers can develop, the chapter proposes a two stage framework and individual methodologies. This framework is based upon the notion that individual designers poorly understand design domains for people with dementia and older people so a broad scoping enquiry can help them identify initial areas for enquiry and approaches to designing a solution. The next stage of the design process then focuses on the possible designs of technology to meet with the needs expressed by the groups and, to better facilitate close contact between designers and participants, this stage is conducted with the most engaged people from the previous work. The process calls for the development of highly individual meetings where unique, tailored devices are constructed for each participant.

In Chapter Four the process is applied in the design of a safe walking facilitation device for people with dementia and their older care-providing partners as part of a larger design team in the Keeping In Touch Everyday (KITE) project. The domain of safe walking is particularly interesting because a review of previous work in the area shows a tendency for ignoring the person with dementia in favour

of talking to professional or informal caregivers, and a tendency to medicalise problems. This medicalisation means that the emphasis of research and development in the field has been on preventing people with dementia getting lost rather than allowing them to reclaim activities they could perform before the onset of dementia. In the course of applying the design approach there are several unexpected developments including a shift in the participants' attitudes as they engage in the design process and a shift in the attitudes of the author whilst working as the consistent point of contact with them. The chapter concludes with an assessment of the design methodologies that were employed and the lessons that were learnt applying the process. These lessons centre on the need for less analysis of participants input to the design process, the need for more structure in individual meetings in order to allow a more rapid development of prototypes and the need to support the older people and people with dementia as they attempt to imagine future technologies.

Chapter Five responds uses the shortcomings found in the design framework to inform the development of a new approach for working exclusively with older adults. Due to the extra time that working with them entails and a desire to see how else the process might change when working exclusively with cognitively able users unimpaired older adults are worked with in this process. This is followed by reflection on this in the discussion. The new framework is presented in its final stage, with the modifications made in light of three design studies already incorporated into it. The new framework discusses the issue of diluting the voice of the participants in analysis and counters the issue in two ways, the first is to make the questions in the analysis process and the questions asked in the design meetings much more closely linked so the participant directly answers the questions asked in the analysis, so less interpretation of their answers was needed. The second part of addressing this issue is the lack of structure in design. Techniques that structure the design meetings are introduced and the output from the final stages of these sessions is brought closer to the requirements that designers typically work with than the output from the previous process.

Chapter Six and Chapter Seven document the three design studies that were conducted. These studies centred on the design of a nutritional adviser to promote healthy eating, the design of an aid for transportation and an examination of various issues around personal security. The nutrition study showed the potential of the new design framework but also highlighted issues with the video that was presented in the study and the challenge in getting older people to engage in hypothetical scenario work. These issues inspired alterations to the first stage of the design process followed in the transportation study, including modifications in the brief given to the video editor to emphasis the construction of a scenario in the video that participants could engage with in the design process, and presenting the video earlier in the design meeting. The final design study around personal safety was not as successful; this study attempted to highlight and discuss issues around personal safety and modified the video making process again. The new video was based on pastiche work [21,22,23] in the hope of creating discussion in the group about a known TV character, Dot Cotton from the EastEnders television show. Whilst the character of Dot was recognised by participants they did not feel like they engaged in the process. The extremely sensitive nature of personal safety also meant

that the process did not flow smoothly and may have been better suited to a more prolonged study with more contact between the designers and the participants.

Chapter Eight consists of reflections on the alterations made to the initial design process in light of the practical lessons from working with people with dementia. This chapter also examines the importance of the group dynamic in design meetings and the struggle to envision the intangible aspects of design. Reflections on the second design approach and the changes in the role of the video prompt over the three different design studies are also presented. There are several underlying themes that pervade both design processes that are documented in this chapter. The conclusions re-examine the field of designing with people with dementia and older people. The key lesson from the work has been the need for an empathic relationship between the designer and the older people or people with dementia. However, the work has also highlighted how difficult achieving this can be. Some of the limitations of this work such as the focus on designing for individuals then extrapolating to a wider group and the difficulty in measuring the quality of a design process are considered. Finally, an examination of the potential to expand the work in the future by including new design techniques into it such as cultural probes [62] is presented.

1.4 AUTHORS ROLES AND RESPONSIBILITIES STATEMENT

The work documented in this thesis has, at times, been performed as a part of wider research projects in which I have worked as part of a team of researchers, designers, film makers and others. This section clarifies my specific roles in creating the work documented here, broken down chapter-by-chapter. Chapter One and Chapter Two are exclusively my own research. In Chapter Three I developed the methodology that is presented; however, the method was modified in light of feedback from the KITE project team. Specifically, Dr. Katie Britain and Dr. Louise Robinson provided feedback based on their previous experiences performing qualitative research and providing primary care for people with dementia.

In Chapter Four the aforementioned individuals collaborate with myself in the recruitment work and when conducting the initial exploratory work with the participants. The analysis of these meetings was primarily conducted by Dr. Katie Britain. After this point, I take responsibility for organising and running all meeting with the participants and analysing the output from these meetings, fulfilling the role of the consistent point of contact suggested in Chapter Three. Other members of the project team, notably software developer Daniel Jackson and designer Dr. Martyn Dade-Robertson, also participated in some of these meetings and the project team as a whole are engaged in discussion regarding design choices made about the prototypes that are being produced. The final designs that are presented in Chapter Four are a product of the entire design teams' work and I am one of four people who work on physically building the devices and coding the software used in them.

In Chapter Five the methodology that is developed is solely my work. The application of this method in Chapter Six is part of the wider project but is primarily my own work as I am responsible for recruiting and running the meetings with older participants and lead all meetings with them guiding

discussions with one other member of the project team, Guy Schofield, present to assist me. In the low fidelity prototyping sessions, I lead discussion with one group whilst Guy Schofield leads discussions with the other group. The video presented in these sessions is written, filmed and produced by professional film maker Jim Kitson, who I work alongside throughout their process of film making and editing. We were assisted in this process by audio-visual technician, David Green. The analysis of all the data gathered in these meetings is my own work. The prototype that is built in response to this process is designed by myself and Guy Schofield and built with the assistance of Dan Jackson.

In Chapter Seven I again perform recruitment, organise and run the design sessions with the assistance of one other member of the project team. The video that is used in the transport meetings is produced in the manner described above. The video used in the security meetings was produced by myself working in collaboration with David Green. The analysis of these meetings entirely my own work. Chapter Eight and Nine are also entirely my own work.

CHAPTER 2: LITERATURE REVIEW

The phenomenon of the ageing population has many implications for society and understanding the full scope of these issues necessitates an examination of public health literature projecting the increases in the number of over 65's in the future and the attendant increase in the number of people with dementia. If design is to be sensitive to the growing number of people with dementia and older people, it will be necessary to understand the impact of their condition on their day-to-day lives and the first step in doing this is to understand the physiological effects of ageing on the older person and the effects of dementia.

There is already a huge amount of assistive technology that has been designed to help older people and people with dementia live independently [46] but review will reveal that there are significant problems with the acceptability and usability of this technology. While the aim is to move beyond a purely medical view of technology design for people with dementia and older people, examining current commercial assistive technologies and proposals by researchers for the field gives an insight into the prevailing attitudes towards design for this population. To limit the scope of the review of this technology, the design of assistive technology for people with dementia is specifically examined.

The examination of the assistive technology and research proposals on the subject lead into a categorisation of some of the challenges that designers face when they design for older people that are not immediately obvious. These include: a different attitude towards technology held by older people; a wider diversity of personal circumstances in the group than in the younger population; ethical issues when working with people with dementia and; a tendency to engage with the caregiver as a substitute for engaging with people with dementia. This all leads to technology that is centred on the medical needs of older people and, with the exception of certain reminiscence and social interaction promotion technologies being proposed by researchers, shows little concern for the quality of their day-to-day experiences.

2.1 AGEING AND DEMENTIA

To understand the importance of design for the ageing population and those with dementia it is important to first understand the significance of the ageing population for society as a whole and for the individual. Statistics detailing the prevalence of the ageing population and its projected growth in the future and the significance of ageing for the individual are examined. As previously mentioned, with this increase in life expectancy comes an increase in the prevalence of age related syndromes

and of these the most significant is dementia. The prevalence of dementia and the impact of dementia for the individual are also examined.

2.1.1 The Significance of the Ageing Population

When talking about older adults it is typically assumed that the discussion centres on people over the age of 65 because this is currently the age at which people retire. However, this is based upon the retirement age in the UK and the USA being over the age of 65. From a medical perspective many of the health problems associated with ageing begin around the age of 50 and the retirement age in the UK is set to increase so the definition of an “older adult” is a flexible one. Throughout this work, when the term older adult is used, it is referring to people over the age of 65.

Advances in healthcare, as well as better provision of food and nutrition and living standards are leading to a dramatic increase in life expectancy globally [115,143,144], particularly for those living in developed countries. Because birth rates are expected to remain relatively constant [114], this shift in demographic means the average citizen is older than they used to be. The phenomenon is widely referred to as the “ageing population” or “global ageing” in academia and the media [143]. Furthermore, this increase in average life expectancy is a trend that is set to continue for the foreseeable future (Table 2-1).

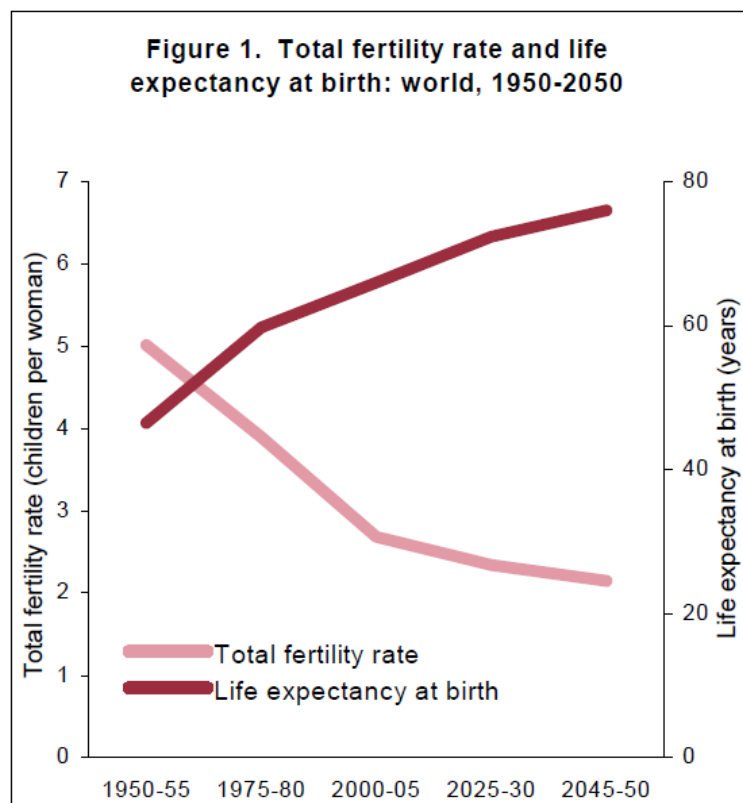


Figure 2-1: Life expectancy and birth rates worldwide (taken from [143]).

In the UK for example, the age demographic of the older population is shifting rapidly, according to the UK Government's Office for National Statistics currently 17% of the population is over the age of 65. However, in the next 25 years this number is set to increase to 23% (see Table 2-2). The most striking increase is in the number of "older old" people (people over the age of 85) who will increase to account for 5% of the UK population in the next 25 years, an increase of 150% on the current numbers, leading to over 3.6 million people over the age of 85 living in the UK [116]. The increase in the number of over 85's is particularly relevant because of the prevalence of chronic illnesses that require care in this population.

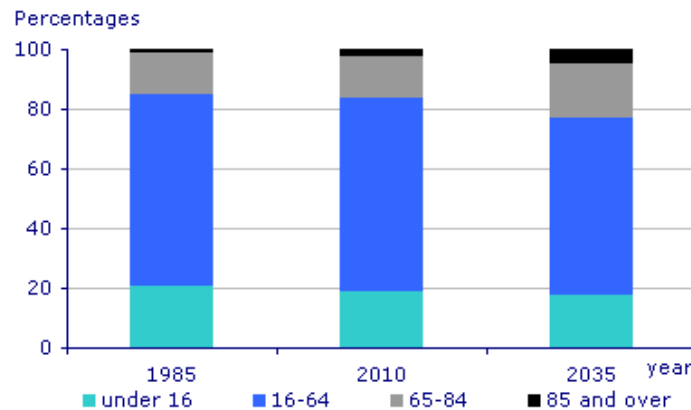


Figure 2-2: Age demographic of the UK population (taken from [116]).

Unfortunately, as people are living longer, there is a proportionate increase in the number of people who suffer from diseases associated with older age including cardiovascular disease, cancer, arthritis, cataracts, osteoporosis and Alzheimer's disease. Many of these diseases cause the person who has them impairments which can impact on their ability to care for themselves and lead to them requiring some form of care. Some of these age associated diseases such as Alzheimer's cause dementia and next section will show that dementia is one of, if not the, most significant healthcare challenges arising from the ageing population.

The costs of caring for people with these age-related diseases are substantial, for example, in the UK the National Health Service (NHS) will spend £122 billion in the year 2010 and around 70% of this will be spent on providing healthcare for older people. Beyond this, many of these diseases are degenerative conditions that lead to the older person needing care outside of hospital and this means that they need some form of residential care. These costs are incurred privately by all but the poorest people in the UK so compiling precise figures on their scope is difficult.

However, it is important not to construe this ageing population as a socially detrimental phenomenon as there are many positive aspects of this increased life expectancy both for the individual who can expect to live longer and for society as a whole. People are healthier for longer and able to work for longer periods of time. In addition, after retirement many older people remain active and are key elements of the composition of many voluntary organisations [146] with estimates of the percentage of volunteers in such organisations over the age of 65 being around 37%. In addition, the majority of

informal care for people with chronic diseases is provided by relatively healthy adults over the age of 65 [159].

2.1.2 The Impact of Ageing for the Individual

The normal ageing process is, in most cases, accompanied by a decline in various senses and cognitive functions. Ageing also leads to an increase in the likelihood of disease a [139]. This process of normal ageing is defined, in healthcare, as ageing that occurs without a decline in the older person's abilities beyond a norm determined by the wider older population [71,139] including decline in:

1. *Physical agility*: As a person grows beyond the age of 65, they generally find that their strength and endurance decrease [139]. In addition to this, physical co-ordination declines, usually as a consequence of a reduction of skeletal muscle mass [139]. With age related conditions such as arthritis, they can also find they are incapable of operating modern appliances such as mobile phones finding the interfaces too small [84].
2. *Eyesight*: In the majority of cases, an older person's eyesight will diminish as they age. However the level of diminishment varies [139] and is heavily influenced by the presence of age related conditions such as cataracts.
3. *Hearing*: Changes in hearing resulting from ageing begin to occur between the ages of forty and fifty as the inner ear cells begin to degenerate at this time. In addition, the outer ear experiences a build up in wax and, as a consequence, deafness or being hard of hearing is a common problem in the older population [139].

These impairments accompanying normal ageing frequently combine to produce an effect which is greater than the sum of the parts would suggest [68]. For example, a combination of poor eyesight and poor hearing can lead to media tailored towards users who have impaired hearing or eyesight (through subtitles or audio description) becoming unusable despite designers attempting to account for impaired users.

There are a wide variety of phenomena that are associated with ageing as a result of these physical changes. For example, older people are confronted by challenges to their personal mobility because of a decline in physical ability, and attendant issues such as arthritis [94]; older people can struggle to eat healthily because of decreased mobility and a loss of motivation to prepare food after the loss of a loved one [161] and; many older people are afraid of being victims of crime [6] despite statistics indicating that they are the least likely group to be the victims of crime [162]. All of these issues shape an older person's outlook on the world around them in ways that a designer should not presume to know.

2.1.3 The Significance of Dementia

In healthcare, dementia is defined as being a global decline in cognitive functions beyond the level typically observed in the general population of the same age. This means that a person with dementia can have impairments in nearly all aspects of their life. Dementia is not a disease but a syndrome that characterises many diseases. The most common cause of dementia is Alzheimer's disease accounting for around fifty percent of all cases of dementia with vascular dementia and Lewy body dementia being the other most common causes. The total number of people with dementia worldwide was estimated to be in the region of 35 million in 2009 [58] and the financial costs of caring for people with dementia globally were estimated to be \$604 billion per year [154]. The Alzheimer's Research Trust and London School of Economics modelling suggested that the cost of caring for people with dementia in the year 2030 would be over £7 billion in the UK alone [44].

Because of the variety of troubling symptoms and behaviours caused by dementia, coupled with the progressive nature of many of the diseases that cause it, at some point people with dementia will need to have a caregiver provide help for them to carry on living independently. In the UK these caregivers fall into two categories: professional caregivers who are paid to provide care for one or more, older people, or informal caregivers who voluntarily surrender their time whether through a charitable organisation to strangers, or to a family member or friend with dementia. Providing care for someone in the later stages of dementia can be extremely time consuming as the person needs help completing many basic tasks and can take all the caregiver's attention [121]. In addition to the care burden, informal carers experience the emotional consequences of the progression of the syndrome first-hand; this often has a significant impact on the mental wellbeing of caregivers themselves resulting in a high incidence of stress and depression amongst them [125].

When the burdens on caregivers become too great they can respond by sending those they care for into day care centres, giving them temporary relief from the effort of caring for the person with dementia. If care lasts for extended periods of time then the caregiver can also make use of respite care services that will care for someone with dementia for several weeks at a time to provide relief for the caregiver. Ultimately, many people with dementia will end up going into care homes once the burden on their caregiver becomes unmanageable [159] despite usually preferring to live in their own home.

Within the UK (and much of the rest of the world) the ratio of available caregivers to people with dementia is declining [121]. If the gulf between current design practice and the needs and experiences of people with dementia and their caregivers can be addressed, then digital technologies may in part provide a scalable solution to this shortfall.

2.1.4 The Impact of Dementia on the Individual

The issues within specific areas of the brain, which are associated with dementia, can lead to a variety of symptoms and challenging behaviours presenting themselves [76,151]. The severity of

dementia is classified as mild, moderate or severe according to the score achieved when a mini mental state exam is taken [61]. Individuals with mild impairment can typically live independently and many people will not appear to be impaired to friends or relatives at this stage. As the underlying disease progresses, friends and family will start to notice occasional problems; however, at first they often dismiss these, for example erroneously believing they are some form of “senility”. Once a person starts to exhibit mild dementia they will start to require assistance completing basic tasks of daily living and by the time their condition is severe they will need full time care.

The most well known of the impairments that arise from dementia are in memory, which can cause a person with dementia to, amongst other issues, become lost or forget how to complete basic tasks of daily living such as preparing food. These problems with memory can lead to extremely distressing situations for the person with dementia when they forget the names of friends and family and some will curtail their activity to avoid being placed in situations that might reveal their memory loss. Other problems can include forgetting to turn off the gas whilst cooking or letting a bath or sink overflow with water, these dangerous problems often lead to the person with dementia being admitted into a care home [159]. When they begin to display this they are frequently forced to be placed in care to avoid being under undue risk. Impairments in one’s ability to reason are another common consequence of dementia that can put the logical sequencing of a task beyond the grasp of some. This contributes to an inability to perform routine tasks as the person with dementia not only forgets how to complete the task, but also loses the ability to complete a task through logical reasoning about the steps and sequencing of those steps required. People with dementia can exhibit very poor personal judgement with regards to both their personal life and safety. These problems can render it impossible to even attempt to learn to use new devices or services.

Problems with language use are a common symptom in dementia, people with dementia can struggle to produce coherent sentences and find comprehending what other people say or write to be challenging. This leads to difficulty following instructions that are too complex or formulating long verbal requests. This makes interacting with those around them without a caregiver difficult and can mean that managing certain aspects of one’s life such as finances becomes impossible. This also contributes to issues when socialising with others and is a contributing factor to experiences of isolation and loneliness common in older adults [87].

Visio-spatial confusion is a symptom of dementia that arises from a decline in the functioning of specific areas of the brain with a variety of classifications for specific problems within this area. The main issue is the lack of ability to orientate oneself and perform path finding tasks. This can be a contributing factor to wandering behaviour discussed below. Similarly, temporal confusion causes a person with dementia to believe that the time is not the one it truly is, this is also a contributing factor to wandering behaviour. The level and class of this confusion varies, in some it manifests itself as confusion about the time of day (e.g. believing it is time to get up when it is 2.00am) whereas in other people it can be so severe as to make them believe they are living in a completely different time period (for example, believing that the year is 1960).

People with dementia exhibit a range of behavioural symptoms such as agitation, pacing and wandering, especially when they have moderate or severe dementia. Wandering behaviour is difficult to define but it is generally when a person with dementia walks somewhere but is not motivated by a specific goal or is motivated by one that is not rational. A precise definition is problematic because it has to take into account a wide variety of causes and resultant behaviours [85] ranging from rational movement in the service of non-rational goals (e.g. when someone attempts to walk to the house they lived in thirty years ago following a logical route from their current location), to non-logical movement in pursuit of logical goals (e.g. when a person with dementia takes a turn down the wrong street whilst trying to get home). In addition, some definitions of wandering include smaller actions such as pacing round a room or standing in place manipulating an object in an irrational way, for example turning a TV remote over and over in ones hands [45]. Many caregivers and health care professionals believe that, of the many challenging behaviours seen in dementia, wandering is the most serious [85]. The consequences of fear of wandering include an increase in already high levels of carer anxiety and stress [121] and a loss of confidence on the part of the individual with dementia. These issues combine to account for a significant proportion of admissions to care homes [29].

2.2 DIGITAL ASSISTIVE TECHNOLOGY FOR PEOPLE WITH DEMENTIA

Assistive technologies are devices that allow people to reclaim the ability to perform some activity of daily living having lost that ability due to a health problem. Some of the most commonly used assistive technologies are the ones that most would not even think of as technology, for example, glasses and walking sticks. Despite this, or as will be discussed later possibly because of this, they are the most widely used [101]. Indeed some of the most commonly used assistive technologies are those which are not viewed as being specifically for people with impairments, telephones and TV remote are amongst the most ubiquitous of these. These technologies are not usually sophisticated and tend to not to be heavily embedded in the “software paradigms” of interaction [124] with interfaces where one action maps to one result. The prevalence of these technologies is telling because it demonstrates that older people (with dementia) are not averse to being supported by technology in living independently and provides context for some of the issues around assistive technology abandonment.

However, the purpose of this review is to understand some of the prevailing attitudes in the design of digital technologies for people with dementia and use this as a window through which the scope and nature of the problem of poor design can be examined to gain an insight into some of the challenges that confront those designing in this field. This review does not provide a comprehensive overview of the different types of assistive technology that are available as the number of devices available is vast. Instead, the focus is placed on digital technologies for people with dementia because they represent one of the few areas in which design has been performed that specifically attempts to address the needs of older people (with dementia) and the field is critically important in addressing the issues around the ageing population. The review focuses on the technologies that are currently available to people with dementia in the commercial domain and those which are being proposed by

researchers to further limit the scope of investigations. Previous studies on the acceptability and level of use of these technologies by their target audience are also examined which support the assertion that design for older people does not adequately address their unique needs.

2.2.1 Commercial Assistive Technology

There is a massive variety of commercially available technologies designed to help people with cognitive impairments live independently. The Trent Dementia Services Development Centre charity manages a consistently updated database including around 300 examples of commercially available assistive technologies that it recommends for use in a variety of different situations specifically for people with dementia [46]. Technologies such as these can either be bought privately or, when deemed necessary, be provided by healthcare agencies. The following work documents a range of types of technology that are commonly used, the issues they address and any common problems with them.

Telecare and Fall Alarms

Telecare (a portmanteau formed from telephone and care) is a term for the provision of healthcare over a distance using various specific digital technologies. Telecare devices can form a mainstay of care for people with dementia attempting to live independently. Telecare devices are amongst the most widespread and systematically deployed assistive technologies and examining their acceptability provides some insights into the realm of digital technology design's effectiveness for older people. Forms of telecare include remote monitoring of blood sugar levels for people with diabetes, phone consultations with doctors for those with poor mobility and the use of fall detectors and panic alarms for people judged to be at risk of a serious fall (figure 2-3).



Figure 2-3: A Tynetec telecare alarm (from [163]) designed to be worn on a belt or waistband or threaded onto a pendant, the red button on the device can be pressed to send an alarm to a call centre.

Since 2005, UK government strategy for providing care for older vulnerable people, including those with dementia, has placed an increasing emphasis on the use of telecare systems to promote independent living [2]. However, a study of 220 health care providers and patients conducted in 2011 found that telecare was still not widely deployed [99]. Even those who are provided with telecare systems are not necessarily likely to use them and studies have found that the devices are frequently not carried [39]. The amount of assistive technology that is abandoned by older users is put at up to 75% of deployed devices according to one literature review [86]. Although the percentages vary dramatically depending on the way in which the measurement is made, the amount of time after use commences that is covered [122] and, as previously noted, the precise types of assistive technology being used. The examples previously given of walking sticks, glasses and remote controls are amongst the technologies that are rarely abandoned whereas digital technologies are frequently unused.

Gas Monitors

People with dementia have been observed leaving gas cookers turned on [150] posing a significant risk to their safety. There are a variety of technologies that can be used to monitor the cookers of people with dementia [47] (figure 2-4 shows two examples).



Figure 2-4: Chubb gas detector (left) and FlowTech wireless gas detector and shut off system (right) (taken from [47]).

When these devices detect gas they shut down the gas supply and can also raise an alarm summoning help for the person with dementia. Problems reported with these devices include shutting down gas supplies too often because they err on the side of caution. The devices can also cause problems when they shut off gas and do not inform the person with dementia of what they have done, leaving them confused and upset when they come to use their cooker and find it not working.

Wandering and Technology

Wandering behavior can be extremely distressing and there are now several technologies that are available to track people with dementia or prevent them from leaving the home. Examples of custom built systems that include the LoJack safety net device which is explicitly marketed to concerned relatives of people diagnosed with Alzheimer's disease [53,89], and the buddi system [28] which is marketed as a device for reassuring family that a vulnerable relative is safe (figure 2-5). Other options for tracking people with dementia include the Track-A-Phone service [142] and the Follow-Ups [160]

service which both report on a mobile phone's location. These devices and services are offered by private companies and their websites do not present any discussion of the ethics of the tracking process or the consent process. In the case of follow-us the system only requires one time access to the mobile handset to set up tracking through a text message sent from the phone. After this point the mobile phone user does not have to be aware of the tracking taking place.



Figure 2-5: The lo-jack safety net system (left) for tracking elderly people with Alzheimer's disease (taken from [16]) and the buddi system (right) (taken from [28]).

2.2.2 Research Area's in Assistive Technology for People with Dementia

Researchers are proposing a variety of different assistive technologies that can be used by people with dementia to promote their independence and help caregivers providing care for them. These are grouped into categories by the area of impairment they address.

Memory Problems

Cohen-Mansfield et al. have proposed devices to help people with dementia recall pertinent facts using a device similar to a personal digital assistant, and found that 58% of the older people they questioned would be happy buying and using some form of electronic memory aid and that 75% were willing to learn how to use such a device [42]. The difference in numbers can be explained by the older adults' curiosity about the device and willingness to learn to use the device providing they did not have to buy it. The study highlighted the fact that, whilst people with dementia would not describe themselves as needing help with an activity of daily living, when the idea of a digital device was proposed to help them, they would become enthusiastic about the idea. For example, whilst only 5% of respondents felt they had trouble remembering appointments, 42% percent reported that an appointment reminder would be a useful or important part of a memory prompter.

Kautz et al. note the importance of implicit prompts in the day-to-day activities of people with dementia and extrapolate from this to propose the use of activity compasses that can be deployed in the home to suggest the next actions that a person with dementia should perform [77]. They also suggest the creation of adaptive prompters that help participants to carry out complex tasks in the

home by prompting them through the different stages of activity step-by-step. They propose that these prompting devices could be triggered by sensing the older persons activities and identifying times when the person is in a confused state, believing that this will require a level of emotional intelligence on the part of the prompting devices.

Domestic Activities of Daily Living

Wherton and Monk showed that there is considerable distress caused for people with dementia by their inability to perform basic activities of daily living that they used to be able to perform such as simple food preparation [147]. The Gloucester Smart Home project went from lab development to real world deployment of ambient sensing technologies that were targeted to address a number of different issues as part of the ENABLE project [4,5,119]. The smart home employed sensors in the kitchen, bathroom and hallways to detect overflowing pots, gas supplies left on and pans boiling dry. The smart home developed technology to address four major issues:

- Bath and sink flooding monitors that shut off taps when they detect that the bath or sink is overflowing.
- A night light system automatically switches on when the person being monitored gets up during the night. The sensors ensure that lights are on as they move from bedroom to bathroom
- A voice reminder system throughout the house to help orientate the occupant with dementia and remind them of appointments.
- A cooker monitor system which detects any smoke or gas, upon detection the cooker is switched off and the knobs are physically reset.

The project was safety focused and opted to be very cautious about giving false alerts rather than risk missing a problem. When the cooker monitor and the night light are deployed in the wild this policy needed further investigation as false alerts caused frustration for the user and this in turn led to them ignoring prompts [5]. This trade off between safety and unwanted intrusion is complex and central to the working of this class of assistive technologies [14].

Mihailidis et al. conducted a more focused study that tested the efficacy of a system to prompt people with dementia through the simple task of washing their hands. This was achieved using a computer vision algorithm that observed a bracelet worn on the arm. Their work showed there was a significant improvement in the performance of the task when their Cognitive Orthosis for Assisting Activities in the Home (COACH) system was deployed [102,103]. The system that was developed used a camera to capture a users actions and a speaker to prompt them with a familiar voice speaking a pre-recorded message when an error in the hand washing process was identified. The camera relied on a white bracelet the user wore on each hand to track the user. A pattern matching algorithm and artificial neural network was used to adapt the system to learn the most efficient type of prompting. The prompts that the system made were grouped into three different levels of detail to avoid being overly patronising with the less impaired individuals.

The number of steps successfully completed in hand washing uniformly increased between 10% and 45% when the system was deployed in a care home with people with serious dementia. The decreases in the number of false and failed assists as the project continued was statistically significant implying the learning adaptation of the artificial neural network was beneficial. Customisation of the prompts given by the system was needed in order to gain the best results (e.g. male vs. female pros and cons with regard to voicing due to the perception of authority vs. friendliness).

Depression and Lack of Social Interactions

People with dementia frequently find that their syndrome leads to them becoming isolated from the people around them [25], which is particularly problematic as they are at a point where others support is vital to them. They find that they have to remain in the home because of their impaired judgement and so are not able to maintain the social ties they used to. When they do interact, people with dementia find that they are often incapable of remembering names or faces which can lead to considerable distress for them. Furthermore, they find they are frequently left bewildered by conversation as they struggle to follow what is being said. Dishman's survey of forty-five households including at least one person with dementia examined the challenges to social interaction that are posed by the onset of dementia in elderly people and the ways that ubiquitous computing environments might help to solve these problems [51]. Ways that social interactions with other people may be enhanced or expanded are examined and older people and people with dementia were found to have two major needs: (i) the need to feel that their relationship with someone was not purely for the sake of making the person with dementia feel better, they needed to feel that they could contribute something to the relationship; (ii) the need for diversity in the relationship. The investigation asserted that many people with dementia found that they were restricted to only interacting with older people like themselves; this was something they found depressing and finally the need for a wide range of contacts to interact with. Dishman also suggested that there are three major barriers that inhibit the fulfilment of the person with dementia's needs: (i) they had a tendency to lose track of a conversation and needed to be reminded of the pertinent points after the conversation concluded; (ii) they frequently found they forgot the names or faces of associates and; (iii) they were afraid to impose upon people in case they were making a nuisance of themselves, this would seem to tie in with the first point regarding their needs. Dishman's work is one of the few examples of a digital technology design that is proposed to improve the quality of life of a person with dementia and not address an explicit medical or safety need.

2.3 ISSUES IN DESIGN

The review of commercial assistive technologies clearly demonstrates a tendency for designing assistive technologies with a focus on addressing impairments in dementia and not on addressing the needs of people with dementia that go beyond this such as the need for social interaction highlighted in research [51]. Many of the digital technologies seem to examine one particular area that is problematic for caregivers and propose a solution to that problem, which makes the person with

dementia more manageable, but with little consideration given to the person with dementia's feelings (for example, the buddi [28] and LoJack [89] tracking systems). Where leisure technologies are suggested for people with dementia, they are generally pre-existing technologies adapted for them rather than being custom built for them [46].

Whilst the ENABLE project has demonstrated that older people can benefit from assistive technology [20], the challenges involved in creating digital assistive technologies are evident when the level of acceptance of the assistive technologies that have been discussed is examined. Studies that look at abandonment of assistive technology find that older people abandon up to 75% of the assistive technology that they are presented with [86,101].

With up to 75% of those provided with assistive technology missing out on its benefits, it is clear that there is a need to re-evaluate the ways in which technology is designed for older people and people with dementia. This section highlights some of the issues that confront designers working in the domain of design for older people or people with dementia. If a design method is to be widely applicable and improve the quality of design for this population, it will need to configure the designers, caregivers and people with dementia in such a way that they can overcome the following issues.

2.3.1 Attitudes towards Technology

Older people are frequently perceived and portrayed as being resistant to technology, for example, there is an attitude amongst some computer trainers that older people are not the intended recipients of new digital technologies and should not necessarily bother to learn to use them [134]. However, when examining the market for a digital memory aid among older people, survey results indicated that fifty-eight percent of older people would be interested [38]. Those who were younger, with higher levels of education, more indicators of poor health and who had someone present to help them were most likely to indicate willingness to try to learn how to use such a device. The main concerns people with dementia presented regarding the use of a digital memory aid were that it would be too expensive, that they might lose it or that they may make mistakes in the operation of it or the device may make mistakes.

Older people and people with dementia are open to new digital technology but digital technology designers need to consider that the fundamental paradigms of interaction [124] that they design around are not the ones that the older generation have necessarily been brought up with, or indeed even have any knowledge of. An example of such a metaphor would be the desktop of a personal computer mimicking an office desktop with files, folders and a bin to place unwanted material in. These metaphors, unintentionally or not, are not intuitive and need to be learnt through use [52] and for the older user, or indeed anyone unfamiliar with the metaphor, they may be unsuitable [68]. When designing any system that the designer intends older people to use, they should carefully consider the metaphors it leverages to avoid producing systems that, at a fundamental level, present the older user with a metaphor they do not understand. In addition, there is some evidence that as people age their ability to adapt to new tasks decreases [83]. Wilkowska et al. studied the acceptability of a personal

digital assistant and found that, whilst older adults' acceptance of technology was a complex process, the key difference between them and younger users was that the older adult was more likely to perceive the device as not being useful and were afraid of failure when using the device more than the younger users involved in the study [153].

2.3.2 Diversity

People with any form of cognitive impairment find that their impairments combine leading to greater problems than may be anticipated by examination of their individual difficulties. Further complicating matter, the abilities of those with some sort of impairment tend towards being more dynamic with both good and bad days [111]. This means that even a design tailored for a specific individual would need to be flexible over time. Even more significantly for product designers, there is a tremendous diversity within the population of older adults and people with dementia. Considering them as one homogenous group ignores the fact that the over 65's are diverse with respect to cognitive ability, living arrangements, age (as within this group there are in fact multiple generations), income and health. In fact, as a collection of individuals, people above the age of 65 years old, comprise a group that is considerably more diverse than members of the general (younger) population [68].

2.3.3 Ethical Issues

Performing research activities with people with cognitive impairment is an ethically sensitive proposition and care needs to be taken to avoid unduly distressing the older adults with dementia that are engaged in the process. In the ENABLE project the ethical considerations were taken very seriously [20], the implications of technology within all aspects of family life and the issues that are raised by technology which can be used to track elders have also been examined [100]. The ENABLE project presented the view that the use of assistive technology to track people when they are suffering from severe cognitive decline is a positive thing; most people are prepared to accept increased levels of monitoring in exchange for a decreased level of privacy.

Cohene used a contextual inquiry approach, observing relevant tasks in users' natural settings when designing interactive life media [43] but expressed concern about the ethics of this approach because of the disruption it caused to the people with dementia being observed. Dewsbury notes that the design of in-home monitoring systems is problematic [48,49], proposing that technology that is obvious and controlled may be easier to accept than an unseen entity controlling the environment around us. Fear of misuse was another concern that the academic research frequently expressed about the technologies that they might deploy. Unfortunately, this may be justified as any technology that might be developed, regardless of the intent of the designer, might be misused and as previously noted some commercial technologies, such as the follow-us service [160], are open to abuse because of the way they are designed.

2.3.4 The Caregiver as a Substitute and the Emphasis on Safety

Studies conducted recently showed that the desire for safety related devices is, in part, an artefact of the process of talking exclusively to caregivers and that, in reality, the devices people with dementia want are more varied than the ones caregivers want and relate more strongly to recovering lost abilities than protecting their own safety and wellbeing [149]. Frequently, literature on assistive technology for people with dementia makes reference to the caregiver of people with dementia as a source of information in the design process. Interviews are carried out with the caregivers and the feedback gained from these interviews is then used instead of first hand information gained from the people with dementia [43]. Unfortunately, the caregiver is not a suitable substitute for gaining first hand information from the people with dementia. Caregivers introduce their own bias to the investigation and do not present the issues in the same way as the people with dementia would do if they were given the chance [149]. Caregivers place a heavy emphasis on the safety of people with dementia. The bias towards personal safety leads to safety oriented systems being developed which do not address the problems that people with dementia express and systems tending towards being used to track the people with dementia or monitor their safety. When people with dementia are asked what they want from technology, the devices they request address social interaction with others [51] and devices that facilitate reminiscing about their past [43] or devices that help the person with dementia reclaim an activity they used to be able to perform [61].

When safety oriented systems are installed, people with dementia do not recognise the utility of them and tend to be less patient with them [4,5]. Cohene and Baecker note that caregiver gives a poor representation of the needs of the people with dementia but noted that despite some bias and the different perspective, the interactions with caregivers was still found to be valuable and contributed to the overall success of the project [43]. Adlam et al. also showed that there was a gap in the requirements generated by the caregiver and the people with dementia [119], again with the caregivers focusing more upon the need for safety while the people with dementia wanted technology to help them enjoy their life. However, the use of technology to track people with dementia has been discussed and framed as being “enabling” for them rather than an intrusion of their privacy by both the dementia advocacy group The Alzheimer’s Society and by Members of Parliament in the UK [8,11,12]. These issues suggest that further work should include both the people with dementia and the caregivers in order to either avoid the bias towards the safety oriented side of technology or re-frame safety oriented technology so that it becomes empowering for the person with dementia rather than just addressing their perceived impairments.

2.4 DESIGN APPROACHES

The review of previous work has highlighted that there are a number of factors that make designing for older people and people with dementia challenging. It is not just that older people, as a group, have wide ranging physical and cognitive abilities, but that their life experiences can often radically differ to those of designers. There is evidence that suggests they have different attitudes towards technology and, when considering cognitively impaired individuals, the diversity in the group is

amplified. In addition, reviewing previous work has highlighted that there is a tendency to work with caregivers rather than people with dementia due to the numerous challenges that engaging with them poses.

Considering this suite of issues raises the question of what design philosophy might be suitable for addressing these challenges. Speaking in very general terms, the process of User (sometimes called Human or Person) Centred Design (UCD) seeks to place the person who uses technology at the forefront of a designers mind [75]. This is a general term and encompasses an enormous suite of design practices. The practice of UCD is intended to counteract the phenomenon of “Thing” centred design, in which designers focus upon the object being created rather than the eventual user of said object []. The “think” focus problem is similar to two of the issues that have been identified in previous work: the tendency to focus on the needs of the caregiver rather than the needs of the person with dementia and; the tendency to focus design work on the issues that arise in dementia as opposed to focusing upon the people with dementia themselves who will have to live with the designers creations.

There are numerous techniques that would allow a designer to perform UCD by gathering insights into the lives of people with dementia and older people including ethnography¹, semi-structured interviews², focus groups³ and co-inquiry interviews⁴. However, the fundamental problem that leads to poor design is actually that these techniques are not frequently used when designing interventions for people with dementia. This problem stems from a prevailing attitude towards people with dementia that is apparent throughout much of western society. Pinfold observed that western societies have a negative disposition towards people with any mental health condition, and in many quarters mental health, as a topic of discussion, is a taboo [123]. Whiteley noted that the level of design attention paid to the artefacts and services of subsections of society increases in relation to the level of worth which society puts on that group [152] and this is readily apparent in the case of people with dementia.

2.4.1 Phenomena Associated with Shifting Attitudes in Healthcare Service Design

In the decades leading up to the 1990s, health and social care services in the UK were frequently criticised for their unsympathetic and inappropriate treatment of people with dementia in care homes and hospitals. People with dementia in care homes and hospitals were frequently drugged or physically restrained to prevent them from “causing problems” for care home or nursing staff [76,127,128]. Even current attitudes towards older people are generally similarly unsympathetic, and ageism and the marginalisation of older people are commonly reported phenomena [30]. The

¹ Ethnography: the practice of observing people within a specific domain to understand their lives and the culture in which they are immersed [59].

² Semi-structured interviews: interviews in which the interviewer has a topic in mind but allows the conversation to be guided by the participant through the use of open ended questions [130].

³ Focus groups: group interviews with more than one participant[17,63].

⁴ Co-inquiry: one-to-one interviews in which interviewer and interviewee work together to generate new knowledge about a specific area, one example of this approach being the Socratic-Hermeneutic Interview [130].

phenomena that emerged to counteract this provide an important theoretical background that can inform the selection of a design approach suitable for respecting people with dementia and older adult's experiences.

A variety of different phenomena emerged that challenged this neglectful culture. The first phenomenon that is examined is the movement towards giving people who live with various impairments a voice in the healthcare processes that take place around them (and in broader societal issues that affect them) which has been rising in prominence [108]. This trend is often surmised as “nothing about us without us” – the statement is widely used and is understood as suggesting that any decision that affects a disabled person should not be taken without consulting them.

The second school of thought that addressed the issues within the UK healthcare services and improved the standard of care they provided specifically for people with dementia was through the adoption of the Person Centred Care (PCC) approach championed by Tom Kitwood. Kitwood's approach centred upon the idea of care providers, such as nurses, doctors and care home staff, respecting patients' experiences of dementia regardless of whether the reasoning that underpin these experiences is rational. Kitwood referred to this as “respecting their Personhood”. Understanding the experiences of people with dementia and respecting that they are real for the individual is central to Person Centred Care. This care process proposes placing the person with dementia at the forefront of a care provider's consideration at all times. If designers can emulate the Person Centred Care approach by respecting people with dementia and older peoples' experiences then the quality of the designs they produce for them can be improved. [81].

The philosophy of the Person Centred Care approach resonates with Wright and McCarthy's call for an empathic relationship between designers and users [155]. In Person Centred Care, a care giver should be both sympathetic towards, and understanding of, a person with dementia; in empathic design a relationship of sympathy and understanding should be formed between the designer and user. Wright and McCarthy propose that empathic relationships arise from a close connection between the designers and their subjects, in which the designer is motivated to help the user and (crucially) is also prepared to listen to them.

Within the NHS, the NHS propose experience-based design as a potential avenue through which users experiences with healthcare can be improved [18]. In this approach the experience of patients with the service is given increased weight and they are engaged in co-design with other stakeholders such as health care professionals. This process focuses on service design and the point “where people come into contact with the service and where their subjective experience is shaped” [18]. This approach is followed and is built upon by work that was performed as part of the 5 year User Centred Healthcare Design project (UCHD). Again, this approach acknowledges the experience of illness as distinct and unique to individual patients and tries to capture it through a variety of different design activities. The process is healthcare oriented, specifically healthcare service design oriented but has a focus on understanding the context in which patients live their lives and trying to understand their varied experiences with respect to their illnesses.

2.4.2 Considering Specific Design Approaches

A common theme throughout the approaches examined is the need to engage with the target group and respect their experiences. The lessons of PCC, the “nothing about us without us” phenomenon and the more fundamental change in orientation of the NHS are not often applied to the design of digital technologies for older adults or people with dementia but, if an appropriate approach to design can be found, then a focus on the experiences of people with dementia might be achieved.

Narrative approaches to design [66] were employed in the experience based work of the NHS Institute for Improvement and Innovation [19]. Advocates of this approach consider a narrative to be a tool that can be used to make sense of experience (among other qualities) which can be elicited through a variety of techniques such as narrative interviewing in which a researcher collects stories and examines their coherence and meaning in context. Although this approach was not considered prior to the development of the design approaches detailed in Chapters Three and Five, some of the qualities of the approach resonate with the findings from these approaches. In particular, the collective sense making approach to design [66] has several similarities to the later tailored design sessions that would be engaged in as part of the KITE process in Chapter Four.

This project would eventually choose to use participatory design methods to realise its goal of engaging with older people and people with dementia’s experiences because of: (i) their commitment to democratizing the design environment [106] mirroring the respect that Kitwood suggests is needed to understand people with dementia’s experiences [81] and; (ii) the close contact that it requires between the designers and participants, comparable to the ideas Wright and McCarthy propose [155]. In addition, the majority of the previous approaches and phenomena examined with respect to their impact on improving healthcare provision also incorporate participatory design work. Experience based design practitioners such as those at the NHS Institute for Improvement and Innovation and the UCHD project also consider a participatory element that “*sees users directly involved in the design and development process for a product or service (no third-party representation)*” [19] is a vital part of experience based design as well [18,24]. Finally, when examining the field of narrative design, Greenhalgh et al characterise “*collective sense making*” as one of the four pillars of narrative based approaches to improving design quality.

Participatory design involves close contact with the users, potentially even co-creating designs. Many participatory design techniques also explicitly aim to democratise the design process [106] by placing designers on an equal footing with the participants, again in a manner reminiscent of the respect for Personhood of the Person Centred Care approach. Whilst there are many potential design challenges to conducting participatory design for people with dementia – including the problems they can have with memory, reasoning, abstract thinking and expressing themselves – these challenges are not insurmountable, as the spirit (and in some cases detail) of a number of examples from the review of previous design studies demonstrates [65,70]. In addition, there are several examples of participatory techniques being used with older adults [97] and with younger cognitively impaired people [157].

Participatory design methodologies originated within the context of use within the workplace as part of the effort to democratize the introduction of new technologies in Sweden in the 1970s [32]. Because of this, many participatory design techniques have inbuilt assumptions about the environment they will be applied within. Techniques assume that there is a specific task to be understood and designed for, that there are a range of experts that need to be engaged in the design, that focus is on work and productivity as opposed to experience and the participants are assumed to be cognitively able. This means that the specific techniques within participatory design do not necessarily translate to being used in social, experiential domains. However, participatory approaches have been modified, “Empathy probes” [98] are an example of a participatory design approach modified to promote a holistic understanding of day-to-day experiences.

Beyond insights into the experiences of people with dementia (and to a lesser extent older adults), empowering them through engagement in design has the potential to alter the ways in which we think about the role of technology in their lives. As previously noted, it is the caregiver who is the source of information in the design process [120] with feedback gained from interviews with them used instead of talking to people with dementia [149]. Commercially available assistive technologies for people with dementia tend to be safety focused and this appears to be, in part, an artefact of talking primarily to caregivers. However, when people with dementia are empowered through being given a voice in design, we see devices built that address social interaction with others [51], that facilitate reminiscing about their past [43], or that help the person with dementia reclaim the ability to perform an activity they used to be able to carry out prior to the onset of dementia [149]. Therefore, the caregiver is not a suitable *substitute* for talking directly to people with dementia as they introduce their own bias into design that prioritizes their needs. Previous work has shown there was a gap in the requirements generated by caregivers and people with dementia [120] and found that family caregivers do not accurately represent the needs of their loved ones [43]. However, despite caregivers’ specific perspective on the issues, interactions with them were still informative. We need to talk to both people with dementia and caregivers but need to engage with caregiver’s responses critically if we are to design appropriately for people with dementia.

Empowering people with dementia through engagement in the design process also has practical benefits. When safety-oriented systems are imposed, people do not recognize their utility and tend to be less patient or willing to use them [5]. Even the design of safety oriented technologies can benefit if they can be framed as “enabling” rather than disempowering or dehumanizing. For example, members of the Alzheimer’s Society are optimistic about the role that electronic tracking technology can play in the lives of people with dementia because of its potential to let them reclaim the ability to walk safely [8]. However, further work must include people with dementia and caregivers to avoid the tendency to focus on safety oriented technology. In this way, technology can empower the people with dementia rather than solely addressing their impairments.

2.5 CONCLUSION

The context in which the work will be conducted has been examined looking at the relevant data regarding the shifting demographics of the ageing population to gain a sense of the overall significance of the work. To ensure that the issues are fully understood, at a basic level some of the medical characteristics that are associated with both ageing and the onset of dementia are explored. Examining assistive technology designed for people with dementia gives an insight into the attitudes of designers when specifically targeting older people and people with dementia. There are distinct differences between designers and the people with dementia and older peoples' life experiences. Designing to address the unique variety of experiences each older individual, or person with dementia has includes the need to address: a variety of medical issues ranging from poor eyesight and hearing to cognitive impairment and physical disability; a different frame of reference for the older person when interacting with technology; a tendency to medicalise the design issues rather than consider them holistically; ethical challenges in engaging the cognitively impaired in design; an enormous diversity in the target population that makes selecting any one participant to engage with as a representative of the whole challenging, and difficulties older people encountered when envisioning future technologies. Finally, when working with those who need care to be provided to them, there is an overarching phenomenon of engaging with the caregivers rather than those being cared for and, as a result of this, an emphasis on the safety of people involved in the process rather than an emphasis on allowing them to reclaim the ability to perform tasks they were able to do previously.

Having gained an understanding of the area of assistive technology and design for older people and people with dementia, the focus moves on to examining the potential ways that the various techniques used in participatory design can be leveraged to bridge the gulf in understanding between designers and people with dementia and elicit information from people with dementia whilst avoiding causing them any distress or upset. The next chapter will also detail the design methodology used and the outputs from focus groups conducted as part of this project.

CHAPTER 3: THE KITE DESIGN APPROACH

There is potential for digital technologies to assist older adults and people with dementia in their day-to-day lives. However, designers struggle when designing for this group for a variety of different reasons that revolve around their lack of understanding of the experiences of this group. This lack of understanding arises because the group are drastically different to the designers themselves. Looking at previous work in the UK healthcare, which had struggled with similar problems previously, suggested that overcoming this difference requires engagement with the older adults and people with dementia but, beyond simple engagement, the designers need to be conscious of and sensitised to this group's needs and differing life experiences. This chapter presents a design framework that configures designer and participant in a way that allows the designer to better understand the participants' needs. Kitwood's work on this topic [81] is particularly influential on the design framework that is presented in this chapter as it attempts to respect his central tenet of affording respect to people with dementia. The work of Wright and McCarthy [155] and Suri [140] on the role of empathy in design also influence this approach as it demands close contact, respectful engagement and a willingness to help on the part of the designers

This chapter presents: an examination of previous participatory design work with older adults, people with dementia and other groups with cognitive impairment to discern the techniques that are utilised to overcome cognitive impairment and a specific framework for engaging older adults based upon the previous work and the overriding goal of creating an empathetic link between designers and participants. The participatory design approach is broken down into four distinct sections: stakeholder identification and recruitment identifies people most likely to be able to contribute to the process to work with and attempts to establish meetings in a setting that supports these individuals; early focus groups give the designers an opportunity to start to understand the domain in which they are working; workshops are intended to allow the designers to start to understand what sorts of digital technologies intervention might be most useful and; personally tailored design work works with individuals on a one-to-one basis. This final stage involves iterative meetings to develop prototypes informed by the earlier workshops, develop a closer contact between designers and participants allowing for greater insights into their lives and help mitigate the impact of cognitive impairment on the participants by removing much of the abstract thinking that design requires through presenting them with concrete, physical, usable prototypes.

3.1 PRINCIPLES DRAWN FROM PREVIOUS APPROACHES

Previous participatory approaches to design with people with dementia and older people have addressed a number of challenges that have the potential to inform the development of a new design framework. Techniques for overcoming challenges for conducting participatory design with people with dementia – such as memory, reasoning, abstract thinking and self expression problems – are particularly relevant [97]. Although there are considerably fewer accounts of participatory design with people with dementia, as compared to design with people with other forms of cognitive impairment, the techniques employed in overcoming the impact of other forms of cognitive impairment are also relevant to the process of engaging people with dementia in a design process. This section presents a sample of the related work to illustrate the primary techniques and approaches found in this area

3.1.1 Design with Older People

Previous participatory design studies with older people have suggested that older participants are more adept than the average member of the younger population when it comes to certain participatory design tasks, such as critiquing prototypes, but less proficient, or less engaged with, tasks such as *Paper Prototyping* [96]. Playing to older peoples' strengths in participatory design might be one approach to reducing barriers to input from the participants and facilitating the development of a more democratic relationship.

Massimi et al. follow a participatory design approach with older users to design a mobile phone [96,97]. Scenario based work and artefact analysis were used in group meetings with older people to solicit requirements. In the scenario-based work the designer guided older users through the process of devising best, normal and worst case scenarios, and through the description of the features which they would want a device to have to support them in these scenarios. Massimi et al. observed that the older users had difficulties with this task because they struggled to envision future technologies and scenarios but they also used artefact analysis, which involved examining objects currently used in a task and discussing the participants' feelings about the role the object played in their lives and the emotions they associated with its use. The older users performed well in this task coming up with numerous novel insights into the design of the technologies under discussion, possibly because of the link to tangible items grounding the conversation for them.

These requirements were used to develop initial designs for a context aware phone for older people that would help them recall the names of people they met. *Paper Prototyping* with the older people was then used to design a user interface for the phone. Massimi et al. [97] reported how the older adults were initially reluctant to take part in the *Paper Prototyping* because they felt they lacked the creativity needed to participate; but that when they eventually became engaged in the process, they started to generate useful insights (for the designers) relating to details of the user interface design . Notable occurrences included a number of arguments that arose between the group members, which was addressed by dissolving the group structure and using one-to-one interviews. Although not part of the original design methodology, the design team reported that they received useful feedback from

one-to-one work in these later stages of the design process. This suggests that not all participatory design work needs to be group-based and that there are uses for one-to-one work with older adults in design. In summary, Massimi et al. concluded that “seniors were good at critiquing design, mediocre at screen designing and bad at imagining next-generation technology” [97].

In the area of design for older users, researchers with a long standing interest in older people and technology at Dundee University have proposed a number of related design philosophies, including *Design for Dynamic Diversity (DDD)* [67] and *User Sensitive Inclusive Design (USID)* [111]. DDD is founded on the observation that older users have a much more varied set of attributes than the younger population designers typically consider. In addition, any individual’s faculties will vary over time, for example older people’s health tends to fluctuate more than younger peoples, so each individual’s faculties are dynamic, and design should consider this explicitly. USID’s approach to addressing this dynamic diversity, is to suggest that no single user should be assumed to be representative of the entire user group, instead technology should be designed for anyone to use, including people with disabilities. The authors argue that participatory design, with its focus on only a small group of users, is not an ideal expression of the USID paradigm because it risks excluding other people. However, others would argue this is not an appropriate interpretation of how participatory design works. For example, Holmquist [73] argues that his process of extremely personal participatory design is simply an approach to inspiring designers and that the findings from these designs can be more insightful than those taken in larger groups. Furthermore, some critiques of USID, including Alan Newell himself, believe that design for all can hamper the process of design for both the majority (which is not necessarily a problem) or design for groups with specific disabilities (which is definitely a problem). So rather than having an excellent design that has been carefully tailored for a specific impairment, and the user will have to make do with a lowest common denominator solution.

3.1.2 Design work with People with Dementia

One important question is whether or not people with dementia, rather than their carers or other stakeholders in dementia care, can make meaningful direct contribution to a participatory design process. Hanson et al. used early engagement in the design process with people with dementia and their caregivers while developing an online repository of information about care provision [70]. Their approach leveraged the experience of caregivers of people with dementia by having them facilitate design sessions. These sessions were conducted at regular intervals over a nine month period. The product of the work was evaluated by a larger group of people with dementia after the project was completed, and the feedback was generally positive. Although the nine month timescale has obvious practical drawbacks, the project demonstrated that people with dementia can contribute to a participatory design exercise, and, more importantly, that results of working with a small group of people with dementia can generalise to a wider, more diverse group of people with dementia.

A landmark project for design for dementia was the Bath Institute for Medical Engineering’s design of a set of smart-home devices and their actual deployment in the houses of people with dementia

[4,5,119]. The priority of the designs was to keep people with dementia safe in the home and prevent them from becoming lost. During this process, a modified user-led design⁵ methodology was used that involved eliciting feedback on prototypes from participants with dementia and modifying them accordingly. This approach was altered when it was discovered that some people with dementia became upset when a prototype did not work, tending to blame themselves for the prototype's shortcomings. This led the Bath team to modify their user-led approach, with caregivers only taking part in initial prototyping, and only involving the actual people with dementia once the prototypes had reached a more mature stage. The project also found people with dementia could provide interesting and useful insights into the items being designed but those with more severe dementia were less capable of contributing. Of particular interest was the observation that there was a significant difference between the needs the people with dementia expressed, and those expressed by their caregivers. The people with dementia were keen to have access to technologies that helped them reclaim their ability to perform basic tasks that they had lost with the onset of dementia. By contrast, caregivers were primarily interested in applications that would keep their relatives safe. This illustrates a basic conflict, and the potential pitfalls of relying exclusively on the caregiver to provide a voice for people with dementia.

Hawkey et al. conducted a number of interviews with people with dementia and their caregivers in the process of designing an aid to prevent repetitive question asking [72]. The project used short interviews conducted inside the home and found being in a familiar environment set the people with dementia at ease. Challenges reported included that many individuals did not think that they had any particular problems with memory, and frequent conflicts between what a caregiver said in interviews and what the people with dementia said. Hawkey et al.'s conclusions contrast with Wherton and Monk's in a project investigating possible cognitive supports for people with dementia [149]. Whilst Wherton and Monk found that people with dementia did hold differing views to their caregivers, they did not believe these to be fundamental problems for the requirements gathering process in that many of the views people with dementia held, that contradicted those expressed by their caregivers, were accurate [148]. Wherton and Monk concluded by emphasising that to improve understanding of issues around dementia it was important to talk directly to people with dementia that had mild or moderate impairments (as well as their caregivers).

In summary, this relatively small amount of previous work demonstrates that people with dementia can contribute meaningfully to the design process, providing they are not severely cognitively impaired. The person with dementia and their caregiver can hold different but equally legitimate positions on designs, but eliciting the opinions of people with dementia is time consuming. Whilst participatory design approaches have been used with people with dementia, these approaches have been located at the "information gathering" end of the participatory design spectrum [80]. Past work

⁵ User-led design: design processes in which the user is placed at the forefront of the design effort through principles such as engagement, fast prototype, in context testing and the use of virtual environments [35].

has not sought to facilitate a truly empathic relationship with them, and instead focus on eliciting “requirements” to which a designer would respond rather than allowing the person with dementia to lead the designers.

3.1.3 Design with the Cognitively Impaired

As mentioned earlier, dementia is a global decline in cognitive function. Therefore, many of the issues that present themselves when working with other groups with cognitive impairment also appear when working with people with dementia. A longstanding programme of research at the University of Toronto explored methods by which amnesic individuals could be more deeply involved in the design process of assistive technologies [97,157,158]. These included using brainstorming sessions, *Paper Prototyping* and high-fidelity (software) prototyping in the design process. Paper Prototyping [138] was found to be problematic for the amnesic participants, although useful for provoking discussion about how specific parts of a design might interact with a participant’s cognitive impairment. *Paper Prototyping* was also found to stimulate a lot of discussion, although not always related to the specific item being prototyped. When evaluating high-fidelity prototypes, it was reported that participants identified several design flaws in a prototype which were detrimental for any user, not just those with amnesia. In a second study, the cognitive issues around memory loss and participatory design were examined through the design of an orientation aid for people with amnesia [158]. Participants were selected on the basis that their memory impairment was not severe enough to prevent them from remembering previous design sessions, echoing Orpwood et al. [120] who found that individuals with severe cognitive impairment are not always capable of being helpful in the design process. A four-step methodology to adapt a participatory design process for any group with cognitive impairments was proposed. In the first step each participant is assessed to establish how their impairment impacts on them and their interaction with others. The second step involves the identification of the cognitive problems that a person might have, here an understanding of the cognitive domains used in design is needed. In the third step design techniques are identified and the assumptions made about the cognitive ability of the people involved in the design process are explicitly identified, that is, where the assumptions conflict with the capabilities of the cognitively impaired participants. With these areas of conflict identified, the fourth step is to modify the methodology to minimise or remove the impact of the cognitive deficit on the design process.

The consequences of applying this method include: extensive documentation for the participants to review in the form of audio and video recording, notes and other material compiled by the meeting facilitator; extensive review of the documentation led by the meeting chair at key points in the meeting; and an imperative to engineer the environment to help participants recall design decisions. As memory issues are a significant problem for people with dementia these principles can be integrated into the design framework proposed in section 3.2.1.

3.1.4 Implications of Previous Work

Design for people with dementia has often relied on the opinions of the caregiver as a substitute for talking directly to the person with dementia. However, some design work previously undertaken with people with dementia, and with people with other forms of cognitive impairments, shows that involving these users in design is both possible (if appropriate measures are taken) and beneficial. Previous work shows a clear need to adapt participatory methods to work with cognitively impaired users and the need for patience when working with them. In general, older people have been found to be very capable of critiquing designs, suggesting that workshops involving older caregivers and older people with dementia will be most productive if they focus on presenting design options rather than framing activities as overtly creative endeavours. However, any process that embodies a genuine respect for people with dementia, and treats them as the expert in the design domain, must afford them the opportunity for both creative and critical input. Such a framework will need to take special account of how it can stimulate and support creative thinking on the part of the people with dementia. It must also take full account of supporting more mundane aspects of their involvement, including the supply aids to memory in various forms, and maintaining consistency through design meetings. Whether contribution made by people with less severe dementia can be generalised to a population with more severe cognitive impairments remains an open question, but one that can only be answered through application of such methods and the wider evaluation of the subsequent designs.

3.2 A NEW PARTICIPATORY DESIGN FRAMEWORK

Whilst people with dementia are older people with cognitive impairments, simply combining lessons from the participatory design literature for each cohort will not suffice. The interplay between health problems and the older people's issues with, experience of, and attitudes towards technology gives rise to new issues. The KITE method proposed here does not seek to create new techniques, but instead it focuses on the creation of a relationship between the designer and the person with dementia that supports the process of drawing out the insights of the person with dementia and the caregiver through carefully contextualised conversations. In simple terms, the primary aim of the framework is to create an empathic relationship between the designers and the people with dementia and their caregivers; and fostering an empathic disposition on the part of the designers (for the people with dementia and their caregivers) will yield an environment in which the people with dementia can speak openly. An important prerequisite is that equal weight is given to caregivers, people with dementia and designer's ideas during the design activity, this is, that it democratises the design process "in the small".

Figure 6 gives an overview of the KITE design approach. KITE involves broad scoping work using focus groups followed by design meetings conducted using brainstorming and prompting techniques, and seeks to draw on the experiences of a range of people with dementia and caregivers. The focus group gives a broad understanding of the design domain and the issues which the people with dementia and their caregivers encounter in day-to-day life. These allow the designer to start to elaborate both the problem and the design space. These issues and the designer's initial ideas about

possible interventions feed into the first set of design workshops which are conducted with the same groups approximately two weeks after the conduct of a focus group meeting. The goal of the design workshops is to validate the designer's assessment of the domain and to start focussing participants critical skills on the specific interventions the designers are considering (presented through the prompt technique). Technology selection and development occurs after the exploratory stage to allow the widest possible set of design responses. These sessions also provide an opportunity to *interview* the participants and identify which are most engaged in the process, and which are good candidates to continue working with the designers in a set of *personally tailored design meetings*. Personally tailored design meetings involve deeper engagement with a smaller number of caregivers and people with dementia and frame the activity as a process of design for the personal context of the participants involved (i.e. not a generic solution for all people with dementia). These smaller, more intimate sessions, are where a more empathic relationship between the participants and the designer must develop. The work with individuals produces customized prototypes that respond to each participant's individual needs.

Each design meeting should be audio recorded and transcribed for the designers to reflect upon after the event. This places a requirement on the designer to go back over the discussions to ensure that the impressions they got from the meeting matched with what participants actually said. In practical terms, the process is time consuming, and participants' awareness of this can also make recruitment more difficult. It is desirable that the time between individual sessions should be from 2-4 weeks. In the exploratory stage each group will be asked to participate in one exploratory meeting and one exploratory design meeting. The participants who are asked to carry on into the tailored design will take part in several design meetings.

The KITE process is presented in detail below in five sections. *Design Conduct* examines how the designer should conduct themselves and run design sessions with participants. This includes guidance for how they should talk with participants and how to set the right atmosphere in meetings. *Recruitment* explains how to identify relevant stakeholders in the process and how to find avenues through which these potential participants can be approached. *Meetings* detail the structure for individual sessions, who to work with and how many people to include per session as well as giving a goal to work towards in each session. *Techniques* are closely tied to *Meetings* and detail specific activities to perform in the design sessions in order to meet the session's goals. Finally the *Framework* itself explains how the different Meetings fit together – the ways in which they inform and support each other – and explains the choice of durations between meetings.

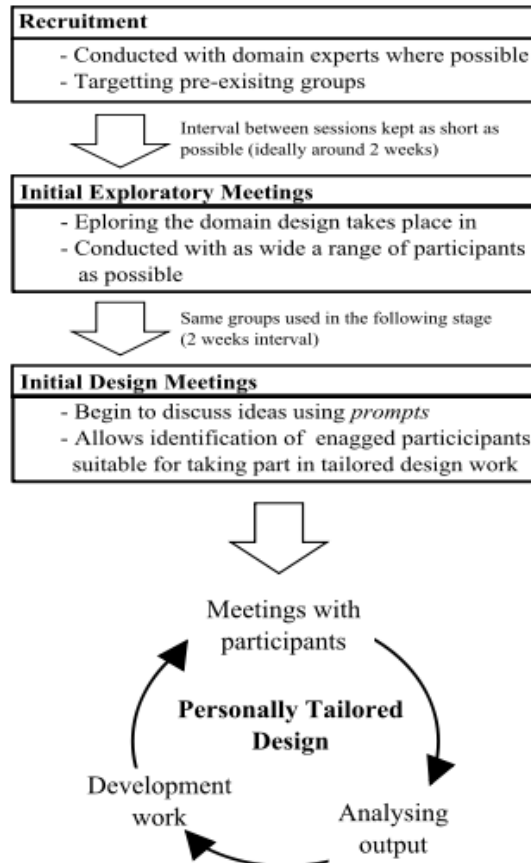


Figure 3-1: The KITE Design Approach

3.2.1 Design Conduct

Creating an appropriate tone in meetings, one in which participants feel they can divulge sensitive information without being judged, is important for achieving an empathic relationship between the designer and the participants. Achieving this means working with suitable people and being mindful of the way that meeting facilitators conduct themselves. These considerations are applicable regardless of the specific design session being performed.

Under this framework each participant will be involved in two or more meetings, to reduce confusion the meetings should be facilitated by the same person each time. This person is termed the *consistent point of contact*. The consistent point of contact is a designer but is also the person who is responsible for creating the empathic relationship between designers and participants. The consistent point of contact can also introduce other members of the design team into the meetings with participants allowing the voice of the users to be heard by, and influence, more people within the design team. This alleviates some of the burden on the analysis process to extract and present the voice of the user to the rest of the design team. Once the designer has a grasp of what is required in terms of stakeholder profiles and meeting atmosphere, the process for recruiting the participants can

be considered. The next section will outline how the overarching design conduct guidelines are realised in the recruitment process.

The use of *existing groups* can provide support for the individuals in that group. This idea ties into the basic concept behind a focus group that interplay between the participants can generate new data and questions [63]. Many people with dementia attend support groups run by voluntary organisations to help them learn strategies to cope with problems they may face and to provide a venue to talk with other, sympathetic people who understand the challenges which they face. Support groups are an ideal place to recruit existing groups as for the participants they are a trusted place for the discussion of personal problems for people with dementia. This can be enhanced by conducting meetings in familiar environments in which participants are more likely to feel at ease [72]. Caregivers can also provide support for the person who they care for in conversation. When a person with dementia struggles to articulate themselves their carer can often help them, and in this respect the caregivers presence in the design sessions, with people with dementia, can be helpful.

Previous work has highlighted the benefits of working with people with milder levels of cognitive impairment as opposed to working with people with severe cognitive impairment due to the struggle that arises trying to elicit any information from people with severe dementia, let alone engage in cognitively demanding design work [119]. Although conducting a review of the severity of someone's dementia would be impractical (and raises ethical complication in the UK because it is a medical test), the gate-keepers through which people are recruited, and the people and their caregivers themselves, can provide a reliable assessment of the severity of their dementia in terms that relate to the likelihood of their active participation in the activities proposed. As a general rule, support groups for people still living alone in the community are likely to include people less severely impaired than day care centres, which in turn will include people less severely affected than will residential care or nursing homes.

The most important component of KITE is the development of the relationship between the designer and the participants. For designers to be able to understand the perspective of the people with dementia, they need to accept the narratives put forward in the exploratory work rather than challenge them. The factual accuracy of a person's narrative is secondary to what it reveals about their experiences. The participants should feel that they can say what they feel without the need to justify or defend their opinions. Achieving this requires that the designers to address participants in a way that is clear and free of jargon. Creating a *common frame of reference* between the people with dementia, their caregivers and the designer will significantly facilitate productive meetings. The act of sharing experiences and analysing and developing designs should lead to the development of an understanding of the domain shared between all the design session members. This gives the discussions a context to place the discussion in that can be shared by all those involved.

In summary, these factors combine to create a situation where the designers treat the caregivers and people with dementia as the experts in the field and the designers humbly seek their knowledge. This ensures that the atmosphere in the design meetings is open and amicable. And while this

environment creates an opportunity for the designers to empathise with the participants, the degree to which this occurs is inevitably also a function of the motivations, attitudes and personalities of the designers themselves. This sort of relationship cannot be developed instantly; it requires time and effort on the part of the designer and willingness on the part of the person with dementia or caregiver to engage with the process.

Incorporating review into the structure of the meetings (see also [157,158]) has several benefits including focusing attention, ensuring that the design team's interpretation of what the participant says is correct and helping the participants remember the discussion. This necessitates creating extensive documentation throughout the process. In addition, the act of cementing user concerns – whether in the form of writing down a note, making a point for a recording device or altering a paper prototype – serves to focus participants' attention and ensures that concerns are voiced more readily should a participant feel that a point is being made erroneously or ambiguously. If all the participants are consulted on the note this also ensures everyone has a chance to voice their opinion and this allows the discussion to move to a new topic through a clear indication of the closing of the previous topic. Reviews can take the form of recapping previous design sessions at the start of a meeting or reviewing each individual section of work.

The level of engagement of participants is important to any participatory design process [41]. To this end the exploratory stage of the work acts as a *screening* for participants more likely to engage with and maintain their engagement with the tailored design stage which follows. Inevitably, this raises questions regarding those participants that are not engaged, the reasons for their disengagement, and thus the limits of the proposed democratisation of design. In practice, the means of recruitment has already screened those users that are more difficult to reach, and there is little to suggest as to the desirability (and mechanism) by which this might be addressed. In KITE, participants who in the focus groups demonstrate enthusiasm about the idea of a design being actually developed, and who present interesting or novel concepts, are the ones requested to remain involved in the process in the tailored design stage.

3.2.2 Stakeholder Identification and Recruitment

Identifying appropriate stakeholders is a critical part of a participatory design process. Without the correct stakeholders being engaged in the process much of the espoused value of participatory design approach is lost. The process of identifying relevant stakeholders needs to follow the principles highlighted in the previous section, engaging with caregivers as well as people with dementia, engaging with people with milder dementia in favour of those with more severe dementia and working with pre-existing groups. The recruitment process should concentrate on recruiting people with mild dementia and thus people with dementia who still live at home. These people can be contacted through charitable organisations, support groups, and day care centres (approached through their management). The involvement of domain experts at this stage can be extremely helpful as they can provide insights into stakeholder identification and the avenues for recruiting participants.

Talking to established groups leverages the existing dynamics within the group (to provide mutual support) and the trusted environment in which participants feel safe to discuss sensitive issues. Engagement with caregivers not only helps incorporate their perspective of living with dementia, but helps identify general errors made by designers that are not specific to cognitive impairment [97] which for some design tasks can be relevant. Once groups of participants have been identified and familiar venues to run the discussion found, the design team can move forward by setting dates for the exploratory focus groups.

3.2.3 Exploratory Meetings

The purpose of KITE's exploratory meetings is to develop the designer's understanding of living with dementia and establish a common frame of reference for the consistent point of contact with the group and the participants. Importantly, the aim of these sessions is not to imagine new designs, so any discussion of technology should only occur if it is volunteered by the person with dementia or their caregiver. Meetings will last between forty-five and ninety minutes. Designers should be careful not to erroneously imply in these meetings that the topic of the focus groups is "technology", although if the participants discuss technologies, as a consequence of their own direct experience of using it, then this can be investigated further.

Exploratory meetings follow a focus group structure, this means keeping questions as open ended as possible in order to stimulate discussion and allow co-questioning to emerge from the process [63]. Co-questioning refers to occurrences in focus groups where participants ask each other questions about their experiences. Its value stems from the ability of participants to ask each other questions which a facilitator who is unfamiliar with the domain or the participant might not think to ask which is particularly relevant in a domain as unfamiliar as the one that is being worked in here. However, meeting facilitators should be prepared to initially prompt discussion so some research into the design domain should be done to help in the construction of a Topic Guide for the meeting that outlines relevant topics for discussion. The meetings should be carried out with multiple groups of between three and six people with dementia and their caregivers [17]. The experiences applying the framework, documented in Chapter Four, shows that in practice numbers cannot be precisely controlled. When conducting these meetings with people with dementia, the presence of caregivers, whether professional or family, supports the person with dementia in articulating their views and experiences. However, often caregivers are more articulate than the people with dementia, and they must not be allowed to dominate the discussion. Therefore, it needs to be made clear to them at the start of the meetings that an important role that they should be playing is to support the person they care for to participate. At each of the exploratory meeting stages one group that exclusively involves caregivers can be held if it is felt that their perspectives are not fully discussed at the standard meeting. Talking exclusively with caregivers also allows the identification of areas of conflict or inconsistencies between their accounts and those put forward in the other groups by people with dementia. These conflicts are areas where design work can be focused because the issues between caregivers and the people they look after will need to be addressed in the work.

Just what an appropriate number of groups to involve and the exploratory stage are not possible, as the scope of a project and the resources available will naturally dictate the total amount of work done. However, the apportionment of effort between stages within the project needs careful consideration. In cases where the domain area is poorly understood the focus should be on the exploratory stage to develop a picture of the day-to-day life of the participant as it pertains to the design domain. In addition, in cases where a project has reason to be concerned about finding individuals suitable for participating in the later tailored design process the exploratory stage needs to be extensive as well in the hope that suitable candidates can be identified.

Thematic Transcript Analysis

The transcription and analysis of recordings of meetings allows designers to fully engage with the people with dementia and their caregiver's narratives. The analysis involves designers looking beyond what users say to find underlying values or concepts. Thematic analysis is not the preserve of traditional participatory design practices as participants would usually be more directly involved in the construction of explicit requirements (for themselves and the designers). In KITE, thematic analysis is a means to take some account of participants' cognitive impairment by reducing the burden on the participants to make their needs explicit (see later for a discussion of the pitfalls of this approach).

Our approach to 'Thematic Analysis' [26] begins with the consistent point of contact identifying interesting or significant sections of the transcript and highlighting or 'coding' them. Groups of codes with a common underlying theme can be identified on a second read through of a transcript and these are grouped into themes. Themes are then grouped into different categories which will include all coded sections related to them (some coded sections will fit into multiple categories). Under the hierarchy of concepts and categories, coded work can be re-examined and theories about the domain constructed. The themes and concepts, which the analysis draws out, need to be validated by the participants before they are accepted. The analysis process will give the designers some ideas about possible technological interventions which might be suitable. In the next stage of the process, the design team will have the chance feed back their analysis to the through the technique of prompting.

3.2.4 Exploratory Design Workshop Meetings

The aim of these meetings is to elicit participants' reactions to the designs proposed by the design team in response to the thematic analysis of the exploratory meetings. These workshops leverage a group brainstorming approach⁶ and the participants are also be presented with prompts (explained below) to promote discussion around the design ideas the designers have had. Workshops are conducted with the same groups that participated in the exploratory stage. The designer should have started to develop a friendly relationship with the interested participants. Meetings begin by reviewing the analysis of the exploratory meetings to focus the attention of participants onto the topics being

⁶ Brainstorming group work: These sessions focus on generating large numbers of unrefined ideas, they are useful in initial design stages when there is not a single design concept to engage with and critique, as they encourage abstract, uninhibited thinking [130].

discussed and to check the accuracy of thematic analysis. This also reinforces the common frame of reference for the meetings. The meetings then discuss the initial design concepts that were created based on the thematic analysis. Previous work has noted that many older participants struggle to envision future technologies. To help with this, the consistent point of contact will present a range of physical artefacts to the participants to act as prompts for discussion. These devices are selected to be physical manifestations of the design concepts. For example a satellite navigation system might be presented if the designer believes that participants would find route planning and guidance useful. The presence of the physical devices is intended to serve as a tangible prompt that reminds the participant what is being discussed.

The selection of objects to be presented can overly steer the course of the discussion and detract from participants' opportunity to make original or personal contributions. Therefore, a wide range of artefacts should be presented at the start of the discussion. Participants can then lead the discussion by, after having all the artefacts explained to them, selecting the ones they want to discuss. The caregivers group are presented with the same technologies and asked to envision their own devices. They are also asked about the sorts of devices that their loved ones might carry and their functionality. These sessions are recorded and transcribed and the analysis of this work also feeds into the next stage of the design process. Again, thematic analysis is used to distil the output of these sessions into a problem descriptions and requirements that the design team can respond to.

3.2.5 Personally Tailored Design Meetings

The second stage of the design process focuses on creating individually tailored prototypes. Individuals are engaged with on the assumption that it is not feasible to create prototypes specifically tailored to each of the participants. The relationship between the designers and the two or three people with dementia involved will be strengthened through the participatory design of these prototypes. This stage follows an iterative approach meaning the development moves in cycles every three-to-four weeks with a focus on producing new designs or prototypes to be presented to the participants. This allows the participant to see how their input is being interpreted and to provide feedback on the design. These sessions inherently involve prompts in the form of the new design objects, storyboards and paper prototypes that help counteract the participants when envisioning novel technology [97]. The exclusive focus on their own very personal experience of living with dementia contributes significantly to their engagement and, coupled with the frequent meetings, reduces the chances that topics discussed in one session will be forgotten by the next. In this stage it is also be critical to use techniques to keep the participants memory fresh, as discussed previously, by keeping the design process consistent and focused. Of course, the iterative design and development at this stage ensures that the design remains centred on the participant and that they are not forgotten in the design process.

There are a variety of techniques that can be applied in the tailored design sessions to gather more information from the participants depending on the types of information which the designers feel they

need to elicit. The information gathered from these techniques can be combined with the information taken from the wider selection of people with dementia and caregivers interviewed in the exploratory stage to help produce new design artefacts and, eventually, prototype devices for the participants to use.

Storyboards

Storyboards promote discussion around participants' routines. There are numerous ways to use a storyboard in design and our variant involves a designer creating a storyboard showing how they perceive a typical day in the participants' lives. The approach allows us another avenue to present questions to the participants and places little onus on them to exhibit particularly creative skills. The participants then fill in dialogue, thought bubbles and other notes to indicate what they would be thinking about in the various scenes. Storyboards allow designers to introduce some sense of context to the design of future mobile devices without having to go outdoors and use the device. The storyboard presentation allows notes to be taken and tied to visual cues for the individuals' reference and places focus on physical artefacts in the design sessions. Storyboards are also easily produced and show the participants something designed in response to their comments, so reassuring them that their comments are having an impact on the design process.

Paper prototypes

Paper Prototyping design activities allow the participants to show their ideas on paper using equipment provided for them by the consistent point of contact. The sessions require a degree of creative engagement (previously identified as potentially problematic) but it allow participants to express themselves through different modalities which sometimes may be easier for them to communicate in. The very personal nature of the use case (the participants own lives and individual problems) should help reduce the barrier to envisioning technology use. The sessions also democratise the design process as the tools used to generate ideas are not ones that one side of the process has an inherent advantage over the other in using, unlike, for example, computer software or note taking on a meeting facilitator's clipboard. A particularly good time to engage the participants in *Paper Prototyping* activities is when developing user interfaces. These sessions also serve to focus discussion around the problems that the participants have using specific features in relation to their own personal issues [97].

Trial Runs

Trial Runs allow users to evaluate the prototypes developed for them by letting them take it with them and use it in their everyday life. This exercise is useful because it removes the conceptual element of the design process and gives the user something very concrete to critique, playing to their strengths. Inevitably this is application-dependant technique so creating guidelines in advance of creating a design prototype is not possible.

3.2.6 Final Prototypes and Reflections

The final devices which are produced after completing the personally tailored design process should embody the attitudes and values of the participants as well as the necessary functionality for an acceptable intervention in that domain. The devices (or otherwise) will have aspects of their design which are tailored to each individual but there should also be overarching lessons which can be applied to more general design in the domain embedded in them as well. Reflecting on the products of the process and examining them in light of the more general comments of the participants in the exploratory stage will reveal how the attitudes or values they have expressed are realised in the design process.

3.3 CONCLUSIONS

KITE – a participatory design method for designing with people with dementia that fosters and is founded on an empathic relationship between the designers, the people with dementia and their caregivers – has been proposed drawing inspiration from Kitwood's Person Centred Care. KITE has two central propositions. The first is that empathic design is important in the successful design of technological interventions for older adults and people with dementia because of the gulf in life experience between them and the 'average' designer. The second is that a participatory design approach can produce this empathy if it involves older adult caregivers, people with dementia and the designer in an appropriate way. The design process that was outlined to achieve this proposes initially broad scoping work and shows how it might be used to generate accounts of experience which set a context for tailored design work with an individual with dementia and their caregiver. The techniques used to realise this are intended to minimise the impact of the person with dementia's cognitive deficit in the design process by reducing the cognitive load placed on them. In the next chapter, the framework which has been developed is applied in the domain of 'safe walking' for people with dementia. An analysing the application of this design process will reveal some of the strengths and weaknesses of KITE.

CHAPTER 4: APPLYING THE KITE DESIGN APPROACH

The quality of design for older people can be improved by sensitising designers to older peoples' experiences. This can be achieved by engaging older people in the design process using participatory design techniques. However, working with older users and people with dementia creates many challenges. In response to these challenges, the KITE method provides a framework and techniques for conducting a design process to mitigate these issues. To evaluate the effectiveness of KITE, it is applied to the domain of safe walking, a frequently neglected but important activity that has a positive impact on the wellbeing of older people with dementia and their caregivers. Whilst the safe walking is not well defined, it has a wide possibility space and lies in the domestic or social domain. The evaluation of KITE, through its application to safe walking, will provide insights into how well the participatory approach has been modified to account for the daily lives of people with dementia and their caregivers.

Our account of the application of KITE and its evaluation is presented as follows: first, the field of wandering and safe walking is introduced and the issues that people with dementia and caregivers encounter are discussed. Reflections on the application of KITE are presented and at the end of this section the final prototypes which were produced are discussed in order to discern the core design concepts embedded within their design that are relevant to the problem area. The chapter concludes with a reflective examination of the process. The individual techniques and methods leveraged are examined and the principles that worked well and those which did not, are discussed. This reflective process develops key issues that need to be addressed and is used to inform the development of a new methodology targeted more generally at older people which is presented in Chapter Five.

4.1 'SAFE WALKING' AND WANDERING

Safe walking is a loosely defined term that refers to occasions when people with dementia go walking and return safely without causing stress (or even panic) for their caregiver. Safe walking is a frequently neglected but important activity that has a positive impact on the wellbeing of older people with dementia and their caregivers. Despite its positive impact on wellbeing, safe walking activities can be curtailed because of carers' sensitivity to the perceived risks of wandering behaviour [132]. There are many benefits associated with people with dementia being able to walk outside their home independently and safely. These include opportunities for social interaction that can stimulate the

person with dementia, which may help to alleviate the progression of their condition; a temporary relief from the stress that caring places on caregivers, provided they are not worried about the activity; the activity gives the person with dementia healthy exercise and this is also linked to slowing the progression of some forms of dementia [128]; and when a person who has dementia can move outdoors without a caregiver there is a decrease in reliance on others for support and for the person with dementia to retain their sense of Personhood. Whilst safe walking is threatened by older peoples' declining mobility, perceptual skills and confidence, the most significant threat is wandering behaviour and caregivers' fear of wandering behaviour [57,129].

Wandering behaviour is characterised by situations when a person with dementia walks somewhere but is not motivated by a specific goal or is motivated by one that is (apparently) not rational. A precise definition is problematic because one must take into account a wide variety of causes and resultant behaviours [85], ranging from rational movement in the service of non-rational goals (e.g. when someone attempts to walk to the house they lived in thirty years ago following a logical route from their current location), to irrational movement in pursuit of logical goals (e.g. when a person with dementia takes a turn down the wrong street whilst trying to get home). In addition, some definitions of wandering include smaller actions such as pacing around a room or standing in place manipulating an object in an irrational way, for example, turning a TV remote over and over in ones hands [45]. Many caregivers and health care professionals believe that, of the many challenging behaviours seen in dementia, wandering is the most serious [85]. Fear of wandering leads to an increase in already high levels of carer anxiety and stress [121] and a loss of confidence on the part of the individual with dementia. Critical incidents of wandering account for a significant proportion of admissions to care homes [29].

Whilst the problems of wandering and the associated risks has received some attention in research and technology development, the field of safe walking receive little attention [76,127,128], despite its potential importance to the conduct of a healthy, independent, and fulfilling life. Monk and Wherton found that caregivers place much more emphasis on safety [149,150] than the person with dementia they care for. It is likely that the lack of attention given to safe walking has arisen as a result of the focus placed on caregivers' in the design and research agendas for dementia. The emphasis on wandering behaviour in the medical and social care literature, and commercial technology development, is understandable when placed in the context of how problematic wandering can be, but this is not an argument for neglecting safe walking and all its benefits.

The fear of wandering itself, when placed in context, is not always entirely rational. Rowe and Glover documented the number of cases of injury or harm occurring as part of the "Safe Return" program [132,133] and showed that the actual number of deaths or injuries occurring as a result of becoming lost is extremely low. However, the perception of the risks and the possibility of extremely serious consequences, combined with the tendency for such incidents to receive media attention [10], means that the problem is often at the forefront of caregivers minds [65]. Because of this, a designed intervention needs to be attentive to emotional aspects of these groups' experiences. The aim of KITE

is to let the participants and designers develop a relationship that allows a better understanding of the experiences of the person with dementia, and it is therefore intended to help address design topics where there may be conflicting views of appropriate behaviour by people with dementia. The current state of the art (i.e. assistive technologies designed to address wandering) will be examined from this perspective on the nature of the design domain. This will show that there are no solutions explicitly designed for facilitating safe walking and that all of the proposed and commercially available designs address a particularly safety-oriented view of wandering.

4.2 CURRENT INTERVENTIONS

Techniques that are used to control or counteract wandering behaviour in people with dementia vary in terms of cost, efficacy, training required for the caregivers and the level of commitment needed from caregivers. The interventions have varying levels of ethical acceptability as well. Examining the various interventions that are used in the home and in care centres will develop an understanding of the context of the problem domain both technically and in terms of stakeholders views of the problem). The most benign solution for people with dementia still residing at home is observation by caregivers or loved ones who can assist them should they exhibit wandering behaviour. Inevitably, this is time consuming and in many cases not practical.

In care homes, the observation of patients is less common (on cost grounds) and other means of “control” are used [60]. A simple technique used in care homes with minimal risks or infringements on individual’s rights are “visual barriers”. Rooms have drapes put across doors or seating arranged so as not to face a door, thereby making exiting the room a task which requires more complex planning on the part of the person wishing to leave [127]. However, the problems that cause wandering do not necessarily impair someone’s reasoning process so as an approach it has limited applicability [109]. Baffle locks, and door locking mechanisms that are designed to require some learning or skill to operate, are a related approach. This challenges someone in confused state and can prevent them from opening the door [50] again assuming a deficit in reasoning on the part of the person with dementia and is therefore not guaranteed to work. These methods are considered appropriate by most caregivers [3,13], whilst other methods employed in care homes, particularly for the care of those with more severe forms of dementia include both drugging and physical restraint in order to prevent wandering behaviour. This is common in some care environments although such approaches are increasingly being challenged as an infringement of the person with dementia’s basic human rights [60] in that they are, in a very real sense, imprisoned in the care home.

Technologies employed to address wandering behaviour generally have two primary functions, as *elopement detection* they identify a person with dementia leaving a specified area and alerts the relevant caregiver(s); as a *recovery aid* they allow caregivers to find someone who has managed to elope undetected. Closed Circuit Television (CCTV) is an example of elopement detection technology which is frequently used to monitor patients in care environments despite arguments that it constitutes an invasion of their privacy [100]. CCTV is widespread in dementia care homes, particularly around exits such as the entrance foyers and fire doors.

Radio Frequency Identification (RFID) tags provide another technical solution to elopement detection and can facilitate recovery [104]. Such systems require the subject being tracked to wear some form of identification tag. Securing these devices can be challenging, with solutions on the one hand being either intrusive or unpleasant for the person with dementia (see Figure. 2-5 for an example) or on the other hand results in the tag being easily removed. Elopement detection is achieved through the use of a “geo-fence” where a mobile antennae unit raises an alarm when a tag goes beyond a certain distance. The mobile antennae is aware of the direction of a tag’s location as well as distance from the antennae and so also acts as a recovery aid as the caregiver can take the antennae unit with them to track down the person who is lost [90]. Several issues with RFID tagging include concerns over the complexity of the mobile antennae device for older caregivers and the need for the participant to wear the tag itself [90].

Devices with embedded Global Positioning Systems (GPS) and Global Systems for Mobile Communications (GSM) provide a more flexible approach. GPS provides fine grain information on a unit’s location while GSM can communicate the details of this location over mobile phone networks to relevant parties. Commercial applications for GPS already exist such as “Sat Nav” (Satellite Navigation) devices and personal navigation systems are a feature of many Smartphone’s [136]. However, instantiations of personal navigation are not designed with people with dementia in mind [96]. These devices also require the person with dementia to remember to carry them, which is going to be considerably less likely when the person is in the state of mind that is concurrent with wandering behaviour.

In the domains of safe walking and wandering there are only technological aids designed to prevent and mitigate wandering, there are none designed specifically to facilitate safe walking. Current elopement detection systems and recovery aids are not suited to facilitating safe walking as they assume that a person needs to be found and returned as swiftly as possible. The focus on facilitating safe walking activity – as opposed to simply developing a new form of elopement detection or recovery aid – illuminates a new region of the design space for assistive technologies for people with dementia. The interventions developed are not intended to be a replacement for elopement detection and recovery but instead target mildly impaired users and function as a means to extend their independence. Inevitably there will be many caveats on the interventions use but its development also serves as means to call into question the assumptions made around wandering management and safe walking activities.

4.3 EXPERIENCES FOLLOWING THE KITE APPROACH

The application of KITE to designing a solution for safe walking was done as part of the Keeping in Touch Everyday project. The author worked as part of a multidisciplinary team including a General Practitioner who specialised in working with older adults with dementia, a social gerontologist, an interaction designer, and two engineers (software and hardware). My role was to develop the design method (KITE) and act as the meeting facilitator and consistent point of contact for the people with dementia and the caregivers who participated in the project. I also engaged in the design work and

evaluated the process. The evaluation was performed in light of the feedback received from the participants, analysis of the design session transcripts and the final designs and prototypes that were produced. In addition, my own personal experiences as the consistent point of contact with the group are reflected on.

4.3.1 Stakeholder Identification and Recruitment

This process began with the identification of relevant stakeholders. These were professional caregivers, informal caregivers and the people with dementia. The team's social gerontologist and general practitioner had extensive experience working with older adults with dementia and indicated that people with dementia living alone have different experiences of safe walking to those living in care homes. They also supported the lesson taken from literature that people with more severe dementia were unlikely to be able to contribute meaningfully to the design process. As a result of this the focus was placed on recruiting caregivers and people with dementia who had less severe cognitive impairments but who were still at risk of wandering. The team initially approached the Alzheimer's Society⁷ and asked to be put in touch with support groups for people with dementia who had not entered into day care as well as caregivers.

Representatives from the Alzheimer's Society who had worked with the team's social gerontologist were contacted first and, because they were familiar with the team member, were happy to cooperate with us. They discussed the project with team members to get a thorough sense of its aims before offering to approach support groups for people with dementia and caregivers to gauge their interest in the project. The support groups were regular meetings of between four and eight people with dementia and caregivers, or just caregivers. The support groups were close-knit, tending to make their decisions as a group, and discussed the proposal in their meetings. At this stage the aim of the project was presented as being a study looking at "getting out and about" when someone had dementia with no mention made of the specific term "participatory design" because of people's concerns that this might be intimidating (be required to engage as a designer). The groups, if they consented to be approached by the team, were sent letters explaining the planned process.

The team was aware that there would be an issue if some members of the support groups approached wanted to take part and others did not. Given how important these regular support meetings were to the people involved, members of the project team felt it was unethical to risk disrupting the groups. The decision was made to only work with groups if all members of the group agreed to participate. In practice, the nature of the collective decision making of the groups meant this did not happen.

⁷ The Alzheimer's society is a charitable UK organisation which runs support groups for both caregivers and people with dementia, despite its name the groups involve people with any form of dementia, not just Alzheimer's disease.

Meetings were scheduled to run as sub-components of the regular group meetings, the consistent point of contact would arrive part way through a session and talk to participants for approximately an hour before leaving again. When attempting to perform the design sessions two of these groups were unavailable and so the team's social gerontologist ran a second round of recruitment by approaching the Dementia Care Partnership⁸ (DCP). The DCP were able to help set up meetings with groups of friends who attended the day care centres who were willing to take part in the study.

In total, the project worked with six groups consisting of two Dementia Care Partnership groups comprised of people present at the day care centres, three Alzheimer's Society dementia support groups that agreed to participate and one Alzheimer's Society caregiver support group. In total the project talked to sixteen people with dementia, three Alzheimer's Society volunteers, one professional caregiver and eleven caregivers (see Table 4-1 and Table 4-2).

| Group | Number of Caregivers | Number of People with Dementia |
|-----------------------------|----------------------------|--------------------------------|
| Alzheimer's Society Group 1 | 2 Volunteers | 2 People with Dementia |
| Alzheimer's Society Group 2 | 2 Caregivers, 1 Volunteer | 4 People with Dementia |
| Alzheimer's Society Group 3 | 3 Caregivers | 4 People with Dementia |
| Alzheimer's Society Group 4 | 4 Caregivers, 2 Volunteers | |

Table 4-1: Exploratory meeting groups.

| Group | Number of Caregivers | Number of People with Dementia |
|-----------------------------|----------------------------|--------------------------------|
| Alzheimer's Society Group 3 | 1 Caregiver, 1 Volunteer | 2 People with Dementia |
| Alzheimer's Society Group 4 | 4 Caregivers, 2 Volunteers | |
| DCP Group 5 | 1 Professional Caregiver | 5 People with Dementia |
| DCP Group 6 | | 2 People with Dementia |

Table 4-2: Design workshop groups.

Alzheimer's Society Group 1 included a male person with dementia, Bob and a female person with dementia, Maureen. Bob was getting out and about less and less and largely due to his loss of a car. Maureen got out and about more but discussed experiences of becoming disoriented, for example having to walk up and down a street to find out where a shop was.

Alzheimer's Society Group 2 included 4 people with dementia: Maureen was quieter than the other participants and had started losing confidence travelling around her local town, she was willing to go out to meet friends though; Mark's family opposed him getting out and about and he himself had started to doubt his own safety and competence slightly as a result; Harry was much more confident

⁸ The Dementia Care Partnership was a local group that runs day care centres for people with slightly more severe dementia than we found in the Alzheimer's Society groups [1]

and owned and walked a dog every day still, he kept and maintained his own allotment; Alex usually got out and about for at least several hours each day and was strongly opposed to other people knowing where he was at any time.

Alzheimer's Society Group 3 was the group that would go on to take part in the tailored design process and they had considerably more to say than many of the other groups and we gained a much more detailed sense of this groups experiences with dementia. This group consisted of a lady, living on her own, with mild dementia (referred to as Alice), and a husband showing signs of early onset dementia (John) and his wife (Mary). This group was chosen due to the mild nature of their impairments meaning they found conversation easy, the very different personal circumstances, and their enthusiasm for the process. John and Alice wanted to maintain their independence; John was a keen runner, while Alice still regularly drove alone to the shops or to visit friends. John had been diagnosed with dementia two years ago but Alice had only been diagnosed recently and both behaved in ways that were consistent with someone with mild dementia⁹. John occasionally displayed some confusion in meetings and both Alice and John struggled to remember past events including discussions from previous meetings. John was cared for by Mary but Alice had no caregiver and this opened up a field of inquiry that, until this point, had not been drawn out of the work: what the designs could do if no caregiver was available. John lived with his wife whilst Alice lived alone. John did not have any other medical conditions but Alice had arthritis and a problem with her ankle that meant she struggled to manipulate small objects and used a walking stick. John carried a mobile phone when he remembered too but he often forgot it or deliberately left it when he went running saying that he disliked carrying it because it weighed him down or would fall out of his pockets. Both Alice and John had talked at length about the importance of routine in their lives including its significance when remembering to carry things with them when they went out and remembering to charge mobile phones for later use. This group also initially included 2 more people with dementia, David and Matthew although they did not take part in the process after the first meeting. David, who still drove, had a cheerful attitude and referred to getting lost as a "mystery tour". Mathew occasionally became lost in the supermarket and probably had more severe issues than the rest of the people in the group.

Alzheimer's Society Group 4 consisted entirely of professional and informal caregivers. The two men, Christopher and David, both provided informal care for their wives. Both of the Alzheimer's Society volunteers were female and had some experience volunteering to help friends. The remaining two ladies, Yvonne and Wilma provided care for their husband and had recently lost their husband respectively. All the members of this group were used to much more severe forms of dementia and their comments reflected this.

DCP Group 5 was a larger group of female participants who Ada, Heather, Joan, Audrey and Deborah. These participants reported more severe issues caused by their conditions and would

⁹ This is based on the analysis by the team's social gerontologist and on the self-report of the participants. There was no formal evaluation of the participants mental capacity because we believed this would require a more substantial ethical approval process.

sometimes struggle to get out and about on their own. DCP Group 6 consisted of two female participants, Christine and Bridget, who were close friends who regularly stayed for the day in one of the DCP facilities. Christine's Mobility was much more limited than Bridget's but both of them were very tech savvy, discussing the usefulness of mobile phones for them (although they had some experiences of problems using the devices or letting them run out of charge at the bottom of their handbags)

4.3.2 Exploratory Meetings

These meetings aimed to gain a sense of the wandering and safe walking experiences of people with dementia and their caregivers. The process uses open questioning to trigger co-questioning to elicit information. These question structures opened up a wide space for participants' replies and allow them to ask questions of each other that might not have been considered by the consistent point of contact, who is not the expert in the design domain. Four meetings were run using this approach, one with each of the groups (see Table 4-1). The meetings were recorded, transcribed and analysed to discern themes and present designers with a narrative of the field.

Process

This stage leverages an open structure for questioning and aims to elicit co-questioning in the focus groups. However, it is important to have a Topic Guide prepared: to ensure that conversation stays within the domain of safe walking and wandering; enable facilitators to prompt discussion if the conversation falters; and ensure that all the topics that need to be addressed are considered. Whilst designing this guide it was not necessarily anticipated that all the questions would be asked directly in the meetings, instead it was anticipated that the conversations would develop to cover some areas unprompted. This natural development often occurred. The following list details the subjects that were addressed in the Topic Guide and explains the rationale behind each:

Getting out and about – Asking about this introduced the concept of safe walking. As the term safe walking might imply an interest in measures of the phenomenon, or it may intimidate the participants the phrase “out and about” was used instead.

Feelings about getting out and about? This follow up was used for introducing a more emotional quality to the discussion. This question, in combination with questions about planning, balances the emotional and functional aspects of the discussion.

Planning for walks? Or just get out and about? Touched on the more practical aspects of the safe walking issue and can be used to open the discussion to the subject of routine.

What kind of journeys do you make? And who with? Introduced the social aspects of safe walking.

Walking Do you go for walks, for example in the countryside, do you walk purely for pleasure still?

Have any of you gone for a walk and then felt unsure as to where you were? Touched on wandering experiences having established some rapport with the participants. This question was left until later in

the sessions as it is a more sensitive issue. The term “wandering” was due to its overly negative or distasteful connotation.

Do you ever feel vulnerable when you're out? (with examples) Elicited the emotional qualities of wandering.

What did you do when this happened – or what would you do? Began a discussion about the strategies at play in relation to wandering.

Is there anything that helped you find your way again? This question was included to probe for inspiration for the designers to help them develop prompts going into design workshops.

Use of reminders or guides Do you use any item specifically to help you re-orient yourself? For example, a notebook, map or compass.

Technology Have you ever used technology to help you get out and about or when you have felt vulnerable? For example a mobile phone, Sat. Nav. or other similar device?

Transcript Analysis

At this stage of the process the thematic analysis is broad, seeking to try to describe the entire domain. Later on in the process, when working in more intimate settings, the process of analysis becomes less pronounced as the participants take more control themselves and are able to make their desires more explicit. The participants identified with the idea “getting out and about”, recognising it as an area they had thought about in the past. They needed little inducement to start recounting their stories. This section discusses the themes that emerged from the meetings and presents particularly relevant quotes that were coded in the analysis illustrating the richness of the narratives that emerged. The quotes presented throughout this document have had personally identifying features removed from them. Gender and relationships remain consistent but locations and names have been altered.

Caregivers and those with dementia spoke about getting out walking, going running and driving, with many talking about their “anxiety” regarding getting out and about. Participants in the early stages of dementia were constrained because of their anxieties or the anxieties of those around them. One of the participants used to go out a lot more, which he missed, and spoke about his family not wanting him to.

“Walks, yeah. I used to walk for miles, but me family don’t want us to go away far, you know, but ...Well the family really, they’re frightened, you know, but I’m not, I’m not..”

- Mark, ASG2

Several participants mentioned that venturing outside can become a problem because of their loss of confidence.

"Yes I am afraid it happened just the other day. I seemed to be walking round and round in the Whitley Lodge area and I just couldn't put it right.... Yes, but it's the first time I have had this happen, and I think an omen perhaps of what is going to happen before much longer. (Interviewer: Has it made you feel less confident now, or worried at all...?) No it hasn't made me less confident, no."

- Male Person with Dementia

However, others highlighted how they overcame the feeling of being unsure.

"If you go the wrong way (in the car) you just have to turn around and just back out and got back up."

- David, ASG3

Many caregivers recounted stories of times they didn't know where the person they cared for was. In some cases this changed the way they went out and about, or changed the way in which they managed things within the home, for example, ensuring that the person with dementia was locked in. There were also instances within these accounts where the person with dementia made their own way home. One caregiver talks about how her husband walked along familiar roads and places in order to get him back to his home and theme of familiarity runs throughout the discussions. The majority of caregivers spoke about their experience of not knowing where the person they were caring for was and how this caused them to 'worry' and feel anxious.

"Before Bob reached this stage, before we moved here, he used to go to the club every day for a pint, and it got to the stage where he forgot the way home and then he forgot how long he had been out and what not, and that was when I decided it was time to move to a different location, because that wasn't conducive to the rest of our lives to live where there was just streets to walk round, so we come down here where it is pleasant to walk, but he can't go anywhere on his own, he has to, that, I mean, he'd just be lost, but he wants to go out the whole time, I mean I get no peace and I have got very bad arthritis so I find it difficult, so if we have been for one walk, I mean a walk of a mile or two mile, that's my limit for that day,..."

- Yvonne, Female Caregiver, ASG4

Often an incident would instigate a change in how the carer managed within the home or out and about and many talked about times they "lost" or didn't know where the person they cared for was.

"...but from then on I mean, if I went anywhere, he had to stand beside me you know."

- Wilma, Caregiver, ASG4

This happened when they were out shopping or when the person with dementia was being cared for by someone else, for example when in respite care¹⁰. Another concern that emerged was the person with dementia getting out of the house at night.

"I mean the way she used to wander through the night, and we were in separate rooms then, but I have always been a light sleeper, and if she got up, I was up as well, so I wasn't getting any rest.....I was constantly watching her. If she did get out, which was very rarely because she couldn't even open the door, and when she was in the house, the door was always locked,"

- Christopher, ASG4

Participants with milder dementia expressed a desire for a device that enables them to be supported in getting out and that would provide them with a sense of reassurance (that they would not get lost). The caregivers, whose accounts have been about when the person they are caring for is 'lost', focused more on devices that can locate the individual ('tagging' and 'alarms'). However, the use of technology was not always acceptable to people with dementia.

"Because it makes you feel like your freedom is taken away from you, and if somebody sees you have a card or something, they think well, I'm stupid you know. I mean if I don't know where I am, I ask somebody, I will stop them and ask, I wouldn't carry a card like that, no."

- Maureen, ASG2

There were also those who did not want to use technology or let their family know where they were.

"I've seen people a few years ago, people with...and that, and I says well I don't want that, I know where I'm going, I know how long it's going to take me, I know I'm going to have a drink in a pub possibly sit down there for half an hour and then carry on with what I'm doing. If I go out - if something happened really there to me, I would get somewhere properly, I mean I'd go to a hospital and I'd come back out. Otherwise I'm not frightened in that way, if I was...I'd get back."

- Alex, ASG2

A number of participants spoke about using mobile phones but one participant said that he'd given away his mobile phone because he just 'likes to go where he wants to go and wants to go his own way'.

"He'll get on his mobile "where are you?" or if he's going to be,...you know, if he's taking too long then I will get on mine "right, I'm such and such a place, where are you? You stay there and I'll come and find you."

- Matthews caregiver, ASG3

¹⁰ Respite Care Homes take people with dementia who live with their caregiver and care for them for around a week to let the caregiver have a rest and to start to acclimatise the person with dementia to being in care.

Participants not only talked about technology in terms of mobile phones and satellite navigation devices but also about identity cards and having some sort of information to hand in order to help them in case they become unsure as to where they were.

"...I made sure, we made sure; I always made sure that in his wallet, he had his name and address, well our phone number. I would put, it wasn't the address, I just put a phone number, in his wallet you know..."

- Yvonne, ASG4

A challenge to incorporating technology into the lives of people with dementia is overcoming the impact that their loss of memory will have on whether or not they remember to take the device with them. Another potential barrier highlighted was the weight and size of any device. If it was perceived to constrain the activities of the person in any way then it is unlikely to be used.

"I think I find the problem with the weight of the mobile, you know, if he's out jogging."

"Yes, jogging, it just goes up and down."

- Mary, ASG3

Other barriers to using any device in aid of getting out and about include the lack of importance placed on such devices.

"Well I could only suggest that it would be a waste of time because, once you reach my age, you are faced with something electronic, you would ignore it."

- Alex, ASG2

A wife of one of the participants spoke about wanting reassurance, "Just to know that he was alright, he hadn't gone in the wrong direction." Another participant said that he would like a device so his "family could keep in touch" and just know where he was. Similarly, within one of the caregivers' discussions one respondent brought up the idea of using satellite navigation technology in the early stages of dementia. Several of the caregivers within the group felt the person with dementia would not be able to understand it, thus returning to what is perceived as a barrier to its use.

"...and you know these things they have in the cars, from the, the car knows where you are going...(sat nav)...I think satellite navigation would be good because then they could find their home, you know the thing that says turn left, turn right, I think something like a personal sat, what do they call them..?"

- Alice, ASG3

The desire for a device to be discreet also emerged.

"we were just saying that, if there was a device, that it would have to be something small and discreet that you could wear on your person, rather than a big, black...something like that, really stood out, because it would put you off wearing it, so yeah, something small."

- Mary, ASG4

Within the caregivers' discussion, the issue of safety was raised and how devices such as hand held satellite navigation might make the person with dementia a target for 'muggers'. This is an aspect of device ownership and use that is a potential barrier to the adoption of a design; if it is perceived either by the carer or the person with dementia to make a person vulnerable then it is unlikely to be used. This also relates to the idea of the device or technology being 'hidden' and not visible.

"...well you'd find they'd be getting mugged for it, I mean look at all the..."

- David, ASG4

Some of the caregivers who had experience of the later stages of dementia and 'losing' the person they cared for were in favour of the use of technology enabling an individual to be located. One carer spoke about technology being "implanted" to ensure that the person with dementia would trigger an alarm alerting the carer if they tried to get out of the house.

"I mean you don't know as its under the skin, but it's there forever, which is what is necessary, and you don't want a big thing on their wrist or on their you know, like these tags, and I don't believe in anything like that, apart from the fact they would get so, and if anybody like my husband, he would be pulling at that all the time, but if, so I was thinking technology would have to be that advanced, not something you know."

- Yvonne, ASG4

Other themes that arose included the existing activities that people engaged in; these were raised by caregivers and people with dementia. When discussing those issues anxiety and the curtailment of activities because of this anxiety were prevalent. The level of anxiety varied with some people describing experiences of being stuck in the home because of fear, whilst others were more outgoing and talked about tackling the problem of being lost and when it occurred. In the accounts there was disconnection between accounts of those living with mild dementia, and caregivers who had experienced living with someone with later stage dementia.

Caregivers who have experienced the person that they have cared for being lost stressed the importance of safety and changing how they lived at home to reduce the risk of this happening. After such events it was common practice to reduce the number of trips outdoors, or impose strict new rules to try to ensure that the person with dementia did not become lost again. Eloping from the home was a problem for many caregivers as well, particularly those who had a relative in the later stage of dementia, such as those in the caregiver support groups. The session with these caregivers reinforced the importance of "familiarity"; this was often mentioned as being a tool to combat the threat of becoming lost.

The use of digital technology was widespread within the groups, but it was not always perceived as helpful and attitudes towards its use were diverse. Caregivers and people with dementia discussed using mobile phones to try to assist them but many problems associated with their use were raised. Some people with dementia expressed an anxiety about being monitored by the devices, whilst others were unconcerned (and said as much). In contrast, some caregivers were willing to go to extremes to

monitor the people with dementia, even suggesting embedding tracking technology in their bodies. People with dementia preferred the idea of discreet devices that could be easily carried and both groups felt remembering to take the devices with them would be an issue.

Design Concepts Based on Thematic Analysis

The analysis of the participants' accounts revealed that "fear" or "anxiety" about becoming lost was the most significant inhibitor of getting out and about, so the design team decided that exploring ways to help with this was important. The accounts of being lost showed people initially trying to orient themselves. The process of orienting oneself led to examination of satellite navigation devices. If self-orientation failed, participants said they would try to ask for help before finally resorting to trying to call caregivers.

The design concepts that emerged from the transcript analysis of the scoping work were used to inform the selection of physical prompts to take into the exploratory design workshop meetings. These prompts were to be shown to stimulate discussion and introduce a sense of what may be possible with technology (see Figure 4-1).



Figure 4-1: Prompts used to facilitate discussion in the focus groups, from top left: iPod-nano [165]; handcrafted digital jewellery[118]; Nokia N95 Smartphone [164]; Personal Desktop Assistant [166]; TomTom satellite navigation device [167]; tracking bracelet specifically designed to monitor people with dementia [168]; fall detector/personal alarm [163].

The *iPod-nano* was selected to prompt discussion around futuristic aesthetic; it was believed that participants would feel it was not a device for them but intended for a younger generation. The *Digital Jewellery* was a custom made piece tailored to an individual [145]. This piece was intended to demonstrate to participants that technology did not have to look like a mobile phone or a computer if they did not want it to. The desire for discreet devices also seemed to be important to many participants, and both the iPod and digital jewellery were relatively small. The *Nokia N95* served the dual purpose of eliciting discussion around Smartphone's and digital cameras. Smartphone devices

seemed to be a potential solution to the issue as they would allow self-orientation through their GPS and could call a caregiver if their help was needed. The *PDA* was intended to spark discussion around touch screen interaction with devices. Demonstrating how the *TomTom* worked was intended to introduce the concept of location aware technologies. Finally, the *Tracking Bracelet* and *Fall Alarm* were intended to promote discussion of current tracking and social alarm technologies.

4.3.3 Exploratory Design Workshop Meetings

These sessions use the classical Osborne brainstorming technique that allows participants and facilitators to generate many ideas with little development of each one. The aims of these sessions is to validate the analysis of the scoping work, to start to get a sense of what is acceptable within the design space, and to identify the participants who are interested in taking part in the tailored design sessions. The sessions were conducted three weeks after the scoping stage (see Table 4-2.). There were four sessions, one with the Alzheimer's Society carer support group, one with an Alzheimer's Society support group for people with dementia and two with groups from the Dementia Care Partnership.

Process

The sessions took the idea of being out and about, and wanting to re-orient oneself, and explored possible design solutions. The caregivers who looked after people with more severe dementia struggled with this idea as the people they cared for were too ill to go out. They were asked to think back to the times when the people they cared for still got out and about when answering the questions. The sessions began by reviewing and gaining general agreement as to the output of the previous meetings; groups were presented with a summary of the points that the design team had drawn from the exploratory meetings. The agreement from groups which had not been involved in the initial work suggested the results were representative of the wider community of caregivers and people with dementia. Working with participants from the day care centres was more challenging than working with the participants from support groups. The conversation drifted off topic more often and the consistent point of contact had trouble being understood. This could in part be explained by the fact that the level of cognitive impairment the participants had appeared to be more severe (which also accounted for them being in day care rather than still living completely independently).

Outcomes

The analysis approach differed from that used for the scoping meetings which highlighted issues and narrative; it instead focused on eliciting what the people with dementia and caregivers believed they needed from an intervention to support safe walking. The themes that emerged are grouped into tables that were used to explain their desires or needs to the designers and developers that did not attend the meetings.

A broad theme about the context in which design takes place emerged, (see Table 4-3). Participants who had milder dementia focused on getting out and about, but caregivers with experience of looking

after people with severe dementia focused on the need to contain and track them. The differences between the perceived needs from the caregiver group and the groups comprising of people with dementia with their caregivers only present to give support highlighted the need to explicitly decide who to target with the design. The goal of promoting safe walking lead to placing the focus on the earlier stages of dementia, when going outdoors unaccompanied was still a possibility. In connection with this the tracking bracelet and fall alarm were the subject of much discussion as people judged them useful in severe enough cases but “not for them”.

| Circumstance | Examples | Possible Impacts |
|-----------------------|---|---|
| Country | UK, Southern Ireland, France, USA, etc. | Attitude towards dementia, financial matters, cultural perceptions and the prevalence of diagnosed cases of the disease |
| Severity of Dementia | Mild, Moderate, Severe | Global decline of cognitive abilities impacts on the needs of the user and their ability to learn to use the device provided |
| Home | Independent, Day-Care, Sheltered Housing, Respite, Care Home | Affects the context a device will function in, who will take emergency calls and who will be in charge of maintaining the device |
| Carer | Present, Not present, Living with, Living close by, Living far away, Family, Professional | Effects the information people will be willing to send, the availability of the recipient and the actions they can take in response, the caregivers attitude towards the system |
| Other Impairments | Arthritis, Deafness, Short/Long-Sighted, etc. | The ability of the user to use the device they are provided with in a wide range of ways |
| Caregiver Impairments | Arthritis, Deafness, Short/Long-Sighted, etc. | Affects the caregivers ability to respond to problems and their availability |

Table 4-3: Circumstances of people with dementia effecting design.

Another theme that emerged from the analysis was the importance of working with people’s existing routines (see Table 4-4). This developed from the idea of familiarity being important that arose in the exploratory meetings. Participants felt that any intervention to promote safe walking would be weighed against the inconvenience of integrating it into routine. This made the design team closely examine the nature of routines and its role in the everyday lives and experiences of the participants. This revealed routine was an important coping strategy for tackling cognitive impairment. Disrupting this routine could potentially exacerbate challenges the participants faced and, when people were resistant to change, this was often the cause of problems. Devices like the Smartphone and PDA were the focused of such comments as the participants disliked the idea of needing to learn to use these “fiddly” new devices.

| Routine | Examples | Impact |
|------------------------------|---|---|
| Current Coping Methodologies | Paper notes, Mobile phone, Accompanied on walks | Whether device aims to assist in coping methodologies, replace coping methodology or eliminate the need for |

| | | |
|---------------------------------|--|--|
| | | that methodology |
| Current Technology | Phone, Mobile, Digital Camera, etc. | Users familiarity with technology, willingness to use device, metaphors of interaction |
| Caregivers Current Technology | Phone, Mobile, Digital Camera, etc. | Caregivers familiarity with technology, willingness to use device, metaphors of interaction |
| Pre-Existing Device Integration | Device integrated into the users existing devices, Unique device | The design of the device for both caregiver and person with dementia, affected by current technology |
| Ensuring Carrying | Integrated into items of daily life, Integrated into existing tech, Reminders as leaving the house, Wearable | Whether or not the user will need to have door sensors installed, affects where the sensors are installed and how they alert the user to specific problems |

Table 4-4: Routines of person with dementia and caregivers life affecting their use of technology.

The final theme that emerged from the analysis was the potential function of a designed device for people who were out and about (see Table 4-5). The participants felt that any device would need to ensure it was carried and not forgotten. They wanted a device that did not stigmatise them when they used it which echoed points in the discussion around discreetness from the scoping work. The prompts that were selected around this theme, the i-Pod and PDA, made the participants more open to the idea of a technological intervention. In contrast, the aesthetics of the safety and social alarm prompts, the fall alarm and tracking bracelet, upset the participants and were considered examples of designs that had to be avoided.

| Device Feature | Examples | Impact |
|----------------------------------|---|--|
| Self Help | Being able to re-orientate oneself, reminder of the task being undertaken or map showing location | The participants wanted a device that could help them to help themselves in the first instance. This tied back to their normal approach of attempting to orient themselves first when lost or confused |
| Talking to Someone | Help from a caregiver, help from a third party | Participants wanted the a solution that would help them do this if they failed to re-orient themselves on their own |
| Panic Button | Send out an alert to bring help | A 'panic button' feature was discussed at this stage but participants did not feel it was more important that the device have the ability to let them help themselves or talk to someone else |
| Device Evolution | Progression in features available, shift in emphasis on devices features | The features available on the device as presented, the plug ins left for future evolution of the device, users shift in perception of device over time |
| Attitude Towards Possible Stigma | Not a concern for the individual, Device they can hide, Device that is disguised | Affects the design and size of the device, may be user wants a device that looks like a mobile phone or may want a small concealable device |

Table 4-5: Aspects of design of mobile devices for people with dementia.

One area that was not discussed was the ethics of tracking. In groups where some participants had previously expressed concerns about this issue, they set aside the issues they had and did not talk about ethical issues or concerns over family having access to private information. The absence of this is expanded on further in the discussion section 4.4.4. During this stage one group was particularly engaged with the ideas being developed, (see AS3 – Table 4-1) and they were asked to move forward into the next stage of work.

4.3.4 **Personally Tailored Design**

The personally tailored design process takes the exploratory work as a starting point for tailored design meetings and asks questions of the participants about their experiences and the devices that they would want to use to help them carry on walking safely. Originally, the project had intended to work with individual people with dementia through the tailored design however, with one group being so enthusiastic, meetings became group sessions rather than being conducted as interviews with individuals.

During this stage several meetings were conducted with the participants to elicit feedback on the design work. Each meeting included the consistent point of contact familiar to the group and another member of the project team. The meetings always began with a recap of the previous design work and then went into detail on the progress of the project. These sessions were recorded and transcribed but subjected to a more cursory analysis as the design requirements were made more explicit by the participants.

Over the course of these meetings the relationship between the consistent point of contact and the participants became relaxed and amicable. Participants talked about more personal issues in the meetings and said that they looked forward to the meetings because they were eager to find out how the work had progressed since the last meeting. Because of external constraints on the project not all the features envisioned in these meetings made it into the final prototype but careful management of the participants expectations, combined with usually having some sort of designed artefact such as storyboards to show the participants, meant that they remained happy with the process and engaged with it.

Meeting One – future workshops and routine

In the first tailored design meeting the consistent point of contact introduced an interaction designer working as part of the design team to Alice and John. The designer presented Alice and John with several sketches of different design concept that addressed various issues that had emerged in previous sessions. The participants were quizzed about their routine leaving the house because of how important it was found to be in participants' lives in general and for remembering to carry things with them when out and about.

The design John liked was one which focused on the activity of running, a device that could be worn in shoes, on the waist band, on the upper arm or on the wrist with a reference point for the aesthetic

being the iPod-nano (see Figure 4-1) presented to them in the design workshops. The device would relay John's location to his wife and would include a button to press to raise an alarm as well as giving feedback on the run (time, distance, etc.). When asked about the routine around leaving for a run John said he left via one specific door when he went for a run and typically carried a watch with him but there was not a particular time he would go running. The design team considered how to ensure the device would be carried and not forgotten based around this routine. The device for Mary was simpler because she cared little about aesthetic, she simply wanted a device that would be attached to John's and let her know if he was in trouble. The team envisioned that a device set in the home would give implicit feedback to Mary. Suggestions included a picture frame that changed colour or a statue that was motorised to alter posture depending on John's movements [64,95,131]. However, Mary disliked this idea and was in favour of a more direct source of information. The participants were often very unreceptive to the designers more "creative" (in a non-traditional sense) ideas when discussing tracking and this phenomenon is discussed in section 4.4.

Because Alice lived alone and had no one to report her location to, she was presented with a design for a mobile device that would remind her about everyday tasks whilst she was out. Alice would record a list onto the device in the house at her recharging point and these reminders (possibly location based using GPS technology to select appropriate suggestions to give her) would help her through the day. Recharging the device could be handled at the same base station in the house as recording. The intention was to only have a playback feature on the mobile device that would help the user to operate the device even when confused and not have to worry about recording over the current device content whilst out. This fitted with the routine already in place as Alice used a notebook to remember her to-do list and wrote it in the house before leaving and did not alter it when out of the house. Alice was concerned about stigma the device might elicit and asked that the device be discreet. The team asked Alice about her routine on leaving the house in an attempt to ensure that the base station be integrated into it but struggled to elicit one.

Meeting Two – storyboarding

To gather more insight into Alice and John's routines, the consistent point of contact and the interaction designer presented them with storyboards that showed the design teams views of their routines and asked them if they were accurate. This also served as a recap of the discussion that was held in the previous meeting. Participants were asked more probing questions in this session than previously and were asked to justify their opinions more when they disagreed with the designer's proposals. This was a sign of the increasing level of comfort felt between the attendees of the meeting. This more challenging questioning also improved the quality of the information elicited as it opened up underlying reasoning behind decisions.

The idea of creating some sort of home base for the mobile devices, based on the previous design sessions discussion around the importance of routines, were introduced at this point. These home bases could integrate into participants' routines, serve as recharging points for their mobile devices and act as reminders to recharge the devices by appearing unattractive without the devices in place.

John's home base was envisioned as being a unit that gave him feedback after a run and Alice's as a digital photo frame that switched on when her device was plugged in that would also allow her to record her to-do list for the day.

The storyboards revealed that, although there was a routine associated with leaving the house, John had no particular routes he took when running and did not go at particular times. The storyboard also explored John's return to the house and this revealed some routines around changing and showering. His wife was asked about what she did when John was out and where she might be. Mary said that she was often out of the house but carried a mobile phone with her and having that phone take alerts from John's device would be convenient.

Alice had less routine associated with leaving the house, she was presented with several branching scenarios via storyboard but thought that all of them were possible and more. However, the team noticed the walking stick she carried was central to all of them. At this point Alice started to express the idea that she would like to be tracked even if the person informed could not be established at this point. When her walking stick was a possible location for a device, she was strongly opposed to the idea. At first Alice could not articulate why this was but eventually she revealed it was because she had a "hatred" for the stick. Alice had hoped that her new device could be something that she was proud of to show off to her friends and placing it on her hated walking stick which had the opposite emotions associated with it was an unpleasant thought for her.

A concept that emerged at this stage for the design team was the need for some '*added value*' for the designs as a part of the process of fitting into participants' routines. Devices that were only concerned with safety were not wanted and forcing them into participants' routines was viewed as an unwelcome intrusion that constantly reminded them that they needed to be afraid of something. With the idea of added value the devices shifted in participants' perceptions to become desirable items to be welcomed into their routines and carried with pride. This insight into the emotional and experiential aspects of carrying a tracking device illustrated the value of carrying out such a close process with people with dementia and is discussed in depth in section 4.4.

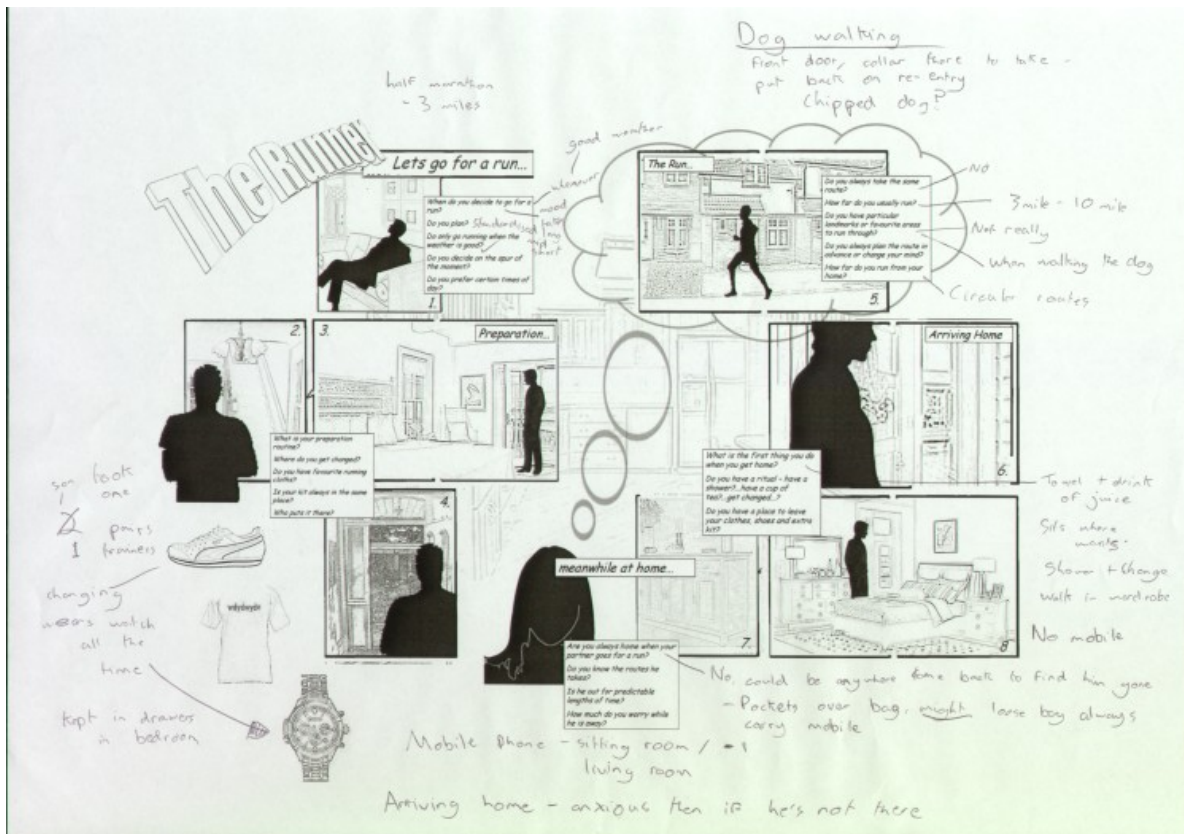


Figure 4-2: Sample storyboard for John and Mary constructed by designers with thought bubbles and speech bubbles completed by participants

Meeting Three – initial prototype presentation and feedback

This meeting revolved around the evaluation of initial prototype devices along with brief *Paper Prototyping* activities for the caregivers interface to the system for Mary. At this stage the consistent point of contact introduced the participants to one of the team’s software developers that were in charge of developing a user-interface for the participants. Until this point, the design team had struggled to create a simple, disguised interface to a reminding device that Alice could use, particularly given the size of the tracking device. The solution was making a notebook and placing the tracking technology within it. Alice was very pleased with this idea and had pictures of the notebook she currently used taken as a reference point for the design aesthetic.

Interface prototyping for the mobile phone was performed with Mary to design her interactions with the phone based alerts. Mary thought a phone call would be best way to receive alerts if the help button had been pressed. When she was within the house, the design team proposed that a channel was built into the TV’s digital set top box to track John having found in the previous session that the TV was constantly turned on to give some background noise in the house at all times. Alice and John were asked at this stage about feedback from their mobile devices if an alarm was to be pressed but, without a screen to explicitly tell them what was happening, this was very difficult. This aspect of the design process was also difficult because there were no strong opinions expressed about the feedback despite spending a lot of time discussing it. This is discussed in more depth in section 4.4.

Meeting Four – prototypes and trial runs

The final prototypes that were produced for the participants constantly report their position to a central server that can be interrogated online through a mobile interface. Both devices also have a panic button that can be pressed to send a phone call to the associated mobile phone that, if not acknowledged, can be propagated to other devices (see Figure 4-2). The aesthetic of John's prototype is drawn from the idea of a runner's arm-band. Alice's device is built into a leather bound notebook with her initials embossed on the front of it. The electronic device dimensions are 11cm x 5.5cm x 3.6cm and the cases slightly increases this. The final prototypes did not have home bases to be docked to, recharging was done by plugging in a cable but there was no feedback from this prototype on the time it took John to complete his runs.

The consistent point of contact and the design team's software developer presented these devices to the participants. Both John and Mary criticised the size of their prototype, John was concerned that the device could slip down his arm while running and he thought the device would be improved if buttons and lights were located along the top of the device and so would be easier to see when worn on the arm. He noted that the strapping was not clear enough as it did not clearly mark the hole through which the arm band was threaded and suggested it would be useful for rainy days if he could have a belt strap on the device so he could wear it underneath a raincoat. However, John liked the device and agreed to carry it on a test run. He reported that the device was more comfortable than he thought it would be and he felt happy wearing it.

The size of the device was more of a concern for Alice as it would not fit it into the bag she carried because of the size of the circuit board embedded in it. Alice felt that having her address and telephone number printed inside the book cover was a "neat touch" and would help her re-orient herself if she became confused. Alice was concerned about power indicators saying that a device needed to reassure her it was switched on, that it had sent a signal if she needed help and that help was on the way; ideally this would be done via a speaker built into it. These thoughts only emerged when Alice had the device in front of her despite the previous session focusing on these issues. This reinforces the usefulness of having a physical device present to focus participants thinking. Despite these issues, she liked the concept and its style feeling that if the device were smaller she would enjoy carrying one.



Figure 4-3: From left to right John's armband tracker, The Driver's notebook tracker, (bottom) The Wife's mobile interface and (top) the internal electronics of the device

4.3.5 Reflecting on the Prototypes

The final devices are not necessarily appropriate to a wider audience of people with dementia but the specific principles or ideas they were designed to realise are relevant to a wider group [73]. The devices are tailored to individuals and features such as mimicking the aesthetic of a runner's mp3 player in an armband were not intended to be generalised to the wider population of people with dementia. However, the final designs do illustrate some key features for devices that attempt to promote safe walking or mobile devices for people with dementia that can be applied to the wider population of people with dementia.

GPS and Alarm – critical backups

Both the devices had a GPS tracking system and a GSM unit that could be used to call for help if the carrier becomes lost. Despite previous works findings suggesting people with dementia are not concerned about their safety this backup needed to be in place before the participants would consider using the devices seriously. Although design sessions appeared to reveal a need for a device that went beyond simply being a tracking device (considered something that made the participants "feel disabled"), there was a lack of willingness to engage with less familiar design concepts without the tracking/alarm safety net in place. For example, Mary would not consider having a device that gave implicit feedback about John and Alice asked for the device she had to have a tracking unit built into it in the later stages of design process. This may demonstrate the amount of fear associated with

wandering or becoming lost and show that it is a problem people with dementia are more fearful of than others. Alternatively, it may be that one the people with dementia started to engage with an idea more they became more worried about it.

Routine – adopting and remembering to carry a device

How a device integrates into the existing routine of a person with dementia is important when they are deciding whether or not to use a device. The participants used routine as a way to cope with their increasing cognitive impairment, so are sensitive to anything new that interferes with it. They felt that integrating into routine, as opposed to forcing participants to create a new one, was important in ensuring a device was carried with and remembering to charge a device when they got home. The idea of a home base for the devices to charge at arose from aiming to embed the devices into routine. This highlights the need for *holistic* technology for people with dementia, technology which is designed in every aspect and which is evaluated against a person's existing routine. When working with people with dementia, details like ensuring that a device is charged seriously affect its acceptance and utility.

Added value – moving beyond safety considerations

The participants felt that the designs they created should be more than just a tracking and locating device, though the exact nature of this *added value* depended on the participant. This stems from the desire to not be constantly reminded of their problems, they do not want to carry a device with them that reminds them they have dementia and that something may go wrong even when performing simple everyday activities. Participants' fears of something going wrong (wandering) is so great that they feel the need for a safety net to be in place but that safety net must not constantly remind the participant of the issue it is designed to alleviate.

Discreet, disguised or aesthetic – avoiding stigmatisation

The participants wanted a device small enough to hide out of sight or that looks like something else. They did not want the device to identify them as having dementia. This is understandable as people do not always treat those with mental illnesses in the same way they treat those without it [91,123,134]. However, when the devices were shown to them and were considered aesthetically pleasing this attitude shifted, the participants became happy to talk about the devices and wanted to show them off to their friends. This emergence of this sentiment can be seen when it was suggested that Alice have her device built into her walking stick and she resisted the idea in part because that would mean she would not value her device as much. When designing technology for people with dementia considering how this will be addressed will impact on whether a device is adopted in the first place and what a person experiences when using the device.

4.4 REFLECTIONS ON KITE AS A DESIGN METHOD

The results of applying KITE are inevitably a function of the participants within the process and the creativity of the designers. However, the conversations that were facilitated by KITE led to new and interesting insights into the safe walking that would have been unlikely to arise using a more

traditional design approach. The relationship that formed between the designers and the participants, whilst also dependant on the individuals involved, is also a marker of the success of the process and is reflected upon.

4.4.1 Recruitment

Recruitment was a relatively simple process and this is attributed to the presence of domain experts in the project team with links to existing organisations who acted as facilitators for recruitment. Without these links, the drop out of two groups because of scheduling issues in the first stage would have been more of a problem. In this project, the domain experts were able to solve this problem by approaching other contacts. The participants of pre-existing groups that were worked with often helped each other to recount stories but, for the caregivers without cognitive impairment, this was not as important. These older people were very capable of recounting stories without the assistance of others but still engaged in co-questioning. This suggests recruiting pre-existing groups for people without cognitive impairment may be unnecessary especially when other research notes that doing so can stifle discussion sometimes [63,82,130].

The process of identifying participants and ensuring that they are suited to participating was complicated by the lack of precise evaluation of severity of their dementia. However, evaluations using a technique like the mini mental state exam¹¹ would take significantly more effort and doing so complicates the ethical procedure for conducting the research as this would be considered a medical examination. The process was slowed by the layers of complexity added by going through mediators to access participants and trying to arrange to meet with groups but both of these approaches were worthwhile because of the rich narratives gathered from working with the pre-existing groups in familiar locations.

4.4.2 Meetings and Techniques

The problems which were encountered in the initial scoping work would prove to be recurring features of the process and mirrored some detailed in previous literature [34,97,119,120]. Many individuals were prone to discussing a friends problems rather than their own believing that they were still “doing OK” regardless of the severity of the problems they faced. This would frequently come to a head after discussing hypothetical features for devices in the exploratory design workshops and having participants state they would never use the device that had been discussed although their friend, who did have some problems, might. This was not a feature of all of the groups though and it was most prevalent in the groups conducted with the dementia care partnership participants who were new to

¹¹ The Mini Mental State Exam (MMSE) is a standard measure of cognitive impairment used in the UK. It involves asking thirty questions and ranking a participant based on the number they get right. Administering the test takes approximately 20 minutes and it is considered to be a medical examination which drastically alters the ethical approval process.

the project. However, this shows that the topics that were discussing were sensitive enough to be withheld from an unknown interviewer and demonstrates the importance of getting to know the participants and establishing a common frame of reference before asking for any significant personal disclosure.

A recurring theme throughout discussion with people with dementia was the repetition of information by individuals either across design sessions or within a single session. At times this was dealt with by letting them talk but at other times other individuals within the group would point out to them that they had already told the story. When an individual would give their narrative but forget it part way through another individual from the group who was familiar with the story often finished it for them. This meant that conversation did not proceed quickly but, by accepting this, it was possible to still evoke rich accounts from the participants with dementia.

Examining the transcripts showed the people with dementia tended to make much shorter utterances than their caregivers. Even in groups where the caregivers were only there to support the person with dementia they would often dominate the conversation by speaking much more than the participants with dementia. This was challenging because interrupting them could be seen as rude, and would disrupt the otherwise friendly atmosphere in the group sessions. The solution used was to allow the caregiver to talk but then question the person with dementia they were speaking for on the topic to see if they agreed.

Caregivers tended to give significantly different accounts of what they felt was needed from the design process and they tended to look for solutions to the safety problem of wandering rather than engage with the idea of promoting safe walking. When considered in combination with their ability to dominate conversations by talking much more than the participants with dementia this demonstrates how easy it is to design for the caregiver rather than the person with dementia. In the future, conducting sessions solely with people with dementia may address this issue although it raises its own set of questions about ethics.

Because of the combination of some participants controlling conversation too much, some frequently repeating themselves, and others tending to go off topic, the meetings sometimes lacked structure. This meant that important issues were under addressed sometimes and that important design decisions were neglected. This also had a knock on effect in requiring more rigorous analysis (see 0.). The use of prompts to provoke discussion around design concepts in the design workshops had mixed results, participants often extrapolated from the devices to construct scenarios where they may be useful or aspects of their design which would limit their utility to them. The reactions to some of the devices were surprising, for example, the reaction to the iPod-nano which participants liked a lot. Many participants were charmed by the small size and modern design. This forced the design team to reconsider what would be an aesthetic device for the older person and acknowledge that individuals would have different opinions. The personally tailored design sessions also showed the need for the people with dementia and the older caregivers to have access to tangible artefacts to critique, whether these are prompts as seen in early exploratory work or design artefacts in the tailored design

work such as illustrations, in order to get the most from them. For example, the issues around eliciting their thoughts on the alarm raising process were, to some extent, resolved when the prototype devices were put in front of them. The rapid development of some sort of design was very important and low fidelity methods for feeding designs back to participants proved extremely valuable.

When discussing intangible issues of design, such as the ethics and privacy issues of tracking, participants were much less vocal. The participants struggled to envision these issues and the design team could not, for example, have a physical prompt for ethics. However, the rare informative discussions around these issues often started based on the tangible prompts. The problem was realising which of the prompts would provoke discussion around more intangible or conceptual aspects of the design and the direction in which the participants would take discussion based on these prompts. The next design process will consider how to better utilise this phenomenon.

The empathic relationship established with the people with dementia and their carers also changed the nature of the relationship between the consistent point of contact and other members of the design and development team. The consistent point of contact found himself becoming an advocate for the participants at design team meetings where their opinions might otherwise have been marginalised. Furthermore, as a consequence of members of the design and development team meeting participants – an event that was greatly facilitated by having the consistent point of contact to make introductions at group meetings – the design team members often expressed surprised at the opinions of the people with dementia and radically re-evaluated their opinions on different aspects of the design.

4.4.3 The Analysis Process

The analysis of participatory design meetings was valuable as it allowed the design team several insights into the thinking of the participants and reflecting on the participants' statement allowed those present to clarify in their own minds what had been said. However, the processes for generating requirements could also be problematic as they run counter to the idea of participatory work as ideally design decisions should be shared between designers and participants. To compensate for this, in the process the final decisions were fed back to participants who could critique or even veto them. A second issue is the lack of scalability in the approach. The team's developers and designers were able to be introduced to the participants in this project by the consistent point of contact and, through interacting with them, were able to gather a sense of the design domain and sympathy or the participants. In larger development settings this is not a practical approach and raises questions around how information from the participatory design process can be fed into the development of products whilst preserving the authentic voice of the participants.

4.4.4 Framework and Principles

KITE engaged the people with dementia in the design process and they viewed the activities as enjoyable, they looked forward to designs sessions and took pleasure from seeing their design ideas

being realised. Setting the right atmosphere in the meetings was important and being able to talk honestly and openly with participants in the tailored design and critique their ideas as they came forward with them as they criticised the designer's ideas lead to the creation of new knowledge for both parties about the design domain. The best example of this was in *Meeting Two – storyboarding* where Alice, the consistent point of contact and the designer involved in this session debate the use of the walking stick as a site for a tracking device. This process made Alice to re-examine her own attitude towards the walking stick and the design idea and articulate them more clearly.

Meetings with the rest of the project team took place weekly as opposed to the once-every-three-week meetings with the participants and there was a danger that the participants' contributions would be drowned out by the volume of input that others had into the design process. This did not happen as the consistent point of contact became the advocate for the participants in the design process. The consistent point of contact and designers who had been introduced to the participants frequently argued for the participants with dementia in these meetings. This led to an unusual dynamic to the work with the consistent point of contact almost becoming a part of the group of participants with dementia during the tailored design process.

Following the design framework results in complexity, as can be seen in the ways that design concepts change over time to become more and more nuanced. For example, a simple idea such as having a device which fits into the existing routine of a person with dementia became an extensive exploration of their day-to-day life and their attitudes towards the problem domain and technology. Whilst this richness of information is useful the framework is time consuming with multiple meetings taking place over several months requiring extensive planning and analysis work. The time consuming nature of the work is one of the major concerns with this process. This is due in part to the amount of time spent retreading old ground in design meetings with participants and in part to not being willing to try to cover more material in a single session because of the individuals cognitive impairments.

4.5 CONCLUSIONS

Safe walking (and wandering) is a particularly interesting challenge for KITE. The current crop of wandering interventions are not suitable for promoting safe walking as they focus on the more safety oriented fears that surround wandering. Following the design process through recruitment, exploratory scoping, design workshops and personal tailored design exercises showed that, whilst there are practical issues that arise when applying it, the design framework can work and leads to novel and useful design insights. The relationship between the people with dementia, the carer, and the consistent point of contact became closer over time, leading to a change in the nature of discussion. Meeting became more informal, and there was more back and forth between participants and designers as both "sides" became more willing to critique ideas from the other. Reflecting on the prototypes that were produced reveals important areas to consider in order creating successful designs in the domain of safe walking.

Reflecting on the process reveals several issues that arose in the design process. The struggle getting participants to discuss intangible aspects of design, and the fact that the physical prompts unexpectedly helped with this, raises a question for further work of how to address situations where participants are asked to consider the implications of designs on conceptual levels. Another concern is the amount of time it took to complete the process and how time intensive the work. This was at least in part due to the cognitive impairments of several of the participants but also due to the time consuming nature of the process. Finally, the process of analysis and presentation of experience and need is challenging when the people acting on the design cannot engage with the users themselves, as shown in the debates had within the design team between members who had and had not engaged with the participants. The next chapter will seek to address all these issues with a new approach for working with older adults without cognitive impairment that focuses on rapid engagement with users in more structured design environments whilst attempting to keep a respect for the everyday experiences of the participants.

CHAPTER 5: THE OASIS DESIGN APPROACH

The KITE participatory design process created a digital technology to promote safe walking and the process elicited novel insights into the domain by developing a relationship between the designers and participants. However, reflecting on the process also highlighted a number of issues: the process's in-depth analysis of transcripts undermined the participatory nature of the process by inadvertently excluding the participants from directly making design decisions; the meetings lacked structure and could break down into general discussion, meaning not all topics meriting discussion were covered; the process produced results that were challenging to convey to other members of the project team; and the process did not support the older people when they tried to discuss intangible design issues. Of these issues the most troubling is disempowerment of the participants in the process through the way the design output was analysed. Analysing the output from meetings conducted following the first design process diluted the voice of the people with dementia in the design process and took decisions on their behalf. In addition, this process took more than nine months to complete from start to finish.

Therefore, this chapter presents a modified participatory design framework, applied and refined as part of the European Union funded OASIS project, which keeps the close contact between participants and designers whilst addressing these issues. The approach is specifically tailored for working with older people (rather than also engaging with people with dementia) to evaluate how well the techniques gleaned from that domain carry over into designing with older people. By working with older people who do not have dementia, it will be possible to shorten the time needed to recruit participants, reduce the number of meetings that will be required to work with those participants and increase the number of issues discussed in each meeting whilst reducing the complexity of the ethical approval process.

In addition to the changes made because of the experiences applying the KITE method to the domain of safe walking, modifications have been made to the OASIS method in light of design work conducted in the problem domains of healthy eating, transportation and personal security. The next two chapters document these experiences applying the design process and the changes made in light of them. These problem domains are again situated in day-to-day life and, as with safe walking, open up a wide space in which to explore a variety of solutions to allow the participants as much scope as possible to be creative.

This chapter will explore the impact of the decision to work with people without dementia in the new process and examine the specific issues that confronted the original design framework and their underlying causes. The chapter will then explain the potential to use a more focused analysis, interlacing quotes from participants with requirements to better allow their voices to be presented to the other team members developing the system. Discussion follows this on the topic of the use of video to present a prompt that can help people envision intangible issues that might arise for them when using future technologies. This chapter presents specific participatory design techniques that can introduce structure in design meetings and move away from the need for in depth analysis of design session transcripts and outline a design framework that incorporates these new techniques. This process has two meetings rather than the multiple ones used previously. These consist of an exploratory meeting where invisible design and scenario work occur and a low-fidelity prototyping meeting.

5.1 RESPONDING TO KITE

The previous design framework used engagement with older people to compensate for the differences in life experience between them and designers [78]. The relationship that formed supported the elicitation of the older people's narratives concerning the problem domain. Showing respect for the participants by treating them as the experts in the problem domain was central to this process. Trying to understand the domain prior to engaging in design through exploratory work and establishing a common frame of reference for the work was also important. The aim to engage with the target population and the overall structure of the process population remain unchanged in the new design framework.

However, whilst the design work with people with dementia allowed numerous insights into their everyday felt-lives, the process took a team of designers nine months to complete due to the time consuming recruitment process and the number of design meetings that needed to be conducted. The recruitment in the OASIS approach does not need to focus on finding pre-existing groups as people without cognitive impairment are able to recount their experiences without relying on other members of their group to help them and each individual design session will be able to cover more topics when working with individuals who are not cognitively impaired, so there will be fewer sessions to run. In addition, the ethics process will also be shorter because it will not need to account for working with people with medical conditions.

5.1.1 Analysis and Presentation Process

The process in Chapter Three assumed that the consistent point of contact, the person who facilitated the design sessions, was also a central part of the team developing the interventions. This point of contact performed the analysis of the meetings and presented the findings to the rest of the design team. Members of the design team also intermittently took part in the design sessions with the participants to gain a better sense of their experiences and needs. Performing analysis meant participants did not have to directly articulate their requirements to the designers as the process

allowed the discovery of themes that were not made explicit during the meetings. This reduced the demand placed on the people with dementia in the process as they did not have to clearly articulate themselves, if it can be assumed that the analysis correctly interpreted their intentions. The lack of structure in the KITE design process also meant that issues that the design team wanted to address were not always discussed. In these cases, the analysis process provided some guidance on the issues that were not talked about.

However, performing an analysis of the output of a participatory design process is problematic because it runs counter to the ethos of participatory design and dilutes the voice of the participants. The analysis can even be seen to disempower the participants with dementia, something that had been identified as a challenge for design work with people with dementia that the process had aimed to avoid. By drawing out narratives from what the users said, and adding a layer of interpretation, the process risks: reducing the participants input; misinterpreting the participants; creating a divide in the design process between designer and participant that reduces the quality of the connection between them and; preventing the participant from directly influencing the design. The KITE process also requires that the people engaging with participants engage in the rest of the design process. The process may not be as applicable in other environments as it could be due to of its time intensive nature and because it does not produce a conventional set of requirements.

Typically, participatory design approaches construct requirements explicitly in the sessions through discussions between participants and designers. The participants in the OASIS design approach are older adults who are not cognitively impaired so they can more clearly articulate themselves than people with dementia. Therefore, the new design process will ask the participants more direct questions about the design domain. As in the KITE method, the coding and thematic analysis process will be used to reveal issues or narratives that are relevant to the design process but the questions or areas that are coded for will more closely relate to the questions asked in the design meetings. This will also involve a change in the techniques used to structure the design meetings with participants, who will now construct requirements with the designers in the meetings. This will produce requirements for the developers that will be formalised through linking interesting quotes that can embody the requirements with the requirements document. The process also preserves a link from the requirements to the authentic voice of the users. This will help maintain the sense of the empathic relationship and sensitise those designing the technologies to the needs of the target population.

5.1.2 Lack of Structure in Design Sessions

The previous design sessions focused on the quality of the relationship between the designers and the people with dementia to allow the designers to gain a sense of the experiences of the participants in their day-to-day activities and to create designs for these experiences. This sensitivity led to an understanding of the importance of routine in the participants' lives and their desire for a designed object that they could be proud of rather than something that they were ashamed to carry or that marked them out as different.

However, this relationship was built by keeping the structure of the design meetings relatively open to allow free back-and-forth conversation between the participants and designers and meetings frequently turned into informal “chats” rather than design sessions. This lack of structure resulted in problems as designers were not always able to explicitly address design questions. This was also a contributing factor to the need for conducting an analysis of the design process.

To help overcome this, two new techniques are integrated into the process, scenario work based on the Task Analysis Framework [36,37] and a PICTIVE session [106,107]. These techniques produce much more explicit requirements without the need for in-depth analysis. Both of these processes move towards engaging the participant in analysing what they say by re-presenting their statements to them. For example, in scenario work participants are asked to critique their ideas against the scenarios they devise. This also links to the idea of focusing a group’s attention with having artefacts or through the act of note taking.

Scenarios in Design

Scenario work is a common feature of participatory design and scenarios are used in a wide range of participatory design techniques such as *future workshops* [9], the *design collaboratorium* [31] and *participatory analysis* [40]. Participants construct scenarios about hypothetical individuals and then critique their design ideas by envisioning how they might fit into the scenarios they created. Using scenario work taps into the phenomenon observed in Chapter Four of people being happier to talk about other people or “a friend” when designing an artefact than they are to talk about themselves. The approach used in this framework takes *task analysis* and the *task-artefact framework (TAF)* [36] as a starting point for structuring meetings but the approach is heavily modified in light of analysis of the previous design work and because of concerns that people do not view everyday activities as tasks and because in light of experiences applying the approach with older people as documented in Chapters Five and Six.

The TAF focuses on early engagement with potential users of future devices in participatory design activities. Because of the early nature of the engagement, the process is sometimes referred to as participatory analysis (in contrast to the more typical approach to design of digital technologies where this stage would be termed requirements analysis). Because the TAF is intended to be used at the early stage of design work, before any physical item is created, a lot of consideration was given as to how participants in the process could be supported in envisioning intangible concepts. This is what gave rise to the use of task-analysis in TAF (see Figure 5-1).

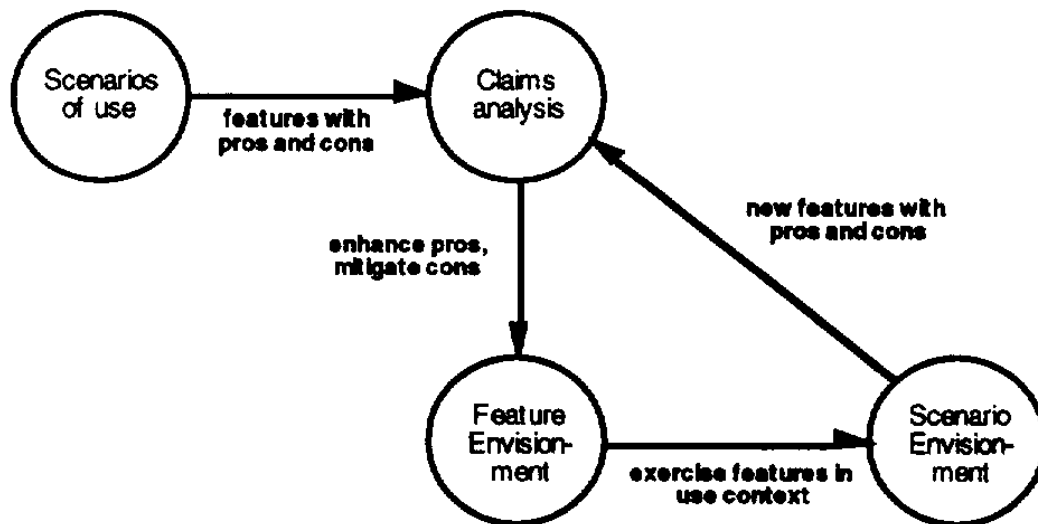


Figure 5-1: Task analysis as performed in the TAF (taken from [40])

The design meetings begin with facilitators posing current scenarios of use of a specific technology and refining these in discussion with the participants. These scenarios are then analysed to extract *claims*. A *claim* in this context is said to be an enabling or disabling aspect of either the current technology being analysed or the environment that it is used within; a trivial example of a claim might be that a specific page for data entry in a purchase order management tool is disabling because it times out after a certain amount of time left open and orders take longer than this to complete sometimes. These enabling and disabling *claims* are then fed into a process of feature envisioning in which participants try to envision new features that could help them in their tasks. To go back to the previous example, this might be the participants envisioning a new order page in which purchases do not time out. Finally, these hypothetical features are critiqued by being placed into future scenarios and evaluated within them to see if they are useful or not. To continue the example, the participants might find that their new, non-timing out feature would not work as well as they initially thought because each purchase order is stored on a central server that creates a unique id for each entry that is tied to the time it is created and becomes invalid if not filled within a certain time limit.

The creators of this approach argue that they are essentially formalising a process that most people intuitively perform when they do design work. They suggest that the benefit of the formal approach is that it makes each stage of the process visible to other members of the group and allows them to mutually inspire each other as they see solutions to issues that their compatriots do not. However, this process is not suitable for use with older people in exploring every-day, lived experience as it focuses on specific tasks and takes as a starting point for discussion existing digital technology solutions. In addition, the work assumes some pre-existing scenarios are constructed and only need to be refined in the design meeting.

As such, the approach to using scenarios in design that is detailed in this chapter modifies the TAF in several critical ways. The process, as presented to our participants, is couched in very different

language with talk of *claims* being replaced with talk of reasons for things being the way they are, scenarios are now couched as good and bad cases and tasks are referred to as experiences within specific domains. The process of constructing scenarios of use is broken down into an information gathering stage, a prompt viewing stage (more on this in the next section) and then a scenario creation phase. As previous literature and experiences applying the KITE process have highlighted, older participants can struggle to envision future technologies so this process is also supported through the creation of the prompt detailed in the next section. Finally, the idea of *scenarios* is tied heavily to the creation of characters in the approach that is outlined below. This is again done to suggest that

The approach is described in detail in section 5.2.3. The exploratory work of the previous design framework is compressed into this single session with participants. The output of the first part of these sessions will be some narrative about the individual's personal experiences in the problem domain. The second part is a set of requirements for a variety of interventions for a pair of hypothetical characters in the design domain. This more formalised output is closer to the normal requirements that designers expect and requires a less interpretative analysis approach, described in section 5.1.1.

Invisible Design to Assist in Envisioning the Intangible

The application of the KITE process showed that both people with dementia and the older caregivers struggled when imagining future technologies or abstract concepts, which concurs with previous works findings [97]. In previous design work, the times that participants were most vocal discussing abstract concepts was when their discussions were triggered by some sort of prompt in the design workshops. However, the prompt artefacts were not always interpreted in the ways anticipated by the designers. For example, section 4.3.3 described how the iPod-nano presented to the participants was well received even though the design team anticipated participants would dislike its modern aesthetic.

The OASIS design approach will try to engage the user in discussing intangible issues through the medium of a tangible prompt. However, this time the framework will use a video prompting technique based upon the *invisible design* concept [27]. In this approach, the participant is presented with a video that illustrates a scenario in which actors have and discuss a fictitious future intervention for the problem domain. Previous work has attempted to make use of film to present design concepts to the user but presumes that the designers have already decided what to build and want feedback on their ideas [15,92,93].

The *invisible design* format of video or story does not constrain or direct users towards specific features or aesthetics for a device because *invisible design* never shows the device being used or makes any details of it explicit (hence the term invisible). By hiding the technology from the viewer, the *invisible design* technique attempts to give primacy to the quality of experience portrayed in the videos. All that the viewers see relates to experiences with the technology and specific features are only hinted at.

The approach takes some effort but can be of great use when working with older users because it leverages a convention they are familiar with (film and storytelling) in order to present them with a scenario that they will not be familiar with. The older people deal well in criticising physical artefacts and they appear to respond to the device discussed in the video as if it were real more easily than they can imagine a hypothetical device, with the additional benefit of not getting caught up in criticising the particulars of a device as previously observed. Another benefit is that participants use the depiction of intangible issues in the video as starting points for their own discussions about intangible issues that relate to the design domain. For example, in the nutrition study the brief depiction of a future device being dismissed by one of the characters because it was annoying by one of the characters lead to much discussion around the ways to make suggestions and how devices must not harass users. Participants can also project their own reactions onto the characters and give voice to them through discussion of how they believed the characters felt.

As noted previously, one issue with the TAF approach is its focus on technological solutions rather than everyday experiences. The *invisible design* approaches ability to shift focus onto experience was therefore viewed as an opportunity to, in part, counteract this. While this approach seemed to work in its first application, the construction of scenarios was still somewhat stilted and so the *invisible design* video created for the transportation groups (Chapter Seven) was reworked to portray two characters who could act as starting points for discussing our best and worst case scenarios i.e. one character corresponded to a best case situation and experienced no problems in the area of investigation but the other character struggled with numerous issues or challenges. The participants would then construct their scenarios and claims around these characters drawing upon their own personal experiences to expand upon the starting points presented in the video.

At the same time these videos take care to not present one point of view as the correct point of view. The videos that were produced often centred on a pair of characters and the interactions between them never showed a definitive right or wrong answer to the questions they raised. Closure in the videos came from the personal interactions between the character and the future device. Achieving this deliberate ambiguity requires thought and planning and design teams may need to recruit outside assistance to perform this work. By carefully guiding the script and direction of the video, the designers can present the users with intangible issues and elicit a wide variety of responses.

Low Fidelity Prototyping

The KITE process introduced the concept of *Paper Prototyping* and section 4.3.4 described the experiences using the technique in a design session with a cognitively able caregiver. As previously stated, the benefits of this sort of low fidelity prototyping include a low barrier for entry for the participants meaning that most people can readily be involved in the process, democratising the design environment as the tools and materials being used are accessible to everyone and being an intuitive medium for developing screen based user interfaces [106,107]. Including a *Paper Prototyping* session will place more emphasis on the user interface development in the new process and may also

encourage participants to discuss how the different aspects of the design relate to their own impairments

The specific approach that will be implemented in the workshop is inspired by *PICTIVE* [106]. *PICTIVE* is a low fidelity prototyping approach that involves filming a workshop with participants using building materials such as paper and pens to construct prototypes. The use of everyday tools democratises the process of inquiry in group work as participants have the opportunity to contribute on equal footing with designers. The use of very basic creative material is also inspired by observations by Massimi et al. that groups of older people become more engaged in focus groups where there is a hands-on activity to be performed [97]. The act of recording the session allows designers to see how temporal relationships are created between different elements of the interface and, when participants present their work, serves as a focus point where all of the participants' opinions can be elicited.

5.2 THE OASIS DESIGN FRAMEWORK

This section outlines a shorter, more focused framework to guide design work. The framework is still composed of the same components that were outlined in Chapter Five. An overview of the process can be seen in Figure 5-2. Design conduct examines how the designer should conduct themselves when engaging with participants and includes guidance for how they should talk with participants to set the right atmosphere within sessions. Stakeholder identification and recruitment explains how to identify relevant participants and how to find suitable avenues through which they can be approached. Exploratory work is done with one meeting rather than the two used in the previous work. Similarly, the design work is limited to one meeting in which the participants engage in a much more focused design task.

Initial scenario work is used to gain a sense of the design domain and the issues that the participants encounter in their day-to-day lives. Unlike the previous method this is accomplished in one rather than two sessions. The designers can create potential solutions to these issues or challenges informed by the analysis of the groups. The issues and designers' initial ideas about an intervention feed into a low fidelity design workshops conducted with the same people that took part in the exploratory session. The goal of this workshop is to validate the designer's assessment of the domain and to start gathering insights into the specific design of an intervention. Technology selection and development occurs after the scoping sessions with users allowing for a wide variety of potential solutions.

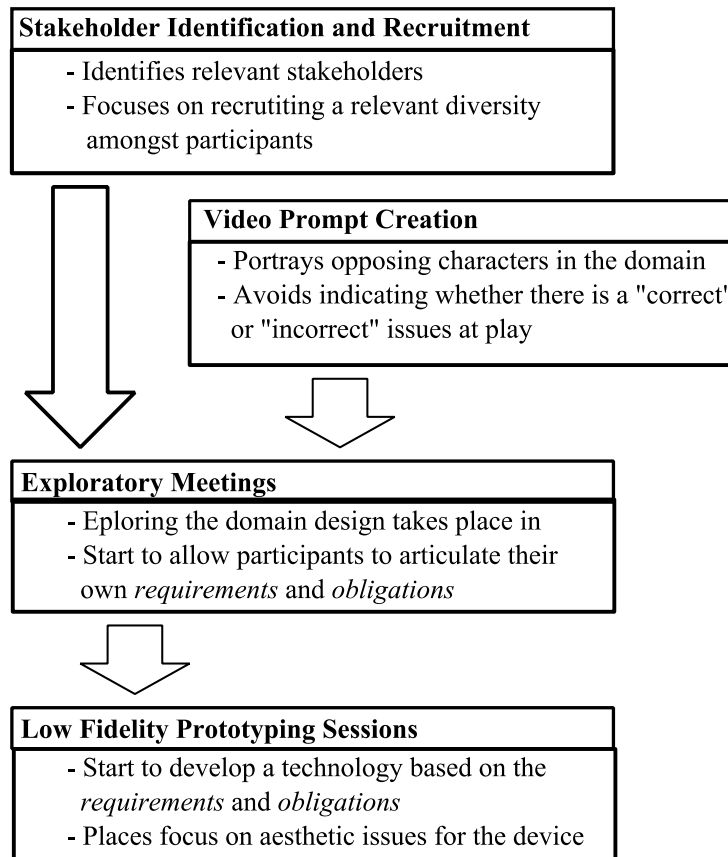


Figure 5-2: The OASIS design approach

5.2.1 Design Conduct

Following the KITE process demonstrated how important it was to develop an open, friendly atmosphere within each meeting as it has a significant impact on both the participants' willingness to contribute to each design session and to the quality of the narratives they were willing to divulge [55]. The creation of a friendly atmosphere can lead to users mutually inspiring each other as a result of the social interactions that arise through collaboration. The groups' consistent point of contact must not "drive" the activity rigidly but communicate to participants that in the early stage of design there is no "correct" answer and that all opinions are can be explored.

Previous work on the subject has also shown that group interaction, particularly amongst older people, plays an important role in determining the quality of output from a focus group process [17,56][63,126]. Older users tended to be comfortable talking amongst themselves and, when the interactions between group members was open and friendly, the confidence carried over into the design exercises with no single participant dominating the meeting. Conversely, in the work on personal security when the atmosphere was less congenial, certain members of the group tended to dominate the discussion and others became less willing to contribute. In order to foster an open relationship, participants are given five to ten minutes to chat amongst themselves before the group facilitator begins the process. This can be done by having refreshments available in a separate room or by introducing participants to each other before the session starts as they arrive. The locations in

which the design meetings are held need to be set up and the meetings moderated in a manner that is sensitive to the capabilities and preferences of older people to facilitate them in contributing to the meetings and help create the friendly, open atmosphere that will make participants eager to engage in the second meeting of the process [88].

The design exercises should be located in a building that is familiar and accessible for the participants. General deficits in sight which occur as part of the normal ageing process [71] mean that rooms in which participatory analysis exercises are conducted should be well lit. Locations should be quiet and free from distractions and high ambient noise levels. Participants should have ready access to toilet facilities which they should be made aware of at the outset. The selection of an appropriate timing and structure for activities depends on the participants and they should be made aware of the structure and timing of the meetings when they are being recruited and then reminded at the start of the meeting. Even when sessions are going well, the stated time schedule should be followed to guard against the risk participants feel pressured to participate to a greater degree or for longer than they intended.

The consistent point of contact needs to be mindful of using appropriate and accessible language when guiding discussions and providing instructions and seek to keep focus on the activity during group work. They must ensure that all of the participants are given the opportunity to contribute and be aware of the fact that many older people are not familiar with state of the art consumer technology. The consistent point of contact should also understand that there will be a large amount of discussion which is not strictly related to the subject matter. In these cases all the facilitator can do is attempt to bring the conversation back on track.

The creation of a common frame of reference for both the participants and designers remains an important part of establishing the right atmosphere in group work. This means that the participants will talk at cross purposes less often. Establishing the common frame of reference leads to the creation of a new set of jargon that helps the participants express their thoughts in the design domain, contributes to democratising the meeting and helps create a sense of community or shared purpose within the group by giving them their own 'insider' language.

5.2.2 Stakeholder Identification and Recruitment

Recruitment needs to begin well in advance of the design sessions as, although it is not labour intensive, it requires time. Beginning at least eight weeks before the design meetings is recommended and having concrete dates for the design sessions at this early stage makes it easier for older people to schedule meetings into their calendars. Based on previous experiences, the recruitment for meetings can take as little as one week but unfortunately the variability in the time it takes to arrange them is vast.

Groups should consist of between four and five participants but experience has shown that when recruiting experience has shown that it better to over recruit as older adults are prone to cancelling at

the last minute. Previous experiences and literature both suggest recruiting twenty percent more older adults than required [17] but it is possible that all participants arrive. Development teams can recruit their participants through a variety of means including contacting local charity groups for older people and local advocacy groups.

During the process documented in Chapter Four, stakeholder identification was made considerably easier by the presence of domain experts with links to relevant organisations that could act as an avenue for recruitment. As discussed previously in 2.3.2, the over 65 age group is considerably more diverse than any other single age group so identifying the position for the design work within this area is essential. The domain in which the design exercise is being conducted has a major impact on the characteristics of the participants that will most severely affect the design process. It is important to try to ensure that there is *relevant diversity* in the participants. For example, when recruiting for a transport based study a group with a range of different levels of personal mobility and differing typical means of transport was sought. The following section presents a range of factors which should be considered against the design domain to determine their relevance during recruitment.

Age and Age Variation

The over 65 age group is not a truly age homogenous group and has specific generational differences that impact on their attitudes, and previous encounters with technology, have different health problems, differ in their finances, and their views on social issues (such as privacy and gender roles). As such, even when additional factors described below are taken into account (culture, cognition, etc.), treating users over the age of 65 as a homogenous group is unlikely to give rise to generally applicable findings and can cause problems in group work. Recruitment must recognise where differences in attitude and behaviour that arise due to generational differences are relevant to the application and select participants accordingly.

Issues with Sensory Ability

In addition to variations in physical abilities the ageing process will cause a wide range of deterioration in sensory abilities to be present in groups of older adults, in particular eyesight and hearing [71,139]. Recruitment should attempt to span this range of abilities as appropriate and elicit participants' accounts of their degree of sensory impairment with a view to understanding the character of the group of participants and the likely impact of this on both the design itself and the design process. Furthermore, recruiters need to be aware of how the method of contact they employ to recruit elderly participants may affect participation [88]. For example, phone calls can prove challenging for the hard of hearing whilst letters can prove difficult to read for those with visual problems [17]. In light of this, adopting a multifaceted approach is recommended.

Diversity in Personal Circumstances

Considerable variation exists in the range of personal circumstances in which older people find themselves [137]. These should be considered separately from the social, cultural and national variation discussed previously. For example, the living arrangements of an individual can range from

living alone, co-habiting with a partner (married or otherwise), living with younger or older relatives (many older people are caregivers), living with extended families, living in sheltered accommodation, and living in residential accommodation.

5.2.3 Exploratory Work – Invisible Design and Scenario Work

These sessions are based around the construction of scenarios to explore the problem domain and develop requirements for the design of a device. The sessions begin with an information gathering stage like the initial exploratory work from the KITE design process but drastically shortened. In the most successful design study, the group is then asked to watch an invisible design video prompt that shows a pair of distinct characters discussing some never-shown future technology relevant to the domain being discussed. The characters will discuss their interactions with the future technology arguing about both positive and negative aspects of the design whilst never reaching a conclusion about the quality of the design. The participants then create a best and worst case scenario centred on the invisible design video already shown. In the most productive sessions the characters in the video were also the best and worst case scenarios that were outlined. These scenarios are examined in the claims analysis process to try to gain an insight into the underlying problems that cause them. Participants then start to envision solutions to these problems before finally trying to work them back into their original scenarios.

Group facilitators should prepare prompt questions in order to spark discussions for each stage in case conversation does not start naturally around appropriate topics. These prompts can be drawn from existing literature on the problem domain. The concept behind each stage is outlined below along with a sample of the way in which they should be presented to the older participants.

Information Gathering (15 minutes)

The consistent point of contact begins the discussion with participants by asking about their current actions within the domain in their daily life by asking something along the lines of:

“So to kick the meeting off we want to get to know you a bit better so tell us a bit about yourself, what sort of experiences you’ve had in <DOMAIN> and what sort of experiences your friends have had?”

This stage gives all the participants within the group an equal footing by establishing a *common frame of reference*. Establishing this allows people to participate and gives them the language or shared concepts they need to refer to when expressing themselves. The accounts of experience elicited also help inform the creation of a narrative around the participants’ activities and a source from which to draw quotes to support and enhance the requirements presented to other members of the design team. The information from this stage is also used in the next stage to inform the creation of scenarios.

Prompt Viewing (10 minutes)

After getting an idea of the participants perspectives on the domain the facilitator will move on to show them the *invisible design* video:

"Ok we're going to watch a short, fictional video now that's set in the future where someone has actually gone ahead and made a device to help with issues in the <DOMAIN>. We're going to see what sort of affect it's been having on a couple of people and then after the video we'll have a chat about it."

This promotes discussion and provides scaffolding for participants to describe their own thoughts about future interventions. This also introduces the participants to the idea of creating scenarios of use for a future device and moves the participants away from trying to create detailed designs early in the process.

Scenario Generation (20 minutes)

The facilitator moves the group on to the development of scenarios based upon the information gathered in the first stage. The participants' accounts of their own lives provide starting points for the generation of these scenarios and different elements of them can be combined to create new, but familiar, scenarios that all the participants can engage with:

"We'd like to move on now to try and discuss what we think are the main differences between Alice and Bob in the video. What are Alice's characteristics that make her so capable, what are the things about Bob that lead him into trouble? Outside of the story we've watched how do you think the two behave?"

In the most successful design exercise that was conducted, the characters of Alice and Bob corresponded to the two participants shown in the invisible design video. The facilitator should record the scenarios being generated in some shared space in order to focus the attention of the participants, for example, on a white board or large sheet of paper. Pre-prepared story boards can be used to record the scenarios and give an idea of what is expected from participants as well as serving to keep the scenarios fresh in the minds of the participants as the work continues. During this stage participants may simultaneously generate information and develop scenarios when they offer anecdotes about their experiences.

Claims Analysis (20 minutes)

During this stage participants think about why the scenarios play out the way they do. Claims analysis can be presented by asking "why" given scenarios are the way they are. For example, if a "bad" scenario features a person who struggles to bother to prepare food in the evening, claims analysis will look at why this might be. If scenarios are thought of as detailing someone's symptoms, claims analysis attempts to diagnose the cause of these symptoms:

“Now we’ve come up with our stories about Alice and Bob it’s time to try to work out why they are so different. What does everybody think might be the reasons which make the difference between them? Are there physical things or mental things? Are there things that make Alice’s life easier or things that make Bob’s life harder?”

By performing this stage, the group facilitators will gain greater insight into the domain. This stage also informs the feature envisioning by exposing some of the root causes of negative and positive experiences.

Feature Envisioning (30 minutes)

The claims feed into this stage as participants envision ways to reduce their negative and increase their positive impacts. Running over these claims at the start of this stage will keep them fresh in the participant’s minds:

“So we’re starting to understand the area a bit better thanks to all the useful ideas that we’ve gathered and put up here on the whiteboard, I’ll just run through them quickly and see if anyone thinks we’ve missed anything important out.”

Participants are asked to describe new features they imagine a new system having. Feature envisioning can be presented to the participants by asking them to think of anything that could help Alice and Bob in their day-to-day lives:

“Ok now we’ve run through those idea’s let’s move on to think about how we can help out Alice and Bob a little bit and make their lives easier. Alice has a few things that really help her out in her day to day life. What can we do to make sure those things keep happening? Bob on the other hand has lots of problems in his day to day life, so what can we do to get rid of them for him and make his life run a bit more smoothly, like Alice’s?”

Participants talk about their ideal solutions at this stage and frequently exceed the bounds of what is feasible. However, this stage reveals their aspirations which give important insights for the designers. This stage produces the bulk of the *requirements* discussed in the analysis section.

Scenario Envisioning (30 minutes)

Finally, participants are asked to consider how their new idea might interact in the old scenarios and, through this, imagine new scenarios. For older people, the process of envisioning future scenarios can be difficult [96] so this stage should be presented to them by asking them to speak about what could go wrong with their ideas when included in Alice and Bob’s lives.

“So we’ve thought of some ways to help out Alice and Bob now, the last thing we want to do is consider why these idea’s might not work out the way we want them too, what sorts of problems might crop up if we imagine each of these pieces of technology in the stories we came up with about Alice and Bob to start with? We’ll go through the different ideas on the whiteboard starting with...”

The information generated here will produce negative requirements, possible flaws in a new system that need to be avoided, referred to as obligations. These sessions are recorded and transcribed for further evaluation. It is also important to keep a record of the scenarios that are constructed. Unlike early exploratory work in the previous chapters, the solutions to the scenarios should be explicit and well understood by the members of the design team present in these meetings.

Analysis

The process of analysis in the KITE approach allowed themes from the meetings to be drawn out to create a better understanding of the design domain and reduce the burden on the cognitively impaired participants to articulate themselves fully. The analysis necessitated looking beyond what participants say to try to find underlying concepts or values the participants hold that are relevant to the design domain.

In the OASIS approach, the analysis begins to formalise design requirements in a way that is more directly aligned with what the participants say. The analysis process formalises the participant's comments in the first design session and generates a Topic Guide that will be used to guide discussion in the second design workshop.

The analysis of the information gathering stage draws out quotes and gathers them into themes in the same way that the analysis described in section 3.2.3, looking for themes to emerge from the discussion. When working on the scenario generation and claims analysis the coding should look for comments relevant to the scenarios and group them around the characteristics of the two scenarios. Analysing the later stages is guided by a simple process: codes related to potential features for a design are grouped in *requirements* and codes related to potential problems with a solution that must be avoided are grouped under *obligations*. Requirements tend to emerge from discussion in the feature envisioning stage whilst obligations come from scenario envisioning. By searching the transcript from the meetings for the participants' statements of requirements and obligations, the participants are given a more direct impact on the designs that are produced. The requirements can then be supported by tying them to the codes taken from the output from the earlier scenario work and information gathering. For examples of how this is presented see Tables 6-3 to 6-10.

In this way, the output from these sessions can also be presented to the other members of a project team couched in language they can understand but supported by the authentic voice of the user. These should be presented to the project team in a way that preserves the link as much as possible. This might be in the form of documents that compile selected quotes or through more innovative means like using a website that links requirements to the sections of transcript that relate to them. In the low fidelity prototyping sessions the designers feed their analysis back to the users and let them comment on it, to validate their findings.

5.2.4 Design – Low Fidelity Prototyping

These sessions have a similar role to the personally tailored design sessions outlined in the KITE process but compress what was an entire stage in KITE into a single meeting. The more structured approach in this low fidelity prototyping work is a response to the lack of structure that was found in meetings in the previous approach. The goal of this session is to produce further requirements for a design focusing upon more specific features of the device and this meeting lets participants articulate their requirements for the functionality, aesthetics and experience of a specific design.

The consistent point of contact should create a Topic Guide for the process in which they detail the key subjects to be addressed whilst being realistic given the time allotted to each meeting. The Topic Guide needs to select a design or suite of requirements from the previous design session to implement. This will be the first thing to establish in the meeting with participants and should be couched in the language that they used when suggesting the idea when presented to them so that it is clear that this is the participants ideas being realised. When creating the Topic Guide the consistent point of contact should look for cases where there are directly opposing requirements drawn from the design process. The Topic Guide should promote discussion aimed at resolving, or at least understanding, this issue. Key subjects should be selected based on elements that are most strongly linked to the user interface aspects of the design, as this is the strength of the low fidelity prototyping.

The session is conducted with the participants from the exploratory work about a week after those sessions and refines the high level goals developed in them following the PICTIVE process [106]. The sessions must be video recorded and so need to be conducted at a location with suitable facilities for this. When recording the participants should not be the subjects of the recording but instead the shared workspace they work on should be (e.g. the tabletop on which the workshop is conducted and around which the discussion is held).

The duration of the workshop will depend on the nature of the given task and the capabilities of the participants. If a group has shown itself to be creative and tolerant of extended discussion about the design domain, these workshops can stretch to three hours. The attendees to a workshop should be provided with material that sets the scene of the participatory analysis and design and this should include the Topic Guide and a summary of the analysis of the exploratory work. This introduction serves to set the scene for the rest of the workshop to ensure that all the participants have a common frame of reference.

The consistent point of contact will prepare for the workshop through the creation of appropriate tools and materials for the exercise. Tools can be classified under two categories: (i) office tools such as pens, paper, post-it notes, coloured pencils, rulers, erasers etc; and (ii) specialist tools, for example, paper in the shape of interface windows, or actual devices that can embody design domain and facilitate the activities of the workshop.

Analysis

The analysis of the data gathered in these sessions is used to produce sets of requirements statements that will feed into the development process. These requirements statements are accounts of desired features, desired experiences and suggestions about aesthetics that guide the development work. When coding for requirements for a device, the experience showed that they tend to naturally fall into categories of functionality, form factor and user experience. Form factor is often avoided by the older users who feel they have no real expertise in the area. User experience requirements are vague and overarching and functionality relates to operations that the system can present. If the design team is separate from the development team then it is critical that the design team links each issue to its respective coded section. If requirements shift or features need to be dropped design teams can see why each of these was valued by the participants with a sense of their authentic voice through the link to guide design compromises.

Maintaining the original paper prototypes and videoing the sessions ensures these are grounded in recorded discussion or physical artefacts. The risk of misinterpreting statements should not be underestimated and having the facility to revisit the origins of later design decisions is an important aspect of the process. High fidelity prototyping sessions will elicit feedback on the design and confirm the interpretations made in this analysis.

Video editing software is required to annotate film and pull out the relevant clips. The process of selecting interesting and relevant clips is analogous with coding the transcript as previously discussed in section 3.2.3 with the same process employed to decide on significant topics. Further work needs to be done to extract information from physical artefacts developed during the process. These should be photographed using high resolution camera's to capture the layout.

5.3 CONCLUSIONS

The OASIS framework addresses three flaws found in the KITE design work: structure breaking down meaning that not all topics needing discussion are covered; in-depth analysis undermining the participatory nature of the process and disempowering the participants as well as being hard to convey to other members of the project team; and not facilitating older people elaborating on intangible design issues in discussion. To address these issues we: formalised the design process for each meeting and reduced the number of meetings needed by only working with older adults; reduced the role of analysis in the process by making discussion of a future system more explicit in the exploratory work; and included invisible design videos that allowed concrete discussion of intangible concepts.

Despite these changes the underlying aim of the work remains establishing an empathic relationship between designer and older person. The structure of the work remains the same with exploratory work followed by design work but the number of meetings used is shortened to make the rapid application of the process more feasible with physical prototypes occurring much sooner in the process.

In addition to being based on the lessons learned in the KITE design process, the OASIS design framework presented in this chapter has had several small adjustments made to it in light of experiences applying the framework and the next two chapters discuss these as part of the OASIS project.

CHAPTER 6: USING THE OASIS DESIGN APPROACH

The OASIS design approach was first evaluated in the design of a digital technology to promote healthy eating as part of the OASIS project [113]. The design approach has been modified resulting in three main differences. These are: (i) the recruitment process takes its participants from a city centre venue without considering the impact that this would have on the makeup of the participants that attend the design meetings; (ii) in the exploratory work, the invisible design video prompt is shown after scenario generation and claims analysis rather than before as documented in Chapter Five; and (iii) the video prompt is not developed to portray a particular scenario that the participants can work from when creating their own scenarios. The process of following the design process outlined in this chapter would highlight issues that lead to these changes being made.

The field of healthy eating is an area that can be uniquely problematic for older people because of issues such as the loss of a partner who used to cook, decreasing motivation to cook, decreasing mobility meaning that buying fresh food is difficult or a lack of funds meaning that buying ingredients is challenging [161]. The healthy eating area is again located in the wider context of digital technology applications for the home that has come about with the third wave of human-computer interaction meaning that the issue is not work or task oriented but instead more around influencing the outlook and attitude of older people towards food preparation and consumption.

The OASIS project calls for the development of a mobile device and a home device to help elderly people manage their nutritional habits and to guide them towards more healthy eating practices. The work that was performed began with open questioning in the exploratory work but when taking the participants initial requirements into the low fidelity design work, the remit of the project meant that the emphasis was placed on specific issues that the participants described which were more suited towards being developed to work on these devices.

6.1 RECRUITMENT

The OASIS design method calls for recruitment to begin by identifying characteristics that are relevant to the design domain and to attempt to recruit groups of users that are diverse with respect to these characteristics. In this design study, the level of personal mobility that people exhibited, their age and where they lived (rural or urban) were identified as having major impacts on the domain of healthy

eating. In retrospect, the process had been fortunate to also gain a group that were diverse in personal living arrangements as well as the process highlighted that this was another areas that heavily influences personal nutritional habits and healthy eating practices.

Several charitable groups and recruitment agencies were approached in the recruitment process before finding one that would agree to help us, the Newcastle AgeUK¹² charitable group. The contact at AgeUK approached people during their “tea and biscuit mornings” to ask if they would be interested in take part in a study. The AgeUK contact remarked that they found it much easier to recruit people when a time, date and place were set for the meetings as the potential participants could then give a definitive yes or no answer about whether they could make it and groups of friends were able to arrange to attend the meetings together.

The participants recruited for the design of a healthy eating promoter all had distinct, well developed views with regard to nutrition and their personal eating habits with diverse attitudes towards buying and preparing food. Conversations tended to move onto tangents regularly which might not appear to bear relevance to the topic at hand but in these cases the consistent point of contact would attempt to steer discussion back onto the topic rather than impose the return upon participants.

Two groups of participants were recruited (see Table 6-1 and

| | | | | | |
|-----|--------|-------|-------------------|--------------------------------------|----------------------------------|
| Ann | Female | 60-65 | Retired secretary | Still drives and husband still works | Exploratory work and design work |
|-----|--------|-------|-------------------|--------------------------------------|----------------------------------|

Table 6-2) with one participant unavailable despite several attempts to contact them by phone, hence the different numbers of attendees for each group. When moving on to the second stage of the design work, three more participants dropped out (two unexpectedly). The two groups included people with a diverse set of backgrounds and a range of different ages between sixty and ninety were present.

In group one, Mike was the youngest member of the group, he was a retired nightclub manager who actively practiced Tai Chi every morning and felt he was very in touch with his own body and dietary needs although he kept an odd routine due to his time working night shifts as a night club manager. John, the other male member of the group, was a retired painter/decorator who lived with his wife who did most of their cooking although he did go with her to the shops. Pearl lived with her husband and cooked weekly for a group of up to 17 people including friends and relatives. Janet lived alone but still cooked a lot and bought fresh food from her local supermarket.

| Pseudonym | Gender | Age | Occupation | Mobility | Meetings Attended |
|-----------|--------|-------|---------------------------------|--------------------------------|-------------------|
| Pearl | Female | 71-75 | Retired but does voluntary work | Good mobility, does no driving | Exploratory work |

¹² AgeUK are a charitable older peoples advocacy group who run regular “Tea and Biscuit Mornings” with groups of older people at locations around the UK

| | | | | | |
|-------|--------|-------|--------------------------------------|--|----------------------------------|
| Mike | Male | 66-70 | Retired executive night club manager | Good mobility, doesn't need to drive | Exploratory work and design work |
| Janet | Female | 66-70 | Retired auxiliary nurse | Had a knee replacement, fine walking now | Exploratory work and design work |
| John | Male | 85+ | Retired painter/decorator | Still drives | Exploratory work |

Table 6-1: Group 1 Participants.

In group two Cyril was the only male member, he was a retired probation worker who tended to drive to shop at more expensive food stores although he had a tendency to prepare ready meals for himself. Sophie was still an active volunteer at her local hospital and was more concerned about the nutritional issues she saw in the hospital afflicting patient than about her own nutrition. Harriett was a less confident cook than others in the group and had broken her hip recently and felt she had slowed down since then. Marianne enjoyed cooking and had a regular cooking day where she tried to make a lot of food in one go then eat it with fresh vegetables throughout the week. Ann was the youngest member of the group, she felt that having her gall bladder removed was a major impact on her habits around food as it had made her much more conscientious of the ways that she approached food shopping, she noted that her husband had also benefited from the improvements of her approach to food.

| Pseudonym | Gender | Age | Occupation | Mobility | Meetings Attended |
|-----------|--------|-------|--|---|----------------------------------|
| Sophie | Female | 71-75 | Works two half days a week at a local hospital | No problems with mobility, doesn't drive but can if they choose to | Exploratory work |
| Cyril | Male | 71-75 | Retired probation officer | Lives alone, still drives and no other mobility problems, lives in rural area | Exploratory work and design work |
| Harriett | Female | 71-75 | Retired switch board operator | Broken hip but still gets out and has never driven | Exploratory work and design work |
| Marianne | Female | 80-85 | Retired community care nurse | Describes themselves as slowing down and has never drove, lives alone | Exploratory work and design work |
| Ann | Female | 60-65 | Retired secretary | Still drives and husband still works | Exploratory work and design work |

Table 6-2: Group 2 Participants.

One issue that became apparent through discussion with the groups was that the majority of the participants considered themselves to be more mobile individuals than the typical older population. This was problematic because the one of the relevant areas of diversity was the level of mobility of each of the participants.

“And while you were away we were talking about how useful bus passes and metro passes are, now that gets elderly people out, that gives them exercise, that makes them able to go and get provisions more easily and I think that is a wonderful promoter of health.”

- Cyril, Meet Two

“I can either take the car to the supermarket or basically I’m in town every day so I do my shopping in town...”

- Ann, Meet Two

The issue could not be addressed in these meetings but would lead to the recommendations about considering recruitment avenues and venues. For example, the AgeUK unit that was recruited from was located in the centre of Newcastle upon Tyne and would need attendees to drive or take the metro or bus and walk some distance to visit it. Later design work on personal security and transportation would work with age concern units located in towns and villages that were attended by people with more diverse levels of personal mobility.

6.2 EXPLORATORY WORK

The exploratory meetings and design meetings took place at Newcastle University as the participants felt that this site was easier to access than the AgeUK centre that they usually went to. The participants were introduced to two consistent points of contact in this work rather than one as the team working on the project were aware that they would be working intensively in the meetings and wanted to be able to cope with multiple discussions taking place.

6.2.1 Invisible Design Video Prompt Filming

The invisible design video prompt was shot by a professional film director/writer with the role of the mother and the daughter played by professional actors. The script writing was performed by the director/writer with input from the design team to centre on conflicts that the review of previous literature had discovered whilst obeying the constraints of the invisible design process.

The film maker was initially given a brief that centred on the known issues that arose in this domain based upon a review of previous literature. Issues that were highlighted to him included the tendency amongst some older people to not eat as much as they should because they believed that this was healthy or because of economic problems [161] and the tendency of some older adults to forget about meals [14]. This process produced three different iterations of the script over a period of 3 weeks with changes made based on our feedback from iteration to iteration.

The video created for the design sessions examined the interaction between a mother and her daughter in the mother’s kitchen as the daughter discovered that her mother was not eating properly. The film starts with the daughter part way through explaining her problems at home with a broken

water main as she is preparing food for a group of friends at her mother's house. The daughter notices that the cupboards don't have much food in them and this causes an argument with her mother about not eating enough. The progression of the argument reveals that the mother has a device that is meant to help her eat healthily but she complains about it for a variety of reasons. The daughter demands to know why this is the case and why the mother was not using her "machine". The script suggested that the "machine" somehow monitored and helped plan meals and was easy to use but the device was never shown in the film, only pointed at and the film concluded avoiding showing the precise functionality of the device and whether the mother would start to use the device so keeping the device ambiguous.



Figure 6-1: Still screenshot from the invisible design film.

6.2.2 Information Gathering

The opening discussion acclimatised the participants used to talking to the group whilst being recorded discussing relatively trivial aspects of their day-to-day life. The discussion also started to establish a common frame of reference for all of the group members. Participants would typically begin with a discussion of the location of shops and sometimes intermingled with this, a discussion of the food which they bought:

"At the moment I find food shopping fairly easy because of the location where I live, so I've got sort of access to ASDA by car or by bus or by walking if I choose to, depending I need to carry and also my local Sainsbury's so I don't have a problem with access to supermarkets."

- Ann, Meet Two

Some participants were happy to talk at length at this stage, but it was important to ensure that the group did not spend too long on this aspect of the work although all the information produced is valuable in establishing context for the meeting:

“Well for shopping I use quite often Fenwicks Food Hall and I buy such things as Scotch pies and Savloys and the odd pork pie, and Cornish pasties and things like that which I warm up. And I would buy tomatoes, spicy pasta from there and I would also buy porridge oats there, cornflakes, rice crispies and I also shop in Marks and Spencer’s as well, banana’s, fruit. I’ve gone off lately Marks and Spencer’s prepared meals but I don’t do a lot of cooking for myself and if I do its really scrambled eggs for breakfast, but I don’t do that very often. So my pattern to shop in that way, a rather basic shopping budget.”

- Cyril, Meet Two

Participants frequently discussed problems forgetting lists and buying food that was not needed and this would be revisited in feature generation when talking about possible digital technologies to help them when in shops. As the discussion moved on participants showed they held a diverse range of opinions and views around the preparation of food and the times at which they would have meals:

“About three meals cause you have breakfast and then about lunchtime, ten to one I have a little sandwich it may be something else and a sandwich and then about seven.”

- Marianne, Meet Two

Other participants showed that they had habits which centred considerably less on any one specific or conventional routine:

But that’s only because I used to work at night, I didn’t get to bed before five. So when I get up at twelve I’ve only had seven hours sleep but my friends will say ‘Oh you get up at twelve? God you’re too lazy’.

- Mike, Meet One

As well as having a wide variety of habits related to cooking and the strategies they employed when cooking, the participants showed a wide range of levels of enthusiasm cooking with some being highly motivated to cook whilst others seemed less concerned and even considered it a nuisance:

Harriett: “It’s just put in a dish and hope for the best.”

Cyril: “Yes it brings out all your inadequacies in certain areas in your life.”

- Meet Two Discussion

In both groups, this led the discussion around to the motivation to cook and also turned to the subject of motivation to cook when only one person was eating, something many people identified as a problem for them or for someone they knew:

“That’s right and they work because I don’t want to cook for just me, sitting for a meal on the end of the table by yourself is not a lot of fun”

- Janet, Meet One

The motivation theme would carry through to the later discussion of functionality where people would suggest that the machine needed to help people become motivated to cook.

6.2.3 Scenario Generation and Claims Analysis

Information gathering drew to a close approximately twenty minutes into the meetings and participants were asked to discuss their specific views on what might be constituted as being the best, worst and middle cases for elderly people with regard to eating healthily. At this stage the OASIS method called for a middle ground to be discussed as well as the worst and best cases and did not leverage the video as it would in its final version. Whilst participants were very vocal, the process of actually creating scenarios proved challenging as participants tended to revert to discussing their own personal circumstances or experiences:

“I do the shopping. On the odd occasion I think it’s Christmas like four or five years ago, I was abandoned. I was rushing round like a mad thing and all I could hear from laughing and you know my husband had met friends and he was just stood there with the trolley and I thought ‘Well I’m not taking him again’.”

- Pearl, Meet One

The participants had difficulties separating the first and second phase and at the same time, the participants also tended to naturally include some degree of claims analysis when they spoke about their scenarios, this natural conversation pattern is shown below where a man in the second group states a problem then explains why he believes this to be the case in the next sentence:

“But I think I’m right in saying just as one’s appetite for food goes down you don’t need as much when you get older. I think you’re actually feeling of hunger isn’t there in the same way”

- Cyril, Meet Two

The experience of the first meeting with regards to the difficulties around getting people to discuss the best, middle and worst case scenarios led to the consistent point of contact attempting to impose this structure more in the second meeting. The first group spoke at length about what they perceived to be the negatives factors affecting personal nutrition though not as part of any specific scenario, instead the group facilitator ended up surmising the general consensus in order to provide some basis for the scenarios. Although this stage revealed new information, it did not create the formal scenarios that it was intended to.

At this stage, the individuals in the different groups started to diverge in subject matter as members started to show distinct preferences towards discussing different issues they had identified. At this point participants were still heavily bringing their own personal circumstances into discussion rather than discussing fictional actors. Most of the participants were very aware that there was a substantial difference between men and women with regards to nutrition and the point came up several times. The discussion of negative scenarios, when it did happen, centred on the problems with decreasing appetite which some people experienced:

“But I think I’m right in saying just as one’s appetite for food goes down you don’t need as much when you get older. I think you’re actually feeling of hunger isn’t there in the same way”

- Cyril, Meet Two

With regards to the positive and neutral scenarios, participants were considerably less focused although some comments were made around the importance of support from the family:

“So this is the same reason cause I know a gentleman now who doesn’t cook for his self but his daughter when she does two dinners on a Sunday, ‘Oh yes, I have another dinner left over so I pop it up for my Dad’ and he’s got three dinners for the week.”

- Ann, Meet Two

When discussing the good case participants noted that the needs of people in relationships would be less urgent than those of someone who lived alone. There would be some issue in understanding who was responsible for the system and reacting to it. The claims being made were similar to a separate discussion in the first group where people noted that the act of shopping with a partner was interesting and for some people an opportunity to socialise with them

Care homes and healthy nutritional habits would prove to be an issue that several people commented on in the second group, one participant in the group had an elderly relative in care and another had experience of being a community care nurse and they discussed at length the issues they perceived around the care of people more elderly than themselves who were in care:

“The element of care and the standard of care that this Aunt got in her home was at times absolutely atrocious.”

- Ann, Meet Two

These issues lay beyond the scope of the OASIS project but the consistent points of contact were reluctant to stop the discussions as the topics were obviously ones that the participants felt strongly about.

Claims analysis was presented to the participants as being an activity that centred on how the various aspects of the scenario made the actors in those scenarios feel and asking why things were the way they were within the scenario. The lack of clear distinction between the three initial stages meant that the users tended not to like discussing the claims as much as there was a lack of distinction between themselves and the actors within scenarios constructed:

“I wouldn’t like them to look after me. I wouldn’t honestly, it’s like I say you always look after someone the way you would like to be looked after, not like a dog, I’ve seen that. And the same person that’s been treated like a dog has been a very, very well educated person.”

- Sophie, Meet Two

Although the participants did occasionally make what could be construed to be claims analysis tackling the motivation of people with regards to cooking, as has already been seen in some quotes:

“If the wife went and her husband was left he probably wouldn’t have a clue on where to begin. So therefore they either withdraw or they don’t cook”

- Marianne, Meet Two

6.2.4 Invisible Design Video Showing

In this first version of the design framework the role of the invisible design video was only to hint at future technologies that might be available to promote healthy eating or which might be developed as part of the design work. Participants took away different messages from the video ranging from noting the bereavement issues to perceiving the video as mainly being about older peoples issues with technology, which suggested that, was intended, the video covered enough issues to allow the participants to see their own point of view portrayed sympathetically:

“And the lady at the stage of life had obviously lost her husband and was not interested at all.”

-Janet, Meet One

Mike: “Also the other people, an assistant. This would all be difficult but the over sixty-fives they can’t, they can’t text so yeah, again people say they ‘I want that’ just text them, but seriously.”

Janet: “Ted can switch it on.”

John: “I can’t text.”

- Meet One Discussion

In the second group an interesting point which the video raised centred on nagging and the “food police”:

“And I thought I could identify with it because I have children and they turn into the food police.”

- Marianne, Meet two

This comment led to a large amount of discussion around the role of prompting within a person’s life and the idea of nagging and the term food police became a part of the common frame of reference from the second group who were much more concerned about nagging than the first group. The video also seemed to serve very well in focusing the discussion of the group onto the issues with nutrition as numerous ideas were generated in the following stages, one individual also noted later on whilst taking part in design when trying to illustrate a point that:

“You had a good reminder on at the first group when we watched the film and the daughter was reminding her mother and she says ‘your cupboards were empty, when are you shopping, when are you eating?’ And she says ‘Well I’ve got a sandwich’”

- Mike, Workshop

This showed that the video had left a lasting impression on this particular member. Considered over the whole group, the number of reactions to the video strongly suggests that the video is affective in prompting users to discuss or raise points. Due to the wide number of issues raised in the video each participant is likely to see an issue mentioned, if only in passing, which resonates with them personally. At the same time, the fleeting nature of discussion of any one issue within the video, along with an avoidance of portraying any one individual as being ultimately “correct” with regards to that

issue, prevents anyone's viewpoint from being challenged which may in turn lead to them not raising it. Finally, the humour portrayed in the video was noticed by the individuals:

"No, no, no it was quite amusing, I can see older people's point of view of this."

- John, Meet One

"I thought it was humorous, yes."

-Sophie, Meet Two

The humour was considered to be important because it softened any impact the film might inadvertently have on the individuals watching it. This supports the film's goal of bringing issues to the forefront of people's minds without imposing solutions or answers upon them.

6.2.5 Feature Envisioning

This stage in the focus group was presented to participants as revolving around the scenario presented in the video. Participants were asked to imagine tasks in which a futuristic device might assist them and discussion was wide ranging as users constructed various different ideas. This high level of involvement is not typically reported with older users attempting to envision future technological services and it is attributed to watching the video beforehand. The second group neatly surmised the topics covered from a User Experience perspective early on in the discussion of requirements:

Harriett: "I don't need any help, I need information."

Marianne: "Yeah, and motivation."

Facilitator: "So motivation and inspiration are more important to you"

- Meet Two Discussion

The discussion of features is divided into two sections as dictated by the nature of the OASIS healthy eating device. The first deals with the device in the home and the second with a device that helps the user when they are shopping. Participants talked about the possibility of having a device to remind them when they were running short on perishable food produce as well and mentioned the possibility of getting a list from the device which could help them to remember items when shopping, unfortunately participants' suggestions for how this might be achieved tended to skirt close to the things they said they wanted to avoid in other parts of the discussion:

Pearl: "A screen where the text is big enough maybe."

[All agree]

Mike: "And a flashing light or something to attract your attention."

Janet: "Yeah definitely."

Pearl: "Maybe like a list would be excellent."

- Meet One Discussion

This tied back to the earlier discussion, participants hoped that a system would help them to remember to buy food when it was needed and which would make sure that when they left to go to

the shops the system does not let them leave their list behind. One individual commented that a device might be more easy to use than a cookbook, although this would depend on an individual's willingness or lack thereof to use a cookbook, this discussion carried on and people were questioned in low fidelity design more about the format that a device should present recipe options to them in. In the second meet some people discussed the possibility of a device being aware of the surroundings and ensuring that kitchen was safe:

Ann "lighting the gas and when you turn the gas off, fair enough on mine..."

Marianne "Now something that could alert you and think now what's on here or...?"

Ann "...it's getting hot you know, 'Oh well I've done that'."

- Meet Two Discussion

Whilst this went beyond the scope of the designed interventions possible in the OASIS work, it highlighted the problems with the original scope of the work not necessarily covering the ideas that participants wanted to have addressed. A participant noted the need for a device to understand the difference in the ways that a man and woman might view the device:

"Also you've got to think about agendas, I mean what a woman might like in her kitchen is not the same as what a single, say a single or single man might like in his kitchen, I mean you know you can have all these things like steamers and George Forman's and this that and the other but perhaps a man might not be interested, he just wants a cooker and you know and there's a few odds and ends. I seem to have loads of electrical gadgets all over the place and most of it I can't remember when last I used them, they'll all rusty, but I've got them all. I used it once or twice and then I found, what do I wanna use a steamer for, I've got a pan here..."

- Mike, Meet One

When it came to discussing size, the participants tended to indicate it by using their hands, at this stage it is obviously important to record what the participants indicate in some way so it can later be revisited. The participants discussing the Nutritional Adviser expected a device to have dimensions best described as similar to those of a laptop:

Pearl: "Well bigger than this [Laughs] and smaller than that. [Laughs]."

Janet: "Bearing in mind it's got to fit in with most people's kitchens"

- Meet One Discussion

Still on the subject of a device within the home, some individuals commented upon how motivation could be drawn from the presence of someone to cook for. Devices could arrange for people to meet up with friends and share meals. Some users reacted positively to this idea whilst others felt that this was something they could do or did do already. An unrelated issue raised in both groups centred on the usefulness of having a system integrated with the person's medical information available:

"You see I would find that really good because I have a blood test every year because of my blood pressure medication and I can never remember when that is, I know the surgery will tell me but if I could be reminded of what I had when and you know that would be quite useful."

- Pearl, Meet One

At other times in the discussion, the subject of getting information from GP's and using it had already risen in the Information Gathering work. In the second group people discussed the need for diets to be personalised or tailored to individuals needs and desires, the discussion around this moved into future scenario envisioning as individuals felt that in many ways this functionality could be make or break for a device:

"I know and it's just a thing that, I've got this diet sheet that says you know make cauliflower cheese but use full cream milk. Yet I mean I eat loads of yogurts and things that I think give it to me in other ways, you know I'm quite a good cheese eater and things like that."

- Ann, Meet Two

The flashing light was envisioned on the device in the home to remind people when they left that they needed to take the list with them, not on a PDA-like device which people would carry with them, the distinction is important in light of some of the comments made in the future scenario envisioning section specifically noting that participants would not want a flashing device. The need for such a list ties back to the comments made by both groups that they forgot to take lists with them:

"I write a list and I forget to take the list."

- Pearl, Meet One

6.2.6 Future Scenario Envisioning

Future scenario envisioning was presented to the participants as focusing on the negative aspects of the technologies that they had imagined. The participants were asked to identify potential pit-falls with the question posed to them "If something were capable of doing the things we have just discussed, what might prevent you from using it, event then?" The participants were encouraged to relate their designs and ideas back to the scenarios they had been envisioning. Whilst the process was successful, there were several issues that hampered progress, the most significant one being the tendency for people to talk at length about personal experience and their opinions about what constituted healthy nutrition. The two meetings did produce several ideas and requirements for a device though one overriding concern was that the device was easy to use, a somewhat nebulous concept. This is an obvious requirement but the trade off which many older users articulated was for a device which would do less but do it well:

"I would like it to be nitty gritty, and minimal and make clear the basics fairly simple. I wouldn't like it to have a lot of subordinate clauses and qualifications and be too technical."

- Cyril, Meet Two

A "less is more" attitude to the functionality of the devices was something advocated by many of the participants, participants would prefer to have a device that did one thing well over a device that did many things well but presents them with a confusing range of options. In addition to this, some of the participants voiced concerned as to how any reminders or instructions would be presented:

Harriett: "It'd have to be quite subtle in the way that..."

Cyril: "Persuasive rather than mandatory."

Ann: "Bit their tongues."

Facilitator: "Absolutely yeah"

- Meet Two Discussion

The fact that people differed in their attitude towards the devices level of interference implies that the device needs to offer them a variable level of response, sensitive to user's needs. This concern tied in to another issue centred on fears that allowing a device to run your life for you too much would lead to your own cognitive decline:

"You know if you keep seeing this thing going all the time you don't use your brain, you'll just wake up and you'll think, you don't have to use anything, you just..."

- Mike, Meet One

6.2.7 Analysis

The following section shows the themes that emerged from meetings when discussing the functionality of the device and group these into categories within requirements and obligations for a digital technology. The distinction between them is that requirements are aspects of a system which relate to specific functionality or features and these may or may not be implemented in the final development. Participants construct their obligations around numerous different scenarios and devices and so the requirements are grouped accordingly. Designers may pick which of these areas they develop moving forward. Obligations, in contrast, are mandatory and act as almost "negative requirements"; this is to say, things the system must not do. They typically fall into categories of negative experiences that the participants wish to avoid when using a new device. Examples would include making the user feel the system is taking over their life or annoying the user by not being flexible enough for them.

The requirements are presented broken down by themes and are followed by the quotes of participants who were engaged in the process to give a sense of the sorts of things they said with respect to each issue. These quotes include background material pertinent to the issues as well as some directly articulated requirements. When working within a theme it can be worth looking at all of the quotes that are given for the various different requirements to gain a fuller sense of the background to each item.

Requirements

Many of the participants felt that they would like to have some help when preparing meals but were unsure about the exact form that it might take. The participants discussed issues ranging from guides for preparing food through to safety kit that would warn them when they had made potentially dangerous mistakes in the cooking process.

| | |
|--|--|
| Cooking aid: Recipe prompt | Participants expressed some interest in the idea of having a recipe guide which could help them cook new, interesting, healthy food |
| <p><i>"I don't need any help, I need information."</i></p> <p><i>"come up with a calendar that would suggest these basic things for health and link it up with what's seasonal from January to December."</i></p> <p><i>"If on there, where ever it is, you know it (The System) told you a few things you could do with it and you think 'Oh great, you know I can add that to this, you know, I'm getting this so that will go down nicely with it' and you're more likely to get it."</i></p> | |
| Cooking aid: Safety | Desire for a device which could warn participants if they had left a grill on or left the gas switched on |
| <p><i>Female One: "lighting the gas and when you turn the gas off, fair enough on mine..."</i></p> <p><i>Female Two: "Now something that could alert you and think now what's on here or...?"</i></p> <p><i>Female One: "...it's getting hot you know, 'Oh well I've done that'."</i></p> | |
| Cooking aid: Customisation | Participants wished to have the ability to tailor the food which they were presented with to their own personal tastes and cooking abilities/equipment |
| <p><i>"I mean what a woman might like in her kitchen is not the same as what a single, say a single or single man might like in his kitchen, I mean you know you can have all these things like steamers and George Forman's and this that and the other but perhaps a man might not be interested, he just wants a cooker and you know and there's a few odds and ends. I seem to have loads of electrical gadgets all over the place and most of it I can't remember when last I used them, they'll all rusty, but I've got them all. I used it once or twice and then I found, what do I wanna use a steamer for, I've got a pan here..."</i></p> | |
| Cooking aid: Treats | One participant noted that a device was more likely to be listened to if it presented the users with "treats" as well as giving them healthy food |
| <p><i>"December 25th treat yourself to a nice piece of Christmas cake as a treat."</i></p> | |
| Cooking aid: Health Links | Participants wanted the device in the home to be aware of medical conditions and adapt their diet accordingly |
| <p><i>"You see I would find that really good because I have a blood test every year because of my blood pressure medication and I can never remember when that is, I know the surgery will tell me but if I could be reminded of what I had when and you know that would be quite useful."</i></p> <p><i>"I know and it's just a thing that, I've got this diet sheet that says you know make cauliflower cheese but use full cream milk. Yet I mean I eat loads of yogurts and things that I think give it to me in other ways, you know I'm quite a good cheese eater and things like that."</i></p> | |
| Cooking aid: Fridge and Freezer | Reminders telling users when food was going off in their fridge or in their freezer and needed to be used up |

Female One: "A screen where the text is big enough maybe."
 [All agree]
 Male: "And a flashing light or something to attract your attention."
 Female One: "Yeah definitely."
 Female Two: "Maybe like a list would be excellent."
 "I'd say the most important thing for me is I can never remember what I've got in my freezer."

Table 6-3: Potential requirements for cooking aid.

Participants often mentioned problems with forgetting to perform various food preparation actions and shopping tasks that caused them problems. A range of different reminder functions were proposed that would help them.

| | |
|---|--|
| Reminders: Taking Shopping Lists | Participants complained of forgetting shopping lists which they had written and wanted a reminder as they left the house to take a list with them |
| <p>"And a flashing light or something (on the device in the kitchen that printed out a shopping list) to attract your attention."</p> <p>"I write a list and I forget to take the list."</p> | |
| Reminders: Meals | Some participants noted that worst case older people (Those in care) might need to be reminded to eat at certain times |
| <p>"But I think I'm right in saying just as one's appetite for food goes down you don't need as much when you get older. I think you're actually feeling of hunger isn't there in the same way"</p> | |
| Reminders: Drinking Water | Participants said that they themselves found that they did not drink enough water daily and a reminder/monitoring of the amounts they drank would be welcome |
| <p>Male: "Have you got to consider the amount of intake of water that people are taking?" Facilitator: "If you haven't raised it as a problem but do people find that they forget to drink water?" Female One: "Yes." Female Two: "Yes."</p> | |

Table 6-4: Potential requirements for reminders.

Participants mentioned little about the look of a system but they did feel that it should appear like it belonged in the kitchen and that it does not draw unwarranted attention.

| | |
|--|--|
| Aesthetics: Appearance | Most participants felt that a device should fit within their kitchen to some extent |
| <p>"I mean it doesn't have to be a design if it looks part of the kitchen, not for me I don't think." Female One: "Well bigger than this. (Participant indicates a phone) " Female Two: "[Laughs] and smaller than that.(Participant indicates a closed 15' laptop) [Laughs]." Female One: "Bearing in mind it's got to fit in with most people's kitchens"</p> | |
| Aesthetics: Attention | Participants wanted a device that did not draw attention to them when they were out shopping |
| <p>"If it had a recognisable bell whatever, that other people would know 'Oh that lady must be using so and so'." "Or glowing. You don't want it glowing around you do you?"</p> | |

Table 6-5: Potential requirements for aesthetics.

The participants often mentioned that they lacked the motivation to prepare a full meal and mentioned two different ways they felt that their motivation could be improved.

| | |
|---|---|
| Motivation: Suggestions | Participants felt that they might be more motivated if their device proposed new recipes and integrated the ingredients needed into their shopping lists |
| <p><i>Female: "It's just put in a dish and hope for the best."</i></p> <p><i>Male: "Yes it brings out all your inadequacies in certain areas in your life."</i></p> <p><i>"If the wife went and her husband was left he probably wouldn't have a clue on where to begin. So therefore they either withdraw or they don't cook"</i></p> | |
| Motivation: Socialising | Participants commented that they tended to find it harder to motivate themselves to cook if they were on their own, if a device could somehow help in cooking for others then this might be welcome |
| <p><i>"That's right and they work because I don't want to cook for just me, sitting for a meal on the end of the table by yourself is not a lot of fun"</i></p> <p><i>"I joined a dance class and then the group of ladies have been there a lot longer than I had, and we all have a cup of tea or coffee afterwards and we have a natter and again it's another social circle."</i></p> | |

Table 6-6: Potential requirements for motivating users.

Participants discussed their experiences when they were out shopping in some detail and, although most of these did not relate to anything that could be implemented (see Table 6-7). The participants did mention a few issues they would like support with such as locating items in the shops and reading the labels on shopping items.

| | |
|--|--|
| Shopping: Shopping Lists | Participants seemed to find the idea of having a paper shopping list to take with them to the shop to be the most agreeable solution to how a device might influence their shopping habits |
| <p><i>"(If the recipe planner could make) maybe like a list would be excellent."</i></p> | |
| Shopping: Locating Items | Participants reported that sometimes they found it hard to find food in the supermarkets, particularly when the shop had been re-arranged |
| <p><i>Female: "You're brain gets, you know you think it's there and then..."</i></p> <p><i>Male: "Yes you're used to going and heading for it."</i></p> <p><i>Female: "...particularly after Christmas everything gets moved around. And the supermarkets easy to go and look for them."</i></p> | |
| Shopping: Reading Labels | Participants noted that labels on food were too small to read |
| <p><i>"They (Keiser supermarket chain, Germany) have magnifying glasses on the counters."</i></p> | |
| Shopping: Understanding Health Implications | Participants noted that the health implications of food they bought often escaped them as they could not understand the labelling even when they could read it |

"You've got to be a scientist you know, to know Sodium 0.8% what does that mean?"

Male: "What would be ideal is there could be a kind of thermometer which did exactly the same as the hypothermia thermometer, that you put it in your mouth and after a few minutes or two..."

[All laugh]

Male: "...it can tell you whether you've got a healthy diet and you're..."

[All laugh]

Male: "...and blue if you're deficient."

Table 6-7: Potential requirements for shopping help.

Obligations

The obligations described potential issues with future systems usually focused on experiences that the system should not cause if it is to be accepted by the older participants. The older users were quite confident when articulating these aspects of the design and needed little encouragement although many of the topics that they covered were quite vague. For example, the older participants stressed the need for any interfaces to a device to be simple but could not elaborate on *how* they should be made simple. The issue that participants were most concerned with was the potential for a device to be annoying.

| | |
|---|---|
| Nagging: Reminders | Participants were concerned that reminders could quickly become very tiresome |
| <p><i>"I have children and they turn into the food police."</i></p> <p><i>"Because you know that's when I'm thinking, you know after a few months are you going to get fed up with it or, especially when you're on your own."</i></p> <p><i>Female: "But when its constantly reminding you of something you've ran out that would be..."</i></p> <p><i>Male: "I wouldn't like it."</i></p> | |
| Nagging: Fear Mongering | Some of the participants felt that a device could make them feel worse about their health by constantly worrying them |
| <p><i>"Yeah so the downside on that is, you've probably heard the old expression, 'it's not what you're eating it's what's eating you', and you might start and get too morbidly worried about everything you're having."</i></p> | |

Table 6-8: Obligations to not nag users.

The participants felt that a device must not disrupt their routine in any way when they used it but should instead fit into their existing routines (see Table 6-9). This manifested itself in concerns about cooking times being forces on the user and disruption to their normal routine whilst they are shopping.

| | |
|--|--|
| Routine disruption: Mandating cooking | Participants were concerned that a device would not necessarily adapt itself to their personal habits, for example their home cooking might not be integrated into the devices options available |
| <p><i>"I cook for myself, I have a day cooking, supposing you get a pound of mince, a pound of steak, a pound of bisket, I have a day cooking."</i></p> <p><i>"I used to work at night, I didn't get to bed before five. So when I get up at twelve I've only had seven"</i></p> | |

| | |
|---|--|
| <i>hours sleep but my friends will say ‘Oh you get up at twelve? God you’re too lazy’</i> | |
| <i>Female: “It’d have to be quite subtle in the way that...”</i> | |
| <i>Male: “Persuasive rather than mandatory.”</i> | |
| <i>Female: “Bit their tongues.”</i> | |
| <i>Faciliattor: “Absolutely yeah”</i> | |
| Routine Disruption: Backtracking in shops | Participants’ were worried that a mobile device. Shopping list would present food in the wrong order forcing participants to backtrack though shops looking for the food they needed |
| <i>“Because you would probably have to backtrack, you would hope if you were baking, you would hope the flour and then you would find you needed sugar to go with that recipe which you didn’t happen to have special sugar and then you would have to backtrack. That would drive me mad.”</i> | |
| Routine Disruption: Over reliance | Participants were concerned that a device would remove the need to think and remove some of the purpose from their lives |
| <i>“You know if you keep seeing this thing going all the time you don’t use your brain, you’ll just wake up and you’ll think, you don’t have to use anything, you just...”</i> | |
| Routine Disruption: Finances | The shopping lists that a device develops need to be appropriately tailored to the price range of the individual concerned |
| <i>Female: “Smaller portions, excuse me. “</i> | |
| <i>Facilitator: “Smaller portions... So some way of getting hold of smaller portions.”</i> | |
| <i>Male: “It’s very important for single people you see.”</i> | |

Table 6-9: Obligations to not control a user’s life unduly.

Participants expressed general concerns over the usability of any device that was built but could not articulate very specific details about what would need to be different to make a device usable.

| | |
|--|---|
| Usability: Simplicity | Participants felt that they would not learn how to use a device easily and for that reason they hoped that a device would allow them to use it easily with no extraneous features |
| <i>“I would like it to be nitty gritty, and minimal and make clear the basics fairly simple. I wouldn’t like it to have a lot of subordinate clauses and qualifications and be too technical.”</i> | |
| Usability: Impaired Senses Accessible | Many participants were concerned that a device would not be accessible to those with poor eyesight/hearing or might not take account of a users limited mobility |
| <i>“Well the problem is people that are partially sighted, if they can’t see a screen they know what they’re doing but they can’t...”</i> | |

Table 6-10: Obligations to not be too challenging to use.

6.3 LOW FIDELITY PROTOTYPING WORKSHOPS

Between the exploratory meetings and the low fidelity prototyping the design team needed to devise a more specific form for the digital devices that could be built. Reflecting on the transcripts and the requirements led to the decision that developing an in-kitchen healthy eating digital technology that helped the participants by presenting healthy recipe options and which reminded them when food was about to go off in their fridge would be the best option. The OASIS project also called for a mobile

device to be created that would help the older people when they were out shopping and so the requirements for this were also to be further developed in the low fidelity prototyping.

Two members of the eight person development team which would build the final nutritional adviser were brought in to help conduct these low fidelity prototyping workshops so that they could gain a sense of the participants' views. They were given an overview of the previous work and worked with the second group of older people under the supervision of one of the two consistent points of contact. Two groups were held on the same day to perform low fidelity design activities located in the same room at the same time. The presence of two groups was not detrimental to the process and the groups met over refreshments and discussed what they were working on and this discussion led to new ideas being generated by both groups. The experience suggests that, if the opportunity presents itself, consistent points of contact may want to promote cross over discussion between groups at some point in the design process.

6.3.1 Preparation

Once the OASIS meetings were conducted, the result transcribed and analysed the next step was using these results to help devise a Topic Guide for low fidelity prototyping sessions. The Topic Guides construction took into account several factors including: (i) the limitations on the project and the direction in which the developers felt it would be most productive to take the design; (ii) the participant's feelings as expressed through their requirements and the consistent point of contacts feelings about the sorts of technologies they would be most interested in prototyping and; (iii) the activities that would be best suited to being performed in low fidelity prototyping sessions, particularly those that related to the screen design of a device.

The Topic Guide created for the workshops divided the subjects that needed to be covered into distinct areas and then further sub-divided the work based on different aspects which needed to be discussed within that area. Prior to the arrival of participants, designers developed a number of visual aids and props for the groups to use and these included images that the designer felt would be useful such as pictures of food, recipes in various sizes, digital and analogue clocks and calendars. Participants were provided with the necessary equipment for performing *Paper Prototyping* activities and were briefed based upon analysis of the exploratory work.

Unfortunately, it was not possible to have both groups cover all the points on the meeting's agenda. In order to compensate for this one group started by considering scenarios for an in kitchen healthy eating prompt whilst the other group considered the shopping assistant. Had it proved to be the case that the participants covered more ground than was expected, they could then re-examine areas which the other group would already have covered in some detail giving richer information for the designers to work with and analyse.

6.3.2 Workshops

The workshops were conducted by the consistent point of contact and several other designers simultaneously with the consistent point of contact moving between both groups and talking to everybody involved. The workshops involved three users in two groups with both groups briefed together then taken to separate tables in order to conduct the work. The groups started off by writing down how they laid out their shopping lists when they went shopping, this activity had two purposes, firstly the exploratory work had revealed that individuals had varying layouts for their shopping lists and secondly it got participants used to drawing and writing on shared paper. Both groups took part in this before moving on to discuss separate issues, sample quotes show how the discussion progressed around recipes presented within the kitchen. The Topic Guide is shown in Appendix A. Realising that there would be too much to discuss for one group, the participants were questioned about different potential facets of the design of the nutritional adviser. Participants engaged in the topics enthusiastically most of the time and there was little of the initial reluctance in groups which previous work had reported.

6.3.3 Analysis

The final output from this work for the development teams is in the form of the tables of requirements that revolve around form factor, user experience, and functionality. Each of the sections contains multiple issues and each point is supported by quotes from the short transcripts taken from the design sessions. The requirements are presented through a web interface that can be seen online at <http://irgen/oasis/?p=OPAF-3-ReqExt> and video footage and pictures of the artefacts produced in the process are linked to from this more flexible interface. Designers can browse through the requirements (see Table 6-11, Table 6-12 and Table 6-13) and whenever they wish hear the voice of the user and see the artefacts that were produced in the meetings. This allows them to gain a sense of the voice and feelings of the user as they develop the digital devices.

| Category | Concept | Description |
|------------------------------|----------------------|---|
| FF1: Shopping List | FF1.A: Paper List | The participants eventually agreed that a paper printed shopping list should be available with a simple one button interface). This echoes points made in the exploratory work and supports many of the requirements for the system |
| FF2: Menu Screen | FF2.A: Screen Savers | Use of a screensaver-like rolling screen showing images of healthy activities and recipes (Pic 3.1, Clip 4). Alternatively cycling images of what was in the fridge and cupboards as an aid to memory |
| | FF2.B: Pictograms | One participant went into some detail, describing pictograms (Clip 4) suggestions were made such as using symbols rather than words were a lot of complex information was presented at once |
| FF3: Food Planning Interface | FF3.A: Clock type | The participants showed a marked preference for analogue over digital time displays.(Pic 3.2) |
| | FF3.B: Recipe Layout | Participants suggested layouts for the recipes below, which were to include properties such as calorific contents and nutritional information (Clip 1) |

Table 6-11: Form factor issues from workshops

| Category | Concept | Description |
|---------------------|----------------------------------|---|
| UE1: Routine | UE1.A: Day-to-day planning | Several users said that they currently did not plan meals day to day (Pic 2.1) |
| | UE1.B: Favourites | The inclusion of a number of favourite recipes in the suggested meals function was mentioned (Pic 5.3) |
| | UE1.C: Main-food based structure | Some of the participants suggested that food be presented based on the type of food being consumed (Pic 5.3), this echoes points made in OASIS-2 meetings |
| UE2: Motivation | UE2.A: Motivational messages | The role of the system in motivating the user towards a healthy lifestyle was mentioned (Clip 4) |
| UE3: Obligations | UE3.A: Supermarket Influence | There was a concern about the possible influence of supermarkets and marketing on meal choices (Pic 1.2) |
| | UE3.B: Over-controlling | Participants also raised concerns about the system being over-prescriptive in terms of nutritional information (Pic 1.3) |
| | UE3.C: Irritations | The potential for voice alerts to become irritating was voiced by one participant (Clip 17) |
| | UE3.D: Simplicity | Simplicity and transparency of the technology throughout the system was mentioned as a key point several times (Clip 8, Pic 5.4) |

Table 6-12: User experience Issues from workshops

| Category | Concept | Description |
|----------------------------|-------------------------|--|
| FN1: Entering Food Data | FN1.A: Entry method | Having the option to speak or write the information was suggested (Pic 6) |
| | FN1.B: Categorisation | Participants wanted clear options to select whether the food was destined for the refrigerator, freezer or cupboard |
| FN2: Shopping List | FN2.A: Printable List | Participants asked for a printable shopping list function (Pic 6.1) |
| | FN2.B: Sorting | Items were ordered by popularity (Pic 1.5, Pic 4.2) and/or location in the supermarket (Pic 1, Pic 4.2). Frozen and chilled items could be listed last (Pic 4.2) |
| | FN2.C: Non-food items | Participants suggested non-food items should be included on the list, so as not to necessitate taking more than one list (Pic 1.4) |
| | FN2.D: Nutrition Info | A traffic light system to shorthand nutritional information for items on the shopping list (Pic 1.5). was suggested, it was noted that including complex nutritional information in a shopping list was impractical (Pic 1.1) |
| FN3: Recipe Book | FN3.A: Personalisation | The participants asked for a facility to store and suggest recipes. (Clip 2, Pic 6.2), this was to be accomplished using a simple form (Clip 15) |
| | FN3.B: Nutritional Info | Participants asked for recipes to include information on vitamin content, good fats and saturated fats, calorie content (Clip 19, Clip 19) |
| | FN3.C: Sorting | Recipes could be accessed according to what foods were already present in the kitchen (Clip 18, Pic 6.2) and could be grouped by light or main meal, lunch or dinner (Clip 14, Clip 12). They might also include pictures of meals (Pic 5.2)(although this was thought |

| | | |
|----------------------------------|----------------------------------|---|
| | | unnecessary by some (Clip 15) |
| | <i>FN3.D: One-Person Portion</i> | It was suggested that portions and amounts in recipes should be geared towards a single person eating alone (Clip 10) |
| <i>FN4: Food Planner</i> | <i>FN4.A: Planning</i> | A planner function was suggested whereby users could keep track of food in their cupboards, schedule shopping trips etc. (Pic 6.3) and plan meals through a week (Clip 3) |
| | <i>FN4.B: Reminding</i> | The participants discussed the importance of reminding elderly users to take meals (Clip 16 , Clip 9) although one expressed reservations about this feature (Clip 9) preferring the function to be limited solely to shopping) |
| <i>FN5: Alerts and Reminders</i> | <i>FN5.A: Reminding function</i> | Alerts and reminders could be included in system by using a tone or voice (Clip 7) and could also remind users to drink water regularly (Pic 6.3), take a hot drink before bed (Clip 4) and not to eat too late in the evening (Clip 6). |
| <i>FN6: Customising</i> | <i>FN6.A: Reminders</i> | options for customising the appliance were discussed (Pic 6.4), and options were suggested including being able to turn voice prompts and alarm tone on or off, setting volumes, setting frequencies of alerts etc. (Clip 13 , Clip 17) (Pic 6.5) |

Table 6-13: Functionality issues from workshops.

6.4 CONCLUSIONS

The older adults showed that they were capable of engaging with a problem and producing relevant ideas much more quickly than the older people with dementia that were worked with in the KITE design method. However, the quality of the relationship between the older people and the consistent points of contact did not seem to develop as much as it did in the previous work because of the limited time spent with the participants. However, giving the participants the opportunity to more directly articulate their requirements, even when these were selectively developed, seemed to increase their sense of ownership over the project and lead to them being more willing to engage with the design activities later in the process.

There were several issues with the way that this early version of the design approach was used. Participant diversity in this process suffered because of the decision to recruit from locations that were central to the city and only accessible by people who have a reasonable level of mobility. The alteration in the design framework to consider the venue of recruitment would be made in an attempt to avoid this happening in future studies.

In addition, the participants tended to not engage with the scenario work as much as the design team had hoped they would. Whilst the process worked, broadly speaking, the participants tended to neglect the specific stages in favour of performing several stages in a single utterance. This was so pronounced that it led to combining the presentation of the scenario generation and the claims analysis process in this chapter because the two were so intertwined. In addition, participants had a tendency to talk about their own situation rather than discuss the hypothetical ones that the process tried to elicit. The personal nature of the information being presented led to concerns that it might make other participants in the group uncomfortable with engaging with it critically.

The invisible design video prompt was extremely well received by the participants who enjoyed the humour in the video and felt that some of the issues that it portrayed resonated with their own experiences. The participants produced numerous ideas in both the early exploratory work and the later low fidelity prototyping work, in contrast with previous literature on the subject [97], which further demonstrated the utility of the video approach. Further work adds an extra role for the video to turn it into a prompt to develop conversation around the subject of scenarios.

CHAPTER 7: REFINING THE OASIS DESIGN APPROACH

The previous design work focusing on promoting healthy eating for older adults through digital technologies demonstrated that the OASIS design approach had the potential to elicit novel insights into an older person's day-to-day life and felt experience using a much shorter design process. However, the work also revealed several issues with the structure and techniques used in the design process. The approach is modified by trying to use the video in different roles in the two more design sessions focusing on transportation and personal safety to address these concerns. The modifications made to the process affect the recruitment and the exploratory work so the focus is placed on documenting these stages in this chapter.

In the transportation group the video is modified to present the participants with a scenario that they can tie their thinking to when constructing scenarios, the process of making the video is altered substantially in this process and the video is shown before the scenarios are created. In this way the participants are encouraged to create scenarios around something "tangible" that they can tie their thoughts and descriptions to when presenting their ideas for scenarios to the rest of the group. This prompted some of the most interesting findings and the design method followed in the process is the one presented in Chapter Five.

In the study of personal security the video is modified to present pastiche scenarios to the participants featuring a well known character from television, Dot Cotton an older lady from the long running EastEnders BBC TV soap because of concerns over the level of engagement with unknown characters being potentially distressing. In addition, because this area is less well defined, the video is split into three different areas each showing a different aspect of personal security relevant to older people. This process encounters several problems and reflection on the reasons for these issues is also presented.

In both of the design processes outlined in this chapter the recruitment was more mindful of the issues discovered in the work around healthy eating, the recruitment is done at more accessible locations and the consistent point of contact goes out to these locations to work with the participants so that those with poorer mobility are included in the groups. The results of these studies would go on

to inform the final design process already presented in Chapter Five and demonstrate the potential of video to help participants engage with novel scenarios.

7.1 TRANSPORTATION DESIGN MEETING

The transportation groups focused on the issues which older people have with getting out and about in public. The work was performed as part of the OASIS European Project with a focus on generating requirements for the scenarios based around pre-trip planning and pedestrian navigation in new and familiar environments. The literature on the process suggests that the primary problems in this are relate to the mobility issues of the senior. Elderly people lose their personal physical mobility as they age due to conditions such as osteoarthritis, deterioration in musculature, loss in range of motion of joints and physical balance problems. In addition, the elderly person's personal freedom to travel is often restricted through the loss of their ability to drive. The UK demands regular testing of people over the age of seventies driving aptitude. Impairments in vision and hearing make navigating new or altered environments, due to roadwork for example, much more difficult. These factors combine to make getting "out and about" very challenging for some older people.

7.1.1 Process Modification

The design method was altered in light of the findings from Chapter Six to better facilitate discussion of the scenario rather than discussion of the individuals experiences. The process followed in the exploratory meeting was modified with prompt viewing brought forward in the amended process.

1. *Information Gathering*
2. *Prompt Viewing*
3. *Scenario Generation*
4. *Claims Analysis*
5. *Feature Envisioning*
6. *Scenario Envisioning*

When creating the video for this scenario the instructions to the film maker were altered substantially. The previous video had been constructed with minimal input from the designers beyond setting the scope of the design activity. This allowed the film maker maximum creative freedom and to ensure that the video was entertaining. This time the team felt the need to constrain the setting more to create a more focused scenario. As the study showed through the more protracted and in depth engagement with both the vide and the scenario creation process, these extra constraints did not prevent the film maker from making an engaging piece of video. The film maker was asked to create two characters for the film with one taking the role of a competent, aware older person who could successfully use invisible technology and the other taking the role of an incompetent who regularly struggled to use the technology or even cope with the scenario they were in normally and this led to the development of the script. The film maker likened the characters to the straight guy - fall guy

scenario, a regular feature of comedic writing where the straight guy is a capable individual whilst the fall guy is a comedic buffoon.

The script had to go through several iterations before both the researchers and the script writer were happy with the result with disputes most commonly centred on the design teams concerns that the video either did not portray enough issues relevant to the problem area or that the film portrayed the older character as “in the wrong” too often. Over the course of re-writing the script the writer was happy to take input and drastically re-draft the script in light of the feedback from the research team but asked that the design team did not interfere at the “micro” level of the writing process. In other words, they were happy to be guided on the topics of discussion but did not want parts of their script rewritten.



Figure 7-1: Screenshot from the film used in the transport meetings showing Alice on the left and Bob on the right.

The film the group watched was called Hegel's Bagels, the video showed two older characters, Alice and Bob, on their mobility scooters trying to get to a cafe to meet their friend. The pair used mobility scooters to get round and the video opened on Alice getting her new mobility scooter. Bob, who had already owned and used his scooter for a while was trying to show Alice his expertise but Alice rapidly learned to use her scooter much to Bob's annoyance. Alice had a small device attached to her scooter which Bob hadn't seen before; this device was the *invisible design* artefact. Although never clearly shown it gave Alice a variety of functions to use throughout the video giving her the edge over Bob at all times. The video culminates in a row between the two which leads to Bob going on his own route to the cafe rather than following Alice, this leads to all sorts of problems as he gets stuck at steps, goes down dead ends and gets blocked off by rubbish. Alice finds him because she has hidden a tracking device on his mobility scooter (in a nod to privacy concerns around tracking) and guides him to the new meeting place eventually having been told by the device that their friend they are going to meet says their original meeting place is too crowded so has gone somewhere else.

This approach pre-emptively created characters to fill the role of the best and worst case scenarios talked about in scenario generation themed around getting out in the local community. The intention was that this would help focus the discussion onto the theoretical characters and away from discussion of the self during scenario creation. The ways in which the scenario generation was presented to the participants were altered to enhance this. In the previous work the blurb for the facilitator was themed around the good case and the bad case:

“We’d like to move on now to try and come up with three fictional scenarios, one is going to try to look at the best case for <Design Domain>, it’s going to be really idealised. Another scenario is going to look at the worst case possible, so this is going to be absolutely terrible. The final one will look at the middle ground, the sort of day-to-day normal scenario which we probably all live in.”

The blurb in the final design process is:

“We’d like to move on now to try and discuss what we think are the main differences between Alice and Bob in the video. What are Alice’s characteristics that make her so capable, what are the things about Bob that lead him into trouble? Outside of the story we’ve watched how do you think the two behave?”

7.1.2 Recruitment

Recruitment for this workshop was performed through the local older peoples advocacy group Years Ahead who placed the design team in contact with a residential care home. Years Ahead were asked to look for people with mobility issues as this was assumed based on the literature, to be the biggest issue around personal mobility. Years Ahead were also asked to see if they could find a group that included a mix of drivers and non-drivers. One group was recruited matching the profile with some of the participants in the group knowing each other from living in the same residential care home (see Table 7-1). The work was conducted in the common room of the residential care home to allow easy access to the participants.

Susan and Helen were close friends who both had similar issues with Arthritis. Despite this, they were both still able to get out and about with little difficulty through the use of a taxi service. Susan seemed to take the lead in planning their actions but both seemed to experience minimal trouble because they planned together and travelled together. Bruce still drove had some physical mobility problems and he reported problems of his own getting into shops after parking because of poor availability or arrangements of shop parking. Wesley did not drive himself but sometimes travelled with Bruce and sometimes relied on the bus service. Adrienne was the Age Concern volunteer who sat in on the meeting and occasionally contributed her own thoughts or experiences. Caroline was a support officer at the care home who knew all the participants well and had similar issues to them when it came to public transport.

| Name | Age | Gender | Role | Mobility |
|------|-----|--------|------|----------|
|------|-----|--------|------|----------|

| | | | | |
|----------|-----|--------|---------------------------|---|
| Susan | 65+ | Female | Care Home Resident | Arthritic, very limited mobility |
| Helen | 65+ | Female | Care Home Resident | Arthritic, very limited mobility |
| Bruce | 65+ | Male | Care Home Resident | Still Drives |
| Wesley | 65+ | Male | Care Home Resident | No particular problems but does not drive |
| Caroline | 55+ | Female | Care Home Support Officer | No issues |
| Adrienne | 55+ | Female | Age Concern Volunteer | No issues |

Table 7-1: Participants in the transport exploratory meeting.

7.1.3 Process

Prior to the meeting the participants were briefed by their care home support officer about the possibility of taking part in a meeting with Newcastle University researchers to talk about transport and mobility issues. When the meeting was conducted the participants had the basic structure of the session outlined to them and they were told the meeting would start with everyone introducing themselves and then they would be asked to watch the short video. When the video was shown it was prefaced by saying that it showed two people, one with poor ability to get out and about and one who was very able to do it and looking at how the scenarios played out.

Prompt Showing

The film had a clearly differentiated pair of protagonists who obviously corresponded to the best and worst cases possible. The humour in the film was generally well received although the Group Facilitators did note that the participants tended to not laugh aloud when the two protagonists used even slightly coarse language. In addition, participants tended to vocalise some shock at seeing the mobility scooter user crash in the final scene twice. In general however the video was well received and all participants seemed to say they enjoyed the video.

Discussion after the video did tend to focus a lot on mobility scooter based issues and sat-nav for older people on scooters.

And I noticed he seemed to run out of power almost a couple of times, you know, on his scooter, is there not a way that...

- Susan

The scenario shown in the video may have been too explicit in how it functioned and participants reacted to the “Don’t go sticking things on me bike!” Scene as if it were a joke rather than a possible legitimate feature. The likelihood is that the video strays slightly over the line of “Invisible design” Into the realm of simply illustrating future scenarios using such a device. The participants were not always being inspired to think how a given experience might be brought about as much as they were thinking about how they would react to the technology in the film.

Scenario Generation and Claims Analysis

The group developed two distinct personalities based around the characters seen in the video, the characteristics of the two protagonists were explored in more depth and some suggestions were made about the possibilities of activities beyond the scope of the scenario (Specifically, using public transport).

| Alice (The best case) | Bob (The worst case) |
|---|---|
| <i>Confidence</i> - In attitude, in technology, in herself | Bob is “a grumpy old man” – and he doesn’t try hard |
| Alice is not necessarily able bodied | |
| Alice is prepared to follow instructions - she reads the manual | Needs facilities for shop access |
| | Steps, not ramps |
| Uses public transport - although some services stop scooters which can be a problem | |
| Does not necessarily drive | |
| Because parking can be a problem | Bob has limited mobility and <i>allows</i> this to get in his way |
| Disabled spaces short supply | |
| Distance from shops | |
| <i>Alice plans ahead</i> | Bob doesn’t think or plan |
| New to scooter but still capable because of this | Set in his ways/ Refuses to learn |
| Can plan again on the fly when she needs to | Fails to plan around a problem |

Table 7-2: Characteristics and claims associated with the best and worst case transport scenarios.

The results from the discussion were surprising because all the participants were adamant that the differences between the pair were not a result of differing levels of physical mobility. Alice was not necessarily able bodied but instead she was simply more prepared. One example was a participant noting that the difference was that Alice read the manual and Bob was a “typical man” who wouldn’t read it. Alice was also confident, she was happy relying on herself to get the job done.

“Confidence does a lot of things for people“

- Susan

Alice believed in herself and in the technology which she used. Bob on the other hand was a “grumpy old man”, he didn’t try hard and he didn’t think or plan ahead. Another person pointed out that bob was strongly set in his ways and that was part of the reason that he couldn’t adapt to the challenges which he faced.

The group moved on far beyond the scenario played out in the video, for example, they imagined that Alice would be much more likely to use public transport regularly. At this point the group moved on to discuss the problems with the local public transport situation which had recently stopped mobility scooters being taken onto the subway system.

Susan: As far as I know they've stopped using, they've stopped the large electric scooters going on, yes, chairs and small ones, but the actual chairs, the small chairs...

Bruce: And the shopping ones I think.

Adrienne: They can go on, but the large sort of like motorised...

Helen: Vehicles [laughs].

Adrienne : ...almost vehicles, they won't let them on anymore,

- *Group Discussion*

Another outcome of the group which was not anticipated was that the best case scenario would not necessarily involve Alice driving a car, this was because disabled parking spaces can be hard to find and the spaces that were available were often a long way from the shops. Bob on the other hand need help getting in and out of shops because he wouldn't look around and plan ahead to find the disabled access into shops. Finally, Alice would be able to plan ahead and plan on the fly when she encountered problems unlike Bob who could manage to meet his own basic transport needs but, when he encountered trouble, would start to have serious problems. Both Alice and Bob share a problem in that they can have their days disrupted by unexpected issues cropping up during the time they are out and about. For Bob this is a greater issue than for Alice but she can still lose out in this situation. Some of the common issues include pavements being repaired, road works disrupting their route and streets being closed. Similarly, unfamiliar environments could throw up unexpected problems for both Alice and Bob. Many of the scenarios that the participants focused on were not ones portrayed in the videos. Instead, they stemmed from either their own experiences or their friends experiments but were projected onto Alice and Bob.

Feature Envisioning and Future Scenarios

Participants discussed a variety of different future scenarios, although there was a tendency to focus on scenario's that revolved around the mobility scooters as previously mentioned.

"But when you think about these mobility scooters, like say there's going to be road works somewhere, you get it in the paper, you get it announced on the radio or whatever, but not when there's going to be a pavement dug up in front and there's somebody on a mobility scooter. That would be an obstacle for them wouldn't it?"

- *Adrienne*

The number of scenarios discussed and the way that they tied back to the characters were much more pronounced when compared to other groups as evidenced by the ability to start to construct the characteristics of the participants in the scenarios seen in Table 7-2. The initial scenario that people discussed revolved around the mobility scooter and problems with the range of these scooters, participants said that they would be concerned about a scooter running out of power, referencing back to some of the problems which Bob had in the video. This also tied back to the extensive discussion of pre-planning and the major role that it played in mobility.

"It's true what they say. Where there's a will, there's a way. You know, and, and you will."

- Susan

Someone suggested that a sat-nav should inform the user of how far they might be able to travel on a journey (Scooter-based) and warn them if a plan they entered would be unfeasible. This discussion also mentioned the possible need for training using mobility scooters. This discussion evolved around the theme of pre-journey planning, participants indicated that the main area for this planning was within the house, saying that this was a major location for this, and in the ideal case, perhaps the only place where planning was undertaken. This discussion again tied back to the importance of attitude over physical capability, someone with problems needed to plan for them but was rarely prevented from doing something by their problems. Alice would plan ahead, Bob would not, the group felt that Alice might not need technology to help her but Bob might be helped if medication he needed could be accounted for when he planned a trip. The group felt that Alice did not really need help to achieve this planning and did not discuss Bob at length however the discussion came back around to the common issues they shared in the appearance of an unexpected problem.

Bruce: Re-planning your route.

Facilitator: And that's something that can affect Alice or Bob isn't it really? So, that could be a problem for Alice if she's unlucky, and it is a problem for Bob because he is unlucky all the time.

Caroline : Alice would have to sort it out for him

[All laughing].

- Group Discussion

One core idea suggested was a pedestrian travel information service similar to the Travel-Info broadcast on radios now, or simply being able to call a phone line and receive a report on the local area. This appropriated familiar technology to provide a new service and this was a common theme.

The participants also discussed the concept of sharing information about the transport needs in a local area in some way. One example they discussed was wanting to be able to share people's observations about the provision of accessibility to the different local shops. The group felt that if a shop was not living up to its requirements to provide disabled friendly access they should be able to know about it in advance and avoid or even boycott it. This again tied back to the theme of feeling that it was others actions which led to the older person having trouble in getting out and about. However, some participants felt hesitant about this, believing that the average older person would hesitate to complain, some suggested that "expert users" (i.e. locals with a range of disabilities) could be given the devices and asked to use them and the information might be disseminated to others via paper maps at a variety of locations (e.g. metro stations or in the foyer of residential care homes). The groups also discussed people with poor attitudes to getting out and about, these people might be helped through the development of a system that partnered them with others in similar situations but who were confident in travelling in order to gradually restore their confidence.

A side issue with bus drivers being unhelpful or inconsiderate kept appearing, this discussion tied back to the commonly seen idea of the device which tells you when the next bus is due. A consistent, emergent theme in the discussion was the actions of the local council with the group frequently criticising them. Three issues were pointed out, the removal of the ability to take wheelchairs on the subway system, the unhelpful attitude of some transport sector employees and the removal of a key bus route through the area. These problems contributed to the sense the meeting gave that it was often the actions of others that led to the older person having trouble with their mobility.

The group was not as vocal when it came time to critique the ideas that they had, they mentioned the need for “simple” interfaces to technology with no “small buttons” but did not have many more specific comments except to say that they believed that a mobile digital device for pedestrian route planning would not be welcome, instead they envisaged the information being printed off on leaflets and distributed at transport hubs.

7.1.4 Requirements

The participants in the process generated many different requirements for potentially useful digital technologies including devices that would help them plan their journeys in advance and avoid unexpected problems.

| | |
|--|---|
| Route Guidance: Pre-planning | Participants noted that their main strength lay in planning a route in advance and that technology that helped facilitate this would be the most useful. |
| <p><i>We're very fortunate in having the taxi card service, which is a big help, but as far as going to town is concerned we usually go together. Arrange which shop we want to go to, get a taxi that's near, go to that shop and then come home. We're not able to walk around town</i></p> <p><i>But she's obviously prepared to follow instructions and make the most of the apparatus she's got. the preplanning also, as you said, to be able to re-plan if you get stuck.</i></p> <p><i>Well, we plan a journey into town the day before, you know. We'll do this and that, go out and spend to long out and not get back in time for medication, things like that, reminders of... he would forget to take his next dose with him because he would get carried away when he was off, out having his adventures</i></p> | |
| Route Guidance: Avoiding unexpected surprises | Participants noted that they mainly didn't need any help getting out and about because they had access to all the information they needed but they did note that they struggled when they encountered unexpected problems and they wanted to be alerted to these. |
| <p><i>they're fixing the Haymarket metro that we usually take and there's certainly no announcements about that</i></p> <p><i>When I, when I was still using busses, two or three times I went up to the stop and the bus didn't turn up, and I was meeting someone in town at a particular town. So, you've got to dash back here and phone for a taxi.</i></p> <p><i>Because I, I've been going up there for 18 months now and I haven't got a clue what time they come. [Overtalking]. I just go and hope for the best.</i></p> | |

| | |
|--|--|
| Route Guidance: Pedestrian travel information | Participants liked the idea of having a pedestrian traffic report akin to the ones that are played on the radio. They felt that this would help them avoid unexpected challenges and encourage people to plan journeys |
| <p><i>Yeah, it's the equivalent of needing a traffic report.</i></p> <p><i>Female One: Because, I mean, people that still get on the Metro with a wheelchair even, you can't use a wheelchair on the escalators so you've got to get off at Hay Market because that's the one with...</i></p> <p><i>Female Two: With the lift, you know the certain one.</i></p> <p><i>Kerbs, yes they're very bad for us.</i></p> | |
| Route Guidance: Local travel information leaflets | Participants were averse to the idea of having to carry a device with them that would relay the information that they discuss in the rest of the work but did like the idea of having physical paper copies of information that could be collected either from their care home or from transport hubs. |
| <p><i>And if you could have these available at Metro stations and, you know, so that I can just pick them up.</i></p> <p><i>knowing what's available...</i></p> | |

Figure 7-2: Route guidance requirements.

The participants often mentioned that the source of their mobility problems was mainly external, for example, the removal of bus routes they relied on. The participants seemed to feel marginalised and liked the idea of being able to coordinate with each other and present arguments to the local council.

| | |
|---|---|
| Social pressure: Shop pressure system | Participants noted that many shops did not provide an easy way for someone who was mobility impaired to access them. They wanted to be able to either put pressure on the shops to change their behaviour or share praise for shops that went out of their way to be more accessible. |
| <p><i>But it's the shopping in the town that's the worst because if you want to go into the Bridges [?] you can't get a taxi into the Bridges. You can't walk from where, you know, where it drops you off</i></p> <p><i>If they had a handrail on the side, it's all you need to help you to get in and get out. But two steps in the middle of nothing, you know, you just haven't got the confidence to get up and down.</i></p> <p><i>My understanding is they don't bother doing anything about it unless someone complains.</i></p> <p><i>On a positive level, rather than, to me that's a, sort of, negative thing, is it not possible to have some sort of network that if... you know people, wheelchair users, not necessarily electric scooters or disabled people in general, if they go somewhere where they get good service or useful places that they can pass on, like a network of wheelchair friendly places to visit or shops to go to, that sort of thing.</i></p> | |
| Social pressure: Transport staff feedback | Participants felt that the needs of older people were frequently neglected by transport staff including bus drivers and telephone operators and wanted a way to criticise and feedback on this. |
| <p><i>And they're not allowed to do, but I would have said someone should have made sure that they were getting down okay.</i></p> <p><i>Female Three: I think it should be that they shouldn't, that the buses shouldn't pull off before anyone...</i></p> | |

| | |
|--|--|
| <i>Female Four: No, not until you're sitting down.</i> | |
| <i>Female One: Exactly. I think my opinion with buses at the moment is that with the owners of the company, the people have become like a second thought, making money has become the first thought.</i> | |
| <i>Facilitator: Mm, pick the best and worst of shop access.</i> | |
| <i>Female Four: Yeah.</i> | |
| <i>Female Three: Yes.</i> | |
| <i>Facilitator: That's very interesting, that's...</i> | |
| <i>Male One: So, how would you find that most useful in, sort of, a device you could take out?</i> | |
| <i>Female Two: Well, all we need really is something that we could put a notice on the notice board</i> | |
| Social pressure: Bus routes | Participants complained that the bus routes that they relied on were being removed because they were no longer profitable and they wanted a way to collate complaints and pressure the council into re-instating them. |
| <i>If you were to say to me, what is the problem with public transport for me, I would say the fact that we've got none. That would be my answer.</i> | |
| <i>But the main problem is that there just is no bus, we can't even try to see whether we can get on or not.</i> | |
| <i>We just get the feed-back that well, that's what my opinion is, that we're just not a viable proposition. It's not making money so therefore we don't count. That's the feeling.</i> | |
| <i>As far as I know they've stopped using, they've stopped the large electric scooters going on, yes, chairs and small ones, but the actual chairs, the small chairs...</i> | |

Figure 7-3: Social pressure requirements.

The participants did not construct many novel obligations except for one; they did not want to carry a digital device with them when they were travelling outdoors.

| | |
|---|---|
| Obligation: Avoiding carrying additional devices | Whilst participants liked many of the ideas proposed they did not want to have to carry an additional digital technology with them when they went out travelling to be able to access the data. They would prefer to have had pamphlets they could carry with them or a device set up in the entrance to the care home to avoid this. |
| <i>These kinds of things, I mean, if you didn't want to, sort of, go down the, the route of devices, extra devices, could something like this not be done on a telephone line, like a way to type the number, like, or wherever these free numbers are where you can ring in and say, can I have, like, the... if there's any obstacles on such and such a route, that type of thing.</i> | |

Figure 7-4: Obligation to not produce a digital device that would have to be carried outdoors.

7.1.5 Reflections

This group consistently produced new and novel ideas that related back to the video but was based on their own personal experiences. This affect appears to come from the video prompt concreting the process in the minds of the members. The consistent point of contact also presented the work differently moving away from the idea of using a scenario towards the idea of talking about people. This further de-jargonised the process and made it more accessible to the participants. The atmosphere within the sessions was excellent, participants frequently joked with the consistent point of contact and all seemed to contribute to the process equally. The participants enjoyed watching the

invisible design film and thought that the humour in it was excellent, this may contribute to the good atmosphere in the sessions.

The scenarios that the participants developed were strongly grounded in the video that they were presented with. The participants frequently referred back to both Alice and Bob throughout the first half of the discussion and the traits that were associated with Alice and Bob, particularly planning and confidence, were important elements of all of the scenarios that were developed.

Caroline: It's just two minutes in the car and you don't think about it but if you could, sort of, say, well, I know, you type in your Satnav, I'm going to go from A to B and back again so, it's an eight mile round journey...

Helen: Alice would have that worked out [laughs]!

- Group Discussion

The participants did not produce many obligations for technology design but this seemed to be because they were very engaged with the ideas that they were producing and they developed their ideas as they had them to improve the quality of their suggestions. Some of the requirements, for example the leaflets at transport hubs, are responses to potential problems. Another example was the idea of developing a system that allowed people to praise good shop access rather than criticising bad shop access or report issues anonymously which was a direct response to the issue of people was not being willing to complain:

Especially... especially if it's not totally anonymous, but a fairly anonymous thing... discreet yes, it's not like you've got to go to the shop and say I'm going to say this, yes. You can do it, you can leave the shop or leave the facility then send it off and, you know, yes.

- Susan

I mean it's a well-known fact that isn't it? I think really English people don't complain...

- Helen

One particular issue was that this video portrays Bob as being the voice of opposition to the technology. This could invalidate the criticism of the technology, for example when Bob is later dismissed as being a typical man not reading the manual that participant might be dismissing the problems with technology out of hand:

"Typical man, he doesn't look at the instructions"

- Female Participant, Transport meeting

In the future a better balance might need to be struck between the use of technology and the problems with technology, perhaps having the technology let down the good case character and seeing them work around it whilst the worse case fails to do so. Another option to ensure more balance would be to cast the worst case character as a source for sympathy whilst providing comic relief with the best case character.

7.2 COMMUNITY AND SECURITY GROUP

The work described here is again conducted as part of the OASIS European Project [113], this time looking into the benefits that can be derived from the use of community security facilitating technologies that give the users a sense of security. This topic is wider than the previous design studies and, in addition, is a much more sensitive issue. Older people have many fears and concerns about their personal safety, these fears are not necessarily borne from a high level of crime experienced by older people though [162] as the number of older people who are victims of crime is very low, male and female over-sixty-fives being the least likely groups to suffer from violent crime. This does not mitigate the fact that older adults are more concerned about crime than other groups as can be seen in a wide range of literature [6,69]. In addition, many older people are more vulnerable to crime meaning that, although less likely to be a victim, the effects of being robbed may be much further reaching for an older person and strain their ability to live independently, as such, their greater concern over crime may be viewed as justifiable.

The use of surveillance in the form of CCTV has been proposed as one solution to this issue [6] by older people themselves however the use of surveillance technologies to monitor people may cause more issues than it solves. The fear of crime amongst the elderly may be disproportionately high; the implications of providing technology to combat crime levels when the perception of crime may be the primary issue need to be fully understood. If the older person is overly concerned, the addition of monitoring technology may only serve to bring the issue to the forefront of their minds. In addition to this it is already widely accepted that the U.K. is one of the most surveillance intensive countries in the world [135] and there is a strong negative attitude towards “Big Brother” technology which is frequently discussed in the media [105,141]. This attitude exists to such an extent that now there exist organisations dedicated to countering the rise of surveillance technology and its impact on personal lives [112]. If surveillance technology is presented to older people to alleviate their fear of criminal activity, it must somehow combat this negative perception. The fear of “big brother” may be a legitimate one and if this is the case then the privacy issues raised by incorporating surveillance technology into one’s life must be considered as well.

7.2.1 Process Modifications

There were three major challenges to this design process that were identified early on. The first of these was the broad nature of the domain the work was taking place in. Unlike previous work, the review of literature identified a range of problems that affected the older adults. This led to uncertainty about how to approach presenting all of them in one video with a consistent story. After the design team discussed the problem, the decision was made to manufacture three separate videos and show them one by one with discussion following each:

1. *Information Gathering*
2. *Distraction Burglaries*
 - a. *Prompt Viewing*

- b. *Scenario Generation*
 - c. *Claims Analysis*
- 3. *Domestic Violence*
 - a. *Prompt Viewing*
 - b. *Scenario Generation*
 - c. *Claims Analysis*
- 4. *Street Intimidation*
 - a. *Prompt Viewing*
 - b. *Scenario Generation*
 - c. *Claims Analysis*
- 5. *Feature Envisioning*

The future scenario envisioning was left for one session in the last part of the process as it was hoped that the issues might combine to shape new or novel ideas and because it was anticipated that a substantial degree of crossover between the issues. Concepts the design team anticipated arising included discussions about privacy such as who can see the video and the team planned to inject the community element here with discussion of “Little Brother” technologies. Other topics like the role of community, fears over system security e.g. misappropriation of the video feeds and the ubiquitous need for “ease of use” were also anticipated.

The second issue was the need to discuss sensitive personal issues in this process because problems with family members and feelings of lack of support were going to be highlighted. This tied to the third issue as producing a humorous film on this issue was judged to be lacking sensitivity and so unsuitable. The need to disengage the people from talking about their own personal issues was considered to be important because it was believed that participants would not want to talk about people in their own family circle in the meetings. In addition, there was concern about the potential for such discussion to turn to extremely sensitive, personal details and this was something that was considered both potentially unethical due to the possibility it might distress participants, and counterproductive as it might cause the participants to hold back from engaging in the process. The solution chosen for both these problems was derived from looking into using *pastiche scenarios* in design [6]. Pastiche work leverages well known fictional characters and positions them in scenarios within the domain which the designers are interested in. Scenarios can be constructed in various ways but the one chosen for this work was the medium of film. Dot Cotton and Peggy Mitchell, well known elderly characters from the long running BBC TV soap EastEnders, were placed in situations where they were confronted with personal security related problems. These well known characters are often portrayed in these situations on TV and so it was believed that the participants were less likely to become distressed by the portrayal of sensitive issues encountered by these people.



Figure 7-5: Dot Cotton from the TV show EastEnders answers her front door, the editing suggests that whilst she is doing this, someone is breaking into her house through the back door.

7.2.2 Recruitment

Recruitment for this workshop was performed through the local advocacy group Years Ahead. They were asked to look groups that included some people who lived alone or felt that they might have some security problems. One group was recruited matching the profile with participants in the group knowing each other from attending the same Age Concern centre (see Table 7-3). The work was conducted in a meeting room at the Age Concern centre. All the participants attended and the session lasted for approximately one and three quarter hours. After administering the appropriate ethical consent forms the session was audio recorded for transcription and analysis purposes.

John and Lillian were married to each other and lived in a reasonably quiet suburb of a nearby city. Ron and Audrey were also married to each other and lived in a nice neighbourhood in the same city. Audrey held strong views about the topics that were discussed and her views would cause some conflict. Sylvia and Pat were friends who came from a town that had more problems and Pat particularly had experienced uncomfortable moments when walking alone on streets.

| Name | Age | Gender | Role | Notes |
|---------|-----|--------|--------------------|--------------------|
| John | 65+ | Female | Age Concern Member | Married to Lillian |
| Lillian | 65+ | Male | Age Concern Member | Married to John |
| Ron | 65+ | Female | Age Concern Member | Married to Ron |
| Audrey | 65+ | Male | Age Concern Member | Ron |
| Sylvia | 65+ | Female | Age Concern Member | Lives alone |
| Pat | 65+ | Female | Age Concern Member | Lives alone |
| Barbara | 65+ | Female | Age Concern Member | Lives alone |

Table 7-3: Participants in the security meeting.

7.2.3 Process

Introductions were made by all present, all the participants initially said that they had no problems with crime or intimidation but some of them did later on make comments which suggested this was not completely accurate.

I was born in Sunderland where I live is very good for security. I'm quite happy with where I lived, just outlying places, but always modern

- Sylvia

(Discussing walking past gangs of teenagers later in the session) If I walk towards them, my hand gets tighter on my handbag and the fists are ready. Not that I would do any harm and that, good evening [laughs]. But there you go.

- Sylvia

This appears to demonstrate the problems inherent in discussing such a sensitive issue with participants talking from a personal standpoint. The participants became more willing to divulge personal accounts as the meeting progressed although it should be noted that these personal stories were not the target of questioning. When the format of the meeting was introduced about half the group said they were familiar with EastEnders and everyone present recognised Dot Cotton and Peggy Mitchell.

Distraction Burglary Video

The prompt shown in this section of the work related to the problem that is widely reported of distraction burglaries. The video showed a man knocking on Dot's door and talking to her whilst editing suggested that another man was robbing her. The video also included a short clip of Dot plugging in some sort of security camera system. Unfortunately the participants recognised her son Nick Cotton as the man at the front door distracting her whilst she was robbed.

I least I don't think that character, it was her son, so I know much about raising son, but I don't think... how can I put it? I think she must have twisted [?] herself [?] that much not to realise what she knew herself in order to be [unclear]...

- Pat

The participants also spotted that the video footage used in the pastiche to show the back of the house being broken into actually came from another location:

Pat: The camera was in the Queen Vic.

Facilitator: Yes, that is the problem.

Pat: You should just have put in a phoney (shot).

- Security Meeting Group Discussion

All participants seemed to understand what the video showed although a title card at the start does give the name of the crime being committed and at the end of the clip another card presents some

statistics relevant to the crime being shown to set it in context. When discussing the features associated with Dot, following the idea of avoiding discussing scenarios from the transport work as much as possible, several ideas emerged. Things that would make Dot less vulnerable to this sort of crime included living with a partner, living in a safer location and a shift in her attitude to be less trusting or naive. The group felt that Dot both trusted people too much and, at the same time, needed to have a stronger personality to allow her to refuse to talk with strangers if she felt unsettled. In the worse case they thought that Dot would feel trapped in her house so was more likely to be grateful of any sort of human contact:

They've got nobody visit them, I think and then somebody comes to the door and they're like, oh, won't you talk to me?

- Audrey

Although this Dot would not trust anyone she was miserable because of the isolation and fear this brings. They also felt that poor security habits would be pronounced in her like leaving handbags near doorways or windows.

I'm on me own and I would never put temptation in front of anybody. If anybody was coming, I wouldn't leave me purse out lying.

- Barbara

The features suggested as a result of this included cameras which video the premises, particularly at the back door. The participants stressed that any home security system would have to be easy to use, they also commented that they knew of this sort of system already available and did not buy it. There were a variety of reasons given for this including because of the high price. Another problem discussed was how there was a feeling that it was an invasion of privacy or a general lack of concern. The idea of having a front door camera was also received quite well. However, at this point the participants commented that police did not respond well to this sort of situation and commented that they thought the legal system seemed to support the criminal over the victim much of the time.

Could it work? I think of that case in the paper where them boys broke, break into the house and the lady of the home took a photograph of them and it was playing when the police said they couldn't do anything about it and yet they were breaking into the house. Now they have photograph evidence and they said they couldn't do anything.

- Sylvia

This marked a turning point in the discussion as the participants increasingly started to focus on the likelihood of the police actually taking action against anyone caught trespassing or robbing a house.

Abusive Family Members

This video showed a scenario in which Peggy Mitchell was threatened by her son in her own home. The participants again recognised the characters involved though this video was less well received. People were shocked the violent moment in the film where Peggy was pushed and were more

reserved in their initial commentary. This was perhaps because people tended to talk about a personal point of reference a lot even when speculating about others.

I'm sceptical, so I'm, throughout my life, I mean, I'm that type of person. I think the worst because of, well, of the things I've seen happen. So I tend to go on the safe route for me self as to go

- Audrey

The claims analysis here was not pressed heavily by the facilitators and instead felt it was better to move the discussion more towards the more core and general idea of the problems with betrayal by somebody trusted. One point that did however come out of this was that people were not at all happy with the idea of a camera within their own home, no matter how the data was handled:

"Looking out, that's different."

- Lillian

When discussing problems around trust, participants were more vocal, they talked about issues around online shopping and banking readily, saying that the reason they distrusted them was because of a lack of visibility:

"I like control of my money. I've got no control when it's in there. I've got control when I've got a bankbook"

- Audrey

One idea people liked was having their account spending visualised simply. Another interesting concept was the idea of an account that could check up or observe your own spending but which could not actually control it. The idea here was that the younger relatives could see any unusual activity in the account and notify their parent.

Street Intimidations

The final video showed a character from EastEnders being shouted at and harassed by a group of teenagers when they were walking along at night. The video was very rudimentary and mixed in stock footage not taken from EastEnders to create the effect of harassment. The video here, although short, was quite well received and concerns over the editing were unfounded. The attempt to profile people vulnerable to intimidation on the street by "hoodies" (a colloquial term for groups of teenagers who wear hooded jumpers and have a reputation for intimidating behaviour) was not successful though as the participants started to disagree on the profiles and take offence at other's characterisations of who was vulnerable

Audrey: It would be poorer area.

Pat: Anybody who is in an area, it doesn't matter who we are

Audrey: They will just attack anybody

Pat: Well, I'm in a poorer area, but it's...it doesn't happen there.

- Group discussion, Security Meeting

My grandson he's 20. Well, he's 21, sorry. He's 6 foot nine inches and he's a Goth and he wears this great big black leather jacket [laughter], and he's always [unclear] and everything. And anybody who's seen him probably think, oh, my God! And he's the most softest person you'll ever meet, but just because he looks like that...

- Sylvia

Participants felt that the idea of a camera to record users' surroundings was largely unnecessary except in cases where someone was repeatedly victimised, in this case the participants felt that the police should provide a camera to gather evidence. People were concerned over the cost and quality of this sort of camera, and there was an underlying feeling that these devices would not make users feel safer was noticed. A common concern that a camera would only help in finding the criminal later rather than acting as a real deterrent to that sort of behaviour:

"No. I wouldn't feel any safer, but the thing is, it would, I would think, right, if...because it wouldn't stop you getting mugged"

- Audrey

Conversation moved onto the underlying essence of the problems, the participants felt that promoting a stronger connection between older adults and young people would go a long way towards alleviating the fears of older adults as well as reducing occurrences of the crimes.

getting kids mixing with older people and older people mixing with kids so that [unclear], you know. Especially, the isolated people that only see what's on the news or in the newspaper, get them talking to the kids, and get them realising that, you know, it's not all bad.

- Barbara

The group also commented that older people also felt that the news tended towards over dramatising the issues. They mentioned that having nice news stories rather than constant negative reporting and breaking down generational barriers were more valuable tasks as opposed to deploying more cameras.

7.2.4 Reflections

The tensions within the group meant that the atmosphere within the sessions was not as pleasant as the ones in other design meetings with other groups. The tensions that formed between group members arose from clashes over the different, very personal, issues that were raised. For example one lady clearly took exception to the idea of a poor neighbourhood being one where crime would be more frequent as she lived in a poor neighbourhood but felt very safe. The issue was exacerbated by the tendency of participants to talk about their own experiences in the domain rather than engage with the characters in the video. The large number of people present in the groups meeting also

contributed to problems as people frequently interrupted and talked over each other. The tape recording of the meeting is frequently unusable due to the number of people talking or arguing.

The group did not manage to establish a common frame of reference or a best and worst case scenario in this work because the participants did not engage with the video prompt to start to construct their own scenarios about the environment. One participant mentioned that the use of EastEnders characters lessened the impact that *Pastiche Scenarios* had on her, this is interesting as she said that the fact she recognised the characters lessened the impact of the situations:

“That to me is not serious. That’s not real. They’re characters. And if they had real people in them who’s, who’s vulnerable it would be different to me...”

- Audrey

However at other times they showed some empathy with the character:

“That shouldn’t go on and I can understand how Peggy feels”

- Audrey

Although the video was designed expressly to avoid having the participants engaging too strongly with the scenario, this actually caused its own set of issues as the participants started to refer back to their own, very personal experiences with personal security as part of their own processes of making sense of the video.

I mean, one situation, when I was working, we had a carer who was the most fabulous carer I’ve ever met. She used to do above and beyond the call of duty for one particular lady that, where I was working. She was marvellous. And it was only through sheer chance that a niece discovered, happened to look at paperwork and things, and saw that money had been withdrawn on a given day, and she thought, well, she couldn’t, me auntie couldn’t have withdrawn money that day because she was with me. And it was sheer chance that it was discovered that she, that the lady had given the carer the, oh, I’ve got no money, go and, you know, there’s me card; that’s the PIN number, and then just put it back in the drawer.

- Lillian

When people questioned these accounts it obviously upset the person relaying the account and there was no shared scenario which the group could work from that would allow the design team to speculate about future technologies.

After analysing the output of the meeting, the design team opted to shift the focus away from security camera placement, particularly due to the strong opinions on CCTV in the home held by some of the participants. The project shifted its focus onto the nature of dealing with finances within the home instead.

7.3 CONCLUSIONS

The approach followed in the transport groups meeting produced the most interesting and novel insights into the design domain of all the processes that were conducted. The participants were engaged with the process, all the participants contributed to the conversations and the ideas they devised were so well developed that the design team working on the project struggled to extract specific obligations for the development process from the meeting because, as participants constructed these challenges, they almost simultaneously devised responses to them. For this reason the structure that was followed in the transport group is the one that is presented in Chapter Five.

In contrast, the design meeting about personal security did not reveal new insights and the design team struggled to develop any requirements from them because the participants focused so much on discussing their own personal experiences. The structure of the video in the design meeting was intended to lessen the impact of seeing the unpleasant scenarios occurring but, while this did work, it also disengaged the participants from the video and did not facilitate the creation of distinct characters or scenarios that the discussion could be grounded in. This led to participants talking about their own personal circumstances instead of constructing scenarios around the characters shown in the video and, as the discussion became more personal, the group started to disagree over these issues.

The personal security issues needed a more sensitive approach, the group was too large to form a quality relationship with the participants in just one meeting and the area itself was not suited to discussion between strangers. This work would have been better suited to a design approach that more closely mirrored the KITE approach with more meetings than the OASIS approach. On reflection, this suggests that the cognitive impairment of the individuals is not the defining characteristic of the speed of the design work but it is actually how personal the design domain is that dictates how quickly a design process can be conducted because of the time needed to develop a quality relationship with the participants.

CHAPTER 8: DISCUSSION

In addition to insights into participatory design techniques that can be used when working with older adults and people with dementia, experiences designing with older adults have highlighted the importance of strategies that can be employed within, and across, multiple meetings to maintain respectful and productive relationships with people. This chapter presents reflections on the KITE and OASIS design methods and the techniques that they utilise, and on the strategies that can be employed when working with people with dementia and older adults in the participatory design of digital technologies. Through the course of engagement in design work with both older adults and people with dementia it has become apparent that the differences between the two groups are not as large as had been anticipated. The most noticeable differences include the need and nature of patience on the part of designers in design meetings, and the number of meetings required to elicit similar amounts of information. However, creating an empathic relationship between the designers and the participants is something that cannot be rushed, and so, for an OASIS style design activity to build a relationship of similar quality to one developed in the KITE process, would require more meetings.

This begins with the KITE method; the challenges that confront people with dementia when they engage in participatory design, and how the KITE method inadvertently disempowered the participants. When discussing OASIS the focus is placed on: the changes that were made to the process (from KITE); how the new analysis process presented the output from the design sessions in a developer friendly format; and the form and utility of the video prompting. The differences between older users and people with dementia are also considered and it is noted that the process of working with older people and people with dementia is not that dissimilar (that is, people with mild dementia). Finally, a discussion how low-cost strategies (e.g. consistent point of contact, working with a pre-existing group, providing physical artefacts for prompts) have the potential to be useful for participatory design with this target group more generally (regardless of the specific design method) is presented.

8.1 REFLECTIONS ON THE KITE METHOD

Whilst the KITE design method uses a range of techniques that have been used across a range of prior instantiations of participatory design, its distinctive goal is the promotion of close contact between the designer and the person with dementia so as to cultivate an empathic relationship between them. By giving a designer an insight into the experience of living with dementia, one that is

framed by actual relationships, an obligation is placed on them to design digital technologies that are better integrated into this experience. The KITE method develops the connection between the designer and people with dementia they work with through frequent meetings and a requirement to engage with what the people with dementia (and their family caregivers) say. This engagement is undertaken in a respectful way that assumes their accounts of experiences are valid, meaning that the designer does not critique the accounts or the participant's actions in the experience. For example, when recounting an experience of becoming disoriented whilst driving the developers do not question the faculties of the participant, but do critique the poor roadside signage that contributed to the participant becoming lost.

8.1.1 Challenges Confronting People with Dementia Engaging in Participatory Design

People with dementia who engage in participatory design activities may have to overcome problems stemming from their cognitive impairment, but if designers configure the design meeting in an appropriate manner, they can help assuage many of these problems. For example, people with dementia can struggle to maintain focus on a single or multiple issues. In discussions with them, this manifested itself when they frequently strayed from the design issues that the design team wished to discuss with them. This phenomenon occurred most often when meetings took place in environments that were familiar to the participants, and at times of day that a pre-existing group (that they were members of) usually met (to discuss other matters). By getting involved in these off topic discussions the consistent point of contact could gain further insights into the lives of the people they were working with and improve the quality of their relationships with the participants. The consistent point of contact would typically allow these discussions to run their course, in recognition of the fact that these meetings were intruding on time that would normally be spent socialising. However, where the discussion lasted too long (i.e. after the meeting the participants would think they had not achieved anything beyond a regular meeting) the consistent point of contact would lead the conversation back “on topic” using opportunities to relate participants’ accounts to the design goals.

Memory problems, that are a significant aspect of dementia, had two influences on the design process: (i) participants repeated information across the course of multiple meetings and repeated themselves within the same meeting; and (ii) participants sometimes forgot about the content of discussions from previous meetings. The structure of the meetings, with reviews at the start of each meeting helped participants by reminding them of the previous design decisions. The consistent point of contact was particularly well placed to identify when a participant was repeating a story and where necessary could steer the discussion to new topics.

The family caregivers, who took part in the meeting alongside the person with dementia they cared for, were used to speaking for their loved ones. This meant that the consistent point of contact had to be aware of the correspondence between what a caregiver said, and the views expressed (or not expressed) by the person that they cared for. In its most direct form, this was achieved by listening to the caregiver speak on behalf of their loved one then asking the person with dementia the same

question the caregiver had just answered, to see if they agreed or had anything to add. Occasionally this revealed new issues, but most of the time the person with dementia simply expressed agreement. In other cases it was a matter of the consistent point of contact aggregating and contrasting points made by both the carer and the person with dementia, both within and across meetings. It is clear that the configuration of the meetings placed a practical limit on the ability to elicit first-hand accounts from a person with dementia given their dependence on their carer and the subsequent predisposition of their carer to speak on their behalf.

The total number of caregivers in meetings was similar to the total number of participants with dementia. It was therefore important to manage meetings to foreground the views of the participants with dementia. Here, the act of note-taking played a valuable role. When the consistent point of contact wrote down a note, for example, summarising a discuss, he could draw the attention of the participants to the act as he was doing it, and could draw out any challenges by asking each individual whether they agreed or disagreed with the note. This would also cause the participants to focus on the issues that the facilitator wished to discuss.

The empathic relationship established with the people with dementia and their carers also changed the nature of the relationship between the consistent point of contact and other members of the design and development team. The consistent point of contact found himself becoming an advocate for the participants at design team meetings where their opinions might otherwise have been marginalised. Furthermore, as a consequence of members of the design and development team meeting participants – an event that was greatly facilitated by having the consistent point of contact to make introductions at group meetings – the design team members often expressed surprised at the opinions of the people with dementia and radically re-evaluated their opinions on different aspects of the design.

8.1.2 Design Insights

Whilst the main aim of designing a digital technology to help people with dementia enjoy safe walking experiences was primarily to evaluate the KITE design method, the insights that the process yielded into the lives of people with dementia and their caregivers were also interesting and may be relevant to other work. KITE revealed how the day-to-day life of a person with dementia was organised (by them and their carers) around clearly agreed routines, primarily because of the way it helps them cope with memory issues by incorporating checks throughout the day. It is likely that such well-established routines also help manage other symptoms of dementia such as becoming upset as a result of a lack of control of emotional state. Therefore, integrating a device into an existing routine is an important requirement, and the design will ideally afford an element of re-appropriation. The challenge for product designers is to be able to either: (i) elicit the routines and design appropriately and in a way that is generalisable (something that is unlikely in light of the variety of personal circumstances that have an effect on the lives of a person with dementia); or (ii) create digital designs that have an inherent flexibility and afford appropriation by people with dementia and their caregivers.

The importance of the aesthetic of a device also emerged as a result of following the KITE design process. Participants expressed particular concern over the stigma-inducing potential of an assistive technology for people with dementia – a point that originated in a discussion of people’s negative experiences of fall alarms. Participants coined the term “NHS Aesthetic” to describe the typical visual appearance of personal alarms (plastic white box with a red button) given to frail older people; in very early meetings they made it clear that such a design would not be acceptable. In summary, the integration into routine helps the person with dementia to remember the device, and the pleasant non-stigma inducing aesthetic serves to motivate a participant to use it in public as well as private settings.

Although ethical issues around privacy and tracking were discussed in the meetings, few participants were concerned by the threat to privacy posed by their caregivers knowing where they were. This highlighted how the world view of the older people with dementia differed dramatically from those of the designers and echoes the warnings found in previous work about the gulf in experiences, and the resultant gulf in outlook, between younger and older people [111]. This lack of concern seemed to arise primarily because the people with dementia simply could not see why their caregiver, who was typically a partner or adult daughter, should not know where they were. The participants with dementia suggested they would get a sense of comfort either from their spouse knowing their location or, more interestingly, in knowing that their spouse was not worried about them. Something which surprised the design team was finding in the personally tailored design meetings that John was not afraid for his own safety but wanted something to reassure his wife that he was “OK”. An awareness of the problems caregivers encounter is not undocumented amongst people with dementia but the desire to lessen that burden does not appear to be mentioned in other design work. This highlights the emotional burden a person with dementia can experience knowing that they, in some ways, encumber their loved ones.

8.1.3 Inadvertently Disempowering the Person with Dementia

Analysing transcripts from the meetings with the participants with dementia and adding another layer of interpretation to the needs that they expressed inadvertently disempowered the participants and under-utilised the relationship developed between them and designers. While the analysis did reveal interesting aspects of the participant’s experiences and underlying themes that tied these together in the initial exploratory meetings, the form of the analysis results became a barrier to the designers engaging with the directly articulated views of the participants. Whilst the process of reflecting on the transcripts is still valuable in this stage of the KITE method, taking decisions for participants based on needs that they do not directly articulate (stemming from the belief that the participants would not be able to articulate all their requirements) runs counter to the goal of respecting the experiences of the people with dementia (and their accounts of these). The innate assumption in the approach that participants could not directly articulate their needs echoes some of the issues that were highlighted in the review of previous work which spoke to caregivers instead of people with dementia on the assumption that the people with dementia would not be capable of contributing meaningfully to the design process directly.

8.2 REFLECTIONS ON THE OASIS METHOD

The unique aspects of the OASIS process were: (i) the introduction of the *invisible design* video, this video was intended to answer the problem experienced in the KITE work where participants struggled to envision future technologies; (ii) the introduction of more structure into the design process by formalising the structure of meetings which also feeds into; (iii) an analysis process that gives the participants a stronger voice by analysing their input less and allowing them to more directly articulate their requirements.

The experiences following the OASIS method often closely mirrored those found following the KITE approach but the decreased time spent with the participants meant that the quality of the relationship that formed between the participants and the designers was not so pronounced or intimate. This was demonstrated particularly clearly in the design studies that addressed the sensitive issue of personal safety. When examining the issue of relatives abusing trust, a particularly sensitive issue, the participants were not willing to engage with the design process, even when speaking about the fictional character in the invisible design video prompt. OASIS was developed after KITE in response to issues uncovered in this process (while maintaining the core tenant of trying to elicit empathy for the participants). The OASIS design method is again based around small participatory design sessions that aim to get specific insights into peoples' lives which will then generalise back out to a wider population. The exploratory work from KITE is performed in a single meeting in OASIS as is the personally tailored design.

8.2.1 Analysis Approaches

The analysis approach that was followed in the OASIS process allowed participants too directly influence the design process much more. The presentation of participant quotes to developers reinforced how the requirements should be interpreted or implemented. However, the development work performed under the OASIS approach was limited in comparison to KITE (with two of the design studies not including any development work) and so a full evaluation of this technique was not possible.

The process used in the first meeting looked for narrative in the beginning of the meeting to use in support of the requirements gathered in the later meetings; this allowed the addition of the voices of the participants to the requirements that were gathered. The distinction drawn in the second stage between requirements and obligations also worked well as it allowed the designers to understand through the requirements several different approaches to a digital technology for the domain whilst also gathering obligations that would hold true regardless of the device that was created. The process used in the second meetings with participants was similar but broke down the requirements by form factor, functionality and user experience to allow the participants to express themselves in more detail to the designers. This stage did not have an equivalent of the information eliciting stage in the first meeting so required no analysis directed towards discerning narratives.

Deciding on an analysis approach to use in both KITE and OASIS was particularly difficult, as most work done in the domain of participatory design does not call for transcript analysis. The analysis is particularly valuable, and may be applicable beyond the scope of working with older adults and people with dementia. In any resource (i.e. time and people) bound participatory design activity, the process of recording and analysing what said in meetings can greatly support designers' reflection. However, when doing this, it is important to re-present any analysis to participants for validation. A limitation of the work, that the analysis process highlights, is the dedication to allowing the participants to shape the direction that digital technology development takes. In product development the designers often have many external constraints on technology placed on them in advance and this sensitivity to the form of technology early in the design process is something may not necessarily be broadly applicable outside of the scope of design research.

8.2.2 Video Prompt Role

The role of the invisible design prompt in the initial study, to design and develop the healthy eating device, was different to the role in the final recommendations detailed in the OASIS design method. The video initially only served to promote discussion around future technologies by following the invisible design paradigm and the success this showed when working with the older users was notable. However, when the scenario generation work fell short (due to the tendency to not engage with the scenario's that were constructed and to instead revert back to discussing personal issues) the decision was made to try leveraging the power of the video to better establish the "good" and "bad" scenarios.

In the security meeting the invisible design video prompt was constructed in the spirit of a pastiche scenario and the participants were presented with famous characters, in familiar, fictional environments. This was intended to alleviate some of the shock that participants might experience in reaction to the situation being presented to them. By contrast, in the transport work the video maintained the *invisible design* aspects from the Nutritional Adviser sessions but simply updates the video by also using it to establish two characters that have "best" and "worst" case experiences. This led to much more engagement with, and discussion of, the scenarios, allowing the participants to relate their discussion of future issues around these more rounded characters about whom they more quickly established a shared understanding with other participants.

8.3 THE "PERSON WITH DEMENTIA" AND THE "OLDER USER"

The intertwining of issues relating to older people, and issues relating to people with dementia, is valid, as in many ways, dementia can be considered as a lens on the issues of ageing in general (i.e. physical, psychological, social and cultural). The reason that designers struggle to engage with and design for people with dementia, is the same reason that they fail to engage with and design older people: a gulf in empathy and the lack of techniques to scaffold empathic design engagements. The choice was made to work with people with mild forms of dementia in the earlier stages of their illness. In work with people with more severe dementia, the only consequence was a reduction in the

productivity of the groups (e.g. with participants from the dementia care partnership who resided in day care rather than living completely independently).

8.3.1 Strategies for Working with Older Adults and People with Dementia

KITE and OASIS highlight certain key issues that can be addressed through various strategies in any design process that seeks to work with older users or people with dementia. Working with pre-existing groups of older adults and people with dementia had a number of desirable characteristics. In particular, the dynamic around discussion of personal issues was noteworthy as in many cases, when discussing sensitive issues, participants would tend to talk and discuss them with the other members of the group rather than directly interacting with the group facilitator and these situations demonstrated the benefit of familiarity as the participants felt comfortable discussing sensitive subjects. Another major benefit emerged when participants were able to help each other with the communication of concepts they struggled to express themselves. In these cases, other individuals in the group were able to help them or supply the words they were struggling to find, easing the process. In addition, more relevant events and interesting points were remembered by the participants as the facilitator would ask individuals questions about events that they would profess to have not experienced, only for them to be reminded by another group member of a story that they had told which might be relevant. Alternatively, when recounting a story, a participant sometimes got help from other group members who would supply additional details from their own memory of the story teller recounting the tale previously.

It was important to establish a common frame of reference from the outset of the design process in KITE and OASIS to allow participants to more easily explain their thoughts and issues than they might otherwise. This was done through the gradual build up to design work and through keeping recaps of the previous design sessions couched in the language that the participants used. This required the consistent point of contact, and any other designers present in the meetings, avoid using particularly technical terms when talking with the participants. Getting participants to work from a common point of view on a problem could however be challenging as recruitment would tend to bring in people with their own distinct takes on the issue being discussed. When a common frame of reference was not created, the occurrences of people talking at cross purposes were very high and could spark conflict in the group.

Recapping the events of a previous design meeting frequently served to establish a common frame of reference for the groups and also helped keep the memory of events and concepts fresh for the participants. This was particularly useful when the design team struggled to convey complex ideas or concepts to the participants as these ideas could be introduced slowly in parts recapping on the previous ideas as time went by. Recapping at the start of sessions took the form of reviewing the previous meeting's output and talking about the analysis of it; looking at design artefacts produced in the earlier meetings and discussing them again; and looking at prototypes built in response to participants' requirements and explaining them. Within meetings before the topic of discussion

changed the consistent point of contact would recap the previous discussions before explaining what the discussion would be moving on to.

Giving people with dementia and older user's access to physical artefacts to critique, whether these are prompts as seen in early exploratory work or design artefacts in the tailored design work, facilitated the elicitation of feedback on designs and design questions. The rapid development of prototypes was crucial, and frequent meetings were more helpful than irregular ones, so slow development times can negatively impact on design. It was also helpful to ensure that participants felt that their contributions are being acknowledged otherwise they can lose interest in the project. This meant being able to show them, in each meeting, how their contributions have impacted on the design. However, this process can also lead to participants becoming fixated on specific details or characteristics of a prototype that were never intended to be included in final designs and so needs to be carefully managed. In addition, leading discussion too much with the prompts that were presented was a concern. Whilst leading into topics which needed discussion was something that was aspired to, there were concerns over certain design decisions being suggested to the participants by the prompts.

An issue that had not been anticipated was that sometimes participants were unwilling to critique the designs that were shown to them; this may be because they were concerned the designers would be offended if they were too critical. When the consistent point of contact emphasised that the devices were prototypes and downplayed the effort placed into developing them the participants were much more willing to engage critically with the devices. Another strategy that emerged during this process was establishing a separation in the minds of the participants between the people that they met in design meetings (particularly the consistent point of contact) and the rest of the design team. This was achieved through careful use of language, for example, the consistent point of contact would ask if "they" (the technologies builders) should keep a switch in a given location or if "we" (the participants and the consistent point of contact) wanted it moved.

CHAPTER 9: CONCLUSION

Kitwood's proposals for healthcare practice in relation to [81] to engaging people with dementia, and older people in general, in a design approach attuned to evoking accounts of their experiences could lead to better design. Kitwood's notion of "Personhood in dementia" places an emphasis on respecting the person with dementia and their experiences despite the cause of some of those experiences being irrational. This leads into his idea of Person Centred Care, a healthcare process that focuses on the individual, placing them at the forefront of all healthcare activities that would be conducted through close contact between care provider and person with dementia and respect for their subjective, felt-life. The Person Centred Care approach is mirrored in the design framework that is proposed by creating a space for close contact between the person with dementia and the designer, fostering a dialogue between the designer and the person with dementia and respecting them by treating them as the experts in the experience of having dementia.

Another influence on the form of the design process was other approaches that emphasise empathy and empathic relationships in design [140]. Wright and McCarthy proposed three qualities that are central to empathic design approaches: (i) a quality relationship between the designer and the user that allows the designer to be attuned to the user's needs; (ii) a sympathetic disposition towards the other person; and, (iii) an attention to the affective and emotional quality of their experiences [155]. The OASIS design process is imbued with these qualities by paying attention to, and requiring close contact with the participant; through respectful relationships that treat them as the expert in the domain; and by paying attention to their descriptions of their experiences. There are clearly strong parallels between empathic design approaches and Kitwood's proposals for highlighting Personhood in dementia and Person Centred Care. While empathic design stresses the need for design which extends beyond the realm of the task oriented workflow, Personhood shifts the focus of dementia care practices from medical (predominantly biological) concerns, to the felt experiences of the person with dementia.

Like empathic methods and Personhood, participatory design places a particular value on the importance of working *with* the user and on democratising the process of design [106]. However, design techniques grouped under the participatory design banner needed to be adapted for the classes of users that were sought out to engage with. The adaptation strategies were either based on existing approaches [157] or were created as part of the process, and these included: the use of pre-existing groups; establishing a common frame of reference in the work; having a consistent point of

contact to work with the group; frequently recapping and reviewing the design process up to that point; using physical prompts to spark discussion; withholding criticism of the participants and creating a separation between the consistent point of contact and the rest of the design team in the minds of the participants.

In addition to the challenge of adapting participatory design techniques, a more serious problem was identified: that the means by which analysis of participatory design sessions was conducted had a tendency to disempower the participants. Analysis of the transcripts of meetings in the first iteration of the design process, and the subsequent application of this analysis, diluted the voices of the people with dementia.

As the consistent point of contact, I was the only person who was present in all design meetings with the participants, and as a result of this I found myself having to act as an advocate for the participants, almost in opposition to other members of the design team, in design meetings. This disempowerment of participants was addressed in the OASIS design process by requiring the design team to formulate their questions to the participants such that they more directly related to the design requirements (thereby reducing reliance on subsequent analysis). In OASIS the analysis process focused on presenting the story behind the requirements to the rest of a design team rather than an interpretation of what the participants had said. The design work successfully acknowledged the Personhood of the participants, echoing Kitwood's concerns [81] and the aspirations of empathic design [155]. The process highlighted that the only people capable of truly understanding the experience of ageing or of dementia were the people who live with it, the older people, the family caregivers and people with dementia themselves. Designing technology that is a meaningful response to such experience requires more than stakeholder participation, it also requires a respect for their understanding of the experience.

9.1 REVISITING THE RESEARCH QUESTION AND OBJECTIVES

The inquiry opened with an examination of the social model of disability and this led to the revelation that currently design, rather than benefiting the older population, can often be another avenue through which society disables people with impairments [117]. Therefore, the research question was constructed in terms of how design processes could be reconfigured to take account of this:

How can a design process be configured so that it engages older people and people with dementia in a way that is both sensitive to, and respectful of, their experiences?

The approach to addressing the research question was formulated as four objectives:

Objective 1: To review assistive technologies for people with dementia (and academic proposals for such technologies) and characterise the mechanisms and levels of engagement of users in their design.

The review of previous literature and assistive technologies that was documented in Chapter Two examined the prevalence and effect of aging and dementia to provide a context in which to examine the mechanisms and levels of engagement with older people and people with dementia in design. The review of digital assistive technology showed that there were numerous problems encountered when using this technology and, while this review was not comprehensive, it did serve to illustrate several specific challenges that appear in the design domain and establish that such engagement is difficult to achieve. A number of differences in capability, experience and inclination were identified between the designer, and those older people and people with dementia that they are designing for. For example, designers have exhibited a tendency to medicalise conditions rather than consider them holistically meaning design processes addressed the physical (clinically most apparent) symptoms without addressing the social and emotional consequences of dementia; they have been deterred by ethical challenges in engaging cognitively impaired users in design; they are ill equipped to address the enormous diversity in the target population that makes selecting any one participant to engage with as a representative of the whole challenging; and lack the tools to scaffold older people's visions of future technologies. Finally, there was an overarching phenomenon of engaging with the caregivers rather than those being cared for and, as a result of this, there was a suggestion that emphasis was placed on the safety of people involved in the process rather than an emphasis on allowing them to reclaim the ability to perform tasks they could previously. However, engagement in the design process would reveal that this is perhaps a more complex area than the literature suggests.

While the majority of previous work did not make their approaches to design explicit, some work did. The majority of the work that proposed some specific approach to design could be characterised as user centred but beyond this did not make its design framework explicit. However, some work used explicitly participatory approaches to design and these were reviewed in section 3.1. This review attempted to provide a comprehensive overview of the field of participatory design with people with dementia but found that there was a significant lack of literature on this subject making the review weak. To compensate for this weakness, literature on the topic of engaging older people in design was brought in along with work conducted with people with diverse cognitive impairments and these strengthened.

The previous work was interpreted as suggesting (through its absence) that there is a need to look beyond the medical model of disability and design for the experience of older people and people with dementia. This informed the decision to construct a participatory design approach to support engagement and design of digital technology as seen on Objective 2:

Objective 2: Create a participatory design approach to support the design of technology for people with dementia and older users that facilitates their contribution to the design process.

The KITE participatory design approach is further defined by objective 4 (see below) which suggested that an important quality of this approach was to foster an empathic relationship between people with dementia, their caregivers and the designers. The KITE approach that was outlined responded to the

challenges that were discovered taking inspiration from previous work in the fields of design with older people, design with people with dementia and design with the cognitively impaired. The approach targeted mildly impaired people with dementia (because there were several suggestions that it was not possible to meaningfully engage people with moderate or severe dementia in design work) who could give informed consent (to address ethical issues) and included both people with dementia and their caregivers who were also older people (to avoid relying on the caregiver as a substitute). The avoidance of working with people with moderate dementia is one of the less satisfactory elements of this work and is discussed further in section 9.3.

The design environment in KITE was configured to support older people in general, and people with dementia in particular, through: the use of pre-existing groups; the use of frequent recaps and note taking; the creation of a common frame of reference; and having one consistent point of contact who worked with the participants in each and every meeting. The meetings documented in section 4.3.4 sharply contrasted with other accounts of design work with people with dementia because they involved good-natured but quite adversarial debates which led to novel insights into the design domain or the experiences of the individuals concerned. Examples of this include Alice's revelations about her experiences with her walking stick and Bob's explanations of how important it was to him to provide reassurance to his wife that he was ok when he was out and about.

Talking to people with dementia also helped to avoid falling into the trap of exclusively medicalising their situation, and instead to consider wider social and domestic concerns, such as how to reclaim activities they had lost because of the progression of their cognitive impairment and/or carers' perceptions of risks. The technology that is used in KITE is similar to much of the previously reviewed technology that deals with locating older people, but the purpose of the technology is radically different as it focuses on empowering its user rather than helping someone medicalise their condition.

Following the process led to questioning one of the assumptions about the underlying challenges in working with people with dementia: that engaging with caregivers resulted in an emphasis on safety. The people with dementia engaged in the process also wanted to have safety features built into their devices.

However, these insights came at the cost of working with a broader group of individuals (only 2 people with dementia and one caregiver were engaged in the personally tailored design work in KITE). The insights took several months to elicit and they were quite specific to the individuals that were engaged in the process. In addition, there were issues within the meetings such as the struggles that some people experienced when trying to envision future technologies and struggles with getting people to discuss intangible issues such as privacy in the process. This is reflected in the lack of discussion around these issues.

The process also highlighted shortcomings in the design method with respect to the original goal of enabling and acting with respect towards the person with dementia as the process of analysis that was applied in the initial activities diluted the voice of the person with dementia in the design process.

Two other significant issues with the approach were the lack of structure in design sessions, which made the process unnecessarily time consuming, and the absence of adequate tools and techniques to support people with dementia in the challenging task of envisioning future technologies.

Objective 3: To conduct authentic design activities with people with dementia and older people and through reflection on these activities refine the participatory design method.

The Keeping In Touch Everyday project sought to explore the design space for an assistive technology to facilitate people with dementia walk outdoors safely and unattended. The exploration of this technique highlighted several issues and, in response to these issues, the design framework was refined to produce the OASIS approach to participatory design with older people. OASIS prescribes more structured sessions in which participants directly articulate their needs as requirements. This allows them to more directly influence the design process. For example, in applying the KITE approach in Chapter Four one concern was that the process of analysing participants output – which was an attempt to clarify formalise the participants experiences and needs of technology – diluted their voice because we added our own level of interpretation onto what they were saying. However, in the OASIS process, this did not present as an issue because the participants were a) more directly questioned in the design sessions and b) had their requirements formalised through a far simpler analysis that sought out the things that they might require of a systems functionality and the experiential issues they felt a system should be obliged to not create.

To address the issue of envisioning the intangible (in design) invisible design videos were shown in workshops, which aimed to highlight design issues without committing to particular technological solutions, thereby providing them with a concrete starting point for discussion that is grounded in the fictional characters' experiences as portrayed in the videos. Although attempted in several forms in Chapter Six and Seven, the video format in the transport workshops where characters on screen correlated with scenarios seemed to work the best. This was reflected in the amount of engagement of the group with the video and the constant references back to the video throughout the rest of the meeting to ground ideas in.

However, whilst the quality of engagement is hinted at in the sharp contrast between the quality of feedback or insight provided in this study as opposed to other engagements in literature, this cannot be claimed as strong evidence that the approach works. This is a common issue when constructing novel approaches to design as the approach is extremely dependent upon the individuals that are involved in the process and their openness to engaging with the design work. This challenge is particularly pronounced when critiquing the nature of the empathic engagement with the participants:

Objective 4: To evaluate the method with respect to the nature and extent of the empathic engagement, and the impact this has on the outcome of the design activities.

Both KITE and OASIS attempts to facilitate empathic engagement by: configuring close contact between designers and participants; showing respect for participants and treating them as the expert

in the design domain; and paying attention to the participant narratives. That KITE elicited authentic empathy for the people with dementia is suggested in the change in the relationship between the workshop facilitators and the rest of the design team, with facilitators taking on the role as advocates for the participants at design team meetings (i.e. meetings not involving participants) 4 where the participants' opinions might otherwise have been marginalized as documented in section 4..

However, while the qualities of the relationship that formed between designers and participants in following the OASIS approach in Chapters Six and Seven were similar to those exhibited in KITE – as seen in the frank debates that took place around the video and the disclosure of personal, upsetting experiences in Chapter Six – the quality of the relationship did not appear to be as strong to the consistent point of contact (i.e. the author). This is almost certainly because of the significantly reduced amount of time spent with participants. The less well developed relationship could be remedied by spending more time with participants but a key concern when formulating the OASIS approach was to avoid taking the extreme amount of time involved in the KITE approach. In addition, while the approach might not have formed as strong a relationship, it did still develop a relationship and it did allow the designer to work with and gain insight into the experiences of the participants. However, it is possible that this relationship and sensitivity may, in part, be an artefact of the consistent point of contacts experiences with other older groups. This again hints at a broader issue that relates to the wider design question:

How can a design process be configured so that it engages older people and people with dementia in a way that is both sensitive to, and respectful of, their experiences?

The design approaches that were followed in this thesis attempted to address this problem through engagement with older people and people with dementia following design approaches based upon previous work but constantly modified in light of its results. The approach demonstrated that participants responded to designers when they engaged with them in a respectful way. However, what qualified as respectful engagement went beyond simply taking what participants said at face value to truly engaging with what participants said. Beyond this, the process ultimately led to questioning their accounts of experience critically, not to challenge them but to allow the designers to further their won understanding of the participants' experiences as seen in section 4.3.4. Accepting that the participants were capable of articulating, expanding upon and clarifying their accounts of experience when questioned was an important part of this approach.

However, while this approach developed either novel or significant insights such as those presented in sections 4.3.5, 6.2.7 and 7.1.4, it is dependent upon the designers being willing to engage with the people that they work with. There should be little doubt that simply “going through the motions” with this approach will not create the quality of relationship or the atmosphere within design sessions that can elicit novel or significant insights from the participants. So, the design approaches can be seen as meeting the criteria to be sensitive and respectful to older people and people with dementia but with the caveat that the designer who uses them is prepared to be sensitive and respectful them self.

9.2 POSSIBLE ALTERATIONS TO THE DESIGN APPROACH

The OASIS method was only used with older people, and not with people with dementia (the starting point). People with dementia are not simply “extreme” older people, for example, their particular dependence on, and relationship with, their carer means that the applicability of OASIS to people with dementia cannot be assumed (e.g. how can the carer be introduced without perturbing the dynamic between participants and designers?). Furthermore, the experience of developing and reflecting on a design method points to two particularly pressing challenges for researchers interested in methods for designing technologies for older people: (i) the development of specific techniques (e.g. prompts and scaffolds) to address the diversity of personal circumstances and experience that can impact on the level and nature of participation of people in workshops; and (ii) the process of evaluating the effectiveness and impact of changes in the design method.

The process of working with older people with dementia gave results specific to their area of the spectrum of dementia (Table 4-3). For example, in KITE, when working with Alice (who lived alone), many of the issues she raised did not apply to John (who lived with his wife). This reinforces the need for designer to accept that there is an enormous diversity in the personal circumstances of older adults [68] and particularly people with dementia. Developing an understanding of how the results of working with people with dementia in one domain can be transferred to people in other domains would make the results of conducting the design process much more widely applicable. It is not simply a matter of designing for people who are both married and single, but understanding how such a difference might fundamentally impact on a suite of design alternatives (and ultimately products).

The prompting technique, the presentation of design artefacts to participants (e.g. storyboard, technology examples or prototype), acted as a starting point for many discussions. Where participants could initiate or participate in discussions about some tangible “thing” they were more confident and articulated their thoughts about less tangible matters more clearly. Participants did not always use an artefact as a starting point for the discussion that a designer had anticipated (or wanted). For example, the discussion of the iPod-nano was much more complimentary than had been anticipated and revolved around the discreetness of the device rather than centring on feelings that it was a technology “for a different generation”. There is a real need to understand why the prompting technique helped facilitate discussion, how it could be exploited in later stages of the design process, and whether there is a more systematic means of selecting and rationalising the choice and use of prompts (i.e. move beyond the designers intuitive choices about prompt material).

The exploration of ways to help older people envision the intangible in design (without activating scenarios that incorporated technologies) through video was one of the most interesting, but least conceptually grounded aspects of the design methods research. A significant research challenge remains in understanding how discussion with older people around the intangible aspects of design can be facilitated, and why different approaches are more or less effective. Developing an understanding of how older people envision the intangible and why they struggle with this process (when compared to younger people) is crucially important to researchers and practitioners in

participatory design more generally. To this end, research into *envisioning techniques* has much to learn from the theory and practice of narrative disciplines for which this is already a central concern – such as filmmaking and creative writing. A related issue is the process by which the precise form and aesthetic elements of design is decided upon – this again is a thorny issue that was not addressed. While the creative process, by which decisions as to the aesthetics of a device is decided upon, is not transparent to the participants, they are presented with concept sketches of final designs and their reaction to these reflected upon by the product designer. Developing processes by which participants might be more explicitly engaged in the process of designing these non-functional elements of a product is another area where the empathic framing of the design process can be further leveraged.

Another important area of concern is the way in which empathic links between the designer and the participant can be enhanced. Explicitly personal and dialogical devices such as cultural or empathic probes [62,74,98] have been proposed for just this process, but there are questions with respect to their applicability in group-based design activities because of the very personal nature of the disclosures and narratives that probes can elicit. Suri proposed that role-playing might also have a place in developing empathy on the part of designers for people with dementia [140]. Although this appears challenging, letting people with dementia create scenarios for designers to role-play is potentially another vehicle by which they might more actively convey their experiences to designers.

The success or failure of any design process is highly dependent on the individuals that are involved in it. The conversations that were facilitated by the design framework led to new and interesting insights into the design domain that would not otherwise have occurred. The relationship that formed between the designers and the participants, whilst dependent on the individuals involved, is also a marker of the success of the process and there were many insights for the designers when working in this process. However, judging the success of a design approach based on the quality of the relationship between the participants and the designers engaged in the process is inherently subjective, and it is difficult to determine how novel/valuable/characteristic a disclosure or narrative is, the prioritisation of such information is inherent to the act of designing. Whilst metrics have been proposed for the quality of a users experience with a device, going beyond this to measure the design process that produces these experiences are more problematic. The design process outlined is dependent on both the participants engaged in it and the designers engaged in the process.

Finally, the key element of this design process is the bond that it creates between the participants and the designers. This bond arises from close contact in an open, respectful environment but can this link be maintained in the face of pressure to produce results? The so called third wave of human computer interaction [33] in which the emphasis is placed on cultural, non-workplace situations and the increasing focus on the quality of experience in the design of new technologies [156] suggests that the quality of empathy in design is something that will be valued by the wider design community. In practical terms, the simplest approach for design teams who wish to maintain an empathic link with their participants in participatory design work but who need to work quickly to meet commercial deadlines may be to work consistently with the same group of older people and people with dementia.

In this way the quality relationship can develop over time despite the limited time a resource that can be committed to an individual design activity.

9.3 FUTURE WORK

As mentioned in Chapter Two, the challenge that motivates the development of this design approach is a growing one with the true “explosion” in the over 65 age group coming in the next twenty years. As such, the opportunities to apply this approach may grow over time and, more generally, the significance of considered approaches to working with older adults will grow as well. The approach has shown that it is capable of being leveraged to include and empower people with dementia by giving them their own voice in the technology development process and the chances are that – as the older population group grows and advocacy groups associated with them increase in prominence – the demand for approaches that include them will increase.

Should this demand come about, the design approach presented here would probably first start to see use in the healthcare domain because it is within this field that the tensions between older adults and digital technologies is currently most pronounced. For example, the issues around older adults using assistive technologies are widely acknowledged. This potential to give a voice to people in the design of technology that is intended to be used by them is similar to the situation that underpinned the creation of the original Scandinavian approach to participatory design; the goal in that approach being to include workers who might be excluded from using new digital technologies if they were not consulted about the design and development of them. The politics surrounding this design approach served to ensure that its use became widespread and it is possible that the same synergy of issues might play some role in promoting this approach to design with older people.

However, if this were to happen, it would require that designers become more sensitised to the sorts of issues that the design approach has been developed to counteract. The most likely avenue by which they might be informed of them would be in their undergraduate study at University and having this design approach taught to them alongside the introduction of these issues would be an excellent way to both make an impact with the technique and give designers the sense that, while the challenges designing for older people are considerable, they are not insurmountable. Alternatively, job specific training for designers might introduce the issues and the approach together for those whose work would entail working extensively with older people.

Ultimately, at some point in the more distant future (50 years or more), the need for a technique that sensitises younger designers to an older person’s experiences will might become obsolete because the “typical” designer that has been criticised in this thesis may cease to exist. Design teams, in response to the challenge of the aging population, may start to be composed of much more diverse groups of individuals and not be the preserve of under 35’s. In this case, the gulf in experience between older people and younger designers will cease to be a problem.

Although the politics of the aging population may lead to changes that eventually render this design approach obsolete, the issues around designing for people with cognitive impairment that have been addressed in this thesis may still be a challenge, as, by its very nature, cognitive impairment restricts the ability of those who have it to engage in design tasks. However, not all cognitive impairments are permanent and design teams might seek out members who have lived with some form of cognitive impairment to include them in their work. Alternatively, research might find ways to support people with cognitive impairments in engaging with the design process. If this were to come to pass, some of the lessons from this thesis on engaging people with dementia in the design process might be particularly useful and could form a point to start researching and exploring methods or strategies to help cognitively impaired designers carry on with their work.

The approach that we have applied of attempting to create strong, empathic relationships between people with dementia and designers might also have applications in other domains. The most trivial changes that would be required to the process would be to modify it for use with groups with cognitive impairments other than people with dementia. Indeed, working with people with dementia has tested the approach against a variety of cognitive issues and its wider application might only be a case of reducing the strategies that are employed to those that are relevant to specific categories of cognitive impairment.

When working with people with dementia in particular, the design approach started to draw out issues around stigmatisation. The primary lesson learned was around the need for extensive contact with people who were concerned about such issues before conversations about the issue could take place in an honest, meaningful, in-depth way. Although rudimentary, these lessons could form the basis for further investigation into how groups who feel that they are stigmatised can be brought into the design process.

In addition, one limitation that was acknowledged in section 9.1 was the lack of engagement with people with more severe forms of dementia. The decision to do this may unnecessarily limit the scope and applicability of the design process if it can be shown that it is possible with more severe dementia. Applying the process with this group would require much more resources in the form of effort to gain ethical approval for the process, recruit participants and work with them to elicit novel information but, if a large group of researchers had the opportunity to devote themselves to this process, the insights potentially could be extremely interesting.

Perhaps more interestingly, the approach might also be applied more generally with any group who is drastically different to the design team. The approach might also be applied with people from drastically different societal backgrounds such as immigrant groups or it could be applied with people whose jobs give them particularly unusual experiences. For example, military personnel, fire-fighters, or emergency room surgeons who work in extremely high pressure, time constrained environments are likely to have radically different, even alien, experiences compared to designers and having an approach in place to cross this gulf in experience could be extremely valuable for designers working with them.

Looking into the future and considering the significance of the work from a participatory design perspective, the approach highlights some of the issues that emerged when applying participatory design outside of the scope of the workplace. This issue is an important one to address because it directly effects the application of participatory design in many of the latest fields of HCI research such as design for performance, design for the home and design for health and wellbeing. The work has made a start in adapting participatory design to this domain but more could be done to allow participatory design techniques to easily access the experiences of those that are engaged in the process. The design approach in this thesis has examined the language used in engagement and the framing of questions to investigate experience. However, it may be that more fundamental concepts like meetings with participants need to be adapted to better investigate their everyday lives.

Finally, the environment around us is becoming increasingly digital and increasingly configurable. For example, currently, people design and build their own personal websites, configure the digital technology environments that they work within and configure and change the mobile phones they use to communicate with each other. And yet many of the people who do this do not consider themselves to be in any way technical. In this environment, the ability to design is becoming more and more relevant for individuals and it seems likely that there will come a point where design skills or design thinking is considered, if not fundamental, then at least an important component of the education process. As such, it may come to pass that everyone becomes a designer and configures their environment to their own personal needs. If this happens, then the idea of participatory design may have to change radically to remain useful and relevant. In addition, eventually (in many years time) it may be that older people are able to design for themselves and, do not need any specialist design approach in place to let them access new digital technologies as they are quite capable of configuring it for their own use.

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APPENDIX A: TOPIC GUIDE

All Participants:

- Welcome & coffee
 - Everybody introduce themselves – name badges
 - Demo of touch-screen
 - Demo of Designer
- Consistent Point of Contact will explain the structure of the day to all
- Split in two groups (3 participants each)
 - Group 1: Consistent point of contact
 - Group 2: Members of developer team

Group One

- Exercise 1: Shopping list
 - Each participant write down an example of shopping list in a piece of paper, then it is stick in middle of bigger paper and participant add rationale for structure
 - Group discussion about generating/updating shopping list on the device – barcode reader and/or direct input
 - Explore automatic addition of items based on consumption (recipes) or scan
 - Explore manual inclusion / exclusion of items
 - Explore preferred items / pre-defined list
 - Explore sending shopping list to assistant
 - Explore sending shopping list to ecommerce
 - Explore printing/downloading on mobile
- Exercise 2: Start screen
 - Group discussion about what they would like to see at first and how to activate the device – initial menu
 - Explore context awareness
- Exercise 3: Recipe guide
 - Group discussion about how they would like to see the recipes, list of ingredients, instructions, nutritional information...
 - Explore voice-audio interaction
 - Explore actions they would like to have
 - Add ingredients to shopping list
 - Step-by-step guidance
 - Explore how to introduce own recipes

Group Two

- Exercise 1: Shopping list
 - Each participant write down an example of shopping list in a piece of paper, then it is stick in middle of bigger paper and participant add rationale for structure
 - Group discussion about generating/updating shopping list on the device – barcode reader and/or direct input
 - Explore automatic addition of items based on consumption (recipes) or scan
 - Explore manual inclusion / exclusion of items
 - Explore preferred items / pre-defined list
 - Explore sending shopping list to assistant
 - Explore sending shopping list to ecommerce
 - Explore printing/downloading on mobile
- Exercise 2: Mobile device
 - Group discussion about how they would like to visualize shopping list in mobile
 - check/uncheck items manually
 - barcode reader
 - Group discussion about how to receive nutritional information / recommendations / recipes through mobile

- Explore while buying
 - Explore while eating out
- Exercise 3: Messages and alerts
 - Group discussion about how they would like to be reminded / advised / alerted
 - Explore nagging level
 - Explore type of messages
- Exercise 4: Food planner
 - Group discussion about how they would like to be presented with the menu (day, week, month...)
 - Explore changing meals for alternatives
 - Explore suggestion of new recipes
 - Explore actions
 - Generate shopping list

Both Groups:

- Other Questions:
 - Social aspects of eating
 - Restaurant suggestions based on profile
 - Suggestions to meet friends for going out

APPENDIX B: KITE ANALYSIS

B.1 FOCUS GROUPS

Focus group analysis was led by Dr. Katie Brittain. The results are presented in abbreviated form here as they informed design later on in the process and data was collected by the author and decisions about how to present the data were made by them as well as well.

B.1.1 Early stages of dementia

The current situation

In the initial discussions with the focus groups the participants, both carers and those with dementia, spoke about the activities they currently got involved in. These included getting out walking to running and driving to go shopping. Carers spoke about wanting to keep their independence by supporting partners to carry on as usual and be independent.

Anxieties / worries

Across all of the discussions within this stage of the project, some of the participants talked about their 'anxiety' of getting out and about. Those participants in the early stages of dementia were also constrained in their activities either because of their anxieties or of those around them.

Directed By family: Participants spoke about how they used to go out a lot more, but now their family did not want them to do that anymore.

In themselves: Some participants admitted to being scared of the consequences of going outdoors and becoming lost or disorientated.

Consequences of anxiety

Another theme that came out of these discussions was how anxiety can have a negative impact on a person's social activities and as such they curtailed them. The two quotes presented below highlight the impact these have had on their driving but there are other instances throughout the report that highlight how venturing outside can become a problem because of losing confidence.

Curtailling activities: Some of the participants discussed how they had altered their behaviour in the face of their anxieties.

Environment

Experience of 'getting lost' or 'feeling unsure': The experience of 'feeling unsure' of where you are was often mentioned by the participants. There was one participant who spoke about feeling unsure of getting out and about in the beginning but he got past this feeling and now regularly takes himself off for long walks.

Enablement by a familiar environment: There was a discussion in one of the focus groups around the impact of having moved house. The couple who had recently moved were finding it okay and had no concerns because the area was familiar. The only issue was with forgetting the name of the street in which the new house was. In one sense a move to a familiar area can be seen as enabling but it could also cause concern as highlighted in the next quotation. Familiarity with a place was key for some people in enabling them to get out and about.

Management strategies

In contrast, although some participants spoke about anxieties of getting out and about, there were others who highlighted how they overcame the feeling of being unsure. Participants talked about the different ways that they coped if they did become disoriented. The strategies centred on remaining calm and taking time to re-orient oneself.

B.1.2 Later stages of dementia – care from a carers perspective

Many of the carers recounted their stories of times when they didn't know where the person they cared for was. In some cases this changed the way they went out and about or changed the way in which they managed within the home (e.g. ensuring that doors were locked and keys were taken out). There are instances within these accounts whereby the person with dementia heads back to their home. The theme around familiarity runs throughout all of the discussions in this stage of the project.

Experience of getting out

The majority of carers spoke about their experience of not knowing where the person they were caring for was and how this caused them to 'worry' and feel anxious. Often an 'incident' would instigate a change in how the carer managed within the home or out and about; one respondent even spoke of moving home in order to manage her husband's desire to get out and about.

'Losing' the person with dementia: Carers talked about instances when they 'lost' or didn't know where the person with dementia was. On occasion this happened when they were out shopping. In other instances it occurred when the person with dementia was being cared for in another setting (for example, respite care).

Getting out at night: Another concern that emerged was the person with dementia getting out of the house at night. This was a particular fear for some of the participants.

When being cared for by others: An instance when a partner was being cared for within a local hospital and where they came home unbeknown to the staff were mentioned. Others echoed this concern around hospital care and day-care centres. One carer spoke about how even within the early stages of dementia her mum, who was young when she was diagnosed, became distressed when she must have taken a wrong turn and was unable to get home, she was away all day before being found in a nearby field.

Cares Anxiety / worry

Similarly to the findings presented about the people with dementia, carers spoke about their anxiety and the worry caused when they don't know where the person with dementia is.

Carers Management strategies

The experience of not knowing where the person they are caring for has influenced the way in which some carers managed either within the home or outside of the home. A male carer spoke about how he used 'post-it' notes for his wife when he went out of the house in order to reassure her where he was.

B.1.3 Views of technology

This section focuses on the discussions around technology in supporting people with dementia in getting out and about. It brings together the views, sometimes conflicting, of those in the earlier stages of dementia with those carers who have experience of the later stages of dementia. It is clear from the findings and discussions presented below, that those in the earlier stages want a device that enables the person with dementia to be supported in getting out and about and giving a sense of reassurance. The carers whose accounts have been about when the person they are caring for is 'lost', and often for some time, focus more on devices that can locate the individual ('tagging' and 'alarms'). However, it also needs to be noted that the use of technology is not always acceptable to people with dementia, as in the case of Rosie highlighted in this section.

Existing technology

Mobile phones: A number of participants spoke about the use of mobile phones. One participant spoke about how her daughter wanted her to have a mobile phone so that she could find out where she was but this wasn't something Rosie wanted to use. She later goes on to explain that mobile phones make her "hearing aid oscillate" so she is unable to hear. Another participant said that he'd given away his mobile phone because he just 'likes to go where he wants to go and wants to go his own way'.

Other ways of managing getting out and about: Participants in this study not only talked about technology in terms of mobile phones and satellite navigation devices but also about identity cards and having some sort of information to hand in order to help them in case they become unsure as to where they were.

Potential barriers to technology adoption

Some of the participants had strong views on the use of technology in enabling a person with dementia to get out and about. Some of the carers voiced their concerns about a person with dementia and their safety in getting out and about and the need for 'tagging' or 'tracking' devices. However some of the participants with dementia felt uneasy about the use of technology. Rosie felt that it would take her freedom away.

Memory: One of the challenges to incorporating technology into the lives of people with dementia is overcoming the impact that their loss of memory will have on whether or not they remember to take the device with them.

Weight / size: Another potential barrier highlighted was the weight and size of any device. If it was perceived to constrain the activities of the person in any way then participants felt it was unlikely to be used.

Being a waste of time: Other barriers to using any device in aid of getting out and about include the (lack of) importance placed on such devices.

Not having the ability to use the technology: Some participants felt that they would be unable to learn to use a new technology so wouldn't bother to look at it.

Other external barriers: In the carers focus group a conversation emerged around other 'obstacles' that might stop a person with dementia getting out. The discussion particularly focused on the raised paving within town centres. These have been placed around traffic signals in order for those with impaired vision to feel them under their feet and know that they are near a crossing. This discussion highlights how environmental aspects can potentially inhibit people going out.

Wants

During the course of one discussion one of the participants spoke on a number of occasions about the possible benefits of a satellite navigation system. Although at the beginning, the conversation was in a joking manner, on her last point of discussion she states that she 'wasn't joking' and that she just wanted something that could 'guide' her back.

A wife of one of the participants spoke about wanting reassurance, "Just to know that he was alright, he hadn't gone in the wrong direction." Another participant said that what he'd really like is something that his 'family could keep in touch' to know where he was. Similarly within one of the carers' discussions one respondent brought up (unprompted) the idea of using satellite navigation technology in the early stages of dementia. However several of the carers within the group just felt that the person with dementia would not be able to understand it, thus returning to what is perceived as a barrier to its use.

Non-stigmatising

The visibility or desire for a device to be discreet also emerged. Within the carers discussion the issue of safety was raised and how devices such as hand held satellite navigation might be a target for 'muggers'. This is an aspect that is a potential barrier to the use of technology, if it is perceived either by the carer or the person with dementia to make a person vulnerable then it is unlikely to be used. This links in with the idea of the device or technology being 'hidden' and not visible.

Later stages of dementia – using technology to locate an individual

Some of the carers who had experience of the later stages of dementia and ‘losing’ the person they cared for (whether out shopping or because of external care, i.e. hospital, respite) were in favour of the use of technology in enabling an individual to be located. One carer spoke about technology being ‘implanted’ to ensure that the person with dementia would trigger an alarm alerting the carer if they tried to get out of the house. Again, similar to Molly, this carer was also aware that the device needed to be small and dissimilar to ‘tags’.

B.2 WORKSHOP ANALYSIS

Workshops were conducted with four groups. The workshop transcripts were collectively analysed in an attempt to uncover factors that related to the acceptance of technology by the participants and revealed three major areas: the need for tailored designs for individuals, the need to avoid stigma (which was heavily emphasised) and the importance of routine in people with dementia and their caregivers’ lives. Note there is no discussion of ethics or problems being tracked by people in this section for some reason in this stage and it is not an omission from the coding system.

B.2.1 Individual specificity

Participants went to great lengths to discuss how technology needs differed between them whenever the topic presented itself. When one participant noted what they wanted from a device, others noted that would be no good for them. This seemed to be related to a variety of differing personal circumstances:

Home situation: Participants cited differing living arrangements as meaning they would need to have different functions. For example, living in a care home they felt they would want to inform staff when leaving but if they lived independently this would be too much

Caregiver: The presence or lack of a caregiver was identified as a major influence on what would be needed from a technology to help getting out and about. The lack of a carer raised issues about who the device could call for help if it was needed.

Severity of dementia: The participants mainly had mild dementia so felt they would use a device to get out and about but they felt that as their dementia became more severe they would need more help (n.b. this links to the idea of device evolution, many of the participants are very aware they are going to get worse and this was originally grouped with the routine issues).

Other impairments: This was discussed in two different contexts because it could stop people from really engaging with the tech/ being able to use it and several participants.

Caregiver: The impairments of the caregiver (particularly physical ones) were noted because the participants felt they would not be able to act on warning from the device.

Person with dementia: The participants with dementia noted that they would not be able to use a device because of poor arthritis, eyesight etc.

B.2.2 Stigma

Many of the participants noted that they were worried about being stigmatised because they were carrying a device that marked them out as different/impaired. They referred to fall alarms here as an example of something they disliked. This was mainly about using a device in public and being seen by others. There was a lot of discussion on this issue.

Discreet devices: Some participants felt that if they were going to carry a tracking device with them, then the device would have to be very small so that they would not be marked out as different/ seen using it.

Disguised devices: If a device was made to look like something else (maybe a mobile phone) then some participants suggested that they would have no problem using it in public.

B.2.3 Current routine

Much of the discussion in meetings centred on the current routine of the participants, the importance of a new device fitting into that routine and not unduly disturbing it.

Caregiver technology: Surprised to hear about how much mobile phone usage currently was felt to be an important issue. Caregivers did not want to have to buy something new to monitor their relatives with.

Person with dementia's technology: Some of the participants with dementia had experience using mobiles phones and mp3 players and felt that they would want devices that looked like these technologies or appeared to be similar to them.

Integration: Some carers and people with dementia went a step further and suggested that their new devices be integrated with their older devices.

Evolution: Because they did not want to have their routines disrupted by new technology, participants felt that it was important that they only had one device that was linked to them that they would not need to change even if their condition deteriorated (links to the awareness of state of dementia and likelihood that they will decline).

Coping strategies: Participants had already mentioned their existing coping strategies and were keen that these did not get disrupted by the current device but were enhanced by it.

B.3 PERSONALLY TAILORED DESIGN MEETINGS

This section presents the notes taken and analysis of transcripts from meetings with participants during the personally tailored design sessions. The notes include ideas about the designs to be made and so are important in understanding the context of participant's reactions. The themes extracted

from these meetings are broken down by the individual that is being worked with including John's wife (although the designs often respect issues raised by the other as well) and the meeting the reaction came in.

B.3.1 Meeting One

Alice's Design

The design was presented as a device intended to be used whilst she was out and about in town shopping or performing routine tasks. The concept was the device would act as some kind of reminder system for her and remind her of what she needed to do next should she come to forget what she was doing. The intention was that the device would allow her to record her plan before she left the house, in a manner similar to the way she currently writes a list of tasks before leaving the house (The list is frequently lost or forgotten though). Pat was concerned about the stigma such a device might attract so the initial plan was to build the device into the form of something innocuous and small such as a lipstick holder.

Recharging the device could be handled at the same hard-point in the house as recording was handled, the intention was to only have a playback feature on the device that would allow the user to use the device even when confused and not have to worry about recording over the current device content, this also fitted with the routine already in place as a plan was typically devised in the home and not altered when in town. To ensure that Pam remembered to put the device in to charge when at home, the concept of having a picture frame that lit up when the device was plugged in was presented.

The initial idea put forward was that the device should look like a lipstick holder but with discreet playback feature somehow incorporated into it. She was amenable to this idea. Later on, the discussion turned towards the fact she was looking to buy a new phone with a simple design and large keypad, possibly a flip phone. We proposed the possibility of integrating the device with a flip phone (based on previous workshop findings), making it so the functionality of the flip phone was present when flipped open, but the device had a completely different look and feel to it when the device is closed.

Alice's Reaction

Alice seemed to be happy with the concepts she was presented with.

Loosing items: When she talked about the list she kept with her, she mentioned that she frequently forgot to take it with her or kept it somewhere that resulted in it falling out of her pocket.

Medical issues: She also mentioned that she could not use earphones due to a medical condition, thus meaning more design might be needed around the area of the devices playback feature.

Outdoor visibility: Alice commented that the phone she was looking at had a big screen and that she was concerned that on a visual display device she might have some trouble seeing the screen if it weren't bright enough.

GPS Tracking: In the workshops it was unclear if Alice would require GPS tracking, she told us that she would feel much more confident with the device capable of sending an emergency signal if it were needed. This ties in with the concept of including functionality that's initially not needed but as the dementia progresses, becomes more important and carrying the device providing the functionality is ingrained in a routine.

Routine randomness: There is no significant routine or ritual on leaving the house, however she does typically put on her shoes as the last thing she does, due to finding them slightly uncomfortable to wear. Currently, Alice is rearranging the hall way to include a shoe rack to hold a slim-line shoe closet, she thinks that a recharging point on top of this cabinet would make some sense as then she would be more likely to see the device and remember to carry it with her. This also opens up the potential to have a device that reminds her to pick it up when she opens the shoe closet.

John's Design

The design we presented focused on the activity of running. The device we proposed could be worn in the shoes, on the waist band, on the upper arm or on the wrist like a watch. The device would his location to his wife via means discussed in her section. The device would include a button to press for help. We also proposed to Robert that the device might be able to give feedback on the run (For example, distance, time and steps taken). The reference point for the look of the device was the iPod Nano, implying that Robert wants something that appears to be highly designed, sleek and modern. We discussed the possibility of recharging the device when shoes were put away or possibly having a recharging point that would relay the stats on the run back to Robert, thus helping ingrain the device in routine. Sensors on the door would remind Robert to carry the device with him.

John's Reaction

John was enthusiastic about the idea and particularly liked the idea that the device give back to him information on the run that he had completed when the device was plugged in to recharge.

Confusing/loosing devices: John was concerned with the idea of placing the design on his shoes or wearing it on his belt, the former due to him owning four pairs of shoes and the latter due to concern it would pull down on the waist band over a long run and be irritating. Of the other two options, Robert favoured the idea of the wristwatch over the arm band but considered both to be feasible, so we will present designs around both of these aspects.

Size: John stated that, where the device the right size and weight (i.e. a wristwatch) He might carry it with him all day, this would provide some additional challenges in terms of battery life. If this were not the case he would wear the "watch" Only for running and would replace the watch he usually specifically wore for running with this watch.

Charging routine: He would also like to be reminded in some way when the device needs to be plugged in to recharge, his words where beeping however this could easily become irritating.

Watch Aesthetic: John was most enthusiastic about a watch like device that he could wear for runs, the device would need to be “Small and light” but other than this, he would like a plastic strapped device that could be quite large. His current everyday metal watch has a large display on it. He, like Alice, was concerned that the watch not appear to obviously mark him as disabled in some way similar to the stigma issue raised in workshops.

Random Routine: He left via one specific door when he went for a run and typically carried a watch with him as part of the routine around running but he did not have a particular time when he would go running. This would imply there may be some difficulty in spotting when he is leaving for a run in order to remind him to carry a device with him.

Device carrying: Based on confusion issues, we asked about routine leaving the house. We asked Robert questions aimed at uncovering potential points for reminders to carry a device with him, unfortunately as previously stated, there is no set time for him leaving the house. Robert did mention that he puts on a watch in the morning but changes it for running and did not go out wearing it. Possibly sensing that the “normal” watch has been taken off would be one way of offering a reminder.

Mary's Design

Mary was presented with the idea of a device for out and about and a device that would take over this role in the house. We proposed to Joan that there be a specific point in the house that the outdoor device was placed into which would trigger the house based system taking over the monitoring process. We proposed that the in-house device could be a lamp or something like that would change colour in the event of a problem. The device not having any display but simply having an implicit feedback associated with it was also put forward. We suggested the possibility of having a PDA or outside the house with a map and an alarm on it, or a phone with a few modifications to it.

Mary's Reactions

Mary liked the idea of having something inside the house that would provide implicit feedback on Roberts status, she was however, less keen on the idea of having no display available to her, this may be because she views the device(s) as being safety critical, so is less open to novel concepts around them than she might otherwise be. When talking about a place within the home to put a device, the living room was suggested as the kitchen and bedroom where only used for their typical purposes

Trips: Mary was concerned that they occasionally go away for the weekend or that her husband may wear the device over an extended period of time and as such it may need to be recharged at a mobile point, this would also need to be the case for the mobile device which she would carry, she particularly mentioned an in car charger at this point.

Building into existing kit: Mary said she was unconcerned how the device looked and would be happy with it built in to her phone or placed on a separate PDA device providing that the device was simple enough to use. It was however pointed out that she sometimes struggled to see her current phones display in direct sunlight and sometimes had to go into shade to see it.

Routine and TV: There are no significant routines around leaving the house or returning to it, Joan commented that she moved her phones charger to different places in the house depending on what she was doing. Joan also commented that she had no major issues with forgetting her phone or leaving it behind. Mary commented that she tended to stay in the lounge when Robert was out running and usually watched TV (Assuming she was in the house when he was out running, not always the case). We suggested the possibility of a lay over the TV screen or a channel devoted to providing tracking data.

We were told that the TV was typically left switched on constantly as a source of background noise, it was placed on top of a glass stand with three levels that also held the telephone and the DVD player for it. She thought that something based around this area of the room would be an ideal solution.

B.3.2 Meeting Two

This meeting consisted of the three clients being worked with, the consistent point of contact and one other KITE project designer.

This meeting was used to present to the clients the designs produced based around the information elicited from the first meeting and the analysis of the work done in meetings of the core team. Certain specific choices were made in the run up to this meeting and these choices needed to be relayed to the clients from the outset. Mary was informed that, for a variety of reasons, the project would not pursue in car navigation based aids, something she was not bothered by as she still desired help when she was walking and not driving.

The next part of the meeting involved presenting the clients with the current state of the technology and what would be possible in the time available to us. The clients where informed that we would aim to build functional devices that embodied the essence of their requirements but that in certain cases these constraints might not be met due to the limits on the project. As part of this process the clients where shown the current size of the technology being developed and this helped illustrate the point that the technology would be limited at this time. All the participants indicated that they understood this and where happy to work within these constraints.

Mary and John

Mary and John were presented with a storyboard centred around running and the runner was asked questions based around each panel of the board, initially these questions focused on the actions he took before leaving the house and the routines associated with them. The questioning then moved on to cover the actions he took outside when he was running, the routes he followed and the time he was

gone for. Parallel to this, Mary was asked about what she did when John was out, where she might be and what she might be doing.

TV and Routine: This questioning revealed that although there was a routine associated with leaving the house, the runner had no particular routes he took and he did not go running at a particular time. Finally, the storyboard methodology was used to explore the runners return to the house and this again revealed some routines around changing and showering.

Alice

Alice was asked similar questions using the medium of a storyboard.

Walking stick and routine: Alice proved to have a less solid routine for leaving the house, she was presented with several branching scenarios and noted that all of them where possible actions. Exploration of her routine before leaving the house found that she always carried a walking stick with her and that she always put on her shoes as the very last action before leaving the house, this was due to her being caused some discomfort by the shoes and because she needed the walking stick for mobility.

It was proposed that the walking stick she carried, which she had previously expressed a dislike for, was used to carry the device however, she was strongly opposed to the idea, it was suggested that a redesigned walking stick could be used as well however, when she opposed this idea, the concept was abandoned in favour of other designs.

B.3.3 Meeting Three

The technology developed so far was presented to the participants. In this meeting they noted that they were generally very happy with what they were shown.

Mary and John

Reactions where positive, the couple both expressed a hope they would be able to use the devices and try them on trial runs.

Waterproofing: John expressed particular concern that the device be waterproof for running in the rain.

The mobile interface was presented on a laptop and with a paper copy as well for Mary to play with and write on if she felt she had anything to say. Important points noted where that Mary was happy with using the mobile phones number buttons and selecting the options as displayed above the central top keypad.

Alice felt that colour system seemed a sensible option over the text based option for monitoring activity within the house but was unsure about the reliability of the method to be used to locate husband outside the house. She felt best option might be a map but was concerned about the size of it Thought a phone call would be best option for receiving alerts if help button had been pressed.

Existing device issues: Alice also expressed concern over what would happen if she changed her phone.

Reassurance in an emergency: John felt that vibration would suggest that the device was attempting to communicate an alarm button press but then that sound would convey that it had connected an someone was responding. He expressed some concern over seeing a reassuring light on the device if it was strapped to his arm.

Alice

Alice had the idea of the notebook form for her device presented to her for the first time. and was happy with the idea of the notebook. Alice felt the same system could be applied to her but when questioned if she would feel vibrations or see the lights if she put the device back in her bag she said that the she thought she would keep hold of the device until help came to her.

APPENDIX C: NUTRITIONAL ADVISER ANALYSIS

C.1 EXPLORATORY MEETINGS

This appendix shows the analyses of the output of the meetings conducted as part of the healthy eating theme. The analysis sought to understand a) what the current situation is in the participants' lives and b) the sorts of features they would welcome from a new digital technology device.

This section presents the notes taken from a paper document that was produced during the analysis process sorted under the overarching themes of:

- Requirements – features they would like to see in a hypothetical device that would help them to get out and about
- Obligations – key issues that they feel a hypothetical device must avoid if it is to become accepted into their lives

Relevant themes are grouped under each section with explanations about the nature of discussion around each theme that emerged.

C.1.1 Requirements

Motivation to Cook or Shop

Participants discussed how difficult it could be to motivate their self to cook or prepare food when living alone. Those who had lost a partner in particular noticed a decreased desire to prepare food. Participants suggested that a potential fix would be to encourage social eating in some form, whether going to a restaurant to eat or promoting going to another person's house to share meals regularly. Participants also felt that recipe suggestions ebbing provided to them would be particularly helpful in motivating them, if they could, for example, see a recipe they had not prepared before but which they thought would be particularly enjoyable.

Memory Assistance and Reminders

Almost all of the participants mentioned the occasional problem centred around issues with their memory or simple absentmindedness. Some participants discussed the need for regularly consuming water at an older age but the problems they encountered with remembering too and suggested that an in-kitchen device would be particularly useful if it could prompt them to drink water regularly.

Other participants talked about their absent-mindedness when going out shopping forgetting to take their shopping list with them. This was particularly galling for them as they tended to only discover the absence of the list when they arrived at the shop and frequently forgot critical ingredients in a recipe

as a result. The participants desired an in-house reminder of some sort to prevent them leaving the house without the list.

Finally, within the home participants also mentioned the tendency to forget about food located in their fridge/freezer and as a result they found that either they bought the food when they didn't need to or they let food go past its use-by date. This tied into the following theme:

Managing Food Storage and Spoilage

Participants noted that they didn't really know what they had in their fridge/freezer a lot of the time and they ended up wasting money on food they did not need or they let food go to waste. They cited the fact that the contents of their freezer was "hidden" either because it was frosted over, buried under other food, or because they did not have the necessary mobility to bend down to search through their freezer. Participants were keen to have some way to see what food they had in their fridge as result, either at home or when they were out-and-about doing shopping.

Participants were also concerned with their tendency to waste food because they knew it was going off but didn't have any recipe they could use it in and would like a system to manage their food better for them. The concept was linked in discussion to the idea of a recipe aid.

Digital Cooking Aids

Participants were keen to have some sort of cooking aid but they disagreed about the specific features it could have. Some liked the idea of a safety assistant that monitored their gas hobs and taps and let them know if they had left them on. They felt that it would be particularly useful to have such a device in place because it would grant them the confidence to cook again.

Others felt that the cooking aid should actually go out of it's way to suggest recipes based on the previously discussed issues and felt that the device could take account of disparate factors such as the time of year (for seasonal foods) and dietary requirements when suggesting recipes. They felt that such a device would be more likely to be suggested if it worked treats into the recipes that it suggested.

One point that all the participants did agree on was that this sort of cooking aid would need to be heavily customised or tailored to the individual so that the features that one person wanted, which potentially could annoy another, could be disabled.

Shopping lists and specificity to the individual/shop

Participants discussed a shopping list generator/reminder (to take the shopping list) tied to the idea of the cooking aid. They thought that such a list would need to be carefully organised to respect the ways that they laid out their own shopping lists and that it should not disrupt their own routine (see obligations later for more details on this).

The participants also felt that such a list would need to take into account portion size when buying food. This issue linked with the idea of cost needing to be managed carefully and being one of the primary barriers to good nutrition.

Participants in both meetings mentioned that a particularly important issue was the way in which they organised their shopping list. The organisation depended on the locations of items in the shop to avoid them having to back-track through the shop when doing the shopping.

The portions of food that were made available in the shops upset several of the older adults because they were often too much for them. They particularly disliked “2-4-1” deals in supermarkets as they often wasted a lot of the food from a single purchase of the item in question.

Persuasive or Mandatory Interventions

Participants talked at length about the need for a system that persuaded them to change their behaviour as opposed to developing a system that forced them to engage with food cooking or shopping in a certain way.

In discussion around this theme, subtlety was a recurring concept. Participants were happy to have their behaviour altered if it was done in a way that they were not made aware of. In contrast, they felt that if something obliged them to take certain actions they would rapidly come to resent it.

Desiring Device Simplicity

The participants in the meetings were very keen to emphasise that a device present its options to them in the simplest way possible. IM practice, the only example of how this might be implemented that was discussed was a food thermometer. The food thermometer would give some single, colour coded indication of how healthy a meal was through indicating a “Level” on the thermometer.

C.1.2 Obligations

Demanding Ease of use

Participants stressed that they would not use any device that was too small for them to easily see and use. They said that this would instantly disqualify it from use because it would mark the device as having not been designed with them in mind.

Participants also stressed that they were not very invested in the idea of a new device to help them eat more healthily and any frustration or perceived over complexity would likely instantly lead to a device being discarded.

Not Nagging the User

The participants were very aware Participants that the devices they used had the potential to become annoying over time if they intruded into their daily routine too much. Participants specifically noted that

reminders to do certain activities could rapidly become annoying (particularly if the participant had no intention of doing the activity in the first place).

One participant also talked about it not being “*about what you’re eating, but what’s eating you*” meaning by this that, should the hypothetical device go too far with reminding people to eat healthily or pointing out that they are eating unhealthily too much, it could cause anxiety. Other participants echoed this point.

Not Stigmatising the User

The need for a device to be as subtle as possible also appeared when the participants talked about their desire to avoid being stigmatised because they were carrying a device. They wanted the device to be, in some way, discreet so that other people did not know what they were using it for. This applied to both a device in the home and one that they might take to the shops.

Avoiding Erosion of a “Sense of self”

Participants were keen to retain a sense of self whilst using their devices and were concerned that the devices could undermine their autonomy. To this end, they emphasised they did not want to become overly dependent on the device; they still wanted to be able to think about their cooking plans and take their own decisions. To this end, the participants also felt that the device would need to be tailored to each individual in order to account for their own personal preferences.

APPENDIX D: TRANSPORT ANALYSIS

D.1 ANALYSIS

This appendix shows the analyses of the output of the meetings conducted as part of the transport theme. The analysis sought to understand a) what the current situation is in the participants' lives and b) the sorts of features they would welcome from a new digital technology device.

This section presents the notes taken from a paper document that was produced during the analysis process sorted under the overarching themes of:

- Requirements – features they would like to see in a hypothetical device that would help them to get out and about
- Obligations – key issues that they feel a hypothetical device must avoid if it is to become accepted into their lives

Relevant themes are grouped under each section with explanations about the nature of discussion around each theme that emerged.

D.1.1 Requirements

Avenues for Information Delivery

Participants discussed several different ways in which information could be delivered to them. They suggested the use of print outs, notice boards, radio broadcasts and mentioned, in passing, digital avenues like Sat. Nav systems. Participants favoured lower tech solutions in general but acknowledged that the data needed to be delivered in close to real time which would limit the utility of many lower tech solutions.

Social Pressure and Shop Guides

A major theme that emerged in the conversation centred on the participants feeling that they needed a way to be able to change the configuration of the world around them, whether that be public spaces, travel arrangements by local bus route operators or provisions in shops for older adults. The participants discussed a variety of possible approaches to this and particularly liked the idea of some sort of reward scheme for shops that they felt were making an effort to accommodate for older adults needs. Many different avenues for collating this pressure were mentioned including local newsletters and communal voting or review systems for shops. The participants also discussed blacklisting certain shops for not making efforts to be accessible but they were not as sure about this because they felt people would hesitate to engage in the scheme if they felt they would be harming a shop owner.

The participants also came up with the idea of shops marking the fact that they were disabled access friendly on local maps so people knew they could get into them without encountering serious

problems. They suggested that shops might like to be involved in a scheme where they indicated this accessibility on adverts in local newspapers. The participants felt that local newspapers had the potential to be central to such schemes.

Pre-Planning a Trip

A major theme of discussion was the need to plan for a trip and this was felt to be the most significant issue that determined how mobile someone was. It was suggested that this sort of pre planning could be supported by an in-home interface of some sort that alerted people to potential disruptions in their local travel activities. Alternatively, something like a paper newsletter that alerted people to potential personal mobility issues delivered regularly.

The participants wanted information that would be relevant to their own levels of personal mobility, something like a pedestrian travel report that can be heard on local radio that would talk about maintenance work on pavements and other potential disruptions.

Ad-hoc Re-Planning of a Trip

Another very important area for the participants was ad-hoc re-planning of trips when an unexpected issue emerged on the day. Participants identified several points where this meeting could be delivered including 1) immediately before leaving on a trip by, for example, a notice board or whilst on the trip via a mobile phone call.

Persuasion and Confidence's Role in Device Use

The participants' explained that their confidence in their own abilities often effected their decision to travel. They felt it would be nice if those who were not confident could be encouraged gently by the device to restore their confidence. As an example of this, they noted that some people were particularly "stuck in their ways" and, in order to enjoy a more mobile lifestyle, they needed to be encouraged to alter their behaviour.

The participants felt that offering choice in the ways that different transport problems were approached would help to solve this problem. They said that this was because having choice would help people to still feel in control of their travel.

Bus Specific Assistance and Problems

The participants discussed a set of issues linked specifically to using busses. Some of the participants had encountered problems when a bus driver would pull away from a stop without giving them time to sit down so they nearly fell. Others had wasted time standing at bus stops waiting for busses that never came because the timetables that were provided were wrong. Another issue was a sense that bus stops were located in the wrong places so weren't useful. There was an overall dissatisfaction with the manner in which bus companies conducted business and participants felt unable to confront the companies about this.

Car Specific Assistance

The participants who still used cars described two specific problems that they frequently encountered. The first was that parking when travelling into town was often limited so they could not park their car near enough to shops to walk to them. The second was the poor placement of disabled parking spots. The participants found that these parking spots were often located a long way from the shops they were meant to serve.

Challenges Navigating Public Spaces

Participants spent a lot of time discussing their experiences in public spaces, focusing on the challenges they encountered. The environment itself caused some of the issues, for example, the participants disliked the sloping pavements with raised bumps on them that alerted blind people to the fact they were approaching a crossing because the bumps and the slope were uncomfortable on their feet and ankles. Participants also mentioned that, like the shops mentioned previously, some public buildings did not make sufficient efforts to be easily accessible with poorly built, uneven steps and no ramps for wheelchairs. Participants also complained about the prevalence of maintenance work that disrupted pavements and thought it was particularly problematic for them because they often had pre-determined routes that they followed designed to overcome the other challenges mentioned. They contrasted this with road maintenance work because in the latter case there were mechanisms available to find out about the problem in advance (e.g. traffic alerts on the radio) and plan around it.

The participants also referred to their own health as a source of problems when navigating public environments. They discussed how they needed to think about medication needs they had and plan for them in the journeys they took and they discussed the need to plan for frequent stops when they were travelling to avoid fatigue.

D.1.2 Obligations

The Need for Quality Information

Participants were keen to point out that any system of advice would instantly lose its appeal if the information that it provided was found to be inaccurate. The participants said this would not be tolerated because of the potentially high cost to a user who had come to rely on the system.

Framing the Social Feedback Aspects Correctly

An area of discussion that emerged was tied to the social aspects of the feedback system such as the one proposed for rating shops. Participants felt that if reporting to these systems came across as talking behind a shops back then they would not be very popular. Instead, they felt it was important to frame it as positive feedback or make it a way of reporting to a community to help others out in the future. They felt that if the system was seen as a venue for “ranting” about a shop it would be unpopular.

Participants had mixed feelings about the role of anonymity in the process, some felt that it would encourage people to feedback on the shops they used but others thought it made the process feel

dishonest or like gossiping. Finally, they participants all agreed that the system needed to be seen to be getting something done about the problems reported on it. It would not be good enough to simply warn others away from problematic areas, they wanted to see that the problems that they pointed out were being fixed.

Ease of Use

As in several other design sessions, participants discussed the importance of a device being easy to use and not too “fiddly”. They stated that any device would need to have a clear display that was easily viewable in bright sunlight and that ideally people would receive training in how to use the system after they were presented with it.

Financial Obstacles

The participants were particularly concerned about the costs that might be associated with using a system to help them travel. They worried about a subscription pricing model and hoped the device would not be beyond the means of the average older person who did not have a lot of disposable income.

APPENDIX E: COMMUNITY AND SECURITY ANALYSIS

E.1 ANALYSIS

This appendix shows the analyses of the output of the meetings conducted as part of the security theme. The analysis sought to understand a) what the current situation is in the participants' lives and b) the sorts of features they would welcome from a new digital technology device.

This section presents the notes taken from a paper document that was produced during the analysis process sorted under the overarching themes of:

- Requirements – features they would like to see in a hypothetical device that would help them to get out and about
- Obligations – key issues that they feel a hypothetical device must avoid if it is to become accepted into their lives

Relevant themes are grouped under each section with explanations about the nature of discussion around each theme that emerged. Note that this discussion was less productive than other discussions and produced fewer, less well defined themes that were grouped into requirements and obligations.

E.1.1 Requirements

Camera Positioning

The features suggested as a result of the debate included cameras which video the premises, particularly at the back door (As shown in the film, although one participant recognised the edit to the back of the Queen Vic). The idea of a front door camera was also discussed. People commented that police did not respond well to this sort of situation and as follow up noted that the legal system seemed to support the criminal.

Online Systems and Visualisation

When discussing problems around trust, participants were more vocal, they talked about issues around online shopping and banking readily, saying that the reason they distrusted them was because of a lack of visibility. One idea people liked was having their account spending visualised simply. Another interesting concept was the idea of an account which could check up or observe your own spending but which could not actually control it. The idea here was that the younger relatives could see any unusual activity in the account and notify their parent.

Mobile Camera

Participants felt that the idea of a camera to record users' surroundings was largely unnecessary except in cases where someone was repeatedly victimised, in this case the participants felt that the police should provide a camera to gather evidence. People were concerned over the cost and quality of this sort of camera and Paul identified an underlying feeling that these devices would not make users feel safer, it would only help the criminal be found later rather than act as a deterrent.

Community Connection

Conversation moved onto the underlying essence of the problems, the participants felt that promoting a stronger connection between older adults and young people would go a long way towards alleviating the fears of older adults as well as reducing occurrences of the crimes, older people also felt that the news tended towards over dramatising the issues. They mentioned that having nice news stories rather than constant negative reporting and breaking down generational barriers were more valuable tasks as opposed to deploying more camera's.

E.1.2 Obligations

Ease of Use

The participants stressed that any home security system would have to be easy to use, they also commented that they knew of this sort of system already available and did not buy it because of the price, a feeling that it was an invasion of privacy or a general lack of concern.

Home security camera targeting

One point that did get repeatedly emphasised was that people were not at all happy with the idea of a camera within their own home, no matter how the data was handled. The cameras discussed would absolutely have to only ever look out of the house.

Camera utility/immediacy

Some of the participants pointed out that they would not be willing to use a camera of any sort because they felt that it would not be particularly useful for them as it would not stop a crime in progress. They felt that it might be useful at a later date but even then they were sceptical and thought that local police forces might not take evidence it gathered seriously.