NOT FOR ME, WITHOUT ME

Co-designing assistive technology with people affected by dementia

Rebecca Jury

ACKNOWLEDGEMENTS

ABSTRACT

Dementia is a degenerative disease of the brain that impairs an individual's memory, language, mood, and logic. With the number of people living with dementia expected to double every twenty years, increasing strain has been placed on care facilities to provide better care. Designers are providing new and exciting products to help improve the lives of people with dementia. However, there is a deficiency of collaboration between designers and people affected by dementia in the design process, due to the symptoms of dementia.

To address this problem, this study explored the feasibility of co-design with people affected by dementia. Six co-design workshops were designed and conducted with a small group of people affected by dementia and a member of their family. Qualitative data was analysed from the process to recruit partners, create a dementia friendly toolkit, and facilitate co-design workshops and user tests with people affected by dementia.

The resulting data helped identify what people with dementia value, give evidence to suggest that people with dementia are able to contribute to the design process, and suggests that co-design can be an empowering and positive experience for people living with dementia.

CONTENTS

ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

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1| INTRODUCTION

This first chapter illustrates the current practice for the design of assistive technology for people affected by dementia, and highlights a lack of participation from people affected by dementia in the design process. The researcher also describes their world view to rationalise their use of co-design in this study. This chapter concludes with the research question: how to co-design with people affected by dementia, and describes the outcomes of the research.

CONTEXT

The effects of dementia

Dementia is a long term, degenerative syndrome caused by structural and chemical changes in the brain where nerve cells are either dying or miscommunicating with each other (Gililland, 2010; The Health Foundation, 2011). The word 'dementia' is an overarching term for a collection of symptoms including forgetfulness, language deterioration, mood swings, impaired logic, and a loss of initiative (Budson & Kowall, 2011; Morris & Morris, 2010). However, everyone's' journey with dementia is unique due to variables such as their age, personality, type of dementia they have, and its degree of impairment (Barback, 2012). Consequently, symptoms do not present themselves in a linear pattern and may have progressed further in some people compared to others diagnosed at the same time (figure 1.1). Despite this, people with dementia are often labelled within stages such as mild, moderate, and severe. Such labels are effective at giving an idea as to the overall abilities of a person with dementia, yet tend to focus upon what a person is unable to do rather than able (Morris & Morris, 2010). This sets up the premise of assuming that people with dementia would be unable to

Figure 1.1 The variety of dementia and it's journey

participate in their care because they are unable, for example, to make a cup of tea. A conscious decision should be made to accept that all journeys with dementia are different. People with dementia should be celebrated for their remaining capabilities, thus improving their wellbeing.

With an aging population, it is expected that the number of people living with dementia will double every twenty years, increasing strain on health services and those that care for them. By 2050, the number of New Zealanders diagnosed with dementia will increase to approximately 150,000 (Alzheimer's Disease International, 2015; Deloitte Access Economics, 2012). However, this number only represents those clinically diagnosed with dementia, leaving an estimated 40% still undiagnosed (Deloitte Access Economics, 2012). Consequently, it is expected that two thirds of New Zealanders will know someone who is affected by dementia or be affected by dementia themselves (Alzheimers Auckland, 2014).

Caring for sufferers of dementia

Unfortunately, to date there is no cure for dementia or treatment to delay its progression with current drugs only masking symptoms of the disease (Alzheimer's Association, 2015). A single person diagnosed with dementia typically affects three to four people who provide unpaid, informal care (Tan & Szebeko, 2009). Traditional care methods have focused upon a medical model, with patients being cared for indefinitely, in nursing homes (Ministry of Health, 2013). Newer models of care aim to maximise independence and wellbeing using a holistic approach to care by involving people with dementia and their families in decisions around care and support (Counties Manukau District, 2013; Ministry of Health, 2013; National Care Forum Older People and Dementia Care Committee, 2007). This includes supporting people to live independently at home if the person with dementia and their families want this.

Decisions are often made by clinicians and families to retain the independence of a person with dementia for as long as possible to improve their wellbeing from living in a familiar environment. Over 80% of people diagnosed with dementia value living at home within their community (The Health Foundation, 2011). This is a choice that keeps them in familiar surroundings with known supportive people during a period in their life where they find it difficult to remember new people, spaces, and objects as well as arrange old memories. Independence at home is encouraged by the Ministry of Health (2014) who are increasing their services for people affected by dementia to remain at home, and in their communities, to reduce loneliness, isolation, and increase community support for informal carers. This also has the benefit of reducing the overall cost of dementia care in New Zealand—currently around $1 billion NZD per annum (Ministry of Health, 2014).
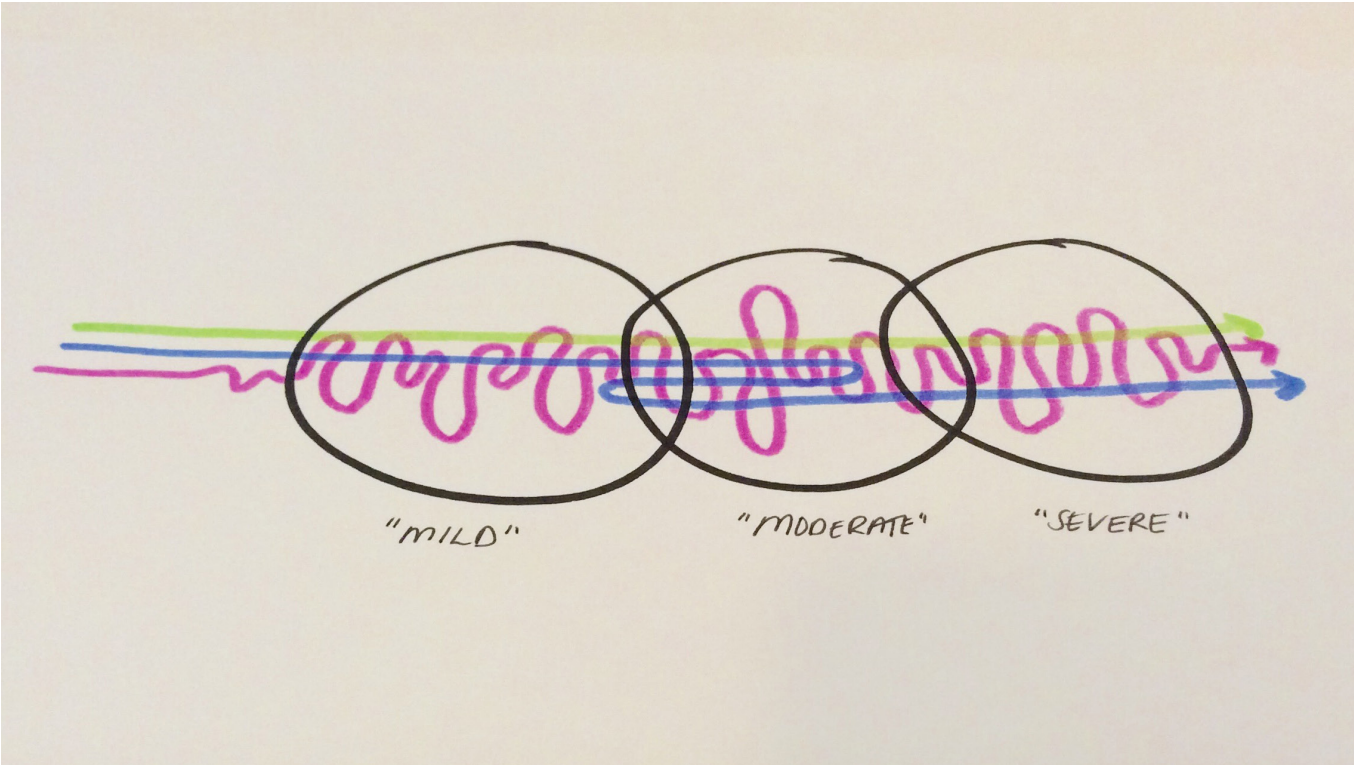
However, despite the benefits of people with dementia being cared for at home, it negatively impacts the physical and psychological wellbeing of their informal carers (McConaghy & Caltabiano, 2005). Thoroughly documented, dementia creates a dramatic increase of stress on carers resulting in carer exhaustion, sleep deprivation, depression, and denial (Smith, 2013). Carer fatigue reduces the capacity, interest, and empathy towards people with dementia resulting in misjudgement, clinical errors, and poor treatment planning (Rossi et al., 2012). This is often due to carers being unprepared to care for people with dementia. Carers committed to taking care of someone throughout their journey with dementia are often ill-equipped, particularly spouses of old age, to handle the later stages of the disease alone (McClendon & Smyth, 2015). Therefore, it is common for people with dementia to be housed in long term permanent facilities once carers can no longer manage their care.

The transition from home life to permanent care is stressful for a person with dementia due to the confusion and anxiety that it brings for them in unfamiliar surroundings (The Health Foundation, 2011). This often results in disruptive behaviour, which the care facility may choose to control using drug therapy. Drug therapy often has little effect for most patients, and can be severely damaging for a small percentage of patients (The Health Foundation, 2011).

Identity, self-worth, and wellbeing

Despite such pervasiveness within communities, there is a negative stigma attached to dementia caused by a lack of awareness (Ministry of Health, 2013). People living with dementia experience a loss of status and power, discrimination, and stereotyping within their communities (Swaffer, 2014). There is also a profound sense of shame caused by a loss of self, independence, companionship, and occupation (Morris & Morris, 2010). These negative experiences severely impact on a persons' identity, self-worth, and wellbeing. The New Zealand Ministry of Health (2013) has aimed to improve the journey of people diagnosed with dementia by providing clear, comprehensive information about dementia within communities and an integrated, holistic approach to dementia care and support by 2019. Research involving people with dementia in the design process, such as this, is one such step towards that goal.

Moreover, people with dementia are assumed to lose their self identity when they lose the ability to communicate it to others (Rossi et al., 2012). Recent research suggests, however, that their identity is merely hidden, rather than lost (Caddell & Clare, 2011). Viewing a person with dementia as less of a person encourages a lack of social interaction with them. This can lead to depression within a person affected by dementia as it exaggerates their symptoms, decreases their self-worth, and allows them to isolate themselves (DeMarco, 2015), all of which are known to negatively impact on a person's wellbeing.

Insights that are noticed, or perhaps missed by the researcher, are often influenced by the researcher's background, previous experiences, and knowledge (Sullivan, 2010). Consequently, this section gives some insight into the character of the researcher as it affects the interpretation and outcome of this research.

I have a bachelors degree in creative technology, which is an emerging discipline. It uses art based methodologies to build or hack technology to express ideas. The act of translating these ideas into technology is similar to solving puzzles including the frustration before you crack the puzzle. However, the projects that I enjoyed working on the most were ones in which there was an end user as I found myself trying to envision who the user would be and how easily they could use what I had built.

Designing for others is a skill that I believe is not turned off. Simple acts become exercises to identify the optimal course of action, not just for myself but also for others. These actions are always up for review and are sometimes analysed to see if I could have done better if the situation were to occur again. To me it feels natural to use design to support others. It is rewarding seeing an end user's response to a design and naturally there are always small changes needed to suit the individual. I enjoy this engagement with users and discussing with them what works for them. Otherwise we are just providing designs for them

to adapt to and I do not believe anyone can produce an optimal result without this engagement.

Throughout this research it has often been asked whether I myself am related to someone diagnosed with dementia. Within New Zealand, two out of three New Zealanders know or have known someone living with dementia (Alzheimers Auckland, 2014). Despite the probability, I am not. In brief I believe my interest in working with older adults is because of the interesting stories they tell, the close bond I* share with my grandparents, The Last of the Summer Wine, and a passing comment made by my mother: "We are all on the same conveyor belt".

THE PROBLEM

From the beginning

This project is an extension of "This is me too" (Jury, 2013), an honours research project that was developed for the Auckland District Health Board as part of their Better Brain Care Pathway. Working with a psychogeriatrician at Greenlane Clinical Centre and Alzheimer's Auckland, the aim was to enhance the experience of dementia in New Zealand's health care system by digitising a paper document called "This is me" that captured and conveyed the life history of a person with dementia to clinicians. After analysing the paper document "This is me", it was evident that the paper document did not satisfy the needs of people with dementia as it often left little room to write who they were and focused on clinical answers. Four prototypes were developed using expert consultations, and rewriting and organising the questions. Each prototype addressed a different aspect that the previous prototype neglected.

"This is me too" assisted the care of a person with dementia by providing details about who they are and what they need when the person is no longer able to remember or communicate it. This is important as when a person with dementia is admitted to hospital, they are suddenly placed in an unfamiliar environment surrounded by people unknown to them. Consequently, people with severe dementia find it difficult to do ordinary tasks such as going to the restroom, which for

example, may result in aggressive behaviour from the discomfort and eventual bed-wetting. Without "This is me too" to signal clinicians of this potential issue early, clinicians may unnecessarily insert a catheter and use drugs to control such difficult behaviour (The Health Foundation, 2011).

The prototypes of "This is me too" were based upon a clinical viewpoint, instead of meeting the needs of people with dementia, as there was no ongoing consultation with the intended users. Consequently, it was felt that the outcomes did not provide a solution to the problem despite being 'user centred'.

Assistive technology for people affected by dementia

Despite an increasing aging population living with dementia, only recently is technology is being recognised as able to provide solutions for their safety, security, and social needs (Astell et al., 2008). Defined as any device or system that increases ease of task performance as well as safety; it can be as simple as a walking frame or as complex as an automated house (Cash, 2003). Due to the variety of different assistive technologies, the research will focus on technology that uses a computing device such as a computer, tablet computer, and mobile phone.

There is a cycle of misunderstanding between technology, the development of technology, and
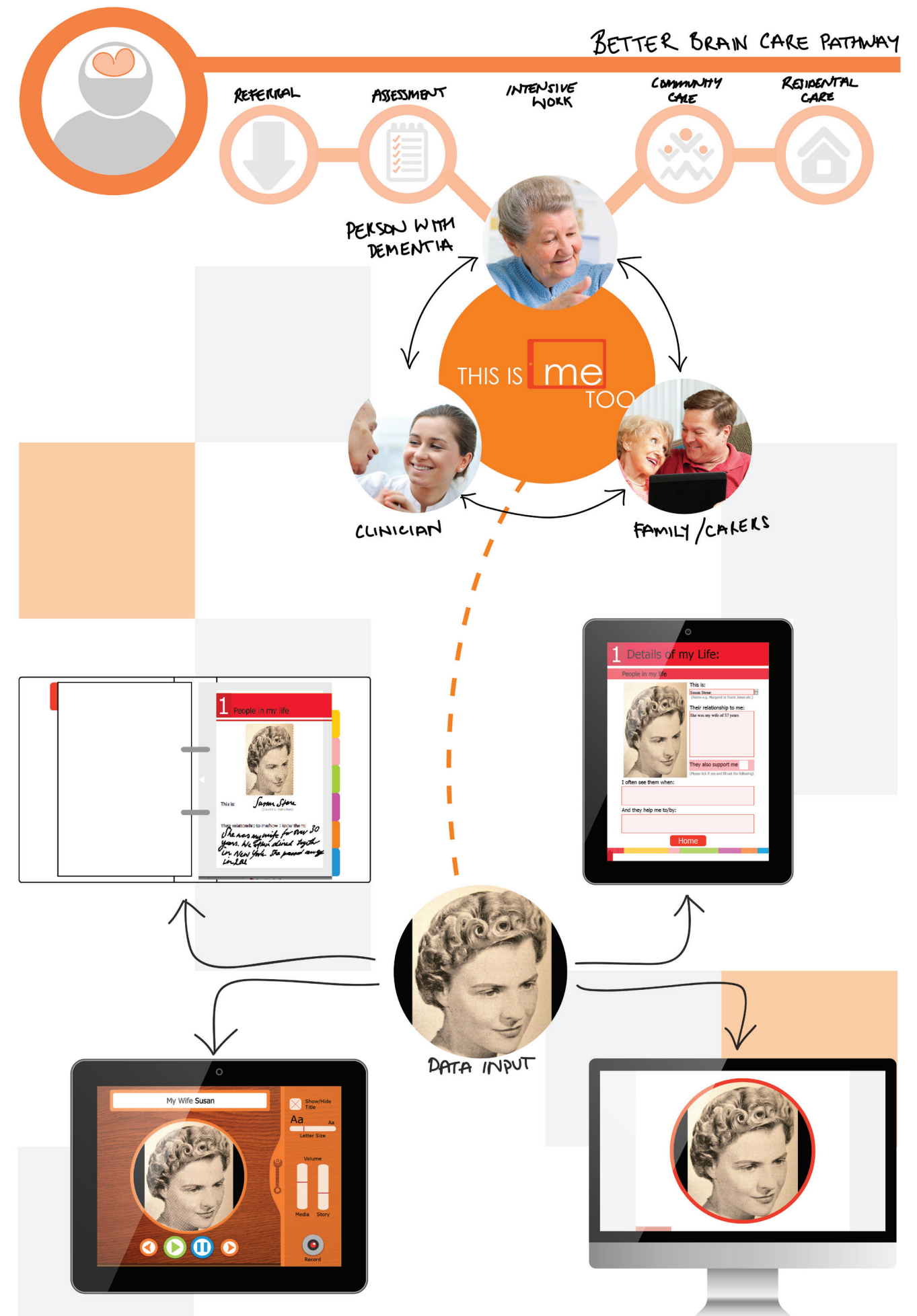
elderly people. Beginning with the assumption that the elderly have little interest in the use technology, sweeping generalisations are used such as "Old people don't want a tablet, they have never used one in their life and wouldn't know what to do with it," which ignores their diverse individualities and requirements (Roberts, 2009). It may be due to this thinking that those currently engaged with driving the development and design of technology do not develop technology to meet the variety of needs required by the elderly or disabled (Lou et al., 2010). Cash (2003) hints that technology is instead made to reduce costs or staff. This results in assistive technology with poor user experiences (Alm et al., 2011). Elderly users of such technology do not enjoy using it. In consequence, they stop using it, which perpetuates the idea that the elderly are not interested in technology .

However, if given the opportunity elderly people as well as people with dementia have responded positively to using assistive technology when it is obvious as to its direct benefit and easy to use (Alm et al., 2011). Upton, Upton, Jones, Jutlla, and Brooker (2011) identified that people with dementia found the tablet computer easier to use than a computer and used it to reminisce, socialise with their peers, and connect with younger generations. However, in the same study, those that used the tablet for one-on-one interaction did not find the tablet as easy to use because it

was difficult to remember how to use it without prompts from a carer (Upton et al., 2011).

Technology used by people with dementia should met their needs and have carer support. When choosing an assistive technology, the individual's needs, requirements, and personality should be analysed so that the technology suits their life and not the other way around (EU biomed II project, 1999). Having something that they are interested in using to assist them, as well as the support from their families, can motivate use of the technology thus breaking the cycle (Harrefors, Axelsson, Lundquist, Lundquist, & Sävenstedt, 2013).

There are examples of researchers, designers, and technology developers including older adults in the development of software. However, the involvement of older adults is often based on providing feedback on a developed product rather than allowing older adults to generate their own solutions (Davidson & Jensen, 2013). Researchers use people with dementia to inform their research question instead of the effects participation has (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). An examination of digital assistive technology products for people living with dementia reflects how often people with dementia are designed 'for' instead of designed 'with'. Involving older adults in the generative process of design may not improve the innovation of a product however it reveals insights

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Need more design WITH people affected by dementia

6 5 4 2 7

Designed for ────────────────────────────────── **Designed with**
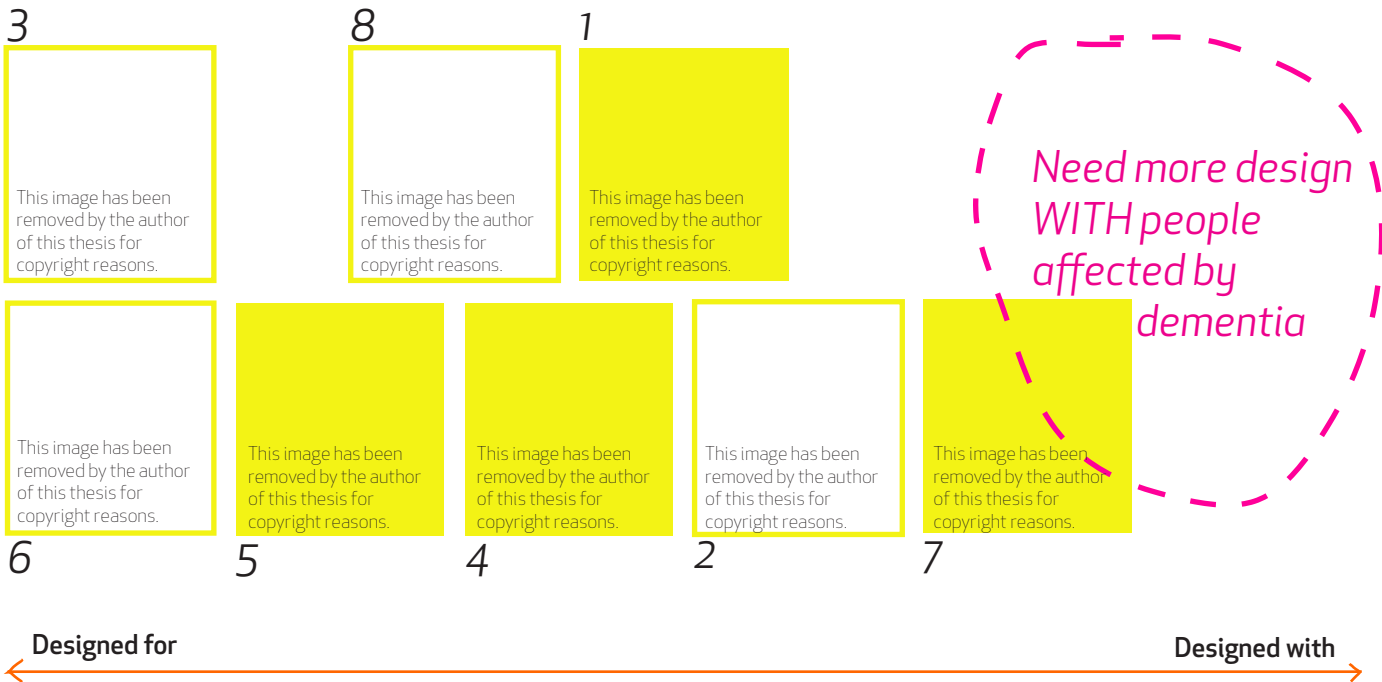
into the needs, priorities, and thought processes of older adults that are not necessarily obvious to a younger designer (Davidson & Jensen, 2013).

1. AVED (Salomon, 2014)
2. Action (Hanson et al., 2007)
3. Brainy App (Alzheimer's Australia, 2013)
4. Circa (A. J. Astell et al., 2010)
5. Cogknow (Meiland et al., 2012)
6. Grey Matters (GreyMatters Care LLC, 2015)
7. Independent (Hagen et al., 2007)
8. My House of Memories App (National Museums Liverpool, 2015)

THE RESEARCH QUESTION

THE METHOD

Due to:
- a lack of design consultation with people affected by dementia, not just in "this is me too" but the research and design of others
- the stigma surrounding older adults and people with dementia that they are incapable or uninterested in contributing to the design or use of assistive technology
- and the researchers belief in collaborative design

the purpose of this research is to explore;

How do we* co-design with people affected by dementia?

*designers, therapists, and anyone interested in working with people affected by dementia

Due to the importance of involving users, and the novel approach of co-designing with people affected by dementia, a co-creative approach has been used throughout the research process with the aspiration to promote the inclusion of people with dementia in the design process. This means that experts were consulted and collaborated with from recruitment through to the workshops co-designing with people affected by dementia.

Using action research as a reflective process to structure the progress of the study, the research question, 'how to co-design with people affected by dementia', has been split into four sub questions. The four cycles are distinguished between each other based on the overall aim, rather than the experts involved (see next page).

1. HOW TO RECRUIT PEOPLE LIVING WITH DEMENTIA?
2. HOW TO BUILD A CO-DESIGN TOOLKIT?
3. HOW TO CONDUCT CO-DESIGN WORKSHOPS WITH PEOPLE AFFECTED BY DEMENTIA?
4. HOW TO USER TEST ASSISTIVE DIGITAL TECHNOLOGY WITH PEOPLE AFFECTED BY DEMENTIA?
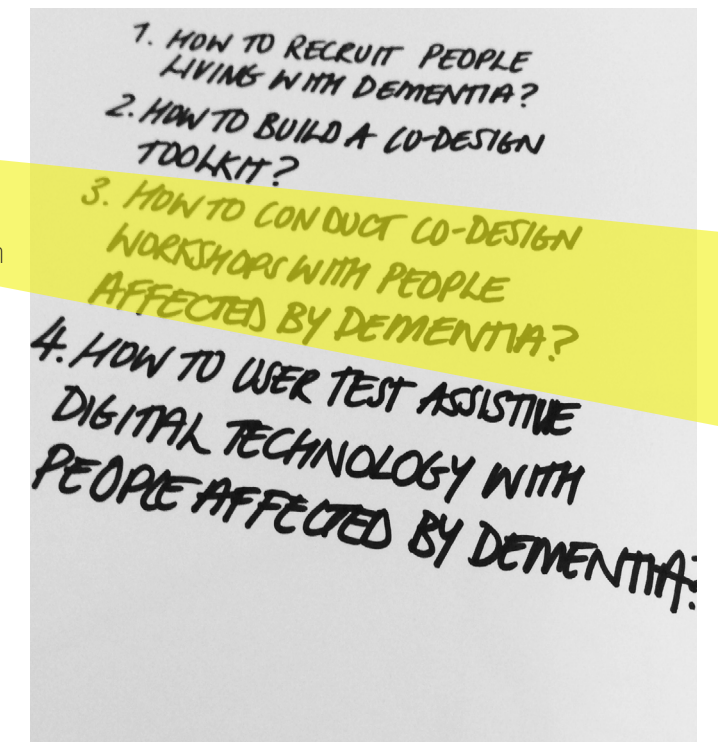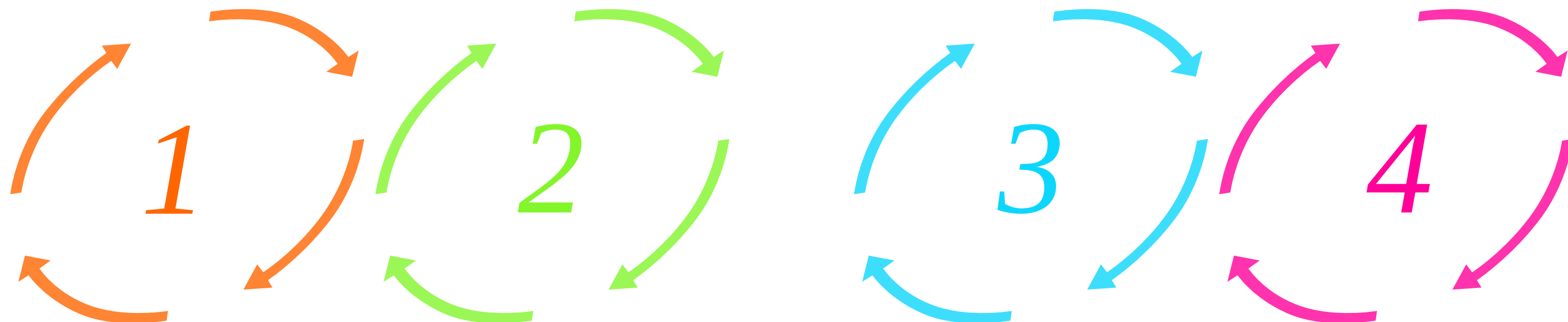
1 — Recruit co-design people living with dementia

2 — Develop a co-design toolkit for people with dementia

3 — To identify what people with dementia value

4 — To user test a prototype with people living with dementia

Experts consulted

Experts consulted

- Psychogeriatrician
- Ethics advisory committee
- Bupa
- Elizabeth Knox
- Howick Baptist
- Alzheimer's Auckland
- Older adults
- People living with dementia
- Informal carers
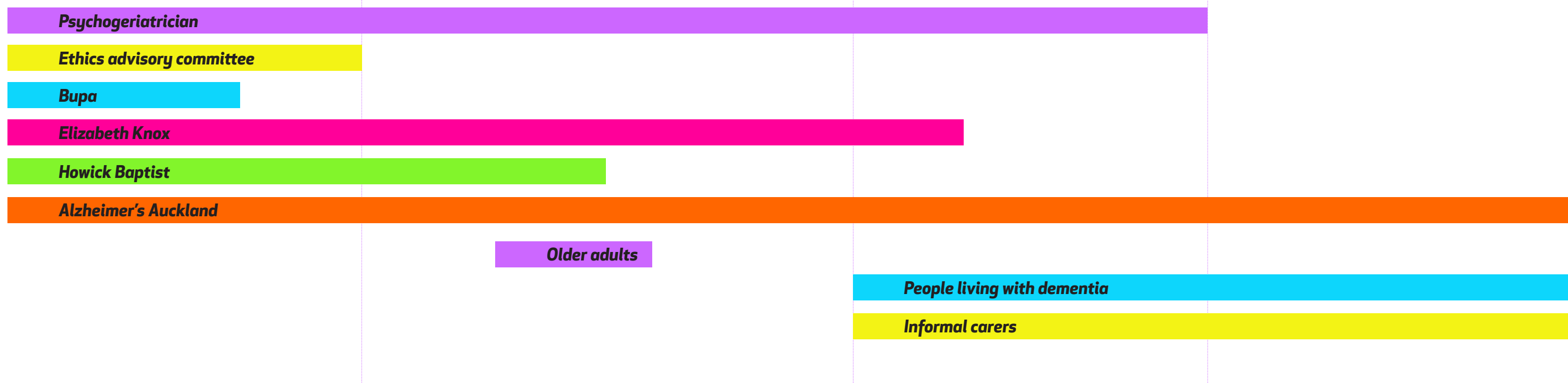
THE OUTCOMES

This research may be of interest to designers, who are familiar with co-design but inexperienced in working with people affected by dementia, as well as therapists, unfamiliar in design, looking for alternative stimulating activities. It may also be of interest to co-designers or therapists of other cognitive impairments that share similar symptoms to dementia.

This research advances the knowledge of co-design by exploring the feasibility of co-designing with people affected by dementia. A guidebook was developed as a product of this research based on first-hand experience. It details the process of recruiting partners with dementia, planning a workshop series, and provides an example of a basic toolkit.

The outcome of the co-design workshops with people affected by dementia is that they want to talk and think. This resulted in a blog prototype that allowed family members to post items of interest to a person with dementia so that they could use it to prompt conversations. Those living with dementia accessed the blog on a tablet computer device. While prototyping it was identified that the tasks people with dementia wanted to do or would enjoy, was already available. However, it was difficult for a person with dementia to access. Consequently, a concept book was developed where the tablet computer was inserted into the book and the pages gave instructions on how to navigate the tablet computer.
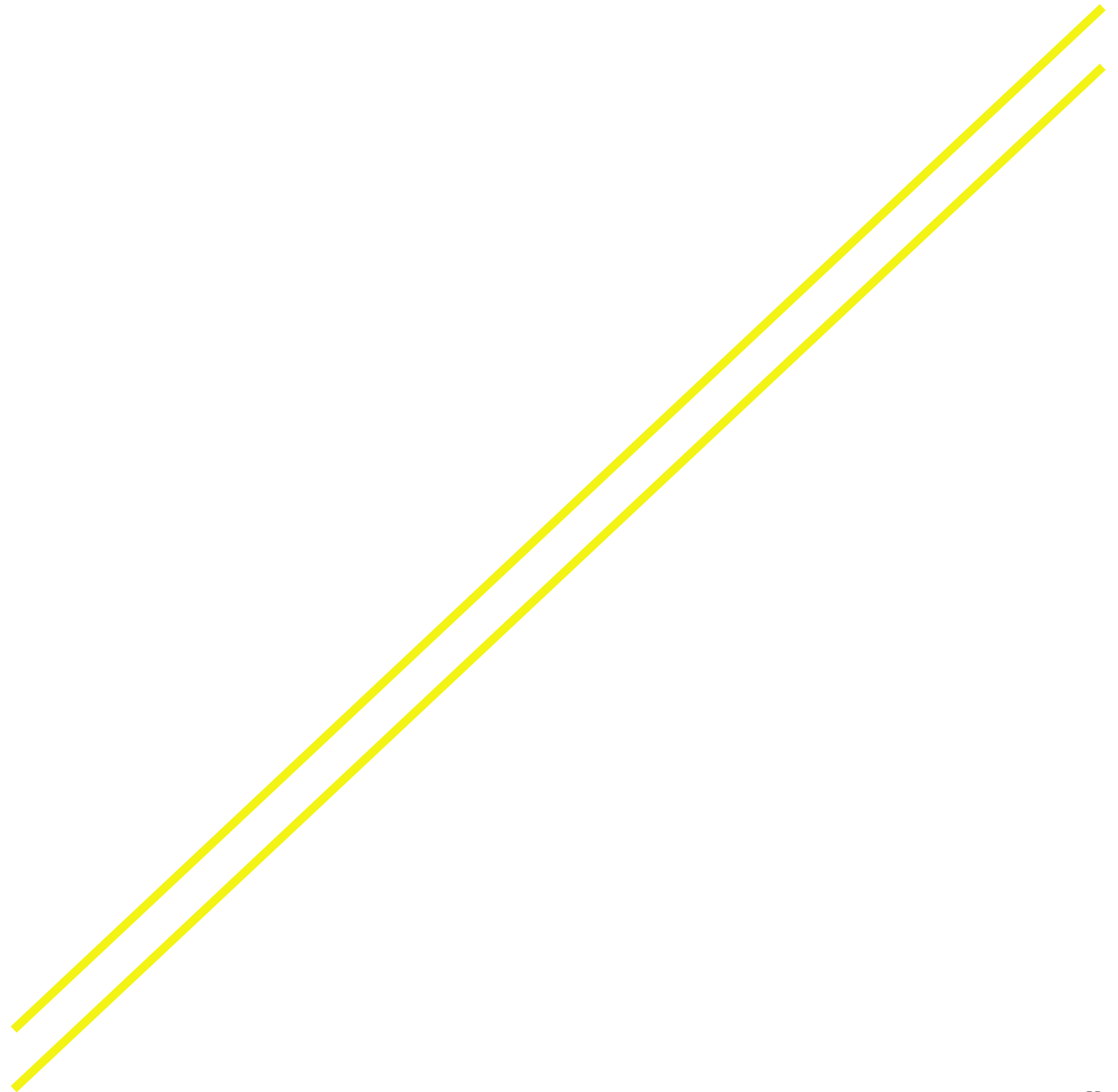
2| METHODOLOGY

Using the framework of Crotty (1998), the methodology chapter has been divided into four basic elements to structure the understanding of the research process. Using Crotty's definitions, epistemology is the theory of knowledge, theoretical perspective is the philosophical stance to provide context for the process, methodology is the strategy justifying the methods, and methods the techniques used to gather data. In addition to Crotty's framework is the sampling and participant characteristics, which discuss the process used to recruit research partners and describes those who were recruited.
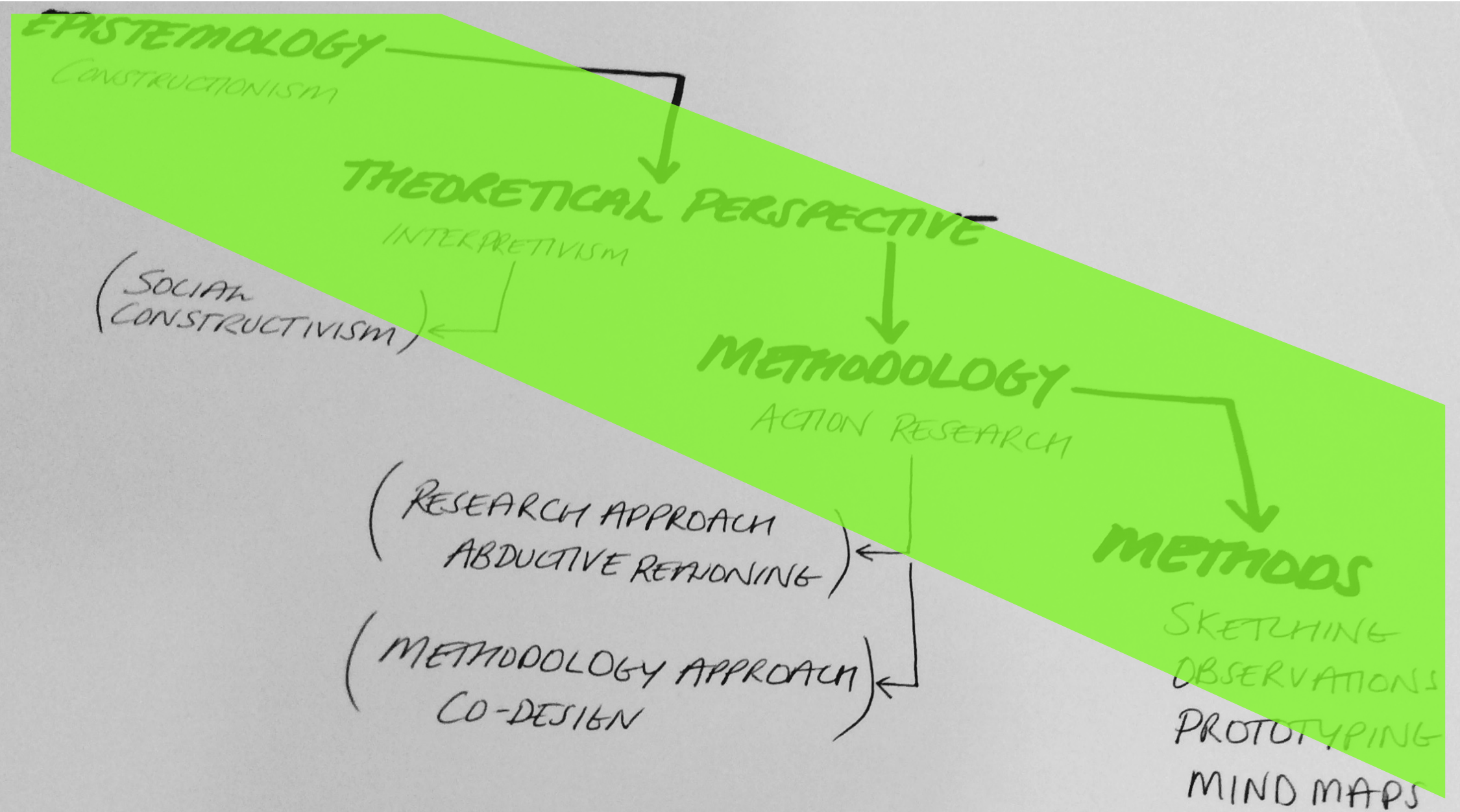
Influenced by the researcher's personal training and experiences, their worldview is based upon a constructionist perspective. A constructionist's world is built upon the subject creating meaning from their experiences to understand certain objects or things (Creswell, 2013). Therefore, how we know what we know is constructed in our minds through our interactions with the world. Consequently, those from different backgrounds, cultures, or eras may construct an alternate meaning to others about the same phenomenon (Feast, 2010).

As the researcher does not have dementia, any products or services for people with dementia may not meet their needs because they would be designed without an understanding or awareness of the meaning people with dementia have of the world. Therefore, the research relies as much as possible on the constructed meaning of research partners*, who live with dementia, using open-ended discussions central to co-design to develop a theory based on the pattern of their answers. Knowledge is limited by the communication of internal meaning given to the object by people affected by dementia, who, because of their cognitive impairment, will experience a phenomenon differently to the researcher.

*Prefer to use research partners instead of participants as it is more collaborative.

THEORETICAL PERSPECTIVE

METHODOLOGY

Interpretivism is the belief that social reality and natural reality are different to each other and therefore require different methods to understand them (Gray, 2004). Due to the complexities involved within understanding how others view the world, a qualitative approach is used to collect data. Interpretivism rejects the view held by objectivists that meaning is constantly available independent of the subject (Collins, 2010).

Social constructivists believe that the subject seeks to understand the world in which they live and work, and accepts that there may be multiple variations dependant on the individual which are equally valid (Creswell, 2013). This is similar to the principles of co-design where the opinion of a research partner is of equal value to the opinions of all the other research partners. This is because the new meanings that the subject has made on the world are based upon their internal reflections and their experiences (Collins, 2010).

To find out how others view the world, a social constructivist's research typically features broad questions so research partners are able to construct their own interpretation of a situation which the researcher listens carefully to (Creswell, 2013). Co-design enables a platform for such broad questions to be asked in a variety of topics that are important to the person with dementia.

As part of the co-creative practices, action research is a methodology that bridges the gap between practice and theory, as it not only provides a solution to a problem, but also seeks to understand the different realities constructed by people with dementia from the same phenomenon (Gray, 2004; Schön, 1983). It follows a cyclic structure where a series of steps are built upon each other and repeated (Figure 2.1). The first step is the plan, followed by the action of that plan, followed by the collection of observations, until finally reflecting on the effects of that action (Collins, 2010; Gray, 2004; Koshy, Waterman, & Koshy, 2011). Action research was used to test and support assumptions surrounding people with dementia and generate new ideas. Despite appearing to occur in a linear manner, action research used a messy exploratory design thinking approach (Figure 2.2) as it allowed the researcher to alter the course and constraints of the co-design journey as new data was obtained (Brown, 2008). This is particularly evident during the co-design workshops as subsequent workshops were modified to improve facilitating co-design with people affected by dementia, or to improve the exploration of values that were identified.

Action research can be interpreted in different ways depending on the subject discipline. Within social science research, action research uses the same cyclic structure but relies upon other partners and democratic decision making for reflection instead of the researcher's individual reflection (Koshy et al., 2011). However, within this
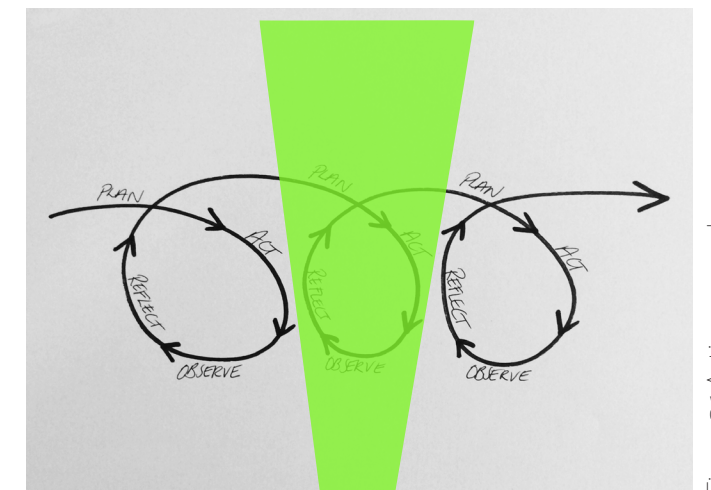
Figure 2.1 Action research
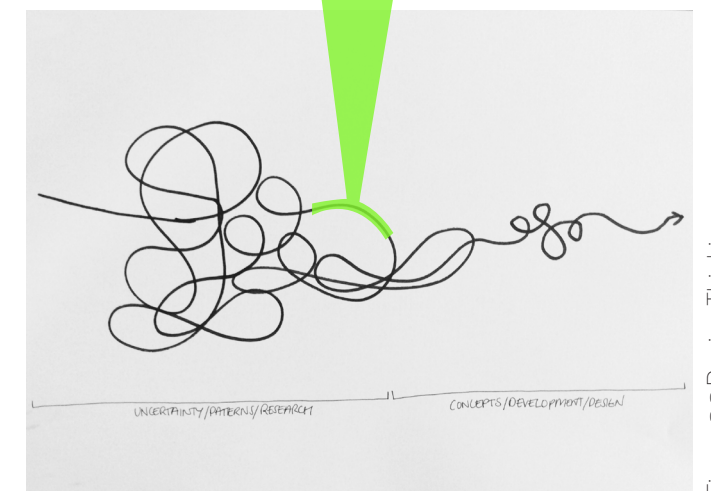
Figure 2.2 Design Thinking

research, decisions were made from the inner reflections of the researcher to use research data gathered from experts and people with dementia to drive change, instead of the democratic vote due to time restraints and symptoms of dementia (Gray, 2004).

METHODS

Methodological approach

Due to a lack of academic analysis of co-design, no single formal definition currently exists (Steen, 2013). Much of this research is exploring what co-design is or is understood to be as interpreted by the researcher. Currently the leading experts in co-design, E. Sanders and Stappers (2012) describe co-creation as 'any act of collective creativity' (p 25) and co-design as an instance of co-creation where the 'user' is the expert of their experiences and is given a partnership role with the researcher or designer in the design process. Due to the researcher's inexperience in people affected by dementia and obtaining ethical approval, the process to recruit people with dementia was co-created with experts in the behaviour of people with dementia and the ethical principles.

The researcher's worldview is that people with dementia experience the world differently to others. In consequence, they are the most qualified design partners as experts of that experience. Co-design was selected as the methodological approach as it helps identify what is important within an experience by stimulating open discussions using techniques that do not rely upon verbal communication to stimulate conversation. This is useful for people with dementia who may find it difficult to communicate their ideas or opinions without prompts.

Co-design also views users as equal contributors in the design process (E. Sanders & Stappers, 2012). This is in contrast with human centred design, where despite the involvement and understanding of users, often views them as subjects and not partners to generate ideas (Giacomin, 2014; L. Sanders, 2008). Therefore the resulting solutions are designed 'for' people with dementia based on the expertise of the designer instead of 'with' which utilises the expertise of all collaborators.

In this study, _research methods_ describe the methods used to understand the theory of both dementia and co-design. _Design methods_ are used to describe the practice of designing the resulting artefacts. Both methods describe the techniques or procedures used to gather and analyse data (Crotty, 1998). The theory and the practice are then combined using action research.

Research methods

Literature Review – was used to narrow down the topic of interest to a point where it supported and justified the research question (Collins, 2010). Due to a lack of guidance on how to co-design with people affected by dementia, the literature review was used to combine the work of others to identify the process of co-design.

Expert Interviews – were predominantly pragmatic, semi-formal interviews conducted with experts about ethical legalities, behaviour of people with dementia, and the anticipated response people with dementia may have to the co-design workshops. These interviews were primarily conducted face to face but also included email and phone call discussions. Due to the flexibility of semi-structured interviews, expert interviews allowed experts the opportunity to elaborate or bring attention to important ideas that the researcher may have missed (Galletta, 2013). The researcher was able to find out how to gain ethical approval and how to facilitate co-design workshops with people affected by dementia. Together the ethics application and the co-design toolkits were co-created with experts who became members of the co-creation team.

Observations – study research partners in their natural setting (Baker, 2006). During the co-design workshops, notes were recorded along with video and audio recordings to capture the verbal and non-verbal behaviour of people with dementia. It was important to capture both video and audio material firstly, due to the potential for one recording method to fail which occurred in two workshops, secondly, to capture the visual cues of people with dementia, and thirdly because the researcher was also facilitating making it difficult to observe each individual at them same time. The researcher's role was peripheral in nature choosing to engage in the co-design activities only to give direction or clarify ideas, but not to participate and give their input (Baker, 2006).

Co-design workshops – were used to generate an understanding of people with dementia by collectively contributing ideas, critiquing concepts, and designing digital assistive prototypes (Martin & Hanington, 2012). As the research partners were unfamiliar in design techniques, collaborating together as a workshop enabled research partners to support each other while doing the tasks and generating ideas (Mitzner & Dijkstra, 2010). Often research

workshops are lengthy day long events over a period of days. However, people with dementia and their carers would such schedules difficult due to fatigue and other commitments. Therefore, the duration of the workshop was more akin to a focus group and structured into six individual hour long, weekly workshops. Similarly, a focus group sized number of research partners participated as there was only one facilitator organising and planning all six workshops. The number of research partners in the co-design workshops was kept above four but below eight enabling each person to be heard by the group and large enough for a variety of opinions and discussions (Neimeyer & Torres, 2015).

Design methods

Co-design toolkit* – was designed to
enable people with dementia to design with the researcher as co-designers (E. Sanders & Stappers, 2014). It was made from multiple components such as pens, paper, post-it notes, and images. The overall co-design process was to create a digital assistive technology prototype. To achieve this, activities were selected within the toolkit to understand what people with dementia value and built artefacts to represent that knowledge. The toolkit was influenced by service design methods, user experience/user interface (UX/UI) methods, Health Service Co-design (Boyd, McKernon, & Old, 2010), Human Centered Design Toolkit (IDEO, 2009), and Convivial Design (E. Sanders & Stappers, 2012).

Probes - were carefully chosen items within the toolkits to produce a response from research partners by the researcher (E. Sanders & Stappers, 2014). The probes were used to test the assumptions of the researcher, including words such as 'dementia' or 'Alzheimer's', into the toolkit expecting people with dementia to discuss it. If there was no response, then it was considered unimportant to people with dementia.

Brain Storming – is an effective way to visually digest large material or multiple concepts by linking words together as they branch off from one another or connect. It is often used to generate new ideas, solve problems, and further develop ideas (Wilson, 2013). Brain storming was used by the researcher to digest large amounts of information to provide structure to thoughts as well as generate ideas. The focus was upon quantity with no 'good' or 'bad' ideas resulting in a steady stream of content. Ideas were iteratively developed using additional design methods to reach their optimal peak.

Sketching – is used to quickly express and communicate ideas. Buxton (2007) describes sketches as quick, inexpensive, and disposable drawings that explore and communicate concepts with a minimal amount of detail. Using sketches, multiple ideas may be developed simultaneously or discontinued by reviewing and evaluating the effectiveness of the sketch. Fragments of discontinued ideas may be used to influence

other ideas that are more developed (Greenberg, Carpendale, Marquardt, & Buxton, 2011). People with dementia were encouraged to sketch, however, none of the research partners expressed themselves with drawings preferring to use words instead.

Prototyping – within UX design, prototypes are used to model and test interactive experiences using a minimal amount of time and resources. There is a gradient of prototypes ranging from low fidelity prototypes, such as paper sketches, to high fidelity fully functioning digital designs. Low fidelity prototypes allow the researcher to explore, communicate, and evaluate initial designs quickly (Bailey, Biehl, Cook, & Metcalf, 2008). Only the researcher evaluated low fidelity prototypes such as paper prototypes, as the prototypes were considered too abstract for people with dementia to understand and provide critical feedback during the research. High fidelity prototypes were used to refine concepts and are often preferred by the users testing them (Sefelin, Tscheligi, & Giller, 2003). Using offline and online prototyping

software, concepts could more accurately display how each interaction worked. Sections that were too difficult to prototype with the current tool were explained to users when they reached it (Allanwood & Beare, 2014).

User Testing * – let end users evaluate a prototype or final design's effectiveness while being observed. It is often viewed as the ultimate standard for testing prototypes as there is no other way to perfect the design without users (Goodwin, 2009). People with dementia were asked to speak aloud their thoughts as they occurred while exploring the prototypes. To prompt users into critically analysing the prototypes in detail they were asked to remark upon ideas that they would change, add, remove, or keep the same (Frohlich, Lim, & Ahmed, 2014). The researcher was involved in the user testing by asking questions surrounding what they were observing to the research partner pair.

*To reduce confusion between the co-design and user testing phases of the research, 'workshops' are associated with co-design, and 'sessions' as associated with user testing.

COLLECTION AND ANALYSIS OF DATA

Data is the material caught from a phenomenon and is often kept in the form of notes, photos, video and audio recordings (E. Sanders & Stappers, 2012). Within the action research model, the researcher often observed the phenomenon and captured data using written notes, brainstorm maps, photographs, and sketches. Reflective thinking by the researcher selected data and grouped the information based upon their interpretations.

During the co-design workshops, data was collected using observations by the researcher, written notes, and material created by the research partners. However, the majority of data was collected using video and audio recording devices as it was difficult to capture the partners' comments or interactions within a large group especially without the use of second researcher taking notes (Buxton, 2007). Full transcriptions were not used as people with dementia often talked over each other and were often more effective at expressing themselves non-verbally (Psychogeriatrician, personal communication, December 16, 2014).

Notes of observations and insights were written immediately after conducting the co-design workshops. Occasionally key notes during the research were jotted down on post-it notes as they occurred. The first initial examination of the video footage was difficult due to the researcher's embarrassment of seeing themselves. However, notes were taken on how to improve the facilitations of future workshops. Video footage was examined multiple times after conducting all six workshops. Viewing the footage after the workshops helped to note insights objectively as the delay made it less personal to the researcher. Moments that were expected, surprising, unusual, or had relevance to the research question were transcribed (Creswell, 2013). These insights were subsequently sorted into common words, themes, and inspirations to be used within the design process.

Ideally, partners' with dementia would analyse the data to identify what was important to them within the workshops. Analysing data together helps to provide information and inspiration within the group (E. Sanders & Stappers, 2012). However, asking research partners' with dementia to do this was difficult as they did not read the post-it notes of ideas. Even if the post-it notes were read out loud, they found it difficult to remember all the ideas and select the important ones. Consequently, the researcher asked if the ideas they had chosen were important to them more than, or less than another idea. Due to time constraints, not all of the ideas could be contrasted in this manner. Therefore, the researcher began with ideas that sparked a response from everyone, or were highly discussed whilst generating them.

Due to research partners being unfamiliar in the design process, they often did not record insights that were valuable but were more likely to discuss these ideas instead. Therefore, the discussed ideas were captured by the researcher either during the workshop or upon reviewing audio and video footage afterwards. As the workshops continued, the carers of people with dementia became better at noting down these insights. However, carers often noted ideas from their own perspective which made it important for the researcher to examine the audio and video footage to identify insights generated by a person affected with dementia. For example, a carer wanted the tablet computer to entertain a person with dementia without their participation. This was in contrast to the person affected by dementia as they viewed the tablet computer as a tool to engage someone in conversation with, not as a solo activity.

SAMPLING

Procedure for selecting partners

Partners were referred to the researcher by Alzheimer's Auckland. Alzheimer's Auckland chose to approach partners from their Cognitive Stimulation Therapy (CST) group as they already meet weekly and are cognitively aware of their condition. Cognitive Stimulation Therapy is a weekly, hour long, social session for people with dementia filled with activities to stimulate conversation.

Partners were invited to attend a presentation by the researcher describing the research project and encouraged to ask questions. The presentation was short and informal to keep the interest of partners with dementia as they would find it difficult to retain large quantities of information. After the presentation, potential partners living with dementia and their carers were given a comprehensive information booklet describing in detail the research project for the family member or carer (see appendix 01), and a short dementia-friendly booklet for those potential partners with dementia (see appendix 02). Potential partners were given two weeks to respond to either the researcher or their familiar organisation to confirm, either in person or by phone, that they would like to take part in the research. Instead however, partners indicated their interest to participate in the research and were keen to start the workshops the following week.

Some consent forms of carers were signed on the day of the presentation. People with dementia signed their consent form at the beginning of the first workshop. A further agreement form was signed by the carers on behalf of the person with dementia. This process was time consuming particularly as people with dementia needed to be guided through the consent form process by their carer. However, it was empowering for people with dementia to have the opportunity to consent despite their incidental involvement by the carers agreement form.

Intended sample size

The aim was to recruit three partner pairs (a person with dementia and a carer) from four different organisations that support, or work with, people affected by dementia. The degree of dementia in these different organisations ranged from people with milder cognitive impairments still living relatively independently, to people with more severe forms of dementia living in a secured location with twenty-four hour care. It was believed that those with milder forms of dementia would desire tablet computer applications to maintain their current independence, and people with more severe forms would likely want collaborative communicative tablet computer applications (Salomon, 2014).

Actual sample size

Due to consent and safety issues, partners with severe forms of dementia were excluded from the study, as a requirement by the ethics committee to protect both the partners and the researcher. Both of the residential care homes declined to participate despite initial interest. One care home found it difficult to understand the co-design process and consequently felt that it was too difficult to describe to people living with dementia. The other care home did not have the time available to conduct the workshops and had difficultly encouraging family carers to come in each week.

In total seven individuals took part in the research. Four were older adults with a clinical dementia diagnosis and three were family member carers. Together they were known as a partner pair. One pair was a trio with a son having both parents living with dementia and it seemed inconvenient to exclude one parent.

PARTNER CHARACTERISTICS

There were two groups of people participating in this research. The primary group of interest in this research were individuals living with some form of diagnosed dementia. The secondary group were family members of the primary group and supported the person with dementia and the researcher. Together they will be referred to as a partner pair.

Eligibility and exclusion

One member of a participant pair needed to have a diagnosis of a health condition causing dementia by a geriatrician or appropriately qualified health specialist. This caused difficultly recruiting from nursing homes as some residents were affected by the symptoms of dementia but were not currently diagnosed with dementia. This is illustrated in more detail in flow of recruitment (Figure 3.3).

Both members of a partner pair were required to have an interest in the research and attend the research workshops and user testing sessions together. Having the involvement of family is considered by Harrefors et al. (2013) as essential to make an assistive device more meaningful to a person affected by dementia as well as increase the likelihood they will use it.

All partners were able to sufficiently speak English to communicate effectively with the researcher. Otherwise this may have placed partners in a potentially vulnerable position if they did not understand fully what was being asked of them.

Major demographic characteristics

There were two male and two female partners all over the age of 60 with mild to moderate stages of dementia. The carers that looked after them were all family members. Two were the children of the person with dementia aged 45 plus and one being the spouse over 60.

There was no measurement used to evaluate the severity of dementia. It is often difficult to describe what 'stage' people with dementia are at as the journey of dementia is different for everyone. Most stage theories focus on what people with dementia are unable to do, rather than the impact symptoms of dementia have on the person affected by dementia (Morris & Morris, 2010). However, to give a sense of the cognitive ability of partners in this research most partners fall between the early-stage to middle-stage category by the Alzheimer's Association (2015).

Interestingly, three partners with dementia were immigrants from Holland, and one carer from Scotland. All partners spoke English sufficiently to avoid any confusion with the researcher. Occasionally Dutch words were used but were either similar to English words that the researcher understood or that the partner carer would translate.

Setting and location

The research was conducted in a quiet meeting room that was familiar to the partners as it was where they attended their cognitive stimulation therapy group. This helped minimise risk for both the researcher and partners as there was additional support around. It also reduced the stress and anxiety for partners getting to and from the location as, for example, they knew where to park.

For the co-design workshops, desks were arranged in the middle of the room with chairs around the outside of the desks. Week to week, partner pairs sat together with people affected by dementia often sitting in the same place as they sat for cognitive stimulation therapy groups.

When user testing prototypes, research partners were asked to consistently sit at one end of the table where it was easier to set up the video cameras filming them.

CYCLE 1:
3| Partner Recruitment

This cycle describes the approach to gain ethical approval and recruit partners affected by dementia for the co-design workshops. Naïvely expecting the process to be straightforward, the process took a long time and needed modifying due to the novelty of the research to both the researcher and the consulted experts. The first phase of the cycle describes the process used to obtain ethical approval. The second phase of the cycle describes how the original consent procedure did not work to recruit research partners and the modifications needed to recruit research partners.

PLAN

ACT

The aim of this cycle was to recruit people living with dementia in the co-design research. Any research involving data obtained from people must obtain ethical approval to ensure that there is low risk of harm to either the research partners or the researcher. The second phase of this cycle is to find any volunteers willing to participate in the co-design workshops. Both of these phases were thought to be straightforward, but were more complex than originally imagined.

Due to a lack of formal guidance on how to recruit people affected by dementia, a co-creative approach was used to develop a safe procedure to recruit people affected by dementia due to their vulnerability. Experts who were familiar with the legal complexities and/or the behaviours of people with dementia were consulted to obtain ethical approval. Their feedback was triangulated

with each others along with literature to build and submit to the Auckland University of Technology Ethics Committee.

Nursing homes and Alzheimer's Auckland were contacted during this process due to their access to and familiarity working with people affected by dementia. It was hoped that their early inclusion in the research process development would aide in recruiting research partners and minimise any unforeseen potential difficulties collecting data from them.

Having obtained ethical approval, potential research partners would be approached through referrals from nursing homes and Alzheimer's Auckland.

The co-creative team

Boyd, McKernon, and Old's (2010) co-design process is to first engage with patients involved with the health service that they are trying to improve. Likewise, IDEO's (2009) co-creative practice engages with stakeholders at the beginning of their process to discuss the design challenge. Similarly, this research began by consulting experts in ethical principles or experts familiar in working directly with people affected by dementia. These experts became members of the co-creative team enabling the research to continue.

The initial engagement of organisations was built upon the relationships formed in the 2013 undergraduate honours work: 'This is me too' (Jury, 2013). A psychogeriatrician was introduced by a referral and the Alzheimer's Auckland operations manager was contacted by finding details of Alzheimer's Auckland online. These relationships were strengthened over time and were used to initiate this research.

As this research involves the participation of people living with dementia, additional members of the co-creative team were recruited who had knowledge of surrounding ethical complexities, or who had access to people affected by dementia, such as nursing homes. These experts were approached using referrals from the original team members.

It was anticipated that nursing homes would be hesitant to take part in this research due to a lack of understanding in assistive technology (Bjorneby et al., 2004). However, in practice this research received overwhelming interest and support from individuals and organisations all willing to share their time and experience in this project.

Involving the co-creative team in the early phases of research design helped minimise unforeseen obstacles by the researcher or other experts. For example, it was unanticipated to the researcher and the ethics advisory secretary that some people with dementia would find it stressful to remember an appointment and would therefore be asked to participate in a workshop moments before it began. Typically research partners would be notified of a research date two weeks minimum in advance.

High influence

Myself

The law

People with dementia

Alzheimer's Auckland

Auckland University
of Technology Ethics
Committee

Carers of people with
dementia

Government

Residential care homes

Co-Creative Team

Low interest

High interest

Clinicians

Wider Community

Low Influence

Figure 3.1
Stakeholder map

Figure 3.1 illustrates a stakeholder map that shows the variety of potential research partners in the co-creative team . It identifies the influence research partners have on the direction of the research, as well as their interest. More focus has been placed on those living with dementia as they are often unheard in other research. A member of their family or informal carer also participated as per the suggestion of the expert consultants to support the person with dementia through the co-design process if required. Ideally, clinical research partners should also be included in the co-design workshops. However, it is assumed that they would dominate the conversations and make it difficult to identify the needs of people living with dementia.

Expert interviews

To increase the chances of both gaining ethical approval and recruiting research partners in the research, hours of consultation were conducted with individuals and organisations accustomed to people affected by dementia.

Interviews were conducted with a psychogeriatrician at Greenlane Clinical Centre, operations manager of Alzheimer's Auckland, cognitive stimulation therapy facilitator for Alzheimer's Auckland, activities co-ordinator of one of Bupa's high security dementia hospitals, development co-ordinator at Elizabeth Knox Home and Hospital, and chief executive of Howick Baptist Healthcare, and the Auckland University of Technology Ethics Committee's executive manager.

This research is challenging in that it involves a potentially vulnerable user group as well as an innovative research method. Consequently, none of the experts were familiar with a similar research project which occasionally resulted in some discrepancy in their advice. However, despite the contradictions of the experts, each were willing to adapt and find solutions to assist the research in going forward.

Below are key suggestions of the experts in co-designing with people affected by dementia:

- Limiting the total time spent as a group to an hour to reduce fatigue in research partners
- Understanding that people with dementia are all unique and have different capabilities at different stages of their journey with dementia
- Carers should be invited to both support the person with dementia and assist communication between the researcher and person with dementia if necessary
- Any recruitment information given will need to be simplified as people with dementia will be unlikely to process large written text
- Abstract thought is difficult for people with dementia but they are capable to say what is immediate or important to them
- People with dementia have both good and bad days
- Ideally what a person with dementia says is what they mean, however they are affected by aphasia, which affects the production and understanding of speech and written language
- People with dementia tend to lose focus particularly in a group situation
- Important insights in regards to research partners' experience of the co-design workshop may happen in discussions after the workshop
- Research partners who attend the research

are consenting to participate. This is important for people with dementia as they may become anxious during the week trying to remember appointments but not being able to recall for what. Therefore, in some instances they might be asked if they want to take part fifteen minutes prior to the workshop

- There is a risk that the facilitator may unintentionally pressure a research partner to remember something they said or did earlier, which may embarrass the participant if they are unable to recall what it was
- There may be a power imbalance between the carer and person with dementia. The facilitator needs to ensure that there is no coercion to participate from the family/informal carer
- When giving a presentation to recruit research partners with dementia, an ideal length of presentation is kept to around five minutes.

Designing recruitment material

The advertisement material of the 1950s inspired the design for the recruitment material. It was assumed that people with dementia would be familiar with the design and remind them of a time when they were in their twenties. Themes that emerged from reviewing the graphic design of the 1950s were a bold use of contrasting primary colours, transparency, and geometric shapes.

To recruit research partners, four different media were used as they each had to meet different requirements. It includes a poster to be displayed in public areas, a pamphlet for people with dementia to show their carer if interested in participating, a detailed information booklet to obtain informed consent designed for carers, and a brief information booklet for people with dementia (see appendix 01-02). The recruitment material was reviewed by experts familiar to people with dementia and approved for use by the Auckland University of Technology Ethics Committee. Interestingly, it was unknown by the experts whether or not the ethics committee would approve of the designed material, as they had never seen anything similar.

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1950s moodboard

All of the material used similar design techniques so that they looked like they were all from the same research. Some of these techniques were:

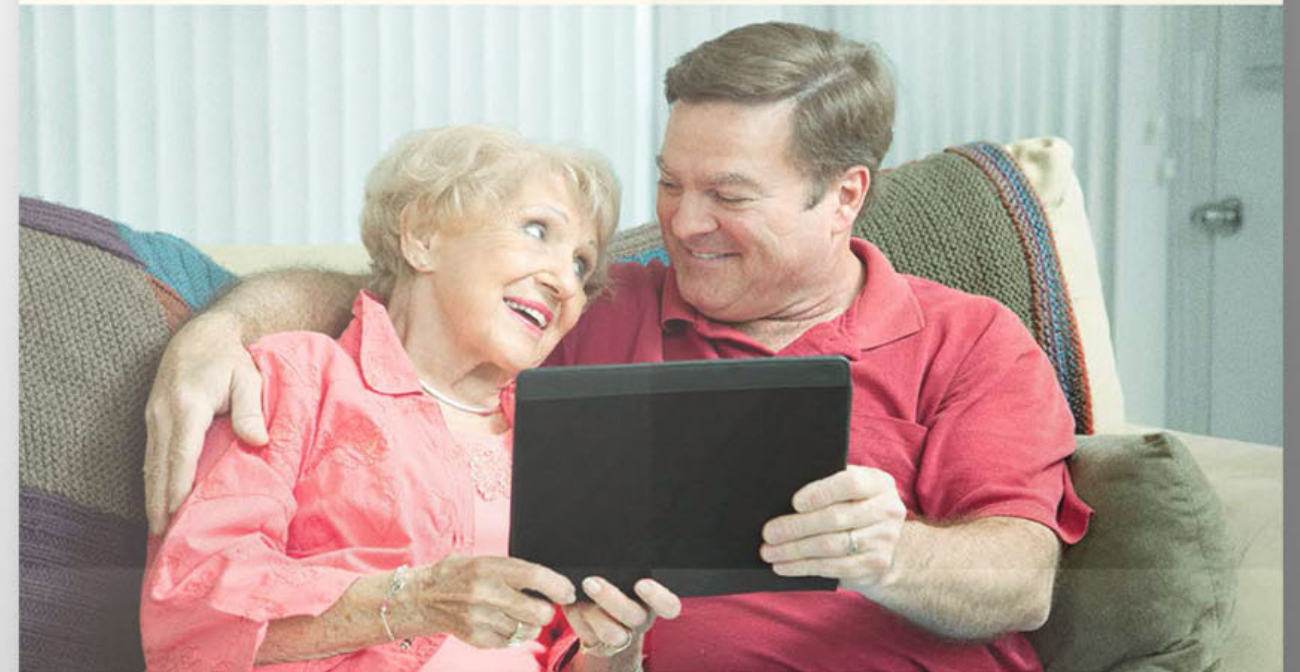- Heavily visual so that people with dementia who could not read would get a sense of what the research was about
- Large serif font to help comprehension
- Does not have a pure white background to reduce some of the contrast that may make it more difficult to read
- The colour palette used bright contrasting colours that were similar to the colours used in the 1950s
- Audience of language used was aimed towards twelve year olds

OBSERVE

It was assumed that obtaining ethical consent to conduct co-design workshops, and recruiting research partners was going to be easy. However, despite heavy consultation with the co-creative team, there were still unforeseen difficulties and barriers in recruiting people living with dementia. Additional amendments were needed to recruit people with dementia in the ethics application around consent and cognitive ability.

Research partner recruitment
Four organisations were approached to conduct the research. Each had their own specific requirements regarding how to approach potential research partners. In particular, nursing homes required the research ethics application to be accepted by their management committee. A letter of formal request was submitted to Elizabeth Knox committee and both nursing homes received a copy of the ethics application to ensure that the research was of benefit to their residents.

Potential research partners were referred to the researcher by the organisations based on their judgement that the person with dementia would be interested in taking part or were thought to be able to give valuable data. Recruitment posters and a presentation was given at each nursing care home to present the research and to allow interested research partners to ask questions.

It is also easier to recruit research partners when their family carer is present. Initially the presentation was intended for people with dementia and their carer together. In practice, it was difficult to arrange a time at the nursing homes that enabled all of the family carers to come together as they had other commitments.

When presenting to solely people with dementia, men were found to be more interested in participating, as they asked the most questions. When presenting to both the carers and people with dementia at the same time, even though the presentation was directed towards individuals with dementia, it was the carers that were enthusiastic and asked questions. Despite intentions to ask people with dementia directly if they wanted to participate, the carers tended to talk on their behalf.

It was explained to research partners that if unavailable, they were not expected to go to every research workshop. It was anticipated that in working with an elderly population, other circumstances would likely arise that would take priority over the research. During this research there were three instances where research partners were unable to attend. One participant had a fall during her holiday and injured her back. Her son deemed sitting down for two hours without a break difficult too difficult for her so they did not take part in the user testing sessions.

Below is a summary of difficulties and barriers unforeseen by the co-creative team to recruit research partners' affected by dementia:

- Nursing homes are busy and it uses valuable time for staff to organise and advertise a research study
- Nursing homes may not understand the co-design process conceptually and find it difficult to describe to residents with dementia
- When describing the co-design workshop as a process to design a computer tablet application, residents with dementia say that they have no interest in using it
- Despite displaying symptoms of dementia, not all of the residents were formally diagnosed with dementia
- Particularly for people with dementia in residential care, families did not have the time to visit the nursing home weekly for a research study
- Family carers were intimidated by the research for a masters student because they did not want to let the researcher down and felt they would not be able to help
- Six weeks is a long commitment for carers
- Some research partners have such severe dementia that they do not remember that they have dementia yet correctly identify it would be better to research those that have dementia

- People with and without dementia do not feel comfortable with the generative process of the co-design workshops in that the outcome is unknown
- It is difficult to get six people together in the same place, at the same time

Ethical amendments
During the process of recruiting research partners, it became evident that the constraints set by the original ethics application severely limited the number or people living with dementia that could be recruited. The first amendment was submitted to improve obtaining consent from a person with dementia and the second amendment altered how to assess cognitive ability during the study as people with dementia have both good and bad days.

Obtaining Consent
In the original ethics application (see appendix 03), it stated that research partners may not participate if they had an active enduring power of attorney (EPOA) as this was used to indicate whether or not they were considered cognitively able to make an informed decision about participating. However, when recruiting research partners, it was found that there were only three potential research partners out of three organisations who did not have an active EPOA. Even if all three had consented to take part in the research, their EPOA may have been activated

during the research thus immediately removing them from the research.

In consultation with Auckland University of Technology Ethics Committee, it was decided that if a person with dementia was deemed unable to make an informed decision about participating in the research, then an individual legally entitled on behalf of a person with dementia could decided whether or not the study reflects the values and interests of the person with dementia (National Ethics Advisory Committee, 2012). A statement of agreement was created using the relative/friend/whanau form 'When a Participant is Unable to Make an Informed Choice' by the Ministry of Health (2008) as a guide. It was also expected that the person with dementia would still sign a consent form, as the researcher did not have the capacity to assess their ability to consent. In essence, this technically meant the researcher was no longer recruiting people with dementia, but carers of people with dementia who then consented to bring along a person with dementia as incidental research partners.

Since the submission of the first amendment, a semi-structured interview was conducted with the psychogeriatrician at Greenlane Clinical Centre for more clarification about advanced directives involving people living with dementia.

It was assumed that all residents of a nursing home would have an active EPOA. However, not everyone has an active EPOA but may have one written up in case circumstances changed. Usually the next of kin is the nominated EPOA of their personal care and welfare. However, this is not always the case. An EPOA may also be a lawyer who would be costly to get approval from, which was not feasible within this research. Similarly, if the next of kin was not in either Auckland or New Zealand, this would make participation infeasible.
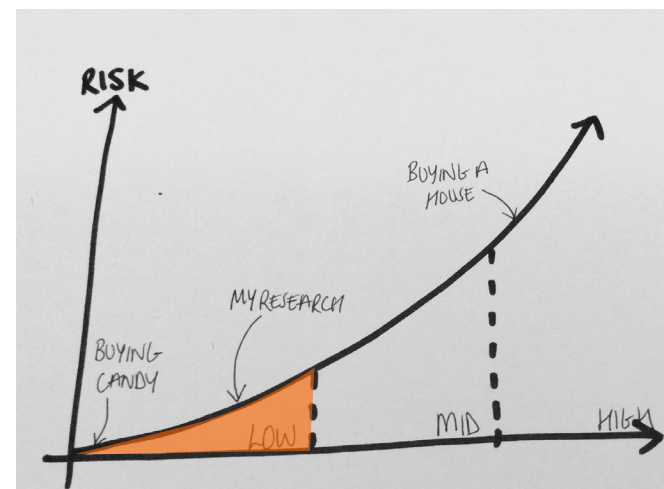
Figure 3.2 Assessment of risk

Only a medical practitioner can activate an EPOA and this is a lengthy and complicated legal process where the medical practitioner has multiple consultations to confirm a persons cognitive ability.

The psychogeriatrician consulted for this research suggested that this research should be able to operate on the assumption that everyone can give consent as the psychogeriatrician considered this research to be a relatively low risk study (figure 3.2). If there was a question of capacity then an agreement by the carer should be signed if there is not an EPOA. If there was an EPOA in place for a potential participant, the EPOA would be required to sign consent.

Despite this, the consulting psychogeriatrician was more concerned about the three questions used to support the researcher to determine the cognitive competency of a person with dementia at the beginning of each workshop included at the request of the ethics advisory committee.

Assessing Cognitive Ability

Due to the previous amendment, an assessment on the cognitive ability of a person living with dementia was not required for their participation in the research. However, being able to assess cognitive ability was a requirement to identify whether the data obtained could be used as occasionally valuable data must be discarded if the participant was deemed not cognitively aware enough. Due to the psychogeriatrician's and Alzheimer's Auckland concerns about the

three questions constantly losing valuable data an alternative was suggested.

It was assumed that the carer would be the most capable to determine instances where the person with dementia was giving inconsistent data. An information sheet was made for the carer detailing what was expected of the carer and included a section where the carer may write down any instances that was not related to the question, or where they did not want included in the research.

Carers were also asked to observe if the person with dementia was no longer interested or was uncomfortable in participating in the research. Carers also were asked to support their partner with dementia when they were having difficultly in the research such as when writing things down. Carers also assisted by interpreting the questions and answers between the researcher and the person with dementia.

On no occasion was it felt necessary to exclude data during all six of the co-design workshops. The requirement to use it was found to be an added distraction at the beginning of each co-design workshop. It was more effective to remind carers to report verbally any instances that they felt were inappropriate to include in the research.

Reflect

Ethics application
Designing Toolkit
Co-design workshop
User Testing

Bupa
(Advance care nursing home)

Despite desire to contribute, people with advanced severity of dementia made it too challenging to continue based on expert consultation

Howick Baptist
(Nursing home)

Wanted the co-design workshop reduced to twenty minutes and found the co-design process too difficult to communicate to residents

Elizabeth Knox
(Nursing home)

No residents wished to take part that were diagnosed with dementia or their family carer was unable to participate

Were interested in participating based on the work by Alzheimer's Auckland but did not have enough time

Alzheimer's Auckland
(Organisation)

7 research partners: 4 with dementia and 3 family members

4 research partners: 2 with dementia and 2 family members

Figure 3.3
Flow of recruitment

Flow of recruitment

Despite assuming that recruiting people living with dementia would be easy, the number of research partners recruited was small. Figure 3.3 is a summary of the final number of all four organisations approached. However, it is unclear as to whether this is similar to other healthcare research or if it particular to recruiting people living with dementia.

Despite appearing straight forward, the process to recruit people with dementia was time consuming and more complex than originally expected. The ethical approval process went through three cycles of action research to balance the legal, ethical, and feasibility requirements as there was limited experience by all involved in conducting a study similar to this.

The ethical considerations surrounding this research were frequently revisited throughout this research and multiple discussions have occurred between the ethics committee representative, the co-creative team, and the researcher. It quickly became apparent that it was ineffective to apply ethical solutions for cognitively able people on people with dementia (Murray, 1994). Despite this, there is currently no straightforward and agreed reusable consent procedure for how to conduct research with people affected by dementia. The ethics committee representatives were extremely useful in planning and preparing the research design and without their assistance, the project would not have been approved.

Describing the experience to recruit research partners affected by dementia may help other researchers interested in conducting similar research. It is expected that other researchers' journey co-designing with people affected by dementia will be different due to different research aims and ethical committees. However, there will be some similarities between these experiences that can be shared. Future research is needed to formalise the recruitment process to involve people with dementia in the research process. If the researcher was a part of an organisation, the research may have been considered a service improvement and therefore would not have needed ethical approval.

CYCLE 2:
4| Co-design toolkit

This cycle describes the process to iteratively design and build a co-design toolkit for the co-design workshops with people affected by dementia. Typically designed for cognitively able research partners, the co-design activities were modified to collect valuable data using the skills people with dementia still have. The toolkit was iteratively tested and designed with the elderly, experts of people living with dementia, and people living with dementia. The outcome is a guidebook and toolkit to co-design six workshops with people with dementia to identify what they value.

Plan

Act

The aim of this cycle was to develop a toolkit that utilises the capabilities that people with dementia still have. Having never interacted with people affected by dementia before, the researcher was invited to visit people with mild and severe dementia to build empathy and understanding of their condition.

Without an existing toolkit for people affected by dementia, design and co-design toolkits were reviewed to identify key elements to the co-design process. A co-design toolkit was sketched and evaluated by experts on the behaviour of people with dementia. The toolkit was modified then evaluated using a pilot test with older adults. The pilot test identified issues surrounding the toolkit and the facilitation of the workshop.

The final co-design toolkit was used during the co-design workshops with people affected by dementia. Between each workshop, the following week's toolkit was evaluated and modified to reflect the insights gained in facilitating co-design with people affected by dementia and the direction the design was heading.

Empathy for people affected by dementia

Prior to starting this research, the researcher had never met a person with dementia. In order to acquire empathy and understanding first hand, they were invited to observe a cognitive stimulation therapy group held by Alzheimer's Auckland and a psychogeriatric care facility owned by Bupa. These experiences became a turning point as the size of the research and its impact on others was understood. The visits and corresponding discussion with clinicians reduced the scope of the research project to those with mild to moderate dementia. The resulting experience of visiting people affected by dementia helped the researcher gain empathy and 'humanise' characters previously based upon assumptions, literature, and expert interviews.

The Alzheimer's Auckland cognitive stimulation therapy group provided a friendly social environment for people with dementia to socialise with one another, while allowing their informal carers to have an hours rest. Observing how the groups were facilitated informed the manner in which co-design workshops should also be facilitated. After carers dropped off their loved ones and leave, the session begins with a cup of tea or coffee, biscuits, and friendly conversations. However, for a co-design workshop, this was suggested to be given at the end of a workshop else research partners would use too much of the research time.

The facilitator of the cognitive stimulation therapy group started the session by asking the same questions at the beginning of each session: 'What is the address they are currently at?' and 'What is the date?'. Interestingly, people with dementia could remember that the facilitator was going to ask for the address and tried to make an effort to remember the answer before they came in but still some were not able to recall the answers. They also used sly techniques so their memory was not needed. One member had the date on his watch and apparently always checked it before giving out the answer. People with dementia seemed annoyed that they could not remember the answers to such simple questions but laughed amongst themselves as they attempted to answer them.

The therapy session relied upon using reminiscence techniques to stimulate conversation and discussion between the members of the group. The facilitator also used current events from the newspaper in which group members always had an opinion or were able to reflect upon in a memory. Group members were also stimulated in multiple senses to evoke memory. The facilitator brought in old kitchen equipment, as well as a heavily scented paste often used on burns. This stimulation technique was used in the co-design workshops when research partners were asked to bring objects to share with the others.

It was easy to forget that the people in the group had dementia. There were only a few instances where members of the group gave any indication of their symptoms with dementia such as

redirecting a question to the researcher who had already answered it. Throughout the year, a few members of the group were able to recognise the researcher, and even recall their name. Such moments were celebrated by the person with dementia.

The secured psychogeriatric ward is home to residents who require more care and were unable to live in their own home. Communication is often limited to small words, grunts, and body language. Talking with people affected by dementia was difficult as residents were no longer aware that they had dementia if they were able to talk at all.

Having met people with dementia at both ends of the journey, it was identified that it would be extremely difficult to use the same co-design toolkit on people with mild dementia as those with more severe dementia. People with more severe dementia found it difficult to control their emotions and behaviour consequently making communication difficult and their presence intimidating to the researcher. However, some residents were able to communicate valid arguments even if the argument was that they did not have dementia and therefore it would be better if you asked the other people around about dementia. It would be difficult to obtain informed consent from people living with severe forms of dementia. However, if consent was obtained, the co-design process would need to be specifically tailored for the individual to utilise their capabilities.

Figure 4.1
Human Centred Design Toolkit

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Figure 4.2
Health Service Co-design

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Figure 4.3
Adobe Kickbox Toolkit

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of this thesis for
copyright reasons.

Figure 4.4 The Double Diamond

Reviewing existing toolkits

Due to an absence of research surrounding what is in a co-design toolkit, three toolkits were found that described a co-creative process. These three toolkits were examined to identify the similarities between them, the differences, and whether or not they would be suitable for people with dementia. The Human Centred Design Toolkit (figure 4.1) was aimed to create innovation from communities in need (IDEO, 2009). The Health Service Co-design Toolkit (figure 4.2) was used to co-create with staff and patients to improve hospital services (Boyd, McKernon, Mullin, & Old, 2012). The Kickbox Toolkit (figure 4.3) was for employees of Adobe to develop a concept to improve Adobe's products and was commercially driven (Adobe, 2015).

All three toolkits used a double diamond approach where they generated ideas, narrowed down to a particular issue, expanded by developing multiple concepts, and refined those concepts to result in a product or service (figure 4.4). This informed the initial concept sketches of the co-design process for the research. Both the Human Centred Design Toolkit and the Health Service Co-design Toolkit used co-creation as a method to discover, make, and market a solution, whereas the Kickbox Toolkit was used as a tool to design and sell a concept (Sanders & Stappers, 2008).

Overall the toolkits were deemed inappropriate for people with dementia as the they focused on idea generation techniques for those that were more cognitively able. However, the Human Centred Design Toolkit provided solutions for working with communities that were unable to speak English highlighting how co-design can be used with an absence of verbal communication to convey an idea.

Sketching the co-design toolkit

The first co-design toolkit was divided into six workshops with each workshop building upon the next. Six weeks was hypothesised to be sufficient to define the problem, create the brief, and design the solution based on the review of other workshops. At the end of the six weeks it was assumed that the output would be a tablet computer application.

It was suggested by Gray, Brown, and Macanufo (2010) that to create an effective workshop, each workshop had to start with a beginning, a middle, and an end. The beginning activity introduced people in the group as well as warm up cognitive thinking, the middle was the core task or activity to answer a question, and the end was to help select the final outcome. However, when describing the activities to the operations manager at Alzheimer's Auckland, it was difficult to explain some activities, therefore it would be too confusing to complete all activities within an hour on those less cognitive. There was also a workshop dedicated to identifying barriers around the tablet computer. It was thought the workshop would result in a tablet computer case to make it easier for people with dementia to hold. This idea had appeal because it would have encouraged people with dementia to physically make models. However, this was considered out of the scope for the research due to time restraints.

Each workshop had both an outcome for the researcher and an assumption of people with dementia to be challenged. For example, creating a collage of a person's life helped the researcher understand what experiences people with dementia had gone through, what experiences they valued, and where in their timeline did they remember the most memories. For the person
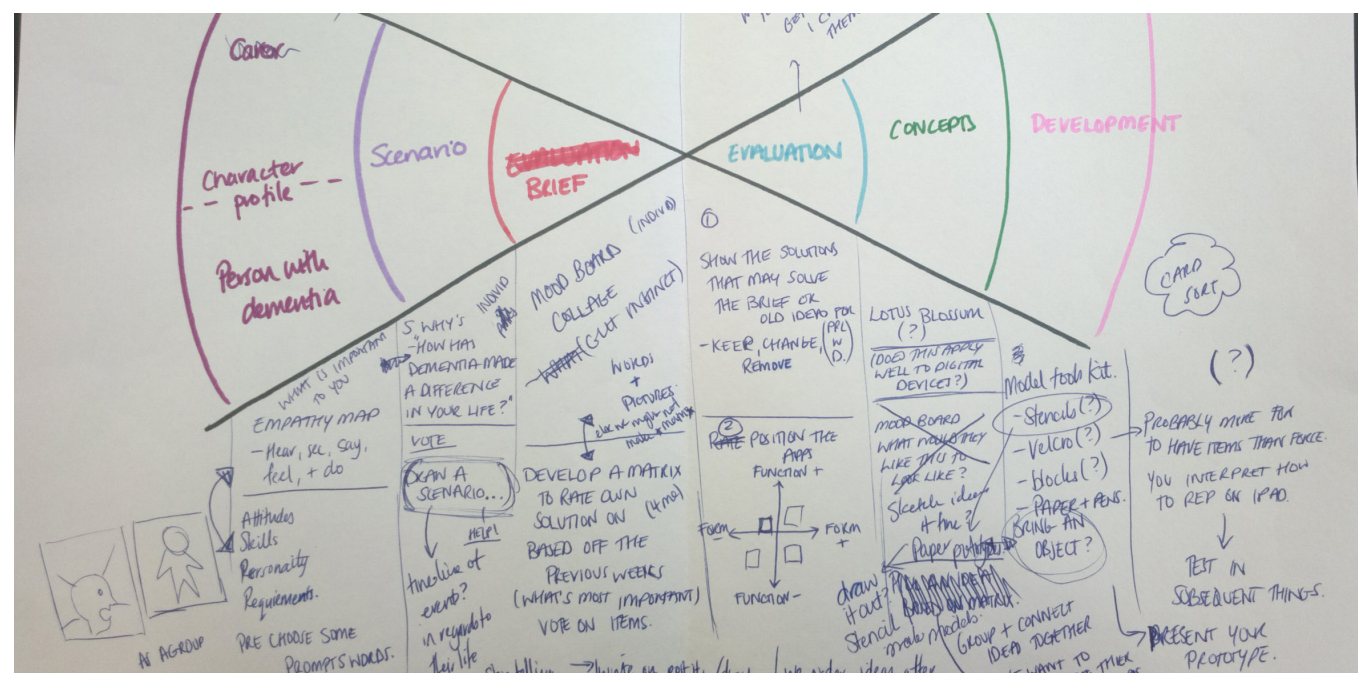
with dementia, it challenged whether they were physically able to cut, write, or glue. This concept was useful in future iterations where the researcher wanted to know questions that the research partner's favourite colour, could be identified by the colours they choose to pick in a collage instead of asking them directly.

1. Persona – Find out about each other in the group and build a character to represent the group. It was also debated whether there would also be a character to represent the carers of the group.
2. Scenario – Using the technique of service design an experience map was created representing the life the persona in the previous week had.
3. Brief – Reviewing the storyboard created in the previous week, people with dementia were to identify a point of pain that they had.
4. Evaluation – To become accustomed with evaluating design, the workshop would evaluate designs for people with dementia including the designs from 'This is me too' (Jury, 2013).
5. Concepts – People with dementia would generate concepts on how they would like to solve the problem identified in the third workshop.
6. Development – The final workshop would result in a paper prototype of the solution.

Pilot Testing

A pilot test was conducted to practice using the toolkit as well as see what an outcome of the workshop may look like. The research partners of the pilot test were elderly in order to test with a similar user age group to people with dementia. It was assumed that the elderly would not be familiar with digital terminology or be as quick to generate ideas as compared to the researcher's peers. If the toolkit was ineffective for the cognitively able elderly, then it would also be ineffective for those more cognitively impaired.

Each workshop was timed to identify how much could be completed within an hour. None of the activities were completed on time due to research partners going off task, having too many activities scheduled, and due to the elderly taking a longer time to do activities (Sanders & Stappers, 2012). When describing the activities, the researcher unknowingly used design jargon such as 'font', which instead of meaning a typeface meant a church receptacle for baptisms to the research partners.

The toolkit was basic and involved the use of thick pens, post it notes, and large brown paper. Based on the researcher's experience of doing design, it was assumed that research partners would eagerly write or draw their own ideas. Instead however, it was intimidating with the research partners nervous in case they did something

'wrong'. Research partners often scribbled up and redrew images that they were not happy with instead of letting the ideas flow.

Generating ideas triggered participants' memory of experiences in their life, often resulting in lengthy stories. The stories contained insights that were of meaning and value to the research partners and related to the workshop. However, research partners did not identify and write down such insights. It was conflicting to the researcher whether they should document these insights as part of the co-design workshop or allow the participant to identify them. Research partners tended to be happier when they themselves found solutions or insights to some of the questions than if the researcher suggested them.

Activities that worked well included creating the persona as they enjoyed talking about themselves and their values. They also appeared to enjoy ordering what they valued using post-it notes as they were easy to rearrange. The lotus blossom method to generate ideas was only half completed within the hour and a participant struggled to create concepts due to the fear of being 'wrong'. The experience map of their daily lives was also ineffective, and at times confusing, in identifying a pain point in their day. Consequently, these activities were not as enjoyable for the research partners and seemed to bore them.

Observe

The pilot test initially made the co-design workshop appear as a failure as it did not result in a concept for a computer tablet solution. One participant who identified values of a good product or service as 'good health', 'responsibility', and 'economical', were already met by their hobby growing a tomato plant. Translating growing a tomato into a tablet computer application was seen as unnecessary to the participant.

On reflection however, the value of the co-design workshops was that it helped identify and communicate what was of importance to the participant and generated empathy and tacit knowledge for the designer. It was also an enjoyable and intimate experience for both the researcher and the participant, which may be engaging for people with dementia who feel isolated.

Figure 4.5 Co-design workshop refinement
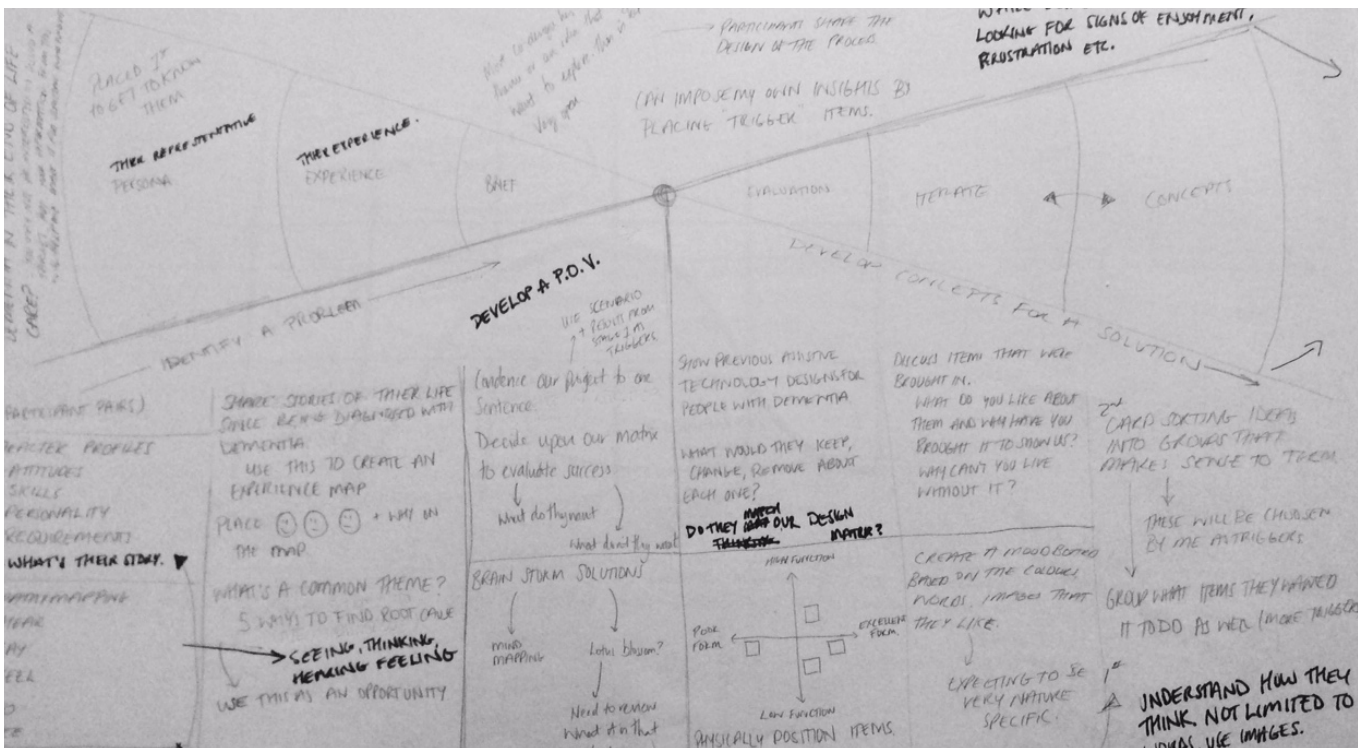
Workshop Refinement

The workshops were refined by sketching the design journey, selecting the activities to best meet the aim, positioning them in order, modifying the activities to suit the needs of the people with dementia, then selecting the materials, templates, and prompts to be used within the workshop's toolkit (figure 4.5).

The workshops were structured to enable people with dementia to develop an application concept for a problem that they had identified themselves. The first three weeks established the characters of the research partners with dementia and enabled them to explore and identify a problem that they wanted a solution for within the scope of a tablet computer application. The last three weeks of the workshops evaluated existing products that may already meet their needs and developed a concept of how their own tablet computer application may look.
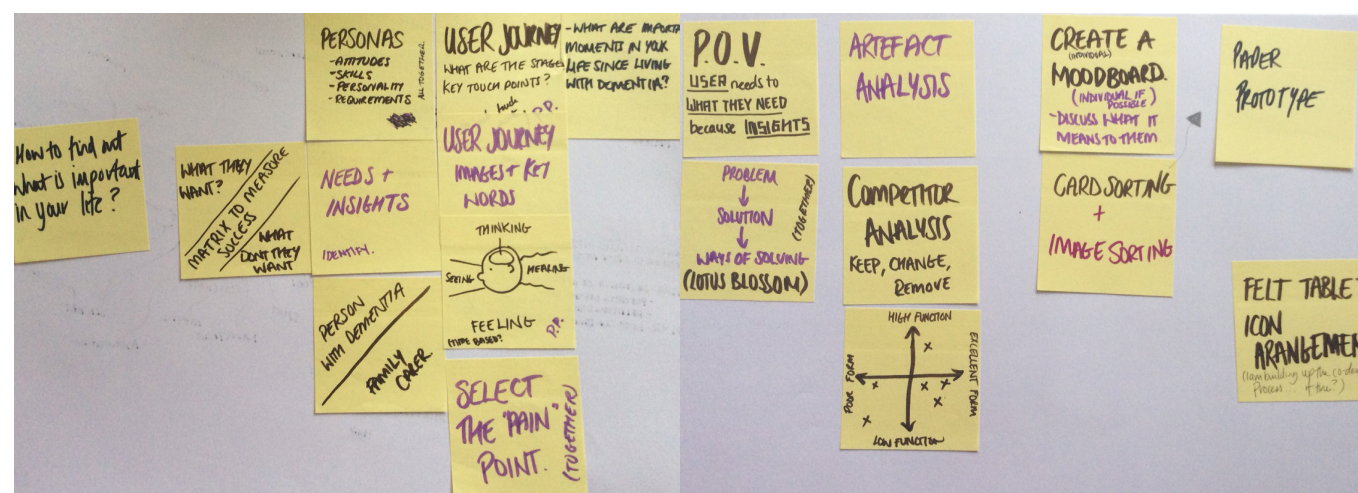
Figure 4.6 Post-it note workshop arrangement

Multiple modifications were made to the co-design workshops as well as the order in which the workshops occurred. Writing the activities on post-it notes allowed the researcher to quickly critique and rearrange the activities (figure 4.6). Difficulties occurred in selecting the optimal method to obtain and anticipate information, while reducing the total number of workshops.

Subsequent iterations reduced the complexities of the toolkits and reduced the number of activities. Each workshop had to be able to stand-alone but also build up upon what was learnt in the previous workshop so that people with dementia did not need to recall what they had previously completed.

Figure 4.7 Basic Toolkit

Each co-design toolkit involved a base set of equipment (figure 4.7). Items within this toolkit were selected to be functional and appeal to older adults and people with dementia. Writing and drawing equipment was chosen due to the thickness of the instrument so it would be easier to grab, particularly in case a research partner was living with arthritis. The post-it notes were the colours of nature, as identified to appeal to older adults during the pilot test more than the bright neon colours originally used. Paper used within the toolkit was of thicker stock so that it would be easier to grab by people with dementia. There was both sellotape and glue available as it was unknown which would be easier to use. Interestingly, the glue stick was not recognised by people with dementia and therefore may be better replaced with a glue paste bottle.

Figure 4.8 Final co-design workshop arrangement

Figure 4.9 Examples of sketching modifications
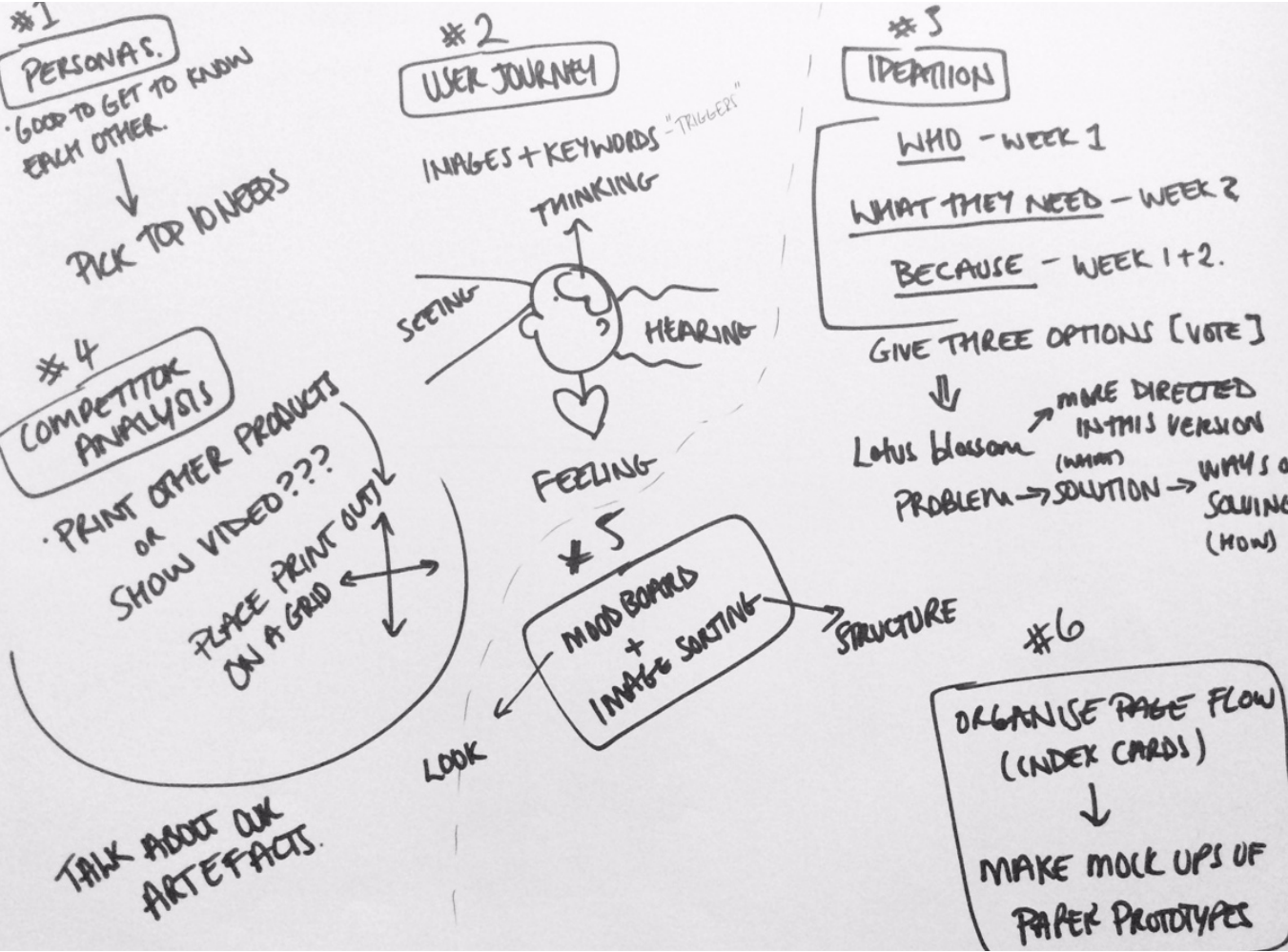
The toolkits were developed by defining the aim of the workshop and anticipating the influence the output would have on the final designed output (figure 4.8).
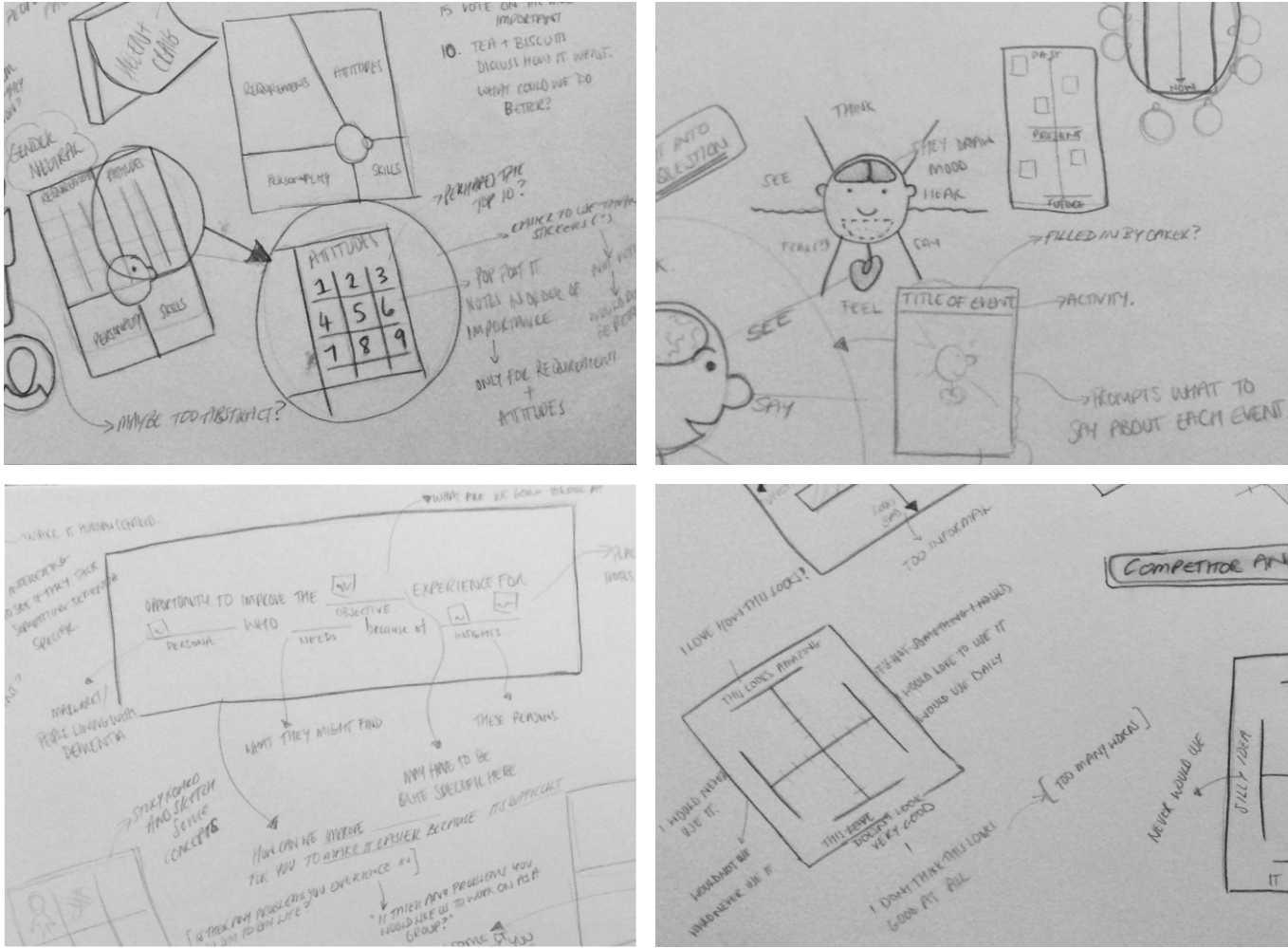
Each of the workshops tookits and templates were refined after each previous workshop using sketches to develop and evaluate concepts (figure 4.9). The modifications to the toolkits were made due to the additional knowledge received on how to facilitate co-design with people affected by dementia.

User interface toolkit

A user interface prototyping toolkit was developed for the final week of the co-design workshops (figure 4.10). However, after working with people affected by dementia the planned toolkit was deemed too difficult for the research partners.

In addition to the general toolkit, the user interface toolkit included:
- Templates of an iPad printed on a heavy weighted paper
- Transparent sheets to overlay notification boxes when prototyping
- Variety of blank removable stickers to draw icon onto as buttons
- Pre-drawn icons onto removable stickers so people with dementia could quickly create a mock up. These icons were both familiar to the user interface design and common household objects such as buttons
- The container that the icons where placed into were outlined with a black marker to help with the depth perception that people with dementia have

This toolkit was not appropriate for some research partners due to their severity of dementia. Some research partners with dementia found it difficult to peel off the larger stickers used for their name tag due to their impaired dexterity, which was also compounded by a lack of contrast of the sticker to the backing paper. The toolkits sticker sizes were too small and fiddly for people with dementia who have motor skill issues. The final deciding factor to not use the toolkit was made after the collage workshop, in week five, where research partners seemed intimidated and uncomfortable at being asked to draw or create a collage.

Potentially increasing the size of the tablet templates and using different materials such as wooden blocks to represent buttons or drop down menus, may be more productive than this toolkit. However, it is not likely that people with dementia will understand the abstract concept of imagining what the buttons do when you press them.
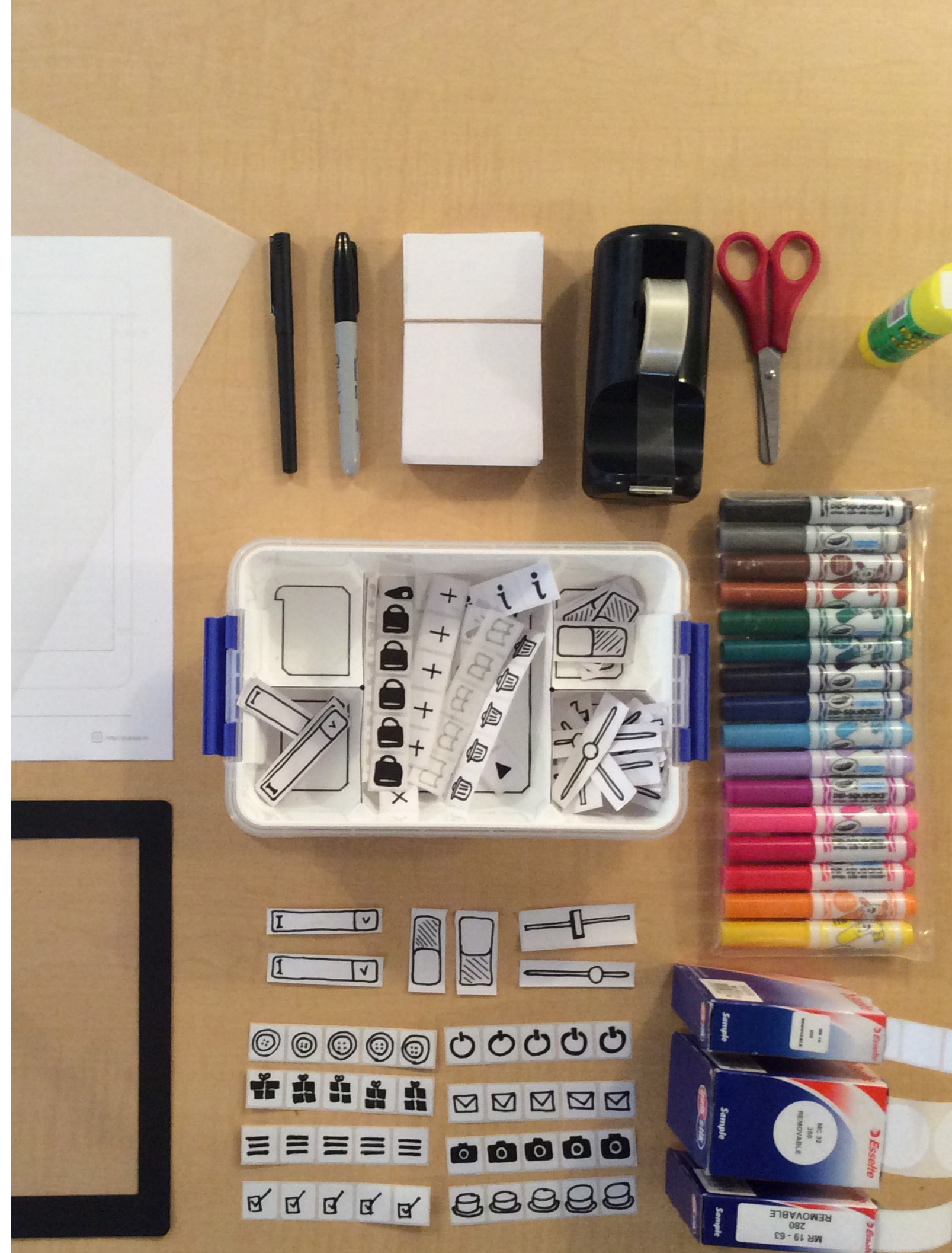
Figure 4.10 User Interface co-design Toolkit

REFLECT
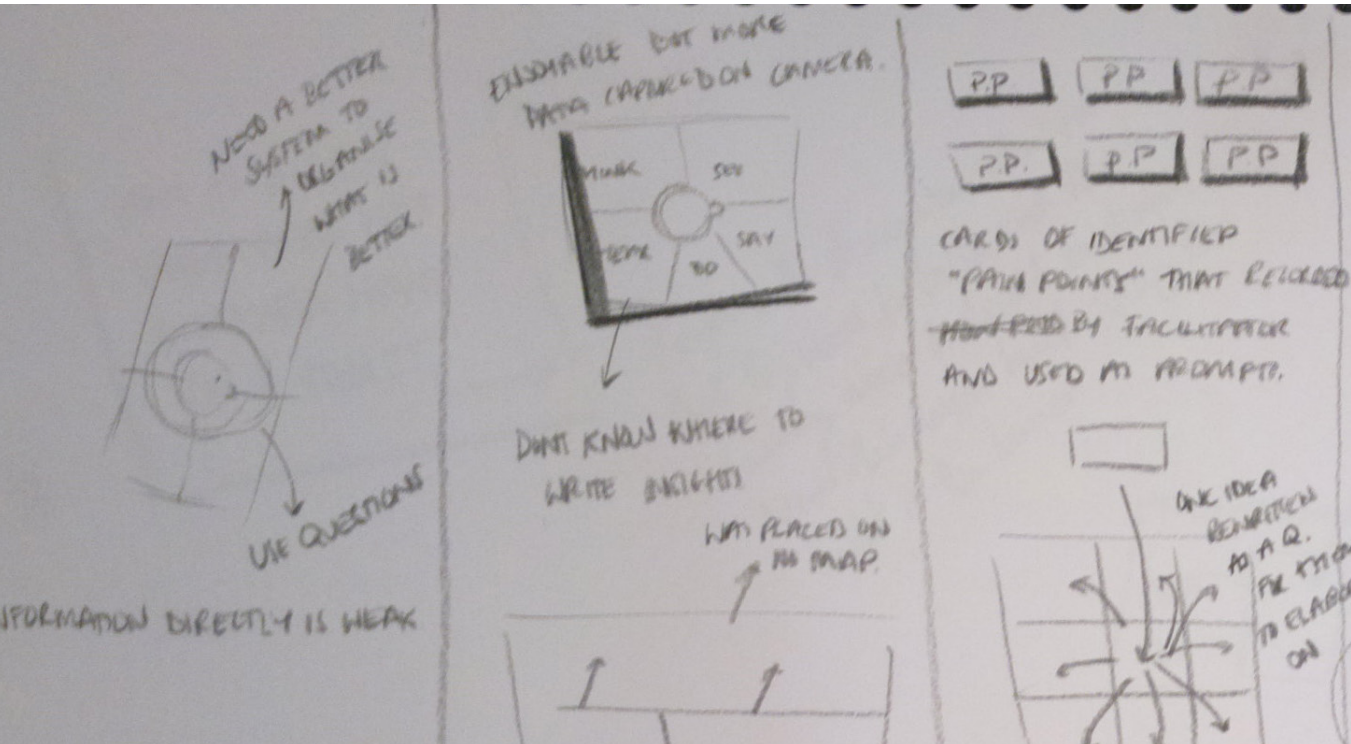
After conducting the workshops with people affected by dementia and a member of their families. All of the workshops and toolkits needed modifications. The modifications were occasionally specific to a particular research partner with dementia as the co-design activities identify their strengths and what they enjoyed doing.

1. Persona - Overall the toolkit worked well. One major difficulty with the toolkit was in deciding which ideas were more important and should be placed in the centre.

2. Experience mapping - The template for the experience map made it difficult for carers to write down insights of people with dementia as they did not know where to write it. The experience map was not used to identify a pain point, but it was effective in introducing members of the group to one another.

3. Design brief - Prompting people with dementia to decide upon the problem to solve in the subsequent weeks was useful to encourage people with dementia to generate their own ideas. The lotus blossom was also effective, although slightly confusing, to generate ideas
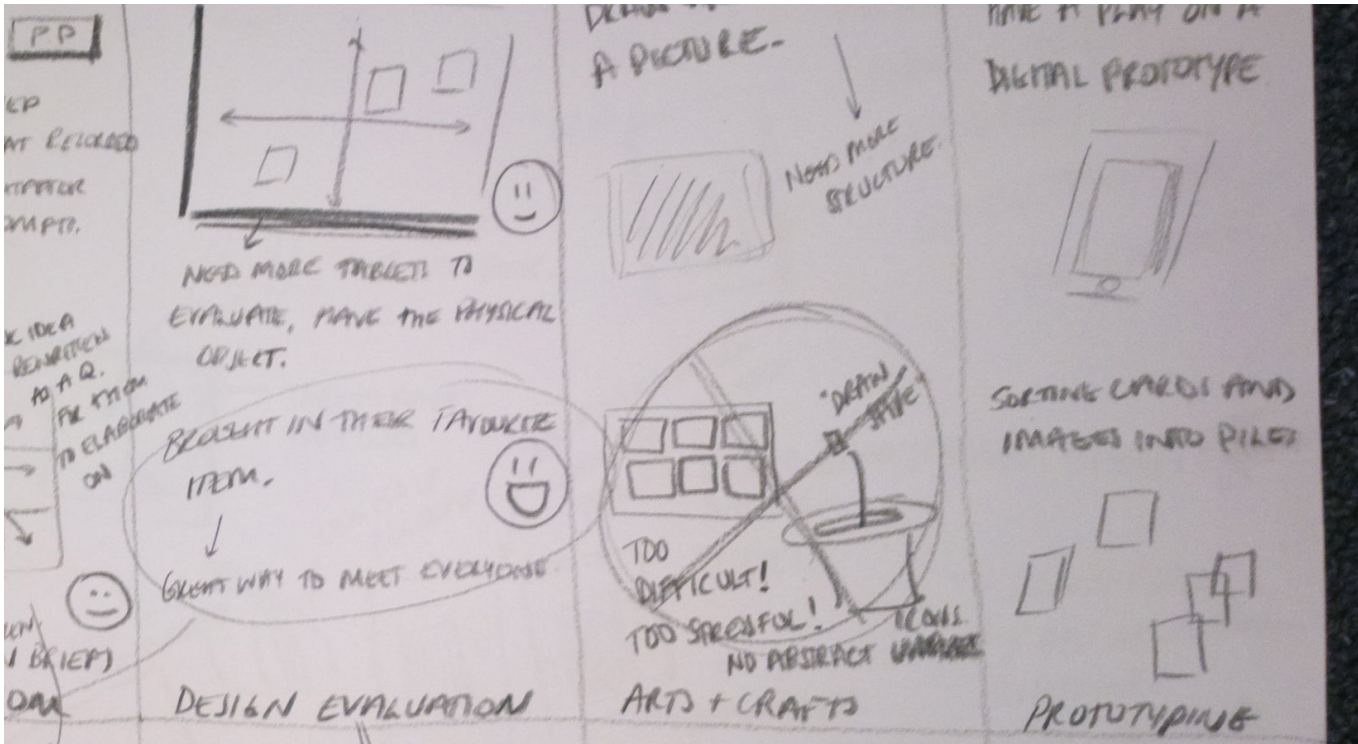
yet people with dementia seemed to enjoy the stimulation from the activity.

4. Design evaluation - Using the grid helped people with dementia position whether they enjoyed a product more than another as they could visually see where items were placed and reorganise if required. When evaluating a product or service, it would have been better if every people with dementia looked and interacted with the product or service at the same time.

Bringing an object from home that was

valuable to the people with dementia generated the most excitement throughout the co-design workshops. This may make an effective first introduction tool as all members of the co-design workshops freely conversed with each other.

5. Arts and crafts - This activity was enjoyed more by the carers than the people with dementia. One person with dementia mentioned that they were unable to draw what they wished to draw, which left them feeling disappointed. More structure is

needed within the co-design workshop so that people with dementia feel empowered. It may also be beneficial to have additional shapes and textures within the toolkit particularly if the research is around developing a tactile product.

Asking people to draw icons was a miserable experience for people with dementia and should not be repeated. One research partner had difficultly keeping up with the group and left out icons as they did not know how to draw what they had in there mind. They then became stressed when they noticed they had left out an icon and could not remember what was meant to be there. Instead it may be more appealing for people with dementia to match words with icons to see if they have similar meanings.

6. Prototyping - Research partners enjoyed evaluating the prototype quickly created using a blog template. The prototype stimulated ideas for the use of the prototype. People with dementia enjoyed watching the videos and songs chosen by the researcher based on values identified in previous workshops.

Sorting card into themes to be used as categories within the prototype was not enjoyed by the research partners however, it was useful in the development of prototypes and indicated that people with dementia were able to complete the task with minimal difficulty.

CYCLE 3:
5| Conducting co-design

This cycle details the implementation of the co-design toolkit with three people affected by dementia. The cycle is divided into the six workshops in the order they occurred. The final product of the co-design workshops was a design brief collaboration with people living with dementia, a member of their family, and the researcher. Key themes that were within the scope of the research were the capabilities of people with dementia, the relationship between the family carer and the person with dementia, the effectiveness of the co-design activities and toolkit, and how to facilitate co-design workshops with people living with dementia.

PLAN

This cycle tests the feasibility of co-design using the toolkit developed for people affected by dementia. Four people with dementia and three of their carers were invited to take part in six weekly co-design workshops that lasted an hour each. To protect their identities, people with dementia selected their own pseudonym based on famous stars of their era that they admired. Carers are referred to by the relationship they have with the person living with dementia.

Setting up the workshops
The start of each workshop evolved to make it more comfortable for the research partners as the workshops continued. A video camera on a tripod was place up high at the back of the room directed at the centre of the table. This point of the room was diagonally opposite the door where research partners would enter so they would not need to walk around it. An audio field recorder was placed at the opposite side of the table to the video recorder. All other equipment that was not needed including the bags for the tripod, camera, and toolkit were hidden under the desk to not intimidate research partners as they entered the room.

Three desks were placed next to each other in a row to make one large rectangular desk. An A0

sized sheets of paper were small in comparison to the desk. All the research partners sat around the desk, often in the same position each week. The toolkit for the workshop was placed in the centre of the desk facing the research partners. The toolkit and its images were spread on the table or in front of each research pair if there were multiple copies.

Post-it notes, pens, and blank nametag stickers were placed in front of each chair on the table where research partners were to sit. The post-it notes were all one colour for each research pair to make it easier to identify who wrote what. The pen lids were pulled off then lightly placed back on so that people with dementia were able to use the pen without assistance from their carer as the pen lids were too stiff for some to remove.

The tea, coffee, biscuits, and crackers were made available by the Alzheimer's Auckland facilitator fifteen minutes before the end of the hour. Carers would make a drink for themselves and the person with dementia while a plate of biscuits was passed around. If food and drink were presented at the beginning of the workshop, there would be a loss of valuable research time as research partners talked amongst themselves.

	Workshop Aim	Methods used	Number of research partners
Week 1	To create a persona that would represent the group and act as the focus user for subsequent workshops	People with dementia were asked to write their attitude, personality, skills, and requirements. They then identified the characteristics that were of value to them	4 with dementia 3 family carers
Week 2	To discuss the experiences in their lives to find out what they value	People with dementia were asked to use images and words provided as prompts to describe their memories. Using the templates provides, people with dementia wrote down what they thought, saw, said, did, or heard	4 with dementia 3 family carers
Week 3	To finalise the brief and come up with some concept solutions	People with dementia were presented with potential design briefs as identified by the researcher. These were used to prompt a discussion of what people with dementia wanted to create and used a lotus blossom to expand the ideas	2 with dementia 2 family carers
Week 4	To evaluate designs that may already solve our problem and find out what people with dementia like as a design	People with dementia viewed and examined prototypes that may already meet their needs in the design brief. Following this people with dementia brought in an item that was of value to them to discuss what they loved about it	4 with dementia 3 family carers
Week 5	To find out what people with dementia liked visually from their drawings	People with dementia made a collage with the materials provided. They then drew their own icons based on common jargon within technology	4 with dementia 3 family carers
Week 6	To test a web based prototype with research partners and structure the categories of information within the prototype	People with dementia experimented with a prototype developed by the researcher and sorted words and images into themes	4 with dementia 3 family carers

WORKSHOP 1: PERSONA

Co-design process

The outcome of the first workshop was to build a persona that reflected the entire group, so that we could refer to 'it' as having dementia. This helped collectively think about research partners' experience with dementia by stepping back from their situation. It was particularly useful as some nursing homes do not allow the use of the world 'dementia' or 'Alzheimer's' and instead used 'memory loss' (Bjorneby et al., 2004). It was assumed that the research partners would then work together in a generative way to identify opportunities for design, rather than trying to solve problems specific to individuals. This exercise also built rapport within the group and allowed the researcher to gain empathy within the group.

For the first task, research partners were encouraged to write words on post-it notes that described aspects of the character's personality, skill, attitudes, and requirements. It was anticipated that this task would be easy to complete as research partners would reflect on their own qualities as happened in the pilot test. However, this task proved challenging due to the confusion when referring to the 'phantom' persona as people with dementia thought there was an actual person.

The second part of the task was designed to help identify the most important characteristics

generated by the group and place them in the centre of the template (see figure 5.1), which would be the basis of our character. However, the research partners did not re-read what they had already put down. It was suggested by one of the carers to read aloud the insights to remind everyone what had already been said. This was ineffective, as people with dementia did not appear to remember in sufficient detail what was just read. It made it difficult to decide upon what was most important to everyone collaboratively as people with dementia had forgotten what the other options were. Ultimately the researcher chose to ask whether a specific insight was important to the research partners by reading aloud the ones that had prompted the most conversation earlier. If it still prompted a response or discussion, it was added to the middle of the template.

This workshop was enjoyable to begin with as everyone got to know one another. Once research partners settled into the task and understood what was required they started to engage with one another. Research partners would, on occasion, offer or make a comment that invited a discussion from other members of the group. Topics that provided the most response within this group were their hobbies, grandchildren, the news, safety, and being a good friend. Consequently, these ideas were included in the following workshops.
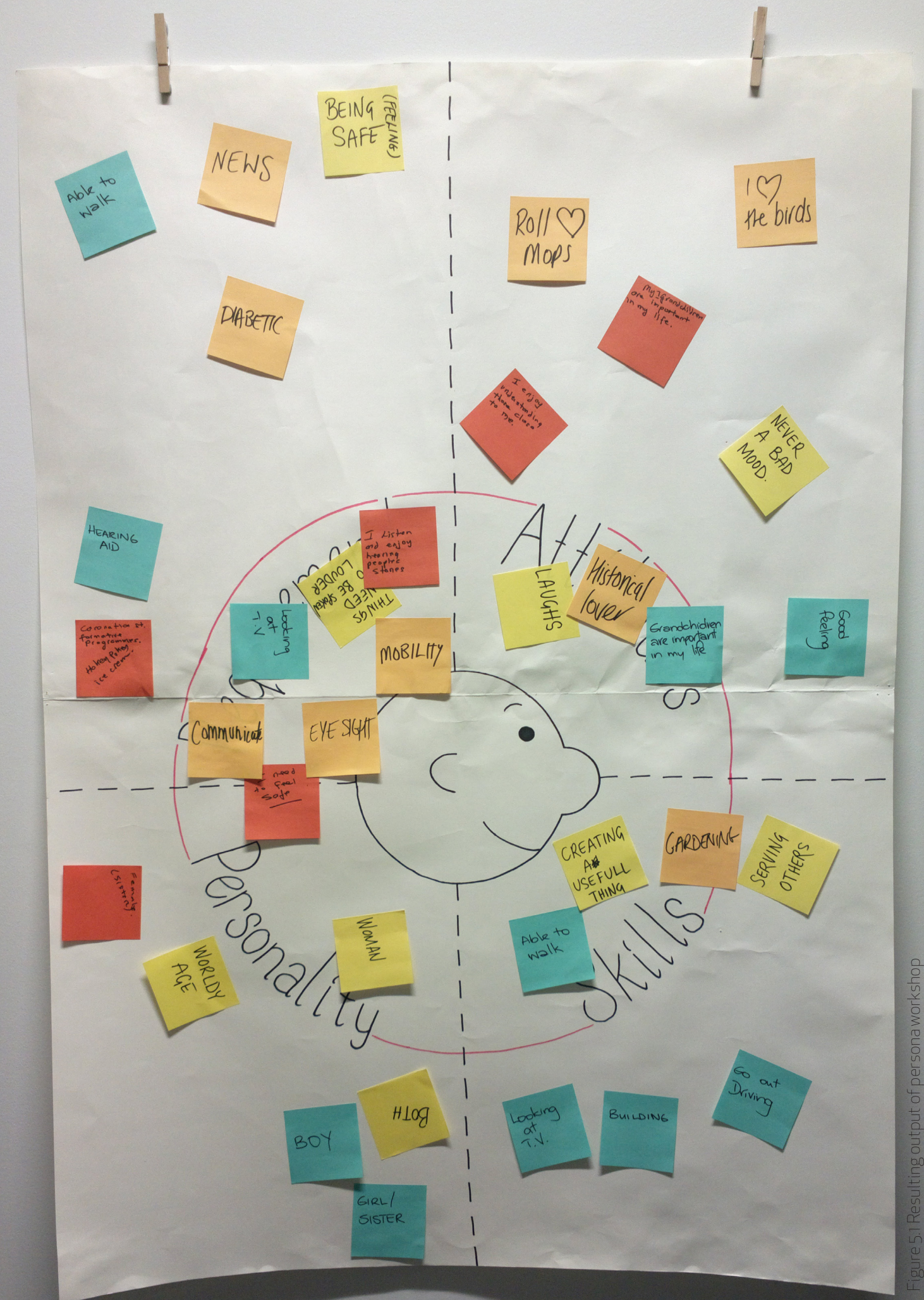
Capabilities of people with dementia

It was interesting to see how dependent some research partners with dementia were upon their carers; although this was expected. It was anticipated that the carer would help translate instructions given by the researcher and write answers or comments made by the person with dementia. This was true for three of the research partners with dementia, yet one participant was able and willing to write their own answers and did so successfully. However, they still sought direction from their carer to suggest what to write and where to place it.

> Rita's Husband: *"Do you think you should write that down?"*
> Rita Hayworth: *"No."*
> Rita's Husband: *"Well I think you do."*
> Rita Hayworth starts writing it down.

Many of the answers given in this workshop by the research partners were superficial to the researcher. However, the conversations that took place while contributing were rich with insights into the lives of the research partners.

> Rita Hayworth: *"The problem about listening to the news and those articles on the TV, for me, is forgetting what I have seen. Enjoying it, but then forgetting it."*

Due to the inexperience of the research partners in identifying such insights, the group did not immediately record insights as was asked of them at the beginning of the workshop.

None of the research partners suggested dementia or symptoms of dementia as a characteristic of the persona being created. This may be because dementia is, and its symptoms are, not something they define themselves with.

Role of the carer

It was immediately apparent, after the first question, how much reliance there would be upon the carers to help communicate the workshops instructions to people with dementia. Carers often needed to repeat the question that was asked by the researcher and occasionally rephrased it for the person with dementia. Despite the confusion of describing a phantom persona, which was a difficult abstract concept for people with dementia, carers initially felt that the exercise was enjoyable and productive.

> Researcher: *"We're trying to build up this whole person. I know it's a bit strange."*
> Cary's Daughter: *"Yeah, I think it works well."*
> However as the workshop progressed, the responsibilities the carers faced in constantly interpreting and translating became apparent.
> Cary's Daughter: *"I think I need my coffee."*

Facilitating

Due to all the research partners coming from the same cognitive stimulation group it was incorrectly assumed that everyone would have previously met each other. It was suggested by the research partners for everyone to write their name on name badges. This had the added effect of reminding the researcher to use a research partners name in the questions if they did not wish another to answer it. All research partners with dementia were able to successfully write their own name after being asked by their carer. In future workshops, some research partners with dementia wrote their name automatically without being prompted.

At the beginning of the workshop the carers were addressed first consequently neglecting the people with dementia. This continued as carers asked more questions about the workshop, resulting in people with dementia sitting quietly and contributing less. It became particularly uncomfortable to the researcher when referring to people with dementia as people with dementia. A note was made to address people with dementia first in the following workshops.

Future Improvements

In future, to identify which characteristics are important, it may be effective to arrange them in order by asking whether they prefer one characteristic more than or less than another.

A more productive persona workshop approach might be had by giving better instructions to carers. For example, an introduction to the activity as well as an example of what is expected may help carers better tailor their questions/support the person with dementia.

One of the research partners often repeated words aloud that he could see, despite having read the words moments earlier. If words were phrased as a question, there was a possibility that as he read the words, he might be prompted to answer a question. In subsequent workshops the toolkits were altered so that single words describing categories were rephrased into a question. However, this channelled the solutions in a particular direction.

WORKSHOP 2: MEANINGFUL EXPERIENCES

Co-design process

The purpose of this workshop was to identify experiences that were meaningful to people with dementia. Images and words were selected specifically to prompt meaningful experiences using a template to document what was seen, heard, said, thought, or felt from the prompted experience (figure 5.2). To assist filling out the template, carers where given an example of one completed to suggest where insights might be written. It was intended that these templates and images would be pasted onto a larger group timeline. This, however, was decided too difficult to organise by the research partners.

There was also an abundance of post-it notes provided for research partners to write down their own experiences. Interestingly these were not used despite running out of templates during the workshop. This may be because research partners felt that there was no where to stick them.

Words, despite occasionally being read out loud, were not as stimulating as images and were not used by the research partners to stimulate conversation. Images that were popular were ones that helped a participant recall something in their past.

> *Rita Hayworth: "It's nice to take us back to our memories."*

The more popular images of landscapes, food,
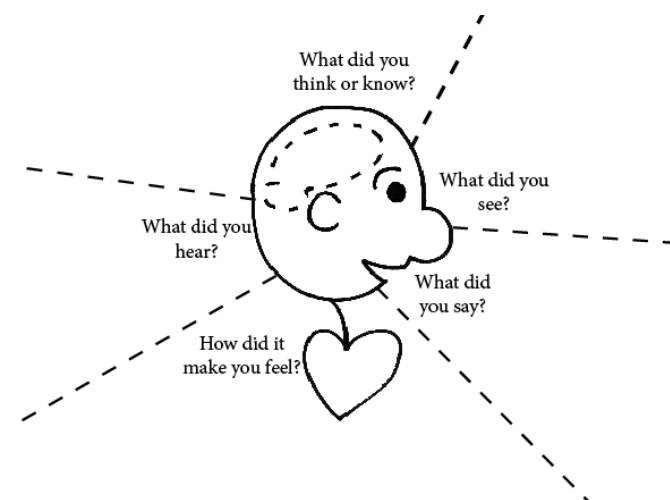
Figure 5.2 Experience Mapping Template

and tools brought out richer conversations, with research partners engaging with each other as a group. Similarly to the pilot test, research partners needed to be reminded to record valuable comments when they became engrossed in a discussion.

Interestingly, despite grandchildren being a popular topic of conversation the previous week, the image of children to prompt a memorable experience was neither chosen nor discussed. It is assumed that this is due to the image not being of their own grandchildren. People with dementia responded to the images that they saw in the present, not what was interesting to them in the previous workshop.

As it was time consuming to discuss their experiences and record them, arranging

everyone's moments along a timeline together was omitted from the research workshop. This made it difficult to identify a point of pain that could be used to create the design brief. The researcher reviewed the templates after the workshop to identify what images or words gained the most response. The templates were also sorted in the final week of the workshops.

The resulting discussion from the workshop did not result in detail around moments that they found difficult. Instead the workshop resulted in understanding what the research partners value as individuals. The data collected about the research partners was used as input data for the digital application prototypes.

Capabilities of people with dementia

It was assumed that people with dementia would describe experiences of the image or words and perhaps deviate towards experiences that held more meaning to them. However, people with dementia often described experiences related directly to the image or word. This may be due to carers feeling as if they must redirect the discussion back to the original image, instead of using it as a starting point to inspire discussion. For example, Ginger's son was trying to correct her that the bird she saw in the photo was a fantail and not a wax eye. This interrupted Ginger voicing her opinion on what she felt about birds and the moment was lost. Only one participant with dementia was able to use an image of Dunedin's

railway station to remind him about the camping grounds at Dunedin.

Not everything that a participant with dementia said is fact. Cary Grant came to New Zealand from Holland unmarried with his soon to be wife so that they could easily gain a visa in New Zealand. Cary asked Fred Astaire if he too also came to New Zealand unmarried to which Fred replied that he had. However, his son and wife quickly corrected that he was married an had even brought his first child over to New Zealand with him.

> *Fred and Ginger's Son "...no you weren't. You [even] had a child!"*

Dementia had also taken away the 'photographic' memories of Fred Astaire approximately two years ago. Currently Fred's memories were all

jumbled up. During the workshops he loudly voiced facts or memories that did not seem significant to the current conversation of the group, and repeated them.

> Fred Astaire: "Where there is an 'r' in the month, that was then you have muscles".

Such outbursts were interesting to note as they were significant to the person with dementia at the time, despite appearing unconnected to anything happening at the time. These outbursts were noted as they helped identify topics of interest to the person with dementia to be used later.

When dealing with memories, some memories may be upsetting to research partners.

> Rita Hayworth: "Sometimes remembering is difficult, but then you just push it away… [especially] if it is stuff you don't want to remember. You just push it away".

During this workshop while speaking, one on one with Fred Astaire about his parents, it was noticed that his tears were welling up. The researcher tried to refocus Fred's attention on another image, but the researcher did not know which image would appeal to him. Consequently, Fred's son was told what was happening and together the researcher and Fred's son brought his attention towards another image.

It is a terrible feeling knowing to have unintentionally upset someone, and worrying about the implications it might have for the research. How the situation was handled was discussed with a psychogeriatrician, who explained that people with dementia have difficulties regulating their emotions, and that this should be interpreted as finding something that was of deep value to Fred (psychogeriatrician, personal communication, 20th May 2015). How the situation was handled was later discussed with Fred Astaire's son to ensure he was comfortable in how the incident was handled, and stilled wished to participate. Fred's son was not concerned and enlightened the researcher that Fred's tears were not from sadness but emotional ability.

Role of the carer
Again carers were relied upon heavily to enable discussions and help document data from people living with dementia. Carers found this task difficult, as they did not know where to put information using the supplied template.

> Fred and Ginger's Son: "This is hard."
> Cary's Daughter: "Yeah it is hard."

They also used the template to design questions for the person with dementia in a structured manner, instead of letting the conversation flow and writing comments down as was heard. Consequently, the conversations were often staggered with neither party fully immersed in the interaction. When a conversation was fully immersed with valuable data, often the data was not recorded. In some instances this data is recovered viewing and listening to the audio recordings. However, as there are multiple people talking at once in the room, sometimes it is too difficult to hear what everyone has said. In such instances, the comments written by carers are invaluable.

Interestingly, carers often selected words or images for a person with dementia to talk about. They would also pass words across the table to other carers if they felt the topic would be of interest to them. Cary's daughter, for example, passed an image of knitting needles to Ginger's son so that Ginger might talk about it. Much to Ginger's son's surprise, Ginger was not interested in knitting and had never knitted.

In a group situation, carers were able to support each other in completing the activities and suggest easier ways to complete the task. This 'bonding' was strengthened in the fifteen-minute social time scheduled before the workshop finished where carers often discussed their experiences of doing the activity. With focus directed away from the toolkits, people with dementia and their carers engaged in lively discussions, which were often a continuation of their last discussion during the activity or were about their experience of the co-design workshop.

Future improvements
Discussing the experiences of people with dementia was an enjoyable activity that resulted in meaningful discussions held not only in individual pairs, but also as a group. However, the process in which research partners themselves collected the data was difficult as it was unclear where to write the insights, which disrupted the flow of the conversations.

Arranging their experiences on a timeline was not effective as it was difficult to remember when an experience occurred for research partners as well as arrange it with other timelines. It may have been more effective to focus upon a day in the life for people with dementia, using images that may occur in their daily lives.

WORKSHOP 3: DEVELOPING THE BRIEF

Co-design

The objective of this workshop was to decide upon the problem to be solved in the four remaining design workshops. Research partners were asked to select values that were important to them. These were then expanded using a lotus blossom brainstorming tool. A lotus blossom begins with a central idea surrounded by eight concepts from that idea. These eight ideas were expanded to identify a further eight concepts of implementing these ideas. The lotus blossom technique received the most interest from the operations manager of Alzheimer's Auckland.

At this stage it was hoped that there would already be a pain point identified from the experience map in the previous workshop. Instead it was unclear about how to progress forward in the design process to the researcher. Consequently, research partners were asked directly if there was anything that they would like improved in their life.

> Cary Grant: "There's always things that you want better, but in my position well, I can't expect things to be better, that's all."

It was assumed that his position was referring to his lack of mobility.

Even for cognitively able people, coming up with a problem when asked directly can be difficult. Cary Grant was shown some of the key insights that was identified from the previous weeks to see if he responded to any. On hearing these, Cary was prompted to describe what held a lot of value to him: mobility. Despite this theme not being identified previously, the core reason he choose mobility was to socialise with others.

The problem that was chosen by people with dementia was to engage their brain and stimulate conversations with others. This was rewritten as a question and placed in the centre of the diagram (see figure 5.3). Research partners were then asked to describe that made them talk or think. The eight concepts were expanded upon and rewritten as a question by the researcher. Writing the concepts as questions was effective as research partners with dementia read the question aloud and answered it, despite have already read and answered the question previously. However, the way in which the question was written dictated the reply of answers and may have restricted potential creative answers.

Figure 5.3 Resulting output of the design brief lotus blossom
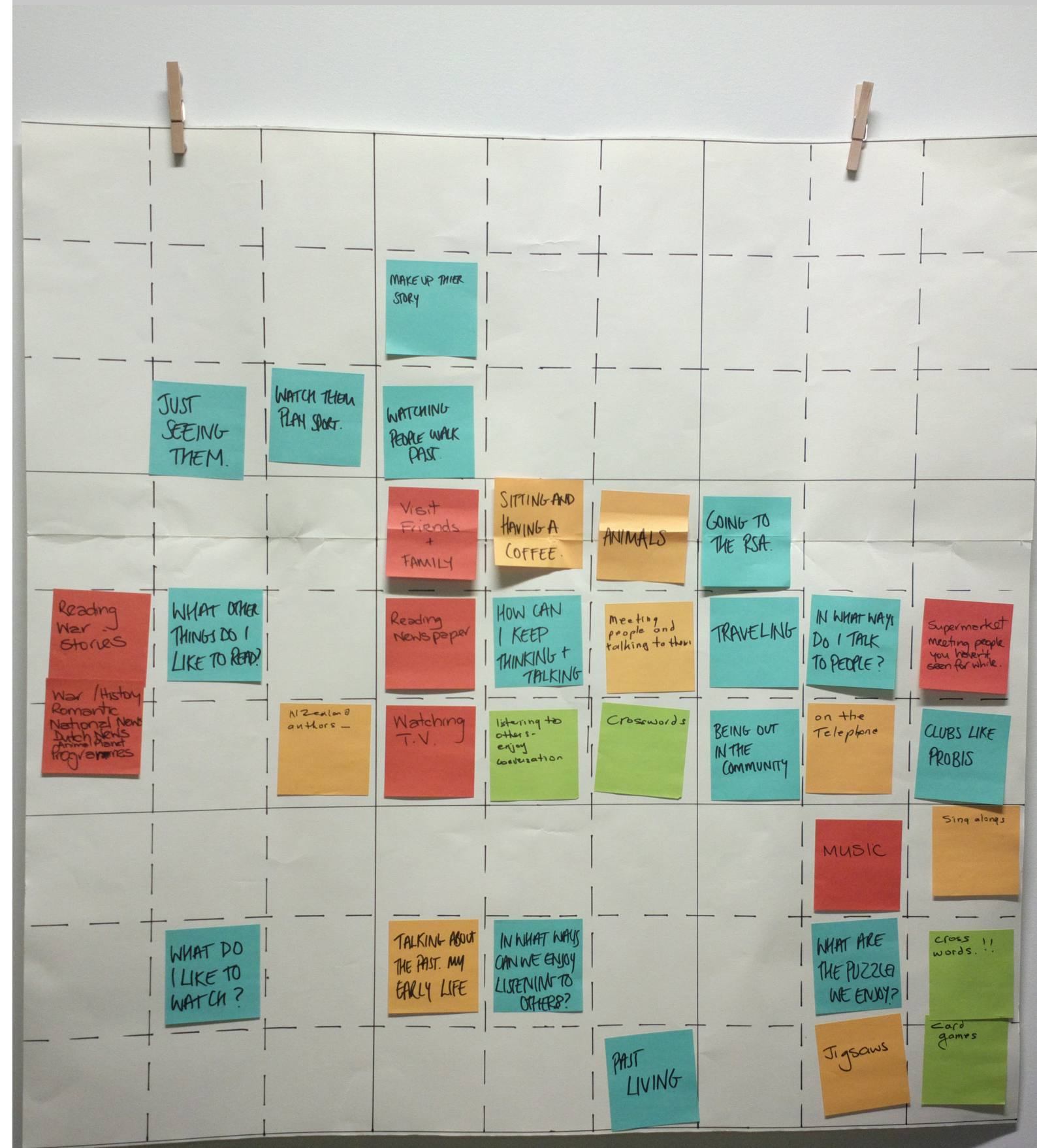
The final brief was finalised with the agreement of the whole group, which was surprisingly easy achieve. Research partners selected the final brief with dementia based on Rita Hayworth's suggestion to think and talk. It then generated an engaging discussion about how much people with dementia value spending time with friends and family. As a result of the discussion, it was decided that talking and spending time with their grandchildren was most beneficial.

> Cary Grant: "Well the thing is when you're younger, you've got interest in all the different things. But when you get older, you know yeah, you've got your own family, you've got your grandchildren, you've got your children, and they're all getting older…"

> Researcher: [What do you like doing with your grandchildren?]
> Cary Grant: "Well if they come, that would be nice."
> Cary's daughter: "Who else would come up and visit you?"
> Cary Grant: "The other daughter."
> Cary's daughter: "Yeah, my other daughter."

In response to asking whether the workshops should focus upon spending time with their grandchildren doing activities that made people with dementia communicate and think Rita

replied:

> Rita Hayworth: "and that should be how it is."

People with dementia

While participating in the activities, the carers were often talking over the people with dementia due to their enthusiasm with the activity. A recurring theme throughout the workshop was the idea that people with dementia were unable to voice their opinions over those more cognitively able. This was supported indirectly by comments made by people affected by dementia throughout the workshop.

> Researcher: [In what ways can we listen to others?]
> Rita Hayworth: (instantly) "By not interrupting them."
> Everyone laughs
> CST facilitator: "There you go [Rita]."
> Cary's Daughter: "Oh gosh. That's a good one."
> CST facilitator: "That was quick about it."
> Cary's Daughter: "She's, she's on a roll here."
> Rita Hayworth: "People do interrupt you don't they?"
> Occupational Therapist: "Yes, yes they can do."
> CST facilitator: "Well…"
> Cary Grant: (interrupts) "That's the only way to talk."

> Everyone laughs
> Rita Hayworth: "Yeah it's the only way to get a word in, fair enough."

The dementia journey also takes away an individual's ability to make decisions for themselves, as carers often make the decisions for them.

> Cary's Daughter: "What else do you like watching on TV?"
> Cary Grant: "You tell me,"
> Cary's Daughter: "Nah, you tell me,"
> Cary Grant: "Nah, you tell me,"
> Cary's Daughter: "Ah. So we're going to play this game are we dad?"
> Cary Grant: "alright."
> Cary's Daughter: "We're going to play this game?"
> Cary Grant: "Yeah we play this game."

This example depicts frustration from both parties, and appears to happen frequently. The perspective of the researcher is that this occurred due to Cary feeling unheard, as he was during the co-design activity. He may also have been having a bad day with his daughter (good and bad days are common with dementia). However, a comment made by another participant indicates that this was a frequent problem for other people with dementia as well.

> Rita Hayworth: "I have to do what I'm told now you see."

Carers

It was easy for the more cognitively able to talk over those with dementia and to make decisions for them in the activities. Having the people with dementia present while designing the brief reminded us that they are people with values.

> Rita's Husband: "Well I think that as they get older, it's hard to get the motivation."
> Rita Hayworth: "They?"
> Rita's Husband: "You."
> Rita Hayworth: "Am I a they?"
> Rita's Husband: "Well no, I'm just saying…"

The role of the carer was to support the person with dementia but they began to coach the researcher in wording questions to be more easily understood.

> Researcher: "[are] there any problems that you have in your day to day life that you would like fixed? Or is there something that just happens?"
> Cary's Daughter: "You might want to just word that again."
> Researcher: "Are you happy with your days?"
> Cary Grant: "So far, yeah. It's alright".

WORKSHOP 4: DIGITAL EVALUATIONS

Facilitating

When facilitating the previous workshops, the researcher stood at the 'head' of the table from where the Alzheimer's Auckland cognitive stimulation therapy facilitator led her group. Immediately this created an imbalance of power whenever the researcher spoke as everybody stopped to listen. During this workshop, the research partners were later than usual due to the stormy weather. When one research partner pair had arrived the researcher sat down next to them to begin the research. When the other research partners arrived, the researchers remained in their seat, which created an unexpected but exciting dynamic within the group. It helped shift the researcher's position of power to being an equal in the design process creating livelier discussions. For future workshops, the researcher did not lead from the 'head' of the table, but moved around crouching between seats to talk with research partners.

Often carers became increasingly engaged in the excitement and generation of ideas, which occasionally resulted in talking over people with dementia. However, looking directly at a person with dementia while they talked encouraged the person with dementia to keep talking despite their carer talking as well. By engaging with the person with dementia the researcher can discretely draw the groups' attention back to the person with dementia.

Future Improvements

Many of the engaging discussion such as a lack of social clubs where they would have met intergenerational people, resulted from the conversations created by conditions set up by the workshop. However, these insights were not identified as 'problems' or 'solutions'. Therefore the researcher recorded such insights with their approval to place them on the lotus blossom.

The carers often generated ideas on behalf of the people with dementia instead of allowing people with dementia to generate their own ideas. However, people with dementia were able to respond to whether they felt an idea was good or not. Potentially with more severe cases of dementia, carers could generate ideas to be evaluated by people with dementia.

Co-design

The first task of this workshop began by evaluating examples of products that would encourage or support a person with dementia based on the brief from the previous workshop; to think and talk. To end the workshop, people with dementia had been invited to bring an artefact or a picture of an artefact that was important to them with the purpose to identify what they liked about it as a criteria for design.

Five digital applications and two books were selected for evaluation within the group. These were selected as they potentially could be used by a person with dementia to 'think or talk', and could communicate or play with their grandchildren. These were analysed by the group based on whether the research partners felt that it would be useful and how visually engaging it looked (figure 5.4). Facebook was ranked the least useful by research partners due to its visual complexity. The journals recording personal data by Life Canvas received the highest ratings in both appearance and the likelihood that research partners would use it due to the perceived familiarity of function and personalisation.

Two of the designs included were the result of the researchers previous honours research. One was a small ring bound diary designed to capture the life and medical history of a person with dementia, and the other was a radio application designed to help document and replay important events in a person with dementia's life. The diary received negative feedback by research partners, which aligned with the researchers final reflection of the artefact.

> *Fred and Ginger's Son: "clinical."*
> *Cary's Daughter: "It looks quite clinical and it looks so intense… It looks daunting. That's the word I'm looking for."*

The journal by Life Canvas enabled a family member to write down interesting facts about their loved one. The carers felt that they could fill in the book at their own pace and people with dementia would pick the book up and read it in their own time. Fred Astaire enjoyed reading what he saw out loud and demonstrated this during the workshop. However, it did not appeal as much to Cary Grant as it did to his daughter. Cary explained that the book did not suit him personally perhaps due to the childlike cartoon illustrations. This is an example of why the elderly or people with dementia should not be generalised as being the same.

Interestingly, the reasons that the research partners liked the book did not apply to the ring bound diary. For example, it was felt that the Life Canvas book could be filled in sections unlike the ring bound diary, which was felt had to be completed in order all at once. This was
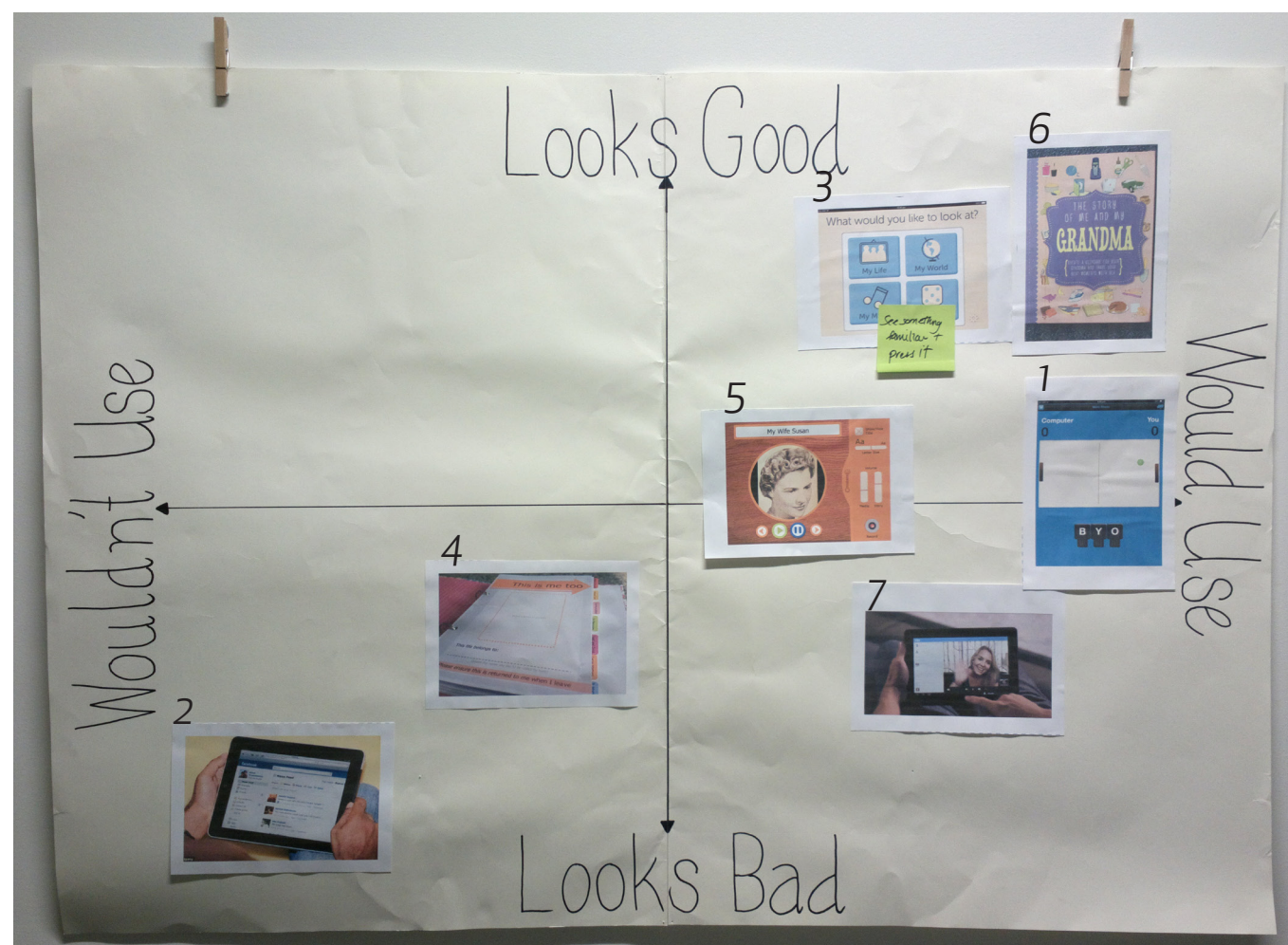
Figure 5.4
Resulting output of tablet computer
applications evaluation

1. Brainy App (Alzheimer's Australia, 2013)
2. Facebook (Facebook Inc., 2015)
3. GreyMatters (GreyMatters Care LLC, 2015)
4. This is me too – Booklet (Jury, 2013)
5. This is me too – Radio (Jury, 2013)
6. The story of me and my Grandma (Parragon Books, 2013)
7. Skype (Skype Communications S.a.r.l, 2015)

disappointing as the ring bound diary was designed for the purpose of being able to fill single pages at a time and for the pages to be rearranged as suited. This may have been due to the content within the diary being written for medical purposes instead of a celebration of who they diary's owner was.

In the second part of the workshop, research partners had brought in objects that were important to them to share with the group. Research partners brought in a diverse range of items, including a pottery butterfly, wedding and family photographs, a picture of a grandfather clock, and a picture of a cabbage shredder. These items were selected because they held meaning for the research partners with dementia. It created a moment were all the people with dementia were excitedly sharing their items and memories and did not wish to stop.

Perspectives of dementia
Allowing research partners to interact with a tablet computer and test application programs appeared exciting for the research partners. It was anticipated that carers would be assisting people with dementia to use the tablet computer. Instead however, carers discussed the potential benefits of the application software amongst themselves such how Grey Matters took a person with dementia to a happier time (GreyMatters Care LLC, 2015). This allowed people with dementia to

explore the tablet computer themselves without supervision.

Cary Grant enjoyed playing a spelling software application called BrainyApp where paddles were rearranged to spell a word and beat the computer at the traditional computer game, similar to tennis, called "pong" (Alzheimer's Australia, 2013). To interact with the tablet computer Cary Grant and Fred Astaire quickly learnt how to slide the paddles by pressing their finger on a paddle and sliding it across the screen to where the paddle should go, and seemed to enjoy the instant feedback from the game. However, Rita Hayworth found it difficult to slide the tiles as her method of interaction was to tap the tile to move, and tap again where she wanted it to go. Even after successfully succeeding at dragging a tile across, she did not appear to understand how she had done it and repeatedly interacted by tapping instead of sliding. Neither Rita Hayworth, her husband, Fred Astaire, or Ginger Rogers had used a tablet computer before, but were engaged in using the tablet computer.

In the second half of the workshop, research partners were asked to present their favourite item. While doing so, all research partners with dementia became highly animated. Ginger Rogers, who was normally a quiet research partner, spoke excitedly to everyone about her cabbage slicer. It was only then that the group learnt how her life

revolved around caring and serving others such as her family. She proudly shared with the group how the cabbage shredder enabled her to make coleslaw finer than with a food processor.

Even though Fred Astaire's turn to talk about his grandfather clock had passed, he was still talking about it despite the fact that no one was listening to him. He kept smiling to himself while he was talking and his words seemed to reassure him.

> *Fred Astaire: "Yeah it still goes."*
> *Fred Astaire: "Yeah it's exactly the same."*
> *Fred Astaire: "It's exactly the same you know."*

Carers

Carers were reminded to bring in an item that was important to the person with dementia. This may have unintentionally meant that the item brought was what the carers felt was important to the person with dementia, which may not have been the same as the person with dementia. Fred Astaire's item was a wooden grandfather clock that he and his son rebuilt together based on the original casing for the clock. The original clock casing was not imported into New Zealand in case the wood contained woodworm. The clock was meaningful to his son, as it was a time that they had spent together before more severe symptoms of dementia had arisen. However, Fred initially saw the clock as the original and had to be

reminded by his son that it was not the same clock.

Carers often answered questions about the item before the person with dementia could reply if no one's name was used.

> *Rita Hayworth: "I brought a butterfly. Because… I dunno… I really really love butterflies"*
> *Cary Grant: [asked where she got the butterfly from]*
> *Rita's Husband: (While Rita is thinking) "The Greek Islands."*

Perspectives on facilitating

When facilitating the evaluation of products that encouraged or supported people with dementia, the image selected as a placeholder for the item impacted the result. Research partners with dementia were unable to retain what the software application was or did based on verbal descriptions. Consequently, they based their response on what they saw immediately.

> *Researcher: [Why do you like this one over that one?]*
> *Rita Hayworth: "The picture would draw me in."*

This meant that images with a screenshot of a person face were rated higher than a screenshot of an software application menu.

Future Improvements

When evaluating the software application on the tablet computer, research partners had to share one tablet computer between the group. This made it difficult for research partners with dementia to remember what the tablet computer application they had previously used to evaluate. One research partner with dementia, despite being the first to use a software application, did not remember having used it when the group was reviewing the application. It would be more effective if each person with dementia had access to a tablet computer while reviewing a program so there was no need to remember what they had used and could form an opinion based on what was immediately in use.

WORKSHOP 5: MAKING

Co-design

Structured as an arts and crafts activities workshop, research partners were asked to use the tools available to create a collage or drawing. The brief was open to allow people with dementia to be creative. Its purpose was to identify what they enjoyed visually to then influence the aesthetics of the design solution without directly asking them. This approach was taken to help reduce or minimise the chance of 'performance anxiety'. In the second part of the workshop, research partners were invited to draw digital jargon like 'save' and 'home', to help design icons that would be familiar and understandable to them.

Research partners with dementia were provided a variety of pens, pencils, paper, and pictures all placed in the centre of the table. This created instant excitement within the room as they entered with particular interest in the brightly coloured patterned paper. After describing the task as a workshop to creatively explore ideas, using any of the materials available, all research partners were confused and requested an example. After creating an example it was explained to research partners that the focus was going to be upon the way they use colour, arrange the page, and express themselves. Only people affected by dementia took part in creating an image with their family carer supporting when they needed help.

Research partners with dementia were hesitant and confused upon what to do when faced with a blank page. With encouragement, some research partners eagerly created work while others struggled and needed constant support from their carer. One participant did not wish to participate as it was not something he found interesting or fun. Interestingly, he proved to have astounding artistic talent unknown to his daughter, and drew an impressive cruise ship from memory of his trip to Holland with his wife years ago (see figure 5.5). He enjoyed talking about his trip with others more than the act of drawing it. His lines were more sure and determined in the picture of the ship than the sun and birds that his carer suggested he draw to complement the picture. This may be because he was no longer drawing from memory or was no longer interested or engaged with the activity.

The second half of the workshop involved research partners drawing words that are terms frequently used in technology such as 'home' and 'save'. For this exercise, both carers and people with dementia were asked to complete their own drawings. This activity was poorly planned as it was difficult for a person with dementia to retain a word and draw its abstracted image. This created some tension, stress, and anxiety amongst the research partners. Due to additional time restraints they were also rushed, creating further pressure.

Research partners were given examples of icons
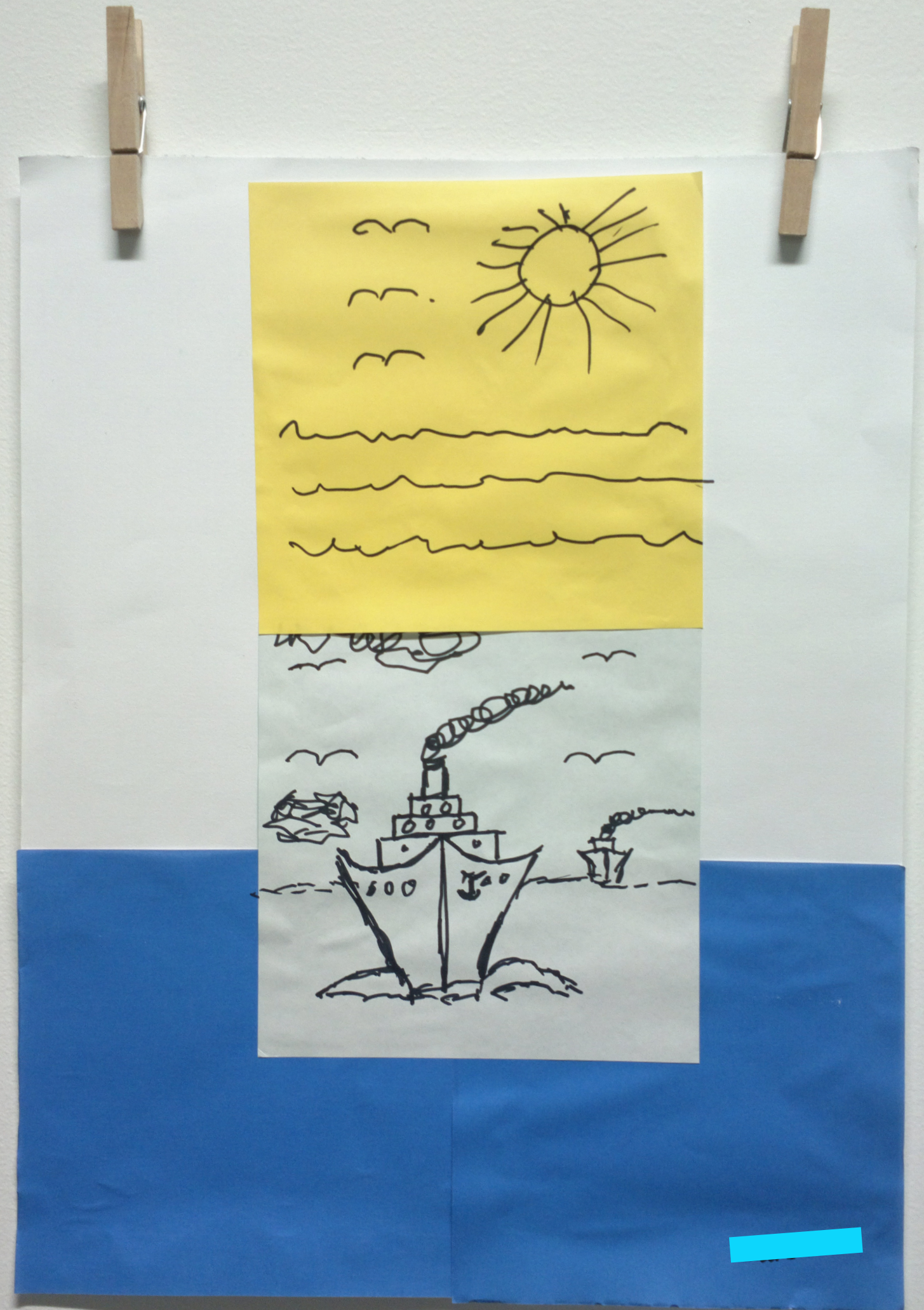
Figure 5.5 Person with dementia's collage output

Figure 5.6 "slippers"

Figure 5.7
"We have to draw these pictures. Not what I like doing."
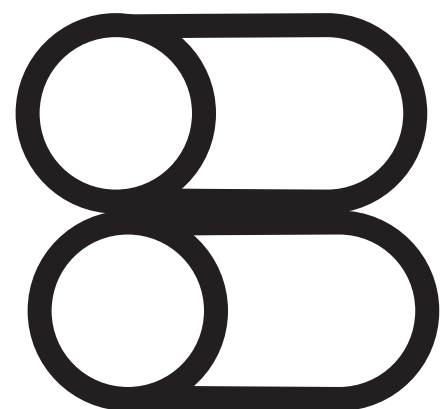
to indicate what was being looked for. Fred Astaire instantly began to describe the icons that he saw and, as expected, the images were so abstract that his interpretation of the images was different to the researcher's. For example, an icon depicting the binocular symbol often used for visual reading lists, looked like a pair of slippers to Fred (see figure 5.6).

People with dementia
Not everyone enjoyed the arts and crafts workshop. However, they were able to let the carer and the researcher know that they did not wish to participate. Carers supported the person with dementia to take part or not based on their judgement.

Cary's Daughter: "I know it's not your cup of tea. Pretend you're building a building. You

know on paper. How about that?"
To reduce the carers' influence, Cary Grant was asked by the researcher whether he wanted to observe or do something else. However, when asked by the researcher he did agree to take part, but made it clear that it was not something he would usually do. His decision to participate may have been due to the inconvenience and attention caused by not participating within the group. However, he was still was able to voice his displeasure in the activities by writing that he did not wish to draw what was asked of him (figure 5.7).

Sometimes people with dementia forget the meaning of words. This makes it difficult to understand them and can lead to disagreements between the carer and person with dementia.

Figure 5.8 Green or Black?

Figure 5.9 Recording sound
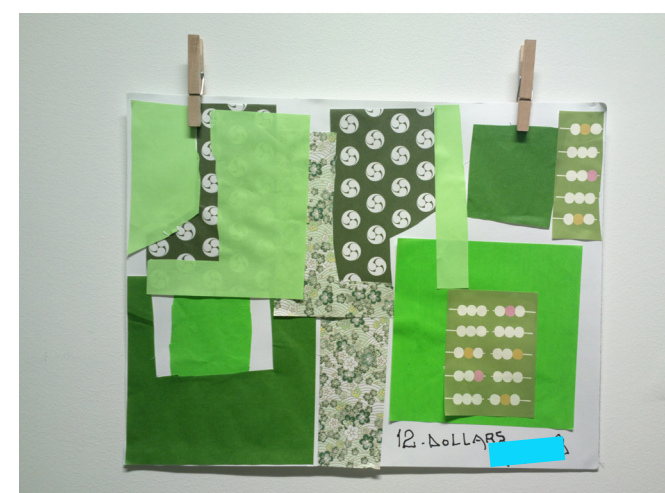
Fred and Ginger's Son: "What colour do you like dad? I know what colour do you like"
Fred Astaire: "Huh?"
Fred and Ginger's Son: "What's your favourite colour?"
Fred Astaire: "Favourite colour?"
Fred and Ginger's Son: "Yeah. What is this?" (points to Fred's clothing)
Fred Astaire: "Green."
Fred and Ginger's Son: "Is that true?"
Fred Astaire: "Yes."

However, his outfit was black. It was unclear whether he no longer remembered what his favourite colour was, or whether he no longer associated the correct word to the colour. Despite the confusion or misunderstanding, Fred was given paper of different shades and patterns of green (Figure 5.8). This was also because there

was only one shade of black.

Cutting out images and sheets of paper was easier for research partners to do than drawing an image. Two of the research partners struggled to draw and often looked lost and unsure even when prompted by their carers. Structuring the craft workshop into small tasks may have reduced the uncertainty and anxiety felt by research partners. It was expected that people with lower levels of cognitive ability would find abstract thought difficult. However, one participant who often exhibited memory loss and loud outbursts had the most creative mind when answering questions or doing activities. In one instance, Fred Astaire had pulled out the word 'record sound' and glued it onto his paper when he could not think of how to draw the word (see figure 5.9).

People with Dementia
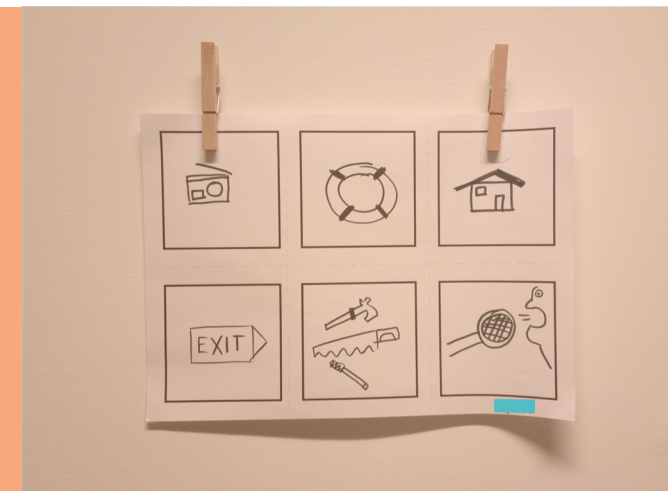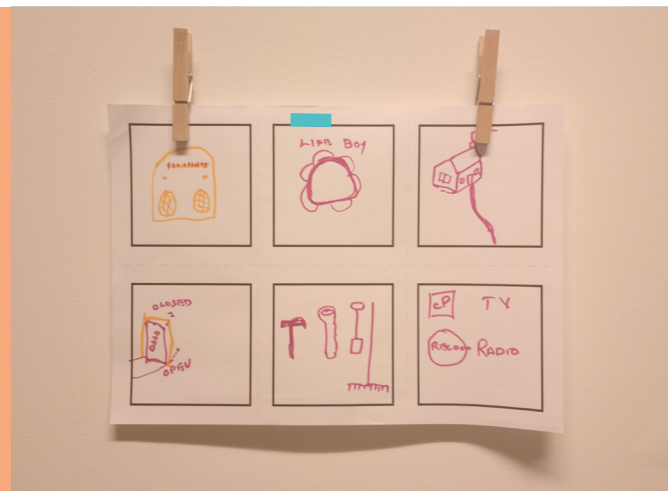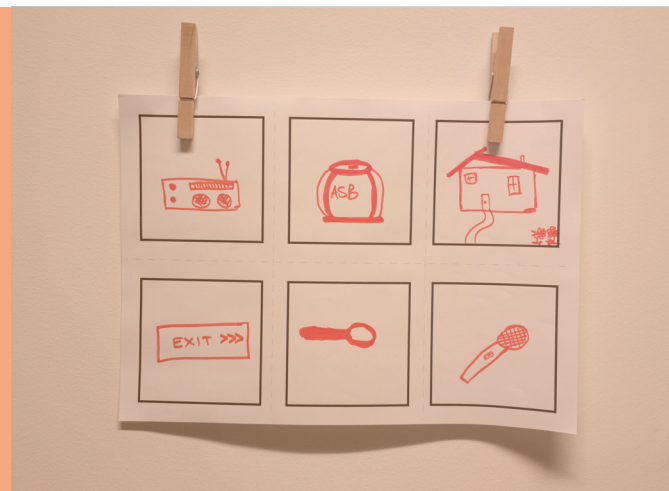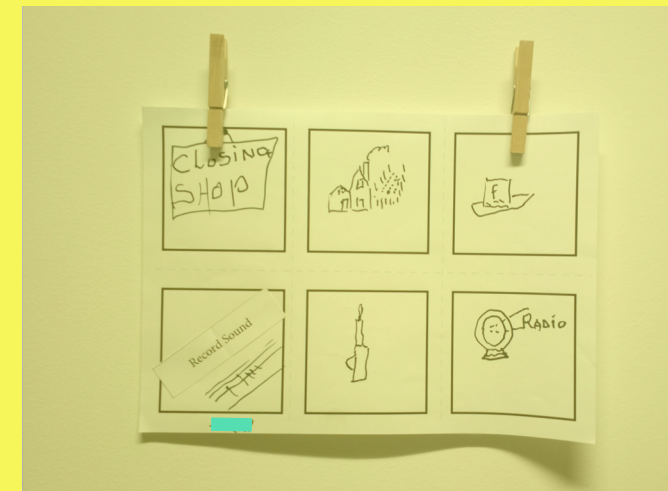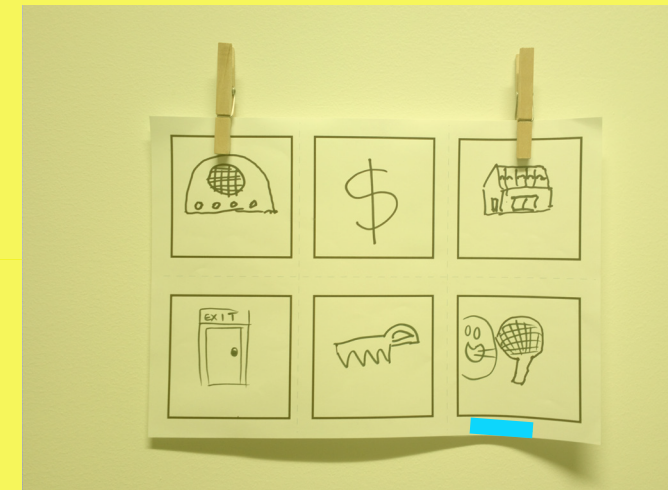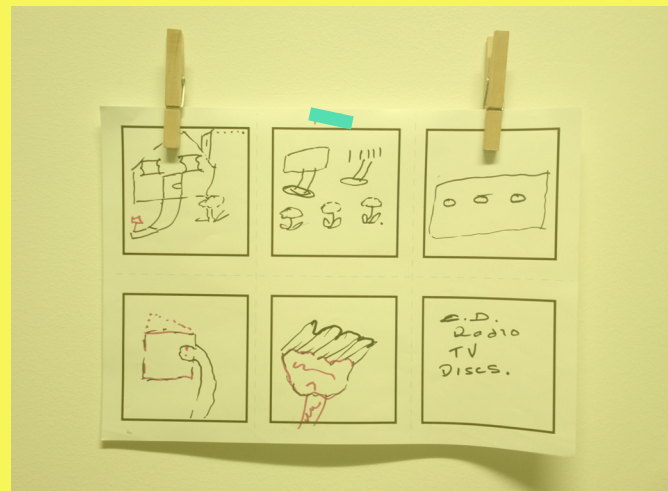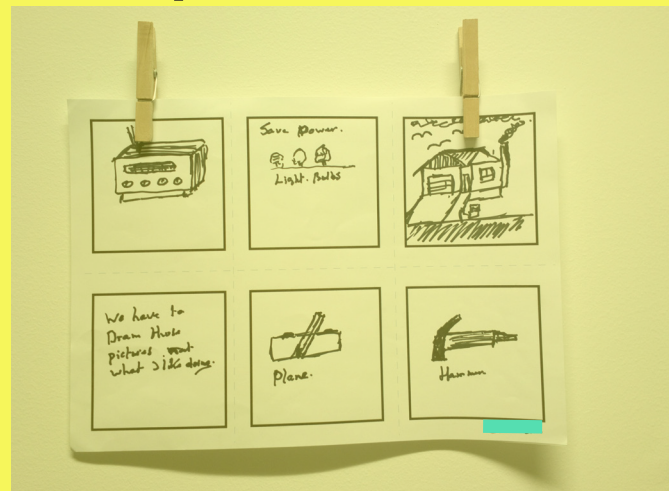
Carers

This is one of the results of the co-design workshop where people with dementia were asked to draw out jargon used within technology such as 'home', 'save', and ' close'.

Above are the images that people with dementia drew and below are the images that their family carer drew.

Carers were very supportive of people with dementia who sometimes had difficulty creating a visual image for a word. You can see a similarity between objects within each participant pair, as well as within the group. This was because people shared their ideas as a group for words that were difficult.

The output of the activity did not result in icons that could be used directly within the tablet computer application as intended. However, it suggested that the images needed to be more literal than abstract.

The activity also identified those with dementia that enjoyed visual thinking and enjoyed expressing themselves in this format. It also identified those who did not.

It was impressive to see the drawing ability of people with dementia who we may have assumed incapable of drawing. In a more supportive environment with no time constraint, this technique may have potential for people with dementia to contribute to the final design with sketches.

Carers

During this collage activity the contrast in the care style of the carers became more apparent. Rita's Husband performed a supportive role with Rita Hayworth who both shared the cutting of objects and consulted on decisions. Cary's Daughter and Fred and Ginger's Son dictated instructions to their loved ones by placing materials in front of them and telling them what to do. This is likely due to the carers being the children of the person with dementia unlike Rita's carer, who is her husband.

Facilitating

Placing all the materials in the centre of the table was ineffective. Not all research partners with dementia were physically able to reach the materials that they wanted without reaching uncomfortably or leaving their chair. This meant that they only used tools and resources closet to them, which were often selected by their carer. Consequently, the carer influence the outcome of the drawing.

When faced with a blank page, asking people to draw something was difficult even for cognitively able people. Providing examples and suggestions helped guide the co-design workshop but did not enable research partners to get over the initial hurdle of starting. Carers were highly supportive in enabling research partners with dementia to start to create something by suggesting the kinds of things that they could create.

Future Improvements

People with dementia pleasantly remarked upon the colours and patterns of the coloured paper. To improve the selection of colours and patterns, a different variety of textures should be included in the toolkit as people with dementia enjoyed the thin texture of the origami paper. This would be particularly useful when using the toolkit to design tactile products.

Alternative activities may be required in each workshop for research partners who do not wish to take part in the particular activity. Potentially they may prefer to assist others, make their own interpretations of others works, or take notes for the researcher. The activity that they choose to do will depend on their personality and what they would prefer doing.

Drawing abstracted icons from words should not be conducted in the way that it was within this design workshop. People with dementia should not feel rushed or examined during the workshop. A matching words and images activity, to find out which images they associate with which words, may be better suited to the abilities of research partners with dementia. It was commented that they knew what they wanted to draw, but did not have the skill.

WORKSHOP 6: PROTOTYPE TESTING

Figure 5.10 First blog prototype made in Wordpress

Figure 5.11 Card sorting
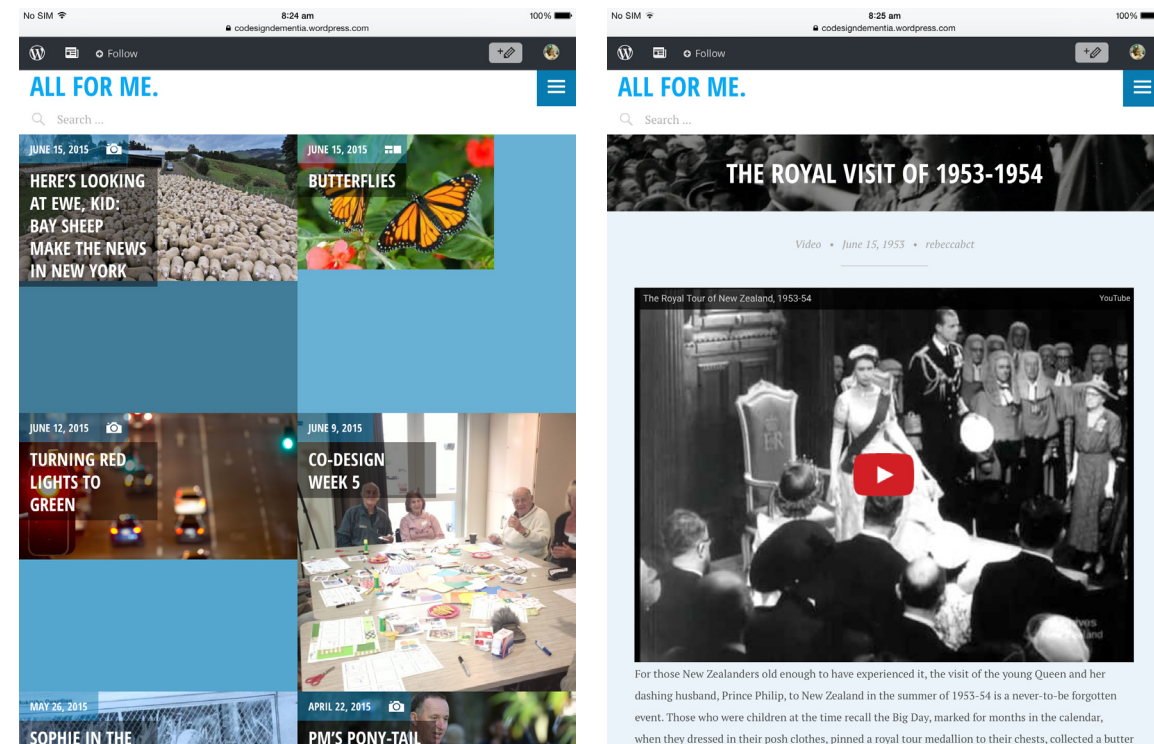
Co-design

In the final workshop, it was hoped that research partners would be able to draw their own application screen with their carer. However, due to difficulties in the previous co-design workshop, it was decided that this would be too stressful for research partners and not productive. Research partners were then presented with a web based prototype built from a blog template to see whether it addressed their needs and should be developed further (figure 5.10). The workshop ended with a simple task of arranging words

that were meaningful to research partners into categories that made sense to them. This would form the basis to structure different categories of their lives in the blog.

The week six workshop was originally intended to provide an opportunity for the research partners to design the application itself. Instead, the workshop began by presenting research partners with a blog template on the tablet computer that was filled with content representing the values the research partners had identified throughout the co-design experience. Two tablet computers
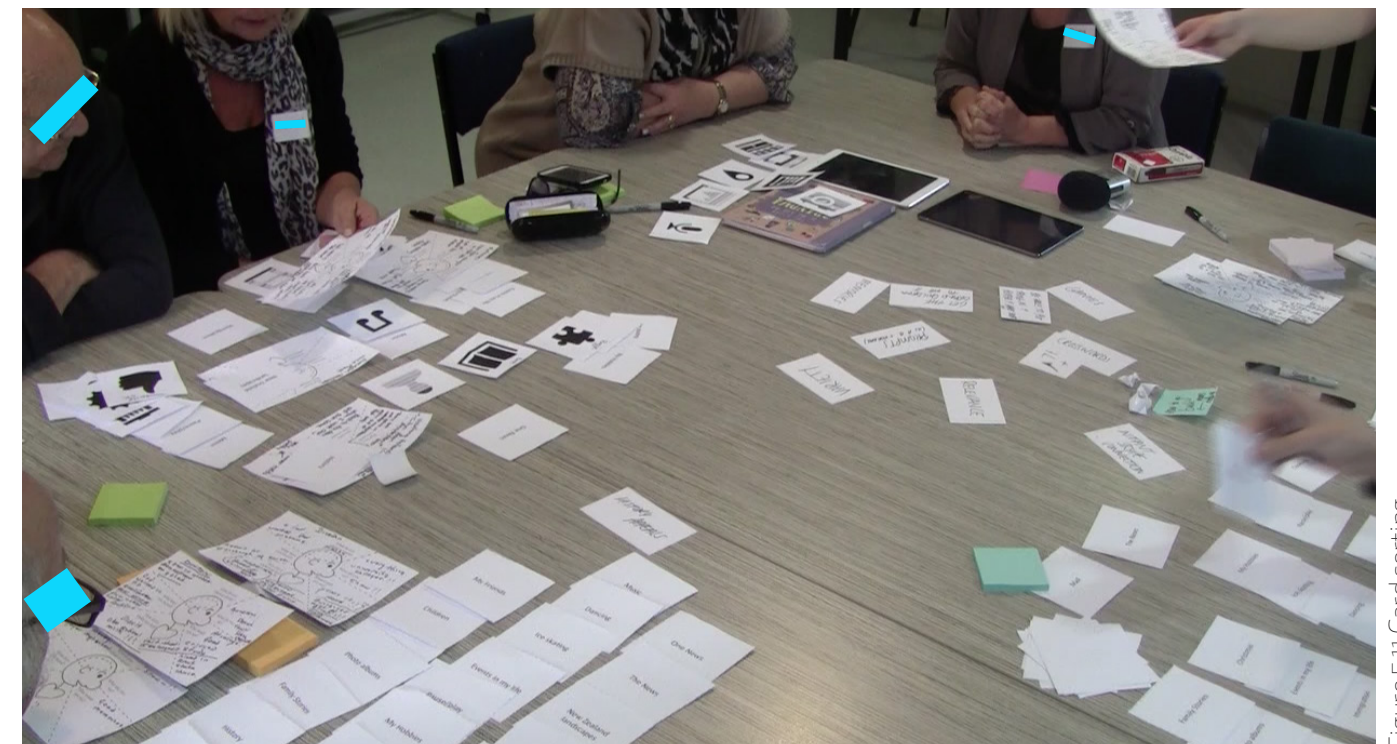
were passed around that showcased the current co-design prototype. Research partners were immediately more responsive when interacting with the tablet computer. This was potentially due to the familiar user interface of touch and its book like form. In contrast, a laptop or a computer has a different user interface system with a keyboard, track pad or a mouse with a potentially harder learning curve. However, this theory was not explored.

The workshop was continued by informally asking research partners what they liked or disliked

about the prototype. Feedback was positive around the content, with research partners expressing how it was relevant to their age and allowed them to reflect back upon their memories. As the content of the prototype was video, music, images, and news articles that were directly relevant to (and chosen by) the research partners from the previous workshops, it helped research partners with dementia to become engaged with it.

For the final activity in the last co design workshop, research partners were given words

Figure 5.12 Identifying icons
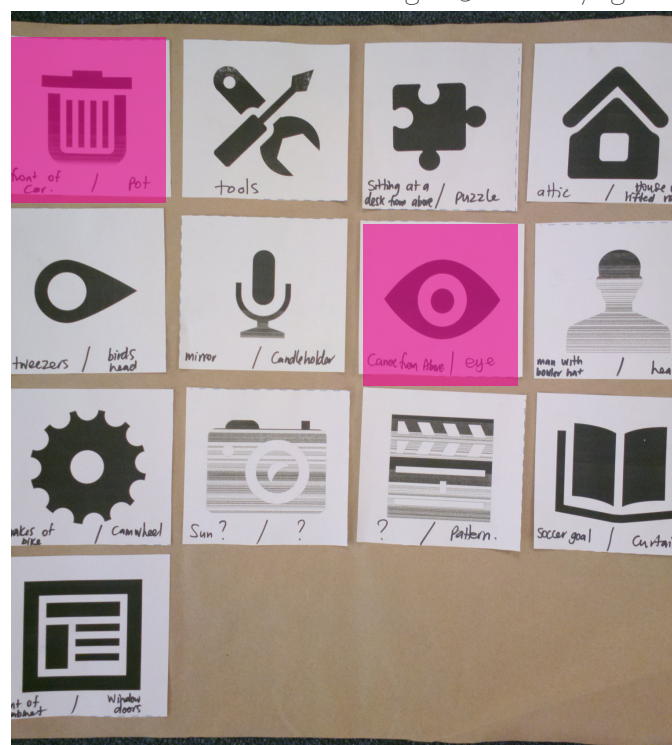
and images based upon topics of their interest, to organise into thematic groups. These thematic groups later guided the arrangement of pages in the prototypes that were developed following the co-design workshops. Each research pair was asked to complete the task together, and to share the results with each other.

Carers heavily influenced the placement of the words and images into the thematic categories. For the final activity of the workshop, research partners were lastly given the look, see, hear, and feel templates that they developed in the second co-design workshop to add to their categories.

Despite the lack of interest from research partners to sort cards, they were engaged throughout the process and were able to fit their memories into the categories they had created (figure 5.11).

Icons were difficult for the research pairs to place and often resulted in a image pile of their own. This was because they either did not recognise the icon, or they did not know what the icon meant. For example, Fred Astaire recognised the image of a rubbish tin as the front grill of a car, and the eye symbol for 'seen' as a man in a canoe (Figure 5.12). Carers began writing down what people with dementia recognised the icons as instead of categorising them.

People with dementia

Throughout the research workshops, Fred Astaire had been very vocal with frequent outbursts of conversation that tended not to relate to any topic of conversation currently discussed. It was easy to dismiss these occasions, as they did not seem to make sense at the time. However, these moments may need further consideration to see if there is an underlying truth.

For example, while the researcher was explaining the blog template, Fred stated:

Fred Astaire: "The acoustic this [sic] in this room is wicked."

(His son laughs and tries to hush him)
Researcher: "Can you not hear me?"
Fred Astaire: "Yeah, it's wicked. Even if you are talking clear, I have to look very well for what you're saying."

Using images that related directly back to the person with dementia was immediately stimulating and interesting. While using the tablet computer, Rita Hayworth took immediate interest in a photograph with her and Rita's husband in it. Her exploration of the tablet computer involved her touching it to try make it larger so she could show her husband. Similarly, Fred Astaire chose to view a video of the Berlin Wall and appeared to be enjoying watching and commenting on it.

Each person with dementia was engaging with different elements of the tablet computer. Rita Hayworth preferred to look at the pictures and started talking enthusiastically to her husband. Fred Astaire appeared to enjoy watching videos play and proclaimed memories to the group as he recalled them. Cary Grant quietly withdrew into the tablet reading the available news articles, and then explored what else the tablet could do.

For people with dementia, it seemed the prototype was seen as a tool to prompt discussions with others.

[What would you like the tablet to do?]
Rita Hayworth: "Add conversation?"
Researcher: "Conversation. How conversation? Would you like to be able to use it to converse with someone or would you…"
Rita Hayworth: "Discuss. Yeah discuss… Discussions are good."

The prototype blog was not solving a problem, rather it was seen by people with dementia as a tool to facilitate conversations. It was considered by the carers as useful for people with dementia and their grandchildren to communicate on common interests, particularly past events which are easier for people with dementia to recall, and may be of interest to younger generations.

Rita's Husband: "… they could remember the old things from the 40s 50s 60s. But going to the modern things, it it [sic] just doesn't seem to be the same appeal to a person with you know … um … Alzheimer's."
Rita Hayworth: "Yeah, that's quite true actually. What happened last week isn't the same as what happened a few years ago."

The research partners with dementia did not realise or remember how they had contributed to get to this point of the design process, or perhaps did not understand how the previous workshops resulted in this tablet computer application prototype.

> Rita Hayworth: "You're a clever girl."
> Researcher: "Thank you, but you're clever too. You guys help me make this. I wouldn't have known what to put in or … what you guys were looking for."
> Rita Hayworth: "so you did some research?"
> Researcher: "You helped me. You did."
> Rita Hayworth: "Did I?"
> Researcher: "Yeah, for the past five weeks. You've been telling me what you want."

This creates a unique situation where research partners are unable to remember their contribution to the design, and are therefore more similar to user testers than co-designers. Consequently, they are able to give unbiased feedback on a design towards validating its effectiveness with people affected by dementia.

Carers

While people with dementia interacted with the tablet computer, the carers played a large role in supporting them. Rita's husband, although having never used a tablet computer device before, was quick to understand how to use it and supported Rita Hayworth in her exploration.

Cary's daughter believed that the tablet computer was too difficult for people with dementia, as they were not used to the technology. She suggested that tablet computers would be fantastic for those in the future who are more used to devices such as these. Her interest in the tablet computer appeared to be a way for her to entertain her father, and take a break from the full time care he required. However, this was different to what people with dementia expected from the tablet computer. People with dementia saw the tablet computer as a tool to think and talk with their grandchildren or others. Surprisingly, Cary Grant was very inquisitive and spent considerable time using and exploring the tablet computer when left alone. When Cary's daughter supported him using

the tablet, Cary Grant let her take full control. During the card sorting activity, carers were very dominant and temporarily forgot that the exercise was for the person with dementia to complete. For example, Cary's daughter enquired to the researcher if one of the cards went 'anywhere'. She was reminded to ask Cary Grant. However, for the most part, carers frequently asked where their partner would like to have placed the word or image.

Facilitating

When experimenting with the prototype, all of the research partners needed assistance using the tablet computer from time to time. The most common request was to 'go back' to where they were previously. In some cases it was beneficial to take them 'back' instead of describing how to, particularly when using gestures. However, they were quick to learn once shown how to 'go back', after being shown or instructed where to press on the screen. From this experience it is probable that demonstrating an interaction, and asking them to repeat the steps would be beneficial.

Future Improvements

When handing out materials to the research partners, the materials should be given directly to the people with dementia instead of the carer. This would encourage the person with dementia to physically complete and participate in the task. This may also have the benefit of minimising the carers influence in the activity. However, the carer was valuable to the research process and data collection as they were able to clarify or suggest why a person with dementia placed a particular word or image in a category. This would be unachievable by the researcher when facilitating such a large group by themselves.

When sorting cards, people with dementia and their spouses found it difficult to understand what icons meant in the context of a tablet computer. Using literal images may be easier for people with dementia to understand the use behind them.

REFLECT

Co-designing with people affected by dementia was a challenge to both the research partners and the researcher due to their inexperience with design and the co-design process. As the workshops progressed, both the researcher and research partners improved in the facilitation and participation of the co-design workshops. The researcher learnt how to effectively interact with people affected by dementia (such as including names in questions) as well as how to modify co-design techniques so that people with dementia can contribute easily (such as rewording categories into questions). Similarly, research partners learnt how to express their opinions and ideas on a topic as well as specific responses that would help the research design.

Despite initial hesitation by the carers to turn up to all six consecutive co-design workshops, only one research partner pair missed a workshop. Their continuous support throughout the co-design weeks emphasises the importance that this research meant to the research partners. It also suggests that co-design was enjoyable to research partners, including people living with dementia who that may not have understood or remembered what they had contributed in the workshops.

Cary's Daughter: "I enjoyed watching everybody interact and get into it."

Rita Hayworth: "Thank you so much. You have no idea how much I want to thank you."

However, it was difficult for research partners to make it to every co-design workshop, and was suggested by carers to conducted the workshops fortnightly to reduce their workload. This should be taken into consideration for future research activities over an extended period of time. This may not be an issue for people with dementia in rest care facilities.

Prior to conducting the workshops the researcher speculated, based on previous interactions and observations with people affected by dementia, which research partners might find the activities difficult, and which research partners might be able to provide valuable information. For example, Rita Hayworth was a participant who appeared heavily dependent on her husband and showed signs of short-term memory difficulties. Consequently, she was expected by the researcher to be less capable of contributing to the co-design workshops. Surprisingly, with and without the support of her husband, Rita was able to voice clever opinions and insightful comments about her experiences with dementia. With all the research partners with dementia, the researcher consistently underestimated how much they could contribute, and they occasionally surprised their carers.

Underestimating people with dementia may be due to the inexperience of the researcher in working with people affected by dementia, but it may also reflect the societal expectation of people with dementia and older adults.

Figure 5.13 Co-design guidebook
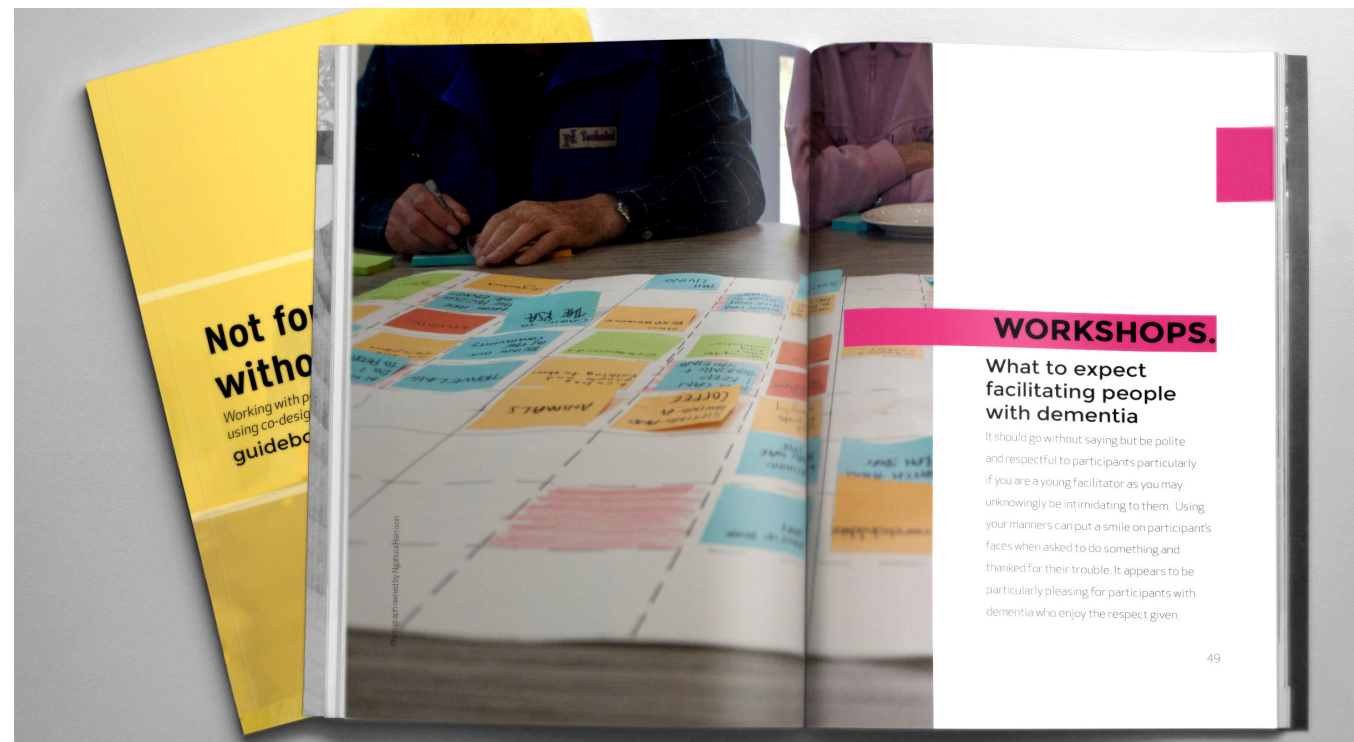
A guidebook was created documenting the experience of recruiting people with dementia and developing the workshop (figure 5.13). It is intended to be a valuable guide for designers or researchers to obtain ethical approval, consent from people with dementia, and plan of the co-design workshops.

It is encouraged that users of the guidebook write their own notes in the thick margins or between the lines as they learn as no co-design workshop will be the same.

This guidebook may be of use to designers interested in co-design or dementia, as well as cognitive stimulation therapists looking for different stimulation activities.

It is important to note that the guidebook does not cover analysing qualitative data in detail as there are many wonderful books already available. However, it briefly mentions how difficult it is to get people with dementia to analyse their own work and makes suggestions on how to make it easier and what to expect.

CYCLE 4:
6| Validating design

This cycle describes the development of a computer tablet application based on the brief created by the co-design workshops and how it was user tested with people affected by dementia. The concept was prototyped and tested on a computer tablet weekly for five weeks in one-on-one interviews. Research partners identified what they would change, add, keep, or remove to each of the prototypes. However, it was identified that what was on the tablet was of more interest to people with dementia that evaluating the tablet computer application. More importantly, it was identified that what people with dementia want to use a tablet for already exists; they are just not able to access it easily.

PLAN

This cycle aimed to develop a prototype based on the brief developed from the co-design workshops; to enable people with dementia to 'think' and 'talk'. These user testings were conducted with only one person with dementia and their informal carer. There were five user testings with two scheduled each month for three months. Two cameras were set up in the room. One camera was positioned in front of the people with dementia to capture their visual reaction, and another camera was positioned behind and above them to capture what they were seeing on the tablet screen. Both recordings were reviewed simultaneously side by side when analysing.

To help people with dementia and their carer give valuable feedback on the design, a template was created that asked four simple questions: 'What would you add?', 'What would you keep?' 'What would you remove?', and 'What would you change?'. Within each category was space for post-it notes to be added.

Reviewing the data collected from the co-design workshops helped quickly sketching concept ideas. Low fidelity prototypes were made using paper. High fidelity prototypes were generated using software such as Sketch3 and Flinto. People with dementia and their carer then reviewed the prototypes and provided feedback to be iteratively incorporated into the subsequent user test.
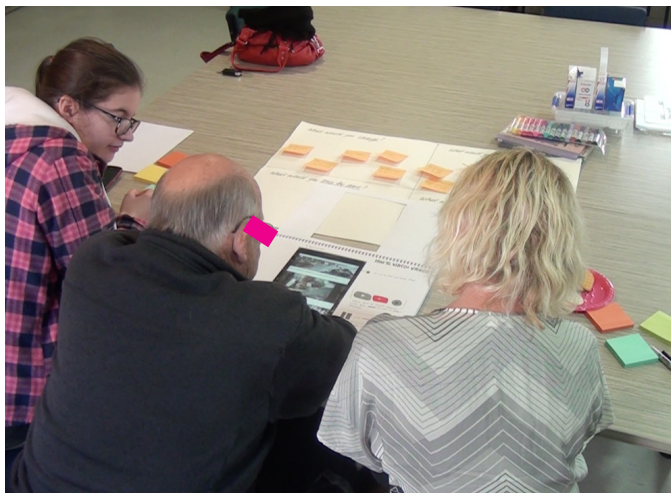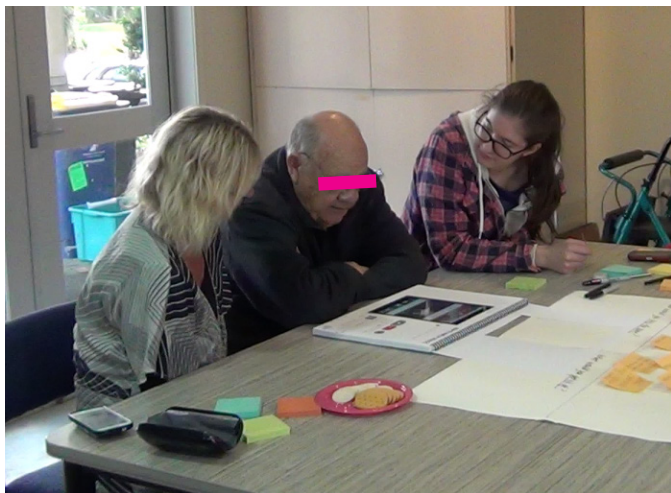
ACT
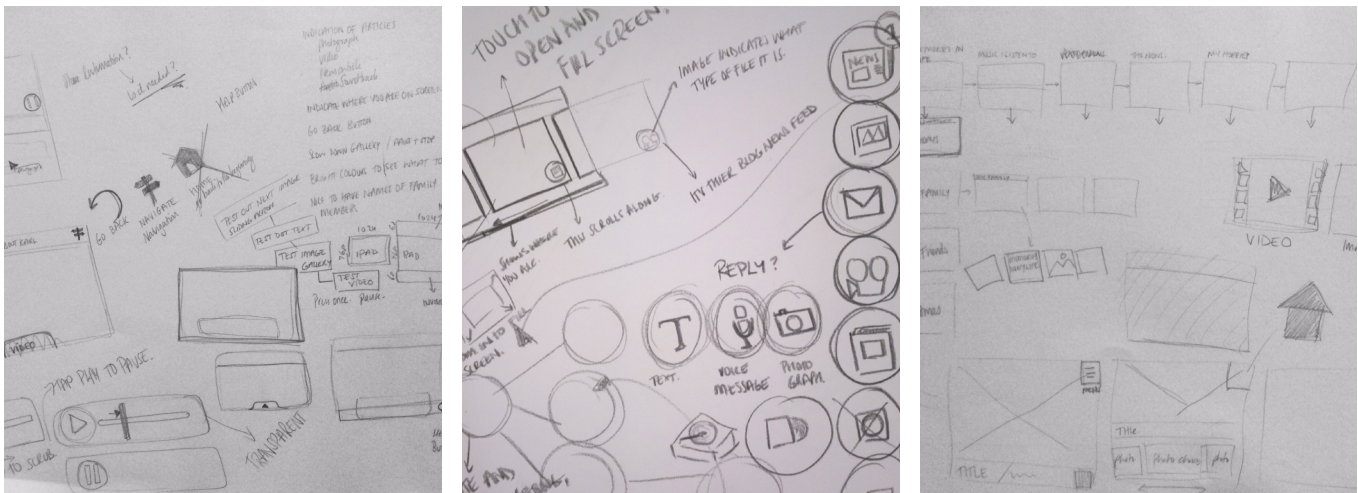
Concepts are initially sketched based on the insights learnt from the co-design workshops. People with dementia wished to have something that enabled them to 'think' and 'talk' particularly with their grandchildren. The sketches were intended to be created in the final co-design workshop with people affected by dementia. However, after the arts and crafts co-design workshop, it was deemed too difficult and stressful for people with dementia and their carers. Focus was upon quantity of the sketches, not on refinement.

Specific ideas were developed on iPad templates to become low fidelity prototypes (figure 6.1). These were used to prototype the interaction between each of the pages. People with dementia did not see these prototypes as they were considered too abstract for people with dementia to give feedback on.
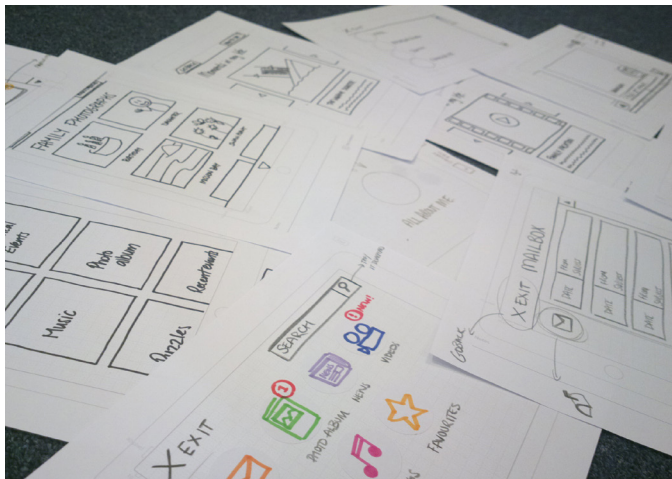
Figure 6.1 Low fidelity prototype sketches

Figure 6.2 Navigation themes
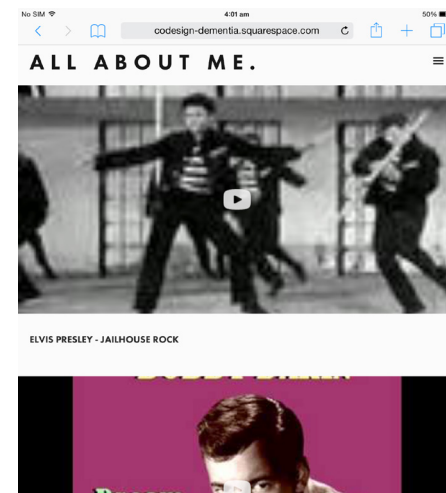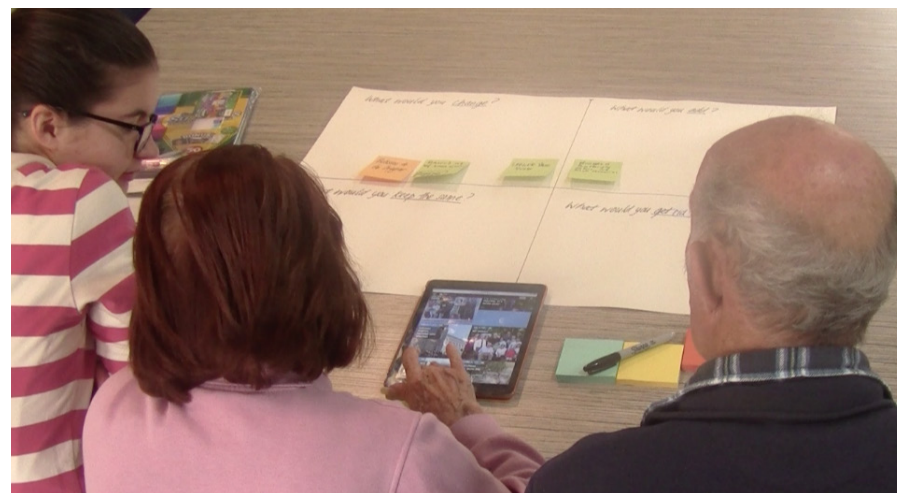
People with dementia and their carers responded to the concept of a tablet computer application that contained images, videos, music, and news reports. Taking inspiration from products familiar to people with dementia, a newsfeed concept emerged similar to Facebook where family of people with dementia could select articles of interest to their loved one and place them in the newsreel. Often within technology, such software already exists to rapidly prototype the concept with. Consequently, a blog template was decided to be most suited to testing such a concept.

Despite receiving an encouraging response from people with dementia in the co-design workshop, the Wordpress blog was too difficult for people with dementia to use. Font size and icons were too small to see, no indication of where to 'scroll', unexpected interactions with videos and images, and difficulties going 'back' were common issues. Due to the limitations of the Wordpress blog in making changes to the blog, SquareSpace was used in a subsequent user test. SquareSpace gave more control and focused heavily on large images. People with dementia found it easier to see and read although there were still difficulties going 'back'. This was because the 'back' button was in the web browser, which also had other confusing and intimidating icons.

Due to the variety of content within the tablet computer application, the researcher used the card sorting information that was captured in the co-design workshops to create a navigation system created by people with dementia (figure 6.2). Despite each partner pair creating their own, the grouping of categories was relatively similar to each other.

People with dementia were not able to place icons into categories with the icons often reverting to a pile by themselves. This is due to the icons not having value or being understood by the person with dementia. Consequently, icons used in future design needed to be accompanied by words. However, people with dementia did seem to recall the location of buttons particularly where to press to go 'back'.

OBSERVE
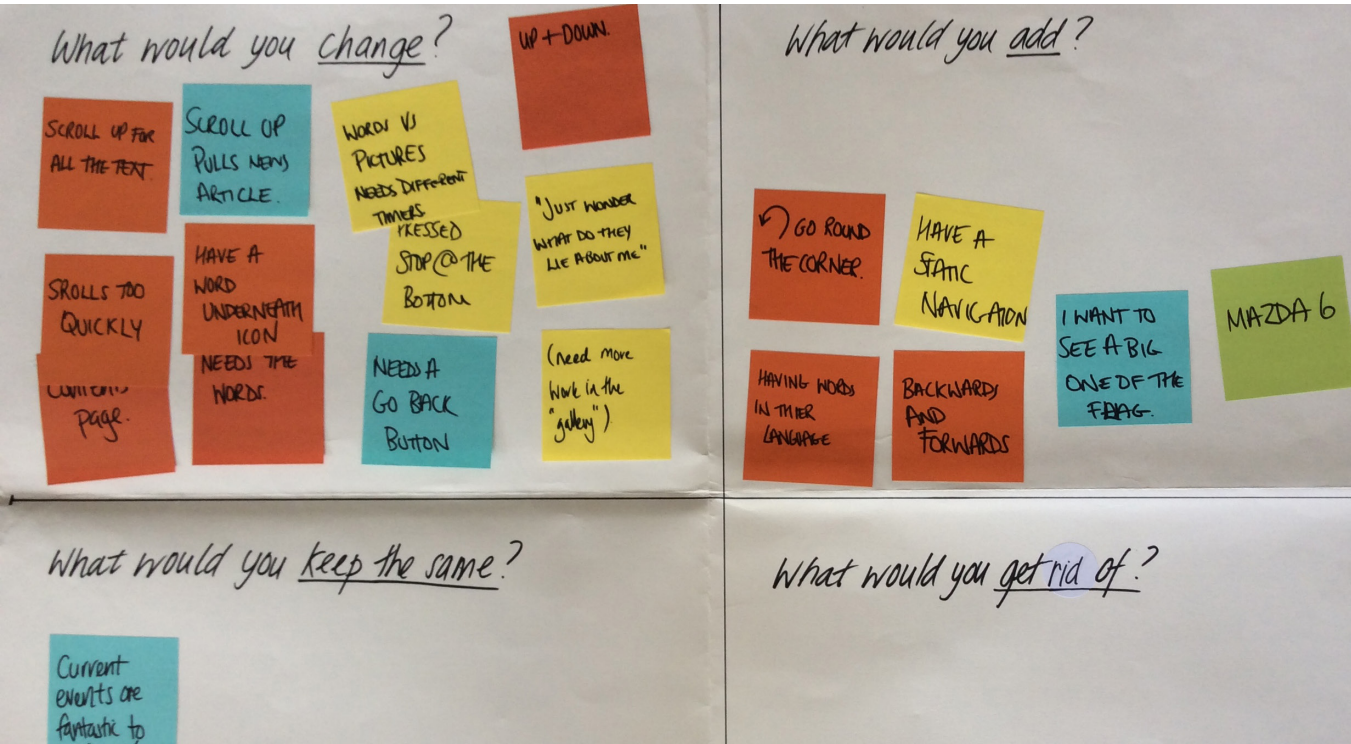
The template used in the user testing was effective at structuring the thoughts of the research partners to provide constructive feedback (figure 6.3). Carers were able to generate more ideas and feedback upon what they would like added or changed to the design. People with dementia were capable of giving feedback on what they were currently using but appeared to have difficulty generating new ideas.

People with dementia were invaluable when gathering information around improving the usability of the design. Observing their interaction with the tablet computer provided a wealth of information, which was captured and written down by the researcher.
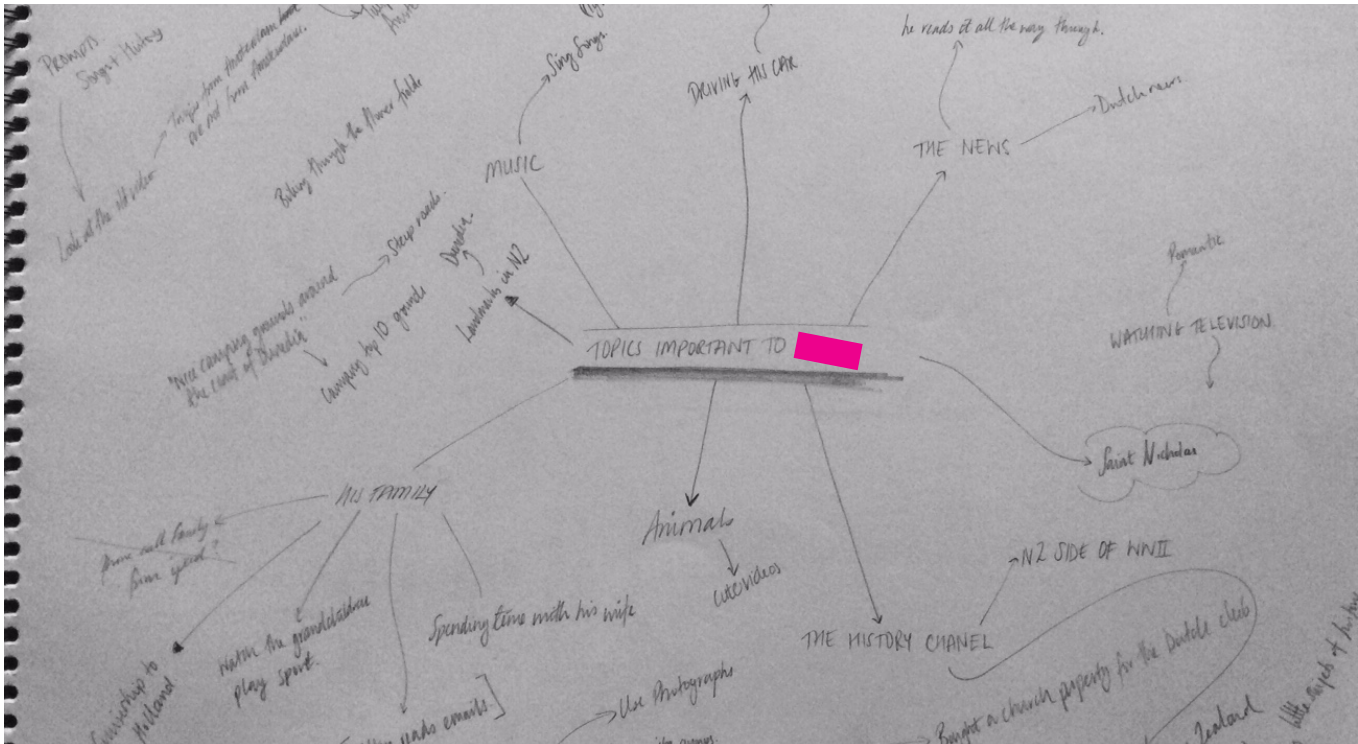
It was observed that people with dementia touched images that had significance to them directly more readily than those that did not. For example, Rita Hayworth was instantly drawn to images of butterflies and always returned to open a gallery of butterflies despite having previously closed it. Additional research was obtained about the research partner individuals were collected from the co-design workshops about their interests to use as content within the prototype (figure 6.4). Using relevant content to the users testing encouraged their exploration of the prototype.

My Memories / Saint Nicholas

Figure 6.5 Sketches of instruction book
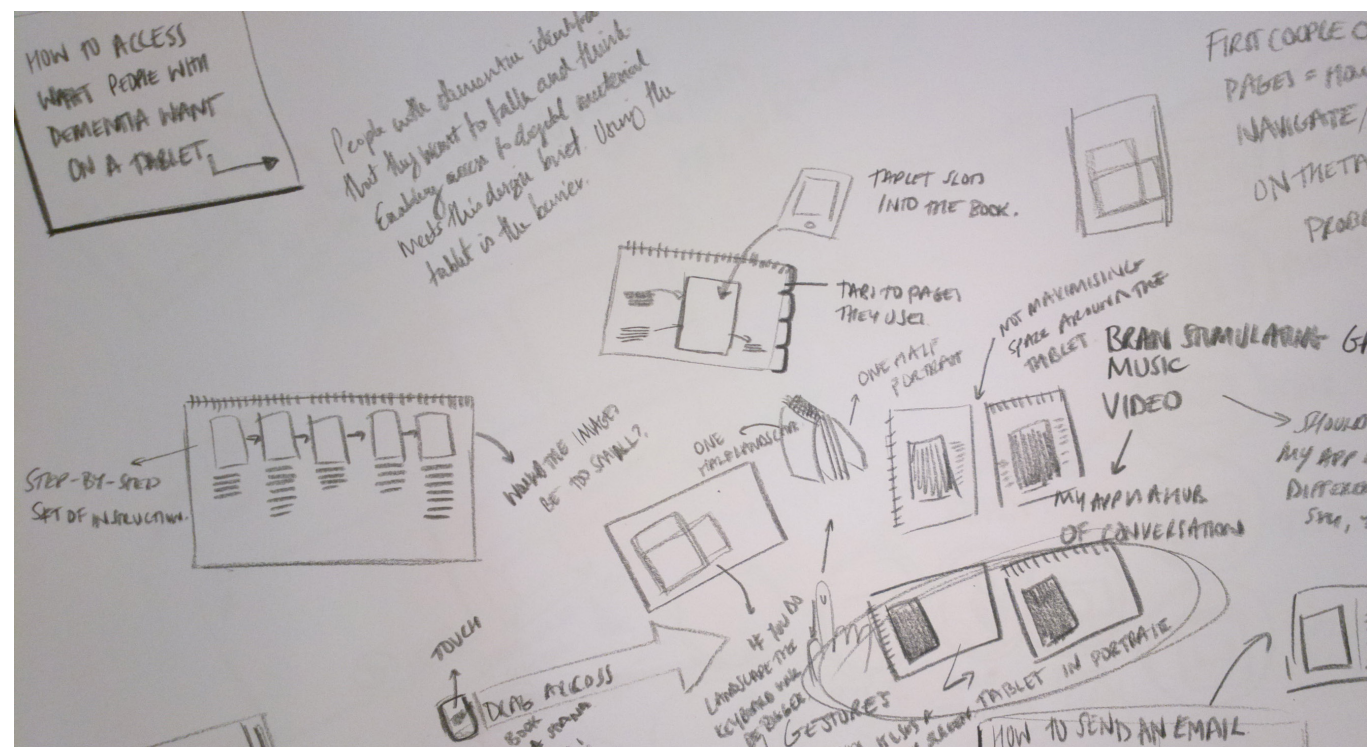
The suggestions and feedback from the research partners on the prototypes presented were often already met by another tablet computer application. For example, it was suggested that music continuously played in the background, which is already possible using iTunes or other music applications. However, this suggestion led to the development of a book that could be used with the table to instruct how to use the tablet computer application. A tablet-sized rectangle of the book was removed so that the tablet could slot into the centre of the book and become an interactive screen. Step-by-step instructions surround the tablet with arrows pointing to the location of the icon (figure 6.5).
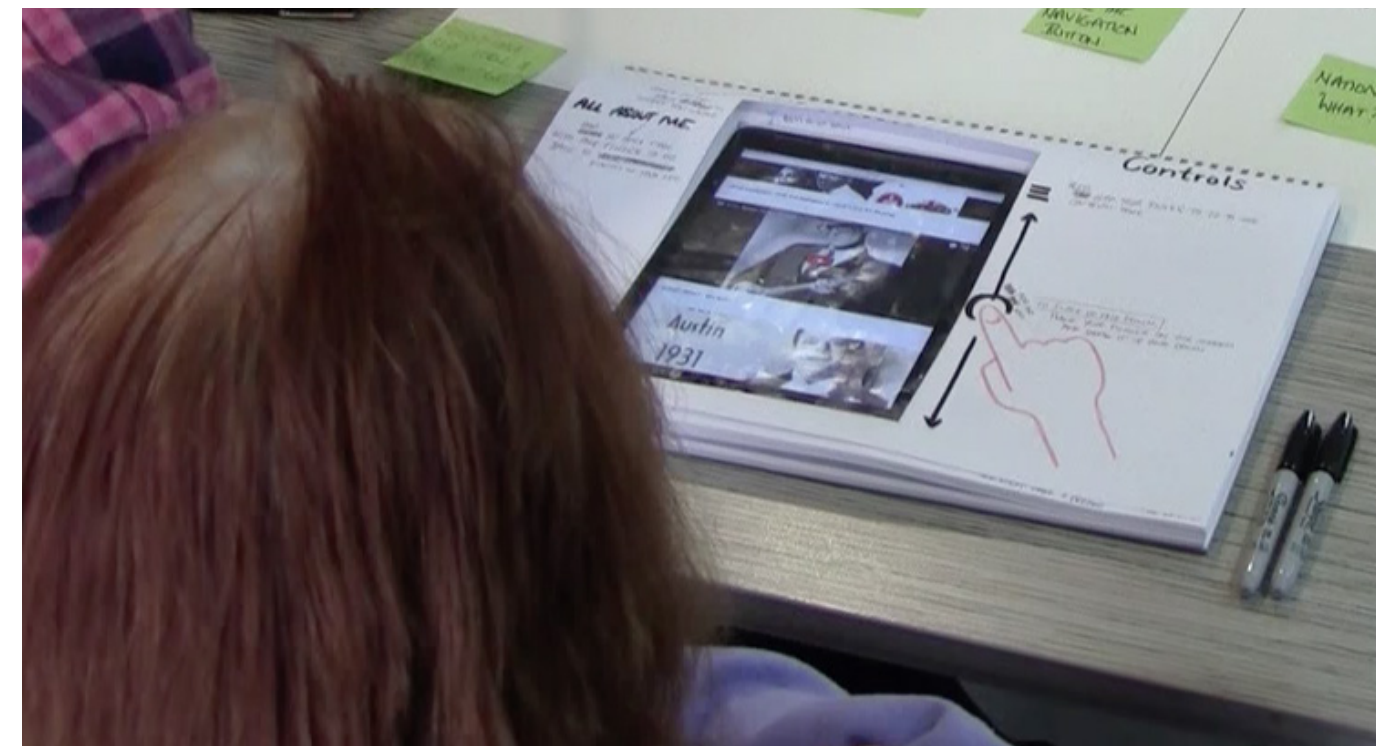
There was an excited response to the development of the book as people with dementia were less reliant on their carer. People with dementia may have felt empowered because it allowed them to be independent and manipulate the tablet computer into playing videos, songs, or gallery slide shows.

Inserting the tablet computer in portrait made it difficult to use the book when the tablet is in landscape mode. This is because where the cut out was made, was not in the optimal space. Prototypes were made so the tablet computer could be inserted in either direction, but it also reduced valuable space to write instructions.

The book was kept hand drawn to encourage people with dementia to make their own adjustments to the book. However, only the researcher made the adjustments as people with dementia and their carers did not seem inclined to do so.

When writing instructions, the instructions had to occur in a linear order as it was difficult for people with dementia to keep track of the current instruction and the next one (figure 6.6).

Figure 6.6
Rearranging instructions on page

REFLECT

User testing with people affected by dementia was informative and enjoyable for both the researcher and the research partners. It was also an honest method of receiving feedback on the usability of a design, as people with dementia were often unable to recall the previous prototype. However, compared to the co-design workshops, there was insufficient experience and planning for the user testing of the prototypes with people affected by dementia.

Despite this, there were valuable insights in how to improve this process:

- It was assumed that one week would be sufficient to develop the prototype. However, it was incredibly difficult to create such a high fidelity prototype within that time frame
- Prototypes presented to people with dementia needed to be of high fidelity so that they could give accurate feedback. It is inaccurate to assume that people with dementia are imagining the interaction the same way as the researcher, particularly when such skills are difficult for people without dementia

- People with dementia did not engage with the prototype unless the content within the prototype related to them directly. For example, an image titled 'my family' was not appealing to the research partners as it was not their family. In contrast, a slideshow of monarch butterflies was engaging for one research partner as the monarch butterflies were of personal significance to them
- Carers were effective at identifying improvements to be made to the prototype. However, this was based upon what they would like for the prototype and not necessarily for the person with dementia
- People with dementia were relatively quick to understand how to use the tablet computer and even remembered the location of key buttons despite the button no longer being there
- Development is needed to identify the effectiveness of gestures. One person with dementia struggled to grasp the concept of dragging a finger along the screen to make the screen move. Another understood the concept of gestures but was not aware that the gesture worked everywhere on the screen
- People with dementia interacted with the tablet computer but may have enjoyed more the opportunity to interact with the researcher rather than test the prototype

The results from the user testing established that the blog concept prototype would be useful for people with dementia and their carers with one pair asking if it was already available for purchase. However, the user testing identified that the content within the tablet computer was more important to people with dementia than the prototype.

There were tablet computer applications that would already meet the needs of people with dementia if they were able to access it. Consequently, a book was designed to instruct people with dementia, and their carer, on how to use the computer tablet application using the tablet computer application developed as a prototype. It was envisioned that the book could be downloaded, printed, and cut to provide access to many. It may also assist those with other cognitive impairments, and other older adults.

7| DISCUSSION.

This discussion builds up and expands questions that emerged during the research process - from gaining ethical approval, designing the co-design toolkit, conducting co-design with people affected by dementia, and the design and user testing of a concept.

Balance between research and ethical principles

The feasibility of co-design with people affected by dementia is limited by the accessibility to people living with dementia. Both the ethics committee and care homes enabled the researcher to conduct research with people living with dementia, and protect all involved in the research. In doing this however, they restricted access to potential research partners. Howick Baptist were agreeable towards research being conducted with people living with dementia, and recognised a need for better end of life care. However, they decided that the co-design process was too confusing for them to explain to their residents, and had concerns that residents would not understand it. Consequently, the care facility made the decision whether a person with dementia is capable of participating or contributing to the research instead of a person with dementia. This scenario is not unique to dementia all and is common to research involving participants (Oliver, 2010).

Neither the secretary of the ethics committee, care homes, Alzheimer's Auckland, or the psychogeriatrician were familiar with conducting a study similar to this research. Consequently, each action research cycle used a trial and error process to protect and recruit the appropriate partners. This resulted in a lengthy process to obtain consent and recruit partners. However,

once access to people with dementia and their families was obtained, the co-design process was enjoyable and empowering to partners, who were given the opportunity to voice their views and opinions. Hearing a partner's gratitude for spending time with them, despite the fact they could not recall the exact moments, was personally rewarding (as reported by the research partners).

People with dementia were not considered able to consent to research without a lengthy formal cognitive assessment process undertaken by an expert psychogeriatrician to determine if they were capable of giving consent. Consequently, for a person with dementia to participate in this research, their carer confirmed that the research was in the best interests of the person with dementia, and signed an agreement that the person with dementia would have willingly consented to participate if cognitively able. Despite the fact that the person with dementia was the focus of this research, they were perceived as being unable to participate until proven otherwise. This contradicts the principles of co-design; that everyone's opinion in the co-creative team is of equal worth (Sanders & Stappers, 2014). In addition, this did not align with the values of the researcher, but was necessary for the research to be formally allowed to continue (through the ethical review process).

Insights of people living with dementia

Despite being openly referred to as people with dementia, or having dementia during the workshops, people living with dementia rarely mentioned they had dementia. Instead it was the carers who frequently used the word 'dementia' or 'Alzheimer's'. When defining the persona who was going to represent everyone, not one partner with dementia referred to 'dementia' or symptoms of dementia. This suggests that dementia may be seen to them as a part of who they are, not something that defined them. Potentially, partners may not have been aware that they have dementia or were reluctant to acknowledge it (Morris & Morris, 2010). However, some of their conversations were about the effects of dementia. Alternatively, these symptoms may also be similar to problems other older adults share.

When first undertaking the project to co-design with people affected with dementia it was unknown how people with dementia would react to participating in research and co-design activities. Even family carers, while familiar with their loved ones, were not sure whether the co-design process would be effective. This may be due to the outcomes of the design process being vague, or how it was described to them. However, there is evidence to suggest that we do not know what people with dementia are capable of doing and do not provide opportunities to let them try

and focus on what they are still able to do (Morris & Morris, 2010). Participants within the research identified this during the co-design workshops.

People with dementia in this study have proven that they are capable of expressing their identity and values. However, the values and ideas they expressed came from concrete thinking as they responded to the prompts or prototypes placed in front of them. Partners with dementia often responded to what they saw directly in the images. Only one partner with dementia gave an abstracted answer to an image. This affects the co-design process as activities described within co-design are developed for those cognitively able in mind (Niels Hendriks, Huybrechts, Wilkinson, & Slegers, 2014).

A recurring theme from partners with dementia was their need to communicate or spend time with others. This had the effect of making them feel good as well as engaging their brain. The people they most wanted to speak to were their grandchildren who they felt did not visit as often they would like. In one workshop, partners with dementia mentioned how they felt they were being unheard and left out of social interactions, such as going to the shop. Ironically, the carers had their own conversations about what would be beneficial for people with dementia over the top of people with dementia. Interestingly, people with dementia, despite having a reputation

for loud outbursts, often did not talk over top of others. However, moments of outbursts did occasionally happen from those that may have been more cognitively impaired.

A co-design process lasting over six weeks was a long time to spend with people who are experiencing a highly personal journey. There are instances where a noticeable decline was observed in some research partners cognitive ability (Hendriks, Truyen, & Duval, 2013). One partner was able to sign their name on the consent form at the beginning of the research, yet struggled later to write as neatly on a post-it note. This decline is normal part of dementia, and over a longer study these moments would be more noticeable.

The role of the carer
The family member is often the voice for people with dementia in that they were able to communicate the needs and wants of a person with dementia because they are familiar to them. Carers were invaluable for restructuring questions to make more sense for a person with dementia, particularly at the beginning of the study. However, it was common for the carer to take control over the conversation or activity . This was not unusual behaviour for people with dementia who were losing their independence, but it interfered with the data collection process when trying to collect data from people with dementia

(Morris & Morris, 2010). Consequently, to reduce this from happening, questions were directed using the names of people with dementia. This indicated to all who the question was directed at. Similarly, giving material to the person with dementia, or within reach of them, may reduce the need for the carer to interfere unless specifically required.

Interestingly, carers had different care styles, which influenced the co-design process. Family carers who were a spouse, were observed to collaborate together with the person affected by dementia in the design activities. The children of people with dementia were observed to be more likely to tell their parent what to do. Consequently, the data collected from partners was not solely from a person with dementia, it was influenced by the care approach from the family carers.

The carer provided details as to the status in the person with dementia's life. Some partners with dementia may not have remembered the researcher each week, but by observing how their trusted carer responded to them, they picked up clues as to how to behave. In one instance, the researcher was greeted with a hug by the carer, which may have signalled to the person with dementia that the researcher was an intimate friend. Consequently, the person with dementia spoke more about their personal life during the research. This created an interesting

dynamic between the researcher and person with dementia throughout the study. The researcher felt closer each week to the research partners despite some people with dementia being unable to recall details about the researcher. This may create implications in future research if the person with dementia feels that the researcher is overly friendly, consequently making them feel uncomfortable.

The impact of co-design
The co-design process enables partners to express themselves using techniques that enhance the abilities they still have. Instead of being a process that identified what people with dementia did not know, it explored and discovered information or values that they did know. In understanding the basic limitations people with dementia experience, such as difficulty with abstract thought or anxiousness in being asked to recall a particular instance, the co-design activities could be developed to avoid challenges and enhance the skills they do have. This positively impacted on the partners who were actively engaged in the research and may have created positive behaviours outside of the research by increasing awareness of their remaining abilities and reducing the potential of the person with dementia to be seen as the victim (Swaffer, 2014).

Often people with dementia are restricted unintentionally, by the assumptions of others,

limiting abilities they would otherwise have (Morris & Morris, 2010). However, no one consulted was able to predict how people with dementia would respond to the co-design activities. By participating in the research, carers found out new things about their loved ones. People with dementia appeared to enjoy the opportunity to freely express themselves and did so by engaging in all the activities.

Whether or not co-design is the optimal method to obtain data from people with dementia may be only part of the importance of this research. Co-design enabled an opportunity for the researcher to observe partners with dementia and help develop the researchers tacit knowledge and empathy for this user group (and subsequently improve the user experience of products). It also provided an opportunity for people with dementia and their carers to spend time together, as well as empower people with dementia.

Facilitating co-design
Co-design with people affected by dementia focuses upon enabling maximum participation. Consequently, activities were modified to enable people with dementia to more actively participate. The tools used within the toolkit were specifically chosen for this purpose. At the beginning of each workshop, partners were asked to write their name on name badges with a vivid pen. However, the caps of these pens were

difficult for the partners to remove. Partners did not know whether to pull or twist the pen, even after being shown, because it was too difficult for them to separate the lid from the pen. This initially created a negative atmosphere within the group as the partners who, unable to open the pen, felt belittled. In future workshops, carers assisted them to open the pen, which may have increased the level of ongoing assistance throughout the workshop. All that was needed however, was to pull apart the pen slightly at the beginning of each workshop so that the partners with dementia were able to independently remove the lid from the pen and write their own name.

During the co-design process, partners were encouraged to identify their values, make decisions, and describe what was important to them. Within a typical co-design workshop, the needs would have been analysed and determined by the partners themselves. This task was too difficult for people with dementia to complete independently. They found it difficult to remember information and then to structure it, let along being able to then restructure in a way to be useful for subsequent analysis. Similarly, Hendriks et al. (2013) found that people with dementia had difficulty making decisions, understanding an activity, and staying on task while working. Consequently, the researcher helped identify their needs and confirmed it with partners by asking partners if it mattered to them. This meant that the values of the researcher may have influenced

the data collected. However, during the course of the study, the researcher made their toolkit better, as people with dementia and their carers learnt how to identify some of their values and insights.

People with dementia find it difficult to remember events, particularly those held in their short-term memory. Asking a person with dementia if they remember an event or idea may make them anxious as they could feel quizzed and feel pressured to get the answer correct (Psychogeriatrician, personal communication, December 16, 2014). Therefore, each design workshop had to be completed within itself and not rely on previous workshops, as partners with dementia may have been unable to recall events; not just what they mentioned, but also what occurred in previous workshops (Wu, Richards, & Baecker, 2004). However, it was possible to prompt a specific idea or topic that they had mentioned before, and receive a similar response given previously.

One of the difficulties identified in facilitating the workshops was the power balance between the facilitator and the partners (Oliver, 2010). When positioned at the head of the table, the facilitator was not viewed as an equal within an activity. This meant that the conversations stopped when the facilitator spoke. When the facilitator was positioned within the group, this created a more relaxed atmosphere and enabled effective

collaboration. However, due to the age difference between the facilitator and partners, it became more difficult for the researcher to redirect conversations towards different topics without appearing rude.

A conscious decision was made about the co-design toolkit to be of a do-it-yourself nature. The hope was that it would not intimidate the partners, and following the researcher's lead, they would feel comfortable manipulating the tools. Despite this, partners would initially ask for approval to write on documents in the toolkit. Potentially they may not have if the tools had been more permanent.

Assistive technology for people living with dementia
People with dementia and spouses of similar age, despite being older adults, were able to use the tablet and appeared to enjoy doing so. The tablet provided a simple interface of touch to interact with similar to a book. A computer or a laptop often uses a mouse or a track pad, which first involves learning how to operate it, creating a barrier for people with dementia (Babbage, 2014). Often people with dementia were content to view moving slideshows or videos and did not navigate away from them until suggested. Partners with dementia would explore an application themselves, especially if their carer did not interfere. Patience was required from both the

carer and the researcher to allow partners with dementia to explore the application at their own pace.

Carers wanted people with dementia to be able to use the tablet computer without their input as this gave the carers a break from care. However, people with dementia wanted the tablet computer to act as a tool to help communicate, and liked to discuss content with other people present. This conflict of ideas made the design of a product concept more difficult during the user testing sessions, as the carers did not want to be actively involved and wanted the interaction with the tablet computer to be passed onto someone else (such as their children or grandchildren). This meant that any design solution needed to be simple for people with dementia to engage and use where carers and family members can interact with it at a time or location that suits. A concept solution identified in this research was a simple private family blog, set up by family to post original content for the person with dementia to view and reply to. A prototype of this concept was tested with people with dementia and their carer and received a positive result.

This research identified that what people with dementia want, such as watching old videos, or video calling their family overseas, is already available on the internet. A barrier is instead helping them to understand how to access it or simplifying it. Encasing the tablet in a book that

provided instructions on how to navigate through the applications received positive feedback from partners. Using the two tools, people with dementia and their carers made accessible material that they could then use to communicate with. It is thought that this would be particularly effective to help increase communication between grandparents and grandchildren. It may be interesting to test the tablet computer application concept on those with other cognitive conditions, such as a brain injury or other cognitive impairment.

User testing with people living with dementia

User testing prototypes with people living with dementia was extremely difficult compared to generating ideas. Hendriks et al. (2013) suggests conducting this phase of design with the formal caregivers and not the person with dementia, or their family carer, to improve the effectiveness of the design across a larger audience as well as reduce over analysis on a single comment. Within this research however, it was a concern that the formal carers might redirect the design to better suit their use of the product.

To get a response from a person with dementia, the data in the application needs to relate personally to them (Hendriks et al., 2013). Ethical approval was not obtained to use personal photographs or videos for prototypes therefore stock images were used instead. However,

partners did not wish to view such images if they claimed to be their family, as they knew this was not the case. Data about the user was collected from the co-design workshops and was used to supplement the tablet application. Potentially the co-design workshop could be used as a tool to gather information about a person with dementia to put into the tablet application at the early stages of the application's use. However, this would likely have be done independently by families once the blog was developed.

Low fidelity prototypes are regarded as a way to gain valuable feedback in the early stages of developing a design solution (Bailey, Biehl, Cook, & Metcalf, 2008). However, people with dementia do not have the skills to abstractly imagine how paper prototypes might be realised, and consequently would be unable to respond effectively to the design. Furthermore, they would likely not have understood what was being asked of them. This created a challenge as prototypes of high fidelity take considerable periods of time to develop. Also, if a sophisticated solution is presented, participants might not feel as though they can make suggestions or changes. People with dementia were unable to think creatively about the interface design but were able to make suggestions on the content within. The carers suggested changes to how users might interact with the tablet application, and suggested additional features.

Interestingly, people with dementia did not remember the application from the previous week, but did not altogether forgot how to interact with the tablet computer. This created a unique situation as partners with dementia user testing the application are potentially 'viewing' the device for the first time (repeatedly). However, there is potential for partners to retain knowledge about using the device without their knowledge. This may then be mistaken for improvements in the design.

Method
The co-design process was limited by the experience of the researcher who was not familiar in facilitating or conducting workshops. This was evident in the exploratory research process that the researcher used, although the research question and purpose of the research was not focused towards a specific outcome/design. However, this lack of experience may have unknowingly resulted in a positive impact for people with dementia as there were few preconceived ideas about what people with dementia were able, or unable, to do. Consequently, the toolkits explored multiple methods of interaction, as it was unknown how people with dementia would react to each method or challenge throughout the co-design process.

The co-design process began as a way to help enable people with dementia to design their

own tablet computer application. However, the co-design process may have extended beyond this, and had additional positive effects for the research partners, that were not intended at the initiation of the research. People with dementia were given the opportunity to challenge themselves with design in a supportive environment. Prior to this, it was not known by the researcher, experts, or carers, what people with dementia were capable of doing as co-designers or participants in a research process. This may have positively empowered research partners by influencing their behaviour outside of the research. They were able to better express their capabilities in a society that stigmatises them for what they were unable to do, rather than rewarding them for what they were able to do. The co-design process also built and strengthened relationships between the people with dementia and the carers, as well as the research partners and the researcher. The research became an intimate and personal journey for all involved.

Co-design encouraged all partners included in the workshop to be equal collaborators in the design process (Sanders & Stappers, 2014). However, this turned out to be unrealistic as people with dementia appeared to lack the cognitive ability to creatively imagine a future state or designed solution. Consequently, the researcher often made final decisions on the design process, after having consulted in depth with people affected by dementia. There was also difficultly between

the importance placed on what the person with dementia and the carer said. Often the carer and the person with dementia held different ideas as to where they wished the design direction to go. This is not dissimilar to the parental proxy in qualitative research with children, where parents speak on behalf of their kids, who are actually experts in their own experiences (Hutton, 2005). Consequently, due to the researcher's interest in the opinions of people with dementia, the comments made by people with dementia were usually considered over their carers. It was felt that these opinions best represented the values of people with dementia.

Sample size

To gain access to people with dementia, care homes and Alzheimer's Auckland were approached, and they referred potential partners based on the organisation's assumption of whether a person with dementia is capable of participating, and would want to. This may have restricted the number of people with dementia made aware of the study due to the care organisation making the decision whether a person would be able to contribute.

However, without the support of the care organisation, people with dementia may have been too apathetic to wish to take part due to their symptoms, resulting in fewer numbers of research partners. This was also identified within their research where people with dementia participated as a favour to the researcher or to their carer (Hendriks et al., 2014).

Seven people were recruited for this study, four of whom had mild to moderate dementia. Consequently, the sample in this study may be too small too to be generally indicative of the views of a larger dementia population. However, this was a study that aimed to explore the feasibility of undertaking co-design research with people living with dementia, and to help identify what opportunities and limitations might be associated with this type of design led research. Despite the small number of research partners, the results of the research indicate that co-design is an effective and powerful method to gather research data and build tacit knowledge around the development of products or services for people affected by dementia.

It was observed in this research project that the relationship of the carer to the person with dementia had an impact on their care styles and consequently the carer's influence on the co-design process. Future research may include conducting co-design workshops without the assistance of carers or restricting carers to spouses, children, or friends and comparing the results. The results of the workshops may also be impacted by the residential circumstances of the people with dementia as suggested by Salomon (2014): those out of residential care would prefer products or services that assist their independence, whereas people with dementia within residential care would prefer communication tools.

A more effective process is needed to include people with dementia in the user testing phase. It is difficult for cognitively able people to envision the end result of a prototype and give constructive feedback, and even more so for those with cognitive disabilities. Consequently, digital prototypes needed a higher level of fidelity for people with dementia. This took time and made it more difficult to make changes during analysis. However, people with dementia should be included in this process as much as possible. Firstly, because it may encourage their use of the end result, secondly the designer will gain a tacit understanding of the end user, consequently improving design solution, and finally a person with dementia will likely have a better quality of

life through being stimulated and included in new activities that encourage them to think, express their view, and engage in practical creative activities.

Each workshop was limited to one hour due so as not to fatigue people with dementia, and to coincide with the cognitive stimulation therapy group that was on directly afterwards. In some instances, the conversation and energy in the workshop was so exciting that research partners did not want it to end. As the partners with dementia were able to commit to two hours of intensive concentration, it may be feasible for future research to extend the research time. However, partners should not be forced to participate for the full amount of time allotted if they find it tiring. Increasing the workshop time in some instances would be difficult, particularly in care homes where there is often a strict schedule and a perception that the residents would not be able to endure any research longer than twenty minutes.

Future progress should be made towards the development of a guidebook and toolkit that contains activities and modifications specifically for individuals with dementia as also identified by Hendriks, Truyen, and Duval (2013). There also needs to be more emphasis on the accessibility of technology for older adults as well as cognitive disabilities.

8| CONCLUSION.

This research examined the feasibility of involving people with dementia in the design process having identified and experienced an absence of collaboration with people affected by dementia in both research and design. Despite the lengthy process to recruit people with dementia for six co-design workshops and five user testing sessions, the research identified that it is not only feasible, but a valuable and desirable activity.

With a growing percentage of the population being affected by dementia, so to are the number of products and services for people with dementia. Unfortunately, many products or services are frequently designed 'for' people with dementia in mind instead of 'with', resulting in suboptimal designs and user experiences (Wu, Richards, & Baecker, 2004). The theory behind co-design is that it increases the 'value' of a product, service, or brand due to its engaging, creative, generative, and collaborative nature resulting in important insights and design decisions that might not have been gained using other (more traditional) means (for example interviews and focus groups) (Sanders & Stappers, 2012).

The method of co-design supported what people with dementia in this research identified as being of most value to them; to spend time with talking with others and engaging their mind. This research was valuable even disregarding any physical output or design insights from the co-design workshops, as solely the inclusion of people with dementia in a collaborative design process provided more beneficial effects than harm (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). Co-design gave people with dementia an opportunity to participate as equals within the design process by giving them independence, companionship, and a temporary occupation. All of these were identified by Morris and Morris (2010) to affect their self worth and well being. Potentially these benefits may last beyond the workshops, having empowered people with dementia and demonstrated their remaining abilities to carers.

Obtaining access to people with dementia in a research capacity was difficult due to their cognitive decline and age, and as a result they remain one of the largest excluded groups of people (Hellstrom et al., 2007). Despite the research being of relative low risk, it was viewed as high risk due to the vulnerability and mental capacity of people with dementia. Consequently, obtaining ethical approval to work with people affected by dementia was a difficult and time-consuming process, and highlighted that further research around capacity of consent for people with dementia is needed, particularly as more designers collaborate with people affected by dementia.

Technology that people with dementia identified as wanting or needing is typically already developed (such as YouTube for watching 1950s videos). However, older adults and people with dementia need greater accessibility. This may be in the form of simplifying tablet computer applications, or through the use of more familiar innovations, such as, the cut out book concept developed within this research. Enabling accessibility to technology is likely to become more important as technology (and the use of technology) advances and progresses at ever increasing rates. Older generations may find it difficult to keep up with new developments, particularly if those developing new technologies do not try met the needs of the elderly or disabled (Lou, Giuliano, & Mulvenna, 2010).

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AUT
UNIVERSITY
AUCKLAND, NEW ZEALAND

Not for me, without me.
Learning how to co-design with people affected by dementia.

Participating

Who are you looking for?
I am looking for people diagnosed with some form of dementia and their family member or primary carer.

If the person with dementia is unable to provide consent, an agreement must be signed by their family member (who must also be their enduring power of attorney) that the person with dementia would consent to take part in this study if they were able to.

How was I found to take part?
You have been approached because I approached Alzheimer's Auckland and your care home to ask if they knew of anyone who would be able or would like to help me.

Why am I being invited?
You have been chosen because we thought you and your family member might be interested and would be happy to help me.

What are the discomforts and risks?
We don't expect there to be much discomfort or risk in this research. However, you may feel uncomfortable sharing your opinions in a group situation, or feel tired because the sessions are too long.

You are most at risk from other people who are also taking part who may not keep information you give confidential.

How will these discomforts and risks be reduced?
You will be taking part in this research with someone

you know. This should help you both feel more comfortable.

We have also have a member of the organisation present at all the research sessions to make sure you are being looked after. Please don't hesitate to talk to them about any concerns.

Who benefits?
I benefit from your support by using the results of this research to complete my qualification. I also get valuable practice running similar projects like this.

In return, I hope you feel empowered and have fun while doing the activities with me.

How is my privacy protected?
You will not be anonymous to myself or other people in your group which means people will know your name,

and who you are based on what you say at the research sessions.

It is expected that you and the other members of your group will respect each other. You will also all be expected to keep the identity and privacy of each other confidential.

For my thesis, any examples, names, photos, videos, and audio recordings will be changed with your permission so you cannot be identified.

Everything that I collect will be kept for a minimum of six years and then destroyed.

What will it cost to participate?
There are no costs to you for participating in this research apart from the cost of travel and a maximum of ten hours of your time.

The researcher

Hello, my name is Rebecca Jury.
I am currently a masters student studying Art and Design at Auckland University of Technology (AUT). I am interested in designing technology and people.

I would like to ask for your

help in my research which aims to find out what people with dementia and their primary carers actually want to improve their experience in health care using a series of activities.

I look forward to your reply and I hope to see you soon.

The Research

What is the background of this research?
For my honours research, I looked at digitizing a paper document for Auckland City Hospital. It was meant to capture and communicate the personal information of a person with dementia to doctors and nurses to personalize care.

I found that many researchers and designers don't talk directly with people affected by dementia perhaps thinking that they are too difficult to access or work with.

What is the purpose of this research?
I am interested in ways to work directly with users throughout the design process. I modified a process called co-design, which is a using activities from art and design, to understand what people living with dementia

really want in their lives and how I can best give it to them.

The purpose of this research is to find out whether it is possible for designers to design computer (tablet) solutions with a team of people living with dementia.

With your help, the outcome of this research will be a prototype for a computer (tablet) software and a prototype for co-design. I will also be publishing the results of this research in my masters thesis which you will have access to once finished.

What do I want from you?
All I am asking from you is your time and honesty. There are no right or wrong answers in this research. You are the experts of your life and you're teaching me how to design for you!

An overview of the research

Part One - The design.
60 min

Knowing what we are building.

Finding the issue. Creating ideas.

Potential solution.

Part Two - User Testing.
20 min

Testing our idea.

What will happen in the research?
All of the sessions will be photographed, video and audio recorded so I can focus on working with you instead of writing notes.

Part One.
The first part of this research is six weeks long. There will be six people taking part in the activity not including myself and another member of the organisations looking after you.

We will do a few activities in each session that will last

only an hour. After that, we will have up to half an hour to talk with tea/coffee/milo, and biscuits.

Part Two.
The second part of this research is once a month for up to three months. This will be run in pairs who consent together.

We will be trying out a prototype based on our design. Each one of theses sessions will only last around 20minutes.

The key:

- You will be creating designs with the researcher.
- The researcher will be taking photographs of the work as well as yourself.
- The estimated time spent on each session is under the icon. Does not include the half hour social time afterwards.
- The researcher will be video recording your interaction with the design.
- The researcher will be voice recording our conversations.
- The researcher will be recording notes in a note book.
- One person means that only yourself and your family member will be there. Two people means that there will be a small group of people.

This process is up to date when printed. It may be slightly different to what you experience as the process is constantly being reviewed to be more productive.

Represent who we are

1 hour

Objective: To create an imaginary character who represents our values.

To do this, we are going talk about our attitudes, skills, personality, and requirements and use this to develop a character who represents a person living with dementia.

We will then do the same thing to find out about the person that looks after them.

By understanding who these people are, we can talk about what they would or wouldn't want in a digital technology which will be useful to measure success.

1

Explore our experience

Objective: To visually represent our experience with dementia

We will begin by mapping out our journey since being diagnosed as living with dementia.

Looking at our characters from last week, we shall imagine what are the kinds of things they are thinking, seeing, and saying at certain points of their journey.

Together we shall pick a few moments in their journey that our character struggles so we can use it to design our brief next week.

2

Design the problem

1 hour

Objective: To identify the point of view.

We are going to formally write a brief detailing who we are designing for, what do they need, and why they need our help.

We will then pick three things that this product is going to do.

To help us come up with ideas, we are going to look at our problem in detail, find methods to solve the problem, and discuss the different ways we can do each solution.

3

Feedback on other designs

1 hour

Objective: To give feedback on other peoples work.

To get us used to evaluating our own work, we are going to look at what solutions are available for our character now and discuss together what we would keep, change, or remove about them.

We will then rank the projects in a grid based on how well it does what it is meant to, and whether we think it looks good or not.

4

Solving our problem

1 hour

Objective: To find out what it would look like.

I would like to ask you to bring something that you love or something that is important to you to this session.

I would love to hear what about it is that you love about it. Is it what it does? How it feels? How it looks?

Then we shall have some fun by creating a collage with colours, textures, photos, drawings, and images that are attractive to your sense of style.

This will help give the look and function of our solution.

5

Develop our solution

1 hour

Objective: To arrange the layout.

We will start by sorting out cards of different words and pictures into groups that make sense to us. We will talk about why these groups made sense to us.

Then we are going to design and arrange different elements of our solution to test out how we might use it and discuss what works and what doesn't.

6

Testing our designs together

20 minutes
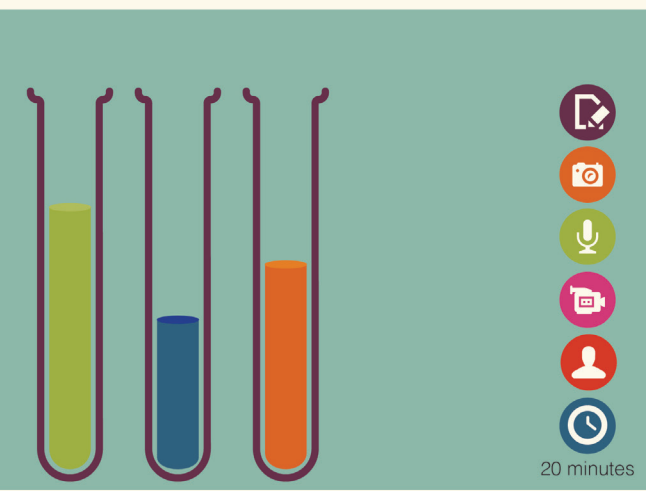
Objective: Try out and give feedback on our design.

After you have helped me through this design process I am going to create a digital prototype based on what we have decided together.

You will each get 20min in pairs to have a play with a prototype and then talk about the things you like, would keep, and would get rid of.

This will happen in total three times so we can refine our ideas and make our design fantastic.

7a 7b 7c

Invitation to A&D2015

Unknown

Objective: To celebrate all of our hard work.

In thanks for all the time and hard work you have put in. I would like to warmly invite you to the 2015 Art and Design exhibition at Auckland University of Technology where our design will be shown. Details of date and time will be sent when known.

You will also receive a summary of the research findings and a digital copy my exegesis and, if ever available, the digital application we designed together.

You will always be thanked for your hard work in any future publication using this research.

Consent Process

How long do I have to think about this?

You will have two weeks to contact either myself, or your organisation, whether you would like to take part or not. This decision is up to you. If we do not hear from you we will send a reminder in case you have forgotten.

If you need further information please don't hesitate to ask any questions to the researcher, Alzhiemers Auckland, or your residence facility. We will be happy to answer them.

How do I agree to take part?

If you would like to take part in this journey with me, you will need to let either myself or your organisation know. We will discuss the research with you and upon your satisfaction, ask you to complete a written consent form. A copy of this form is included in your information pack.

You have the right to withdraw from this research at any point, no questions asked. All of the data you give will be destroyed. You also have the right to walk out on a session for any reason if you are not happy or uncomfortable.

Lastly, you don't need to be there for all the sessions. It would be great if you can but we respect you have other things to do. If you can, just let us know.

Contact Details

What do I do if I have any concerns about this research?

If you have any concerns about the **nature** of this research please contact:

If you have any concerns about the **conduct** of the research please contact:

Project Supervisor

Stephen Reay
stephen.reay@aut.ac.nz
09 921 9999 extn. 6719

Executive Secretary of AUTEC

Kate O'Connor
ethics@aut.ac.nz
09 921 9999 extn. 6038

Whom do I contact for more information about this research?

If you have any questions about the research please don't wait to contact either person below:

Researcher
Rebecca Jury
pqx7411@aut.ac.nz

Project Supervisor
Stephen Reay
stephen.reay@aut.ac.nz
09 921 9999 extn. 6719

This research is approved by the Auckland University of Technology Ethics Committee on 10th March 2015, AUTEC Reference number 15/08.

AUT
UNIVERSITY
AUCKLAND, NEW ZEALAND

Not for me, without me.
Co-designing user interfaces with people affected by dementia.

The researcher

Hello, my name is Rebecca Jury.

I am currently a masters student studying Art and Design at Auckland University of Technology (AUT). I am interested in designing technology and people.

I would like to ask for your help in my research which aims to find out what people with dementia and their primary carers actually want to improve their experience in health care using a series of activities.

The Research

What is the purpose of this research?

I am trying to find out how we can include people with dementia and one of their family members (or primary carer) in the design process using something called co-design to design things that they want and need.

Who are you looking for?

I am looking for people diagnosed with some form of dementia and their family member or primary carer. If the person with dementia is unable to provide consent, an agreement must be signed by their family member (who must also be their enduring power of attorney) that the person with dementia would consent to take part in this study if they were able to.

What would I need to do?

I need you to take part in as many research sessions as you can. In each research session I need your honest opinion. You are the ones teaching me how to design for you!

What are the costs of participating in this research?

There are no costs to participating in this research other than the cost of travel and the cost of your time. It is expected that at maximum, you will be asked to spend a maximum total of 10 hours on this research.

What opportunity do I have to consider this invitation?

You will have two weeks to contact either myself, or your care facility whether you would like to take part or not.

This decision is up to you. If we do not hear from you we will send a reminder after two weeks.
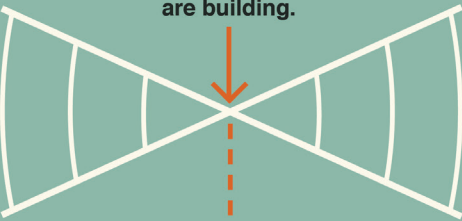
An overview of the research
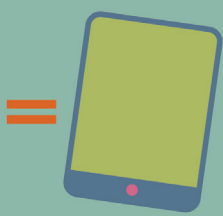
Part One - The design.
🕐 60 min

Knowing what we are building.

Finding the issue. Creating ideas. Potential solution.

Part Two - User Testing.
🕐 20 min

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All of the sessions will be photographed, video and audio recorded so I can focus on working with you instead of writing notes.

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only an hour. After that, we will have up to half an hour to talk with tea/coffee/milo, and biscuits.

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Kate O'Connor
ethics@aut.ac.nz
09 921 9999 extn. 6038

Whom do I contact for more information about this research?

If you have any questions about the research please don't wait to contact either person below:

Researcher

Rebecca Jury
pqx7411@aut.ac.nz

Project Supervisor

Stephen Reay
A staff member of Alzheimer's Auckland
A staff member from Howick Baptist Healthcare.
stephen.reay@aut.ac.nz
09 921 9999 extn. 6719

This research is approved by the Auckland University of Technology Ethics Committee on 10th March 2015, AUTEC Reference number 15/08.

APPENDIX 03

Please do not staple your application

For AUTEC Secretariat Use only

AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE (AUTEC)

EA1

APPLICATION FOR ETHICS APPROVAL BY AUTEC

Once this application has been completed and signed, please read the notes at the end of the form for information about submission of the application for review.

NOTES ABOUT COMPLETION

- Ethics review is a community review of the ethical aspects of a research proposal. Responses should use clear everyday language with appropriate definitions being provided should the use of technical or academic jargon be necessary.
- The AUTEC Secretariat and your AUTEC Faculty Representative are able to provide you with assistance and guidance with the completion of this application which may help expedite the granting of ethics approval.
- The information in this application needs to be clearly stated and to contain sufficient details to enable AUTEC to make an informed decision about the ethical quality of the research. Responses that do not provide sufficient information may delay approval because further information will be sought. Overly long responses may also delay approval when unnecessary information hinders clarity. In general each response should not exceed 100 words.
- AUTEC reserves the right not to consider applications that are incomplete or inadequate.
- Comprehensive information about ethics approval and what may be required is available online at http://aut.ac.nz/researchethics
- The information provided in this application will be used for the purposes of granting ethics approval. It may also be provided to the University Postgraduate Centre, the University Research Office, or the University's insurers for purposes relating to AUT's interests.
- The Form is focussed around AUTEC's ethical principles, which are in accordance with the Guidelines for the approval of ethics committees in New Zealand.

To respond to a question, please place your cursor in the space following the question and its notes and begin typing.

A. **Project Information**

A.1. What is the title of the research?

If you will be using a different title in documents to that being used as your working title, please provide both, clearly indicating which title will be used for what purpose.

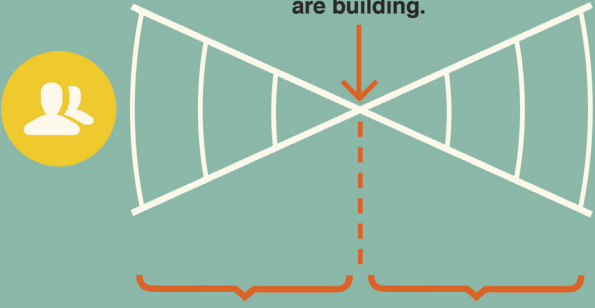Not for me, without me: Co-designing assistive technology with people affected by dementia

A.2. Who is the applicant?

When the research is part of the requirements for a qualification at AUT, then the applicant is always the primary supervisor. Otherwise, the applicant is the researcher primarily responsible for the research, to whom all enquiries and correspondence relating to this application will be addressed.

Stephen Reay

A.3. Further information about the applicant.

A.3.1. In which faculty, directorate, or research centre is the applicant located?

Art and Design

A.3.2. What are the applicant's qualifications?

PhD, Mphil, M.For.SC, BSc.

A.3.3. What is the applicant's email address?

EA1%20Rebecca%20Jury.docx   *This version was last edited in September 2014*

B.2.1. What is the name of the primary researcher if it is someone other than the applicant?

Rebecca Jury

B.2.2. What are the primary researcher's completed qualifications?

Bachelor of Creative Technology
Bachelor of Art and Design (Hons)

B.2.3. What is the primary researcher's email address?

An email address at which the applicant can be contacted is essential.

B.2.4. At which telephone numbers can the primary researcher be contacted during the day?

B.3. Is the primary researcher   ☐ an AUT staff member ☒ an AUT student

If the primary researcher is an AUT staff member, please answer B.3.1 and the following sections, otherwise please answer B.4 and continue from there.

B.3.1. In which Research Institute or Faculty and school or department is the primary researcher employed?

Design and Creative Technologies

B.4. If the primary researcher is a student:

B.4.1. What is their Student ID Number?

1075307

B.4.2. In which faculty school, department, or Research Centre are they enrolled?

Art and Design

B.5. What is the primary researcher's experience or expertise in this area of research?

Where the primary researcher is a student at AUT, please identify the applicant's experience or expertise in this area of research as well.

The applicant, Stephen Reay, is the co-director of the 'Design for Health and Wellbeing Lab', which is a collaboration between AUT and Auckland District Health Board. He also has significant input in the centre for eHealth at AUT and has supervised several undergraduate and postgraduate design and health related projects.

The primary researcher has experience in research design methods having completed bachelors in Art and Design (hons) at AUT. Her honours project focused upon users affected with dementia and has some knowledge of their needs and capabilities through literature reviews and expert interviews. She also authored a summer studentship review in 2013/2014 exploring the ethical components associated with design projects to support people living with dementia.

B.6. Who is in charge of data collection?

The primary researcher, Rebecca Jury.

B.7. Who will interact with the participants?

The primary researcher (Rebecca Jury)
A staff member of Alzheimer's Auckland
A staff member from Howick Baptist Healthcare.

B.8. Is this research being undertaken as part of a qualification?   ☒ Yes ☐ No

If the answer is 'Yes' please answer B.8.1 and the following sections, otherwise please answer B.9 and continue from there.

B.8.1. What is the name of the qualification?

Masters of Philosophy: Art and Design

B.8.2. In which institution will the qualification be undertaken?

Auckland University of Technology (AUT)

B.9. Details of Other Researchers or Investigators

B.9.1. Will any other people be involved as researchers, co- investigators, or supervisors?   ☒ Yes ☐ No

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An email address at which the applicant can be contacted is essential.

A.3.4. At which telephone numbers can the applicant be contacted during the day?

A.4. Research Instruments

A.4.1. Which of the following does the research use:

☒ a written or electronic questionnaire or survey   ☒ focus groups   ☐ interviews
☐ observation   ☐ participant observation   ☐ ethnography   ☒ photographs
☒ videos   ☐ other visual recordings   ☒ a creative, artistic, or design process
☒ performance tests
☐ some other research instrument (please specify)

Please attach to this application form all the relevant research protocols. These may include: indicative questions (for interviews or focus groups); a copy of the finalised questionnaire or survey in the format that it will be presented to participants (for a written or electronic questionnaire or survey); a protocol indicating how the data will be recorded (e.g. audiotape, videotape, note-taking) for focus groups or interviews [Note: when focus groups are being recorded, you will need to make sure there is provision for explicit consent on the Consent Form and attach to this Application Form examples of indicative questions or the full focus group schedule. Please note that there are specific confidentiality issues associated with focus groups that need to be addressed]; a copy of the observation protocol that will be used (for observations); full information about the use of visual recordings of any sort, including appropriate protocols and consent processes; protocols for any creative, artistic, or design process; a copy of the protocols for the instruments and the instruments that will be used to record results if you will use some other research instrument.

A.4.2. Who will be transcribing or recording the data?

If someone other than the applicant or primary researcher will be transcribing the interview or focus group records or taking the notes, you will need to provide a confidentiality agreement with this Application Form.

The primary researcher, Rebecca Jury.

B. **The Ethical Principle of Research Adequacy**

AUTEC recognises that different research paradigms may inform the conception and design of projects. It adopts the following minimal criteria of adequacy: the project must have clear research goals; the design must make it possible to meet those goals; and the project should not be trivial but should potentially contribute to the advancement of knowledge to an extent that warrants any cost or risk to participants.

B.1. Please provide a brief plain English summary of the research (300 words maximum).

It is expected that by 2050, an estimated 150,000 New Zealanders will have some form of dementia (Alzhiemers New Zealand, 2012). Dementia is commonly known for degenerative memory loss however, it also deteriorates the abilities of other activities to the point where people living with dementia are unable to communicate, have abstract thoughts, and suffer significant visual impairment (i.e. they find it difficult to see objects in front of them) . Designers are often expected to work closely with users, during a design process, to better understand user needs, and develop insights to help support the creative design process. These impairments create an interesting challenge for designers who may need to develop alternative methods to understand their primary user groups needs..

In 2013, the primary researcher, as part of their B.A&D honours research, developed a digital prototype designed to capture and communicate the life of a person affected by dementia to clinicians. However the user centred data was based upon literature reviews, expert interviews, and other secondary data collection. Due to the scope of the study, people living with dementia, (or their families) were not consulted during the study. This is typical of similar other design projects, due to the perceived difficulty and vulnerability of working with this user group.

Phase one of this research builds upon the previous work and focuses on using participatory design techniques with people affected by dementia (in and out of residential care) and their family in small focus groups. It will explore the practicality of co-design with people affected with dementia specifically focussed on the use of, potentially enabling, digital technologies. This collected data will inform the design of an assistive communicative tool that may enable people with dementia to more easily communicate, or remember, important events in their lives, when they might otherwise be unable to do this. . Phase two of this research aims to test the results of the resulting prototypes with people living with dementia at different stages of their condition..

B.2. Is the applicant the person doing most of the research (the primary researcher)?   ☐ Yes ☒ No

If the answer is 'No' please answer B.2.1 and the following sections, otherwise please answer B.3 and continue from there.

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If the answer is 'Yes' please answer B.9.1.1 and the following sections, otherwise please answer B.9.2 and continue from there.

B.9.1.1 What are the names of any other people involved as researchers, investigators, or supervisors?
Ass. Prof. Duncan Babbage

B.9.1.2 Where do they work?
AUT University

B.9.1.3 What will their roles be in the research?
Secondary Supervisor

B.9.1.4 What are their completed qualifications?
PhD, PGDipClinPsych, BSc(Hons)

B.9.2. Will any research organisation or other organisation be involved in the research? ☒ Yes ☐ No
If the answer is 'Yes' please answer B.9.2.1 and the following sections, otherwise please answer B.8.10 and continue from there.

B.9.2.1 What are the names of the organisations?
Alzheimer's Auckland
Howick Baptist Healthcare

B.9.2.2 Where are they located?
Alzheimers Auckland: Level 1, Suite 4,48 Surrey Crescent, Grey Lynn, Auckland 1021
Howick Baptist Healthcare: 139 Union Rd Howick, Auckland 2014

B.9.2.3 What will their roles be in the research?
Support the researcher in feasibility and planning of the study. Will initially approach (recruit) participants into the study on behalf of the researcher, , assist the researcher in gaining informed consent, support the researcher and participants during the study, provide a suitable site, familiar to the participants for the study to take place.

B.10. Why are you doing this research and what is the aim and background?
Please provide the key outcomes or research questions and an academic rationale with sufficient information, including relevant references, to place the project in perspective and to show the project's significance to be assessed.

People with cognitive impairments, such as dementia, are often unapproached in the design process as there is uncertainty in how they can be effectively engaged. However this assumption of their (in)capacity, takes away their right to participate, and potentially hinders reaching an optimal design (B. Fox (Alzheimers Auckland), personal communication, September 24, 2014). Often when people with dementia are included in the design process, they are seen as being passive; used to develop project specifications, or are used to evaluate or testing a product once the design process has been completed (Astell et al., 2010; Bjorneby et al., 2004; Meiland et al., 2012; Sanders & Stappers, 2012; Timlin & Rysenbry, 2010).

The aim of this research is to explore how people with dementia might be effectively include in the design process, by using a co-design framework. With this process, participants are considered experts of their experiences and play a significant role in idea generation and concept development (Sanders & Stappers, 2012).

A key outcome of this research is to understand how to adapt co-design methods to better accommodate the capabilities of people affected with dementia and their families, will be created by them with the researcher. If the results of research suggested that co-design activities undertaken with people with dementia, are impractical or unfeasible, the insights gained during the research will be used by the researcher for design an app to help people living with dementia to remember and communicate key events or important information to others who are caring for them. It is hoped that this tool will help to more effectively support people with dementia during their end of life care.

B.11. What are the potential benefits of this research to the participants, and the wider community?

Participants with dementia may feel empowered taking part in activities that mentally stimulate and positively impact on the future care they receive for themselves , as well as others affected by dementia.

Family/whanau of people affected by dementia will have the opportunity to contribute to a tool that will aid the care of their loved one/s.

The researcher stands to benefit with experience in facilitating the design process with participants as well as delivering an informed designed as part of their degree.

The wider community stands to benefit, as the result of this researcher may be applicable to other cognitive impairments.

B.12. What are the theoretical frameworks or methodological approaches being used?

The research uses a qualitative approach to collect data using a design thinking mindset, where an understanding of the users needs and wants comes from iteratively passing through stages of inspiration, ideation, and implementation during the design process (Brown, 2008).

During phase one of the research, the researcher will collect data using small focus groups. Probes (visual cues/design activities) that are typical of co-design processes will be developed by the researcher for use in the focus groups, to help facilitate the sharing of information by the participants . Co-design uses a diverse range of both design and research orientated methods to collaboratively design with a wide range of participants (Steen, 2013).

Phase two of the research will focus on the implementation stage of the design thinking process. Designs prototypes or solutions (outcomes of phase one) will be tested and refined with participants, with the aim of supporting future design iterations, or improvements to better accommodate users (Vredenburg, 2002).

B.13. How will data be gathered and processed?

Phase one involves two separate groups of six people per session in a series of six focus groups. Participants selected with include both a person living with dementia and a relative or caregiver known to them (three participant pairs for each focus group). Each session will last no longer than an hour. The researcher will use a pre-prepared session script that will include the duration of the session, actions to be undertaken, checklists, and prompts for each activity, to facilitate the session in a consistent and effective manner. Each session will have a specific objective, and will result in an output being developed that will be used in the subsequent session. As well as supporting the ongoing research, this may help participants gain a sense that their participation is of productive value, and help them to better understand the co-design process as participants.

It was suggested that participants are not likely to initially discuss what they think about the process during the activities in each session, but will after participating, or completing them (B. Fox (Alzheimers Auckland), personal communication, September 24, 2014). Therefore, at the end of each sessions activity, a half hour 'social time' or informal discussion about the activities will been scheduled. This will also be video recorded with audio (with the permission of participants) to be used to help understand their experiences of the co-design process.

Phase two involves usability tests of a designed app (i.e. ipad application) in participant pairs (person with dementia, and family member or caregiver) lasting 20-30min. Participants will be asked to talk their thoughts out loud while using the developed prototype while being video recorded (with audio). A semi-structured discussion will then be facilitated with the participant pair to understand how useful the app was for them, and to gain input into what features/functions they would want to keep, change, or remove.

Data will be gathered using audio and video recordings along with observational notes by the researcher. Participants will be shown what the video is recording and by shown how to stop or pause recording at any time during the research. Material created by participants during the activity sessions will be photographed.

B.14. How will data be analysed?
Please provide the statistical (for quantitative research) or methodological (for qualitative or other research) justification for analysing the data in this way.

As part of a co-design methodology, some of the data will be analysed by participants themselves, using frameworks similar to other qualitative research projects Creswell (2013). Participants in activities (and work) they have previously created and write them on sticky notes or card (codes). Ideas may then be grouped together (categories) and anonymously selected to create that session's output. Analysing data in this manner can both provide information and inspiration within the group (Sanders & Stappers, 2012).

The researcher will use a similar but more systematic approach as described above when analysing the data from the research as outlined below:

1. Organise and prepare the data for analysis by sorting and arranging the different types of data (types of data, who/what, how was it collected, how many, and dates of collection).

2. Review all of the evidence and data created to start understanding the overall meaning being portrayed by the users. Notes of common words, themes, and inspiration will be recorded to gain a general sense of the data and opportunity to reflect and gather a first impression.

3. Begin analysis with a coding process that captures what is expected, surprising, unusual, and still has relevance to the research question.

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4. Categories will be created from codes to represent important findings that are supported by specific evidence.

5. Findings will then be interpreted by the researcher and reported upon.

B.15. Has any peer review taken place (e.g. approval of a PGR1, PGR2, or PGR9 for postgraduate research)? ☒ Yes ☐ No
If your answer is 'Yes', please specify and provide evidence.

A PGR1.

C. General Project Details

C.1. Likely Research Output

C.1.1. Will the research result in one or more of the following

☒ a thesis   ☐ a dissertation   ☐ a research paper   ☐ a journal article
☐ a book   ☐ conference paper   ☐ other academic publications or presentations
☒ an exhibition   ☐ a film   ☐ a documentary   ☐ some other artwork
☒ Some other output, please specify

An assistive technological prototype in the form of a tablet application.

C.2. Research Location and Duration

C.2.1. In which countries and cities/localities will the data collection occur?
Auckland, New Zealand

C.2.1.1 Exactly where will any face to face data collection occur
If face to face data collection will occur in participants' homes or similarly private spaces, then a Researcher Safety Protocol needs to be provided with this application.
Integrated Neurological Rehabilitation Foundation (INRF): 2 Claude Brookes Drive, Henderson
Howick Baptist Healthcare: 139 Union Rd Howick

C.2.2. In which countries and cities/localities will the data analysis occur?
Auckland, New Zealand

C.2.3. When is the data collection scheduled to commence?
When a significant number of participants is reached (following ethics approval) eqrly to mid 2015.

C.3. Research Participants

C.3.1. Who are the participants?
The participants include people living with some form of dementia and one of their family/whanau member or primary carer. Together these will be referred to as a participant pair.

C.3.2. How many participants are being recruited for this study?
If you are unsure, please provide an indicative range.
6 people with dementia and 6 family members or primary carers.

C.3.3. What criteria will be used to choose who to invite as participants?
- All must be willing to participate and provide written consent.
- Participants should have an interest in participating in the research (especially as it is to create a digital output).
- People with dementia must also have a family member or primary carer participate. This is to help the researcher understand and more effectively communicate with the person with dementia, as well as to help support the person affected by dementia during the research. The family member or primary carer's own input and participation in the design process is an important part of the research, and the co-designed output.
- Participants with dementia need a diagnosis of a health condition causing dementia (including type) by a geriatrician or appropriately qualified health specialist.

- No other acute illness requiring medical attention at the time of recruitment.

C.3.3.1 How will you select participants from those recruited if more people than you need for the study agree to participate?
Participants will be informally screened for high level of interest or enthusiasm from their family/whanau as well as in assistive technology then selected on diversity. This will initially be facilitated by the two services partnering with this research (Alzheimers Auckland and Howick Baptist Healthcare)

C.3.4. Will any participants be excluded from participating in the study? ☒ Yes ☐ No
If the answer is 'Yes' please answer C.3.4.1 and the following sections, otherwise please answer C.3.5 and continue from there.

C.3.4.1 What criteria will be used to exclude people from the study?
- Participants without adequate English comprehension and expression measured by their ability to communicate with the researcher.
- People with dementia without a family/whanau member or primary carer able to or willing to participate.
- Any direct relationship to the researcher.
- Current diagnosis of clinically significant depression.
- Medically unstable or with current diagnosis of potentially life threatening diseases that the research may negatively impact on.

C.3.4.2 Why is this exclusion necessary for this study?
- If participants were unable to understand English it places them in a potentially vulnerable position, as they may not understand what is being asked of them.
- Often for older adults to be interesting in using or learning technology, motivation comes from their family to encourage use (EU biomed II project, 1999).
- This avoids any conflict of interests by participants who may feel they must participate based upon a pre-existing relationship.
- To ensure all participants safety while participating in this research.

C.3.5. How will participants be recruited?
Please describe in detail the recruitment processes that will be used. If you will be recruiting by advertisement or email, please attach a copy to this Application Form

C.3.5.1 How will the initial contact with potential participants occur?
The research will be advertised with the help of organisations listed in B.9.2.1. The organisations will be given a poster to place on their noticeboard along with leaflets to hand out to those interested in participating. The researcher will also present information sessions (co-ordinated by the organisations listed in B.9.2.1) about the intended research for potential participants who may wish to participate.

C.3.5.2 How will the contact details of potential participants be collected and by whom?
Potential participants contact details will be handled by the organisations listed in B.9.2.1. The researcher will collect the preferred method of contact for each participant from the each host organisation once participants have confirmed with the host organisations that they would like to participate in the research. After this the participants will be contacted by the researcher.

C.3.5.3 How will potential participants be invited to participate?
Participants who have indicated their interest to their organisation or to the researcher about participating in this research will be given an information pack. This will include consent forms to participate in the research and consent to the visual and audio recordings. In the case of a person with dementia, a one page brief summary/information sheet of the research will be given with a more detailed document (information sheet available on request). Family or primary carer participants will receive all documents.

C.3.5.4 How much time will potential participants have to consider the invitation?

Participants have two weeks to consider the invitation before being contacted by either their familiar organisation or the research. Through the consultation it was advised that participants be contacted post invitation in case they have forgotten.

C.3.5.5 How will potential participants respond to the invitation?
Participants may respond directly to the researcher or their familiar organisation either in person, phone, or email (where appropriate).

C.3.5.6 How will potential participants give consent?
The organisations listed in B.9.2.1. will assist the researcher in procuring consent having experience working with people affected by dementia and their families or primary carers. Both participants in the participant pair will have to sign individual consent forms prior to the research being held.

Participants who turn up to the research sessions will be considered as giving consent to participate. This is important for participants with dementia, as they may get anxious having to remember when they have something on. It was recommended by Howick Baptist Healthcare that they are asked before each session begins whether they would like to continue to participate in the research or not (B. Robinson, personal communication, December 18, 2014).

C.3.5.7 How and when will the inclusion criteria and exclusion criteria given in sections C.3.3 and C.3.4 be applied?
Participants will not be approached if they meet any of the exclusion criteria, which will be decided by their familiar organisations and the researcher.

C.3.5.8 Will there be any follow up invitations to potential participants?
Participants will be invited as guests to any exhibition or presentation showing the resulting product or the research (where possible) as a thank you for their involvement. Participants will also be asked if they would like to be approached about any related research in the future.

D. Partnership, Participation and Protection

D.1. How does the design and practice of this research implement the principle of Partnership in the interaction between the researcher and other participants?

How will your research design and practice encourage a mutual respect and benefit and participant autonomy and ownership? How will you ensure that participants and researchers will act honourably and with good faith towards each other? Are the outcomes designed to benefit the participants and/or their social or cultural group? How will the information and knowledge provided by the participants be acknowledged?

Participants in this research are invited to participate and consent on a voluntary basis with the option to withdraw at any time (i.e. by leaving the room). They also have the opportunity to contact the researcher to ask any questions or raise any concerns that they may have with any of the information presented to them during the research.

In co-design, every participant/person is viewed and respected as creative and the experts of their experiences (Sanders & Stappers, 2012). The researcher and participants will develop a partnership based upon trust and respect while sharing their knowledge and designing together. Participants and the researcher will understand that all opinions are valid throughout the co-design process, and will be respected regardless of the social and cultural status of the person.

The outcomes of this study will benefit participants by empowering them in the design process, and it is hoped that this research will improve end of life care of people affected by dementia. The researcher will benefit as part of their qualification and will acknowledge the information and knowledge provided by participants in any publications that use this research.

The researcher will ask three simple questions (to help confirm the extent of participants cognition) in conversation prior to each research session. Questions may include "what day is it?" or "who is the prime minister?" If participants are not able to answer the questions, then this will indicate to the researcher the participant does not have the cognitive capacity to consent at that particular time, and will to collect data from them but will allow them to continue to participate (if they wish).

D.2. How does the design and practice of this research implement the principle of Participation in the interaction between the researcher and other participants?

What is the actual role of participants in your research project? Will participants be asked to inform or influence the nature of the research, its aims, or its methodology? Will participants be involved in conducting the research or is their principal involvement one of sharing information or data? Do participants have a formal role as stakeholders (e.g. as the funders and/or beneficiaries of the research? What role will participants have in the research outputs (e.g. will they be asked to approve transcripts or drafts)?

The researcher is going to give an information presentation about the study to advertise for recruitment and to answer any questions. Participants are consultants being asked to share their experiences using modified co-design activities. All of these sessions will be held in a location where their familiar organisation commonly host events and activities.

Phase one of the research involves participants in small groups of six (not including the researcher and a assistant from their familiar organisation) taking a maximum of an hour and a half out of their time, each week for a six week period. Each session will consist of a 30 minute co-design activity, with a 30 minute informal discussion about the design activity/process, and a cup of tea/coffee/milo and biscuits. During the co-design sessions participants will share ideas, create diagrams, and build simple models during the design process.

Phase two of the research involves participant pairs spending 20min per month in small useability/evaluation sessions with the researcher over a period of two to three months. Participants will have the opportunity to use a prototype developed using the data from phase one of the research, and describe (verbally) what they are thinking (their experiences) while using it. The researcher and participants will then discuss what they liked about it, what they would change, and what they would get rid of.

Participants will be asked to approve the use of any material or artefact created by them, or a blocked out image of themselves prior to any publication of material/image/artefact created during the research.

D.3. How does the design and practice of this research implement the principle of Protection in the interaction between the researcher and other participants?

How will you actively protect participants from deceit, harm and coercion through the design and practice of your research? How will the privacy of participants and researchers be protected? How will any power imbalances inherent in the relationships between the participants and researchers be managed? How will any cultural or other diversity be respected?

Participants with dementia are fully informed of the purpose of the study prior with information sheets, information presentation, and have the opportunity to ask any questions of the researcher prior to giving their consent. If they do not have the ability to consent to the project they are unable to participate. The consent process will be assisted by their familiar organisation to protect them from any harm, deceit, or coercion.

The organisations will provide an appropriately qualified assistant to be present at all co-design sessions to support both the researcher and participants. Their experience will assist the researcher in identifying participant's ability to participate. For example, it is anticipated that participants with dementia, as they may get tired during the project. The assistant can then recommend to the researcher to take a break.

All data collected by the researcher will only be seen by the researcher and her supervisors. Any data that is presented in a publication will have all identifiers obscured (e.g. by pixelating participants faces). During the focus groups/activities, participants have access to any recording devices and can stop/pause recording at any time during these activities.

Participants and the researcher are required to value and respect all opinions and creative ideas made within the study regardless of any social or cultural differences. The researcher and supporting organisation will be accountable to identify any power imbalances and to neutralise them if possible throughout the study.

Since consulting with AUTEC (following the previous (unsuccessful) ethics application) is has been determined the researcher is unable to practically gain legal informed consent from people with severe cognitive ability. Consequently, participants residing at Bupa Cornwall Park Hospital will not be invited to participate in this study.

E. Social and Cultural Sensitivity (including the obligations of the Treaty of Waitangi)

E.1. What familiarity does the researcher have with the social and cultural context of the participants?
The researcher undertook a practice led design research project in their postgraduate honours year to digitise a paper document used in hospitals/clinical settings to better understand the history/details of a person with dementia. The researcher consulted extensively with specialists/expects on those living dementia, and wrote a literature review. The researcher has also interacted with people affected by dementia when invited as a guest.

E.2. What consultation has occurred?
Research procedures should be appropriate to the participants. Researchers have a responsibility to inform themselves of, and take the steps necessary to respect, the values, practices and beliefs of the cultures and social groups of all participants. Where a research project targets persons from another cultural, social or language group, consideration must be given to the preferences of the potential participants as far as consultation, language and documentation are concerned. Researchers should also be cognisant of potential implications or interest that the process and outcomes of the research might have for other cultures or groups. The purpose of any consultation is to ensure that research practices are appropriate and acceptable. Consultation should begin as early as possible in the project and should continue throughout its duration (the Ethics Knowledge Base [http://www.aut.ac.nz/research/research-ethics/ethics]). All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members. This is able to be accessed through the Ethics Knowledge Base). Researchers may also find Te Kahui Mangai a directory of iwi and Māori organisations to be helpful. This may be accessed via the Te Puna Kokiri website [http://www.tkm.govt.nz/].

The researcher has consulted with specialists who deal on a regular basis with people affected by dementia and their families.

E.2.1. With whom has the consultation occurred?
Please provide written evidence that the consultation has occurred.

████████ (Activities co-ordinator at Cornwall park hospital)
████████ (Psychogeriatrician at Greenlane Hospital)
████████ (Operations Manager at Alzheimer's Auckland)
████████ (AUTEC secretariat)

E.2.2. How has this consultation affected the design and practice of this research?
The consultants have provided multiple insights that have shaped the practical aspects of this research and continue to be involved in the research in an advisory capacity. Some examples of key insights were:
- Limiting the total time spent as a focus group to an hour to reduce participants fatigue.
- Understanding the capabilities of people with dementia at different stages of their journey.
- Identifying that people with dementia will likely be unable to process large written texts so any information given will need to be simplified. However they will have access to larger documents on request.
- Identifying that people with dementia will find abstract thought difficult, so questions need to be rephrased or use a different activity to achieve the desired response.
- Redesigning the consent and recruitment process from people with dementia in particular to fit the legal requirements.
- Avoiding situations where people with dementia are required to remember as part of the research (i.e. appointments etc.) as they often find this stressful.

E.3. Does this research target Maori participants? ☐ Yes ☒ No
All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members
If your answer is 'No', please go to section E.4 and continue from there. If you answered 'Yes', please answer the next question.

E.3.1. Which iwi or hapu are involved?

E.4. Does this research target participants of particular cultures or social groups? ☒ Yes ☐ No
AUTEC defines the phrase 'specific cultures or social groups' broadly. In section 2.5 of Applying for Ethics Approval: Guidelines and Procedures it uses the examples of Chinese mothers and paraplegics. This is to identify their distinctiveness, the first as a cultural group, the second as a social group. Other examples of cultural groups may be Korean students, Samoan husbands, Cook Islanders etc., while other examples of social groups may be nurse aides, accountants, rugby players, rough sleepers (homeless people who sleep in public places) etc. Please refer to Section 2.5 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures (available from the Ethics Knowledge Base online via http://www.aut.ac.nz/about/ethics) and to the relevant Frequently Asked Questions section in the Ethics Knowledge Base.
If your answer is 'No', please go to section E.5 and continue from there. If you answered 'Yes', please answer the next question.

E.4.1. Which cultures or social groups are involved?
People affected by dementia and a member of their family/whanau or primary carer.

E.5. Does this research focus on an area of research that involves Treaty obligations? ☐ Yes ☒ No
All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members.
If your answer is 'No', please go to section E.6 and continue from there. If you answered 'Yes', please answer the next question.

E.5.1. Which treaty obligations are involved?

E.6. Will the findings of this study be of particular interest to specific cultures or social groups? ☒ Yes ☐ No
If the answer is 'Yes' please answer E.6.1 and the following sections, otherwise please answer F.1 and continue from there.

E.6.1. To which iwi, hapu, culture or social groups will the findings be of interest?

People affected by dementia, family members of people affected by dementia, residential care facilities that have residents affected by dementia, and hospital clinicians.

E.6.2. How will the findings be made available to these groups?
An exegesis will be published in the AUT library of scholarly commons and potentially an app made available on iTunes for download in the future. Future publications may be published as journal articles.

F. Respect for the Vulnerability of Some Participants

F.1. Will your research involve any of the following groups of participants? ☒ Yes ☐ No
If your research involves any of these groups of participants, please clearly indicate which ones and then answer F.2 and the following sections, otherwise please answer 6.1 and continue from there.

☐ people who are given informed consent?   ☐ your (or your supervisor's) own students?
☐ preschool children?   ☐ children aged between five and sixteen years?
☐ legal minors aged between sixteen and twenty years   ☐ aged over seventy years?
☒ in a dependent situation, such as people with a disability, or residents of a hospital, nursing home or prison or patients highly dependent on medical care?
☒ vulnerable for some other reason (e.g. the elderly, prisoners, persons who have suffered abuse, persons who are not competent in English, new immigrants) – please specify

Cognitive impairment as a result of dementia.

F.2. How is respect for the vulnerability of these participants reflected in the design and practice of your research?
People with dementia are considered vulnerable due to their decreased cognitive ability.

The organisations in B.9.2.1. will assist the researcher in the recruitment of suitable participants (those who meets the participant criteria). A member of their familiar organisation will be present at each research session to assist the researcher and participants during the study.

Participants may withdraw from the research at any time and will be freely able to walk out, or leave a session if they do not want to continue to take part or are become tired. If participants fall asleep during the research, the researcher will stop, thank them for participating on that occasion, and give them the opportunity to leave (if they wish).

Participants who are unable to answer three simple questions, as part of normal conversation, to the partner organisation assistants satisfaction will have their data excluded from the research on that occasion, as this will be taken as suggesting that participants will not be at full cognitive capacity at that particular time.

F.3. What consultation has occurred to ensure that this will be effective?
Please provide evidence of the consultation that has occurred.

████████ (Alzheimers Auckland)
████████ (AUTEC)

G. Informed and Voluntary Consent

G.1. How will information about the project be given to potential participants?
A copy of all information that is to be given to prospective participants is to be attached to this Application Form. If written information is to be provided to participants, you are advised to use the Information Sheet template. The language in which the information is provided is to be appropriate to the potential participants and translations need to be provided when necessary.

Participants will be made aware of the study with a poster advertising the study shown in their familiar organisation. The organisations in B.9.2.1. will distribute leaflets/pamphlets about the study to those who may be interested. An information meet and greet session by the organisation for potential participants to attend and ask questions if they wish. Participants who have indicated their interest will be given an information pack and consent forms. After two weeks, participants who have not made clear their intentions to participate or not, will be contacted by their organisation and reminded. After this time, if participants have not consented into the study they will not be contacted further.

G.2. How will consent of participants be obtained and evidenced?

AUTEC requires consent to be obtained and usually evidenced in writing. A copy of the Consent Form which will be used is to be attached to this application. If this will not be the case, please provide a justification for the alternative approach and details of the alternative consent process. Please note that consent must be obtained from any participant aged 16 years or older. Participants under 16 years of age are unable to give consent, which needs to be given by their parent or legal guardian. AUTEC requires that participants under the age of 16 assent to their participation. Where the nature of the research requires it, AUTEC may also require that consent be sought from parents or legal guardians for participants aged between 16 and twenty years. For further information please refer to AUTEC's Applying for Ethics Approval: Guidelines and Procedures.

Participants need to provide written consent to the study, which will also include consent to be photographed and filmed (with audio). Combining these forms is to help reduce confusion (and paper work for participants) during recruitment. Participants will be able to submit their consent forms to either the researcher or their support organisation.

During the data collection/period, some participants with dementia will only be made aware of the study a short period before the study is to commence. While this may appear counter intuitive, consultation with the experts groups suggests that this approach will actually help reduce participants anxiety, as many people with dementia become anxious if they are asked to remember appointments. The partnering organisations will advise which participants this approach will be appropriate for. Participants' attendance of sessions will be taken as part of their agreement to participate in that session. At the beginning of each session, all participants will be asked three simple questions in conversation to help identify if they understand what they are about to do. The researcher will be assisted by a member of the participants organisation to help determine whether the researcher will be able to collect/use data from the participants during that particular session.

G.3. Will any of the participants have difficulty giving informed consent on their own behalf? ☐ Yes ☒ No

Please consider physical or mental condition, age, language, legal status, or other barriers.

If the answer is 'Yes' please answer G.3.1 and the following sections, otherwise please answer G.4 and continue from there.

G.3.1. If participants are not competent to give fully informed consent, who will consent on their behalf?

G.3.2. Will these participants be asked to provide assent to participation?

G.4. Is there a need for translation or interpreting? ☐ Yes ☒ No

If your answer is 'Yes', please provide copies of any translations with this application and any Confidentiality Agreement required for translators or interpreters.

H. Respect for Rights of Privacy and Confidentiality

H.1. How will the privacy and confidentiality of participants be protected?

Please note that privacy and confidentiality are different. For AUTEC's purposes, 'Anonymity' means that the researcher is unable to identify who the participant is in any given case. If the participants will be anonymous, please state how, otherwise, if the researcher will know the participants are, please describe how participant privacy issues and confidentiality of information will be managed.

Participants will not be anonymous to the researcher, other participants, and the organisations that support them. Participants will be asked and expected to keep the identity and privacy of other participants within the focus group confidential.

H.2. How will individuals or groups be identified in the final report?

If participants or groups will be identified, please state how this will happen, why, and how the participants will give consent.

Individual participants will be identified in the final report using a pseudonym of their choice. Any information that may identify them will either be removed or altered.

Any examples, photographs or video footage used in the final report will have identities obscured using techniques such as blurring or blocking. Any material resulting from the co-design sessions will be approved by the individuals with their satisfaction of anonymity prior to publication.

H.3. What information will be obtained from third parties?

This includes use of third parties, such as employers or professional organisations, in recruitment.

Organisations listed in B.9.2.1. have contact details of participants prior to the study taking place. The researcher will contact potential participants through the organisations till they receive consent and given the contact details of participants through the organisation or directly.

H.4. How will potential participants' contact details be obtained for the purposes of recruitment?

The organisations will collect the contact details of participants.

H.5. What identifiable information on the participants will be given to third parties?

No identifiable information will be given to third parties.

H.6. Who will have access to the data during the data collection and analysis stages?

The applicant, and the researcher/s.

H.7. Who will have access to the data after the findings have been produced?

The applicant, and the researcher/s.

H.8. Are there any plans for the future use of the data beyond those already described? ☐ Yes ☒ No

The applicant's attention is drawn to the requirements of the Privacy Act 1993 (see Appendix I of AUTEC's Applying for Ethics Approval: Guidelines and Procedures). Information may only be used for the purpose for which it was collected so if there are future plans for the use of the data, then this needs to be explained in the Information Sheets for participants. If you answered 'Yes' to this question, please answer section H.8.1.1 and continue from there. If you answered 'No' to this question, please go to section H.9 and proceed from there.

H.8.1.1 If data will be stored in a database, who will have access to that data and how will it be used and for what?

H.8.1.2 Will any contact details be stored for future use and if so, who will have access to that data and how will it be used and for what?

H.9. Where will the data be stored once the analysis is complete?

Please provide the exact storage location. AUTEC normally requires that the data be stored securely on AUT premises in a location separate from the consent forms. Electronic data should be downloaded to an external storage device (e.g. an external hard drive, a memory stick etc.) and securely stored. If you are proposing an alternative arrangement, please explain why.

Data will be stored in a lockable cabinet in Stephen Reay's office at the AUT city campus. Digital data will be stored on an external hard drive in a lockable cabinet Stephen Reay's office. Consent forms will be stored in a lockable cabinet away from the data in the Art and Design (WE) building at AUT.

H.9.1. For how long will the data be stored after completion of analysis?

AUTEC normally requires that the data be stored securely for a minimum of six years, or ten years for health related research. If you are proposing an alternative arrangement, please explain why.

For a minimum of six years.

H.9.2. How will the data be destroyed?

If the data will not be destroyed, please explain why, identify how it will be safely maintained, and provide appropriate informed consent protocols.

Electronic data will be deleted using erase through disk utility on a mac. Hard copy data will be shredded along with written consent forms.

H.10. Who will have access to the Consent Forms?

The applicant and the researcher/s.

H.11. Where will the completed Consent Forms be stored?

AUTEC normally requires that the Consent Forms be stored securely on AUT premises in a location separate from the data. If you are proposing an alternative arrangement, please explain why.

Consent forms will be stored in a lockable cabinet located in AUT Art and Design building (WE).

H.11.1. For how long will the completed Consent Forms be stored?

AUTEC normally requires that the Consent Forms be stored securely for a minimum of six years, or ten years in the case of health related research. If you are proposing an alternative arrangement, please explain why.

Six years minimum.

H.11.2. How will the Consent Forms be destroyed?

If the Consent Forms will not be destroyed, please explain why.

Consent forms will be shredded.

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required. For those participants with dementia, they will also have the support of their family member or primary carer.

I.1.8. Will any use of human remains, tissue or body fluids which does not require submission to a Health and Disability Ethics Committee occur in the research? ☐ Yes ☒ No

e.g. finger pricks, urine samples, etc. (please refer to section 13 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures) If your answer is yes, please provide full details of all arrangements, including details of agreements for treatment, how participants will be able to request return of their samples in accordance with right 7 (9) of the Code of Health and Disability Services Consumers' Rights, etc.

I.1.9. Will this research involve potentially hazardous substances? ☐ Yes ☒ No

e.g. radioactive material, biological substances (please refer to section 15 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures and the Hazardous Substances and New Organisms Act 1996). If the answer is 'Yes', please provide full details, including hazardous substance management plan.

I.2. Risks to Researchers

If this project will involve interviewing participants in private homes, undertaking research overseas, in unfamiliar cultural contexts, or going into similarly vulnerable situations, then a Researcher Safety protocol should be designed and appended to this application. This should identify simple and effective processes for keeping someone informed of the researcher's whereabouts and provide for appropriate levels of assistance.

I.2.1. Are the researchers likely to be at risk? ☐ Yes ☒ No

If your answer is 'Yes' please answer I.2.1.1 and then continue, otherwise answer I.3 and continue from there.

I.2.1.1 In what ways might the researchers be at risk and how will this be managed?

The researcher may be at risk of physical or emotional harm as participants affected by dementia may suddenly react irrationally. The researcher will not be conducting the research alone, a member of an organisation will be present at all times to aide the researcher as well as the participants family member or primary carer. Both parties will have experience with people with dementia, and may be able to predict such instances, and will also have experience in managing more complex situations as related to persons with dementia. If the researcher becomes upset from any verbal or physical abuse, AUT counselling team is available for their use.

I.3. Risks to AUT

I.3.1. Is AUT or its reputation likely to be at risk because of this research? ☐ Yes ☒ No

If the answer is 'Yes' please answer I.3.1.1 and then continue, otherwise answer I.3.2 and continue from there.

I.3.1.1 In what ways might AUT be at risk in this research?

Please identify how and detail the processes that will be put in place to minimise any harm.

I.3.2. Are AUT staff and/or students likely to encounter physical hazards during this project? ☐ Yes ☒ No

If yes, please provide a hazard management protocol identifying how harm from these hazards will be eliminated or minimized.

J. Truthfulness and limitation of deception

J.1. How will feedback on or a summary of the research findings be disseminated to participants (individuals or groups)?

Please ensure that this information is included in the Information Sheet.

Participants will be given a brief summary of the research findings as well as access to a digital copy of the final exegesis if requested. They will also be notified of the app if developed and will be able to download it for their use.

Where individual examples (i.e. sketches/prototypes) are used in the exegesis, consent will be obtained from participants involved. This will be done by sending an email, or letter with an example of the intent, followed by a verbal conversation.

J.2. Does your research include any deception of the participants, such as non-disclosure of aims or use of control groups, concealment, or covert observations? ☐ Yes ☒ No

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Deception of participants in research may involve deception, concealment or covert observation. Deception of participants conflicts with the principle of informed consent, but in some areas of research it may sometimes be justified to withhold information about the purposes and procedures of the research. Researchers must make clear the precise nature and extent of any deception and why it is thought necessary. Emphasis on the need for consent does not mean that covert research can never be approved. Any deception of participants must be acceptable when measured against benefit to the participants and the importance of the knowledge to be gained as a result of the project or teaching session. This must be addressed in all applications. Please refer to Section 2.4 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures when considering this matter.

If the answer is 'Yes' please answer J.2.1 and the following sections, otherwise please answer I.3 and continue from there.

J.2.1. Is deception involved?

J.2.2. Why is this deception necessary?

J.2.3. How will disclosure and informed consent be managed?

J.3. Will this research involve use of a control group? ☐ Yes ☒ No

If the answer is 'Yes' please answer K.1 and continue from there.

J.3.1. How will the Control Group be managed?

J.3.2. What percentage of participants will be involved in the control group?

J.3.3. What information about the use of a control group will be given to the participants and when?

K. Avoidance of Conflict of Interest

Researchers have a responsibility to ensure that any conflict between their responsibilities as a researcher and other duties or responsibilities they have towards participants or others is adequately managed. Staff members who propose to involve their students as participants in research need to ensure that no conflict arises between their roles as teacher and researcher, particularly in view of the dependent relationship between student and teacher, and of the need to preserve integrity in assessment processes. Likewise researchers have a responsibility to ensure that any conflict of interest between participants is adequately managed for example, managers participating in the same research as their staff.

K.1. What conflicts of interest are likely to arise as a consequence of the researcher's professional, social, financial, or cultural relationships?

There are no anticipated conflicts of interest foreseen.

K.2. What possibly coercive influences or power imbalances in the professional, social, financial, or cultural relationships between the researcher and the participants or between participants (e.g. dependent relationships such as teacher/student; parent/child; employer/employee; pastor/congregation etc.) are there?

It is anticipated that there will be some power imbalance between the family/whanau member or carer and person with dementia. For example the family may always talk for the person with dementia.

It is also anticipated that participants may find it difficult to critique the suggestions and work of the researcher expecting them to be more experienced.

The organisations assisting may have coercive influences over the participants and the researcher.

K.3. How will these conflicts of interest, coercive influences or power imbalances be managed through the research's design and practice to mitigate any adverse affects that may arise from them?

The researcher will remind the family member/caregiver to support people with dementia when they speak, and to try and not speak on their behalf. Asking participants directly may also help mitigate this. It is also hoped that the activities, due to their collaborative nature will minimise this from happening.

The researcher is attempting to co-create with participants, so that they view themselves as the creators and experts.

H.12. Does your project involve the use of previously collected information or biological samples for which there was no explicit consent for this research? ☐ Yes ☒ No

If the answer is 'Yes' please answer H.12.1 and the following sections, otherwise please answer H.13 and continue from there.

H.12.1. What previously collected data will be involved?

H.12.2. Who collected the data originally?

H.12.2.1 Why was the data originally collected?

H.12.2.2 For what purposes was consent originally given when the data was collected?

H.12.3. How will the data be accessed?

H.13. Does your project involve any research about organisational practices where information of a personal or sensitive nature may be collected and / or where participants may be identified? ☐ Yes ☒ No

If the answer is 'Yes' please answer H.13.1 and the following sections, otherwise please answer I.1 and continue from there.

H.13.1. How will organisational permission be obtained and recorded?

H.13.2. Will the organisation know who the participants are?

H.13.3. How will the identity of the participants be kept confidential?

I. Minimisation of risk

I.1. Risks to Participants

I.1.1. Risks to Participants

Please consider the possibility of moral, physical, psychological or emotional risks to participants, including issues of confidentiality and privacy, from the perspective of the participants, and not only from the perspective of someone familiar with the subject matter and research practices involved. Please clearly state what is likely to be an issue, how probable it is, and how this will be minimised or mitigated (e.g. participants do not need to answer a question that they find embarrassing, or they may terminate an interview, or there may be a qualified counsellor present in the interview, or the findings will be reported in a way that ensures that participants cannot be individually identified, etc.) Possible risks and their mitigation should be fully described in the Information Sheets for participants.

I.1.1.1 How much time will participants be required to give to the project?

There will be a voluntary one hour meet and greet held at the organisation to advertise the research and to meet the researcher. Potential participants will be invited, and encouraged to attend.

In phase one of the research, there will be six weekly co-design sessions, each lasting an hour long with a half an hour informal discussion afterwards. The objects of the each session is of note is:

1. Developing a character to represent their (participants) needs
2. Exploring their experiences since living with dementia
3. Deciding upon the issue (problem) we are going to solve
4. Evaluating others solutions
5. Developing our own design solutions
6. Designing how our design will look

In phase two of the research, there will be a once per month usability testing session with each participant pair (lasting 20min) for a two to three month period.

Participants will also be invited to attend AUT's end of year exhibition, if the final research/work is exhibited

I.1.2. What level of discomfort or embarrassment may participants be likely to experience?

At worst, a minimal level of discomfort or embarrassment is anticipated., However it could be caused by:

- Being in a group setting
- Presenting ideas
- Drawing images or making collages
- Feeling pressured while trying to remember
- Being filmed
- Participants may also get tired (age related)

I.1.3. In what ways might participants be at risk in this research?

It is not anticipated that participants will be exposed to a high level of risk, however participants may be at risk from each other physically and psychologically. Discussing ideas may exhibit strong emotions and when criticised in an abusive behaviour though not highly likely. There is also a degree of trust within the group to keep all information and data about each other confidential. It is not expected that this would be any different to group setting that participants would normally attend.

I.1.4. In what ways are the participants likely to experience risk or discomfort as a result of cultural, employment, financial or similar pressures?

Participants are not anticipated to experience such risk or discomfort. They may feel discomfort having been selected to participate based on their diagnosis of dementia, but in such cases they are not expected to want to participate in this research.

Participants may also be uncomfortable if the feel the researcher is judging their performance, as co-designers, even though the co-design process is an open, non-judgemental environment. The research will work calmly and patiently with participants and will support them to feel comfortably in the group activities. It is expected that many participants will be familiar with group activities, due to their circumstances (based on feedback during the consultation process).

There is also a risk the research may unintentionally pressure a participant with dementia to recall or remember something that may embarrass them if they are unable to.

I.1.5. Will your project involve processes that are potentially disadvantageous to a person or group, such as the collection of information, images etc. which may expose that person/group to discrimination, criticism, or loss of privacy? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

An individual participant may have their ideas, or may feel himself or herself criticised by another member of the focus group. The researcher will change the direction of the discussion and may remove participants if required from the study. Prior to each session, participants will be reminded that there are no right or wrong answers or views/perspectives, reminded to encourage every participant to speak and contribute to the session, and will be asked that participants keep private information within the focus group.

I.1.6. Will your project involve collection of information of illegal behaviour/s gained during the research which could place the participants at current or future risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

I.1.7. If the participants are likely to experience any significant discomfort, embarrassment, incapacity, or psychological disturbance, please state what consideration you have given to the provision of counselling or post-interview support, at no cost to the participants, should it be required.

Research participants in Auckland may be able to utilise counselling support from the AUT Counselling Team, otherwise you may have to consider local providers for participants who are located nationwide, or in some particular geographical area. You can discuss the potential for psychological impact or harm with the Head of AUT Counselling, if you require.

Participants are unlikely to experience harm. However a supporting member from their organisation will be present to help the researcher identify any discomfort and will support the researcher immediately address it. This also enables the participants to approach their organisation directly during the study, as well as afterwards if

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The researcher has asked for participants (person with dementia and family support/caregiver) to come to the research as pairs, which may empower them as a group to over come any power imbalances.

The researcher will have opportunities to speak with their supervisor as well as the supporting organisations if there are any issues.

K.4. Does your project involve payments or other financial inducements (including koha, reasonable reimbursement of travel expenses or time, or entry into a modest prize draw) to participants? ☒ Yes ☐ No

If your answer is 'Yes' please answer K.4.1 and the following sections, otherwise please answer K.5 and continue from there.

K.4.1. What form will the payment, inducement, or koha take?

The researcher will supply tea/milo/coffee and biscuits for participants to enjoy during or after each research session.

K.4.2. Of what value will any payment, gift or koha be?

Approximately $60-80 in total, for the supply of refreshments.

K.4.3. Will potential participants be informed about any payment, gift or koha as part of the recruitment process, and if so, why and how?

Participants will be made aware of a tea break in the information sheet given out at the beginning of recruitment.

K.5. Have any applications for financial support for this project been (or will be) made to a source external to AUT? ☐ Yes ☒ No

If the answer is 'Yes' please answer K.5.1 and the following sections, otherwise please answer K.6 and continue from there.

K.5.1. What financial support for this project is being provided (or will be provided) by a source external to AUT?

K.5.2. Who is the external funder?

K.5.3. What is the amount of financial support involved?

K.5.4. How is/are the funder/s involved in the design and management of the research?

K.6. Have any applications been (or will be) submitted to an AUT Faculty Research Grants Committee or other AUT funding entity? ☐ Yes ☒ No

If the answer is 'Yes' please answer K.6.1 and the following sections, otherwise please answer K.7 and continue from there.

K.6.1. What financial support for this project is being provided (or will be provided) by an AUT Faculty Research Grants Committee or other AUT funding entity?

K.6.2. What is the amount of financial support involved?

K.6.3. How is/are the funder/s involved in the design and management of the research?

K.7. Is funding already available, or is it awaiting decision?

No.

K.8. What is the financial interest in the outcome of the project of the researchers, investigators or research organisations mentioned in Part B of this application.

The research may try to sell an app on itunes based upon the data collected.

L. Respect for Property

Researchers must ensure that processes do not violate or infringe legal or culturally determined property rights. These may include factors such as land and goods, works of art and craft, spiritual treasures and information.

L.1. Will this research impact upon property owned by someone other than the researcher? ☐ Yes ☒ No

If the answer is 'Yes' please answer L.1.1 and the following sections, otherwise please answer L.2 and continue from there.

L.1.1. How will this be managed?

Focus groups will be held at locations owned by organisations other than the researcher or AUT. Care will be taken to ensure that the location will be respected and left in a tidy manner as when entered.

L.2. How do contexts to which copyright or Intellectual Property applies (e.g. virtual worlds etc.) affect this research and how will this be managed?

Particular attention should be paid to the legal and ethical dimensions of intellectual property. Care must be taken to acknowledge and reference the ideas of all contributors and others and to obtain any necessary permissions to use the intellectual property of others. Teachers and researchers are referred to AUT's Intellectual Property Policy for further guidance.

The app created from this research will remain the intellectual property of the researcher. However, all participants and contributors will be acknowledged for their role in the research and referenced accordingly within the exegesis (or other publications) produced as an output of this research.

M. References

Please include any references relating to your responses in this application in the standard format used in your discipline.

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N. Checklist

Please ensure all applicable sections of this form have been completed and all appropriate documentation is attached as incomplete applications will not be considered by AUTEC.

Have you discussed this application with your AUTEC Faculty Representative, the Executive Secretary, or the Ethics Coordinator? ☒ Yes ☐ No

Is this application related to an earlier ethics application? If yes, please provide the application number of the earlier application. ☐ Yes ☒ No