Collaborative Futures: A Technology Design Approach to Support Positive Experiences in Younger Onset Dementia

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Thesis submitted in fulfilment of the requirements for
the degree of

Doctor of Philosophy in Computing Sciences

under the supervision of
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July 2021

Certificate of Original Authorship

I, Jeanette Bell, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in Computing Sciences, in the School of Computer Science, Faculty of Engineering and Information Technology, at the University of Technology Sydney.

The thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature:

Production Note:
Signature removed prior to publication.

Date: 28 July 2021

The following is a list of publications arising from my candidature:

1. Frost, D., Dillon, S., Grady, S., Thurlow, J., Leong, T.W. & Bell, J. 2020, 'Approaches for authentic engagement: younger onset dementia', in R. Brankaert & G. Kenning (eds) *HCI and design in the context of dementia*, Springer, Cham, Switzerland, pp. 77–93.
2. Bell, J. & Leong, T.W. 2019, 'Collaborative futures: co-designing research methods for younger people living with dementia', *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, Glasgow, Scotland, pp. 1–13.
3. Bell, J. & Leong, T.W. 2017, 'Collaborative futures: a technology design approach to support living well with dementia', *Proceedings of the 29th Australian Conference on Computer–Human Interaction*, Brisbane, Australia, pp. 397–401.
4. Light, A., Pedell, S., Robertson, T., Waycott, J., Bell, J., Durick, J. & Leong, T.W. 2016, 'What's special about aging', *Interactions*, vol. 23, no. 2, pp. 66–9.

Acknowledgements

Producing a doctoral thesis is not a solo journey, and I am deeply grateful for the abundant support and encouragement from those who helped me reach this day.

First, I would like to thank my principal supervisor, Associate Professor Tuck Leong. I am most grateful for your wisdom, patience, and thoughtful approach to this sensitive research topic; helping me unravel the complexity, in a way that I could begin to explore dementia in a methodical way. Your considered and measured approach is one that I will take into my future research activities.

My deep thanks and gratitude to my co-supervisor, Associate Professor Julia Prior, for your calm and insightful guidance on ethnographic fieldwork; highlighting the value of being connected to the people and immersed in the culture you are researching.

Special thanks to Professor Toni Robertson, who invited me into the faculty and sparked my curiosity about HCI and Ethnography. From our first interaction, the way I looked at various social settings and engaged with life, changed forever.

To my family—Greg, Diane, Deb, Brad, Elaine and Bryan—thank you for giving me the emotional headspace to explore the world of dementia while we were also trying to make sense of how dementia was affecting our father, parents, and our broader family.

To the superheroes of this thesis—Dennis, Suzie, Phil, Stephen, Ann, Sebastian, and Jeff—I am indebted to you all. The dignity with which you live is humbling and inspiring. You have made a generous contribution to this research through your dedication and efforts, for which the HCI community is most grateful. Thank you.

Special thanks to my research peers—Tomm, Saud, Eleanor, Jeannette and Max, for your support on this project. Big thanks to Dr. Amber Burns—for the many hours of debate, laughs, and for assisting me to distil volumes of data into meaningful insights. To Jess Cox, thank you for the proofreading and for keeping me focused—who doesn't love a rainbow colour-coded work plan! Heartfelt thanks my dearest friends—Paddy, Jeff, Robyn. Thank you for allowing me to be 'quiet' and dedicate time to this thesis.

To my beloved children—Jayson, Phen, Ruby, and Jonathan. You epitomise joy! I feel loved, grateful, and privileged to share my life with you. Thank you for living bold lives and encouraging me to do the same. While the COVID-19 pandemic continues to keep us apart, I hope we will get to live in the same country again one day—at least for a while.

Finally, to my devoted little dog, Timmy, your listening skills are sublime! Thank you.

Dedication

To my beloved parents.

I dedicate this thesis to you with profound gratitude for your love and compassion for others.
May your spirit shine on forever through this work.

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Abstract

Digital technologies are firmly embedded in the day-to-day lives of people living with Younger Onset Dementia (YOD), like their peers who do not live with dementia. This unexpected insight is one of several from this research into the lived experiences of people with YOD and their use of digital technology.

Dementia is complex and multifaceted. It is a term used for a range of symptoms affecting cognition which go beyond memory loss. Essentially, dementia is a state of cognitive decline with a pathology that manifests in sensory changes affecting language, perception, social cognition, sight, smell, and executive decision-making—all dynamics that can make the dementia experience unique to each person.

Younger Onset Dementia (YOD) is a subset of dementia, and an unexpected event in this age group, often resulting in a greater negative impact on their lives. However, most research to date is situated in Late Onset Dementia (LOD). This is problematic as the experiences and circumstances in YOD are vastly different from that of their older counterparts—as is their use and uptake of digital technologies.

In the HCI setting, as in other research sectors (medical, social, disability, and psychiatry), researchers have couched YOD as one homogenous (dementia) group. This has resulted in technologies designed to support people in a later stage of life, and perhaps in more advanced stages of dementia, e.g., surveillance technologies, reminiscence technologies, and assistive technologies. While this work in LOD is vital, the needs and wants of people within the younger group has been largely overlooked.

This HCI research revealed that people with YOD have very different needs and wants. They are being diagnosed when still in employment, and generally in good physical health. They are also highly engaged with digital technology. Furthermore, people with YOD rally for greater inclusion in YOD research activities. However, current methods in dementia research are often not suitable for this younger group who seek agency and independence.

This study is the first working example of Participatory Action Research and Ethnography in YOD. The PAR cycles include a 2 -year ethnographic fieldwork with a group of tech savvy people with YOD. This research culminated in a series of recommendations for HCI researchers and designers to consider when working in dementia and other sensitive settings.

Chapter 1.

Introduction

> *"The lived experiences are of greater importance than the technologies themselves when considering how to create a new technology for dementia"*
>
> —Composed by a person living with dementia

1.1 Background and context

The quote introducing this chapter reflects the essence of this research. This quote surfaced during a technology co-design workshop in response to the question: *What would you like Human Computer Interaction (HCI) researchers and designers to think about when designing digital technologies for people with younger onset dementia (YOD)?* The person's response was decisive, instructive and inspiring. They are asking the HCI community to first understand their lived experiences before thinking about designing new technologies for dementia.

This clear guidance from a person living with dementia (one of five individuals who joined me on this research journey) echoed that of HCI researchers McCarthy & Wright (2004). While these HCI authors were not speaking particularly about dementia, they suggest that to design meaningful technologies, we first need to appreciate the *emotional, intellectual and sensual aspects of our interaction with technology* (McCarthy & Wright 2004). However, accessing these personal experiential responses to technology is problematic in the dementia setting.

As I set out to understand these complex human experiences in a way that would be engaging, meaningful and insightful, I immediately hit a roadblock on how to approach research with these younger individuals. My broad search across the various academic databases (Medical, IT, Social Science, Economics and Law) for relevant literature on dementia and technology [and ethics] revealed three gaps in the context of HCI research with this younger age group. First, most publications relating to dementia and use of technology, were found in non-HCI databases. Second, I discovered that, while the medical and clinical manifestations of dementia were well researched, the lived experiences of dementia remained largely unexamined. Third, collectively, the research in dementia and technology largely focuses on the more advanced stages of dementia.

To further confound the problem, first-hand accounts detailing the lived experience of dementia proved to be rare, with a limited number of books or articles published. I observed that what we understand about dementia mostly comes from popular media sources, such as news reports, documentaries, movies, magazines and social media feeds. Furthermore, these reports typically portray a person with late onset dementia (LOD): *medically classified as being over the age of 65 years at the onset of symptoms*

Essentially, this image is associated with the advanced stage of dementia: *loss of memory; loss of the ability to bathe and nourish oneself; loss of self; and loss of agency, with a gradual disengagement with life—physically, intellectually and emotionally.* This not only reinforces a homogenous view of dementia: *a person who needs a high level of supervision and institutional care*, it also propagates unnecessary stigma (irrespective of age) through this narrow projection of dementia.

1.2 What I had learned by this point…

The first (of many) realisations I had from my early explorations, was that the YOD group are socially engaged, vocal, independent and intellectually engaged in life; they may also be social lobbyists and representatives for others living with dementia. This was far from the frail person with dementia I had prepared myself to meet (and recruit) into this research. This was a group I wanted to collaborate with, but first, I needed to re-examine what I understood about dementia.

In terms of younger onset dementia, the literature (section 2.2) informed me that a diagnosis of dementia in an earlier stage of life has a higher social impact for individuals and families to endure. Many people with YOD are actively involved in all aspects of life, are still in the workplace, have dependant families, and have substantial financial commitments such as mortgages.

What I understood about late onset dementia stemmed from my personal experience, with my father having lived with Alzheimer’s disease for 10 years. I had also spent 15 years in medical science, working in a multinational pharmaceutical company that looked for pharmacological interventions for Alzheimer’s disease. These two perspectives shaped my deeply held beliefs on dementia. My motivation to research *dementia and technology* came with the realisation that there were no pharmacological solutions or cure on the horizon, whereas digital technology design was advancing to support people to live well with dementia. These technologies were also easily accessible being enmeshed in our everyday lives and may provide relief. I took this as an opportunity to look for ways in which digital technology could provide support to people with dementia—and their families.

1.3 Now, where to start?

Conducting research in the area of dementia is a well-trodden ground across various research sectors (section 2.4). However, during my early investigations, I found that these methods (and approaches) were not necessarily suitable to implement for research with younger people with dementia – who are in an earlier stage of life, and still quite independent. For example, the widespread approach of introducing a proxy to speak and act on behalf of a person with advanced dementia may not necessarily be acceptable for the newly diagnosed, younger person with dementia, who retains agency and autonomy. Furthermore, this step of assigning a proxy may not even be an ethical practice in the YOD research setting.

Before I discuss these methodological issues in more detail and why some practices are ethical in one dementia setting, but not another, I would like to take a moment to focus on the characteristics of YOD, and what it feels like to receive a diagnosis when you are in the younger age group.

This next section is written in a style to support the reader in imagining a person who is experiencing dementia in an earlier phase of life; in other words, to highlight the profound social impact of a diagnosis which is quite unexpected in this age group and at their particular stage of life.

1.4 What is younger onset dementia?

While there are both similarities and differences in how dementia is clinically expressed, the key differentiator is age. People diagnosed with dementia earlier in life have vastly different experiences to those of their older counterparts (Rossor et al. 2010; Sansoni et al. 2016a). Often, this results in a greater negative impact on both the lives of the younger individuals and their families (Greenwood & Smith 2016). A person is medically classified as having YOD when diagnosed with symptom onset under the age of 65 years.

From a medical perspective, if a person is diagnosed with dementia over the age of 65 years this is classified as having later onset dementia. Rossor et al. (2010) describes this age divide as *'a cut-off point that is indicative of a sociological partition in terms of employment* *and retirement age: but this age has no specific biological significance and there is a range of disease features across this arbitrary divide'*.

In contrast, Draper et al. (2016) report that there *is* a biological significance and that generally YOD individuals present in good physical health and may not experience the comorbidities associated with dementia in the older age group. However, both perspectives have merit.

Setting aside the debate on the biological features of dementia for a moment, the sociological partition described by Rossor et al. (2010) places YOD individuals on the working side of the employment/retirement divide. Many are the main income earner and are often forced to leave paid employment because of their dementia diagnosis (Rossor et al. 2010). As Greenwood and Smith (2016) attest, this constitutes a far greater negative impact for this younger age group to endure.

This negative impact is partly due to the timing of the diagnosis. In the next section, I endeavour to provide a window into the experience of being diagnosed with dementia in an earlier stage of life. This is a time when this diagnosis is unexpected due to the stereotypical presentation of person who is perhaps retired and coming to terms with their gradual and changing life circumstances.

1.4.1 A window into YOD

Experiencing dementia at an earlier stage of life is an unexpected and profound event, for both an individual and their family. In clinical practice, the unique characteristics of dementia in this younger demographic are often overlooked. Physicians typically do not expect a younger person to present with dementia; therefore, their initial diagnosis is often 'depression' because depression-like symptoms—such as tiredness, withdrawing from friends and family, and poor concentration—are also presenting features in depression and anxiety. Receiving a (misdiagnosis) of depression can lead to diagnostic delays of up to two years for people with YOD compared to LOD, because an older person presenting with these symptoms would be screened for dementia (Draper et al. 2016; Sansoni et al. 2014). This diagnostic delay leads to treatment delays and, subsequently, delayed access to support services. This is a devastating position for a family to be facing.

1.4.2 What it feels like to be diagnosed with dementia

Here, I offer the reader a sense of what it is like to be diagnosed with dementia to illustrate the felt and lived experience at the moment of being diagnosed with YOD.

The following information is drawn from interview data gathered during my research. It personifies the diagnostic journey for a younger person who is experiencing the first signs and symptoms of dementia; this is at a time when they are most likely employed; in good physical health; and have dependants, financial commitments and an active social/family life (Sansoni et al. 2016b).

The moment unfolds like this:

> *I'm at the height of my career.*
>
> *Recently, I found I'm late for work and missing meetings. Often.*
>
> *This is unusual for me, so I seek professional help. I'm told it's work stress and to take time off—to rest.*
>
> *I'm tired (constantly) and I'm not recognising cues of hunger or thirst.*
>
> *I seek medical help. I'm told its depression; I'm given antidepressant medication.*
>
> *I'm forgetting my colleagues' names, but I know their faces. I joke to hide my forgetfulness. I start to call everyone 'mate'.*
>
> *Now, I'm failing in the workplace—and my relationships are failing, too.*
>
> *I am now experiencing anxiety. Depression.*
>
> *I seek medical help—again. I'm diagnosed with dementia.*
>
> *I feel relieved.*

This evocative prose not only reflects the confronting lived experience for the person being diagnosed, but it also highlights the complexity of forming a medical opinion. I now backtrack and continue to unpack the multifaceted social impact that a person with dementia—and their family—now face.

1.4.3 Unpacking the broader realities of YOD

While the person is coming to terms with this definitive diagnosis, there are realisations of the broader realities to contend with—such as sudden employment loss, emotional shock, isolation and the lack of age-appropriate support services—because governments and social systems are underprepared to cope with the rise in YOD.

Younger generations are now being diagnosed in their thirties, forties and fifties; hence, healthcare, community and social support systems are having to understand and tackle issues unique to this younger group (Sansoni et al. 2014). For instance, some may even be parents of young children, who are forced to leave paid employment because of their dementia diagnosis (Rossor et al. 2010). Conversely, some children will take on carer roles in the family. This introduces an additional layer of complexity (out of scope for this research program), with dependent children often trying to cope with the stigma of a parent having dementia. The social aspects of living with a diagnosis of dementia in in earlier stage of life will be discussed in detail in the next chapter.

Overall, this is a time of rapid change for the family. Families are faced with unforeseen emotional and lifestyle changes, as well as the extra financial difficulties of managing costs associated with the medical and emotional support required for the path on which they now find themselves (Sansoni et al. 2016a; Van Vliet et al. 2012). That said, while there are financial support mechanisms for short-term accommodation and respite, these benefits are somewhat irrelevant for the younger group because they are not ready to be moved into high-care facilities, such as being moved to an aged-care home which (mostly) are not designed to support the needs of a younger persons with dementia.

Next, I will present a medical and economic overview to highlight the scale and costs of dementia at a global level.

1.4.4 The medical and economic impact of dementia

First, the medical perspective. Dementia is terminal, with no treatment or cure currently on the horizon. Scientists still do not know how to prevent the disease from occurring, how to stop its progression, or how to reverse its effects (World Health Organization 2019). Dementia is made further complex by not being one specific disease, but an array of symptoms. It is an umbrella term that describes a wide range of symptoms affecting the function of the brain. These symptoms vary from person to person and involve a slow deterioration of memory and alterations to sensory processing, impacting a person's ability to perform everyday activities (Dementia Australia 2010). The most common causes of dementia include Alzheimer's disease, vascular dementia and dementia with Lewy bodies. Dr Alois Alzheimer first characterised dementia as a pathology in 1906, calling it 'pre-senile' dementia. Prior to Dr Alzheimer's medical discovery, it was believed that cognitive decline was a natural part of the ageing process

(ADI 2017). Although age is the strongest known risk factor for dementia, dementia is not considered to be a natural part of ageing (World Health Organization 2019).

Physiologically, the cognitive domains affected by dementia include:

- complex attention, or the ability to pay attention and process information
- executive ability, which is involved in decision-making, planning, working memory and mental flexibility
- learning, and long- and short-term memory
- language
- perception, which can affect tasks such as picking up an object or handwriting
- social cognition, or the ability to recognise and regulate emotions, behaviours and social appropriateness (American Psychological Association 2013).

The World Health Organization (WHO) recognises dementia as a public health priority, reporting that, worldwide, approximately 50 million people have dementia with an additional 10 million new cases being diagnosed each year. The total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050 (World Health Organization 2019).

Economically, the total estimated annual global cost of dementia in 2020 is more than US$1 trillion. This figure includes costs attributed to informal care (i.e. unpaid care provided by family and others), direct costs of social care (provided by community care professionals and in-residential home settings), and the direct costs of medical care (Paola Barbarino 2020).

Now, that I have presented some preliminary insights into the YOD experience (at the time of diagnosis)—plus the social, medical and economic impacts—I will provide a brief review of the fundamental theories that informed my approach to this research.

1.5 Work of others

In addition to my early conversations with advocacy groups, a review of the literature surfaced two significant gaps: **theoretical**, with a scarcity of first-hand accounts of the dementia experience; and **methodological**, with a lack of tailored methods for conducting research and design in YOD.

The research presented in the next section informed the direction of my work. While not addressing research and design in YOD, this work provided the insight, direction and inspiration I needed to approach research in this sensitive setting. I will begin with earlier work, before moving to the more recent research in dementia that was published at the time of finalising this thesis.

1.5.1 Approaches to dementia research and technology design—past and present

The relationship between YOD and digital technology is an important area for the HCI community to explore, because this generation of people diagnosed with dementia will have aged alongside the evolution of digital technology. Thus, they will likely have a greater aptitude for using new technologies than most individuals who are currently living with late onset dementia. The need/benefits for technological support in dementia, and the issues with learning, useability, and uptake of new technologies, has been discussed in earlier papers, as follows.

HCI researchers (Alm et al. 2003; Cohene et al. 2005; Ly et al. 2016) have reported on digital technologies to support memory function and aid reminiscence. While other authors have written about fostering social engagement by facilitating conversations between young people and people with dementia through digital media (McNaney et al. 2017; Welsh et al. 2018). In other work, Brittain et al. (2010) re-analysed two studies (which involved speaking both to people with dementia and their carers about accessing outside spaces, and the benefits and risks of using technology in supporting them outdoors) suggest that there is an increasing risk of people with dementia being excluded from society as the demands of technology extend beyond their capabilities.

Allen (2016) points out that it is important to ensure that individuals with dementia can use new technologies, by identifying and addressing the barriers to technology use. In the future, this could lead to a range of accessible and usable technologies (e.g., everyday ICT, assistive technologies, telemedicine) to support independence and agency (Allen et al. 2016).

In fact, as societal functions become increasingly automated, the need for people with dementia to remain connected to technology becomes ever more important. This is particularly the case given the degree that social connectedness is facilitated through social apps and platforms, yet, "*while these systems and services are widely available for people without a cognitive disability, the development and adaptation for persons with dementia remains a problem*" (Wallace et al. 2010).

The examples in this section show various applications for technology to support people living with dementia, as well as their carers—through music, reminiscence, safety and surveillance technologies.

However, while there have been digital technologies designed specifically with dementia in mind, I am not aware of technologies purposely designed for YOD individuals.

1.5.2 Personhood and Dementia

In the paper, *A Design-led inquiry into personhood in dementia* (Wallace et al. 2013a) describes ways of posing questions to facilitate an understanding of the experience of dementia. The work of Wallace et al. (2013a) inspired me in two ways.

First, it addresses personhood in dementia research, and demonstrates how HCI researchers / designers can engage deeply with someone with dementia and bring them into the centre of the design process. According to Wallace et al. (2013), *'personhood is the potential for preserving the agency of people living with dementia … yet to date, design research in HCI foregrounding personhood and the self is extremely rare'*. This was the area in HCI that I was hoping to contribute to through this research program.

Second, it alerted me to the fact that couples may need to remain closely connected; Wallace et al. (2013) needed to engage with the husband's experience (in addition to Gillian, who was experiencing dementia) because *their lives and experiences of dementia were so tightly intertwined*. Therefore, even if I had planned to work with the person living with dementia without a proxy, I needed to be mindful of their personal relationship dynamics.

Tomas Kitwood (Professor of Clinical Psychology) progressively and successfully challenged the 'old culture of care' in dementia settings. Kitwood suggests that personhood can be explained as being socially constructed in an interactional environment, defining it as a *'standing or status that is bestowed up on one human being, by others, [implying] recognition, respect and trust'*.

> *To do full conceptual justice to the uniqueness of persons—in any context—is an extremely complex matter, we need to take account of temperament, innate ability, interests, tastes, beliefs, values, commitments, lifestyle, biography, gender, class and culture—at the very least* (Kitwood 1997, p. 14).

Kitwood's call to preserve personhood in dementia research, and the inclusive and respectful approach taken by HCI researchers (Wallace et al. 2013, Tanner 2012) inspired me to broaden the scope of my work—to prioritise the collection of data that would build insights into the lived and felt experiences of people with dementia, as well as to collect data by observing the relationship of the YOD group with everyday technologies.

Still, the guidance on how to conduct this research and the technological solutions (memory, reminiscence and safety surveillance) discussed so far, do not necessarily address the complexity and multiplicity of dementia. Additionally, many research activities are often conducted without people with dementia being represented. This is especially problematic for the younger age group. For example, using **surveillance technology** could be seen as compromising the privacy and freedom of individuals with YOD, who have retained their decision-making rights and agency. Moreover, these technologies are often designed with **input from a proxy**, acting on behalf of the person with dementia. The younger demographic—who express a desire to speak for themselves—do not always require this.

So far, I have spoken briefly about existing technologies that are appropriated for use in the dementia setting and discussed how researchers have worked to characterise personhood and expressed the need to think about the person (not the disease) when conducting research, design and/or when working in healthcare settings. Next, I will present a few examples of more recent views in HCI and dementia research and design.

1.5.3 Current HCI research in the dementia setting

Here, I focus on more recent work in HCI. With relevant publications presented at the 2021 Conference on Human Factors in Computing Systems (CHI).

In 2021, HCI researchers explored the potential benefits of conversational agents in the dementia setting—such as Google Home and Alexa—looking to build insights into how these technologies could empower older adults with mild cognitive impairment (and their care partners). In this research, the care partner needed to anticipate the needs of the person with dementia, and 'set up' a scaffold to support the individual by entering calendar invites and reminders (Zubatiy et al. 2021). This study reminds us of the level of input required by a care partner for the technology to benefit those older adults with mild cognitive impairment.

The inclusion of proxies in dementia research is discussed many times throughout this thesis. In terms of the current thinking about deploying a proxy in dementia research, HCI researchers (Dai & Moffatt 2021) recently published 'Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research'. In this article, the proxy is described as a secondary stakeholder to the primary stakeholder (the person with dementia). The authors caution the reader about the risk of 'overshadowing the voices of people with dementia' and provide guidelines for researchers conducting preliminary work and research design in the dementia setting. They list the following advice:

- Engage with the community extensively to establish trust and rapport with participants and proxies, as well as to allow for deeper understanding of the context.
- Involve relevant proxies and choose appropriate approaches for the research context and spectrum of dementia.
- Explore multiple information sources and facets of research design.
- Assess the power dynamics among participants and proxies and develop concrete redirection plans.

Notably, people with YOD are likely to be more digitally literate than older adults, who have a limited technology repertoire, but this is not to say that being digitally literate is exclusive to younger adults. I base this assumption on the age-related uptake of technology in the general population. In a survey by (Dixon et al. 2021) with 17 'tech savvy' people with dementia (average age 62.5 years old) revealed technology use (for self-management) is driven by people with dementia rather than caregivers.

Interestingly, while these publications (Dixon et al. 2021; Wallace et al. 2013) included participants under the age of 65 years, their work focussed on the broader social framework of technology, personhood, and dementia. This further validates the need for HCI to take a deeper dive into the YOD experience and their use of digital technologies.

How do we work out the needs for this younger age group? People living with YOD are saying that they are unlikely to accept technologies for surveillance and monitoring (this is related to their concerns with human rights). It is also clear that the current methods used in dementia research (such as using a proxy to speak on behalf of a person with dementia) are not only inappropriate for but would be fiercely rejected by those with YOD.

1.6 Wanting to know more—my goals as a resercher

Once I began to understand the distinctions between YOD and LOD, it became evident that I needed to rethink this research program and find an approach that considered these unique circumstances.

There are two key problems that I needed to tackle:

1. The lack of insight into the felt and lived YOD experience.
2. The lack of appropriate methods to understand these experiences.

While research protocols and methodologies for the more advanced stages of dementia are well established in HCI, there was limited guidance (methods or approach) available for conducting research in YOD.

I needed to map out the following key actions:

- Assess current methods used in dementia research and adapt for use in YOD.
- Work out how to approach and engage with this group of people, who are coming to terms with dementia, yet are independent and do not need a proxy to speak and act on their behalf.
- Understand the life circumstances of people with YOD and how technology plays a role in their lives.
- Map the physical and emotional needs of YOD individuals regarding technology design, in a way that would benefit future research in this or similar settings.

With the scant literature to be found, and these goals in mind, I decided take time to explore the environment before launching into the research design (this took me one year). I started by going to dementia-related conferences and visiting local non-profit dementia organisations (including Dementia Australia, who represent people living with dementia and are involved in their care). I also turned to international dementia advocacy groups for guidance. This early step in my research proved to be imperative to ensuring that authenticity, trust and integrity were the foundations of this project, and that the right people/organisations were in place to guide both me as a researcher and those I had invited into this research.

1.6.1 Consulting widely in the dementia environment

Early on, one important group I was fortunate to engage with was Dementia Alliance International (DAI)—a non-profit group of people with dementia from around the world—who campaign for '*a unified voice of strength, advocacy and support in the fight for individual autonomy, improved quality of life, and for the human and legal rights of all with dementia and their families*'. DAI stress that a person with dementia should never be an after-thought in the design process—whether it be designing a piece of technology, building or 'dementia-friendly' community environment:

> *We are very keen to represent ourselves in all matters concerning dementia, in the philosophy of Nothing About Us, Without Us* (DAI 2017).

The significance of a rights-based approach to care is that people living with dementia are now legally entitled to be included in any policy or process that affects them; that is, not simply consulted or represented by others in matters that directly concern people with dementia.

People living with dementia must be included in all work that concerns their future. DAI reflects this in their philosophy: *'Nothing about us, without us'* (DAI 2017).

From the outset, this mantra laid the foundation for each step of my research project.

1.7 Gaps—methodological and theoretical

My preliminary inquiries with dementia advocacy groups—and the expansive review of literature—identified two fundamental gaps in context of YOD and technology. This research aims to address both.

Methodological: While there are available guidelines and methods for research in advanced dementia, (such as assigning a proxy to speak and act on behalf of a person with dementia) this is not necessarily acceptable for a younger person, in the early stages of dementia. Typically, this younger group would like to have more agency in research—with retained decision-making rights, they seek to maintain their independence and have expressed that they do not need or want a proxy to speak on their behalf. Furthermore, they seek a greater level of input and collaboration in the YOD research and design process, however, I found little-to-no guidance on how to approach or design research this setting.

Theoretical: In addition to (and perhaps because of) the methodological gap, there is a theoretical gap. Accounts of the dementia experience are rare and there are very few empirical studies which investigate YOD and their technology needs. This void may be attributed to a lack of visibility of YOD. As mentioned earlier in this chapter, even physicians do not typically expect a younger person to present with symptoms of dementia in their thirties, forties and fifties. In fact, many still view YOD as being much rarer than LOD (Sansoni et al. 2016c); therefore, many researchers (and healthcare professionals) are not capturing the needs of this group.

This research hopes to address these experiential and methodological gaps by taking guidance—from HCI researchers (Vines et al. 2013; Wallace et al. 2013) and from others who have paved a way forward by decoupling the disease from the person (Kitwood 1997; Tanner 2012), and working closely, collaboratively, with people living with YOD.

To explain how these experiential insights will be developed and the methodological gaps filled, I will outline how I set up a research framework aiming to foster collaboration with people with YOD to inform and guide the direction of this research program.

1.8 Looking for a research framework to support those with YOD

Early on, I realised that a large portion of my research would require me to spend time gathering understandings of the YOD experience. As per McCarthy and Wright's (2004) recommendations, to design digital technologies for YOD, I needed to first understand the experiences of my target group. I also needed to take a personalised approach.

Inspired by the researchers mentioned above, I now focused on ways of understanding and mapping the experiences of people with YOD—surfacing their 'needs and wants' for future digital technologies to support living well with dementia.

I needed to find an approach that was not only cognizant of each participant's environment, situation and experiences, but was also thoughtful, sensitive and respectful to their unique needs. Equipped with this awareness, I searched across various disciplines of research for work in similar settings and consulted with my university peers, for insight and direction.

After careful thought and consultation with my research supervisors, PAR was chosen because it addressed all the points mentioned above. This framework facilitated a long-term collaboration between me and people with YOD. The utility of the PAR framework was that it provided 'enough' structure to establish shared goals/plans, try new ideas, collect and analyse data together, reflect, build and validate YOD insights together, adapt, and move to the next cycle of PAR.

PAR has been used in the dementia setting—for example, in a critical participatory action research and arts-based program to develop methodologies for self-management producing resources—to support people with dementia and their care partners (Dupuis et al. 2021). While extremely valuable, this work was not focused on YOD; their life stage or their lived and felt experiences and how the engage with digital technology.

In this PAR program for YOD, three cycles of action research were designed as follows:

Participatory Action Research model for YOD:

> **PAR Cycle 1:** Exploring new ways to research in YOD
>
> **PAR Cycle 2:** Trialling new HCI research methods for YOD
>
> **PAR Cycle 3:** An ethnographic exploration into YOD and the role of technology to develop deeper more nuanced understandings, building on cycle 2

Each cycle informed the design and goals of the next. The PAR model created an environment in which empathy and trust could develop between researcher and participant over time. Cycle 3 included a longitudinal, ethnographic study conducted over two years. The importance of this longitudinal stage (in hindsight) was that only over time could the researcher–participant relationships mature to a level that provided the deep familiarity and robust conversations that surfaced during the final stages of the research.

The reason I introduced an ethnographic fieldwork in cycle 3, was to explore the culture (beliefs, rituals, interactions) of the YOD group—as they live or coexist—in their community and social networks.

The YOD group, which I happened to recruit, turned out to be proficient users of digital technologies and social media platforms (smart phones, tablets, AV equipment, 3D printing and social media platforms). We were all therefore motivated and excited to look at the role of technology was playing, and could play in YOD, now, and well into the future.

Once the PAR cycles ended, I introduced a one-day workshop into the research program (described in Chapter 7). The output from the technology design workshop was a series of personal recommendations by those with YOD (such as their desired features for YOD in digital technology design) for future HCI researchers and designers to consider in the future.

1.9 Scope and research goals

While the emphasis of this research is on dementia, it is not about the biology, anatomy or the physiology of this terminal condition. Nor is this thesis about conducting a deep exploration into the lived experiences of people with dementia.

This research aimed to find ways of working directly with people living with YOD—on their terms. To conduct research that is respectful of their needs and that amplifies (not replaces) their voice and their message. To decouple the disease from the person—as others have done before me such as Kitwood (1997) with his work on personhood.

The research goals were twofold:

1. Work closely with the YOD community to understand what they needed from (HCI) researchers and designers to join our research programs—in terms of methods, tools and approaches.
2. Map the lived experiences of a few YOD individuals over time; to better understand their relationship with everyday technologies and their needs and wants from researchers and designers.

My job was to work out the following: *How do I thoughtfully and respectfully approach this work? How do I recruit? How do I conduct YOD workshops? How do I understand which digital technologies would work best with this younger group?*

These points have been largely overlooked in both the broader dementia research space, and in the HCI literature. For example: *How much do we need to know as HCI researchers about the lived everyday experiences of YOD to design suitable technologies?* I will aim to address these points in this thesis.

While the desired outcome is for the greater inclusion of YOD individuals in future HCI research and design processes, my hope is that the approach outlined in this thesis not only benefits people with dementia (YOD) but may also benefit others in similar sensitive settings.

1.10 Contributions to HCI

This thesis describes an exploration into YOD; it provides insights into the YOD experience while also advancing the knowledge about how technology is currently being used to support people with YOD.

Through the implementation of an action research model; this research makes the following contributions to HCI research practices. It also offers a series of recommendations for HCI technology designers to leverage in future design practices for YOD.

1.10.1 Theoretical contributions

This research offers valuable insights into the lived experience of YOD through a series of biographies: one for each person living with dementia who joined me in this research. Each story is generous, inspiring and unique—as is each person's experience and each person's preferences with technology. This research program and biographies highlight their relationship with digital technology and extends the understanding of how to design meaningful and useful digital technologies for this younger group, and their broader community.

Please note: *In this thesis, all participants who joined me in the research (over four years) are identifiable by name. Even though I started out de-identifying the individuals in my writing, as the research progressed, I was encouraged, and given permission, to use names (not aliases) in my research reports, publications and this thesis. This was considered (by those with YOD) as reinforcing their presence and amplifying their collective voice, while also supporting their agency and sense of self.*

1.10.2 Methodological contributions

Methodologically, this research has produced practical guidance on how HCI researchers can successfully identify, recruit and collaborate with YOD individuals—to design and implement empirical studies with a collaborative PAR framework.

By applying the principles of PAR and ethnography in this research, 'we' have (collaboratively) delivered several methodological contributions for research and design in the YOD setting.

Methodologically, this research:

- Adds to the understanding of how probes can be used productively in HCI in the YOD setting (and other similar settings) by providing a working example of how they can be co-designed with participants, and how participants can self-select and personalise the probes used based on their preferences and strengths.

- Provides practical guidance on how researchers can recruit and collaborate successfully with YOD individuals as co-researchers.
- Describes a co-directed inquiry into the lived experiences of YOD and, as such, advances the knowledge in this area and the role that technology has in the lives of people with YOD.
- Contributes to the small, but growing, number of cases of PAR in HCI, with the first account of how PAR can be used in HCI research with YOD individuals.

At the end of this thesis, there are practical recommendations from those with YOD, for a more collaborative approach to research in dementia: one that is sensitive, respectful and empowering to participants.

Finally, this thesis presents a reflexive view, with a critical reflection about my role in this research program. This considers my family history with dementia; my professional experience in medical science and the emotional load of staying in this research setting for five years. I also share my experience and insights on approaching ethics applications, managing stigma and working with language guidelines for research into dementia.

1.11 Overview of Thesis

Chapter two discusses the key bodies of work that underpin this research program. It includes a review of the literature on dementia and technology, spanning various domains within the dementia setting, for example, medical, disability, geriatric medicine, economics, and the social research streams. This chapter examines the existing literature in 'younger onset dementia, 'technology and dementia', the 'dementia experience', and 'research and design methodologies 'for the dementia setting.

Chapter three provides an overview of the Participatory Action Research (PAR) methodology. It presents the rationale for choosing an action research model and for including a longitudinal ethnographic fieldwork in the final action research cycle. It describes ways that PAR was implemented with the aim to surface first-hand insights into YOD, in research setting that would foster a trusted, respectful, long-term collaborative relationship between myself and people with YOD. Greater inclusion of the participants, facilitated by the PAR model, was of immense benefit to this project as people living with YOD brought their professional and academic insights to the work.

The participants came from careers in Science, IT, Business, and Law, in addition to having a predilection for digital technologies and social media platforms. Chapter three also provides a **Research Roadmap**: a blueprint that illustrates the activity plan for each of the *three action research cycles*. This is a useful tool to guide the reader through the thesis, summarising each stage of the PAR model (3 cycles) and the final study—a Technology Design Workshop.

Chapter four describes the first of the three cycles of the PAR model. This is where I spent 12 months in the field to better understand the methodological gaps in relations to research with the younger group of people with dementia - as identified in the literature review. I also conducted a co-design workshop with the first two participants recruited, to explore more appropriate ways to conduct research and design into YOD

Chapter five describes PAR Cycle 2. The aim of this first empirical study was to test a collaborative and tailored approach to review the methods for YOD research. This formative period in my research also established the researcher–participant imperatives of trust, integrity and respect, and set the overall direction and design of the subsequent two studies.

Chapter six describes PAR Cycle 3 (final cycle), where the combination of methodologies (PAR and Ethnography) facilitated the development of deeper insights into the everyday life of a person with YOD, over a longer period. This cycle was designed to better understand the YOD culture and community practices. I chose a biographical style of reporting from the field, to foster a rich empathy and greater visibility of the YOD group, their community and their culture. Essentially, this chapter provides an alternative way to look deeper into the YOD condition and observe their relationships with digital technologies through ethnographic fieldwork.

Chapter seven presents the design, implementation and findings from a one-day Technology Design Workshop. This was the final activity in this PhD program. At this stage of the research, the collaboration between people with YOD, their families and the university researchers at the University of Technology Sydney (UTS) was well established. There were two parts to this one-day workshop:

> ***Part 1:* Planning the logistics**, with a small team of HCI researchers and the YOD group. The goal was to take the time upfront to understand the logistical requirements for engaging a group of people with dementia in a one-day workshop (e.g., travel requirements, meals, working out what constitutes a 'dementia-friendly' meeting location).

> *Part 2:* **Workshop activities and analysis.** The Technology Design Workshop investigated participants' experiences with technology in context of dementia—and identified how we (the HCI community) can facilitate the input of people with YOD in future workshop activities.

The chapter concludes with a series of recommendations for **HCI researchers** on how to run a workshop with, and for, those with YOD as well as recommendations for **HCI designers** on technology attributes that would best support the YOD group.

Chapter eight concludes this thesis, offering key insights from the people living with YOD, to future HCI researchers and technology designers. In this final chapter, there is a discussion on the opportunities for HCI to look more closely at this subset of dementia and bring them more closely into research and technology design practices. In addition, HCI (experienced researchers) have called for our community to openly reflect about ethical challenges of "sensitive HCI" research, so our community of can learn from shared experiences. Therefore, I make a personal contribution on 'reflexive practice' in the YOD setting to support future researchers who may wish to work in YOD or similar settings.

1.11.1 Thesis structure—a guide to reading this thesis

To support reading this thesis, here I describe a few structural elements and definitions:

Younger onset dementia is a medical classification of dementia—an arbitrary age divide—described as having the onset of symptoms before the age of 65 years. Up until the 2010s, the literature often referred to this younger age group as having 'pre-senile dementia' (as characterised by Dr Alzheimer). However, this term is no longer favoured and is seen to reinforce the stigma associated with dementia. Instead, the terms 'young-onset dementia', 'younger onset dementia', and 'younger people with dementia', are now commonly used (Rossor et al. 2010).

In this thesis, I have chosen to use the term **younger onset dementia,** which I adopted following advice from Dementia Australia. The Dementia Australia website (https://www.dementia.org.au) provides substantial resources for people living with dementia, families, and researchers.

Writing style: The style of writing and reporting changes in some sections of this thesis, predominantly in Chapter 6, where I include a series of biographies - one for each participant in the research. The choice of inserting a biography for each person, was to further enrich the complex relationships through using a storytelling style. Additionally, I make use of photographs, illustrations and personal quotes to add an emotional dimension for the reader of this thesis. This was important because it was a way to provide context and a deeper understanding of the YOD experiences, and their broader YOD culture.

Notetaking: Field data are recounted using direct quotes, which are italicised and indented in this thesis. To assist in capturing the many conversations throughout the course of the research project, I kept detailed hand-written notes with personal observations and reflections added; I cross-referenced these notes for key events and emergent themes during the data analysis activities. All thematic based insights were transferred into a coding spreadsheet.

Terminology: The term 'we' is used to acknowledge the evolving roles, as the research–participant relationships organically moved to research collaborators and then research partners. The evolution of conventional roles proved most fruitful at the Technology Design Workshop (presented in Chapter 7), where we were all familiar with the HCI way of approaching the workshop and had a shared understanding (and motivation) of the goals of this research.

Finally, this thesis aims to illuminate the unique YOD experiences (as defined by people with YOD) and the role of technology, to highlight this area of research to the HCI community.

Please note: While this research seeks to understand the unique experiences of YOD, this focus is not intended to negate the complexities of being diagnosed with dementia in a later stage of life. Rather, this thesis aims to shine a light on the life circumstances of people with YOD, their unique needs and wants, and their underrepresentation in most research and design activities.

The hope is that these preliminary insights into YOD will prepare the reader for the gravitas and complexity of this subject, the unchartered research path that lies ahead, and the opportunities for HCI to further contribute in this and other similar settings.

Chapter 2.

Literature Review

2.1 Chapter overview

This chapter provides a critical review of the literature on dementia from the perspectives of medical science, socioeconomics and technology. It establishes current theoretical understandings of the dementia experience, and how research and design practices are responding to this ever-changing space.

Reviewing the literature in the dementia and technology design space required an extensive search across databases spanning the medical, social, disability, information technology, psychiatry and gerontology domains. This is because, for some time, various research disciplines outside of HCI have been thinking about how digital technologies could support those with dementia, particularly considering the high costs associated with medical and pharmacological solutions.

The literature review revealed, most key publications on dementia and technology were largely situated in the medical, geriatric, disability, and social science databases. Furthermore, the search revealed that articles relating to the younger group with dementia was negligible compared to that of their older counterparts.

The following six categories frame the presentation of literature in this chapter.

1. **Younger onset dementia (YOD)** This section reviews what is currently known about YOD and the relationship that people with YOD have with digital technology—this is the underpinning of this PhD research. The section first introduces YOD then looks at the specific differences between this younger group and the LOD group.

2. **Medical Science** This section provides an overview of dementia, outlining the physiology, diagnostic pathways and treatments, as well as the economic and social impacts.

3. **Holistic approach and modifiable risks** The issues surrounding dementia span medical, government, healthcare and social landscapes; all have varying views, policies and procedures for tackling dementia. Most research efforts to understand dementia focus on addressing the condition's medical and

socioeconomic impacts (Brown et al. 2017; Withall 2014), mainly in people with more advanced dementia. In this section, I introduce a multidisciplinary approach to managing modifiable risk factors for dementia.

4. **The dementia experience** This looks more closely at the experience of dementia. It unpacks social attitudes, such as factors that reinforce stigma, and shines a light on two (rare) accounts of living with YOD.

5. **Digital technology and dementia** This section examines how technology is currently being used in the dementia setting. Here, I examine the importance of understanding the human experience in HCI practices—within the context of dementia—and explore how the dementia experience is currently being considered.

6. **Current methods used in dementia research** This section examines current qualitative research methods in the dementia setting and interrogates the appropriateness of these methods within the context of YOD.

The next section begins with an overview of YOD before presenting the broader perspectives of dementia.

2.2 Younger onset dementia

The term dementia can be confusing, with wide-ranging misconceptions about how it is experienced at an individual level as well as during different phases of life. In the past, impaired memory was a natural and expected part of ageing. This direct association between dementia and the ageing process, however, no longer holds true (World Health Organization 2019). To provide clarity to term YOD, I will unpack its main characteristics and underscore how profoundly impactful a diagnosis of dementia is, when it occurs in an earlier stage of life.

2.2.1 Characteristics of YOD

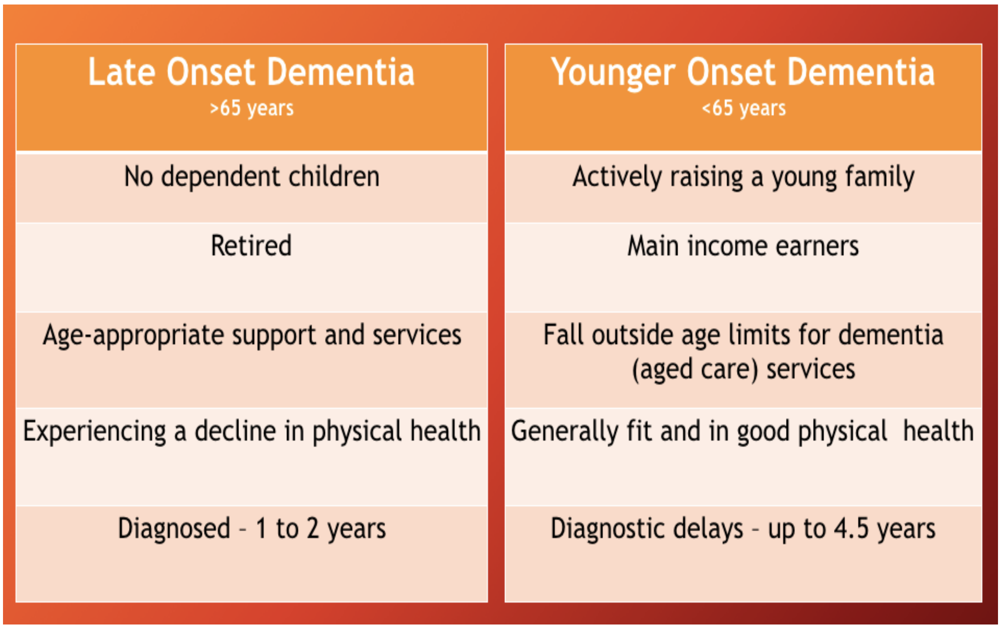
Dementia can affect younger people—those in their 30s, 40s and 50s (Withall 2014). YOD is medically classified in those people younger than 65 years at the onset of symptoms (Draper et al. 2016). With younger generations now being better diagnosed, new issues are emerging that are specific to this group, which highlights the need to better understand how these younger individuals experience dementia as opposed to their older counterparts.

At the time of a YOD diagnosis, people are younger, still employed, physically active and engaged in all aspects and demands of family life. Often, a diagnosis of dementia is quite unexpected and traumatic when a person is aged in their 30s, 40s or 50s. Reports also suggest that few age-appropriate support services are available at the time of diagnosis, making this a confounding set of circumstances for both the individual and their family network (Sansoni et al. 2014; van Vliet et al. 2010; Withall 2014).

The available literature on YOD was primarily concerned with the medical and physical manifestations of dementia, as well as its overall economic and social impact. There are very few first-hand accounts of the dementia experience and essentially no empirical research focusing on the experience of the family unit (Sansoni et al. 2016; Van Vliet et al. 2012). Most efforts from the various academic and commercial sectors have focused on dementia in the aged population (Brown et al. 2017; Withall 2014). The broad multidisciplinary interest described above, with its focus on LOD, manifests a knowledge gap as to the unique characteristics of YOD. In the next section, I will discuss these key differences.

2.2.2 YOD and LOD

The main differentiator between YOD and LOD is both age and stage of life at the time of diagnosis (Table 2.1).



Late Onset Dementia >65 years	Younger Onset Dementia <65 years
No dependent children	Actively raising a young family
Retired	Main income earners
Age-appropriate support and services	Fall outside age limits for dementia (aged care) services
Experiencing a decline in physical health	Generally fit and in good physical health
Diagnosed - 1 to 2 years	Diagnostic delays - up to 4.5 years

Table 2.1 Key Differences between LOD And YOD. Adapted from Sansoni et al. (2016).

Dementia experienced in the later stage of life has been relatively well characterised, in terms of demographics and physiology, while the needs and circumstances of people living with YOD are still becoming known (Alzheimers Australia 2017; Sansoni et al. 2014). Being diagnosed when you are still in employment, often the main income earner, have family and financial commitments and, generally, are in good physical health is vastly different to the experience of being diagnosed with dementia later in life (Rossor et al. 2010; Sansoni et al. 2016a).

Research efforts have contributed to significant understandings of the social and economic needs of people with LOD, which has transformed how dementia care is approached (Brown et al. 2017; Withall 2014), particularly with the exploration of 'personhood' in dementia (Cahill et al. 2004; Downs 1997; Kitwood 1997). However, little is known about the felt and lived experiences of younger individuals. This is problematic because the lived experiences of YOD are not only markedly different from LOD, but there are also often greater negative impacts on both the individual's life as well as the lives of their family (Greenwood & Smith 2016).

Another key feature differentiating YOD and LOD is how actively engaged the younger group are in all aspects of society. As such, the YOD community is calling for the emergence of an agenda for YOD; I will describe this in the next section.

2.2.3 The emergence of an agenda for YOD

While not reflected in the academic databases, there is a growing global movement by people living with dementia who rally for greater inclusion in research practices and policy development activities; most activists are in the YOD group.

There are two key dementia advocacy groups—the Scottish Dementia Working Group (SDWG) and DAI—at the forefront of change in the dementia setting. These groups are self-deterministic, with a powerful 'collective voice' and a growing membership exclusively for people with medically confirmed dementia (DAI 2017). DAI calls for researchers and designers to take a human rights approach to dementia research, which includes taking steps to involve people with dementia at every step of the project, process or policy development that concerns them. Furthermore, DAI asserts that a person with dementia should never be an after-thought in design processes—whether it is designing a piece of technology or building a community environment, they have asked to be involved at each step. DAI expresses this social justice call to action as follows:

> *Our work on claiming the Human Rights for all people with dementia means we are legally entitled to be included, and not just consulted, or represented by others* (DAI 2017).

So far, I have described dementia, explained how YOD is a subset of dementia and emphasised that the needs and goals of people with YOD are quite different from those with LOD. In addition, I have pointed out the complexities of working in the YOD setting and which governing advocacy bodies are seeking change. Next, I will present how medical science views dementia, outlining the physiological, diagnostic and treatment pathways.

2.3 Medical science and dementia

The scale of dementia is both compelling and confronting. At the time of this literature review, 50 million people globally have dementia symptoms. Approximately 10 million new cases are predicted to be diagnosed each year, equating to a new case being diagnosed every 3 seconds. The total number of people with dementia is estimated to reach 82 million in 2030 and 152 million in 2050 (World Health Organization 2019).

People with dementia have now been afforded the equivalent human rights status as any other person with a disability. In 2010, the United Nations recognised dementia as a disability, based on the premise that it causes 'long-term physical, mental, intellectual or sensory impairments, which, in interactions with other various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations 2010).

What this means to people living with dementia, and their families, is better access to support services. For example, the National Disability Insurance Scheme (NDIS), established in Australia in 2013, provides support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disabilities. It also provides early intervention supports for eligible people with disability, or children with developmental delays. The NDIS is Australia's first national scheme for people with disability and it provides funding directly to individuals (NDIS 2020).

The introduction of this thesis briefly touched on the medical, social and economic perspectives of dementia. In the next section, I will explain the medical theories unpinning a clinical diagnosis and treatment approach in the dementia setting. I will also delve deeper into the social and economic viewpoints on dementia.

My motivation for providing this more detailed overview (albeit not HCI-specific) is to highlight the complexity, scale and inherent ethical imperatives of conducting research in the dementia setting. I will begin with pathology.

2.3.1 Dementia a medical and clinical overview

Dementia is not one specific disease. It is a syndrome that describes several neurological conditions, of which the major clinical symptom is the decline in brain function due to physical changes in the brain. This decline can affect individuals differently and can impact different aspects of cognition, including a deterioration in memory and alterations in sensory processing function such as sight, taste, touch, pressure, sound, smell, hunger, thirst, time and proprioception (perception of the position and movement of the body), all of which impact the ability to perform everyday activities (Houston 2018; Rossor et al. 2010; Sansoni et al. 2014).

When executive decision-making is affected, this aspect of the condition has widespread impacts on the individuals' experiences in their everyday lives (Bakker 2003; Houston 2018).

The causes of dementia, and subsequent changes to the brain, vary according to the type of dementia. From a physiological perspective, there are four subtypes of dementia: (Raz et al. 2016).

The causes of dementia, and the subsequent changes to the brain vary according to the type of dementia. From a physiological perspective, there are 4 dementia subtypes: (Raz et al. 2016)

1. **Vascular dementia** a heterogeneous group of cognitive disorders caused by diminished blood flow to the brain, characterised by endothelial dysfunction, atherosclerosis, small vessel disease, ischaemia and haemorrhage.
2. **Alzheimer's disease** the most common form of dementia, characterised by accumulation of Aβ plaques, hyperphosphorylated tau and neurofibrillary tangles, cerebral amyloid angiopathy, and amyloid precursor protein.
3. **Lewy body dementia** the second-most common cause of dementia in older people, characterised by α-synuclein, Lewy bodies, cerebral amyloid angiopathy, amyloid-β, hyperphosphorylated tau and neurofibrillary tangles.
4. **Frontotemporal dementia** a heterogeneous group of neurodegenerative dementias, characterised by atrophy of the brain's front and temporal lobes,

hyperphosphorylated tau inclusions and transactive response DNA-binding protein-43, to list some plaque theories.

Assessing pathological changes to the brain using medical imaging techniques along with analysing markers in blood can be used in the diagnosis of dementia, in conjunction with cognitive changes which will be discussed next.

2.3.2 The clinical diagnosis of dementia

According to the *Diagnostic and statistical manual of mental disorders* (DSM-5), which many healthcare professionals use to diagnose dementia, the condition is a neurocognitive disorder. This means that, from a medical science perspective, the main clinical impact is on cognitive function, which includes thinking and related processes (APA 2013). Based on the extent of the cognitive decline, dementia can be further classified as being a major or minor neurocognitive disorder (APA 2013).

In both the major and minor forms of dementia, six cognitive domains are affected (APA 2013):

1. **Complex attention** This involves sustained attention, divided attention, selective attention and information processing speed. For example, the person has increased difficulty in environments with multiple stimuli (e.g. TV, radio, conversation), or has difficulty retaining new information.
2. **Executive ability** This involves planning, decision-making, working memory, responding to feedback, error correction, overriding habits and mental flexibility. For example, the person is unable to perform either familiar or complex tasks and projects and may need to rely on others to plan daily activities or make decisions. The person may also have problems with abstract thinking, display loss of initiative, or have poor or decreased judgement.
3. **Learning and memory** This involves immediate memory, recent memory (e.g. free recall, cued recall, recognition memory) and long-term memory. For example, the person may repeat themselves in conversation, cannot remember a small list of items when shopping, or requires frequent reminders.
4. **Language** This involves expressive language (e.g. naming, fluency, grammar, syntax) and receptive language. For example, the person has significant difficulties with expressive or receptive language and can often use phrases such as ‘that thing’ and ‘you know what I mean’. As the decline progresses, the person may not remember the names of close friends and family.

5. **Perceptual (motor–visual perception, praxis)** This involves picking up the telephone, handwriting and using a cutlery. For example, the person may have difficulty performing familiar activities, such as using tools, driving or navigating in familiar environments.
6. **Social cognition** This involves recognising emotions and behavioural regulation, as well as social appropriateness in terms of dress, grooming and topics of conversation. For example, the person's behaviour may change, showing insensitivity or making unsafe decisions, or the person may become socially isolated or withdrawn.

Circling back to the HCI community: These sensory changes are particularly important for HCI designers to understand when they are designing digital technologies to support people with dementia. What this means is that each individual with dementia will have differing physiological outcomes. Some will have retained abilities to read, and write, while others will find handwriting quite difficult. This aspect will be highlighted in **Chapter 4** (probes co-designed by people with YOD), in which these cognitive characteristics needed consideration when designing the methodological tools and artefacts to be used in the research program. In fact, it raised the issue of having a one size fits all approach when conducting research in the dementia setting.

The sensory aspects become relevant again in **Chapter 5**, which presents Study 1 (to trial the tools and approach co-designed by two people with YOD). In Study 1 the 'same probe pack' was distributed to each participant. However, the findings revealed that this would have failed as a methodological option, if the participant had not been given a choice to self-select their means of communication (whether this be handwritten diary entries, texts, emails or voice recordings). The approach implemented in Study 1, was designed by those with YOD—this approach allowed for these 'medical' characteristics to be considered in the design of probes, and when collecting data. **Chapter 6** includes personal examples of communication preferences based on the individuals' retained abilities surface.

2.3.3 Pharmacological treatments for dementia

There are no disease-modifying treatments for any form of dementia (Tisher & Salardini 2019). Medications to help with some dementia symptoms include cholinesterase inhibitors, which can provide small improvements in cognition and functioning; however, they also have sometimes serious side effects (Arvanitakis et al. 2019; Fink et al. 2020). Another medication that can be prescribed for people with dementia is memantine, which has evidence of providing a small overall benefit on cognition in people with moderate-to-severe dementia (Joe & Ringman 2019).

Patients may also benefit from non-medication approaches, including activities that engage cognitive activity, such as such as reading, physical exercise and social activities (Arvanitakis et al. 2019).

Several therapeutic tools can minimise the consequences of dementia, including cognitive and behavioural components and strategies to minimise harm. When used individually, these interventions may only improve the quality of life of the person with dementia minimally (Tisher & Salardini 2019). However, there may be more benefit when employed as a variety of strategies and interventions (Tisher & Salardini 2019).

In the next section, I will present emerging theories from the medical, social and economic sectors. I will also introduce the need for a diverse and multidisciplinary approach to understand and manage dementia from different angles.

2.4 Various domains of research in dementia

The issues surrounding dementia span the medical, government, commercial, healthcare and social sectors; all with varying views, approaches, policies and procedures for managing the far-reaching impact of this condition.

Most research efforts to understand dementia focuses on addressing the condition's medical and socioeconomic impacts (Brown et al. 2017; Withall 2014) mainly in populations with the more advanced forms of dementia, and in a later stage of life.

2.4.1 Medical research

Through the medical lens, dementia is a terminal condition, with no cure or effective treatment available. Since 2003, more than 500 clinical trials examining treatments for Alzheimer's disease have been conducted, and more than 50 drugs have failed in phase 3 clinical trials (Bachurin et al. 2017; Cole & Seabrook 2020; Marasco 2020). These include Aβ-targeting agents, β-secretase inhibitors, intravenous immunoglobulin, aspirin, ginkgo biloba, idalopirdine, minocycline, nivaldipine and pioglitazone, among others (Marcuso et al. 2019). The research has focused on testing new medications on people in earlier phases of the disease, before or early into the emergence of cognitive symptoms. Currently, there are 13 drugs in phase 2 or 3 clinical trials for Alzhemier's disease, which target Aβ, tau, inflammation, neuroprotection and metabolism (Cole & Seabrook 2020; Marcuso et al. 2019).

2.4.2 Socioeconomic research

While medical research is keen to develop pharmacological interventions, and improve diagnostic methods (McKhann et al. 2011), governments and academics have conducted widespread research to grasp the socioeconomic impacts of dementia (Brown et al. 2017; Launer 2019; Wimo et al. 2013). From a social perspective, the term 'dementia' is widely used and understood as a disease associated with ageing. This conception of dementia as one homogenous group encompasses the image of advanced dementias, in which the person becomes frailer both cognitively and physically. In some research processes, this term automatically assigns the individual to a vulnerable group.

Through the economic lens, most reports are concerned with the negative impacts of dementia experienced later in life (Prince 2015; Wimo et al. 2013) because this is where the brunt of the economic burden lies. The annual global cost of dementia is estimated at $US 818 billion. Remarkably, approximately 85% of these costs relate to family and social support, rather than medical care. By 2030, the annual global costs of caring for people with dementia are expected to rise to $US 2 trillion (World Health Organization 2019).

2.4.3 Taking a multidisciplinary approach

Many academic, medical, social, corporate and government disciplines are working together to chart a way forward in dementia care, helping to break down the complexity and make sense of the scale and socioeconomic burdens.

A Lancet Commission for dementia, consisting of an international multidisciplinary group of dementia experts, performed an extensive review of the evidence related to dementia prevention, intervention and care (Livingston et al. 2020). The group identified 12 modifiable factors that increase a person's risk of developing dementia, including less education, hypertension, hearing impairment, smoking, obesity, depression, low physical activity, diabetes, low social contact, alcohol consumption, traumatic brain injury and air pollution (Livingston et al. 2020).

Each risk factor can be assigned to a stage of life, although the factor is not always exclusive to one life stage (Figure 2.1). The Lancet Commission experts also assigned a percentage to each risk factor, indicating the prevalence of dementia that could be reduced by if the risk factor was eliminated (Figure 2.1). For example, if hearing loss was prevented, there could be a corresponding 8% decrease in the number of people developing dementia. Taken together, the 12 modifiable risk factors account for about 40% of worldwide dementias, which could theoretically be delayed or prevented (Livingston et al. 2020).

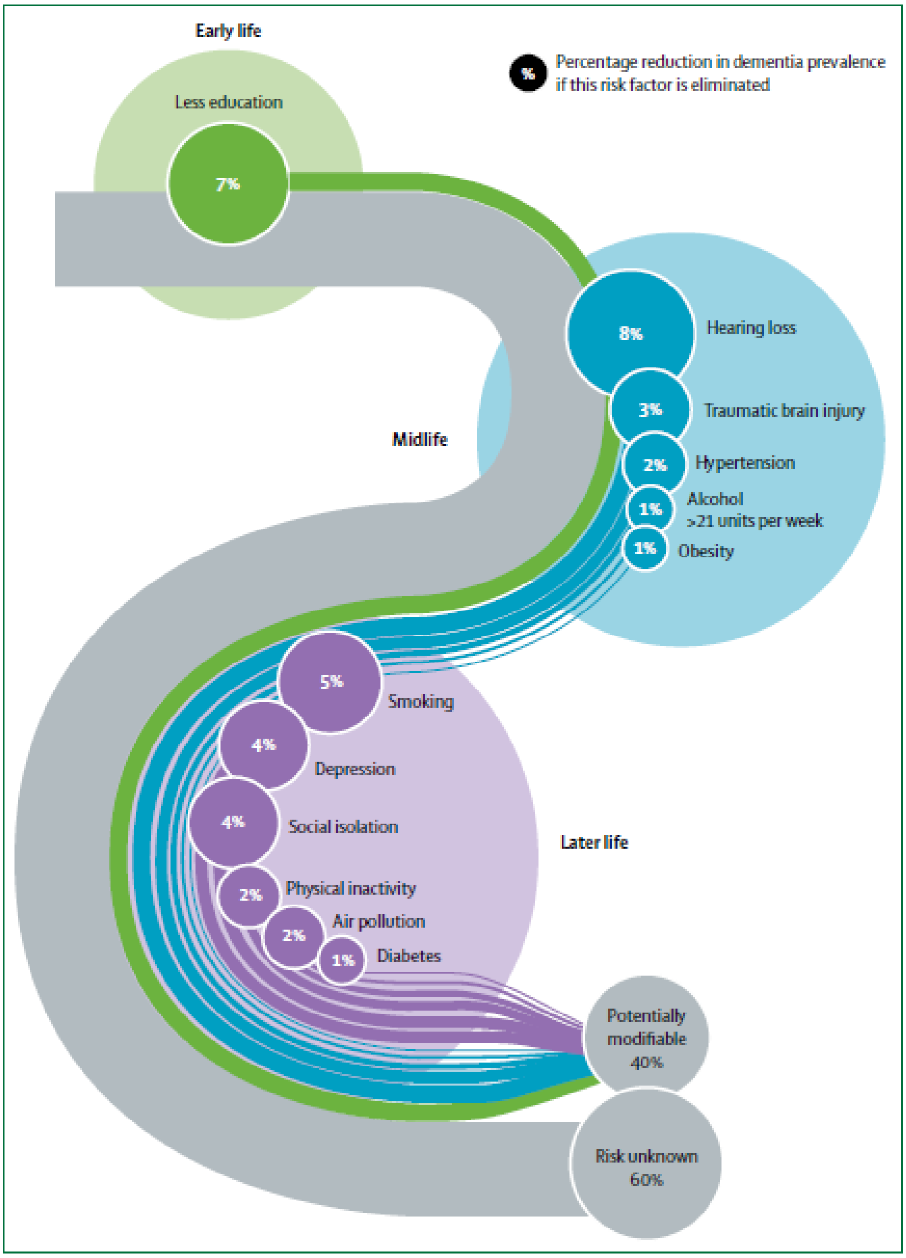


Figure 2.1 The population attributable fraction (PAF) of potentially modifiable risk factors for dementia (Livingston et al. 2020).

Following from this, medical experts proposed two mechanisms for dementia protection (Livingston 2020). The first is by reducing neuropathological damage, and the second is by increasing or maintaining cognitive reserve—which describes the difference between an individual's clinical picture and their neuropathology, in spite of any pathology and / or neuropathological damage. Each of the 12 modifiable risk factors can be mapped to one or both of these protective mechanisms, for which educational, social, and medical strategies can be developed in order to reduce risk (Figure 2.2).

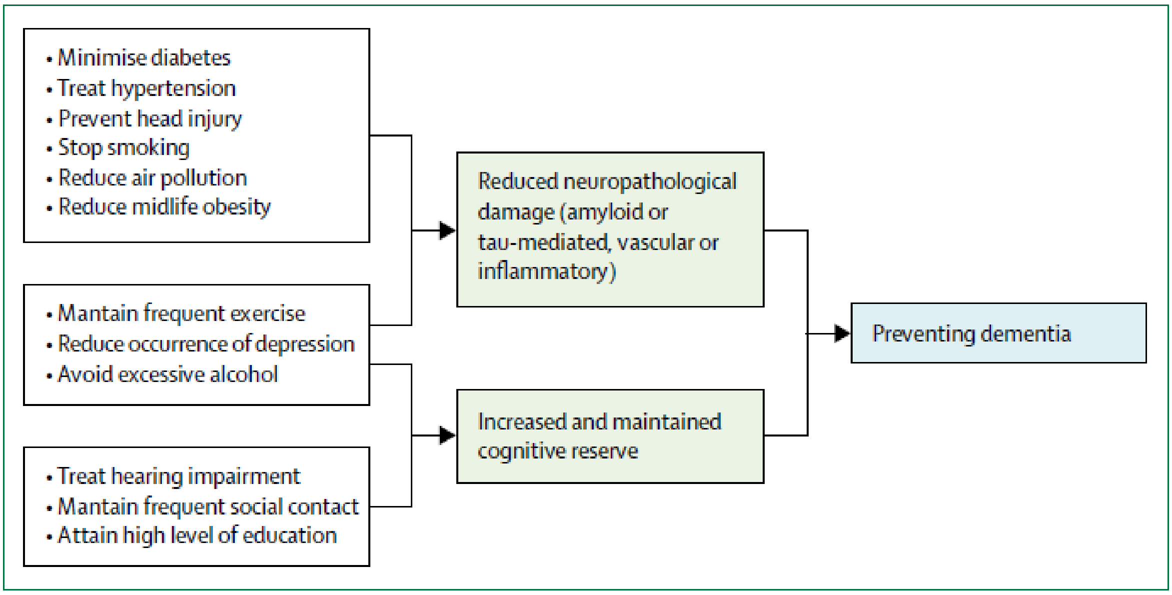


Figure 2.2 Potentially modifiable risk factors for dementia and possible brain mechanisms for enhancing or maintaining cognitive reserve (Livingston et al. 2020).

In parallel with this holistic approach, the HCI community are engaging in the research and design of digital technologies to support people living with dementia. This technological support is particularly pertinent for the younger group—technology is more likely to be embedded in their day-to-day lives.

While not situated in the HCI domain, or specifically about hearing loss, this is an example of where everyday technologies have a role to play in reducing dementia risk in each of the modifiable risk factors identified above. In hearing loss, for example, the use of hearing aids and other hearing assistive technologies, noise-level notifications built into earphones, and noise-cancelling headphones can help to prevent and manage hearing loss. This may inform future technology design and present opportunities for digital technology to support lifestyle factors through biofeedback tools and apps.

2.5 The dementia experience

To be human is to relate, connect and bond with others—these underpin the philosophy of personhood. Personhood is the quality or condition of being an individual person. At its core is 'the self' (that is, who we are, our values and beliefs); therefore, personhood does not diminish as dementia progresses. While dementia can change a person's memory, language, mood, judgement, sensory ability and behaviour, it does not change their personhood or who they are. Failing to consider personhood within the context of dementia is to deny people of a basic human need.

The notion of personhood was first linked to people with dementia by Professor Kitwood, who suggested that it is imaginable to conserve personhood even in the 'extremeness' of the dementia condition (Kitwood 1997).

To respect personhood means that, as researchers, we need to move into a person's world to connect with the individual within. To overlook personhood may result in feelings of denial, fear and needing to take control.

Through his research in the field of geriatrics, Dr Daniel Davis (2004) questioned the biomedical view of dementia as a disease. He suggested that, by looking into the lifeworld of a person with dementia, we may be able to dispel the stigma and associated fear of the dementia condition. As Davis posited, it is this fear that triggers a 'fading away' and 'loss of self' of people who have been diagnosed with dementia.

> *This critique of sociological and philosophical foundations of dementia might offer a way of approaching the dismantling of the self and revise current conceptions of dementia care for the better* (Davis 2004).

Those insightful reflections further inspired me to understand the experience of dementia and its unique challenges—such a perceived loss of identity and associated social stigma—before looking for how technology can support these individuals.

2.5.1 The YOD experience

Table 2.1 presented the key characteristics of YOD and LOD, with the main differentiator being age. A diagnosis of dementia in an earlier phase of life results in vastly different circumstances to those that occur when diagnosed with dementia later in life—when people are often retired and experiencing declining health, and their children have left home. The pivotal moment in the dementia experience (for both YOD and LOD) is the diagnosis. Many confronting, confusing and traumatic experiences are connected to the diagnostic pathway. The literature notes additional challenges on the diagnostic pathways for YOD, which is often prolonged and is reported to take up to four years in some cases (Mendez 2006; Sampson et al. 2004). A reason for this is the stereotypical view that dementia only affects older adults; therefore, anyone who does not fall into this 'older' category confounds the diagnosis.

This homogenous view of dementia often leads to a misdiagnosis because, initially, many people with early symptoms of YOD are diagnosed with stress or depression (Thompson 2011). Once diagnosed, the experience can involve dealing with the loss of employment, added financial burden, emotional shock, lack of age-appropriate support services and the challenge of having dependent children trying to cope with a parent with dementia (Sansoni et al. 2016).

In addition to the lengthy diagnosis time, people with YOD also need to contend with grief, social isolation, feeling stigmatised, and having children stigmatised and burdened as young caregivers (Erol et al. 2015; Sansoni et al. 2016; Van Vliet et al. 2012). This is exacerbated by the lack of social support services tailored for YOD—most are focused on the needs of people with LOD.

From the literature, it is difficult to fully understand the impact a YOD diagnosis has on an individual and their family, and experiential accounts are rare to find.

To foster a richer understanding for the reader, in this next section, I briefly introduce two people living with YOD, who have provided valuable perspectives on the YOD experience.

2.5.2 Living with dementia—a personal perspective

American gerontologist Anne Basting (2003) says it is remarkable that accounts of the dementia experience exist at all. For many, confusion and the loss of being able to communicate make it difficult to perform everyday tasks, let alone record or physically write down one's thoughts. However, these texts are also remarkable for what they teach us about the values and definitions of the 'self' (Basting 2003).

Christine Bryden was 46 years old when she was diagnosed with dementia, and wrote her personal account of this in the book, *Who Will I Be When I Die?* Christine clearly states she wanted to become a survivor and did not want to be labelled with 'dementia', because that implied she was no longer a unique person, after being diagnosed by a specialist one day with an illness of cognition (Bryden 2012).

Another autobiographical account comes from Kate Swaffer. Kate was 49 years old when she was diagnosed with YOD and describes her experience with dementia as 'seeing the world in a new way'. Kate describes her first year, post-diagnosis, as a 'dark place'. Kate was advised to go home and put her 'life affairs in order' and give up work and university, and to consider time in an aged day-care centre.

As already stated, many people think that dementia is a disease that can only appear in later life, in 'old age'. However, ageing is not a risk factor for dementia. Kate says that dementia is the only experience she has ever had where she has experienced what the late Martin Luther King described as a sense of 'nobodiness'. That is, feeling like a non-human being. Despite this, Kate is now living a proactive and positive life, along with her symptoms of dementia. She is an international advocate and activist for aged care and a co-founder of DAI. Kate continues to play a vital role in changing the dementia narrative and addresses human rights issues for people with dementia, globally, and empowers others to live positively with dementia and with a voice (Swaffer 2019). To support herself in these endeavours, Kate uses services such as speech therapy provided by mobile applications (i.e. apps). If Kate is tired at the end of a long day, for example, she uses an app to type and have her words read out.

These paragraphs have provided an introduction—a snapshot—of two captivating and insightful first-hand accounts of YOD. Next, I will contrast this individual perspective, of living with dementia, with the broader social perspective of dementia.

2.5.3 Dementia—stigma and vulnerability

Stigma: There are stigmatising attitudes to dementia. Dementia is understood by most as a disease associated with ageing and a slow decline in cognitive function, and people with dementia considered to be one homogenous group. Language is also a critical element in reinforcing stigma. The literature signalled people with dementia do not want to be known as 'sufferers' or seen as a 'burden'. In fact, they fiercely reject the word 'demented', given its negative connotations. Rather, these individuals are seeking opportunities to 'live well with dementia, not just die from dementia' (Garnett 2017). Being described as 'vulnerable' also reinforces stigma, which leads to compelling and far-reaching social problems.

Two surveys conducted by Alzheimer's Disease International (ADI) assessed dementia-related stigma globally (Alzheimer's Disease International 2012, 2019). The 2012 survey looked at dementia and stigma in 2,500 participants and carers, and the 2019 follow-up survey gathered data from 70,000 people. Both surveys examined global attitudes and their roles in stigma.

The 2019 report reveals the scale of challenges that people with dementia face, and suggests that attitudes to dementia (particularly stigmatising attitudes) are a major barrier to:

- finding information, help, advice, support and a diagnosis
- preventing or delaying the 'planning for a life with dementia'
- accepting and being able to live with dementia.

The range of views uncovered in the dementia survey is underscored by the following:

> *Stigma may be overt; in some countries, it is still associated with witchcraft resulting in people being restrained and isolated. Or it can be subtler; even in countries with national dementia plans and profile awareness campaigns, many people still delay seeking help when they first become aware that something is wrong* (ADI 2019).

The research also reveals that almost 80% of the general public are concerned about developing dementia at some point, and one in four people think that there is nothing they can do to prevent dementia (ADI 2019). Worldwide, almost 62% of healthcare providers think that dementia is part of normal ageing, and 40% of the general public think that doctors and nurses ignore people with dementia (ADI 2019).

ADI's current and extensive inquiry into attitudes about dementia flags the deeper implications of overlooking the stigma associated with dementia to researchers, such as its potential to undermine the quality of interactions with participants as well as research

Participant vulnerability: HCI researchers and designers, gathered at CHI to discuss the notion of vulnerably. The goal of the *Designing for and with Vulnerable People* workshop was: *To explore the positive roles that technology can play in improving the lives of people facing cognitive, emotional, physical, and socioeconomic challenges* (Vines et al, 2014).

While it is essential to address the topic of vulnerability, not all people with dementia want to be couched as vulnerable (Bell & Leong 2017). As Vines et al., suggest that by assigning a person to a vulnerable group may very well be making people vulnerable.

> *Hindering the inclusion of vulnerable people in research denies them access to what many excluded groups need most: a chance for their voices to be heard. Indeed, it is ironic that measures conceived to protect vulnerable people may, in fact, prevent them from changing society for their purposes* (Vines et al, 2014).

This 'assignment' of being vulnerable may also have downstream implications in a research project. In some processes selecting 'dementia' as a category automatically assigns the person to a vulnerable group. This is important to note because researchers are required address this selection to complete the Ethics applications. In the case of YOD, the ethical rigor assigned to research for LOD may not be required (or appropriate) for younger people living with dementia, who may still be in the workplace, hold their driving licence, and have agency over their decisions.

While the risks associated with vulnerability is important to understand regarding the participants in sensitive research areas, it is equally important to consider the risk of researcher vulnerability in HCI sensitive settings.

Researcher vulnerability: In the article *The Emotional Wellbeing of Researchers: Considerations for Practice* (2013) HCI researcher—Wendy Moncur—alerts the HCI community on *"the role that a researcher's emotions may play in research, and the impact which research in sensitive contexts can have on researchers' emotional wellbeing and on research validity."*

This work merges survey outcomes with insights on how other disciplines manage researcher vulnerability. The aim was to offer suggestions for how the HCI community can proactively address the emotional wellbeing of the researchers as part of the research practice. The area that the survey responders worked in was End of Life research.

These survey results revealed three main themes: **personal experience, institutional practice**, and **informal coping mechanisms**. With regard, personal experience, participants (researchers) reported effects of carrying out research in this sensitive HCI setting as:

> *Extended periods of crying, feelings of guilt, bad dreams, and increased sensitization to their own mortality. These effects varied between researchers. Seven researchers (5 female, 2 male) reported that feelings of distress were generated through fieldwork, when they engaged directly with their participants* (Moncur 2013).

In 2015, HCI researchers extended the work presented above—by presenting a series of case studies in "sensitive HCI," from diverse sensitive settings as a way of *"contributing to growing discourse that promotes reflexive practice in sensitive HCI"* (Waycott et al, 2015).

The work conducted by Waycott et al, provides researchers with a list of five key lessons to be mindful of—as follows:

- situational ethics

- the dangers of exposing vulnerability through the design and evaluation of new technologies
- the potential impact of the research on the researcher
- managing the social context of sensitive HCI research
- and managing diverse needs and expectations about how technologies should be designed and used

In summary, current HCI training and education, poorly prepares or sensitises researchers to respond to the needs of vulnerable participants (Vines et al. 2014).

HCI community leaders have called for researchers to openly reflect about ethical challenges so we can learn from shared experiences. My contribution on "reflexive practice" in the dementia setting, will be presented in Chapter 8 –section 8.6.

From here, I will focus on Technology Design in context of dementia. Before presenting the literature on methods of research in the dementia setting.

2.5.4 The dementia experience and technology design

McCarthy and Wright (2004) suggest that user experience is now becoming 'central to our understanding of the usability of technology', and report on a trend in HCI communities to 'foreground experience-centered approaches to technology'. They recommend that, as with any account of the user experience, one must consider the 'emotional, intellectual, and sensual aspects of our interactions with technology'.

While McCarthy and Wright remind us to first consider the experience, before embarking on technology design, they also note that respecting personhood is imperative to any research approach undertaken in a dementia setting.

Wallace et al. (2013a) explored the personhood of a participant with advanced dementia through the empathic design of probes. They remind us about the importance of building technologies for people with dementia based on emotional responses.

Thus far, the literature has demonstrated that dementia is complex, and its experience is unique to each person. There is no cure and no disease-modifying treatment on the horizon. In terms of technology, substantial work has been conducted on dementia; however, this has focused primarily on the aged and frailer LOD group (rather than on YOD individuals).

In the next section, I will present the literature on the applications for digital technologies currently being used to support people living with dementia.

2.6 Digital technology in the dementia setting

Technology evolves quickly. In recent years we have seen the emergence of cloud-based computing, big data, artificial intelligence and machine learning to support connectivity of devices and system networks. These technologies have been readily adopted in social, medical, education, and work settings. Together, with the traditional technologies, such as electronic alarm clocks or timers, these network technologies are finding a place in the dementia setting.

In terms of dementia, presently, technology designers are contributing to areas such as disease assessment and monitoring, assistive and supportive technologies, leisure and activities, and safety surveillance technologies. Looking more broadly, the availability of smartphones, wearable devices and smart home systems (e.g. Amazon Alexa, Google home, robots, virtual reality, augmented reality and artificial intelligence) could potentially contribute to better outcomes if they were designed to support people with dementia.

When looking at more inclusive ways to conduct research in dementia, Craig and Fisher (2020) offer insights gathered over a 14-year period through a '*design-led research enquiry that interrogates the role of design and creative practice in post diagnostic dementia support*'. In this research, a methodological framework was available: **Design Council Double Diamond** (Design Council 2015), where through a co-design process issues are explored, problems defined, and an intervention developed and tested to good effect. Researchers reported on the issues that emerged as the tool was being rolled out to researchers. At the implementation, facilitators pointed out the challenges of engaging people with dementia in a group setting, questioning how to support differing communication needs of group members and ways to engage with and reach individuals with different levels of cognition. Concerns were also expressed in relation to the amount of time it would take to develop materials to support sessions. These points alerted me to pay particular attention to the design methodologies with the YOD group.

Alongside the technological evolution, and technology evolving design approaches is a culture shift within the HCI community. Specifically, recent thinking from the HCI community examines how technologies integrate to form self-management systems.

This is a recent and important shift in thinking where the HCI researchers believe there is a swing from the traditional approach – that is, from where the use of self-management technology is a driver to maintain health, to a position where the person with dementia maintains ownership and management over the entire self-management system (Dixon et al. 2021)

Dixon et al. (2021), conducted a study to support self-management strategies and ways that technology can be designed to better support the ability to manage the symptoms, treatments, and lifestyle changes necessary to live with dementia. In this study, 17 technology savvy people with mild to moderate dementia were interviewed to identify what is of most importance in the configuration of their own self-management system (social as well as technical attributes).

The following three priorities emerged:

- Enabling desired futures
- Functioning in the social world
- Maintaining control.

The goal being to expand the way the field of HCI sees people with dementia, shifting perspectives towards understanding and viewing people with dementia as "inventive creators and capable actors in self-management" (Dixon et al. 2021). This research has broader implications in the HCI technology research and design by introducing the notion of self-management and the need for future oriented, socio- technical, and self-determinate systems.

The next section provides examples of where technology is currently being used in the dementia setting.

2.6.1 Assessment and disease monitoring technologies

Technology has been used in the assessment of dementia for more than 30 years (Chinner et al. 2018). One of the earliest examples was battery-based cognitive assessments; now, digital technologies are commonly used, such as touchscreen-based cognitive assessments, and web-based and app-based assessments (Chinner et al. 2018; Robbins et al. 1994).

Digital technologies have also been used in monitoring disease progression and identifying biomarkers. Examples include the use of magnetic resonance imaging (MRI) and positron emission tomography (PET) scans, coupled with artificial intelligence to facilitate diagnosis, progression and responses to treatment (Alipour & Khademi 2015; Chen et al. 2018; Cheng et al. 2015; Mathotaaraachchi et al. 2017).

2.6.2 Assistive and supportive technologies

The acceptance of dementia as a disability has shifted the gaze from considering dementia as a 'disease' and has encouraged researchers to look at assistive and supportive technologies (Finkel et al. 1997; Mayrhofer et al. 2017; Orpwood 2009).

Designing technology that can play an assistive role to support people with dementia requires knowledge around the delivery of digital prompts. Regarding cognitive assistive technologies, these are systems designed to prompt people. That is, *how best to prompt*, *what to prompt*, and *when to prompt* (Carrillo et al. 2009). One example of this is the coach system, which was created to prompt people with dementia and take them through a hand-washing system. This system combined computer vision that tracks the stage of activity with AI techniques that decide what prompt is required. From this a verbal or visual alert is sent to help with completion of the task (Begum et al. 2013). From this came the idea of "zero effort technologies". That is requiring little to no effort for people to use these technologies. This is achieved by integrating the collection, and analysis on the application, the user, as well as the environment; and utilising advanced computing, such as cameras, sensors, decision making and planning algorithms, machine learning and the Internet of Things (Boger et al. 2018).

Other technologies that utilise cognitive assistance are smartwatches, smart homes, and healthcare apps with notifications for medication administration, prompts for medical appointments, and alerts for medical emergencies (Sprint et al. 2016).

While these technologies go a long way to assist and support people with dementia and their families, other approaches look to address the need to stimulate social engagement for pleasure in everyday moments.

2.6.3 Leisure and activities technologies

Socialising is important for maintaining cognitive function and wellbeing (Astell et al. 2019). Video conferencing supports social engagement and connectedness through social media and video conference technologies such as FaceTime, Skype, and Zoom (Hori et al. 2009; Van der Ploeg et al. 2016).

Another notable technology called CIRCA is a multimedia touch screen device that promotes social interaction. This device has been shown to benefit care giving relationships and improve cognition and quality of life of people with dementia. (Astell et al. 2010; Astell et al. 2018).

In other related work, two research products VITA and SAM have been developed to address the social and emotional needs of residents in day-to-day dementia care. In this project, Houben et al. (2022) argue for the importance of aesthetic and sensory enrichment and creating new experiences in the day-to-day lives of people living with dementia.

The first, VITA, a cushion containing conductive sensors that enable touch-based input for playing audio content, such as music, soundscapes and sound bites, such as a dog bark, chimes and rain amongst other entertaining sounds to invite engagement and curiosity.

The second, SAM, offers multisensory stimuli such as colourful lights, sounds and vibrations to attract the attention of people with dementia. This is a table companion, with four different themes, for people within a communal (dementia care) environment to counteract passive moments.

For both technologies the carer can program the sounds and themes through an online portal. While this may be suitable in the more advanced stages of dementia such at LOD, it may not necessarily be a priority need for a person in an earlier phase of life, and, or, with mild cognitive impairment. As described earlier in this chapter – at the time of a YOD diagnosis, people are younger, still employed, physically active and engaged in all aspects and demands of family life and may not require this type of social technology.

In another study Cutler et al. (2016) focused on improving the overall wellbeing of a person with dementia through gaming technology. In this study, participants reported a sense of achievement and enjoyed the opportunity to socially interact with other people. During the gaming activities, they were also given a choice of whether to use the technology on their own, or in a group, promoting a sense of choice and independence. Cutler et al (2016) suggest that practitioners working in the field of dementia need to be more open to this way (technology use) of supporting well-being and independent in dementia.

Games to improve cognitive function. In terms of improvements in cognition. Digital activities to improve cognition have been explored in the various research settings and are available to consumers for use on smart phones and tablets. There has been considerable attention on the ability to these games to improve cognitive function, however, there is not robust evidence to say that these games can either improve cognitive function or prevent cognitive decline (Astell et al. 2014).

Music for leisure. In HCI, multimedia technology has been examined to support leisure and engagement activities in people with dementia. For example, researchers discovered that people with LOD can share music performance activities—*with little or no scaffold instructions*—enabling them to join in group musical interactions (Favilla & Pedell 2013).

In another similar study, Orpwood et al. (2010), report a strong association between music and Quality of Life (QoL). These researchers had a specific aim: *'to address the design of assistive technology that specifically aims to support an improvement in the QoL of people with dementia'.* In this research, four potential future technologies were recommended for initial development: (1) a music player, (2) device to reduce social isolation, (3) conversation prompter and (4) device to support sequences of tasks.

Virtual reality (VR) and augmented reality (AR) VR and AR technologies have been adopted to support community awareness and healthcare staff training, as well as leisure activities for people with dementia. A recent article published in the *Australasian Journal on Ageing* (Sari et al. 2020) presented a community project situated in the Tokyo metropolitan area, Japan, which examined the effects of a VR educational program on participants' attitudes towards dementia, and their sense of community related to supporting community-dwelling older adults. This work aimed to develop understandings of dementia and build dementia-friendly communities (Sari et al. 2020).

Additionally, a bibliometric analysis conducted by Sobral and Pestana (2020), investigating VR and dementia research from 1998 until 2018, revealed that VR has emerged as a promising tool for the diagnosis and treatment of people with dementia, and their cognitive improvement. This research showed the relevance of VR in improving the health outcomes of patients with dementia, and the increasing growth of VR research as an instrument for dementia diagnosis and intervention (Sobral & Pestana 2020).

Much like the projects mentioned above—which looked at social engagement through music and enhancing QoL through various assistive technologies—VR and AR are seen as useful in the dementia setting for leisure, social engagement, stimulation and physical balance—for example, motion-based gaming systems such as Nintendo Wii and their associated VR components. While not designed for people with dementia, these digital technologies are being investigated to support everyday activities in the dementia setting (Dove & Astell 2017; Joddrell & Astell 2016). People with dementia are also using mainstream entertainment apps (Joddrell & Astell 2016).

2.6.4 Safety and surveillance

In the aged-care and disability settings, personal safety is often monitored through surveillance technologies (e.g. GPS tags, electronic bracelets, video surveillance); mostly, this is to identify and reduce the risk of harm and hospitalisation through falls and other types of personal injuries (Niemeijer et al. 2015).

While technologies can encourage individuals to participate in activities outside of the home, they are often designed to ease the caregiver burden (Sposaro et al. 2010). In an academia–industry project, researchers Wan et al. (2016) assessed the practical and ideological issues surrounding care. This research was designed to understand why the uptake of GPS systems is still very low in dementia care.

This was somewhat addressed in an ethnographic field study, published in *Nursing Ethics*, the authors suggested that the practice of monitoring has ethical issues; it is perceived as an intrusion on privacy and autonomy, with people often resisting surveillance technology because they felt stigmatised and did not like being watched (Niemeijer et al. 2015).

Robots have extended the role of technology in dementia environments; from monitoring to playing a role in caring for a person with dementia. Recent examples include robot delivered virtual visits using video conferencing and in-home sensors, as well in food preparation and assistance in eating (Rudzicz et al. 2015; Coradeschi et al. 2013; Derek & Nejat 2012).

The benefits of companion robots may include reducing depression, alleviating loneliness and agitation. However, there are also ethical concerns raised by researchers including deceit, reduced human contact accountability of the assigned care giver, and infantilisation (Bradwell et al. 2020). This study was conducted to probe the conflict between benefits and ethical concerns of companion robots for elderly people – some with dementia. The inquiry included surveys with younger adults who were ask about the perceptions of ethical issues with companion robots. In contrast to the philosophical literature, in practice when asked, the concerns were not of an ethical nature, the respondents of the survey were more concerned about affordability and accessibility (Bradwell et al. 2020).

The Internet of Things (IoT) describes the network of 'things' embedded with sensors, which connect and exchange data with other devices and systems over the internet. With respect to the dementia setting, the IoT's application can include connected devices and systems to provide a holistic overview of data through in-home sensors; wearable monitors; and devices for healthcare management, navigation, exercise, meditation and sleep monitoring (Dimirioglou et al. 2017; Enshaeifar et al. 2018; Ishii et al. 2016; Shin et al. 2014).

The application for technology can have a positive impact on the life of a person with dementia, and their families. This has been demonstrated with some technologies, such as video conferencing and music for leisure, however, this does not necessarily hold true for all technologies due to the individuality in how dementia is being experienced, and the life stage (and needs) of the person with dementia.

Regardless of the appropriateness of the technology for a particular stage of life, Astell et al. (2019) suggest that digital technology is underutilised. This may be due to affordability, accessibility and, or, ethical issues, such a privacy concerns and data sharing constraints.

Many of these technologies highlighted above have been appropriated for use in the dementia setting, and not necessarily designed for people with dementia, let alone for those living with YOD. Next, I will address the paucity of research in technology design and highlight the opportunity for HCI to better support people with YOD.

2.6.5 YOD and relationship with technology

This section further opens the conversation on YOD and the role of technology, by looking at how individuals with YOD relate to, and use, technology in their daily lives. Due to a gap in the literature regarding YOD and technology (compared to LOD and technology), I needed to gather relevant insights from popular media sources—such as online blogs and documentaries—rather than from empirical research.

When I investigated these non-academic settings, I found that people with YOD actively participate in popular media and social networking streams—much more so than those with LOD. This emphasises that, when sharing their experiences, the YOD group are much more digitally engaged on social media platforms and appear to be more technologically savvy than their LOD counterparts.

The relationship between YOD and technology is important to understand, because the next generation of people with LOD will have aged alongside the evolution of digital technology. Thus, they will likely have a greater aptitude for using new technology than most individuals who are currently living with LOD.

It is also imperative to ensure that individuals with dementia are able to use new technologies, by identifying and addressing the barriers to technology use. In the future, this could lead to a range of accessible and usable technologies (e.g. everyday ICT, assistive technologies, telemedicine) to support independence and agency (Allen et al. 2016).

As societal functions become increasingly automated, the need for people with dementia to remain connected to technology becomes ever more important. This is particularly the case given that the level of social connectedness that is fostered through social apps and platforms (Wallace et al. 2010). Furthermore, Brittain et al. (2010) suggest that there is an increasing risk of people with dementia being excluded from society as the demands of technology extend beyond their capabilities.

To reiterate, the examples in this section show various applications for technology to support people living with dementia, as well as their carers—through music, reminiscence, safety and surveillance technologies. Few have been designed specifically with dementia in mind, let alone tailored for YOD individuals.

This knowledge gap, therefore, offers researchers and designers an opportunity to explore what younger people with dementia want from technology. However, before designing the technology, it is important to first understand the experience of the user—and the context in which they will use the technology (McCarthy & Wright 2004).

From this point, I will explore research methods and strategies to study these unique YOD experiences, while assessing the appropriateness of the tools and methods in supporting personhood and agency within the YOD setting.

2.7 Overview of Research Methods in dementia

To recap, dementia is a complex and individual experience, and can be diagnosed in younger people. Additionally, dementia is more than memory loss—it is a state of cognitive decline with a pathology that manifests in sensory changes affecting language, perception, social cognition, sight, smell and executive decision-making. It is this aspect of the condition that has widespread impacts on the experiences of the individuals in their everyday lives (Bakker 2003; Houston 2018).

This section reviews the qualitative research methods and approaches that are widely accepted in dementia research and design practices, including the use of semi-structured interviews, probes to elicit meaning and facilitate sense-making, and proxies for the person with dementia.

I will begin with the use of assigning a proxy, a widely-used practice in dementia research and design practices across research domains.

2.7.1 Proxies

In most research and technology design settings, the approach of assigning a proxy for the person living with dementia is an acceptable method of research.

As Nelson et al. (1990), who conducted important work in epidemiologic research on proxy respondents, state: 'Proxy-provided information is being used in circumstances where the index subject is the preferred source of information but is not available or is not appropriate for questioning.'

However, the use of proxies may have marginalised the experiences of people with dementia. Social researchers (Cahill et al. 2004; Tanner 2012) have challenged the use of proxies and sought to empower people with dementia by allowing them to be directly involved in the research and design process. Dr Denise Tanner (2012), for example, engaged directly with individuals living with LOD. In her research, Dr Tanner engaged a person with LOD to conduct all interviews jointly with her; therefore, someone living with dementia is co-interviewing another person with dementia. Tanner highlighted the ethical and practical challenges of this approach, but also stressed the personal benefits derived for the participants living with LOD, including gains in self-confidence and self-esteem. This is a promising approach, which Tanner urges to be further explored (2012).

In HCI, the researchers Wallace et al. (2013a) involved the husband of a person with dementia in their research activities to gain better insights into the couple's relationship, and thus better understand how technology can support personhood in dementia. This approach was found to be beneficial (in this research and design work case); however, it does present challenges if this approach is automatically deployed in YOD, where participants may not necessarily wish to have a proxy speak and act on their behalf.

In the next section, I will discuss the use of probes, beginning with the theory before describing some examples from HCI where probes (and proxies) have been used in dementia research.

2.7.2 Probes

Gaver et al. (1999) developed cultural probes as a tool to elicit participants' ideas, thoughts and values, and to gain insight into people's lives in a non-invasive way. In later research, Gaver, Dunne and Pacenti (2004) continued to explore the value of probes and uncertainty: 'taking the approach to understanding users in a way that stressed empathy and engagement'.

> *Probes are collections of evocative tasks meant to elicit inspirational responses from people, not comprehensive information about them, but fragmentary clues about their lives and thoughts. We suggested the approach was valuable in inspiring design ideas for technologies that could enrich people's lives in new and pleasurable ways* (Gaver et al. 2004).

Gaver's evolving concepts on probe use and his assertion that knowledge has limits are important factors when considering the current use of probes in dementia settings. Especially considering the potential limitations of using proxies to speak on behalf of people with dementia, the goal of using probes is to inspire ideas for ways that technology could enrich lives in new ways. Another important factor in the probe process is developing a relationship of trust with the participant.

Wallace et al.'s (2013b) study takes a deeper look into HCI research on dementia. While they agree with Gaver's guidance to use probes to ignite the imagination, they also suggest that many in HCI have missed the point of probes (which is not to produce data and results). They believe that probes need to work harder in sensitive settings, because users can have trouble articulating and communicating their thoughts and feelings. The researchers see probes as objects, which enable deep reflection and gentle ways to give participants access to emotions and experiences.

What differentiates the approach by Wallace et al. (2013b) is that they design probes directed towards the phenomenon they are researching. They recommend that, as much as possible, researchers should immerse themselves in the clinical and social aspects of the condition (e.g. volunteering in dementia settings, doing artist placements in dementia settings or spending time with dementia groups), to get an empathic understanding of the lives of the participants in their research.

Boehner et al. (2007) investigated how HCI researchers use probes. In their paper, the researchers argue that, in some studies, probes are not participatory enough and leave too much control in the designers' hands. In other studies, they claim, the value of the probe approach is that they support users' self-reflection as part of the data acquisition, which allows participants to control what information they record and share. This is especially important in sensitive settings, where there may be a power imbalance between researcher and participant.

In related research, Brown et al. (2014) designed and used probes to capture experiences and seek ways to design better assistive technologies (AT) for people with dementia. In their case, the probe pack included a polaroid camera; family carers of the person with dementia used the camera to photograph events and objects from the living space and stick them into an activity booklet.

While the approaches discussed in this section are valuable steps forward in developing co-design methods for the dementia setting, they do not reflect or support the needs expressed by the YOD community, who want to maintain agency and have the option of being included in all research activities—including probe-design activities.

2.7.3 Interviews—and proxies

In dementia settings, interviews are the most common qualitative research method. However, most interviews are conducted in the presence of a proxy, such as a partner or professional carer (Arntzen et al. 2016; Brown et al. 2014; Cahill et al. 2004; Wallace et al. 2013a). Interviews are a method for researchers to gather information about the participant's everyday life, and their challenges and coping strategies.

Cahill et al. (2004), however, discussed the ethical issues when using proxies in interviews for people with dementia—this was a large focus area in their research. They chose not to use proxies during the interviews. Their participants with dementia were invited to complete an assessment activity (scale), without a proxy. The scale included three test questions to ensure the participant understood the scale and had a question-and-answer format. If participants answered two of the three test questions correctly, the participants could proceed to completing the full 29 item questionnaire. This is a valid example of conducting interviews without a proxy and, despite the assessment being a structured interview, 'many respondents spoke in depth about their QoL issues and much qualitative data was generated'.

There is not a one-size-fits-all approach when it comes to dementia research. While the literature describes the use of cultural probes to elicit personal experiences of living with dementia (Brown et al. 2014; Coughlan et al. 2014; Wallace et al. 2013), it also highlights that in addition to conducting interviews through a proxy, researchers may need to rely on the proxy to *complete* the probe activities (Brown et al. 2014).

While there are widely accepted qualitative methods and approaches used in dementia research and design, I needed to look beyond these methods for my research. I have created the next section to step through the theory unpinning the research framework I chose to engage with people living with dementia who are in an earlier stage of life, and in the early stage of being diagnosed with dementia.

2.7.4 Choosing an inclusive research framework for YOD

At the end of the literature review and my preliminary investigations, I found it encouraging to find evidence that people with dementia wanted to participate in research and, additionally, would benefit from being involved (Tanner 2012).

Brereton et al. (2014), describe an "emerging paradigm" for HCI design, where engagement, reciprocity, and doing, are central to the ethnographic approach. In this paper the authors remind the HCI community that it can be difficult in many settings for researchers to access the "privileged ethnographer position". I took this as an important consideration in how I would approach the design of this research. Setting out as a new researcher investigating dementia, the privileged ethnographer position informed the research approach. In other words, I needed to be mindful that the setting I was working within needed close consultation with the participants and their community throughout the research program.

The next step was to find an inclusive research model and look for similar research conducted in sensitive settings—such as with children on the autism spectrum conducted by Benton & Johnson (2013). While this project was not specifically relating to dementia, it was helpful and provided motivation for how to implement an inclusive research framework for my work in the YOD setting. For example, their study discussed how using a participatory design model could address the power imbalance (and empower children with special needs) by allowing them to participate as *equal partners* throughout the design process.

HCI researchers Green and Kirk (2018) established a precedence for combining methodologies with overlapping elements of three qualitative research techniques 1) documentary 2) ethnography and 3) participatory action research (PAR) in a study with a diverse population of 'makers' (being individuals, groups and communities who 'make' in different contexts). From a methodological perspective, Green and Kirk (2018) argue for a renewed focus on "inclusivity" and highlight a need for a new infrastructure; these researchers integrated the three approaches to support their goal of greater collaboration.

Taking a similar approach, HCI researchers Holtzblatt & Jones (1993) combined the two approaches of *participatory action research* and *ethnography* and have categorised these approaches as **Contextual Inquiry** and **Ethnographic Action Research.**

Essentially, Contextual inquiry is a data gathering method primarily used by researchers in the IT setting to identify the system user and understand how they work on a day-to-day basis. This deep understanding can challenge the developers' assumptions and influence a user-centric system design (Holtzblatt and Jones 1993).

As outlined by Holtzblatt and Beyer (1997) the four principles of the contextual inquiry are as follows:

> **Context:** The research occurs in the work environment (in situ) with an emphasis on experience and data gathering.
>
> **Partnership:** Aims to foster the creation of a shared understanding and unearthing of work practices. In other words, the novice researcher is learning from the expert user.
>
> **Interpretation:** the researcher interprets what the user's words and actions might mean relevant to the designer's intent. An important step in this is the check-in with the participants where researchers share their interpretations with them during the inquiries.
>
> **Focus:** directs the conversation and provides the interviewer a way to stay on topics without taking control back from the user.

While Contextual Inquiry is method of data gathering in the IT setting, **Ethnographic Action Research (EAR)** is a methodology, which enables poor and marginalised participants in developing communities to actively engage with the research by providing thoughts and observations in their own environment.

EAR has four key steps: Planning, doing, observing, reflecting. The steps of observing and reflecting following the action step informs the next cycle of action more effectively. Tacchi et al, (2003) describe this as "informed reflection". While EAR is closely aligned with PAR (which I have implemented in my research program) the EAR methodology has been used in the field of Information and Communications Technology for Development and is described as a practice of using technology to assist poor and marginalised people in developing communities.

In summary, there were a number of factors I needed to consider before I chose a research framework to work closely with people living with dementia, over an extended period of time.

Fundamentally, while **contextual enquiry** – a method of data gathering in the IT setting, and **ethnographic action research –** the practice of using technology to assist poor and marginalised people in developing communities – are helpful in terms of overall guidance, I needed to think carefully about the needs and wants of the YOD participants– being included at each step of the process, and also the goals of this HCI research – to find better ways to work directly with the YOD community to design digital technologies. The collaborative framework for my research will be presented in the next chapter – section 3.6.

Before I introduce the two key gaps that emerged from my preliminary inquiries and validated in the literature review, I will briefly comment on the under-representation of people with YOD in research and design practices, as this led to recruitment challenges and project delays in my research.

2.8 What leads to an under-representation in research?

I became curious about the under-representation of the YOD population—compared to that of their aged counterparts after the literature review following this insight shared by a person with YOD,

Kate Swaffer (2016) lives with YOD, and suggests that once the dementia diagnosis is revealed, 'their' abilities are grossly underestimated due to the associated stigma, and 'they' are overlooked in research activities.

This lack of focus on the younger group with dementia, in research and technology design, may somewhat be attributed to the following factors:

Lack of visibility of YOD: The symptoms of YOD are often not readily visible (as with many other types of disabilities or advanced dementia) leading not only to diagnostic delays, and a lack of support in the workplace—it also makes it difficult to seek out those with YOD to recruit into research.

Limited guidance on how to engage those with YOD in research: Once identified, most qualitative research tools have been designed for use in the older group, that is people living with dementia in a later stage of life, and generally more advanced stages of dementia by the time they are diagnosed. These current tools/methods (use of a proxy, interviewing carers, or health care professionals) are not necessarily appropriate for use in YOD. Perhaps this is stifling the HCI research efforts to engage with the younger population with dementia and a high aptitude for technology in technology design activities.

I conclude this chapter with the methodological and theoretical gaps that surfaced during the literature review. This forms the basis of my research program.

Please note: this research focuses on a group of people who are in the early stages of cognitive decline – and under the age of 65 years. Many of the challenges faced by this group, may also be experienced by their older counterparts who are living with a milder form of cognitive decline. The key differentiator this research is the social divide associated with being younger than 65 years old (YOD) as described in section 2.2.1. this different earlier stage of life, presents different needs and wants for a person with dementia.

2.8.1 Methodological gaps

Although the literature has described qualitative methods and tools for research in the dementia setting—it was not clear how these methods could be implemented to support the goals of people with YOD, who seek independence and want to be involved at each step of the research and design process.

Searching broadly across the various research domains revealed that current qualitative methods have been designed to consider the more advanced stages of dementia, such as assigning proxies. People living with YOD strongly reject this approach—they seek to maintain independence and agency for as long as possible (DAI 2017). They also called for greater participation in research and design practices. This call needed to be acknowledged and addressed.

2.8.2 Theoretical gaps

In addition to, and perhaps because of, the methodological gaps, there is a resounding theoretical gap, with little-to-no empirical research on the unique circumstances and experiences of people with YOD. Partly due to the limited number of first-hand accounts of people living with YOD as well as the literature's overwhelming focus on LOD. It is critical for HCI to bridge this gap, so that technology design reflects the needs and wants of people with YOD, now and in the future.

In response to these gaps, the following research questions emerged:

2.9 Research questions

RQ. How can HCI develop deeper and more nuanced understandings of the lived experience of people with YOD?

2.9.1 Sub-questions

SQ 1. What methodological framework would facilitate a collaborative and trusting research environment to surface the unique first-hand experiences of people with YOD and their relationship with digital technology?

SQ 2. What research approach, methods and tools would best support the needs and wants of people with YOD?

SQ 3. How can HCI use these theoretical and methodological insights to inform a fresh approach when designing digital technologies with, and for, people with YOD?

To address the **methodological gap**, I needed to build a research environment in which relationships could develop and be nurtured; a setting where the participants taking part in the research would feel valued and empowered throughout the research journey.

To address the **theoretical gap**, I developed a long-range plan to spend time in the environment (and lives) of people living with YOD. The aim was to collaborate on ways to document their experience with dementia and the role technology plays in their lives.

While the primary contributions of this research are theoretical and methodological; this thesis presents many insights on what role technology is currently playing in the lives of people with YOD. By observing the use and importance of technology in the YOD setting, in addition to finding new methods, future HCI technology designers can leverage the recommendations outlined in section 7.9.2 in their future work.

2.10 Looking ahead: Next steps

Based on the gaps in knowledge that surfaced during the literature review and considering the wishes of people living with YOD for greater inclusion, I adopted the **Participatory Action Research** (PAR) model to frame all activities in this research program.

The PAR model (with an ethnographic cycle) is novel in the HCI research and design setting; therefore, I have included a short chapter that describes how PAR was co-designed and implemented for this PhD research program. Chapter 3 presents the following information:

- The rationale for choosing an action research model and conducting a longitudinal ethnographic fieldwork in the final cycle.
- Theoretical overviews of the PAR model and ethnography. It describes how PAR supported the goal to surface first-hand insights into YOD, in a research setting that would foster a trusted, respectful, long-term collaborative relationship between me and people with YOD.
- A detailed Research Roadmap: this diagram is the blueprint that illustrates the activity plan for each of the three PAR cycles. The roadmap guides the reader through each stage of the PAR model and the final activity—a Technology Design Workshop.

Chapter 3.

Finding a Collaborative Framework for HCI Research and Technology Design for Younger Onset Dementia

'Nothing about us, without us'

Dementia Alliance International (DAI)

3.1 Introduction

Introducing this chapter is a rousing human rights mantra that has been adopted by DAI as a mandate for the inclusion of people living with dementia across all research, design, policy and processes that concern them. Supporting this ambition, required a research environment that nurtured relationships and facilitated collaboration; an environment that valued and empowered the participants throughout their research journey.

The Participatory Action Research (PAR) model met this brief and was chosen as the framework for this research program. While my research used qualitative research methods and tools, such as semi-structured interviews, journals, probes, ethnography and PAR, they were not implemented in a conventional fashion. For example, all tools and methods were reviewed, tested and implemented in collaboration with five individuals living with YOD. My interpretation of the action research model for this research resulted with three action cycles; refer to the blueprint (Figure 3.2) as a guide for each cycle of the research.

Next, I will provide an overview of PAR to give the reader a sense of why this framework best supports relationship development, inclusion, and the development of trust which is required for generating rich insights into the lived experience of dementia.

3.2 Participatory Action Research

PAR is an approach whereby participants are included at various levels of the research process (Figure 3.1). It is context-specific and can target the needs of a particular group by using iterative cycles of research, action and reflection (Swantz 2008). PAR therefore harnesses the type of social change that challenges inequality and promotes democracy.

According to The Institute of Development Studies (2019), the PAR model seeks to 'liberate' participants, giving them a greater awareness of their situation to take action.

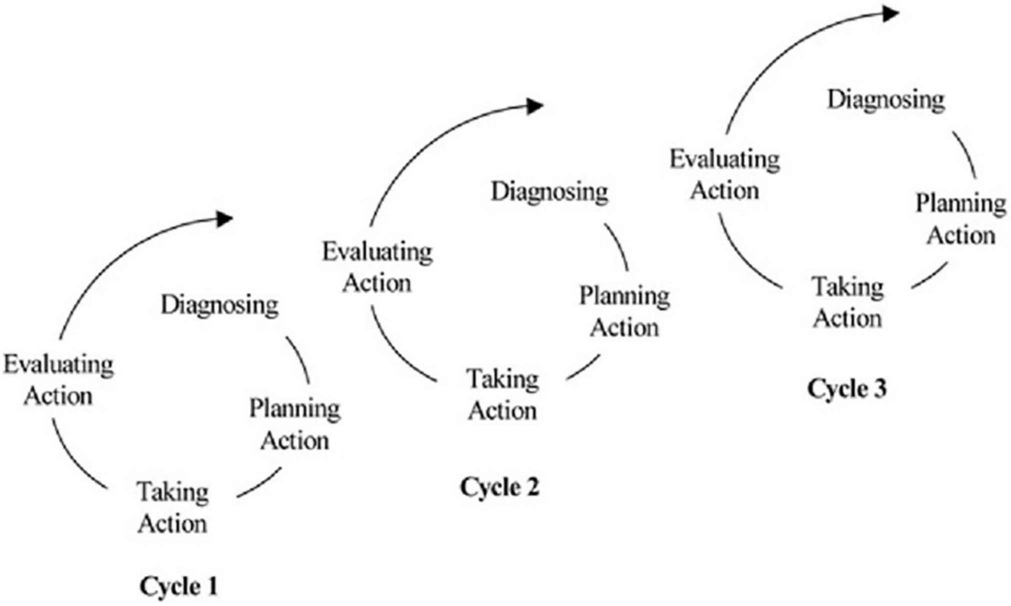


Figure 3.1. Action research results from spiraling research cycles, starting with a process of identifying a problem area, i.e. 'diagnosing' (Coghlan 2019).

Grant et al. (2008) describe PAR as a methodology whereby research participants are included in the research process or creation of solutions. This model has been used since the 1940s and involves researchers and participants collaborating to comprehend issues and create change for the better.

> *[PAR] is a research methodology that attempts to address power imbalances and oppressive social structures. It values the 'researched' community as a vital part of the research project and its members as experts of their own experiences. PAR is particularly concerned with oppressed communities and attempts to create action as a catalyst for social change (*Grant et al. 2008).

Four principles form the foundations of PAR and address the importance of inclusion, empathy and trust (Robertson & Wagner 2013). These are:

1. immersive research
2. relationship building
3. mutual learning

4. ethical impact on participants.

Immersive research This refers to working with people directly in their community, workplace and / or homes (Kensing & Greenbaum 2013), as opposed to artificial research environments. This is important because the meaning of any action is determined by its context. Immersive research thus enables researchers to understand and interpret an action based on elements in the participants' environment(s) (Suchman 1987). In the dementia setting, immersion allows researchers to be aware of how social and family networks interconnect.

Relationship building Forming strong researcher–participant relationships is an important component in participatory research. The researcher can develop robust and long-lasting relationships by establishing trust with the participants and their care networks. Once relationship bonds have formed, participants may feel more comfortable disclosing sensitive information. Additionally, it is beneficial to recruit a 'Project Champion'—someone who will advocate for, and implement, the research.

Mutual learning This is beneficial for assessing the participants' needs and benefits. Sharing knowledge between researchers and participants enables the authentic engagement of participants and their care networks. Mutual learning activities can be utilised during different stages of a research program, from early exploratory activities through to co-designed workshops.

Ethical impact on participants This addresses the power imbalance between the designer / researcher and participant. In HCI research, it is raised particularly in sensitive settings, such as dealing with health-related issues or age-sensitive topics (Vines et al. 2013). Gauging the ethical impact on people with YOD is imperative in supporting their agency and autonomy in the research and design setting.

Understanding these **four principles** of the PAR framework enabled me to bring these elements to the forefront when designing the research agenda for YOD.

3.2.1 PAR in the context of YOD

The PAR model was particularly suitable for this research program because it addressed the power imbalance between participants and the researcher; established trust and collaboration and facilitated relationship-building through the connected spirals of reflection, planning and action.

To complement the PAR approach, I chose to introduce an ethnographic fieldwork in Cycle 3 to develop deeper insights into the experiences of YOD by immersing myself in the community networks. The goal of this cycle was to gain a deeper understanding into the YOD culture and observe what role technology plays in everyday life.

Next, I will provide a brief theoretical overview of ethnography, and the rationale for including this model in Cycle 3.

3.3 Ethnography

Ethnography is the study of people and their environments across wide and varied contexts. It examines the relationships among culture, behaviour and social networks, and how these change factors evolve over time (Fetterman 1998; Forsythe 1999; Hammersley & Atkinson 1995). The premise of taking an ethnographic research approach is based on observation and participation, followed by the analysis and interpretation of the data collected (Bloomberg et al. 2003; Davies 2007; Fetterman 1998; Hammersley & Atkinson 1995).

Willis and Trondman (2002) define ethnography as:

> *a family of methods involving direct and sustained social contact with agents and of richly writing up the encounter, respecting, recording, representing at least partly in its own terms the irreducibility of human experience.*

Ethnography has a dual meaning; it is a process of fieldwork and observation, and a product such as ethnographic writing (Sanjek 1996). The result, or 'product', of ethnography is a written account, which is a 'thick description' of the environment being studied (Geertz 1973). Common tools used in ethnography include video and audio recordings of conversations and interviews, as well as taking notes and photographs.

According to Aldiabat and Le Navenec (2011), there are three major reasons to use ethnography in socio-cultural settings:

1. The approach helps the researcher to interpret a participant's point of view, to understand the experiences and behaviours of people in their situation.
2. The observation of day-to-day instances of a person in their personal environment provides a deeper understanding on which to build context.

3. Ethnographic research allows for the exploration of complex situations, culture (beliefs, rituals, interactions, of a group of people as they live or coexist) and their social networks.

Additionally, several principles reflect the foundations of ethnography (Hammersley & Atkinson 1993). These include:

- Participants' behaviour should be observed within the context of their everyday life, rather than a setting created by the researcher.
- Data should be collected using several different techniques with an emphasis on observation.
- Methods of data collection need to be flexible and unstructured, to focus on what people say and do.
- When analysing data, meanings of observed actions should also be interpreted.

Now that I have provided and overview of PAR and Ethnographic methodologies, I will move to an overview on Probes, and their utility in sensitive HCI settings.

3.4 Probes

As discussed in the literature review (Section 2.7.2), HCI researchers have used probes to allow participants to express their lived experience. Of note, Wallace et al. (2013b) and Gaver et al. (2004) propose that probes can be designed and leveraged in ways that inspire the participants' creative thinking and imagination. This is particularly important when working with people with YOD, who may struggle with one or more aspects of their emotional expression, written and/or verbal communication, cognition and reasoning.

In sensitive research settings, such as the dementia setting, Wallace et al. (2013b) believe probes can be strong tools that support and encourage participants to reflect deeply, access their emotions, and articulate and communicate their thoughts and feelings. Additionally, probes can gently support these processes in ways that make the most sense to, or are the most intuitive for, participants. Furthermore, probes are key to forming trusting relationships between researchers and research participants.

These examples of probes, discussed so far, along with the principles, and methodologies such as PAR and Ethnography, galvanised the key goals of this research in the YOD setting; being to support the gaps and needs of a person with dementia—to be visible, heard, included and informed in every step of the process.

3.5 Taking a collaborative approach for Younger Onset Dementia

Like others before me, I selected a co-design approach for this research. In my research, this was adopted to review and 'redesign' current dementia research methods presented in Chapter 4. This approach was also implemented during the final Technology Design Workshop presented in Chapter 7. In this section, I offer a few theoretical examples of co-design and participatory design in dementia. Albeit in the late onset dementia setting.

Co-design has been used in the development of services to support people with dementia (Tan & Szebeko 2009; Swarbrick et al. 2019; Goeman & Koch 2016; Banbury et al. 2021). Theoretically, 'co-design' aims to involve participants in order to meet the needs of the end-user. Through a partnership, end-users are involved in planning, design, and evaluation which encourages ownership and engagement (Szebeko & Tan 2010; Tan and Szebeko 2009; Clemensen et al. 2016).

For example, Banbury et al. (2021) adopted a co-designed approach in the development of a Telehealth peer support program for isolated dementia carers. Tan et al. (2009) took a community wide approach to co-design by including the dementia community to develop people-centered services for dementia. Swarbrick et al. (2019) collaborated with three independent groups of people living with dementia to develop a co-researcher's involvement and engagement model in dementia.

While Goeman et al. (2016) worked with people living with dementia and their families to develop a culturally sensitive model to help overcome barriers for people with dementia from culturally and linguistically diverse backgrounds.

These four examples illustrate the value of taking a collaborative approach, thus empowering the end-user in the design process.

Co-design in YOD: as a reminder, collaboration was a primary goal of this research given the vastly different circumstances of YOD—such as being diagnosed at a life stage when they are still employed (perhaps the main income earner), have family and financial commitments, and are otherwise generally in good physical health.

McCarthy and Wright (2004) emphasised the need to investigate the lived and felt experience of YOD before launching into technology design, and point out, we also need to understand the emotional, intellectual, and sensual aspects of our interactions with technology (McCarthy & Wright 2004). However, it was difficult to find methods or examples that were appropriate for engaging directly with this younger group in research and design.

While I could find research approaches and methods for those in a later stage of life and in the more advanced stages of dementia (such as relying on a carer to speak and act on their behalf), I needed an approach was deemed more suitable for the YOD group.

3.6 Designing a research framework for YOD

As mentioned in the previous chapter, Green and Kirk (2018) set a precedence for combining methodologies with overlapping elements of three qualitative research techniques (documentary, ethnography and participatory action research). From a methodological perspective, these HCI researchers argue for a 'renewed focus on "inclusivity" and highlight a need for a new infrastructure'; they found an integrated set of methodological approaches supported this goal.

Furthermore, in response to the human rights activism underway, and DAI's call for inclusion, I needed the research framework to foster ongoing collaboration and trust. The goal was to rethink current approaches to research in dementia and find a more suitable way forward for the YOD group.

When looking for an inclusive research model, I drew inspiration from research conducted in other sensitive settings—such as with children on the autism spectrum (Benton & Johnson 2013). This study discussed how using a participatory design model could address the power imbalance (and empower children with special needs) by allowing them to participate as *equal partners* throughout the design process. Additionally, I took into consideration the work of Brereton et.al. (2014), who pointed out that engagement, reciprocity, and 'doing', are central to an ethnographic approach.

Other methodological framework options such as **contextual enquiry** - method of data gathering in the IT setting, and **ethnographic action research** – the practice of using technology to assist poor and marginalised people in developing communities (described in section 2.7.4) were helpful in terms of overall guidance, however, with the focus of this research being on YOD and technology design these were not the most appropriate options for this research program.

Therefore, after much deliberation and guided by the work of more experienced researchers in HCI, I decided to move forward with a combination of PAR and ethnography. The inclusion of ethnography was inspired by researchers who advocate for ethnographic practices as an empathetic approach aimed to gain insight into the human experience (Baum et al. 2006; Dourish 2014; McCarthy & Wright 2004; Van Maanen 2011).

3.6.1 Participatory Action Research

The PAR framework (for this research) includes **three action research cycles**, as follows:

> **PAR Cycle 1:** Exploring new ways to research in YOD
>
> **PAR Cycle 2:** Trialling new HCI research methods for YOD
>
> **PAR Cycle 3:** An ethnographic exploration into YOD and the role of technology to develop deeper more nuanced understandings; building on cycle 2

PAR Cycle 1 Presented in two parts: (Part 1) This first cycle was implemented over a one-year period to allow me to explore the dementia environment. During this early stage of the research the aim was to seek out and understand the perspectives of the healthcare professionals working in medical science—a dominant contributor in dementia research. In addition to this, I attended dementia conferences (both local and international) to access dementia thought leaders who set the international agenda on dementia management: which included the economic, across medical, political, and social sectors.

(Part 2) This cycle finished with methods workshop, designed to rethink current methods used in HCI dementia research and technology design. The output from the workshop is a co-designed customised set of tools and a fresh approach to deploy the tools which were tested before being rolled out to all participants.

PAR Cycle 2 The aim of the second PAR Cycle was to finalise recruitment and implement a study to further validate the methods developed in Cycle 1. Additionally, this first (3 week) study was designed to gather preliminary insights into the YOD experience and use of digital technology.

PAR Cycle 3 This cycle—a longitudinal ethnographic fieldwork—was designed to gather and build deeper insights into the culture (beliefs, rituals, interactions, of a group of people as they live or coexist) of the YOD community by documenting their stories and my observations on the day-to-day life circumstances, experiences, and challenges of YOD.

Cycle 3 was also an opportunity to collect data on the role of technology in everyday life—to be in the field and access both spoken and unspoken communications and build rich more nuanced insights into how technology is being used in this setting. The inclusion of ethnography in cycle 3 was designed to bring insight back to the HCI community on the lived YOD experiences which are difficult for most to appreciate, especially given the few autobiographical accounts available to us.

This combination of methodologies is designed to the extend the understanding on the YOD experience emerging from Cycle 1 and Cycle 2 and to generate deeper insights, by examining the culture, community practices and use of everyday technologies over time.

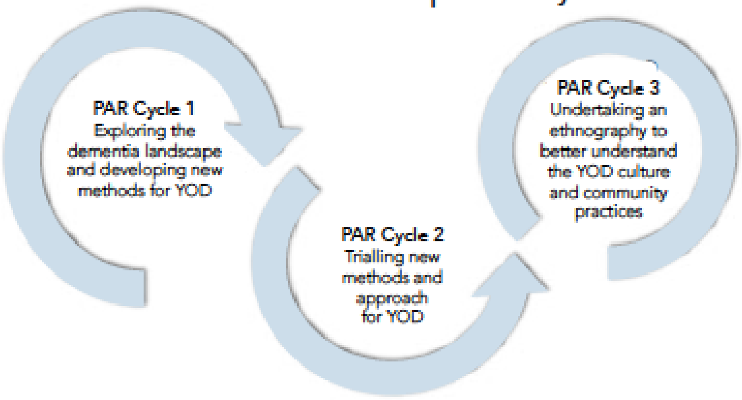
Note: As mentioned earlier, this PhD research program concluded with a Technology Design Workshop (presented in chapter 7). The aim of this final event was to produce a serious of recommendations from those with YOD, for HCI researchers and designers who wish to work in this setting in the future, or other similar settings.

The next section describes the **Research Roadmap** (Figure 3.2).

The people with YOD who joined me on this research journey were highly self-aware of the ramifications of dementia, current research projects, and available technology used in dementias settings. They are active lobbyists for their human rights to be included, to have a voice, and maintain agency for as long as possible.

Including an ethnographic phase to increase the visibility of the (YOD) group and map out the networks, communities, culture and day-to-day relationship with digital technology was a critical element to consider when designing this research program. My thinking was that combining the PAR model with an immersive ethnographic fieldwork would support the goals of the YOD group and facilitate the development of recommendations for HCI researchers and designers.

Research Roadmap: 3 PAR Cycles



PAR Cycle 1: Exploring new ways to research in Younger Onset Dementia (Chapter 4)

Part 1: Preliminary activity (one year)

- Conducted scoping interviews with dementia healthcare employees (those with dementia out of scope) – YOD became the focus of the research.
- Attended conferences on dementia and engaged with advocacy groups. Started recruitment. Two experts in YOD, international advocates, joined the research.

Part 2: Methods review workshop (half-day activity with first two YOD participants)

- Reviewed current methods used in dementia research and co-designed new methods tailored to the needs and wants of people with YOD.

PAR Cycle 2: Trialling new research methods in HCI for Younger Onset Dementia—Study 1 (Chapter 5)

- Finalised recruitment.
- Conducted Study 1, first empirical study.
- Completed (and validated) interviews and probe kits.
- Co-designed methods were further adapted and refined by YOD participants.
- Preliminary data analysis—from interviews and probes—produced preliminary insights into the technology and the communication preferences of those with YOD.

PAR Cycle 3: An ethnographic exploration into YOD and the role of technology—Study 2 (Chapter 6)

- Regular field visits over two years
- Three-day road trip (one person with YOD & researcher): a unique experience to be immersed in the life of a person living with YOD.
- Reflexive insights surfaced for the researcher.
- YOD individuals in this research began to self-identify at advocacy meetings outside of the PhD program—they become lobbyists for YOD, acting on behalf of others living with YOD.
- Insights into YOD and role of technology in their community became richer and more nuanced.

Technology Design Workshop—Study 3 (Chapter 7)

- **Developing workshop agenda** This was co-designed with YOD group prior to the workshop. Planning the logistics, content, aims, and desired outcomes.
- **Morning session** Review of favoured technology by YOD attendees. Discussed why this piece of technology was chosen (unpacking its technical attributes and experiential aspects).
- **Afternoon session** Activity: Imagine a Superpower. Designed to stimulate the imagination, discussion and generative ideas on how everyday technologies could support YOD.
- **Goal of the YOD team** Deliver a series of recommendations for HCI researchers and design practitioners for future research in this setting.

Figure 3.2 Research Roadmap: a blueprint to support the reading of this thesis

3.6.2 The research journey, building relationships over time

Next, I would like to share a visual representation (figure 3.3) of the research journey to highlight the steady formation of a community over the years. The community at the end of this journey was made up of people living with YOD, their partners, friends – along with a team of HCI researchers and designers from similar research settings with a common goal to find better technologies to support people with YOD.

This illustration will be inserted at the beginning of each chapter that contains a PAR cycle and will spotlight specific activities undertaken in that cycle of the research.

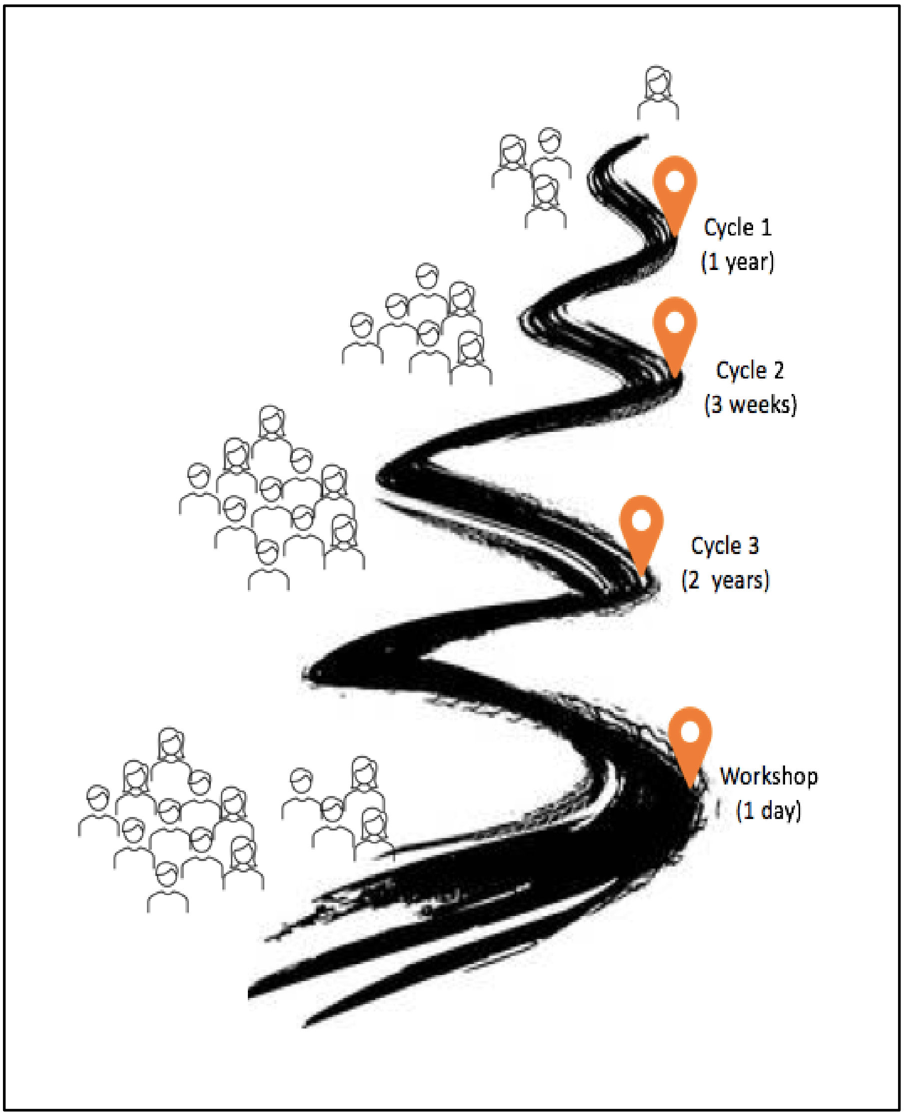


Figure 3.3 The research journey gathers collaborators through each cycle of PAR

3.7 Concluding methodological comments

Elements of PAR and Ethnographic research formed the methodological framework for this research program, which was designed to facilitate a collaborative, trusting and inclusive environment for people living with YOD. Each PAR cycle informed the next—with the learnings and insights taken forward into each new phase.

With the rationale and context for using the PAR framework now established, the next step was to seek out individuals living with dementia for guidance and direct input on how to design the type of research setting the YOD community had been seeking.

3.8 Looking ahead: next steps

While the research framework presented in this chapter provided the structure needed for YOD research and technology design, there was still a need to refine the way PAR, ethnography and probes were being used in the YOD setting.

This required going out into the field and inviting people with dementia to join me on this research. This begins the first of 3 action research cycles with activities as follows:

Chapter 4: PAR Cycle 1

- starts with early exploration of the dementia environment where I interviewed healthcare staff to learn more about this research setting.
- introduces the first two participants, recruited to this research program
- presents a methods (design) workshop, conducted in collaboration with the first two recruits
- concludes with set of co-designed interviews and probes, and a bespoke approach for the first empirical study for this research (implemented in Cycle 2).

Chapter 4.

Cycle 1: Desinging a New Approach to HCI Research in Context of Younger Onset Dementia

"if a program is developed to be truly dementia enabling, it will be inherently enabling to most disabilities"

Phillipson et al. (2019)

4.1 Introduction

The quote above inspired me to pursue a 'dementia-enabling' design for this research program, designed in consultation with key opinion leaders in the dementia community.

To reiterate, the review of literature revealed that while there are readily available methods to deploy in dementia research, these are not necessarily appropriate to use in YOD setting. The overarching goal of this research is to find an inclusive approach for HCI research and technology design—that is more suitable for the YOD group.

In this chapter, I will present the first (of three) action research cycles. Cycle 1 is designed, implemented and presented in two parts:

- **Part 1** is an exploration of the dementia environment and the recruitment of individuals with YOD into this program. In the Part 1, I introduce the first two people who joined me on this research journey.
- **Part 2** describes a Methods Workshop. This early workshop was designed to rethink current methods used in HCI dementia research and technology design – in collaboration with the first two recruits. The output from the workshop is a co-designed customised set of tools, and a fresh approach to deploy the tools which were trailed before being rolled out to all participants.

It is important to note here that the participants on this project were knowledgeable and well-versed in the dementia literature, and prolific users of technology. They were involved at varying levels of activism and embedded in the dementia community often as a representative voice for others living with dementia.

Before I commenced this phase, I gained University Ethics Committee (ETH17-1390) permission begin recruitment activities.

Kicking off Cycle 1 of the PAR model required me to look broadly at the dementia landscape; ask questions of professional care providers and observe how technology was being used in these high-care settings; and observe how existing technologies were being appropriated to support people with dementia and their care providers.

My intention was to learn as much as I could about these complex ecosystems—such as the government, economic, healthcare and social systems—before I began to recruit participants. While I understood the methodological and theoretical gaps after reviewing the literature, many of the insights on being diagnosed with dementia in an earlier stage of life – emerged during cycle 1.

4.2 Aim of Cycle 1

In this research setting, it was also important to establish the best environmental conditions in which to conduct this research. To guide this design, I looked to people with YOD for guidance.

Aim 1: Design the actions for each cycle of the PAR framework and assess if this is an appropriate (and useful) research model for working in the YOD setting.

Aim 2: To recruit people with YOD into this research program.

Aim 3: Work with people with YOD to review current research methods used in the dementia setting and **co-design** new methods for YOD.

4.3 Research questions addressed in this chapter

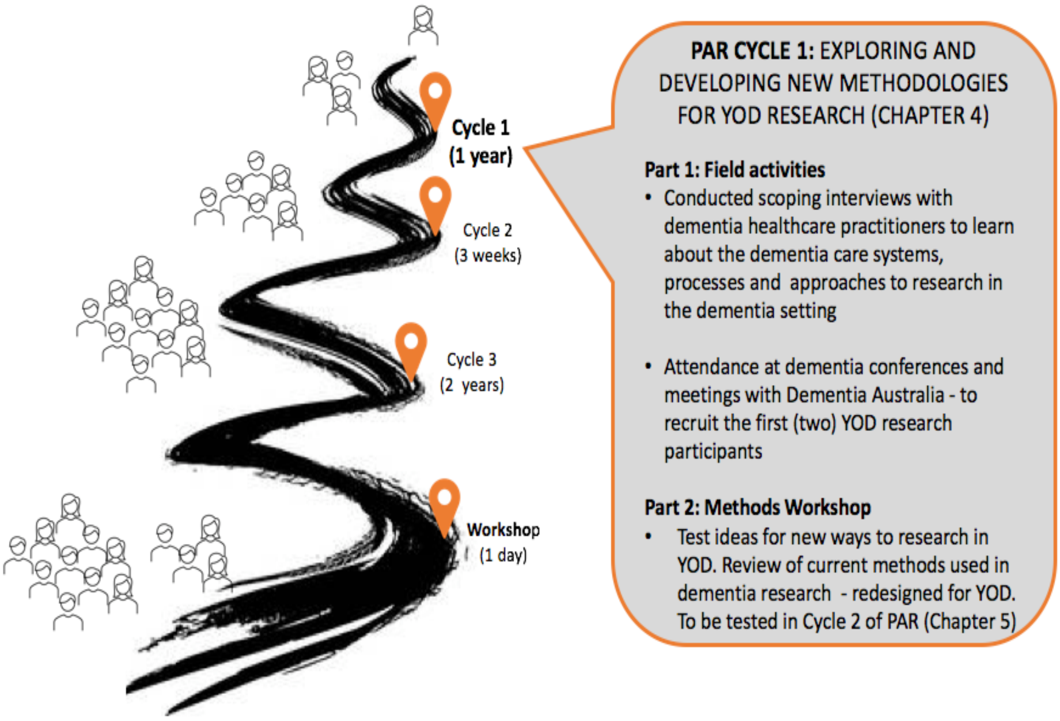
SQ 1. What methodological framework would facilitate a collaborative and trusting research environment to surface the unique first-hand experiences of people with YOD and their relationship with digital technology?

SQ 2. What research approach, methods and tools would best support the needs and wants of people with YOD?

PAR Cycle 1 was designed and is presented in two parts: (1) field study, and (2) methods workshop.

Part 1: The exploratory field study was designed to explore the dementia environment and recruit individuals with YOD, informing and supporting the design and direction of this research program This field study was a vital step for me to learn how to engage directly with people living with YOD. It allowed me to invite the first two recruits into the HCI research and design process—and address their concerns about being included in all research activities—as a human rights consideration. Early in the research, it became evident (and encouraging) that these two individuals were not merely speaking for themselves, they were also speaking and acting on behalf of their (YOD) community.

Part 2: The methods workshop (with first two recruits) aimed to review and rethink the current methods used in dementia research and technology design, and co-design (and test) new and more appropriate research methods for people with YOD.



PAR CYCLE 1: EXPLORING AND DEVELOPING NEW METHODOLOGIES FOR YOD RESEARCH (CHAPTER 4)

Part 1: Field activities

- Conducted scoping interviews with dementia healthcare practitioners to learn about the dementia care systems, processes and approaches to research in the dementia setting
- Attendance at dementia conferences and meetings with Dementia Australia - to recruit the first (two) YOD research participants

Part 2: Methods Workshop

- Test ideas for new ways to research in YOD. Review of current methods used in dementia research - redesigned for YOD. To be tested in Cycle 2 of PAR (Chapter 5)

Figure 4.1 The journey begins with the first two recruits joining this research.

4.4 Part 1: Field activities

Before starting recruitment and embarking on the empirical research, I spent time in the field to better understand the complex dementia landscape, such as the neurological, sociological and experiential phenomena of dementia described in the literature (Davis 2004; Kitwood 1997; Rossor et al. 2010).

Another objective is to network and build strong connections with national dementia not-for-profit organisations—an important step to understand (and get support in) the challenging recruitment landscape of dementia.

4.4.1 Exploring the dementia healthcare settings

Like others in HCI (Robertson et al. 2012), I started gathering insights into this complex environment by implementing scoping interviews. The purpose is to understand how and where technology was being used to support people with dementia. I was also curious about what healthcare professionals considered to be important requirements for future technologies in dementia care.

This was a similar approach to that taken by Guan et al. (2021) as reported in the article 'Taking an (embodied) cue from community health: Designing caregiver support technology to advance health equity'. In their study, the researchers visited an adult daycare facility to interview professionals with current experience in dementia caregiving.

Like those researchers, I sought out a range of dementia healthcare settings, within which to conduct initial scoping interviews. However, I extended these parameters in my research to include not-for-profit respite centres; public hospitals; and interviews with social workers, kitchen and reception staff, and psychologists specialising in dementia research.

During this early stage of the research project, I chose not to work directly with people with dementia, focusing instead on healthcare practitioners and staff working in respite centres, who had substantial experience in this complex and sensitive setting.

The Letter of Support from potential recruitment centres was required for my University Ethics Application (see Appendix 1).

4.4.2 Conducting scoping interviews with healthcare professionals

I conducted open-ended interviews with 12 healthcare professionals who worked in a variety of formal dementia care environments, such as hospitals and nursing homes. Some interviews were conducted face-to-face, while others were done over the phone.

The settings included the high-security dementia ward of a public hospital and several respite day-care centres.

The participants came from a range of backgrounds, all needing a high degree of training to work with dementia patients. Their professional job titles included Team Leader, Assessment Associate, Client Relationship Assistant, Psychiatrist, Social Worker and Volunteer. The work experience of the participants in dementia healthcare spanned from two years to greater than 20 years.

The questions were designed to provide insights into what people in the healthcare setting may imagine as a positive future in dementia care, and how technology may play a role in supporting this future. Section 4.4.4 summarises the results of these interviews.

4.4.3 Getting involved with the community

In addition to the scoping interviews, other activities in this phase included:

- having regular meetings with healthcare professionals
- participating in online forums, helped by people living with dementia
- connecting with others (university colleagues) working in dementia research
- following dementia advocacy groups through social media feeds
- attending international and local (Alzheimer's disease) conferences to network with the large number of people with dementia who attend with family/friends and who also present as keynote speakers.

In the next section, I will discuss the findings from this early exploratory work.

4.4.4 Preliminary findings from the field activities

The findings of the scoping interviews reflected the importance of quality of life (QoL) for people in dementia care. QoL was a dominant theme in data analysis. The interviewees described their focus on supporting the independence, dignity and personal identities of individuals with dementia.

The following areas also emerged as areas for consideration in my research plan:

Equity

During the scoping interviews, some caregivers expressed concerns for the dignity and self-worth of the people they care for. For example, one vision for a positive future is to ensure equity and respect throughout the healthcare system—particularly for marginalised groups. A report commissioned by the Australian Government of Social Services to assess the level of support needed for YOD also raised this concern for marginalised groups (Sansoni et al. 2016).

Healthcare staff also expressed concern that the person with dementia is not involved in choices about ‘when’ and ‘how’ digital technology is used. Many of the healthcare workers stated that they would like to see more effort into conveying the ‘voice’ of the dementia patient when designing technology solutions for persons with dementia.

Stigma

The social stigma that surrounds dementia can affect individuals’ self-worth. The caregivers I spoke with felt that access to education could help break down this stigma. They spoke of needing to change attitudes on what is considered a normal part of ageing and suggested that cognitive decline should not be treated in the same way as problems associated with the ageing process.

Technology

The data analysis revealed that digital technology may enable independence and social engagement. I found that, in formal care settings, healthcare staff and caregivers often use technology to aid communication with dementia patients. However, while the literature review identified using digital technology systems to monitor dementia patients as a key use of technology, there was no evidence of such technology being used in any of the settings I visited.

As caregivers shared their stories, I began to understand how they were finding creative ways to use existing digital technologies and software—including Google Earth, Google Translator, YouTube and iTunes—to emotionally engage residents. While these commercial technologies can be utilised to provide some entertainment and, at times, a distraction in these challenging settings, they have not been designed purposefully to support to people with dementia, or their care givers. This presents an opportunity for HCI to approach technology design more deliberately to support social connectedness for those in dementia care settings.

These initial insights highlighted several marginalised (sub-groups) in dementia settings, such as culturally and linguistically diverse (CALD) communities, the LGBTQI+ community and people with younger onset dementia.

Now that I had an overarching framework with the PAR model and preliminary insights from the early fieldwork, I was ready to focus my research on the people with YOD and their relationship with technology.

4.4.5 Introducing the first two recruits

With a growing understanding of the multi-faceted dementia networks and systems, the next step was to recruit individuals with YOD into the research program. The plan was to recruit two participants initially, followed by pausing recruitment briefly to work directly with the first two recruits in a methods workshop.

At this point, I would like to introduce these first two recruits: Dennis Frost (with a career background in IT and education), and Suzie Dillon (with a career background in medical science, and Law). I mention their career background here, because it was this expertise that helped to shape the tools and approach implemented in this research.

4.4.5.1 Dennis Frost and Suzie Dillon—a little background

I was introduced to Dennis Frost at Alzheimer's Disease International (ADI), a conference held in Japan. This annual conference is a forum to address the global 'crisis' on dementia, with representation from the WHO, Japanese Ministry of Health, World Economic Forum, Global Coalition on Aging and the pharmaceutical industry, among other industries.

Dennis was a featured speaker at this conference, advocating for people with YOD and the need for improved policy development to support their needs. While Dennis advocates for people with dementia (irrespective of age), my early interactions with Dennis reinforced the need to focus on YOD in my research, particularly given his aptitude for and experience with technology.

Not long after meeting Dennis, I was introduced to Suzie Dillon by a journalist, who had interviewed Suzie about her YOD diagnosis, in a featured an **ABC news report** (Appendix 2). Initially, I spent time getting to know both Dennis and Suzie (allowing them time to also get to know me). After pausing recruitment here, I worked with Dennis and Suzie to test some ideas and improve the design for subsequent and larger studies.

This initial phase of relationship-building lasted between one and three months. I took a familiarisation approach, which included regular visits to family homes, informal Skype calls, phone calls, text messages and some social activities (e.g. barbecues and café lunches). The topics of conversation related to everyday activities, hobbies, pets, stories from their younger lives, children, family and partners. As part of the relationship-building, I shared similar stories and my personal family connection to dementia.

The next step was to work with Dennis and Suzie in a co-design workshop so we could review current qualitative methods used in dementia research (which they had personal experiences with having participated in medical research settings). The goal of stopping at this point and reviewing how to collect data and insights for this research, was to bridge the methodological gaps outlined in Section 2.8.1.

4.5 Part 2: Co-design workshop

The activities conducted in the workshop aimed to understand how current tools and approaches could be rendered more inclusive for people with YOD and thus support the agency and independence they seek.

The first step was to think through the structure and logistics of running inclusive workshops with people with dementia. I started with looking at related research for guidance on workshops in a dementia setting to upskill in the basic principles. After this, I engaged Dennis and Suzie for guidance on how to tailor this structure for people in an earlier phase of life, who are prolific users of digital technology, and coming to terms with a recent diagnosis of dementia.

4.5.1 Technology design research in context of dementia

Looking through the related research, there were several workshop activities situated in the dementia setting that designed and assessed technologies taking a co-design approach.

While these design activities mostly focused on technologies for more advanced stages of dementia—and were either conducted with a proxy—or reviewed at the final steps by people with dementia—they were important in helping me understand the structure, challenges and possibilities of taking an inclusive co-design approach, so I could learn and build on this critical work.

4.5.1.1 Day Clock

Boyd et al. (2016) held this workshop to design an assistive technology by developing a day clock to address time disorientation (a common characteristic of dementia) and orient a person with dementia to the day of the week and part of the day (Figure 4.2), while not telling the time as such.

In this workshop, the authors asked carers and occupational therapists to review the prototype before it was evaluated by people with dementia. Individual people with dementia reviewed the prototype in their homes; the study did not involve bringing people with dementia together with the researchers in the early technology design stages (Boyd et al. 2016).

Figure 4.2 Production version of the day clock.

Essentially the design activities for the day clock were conducted in the presence of carers, and the technology was not designed directly with people with dementia.

4.5.1.2 Ticket to Talk

This study explored the use of digital media to facilitate intergenerational conversations, as well as the role of digital media in supporting agency in dementia (Welsh et al. 2018). The authors suggest that starting conversations with a person with dementia can be challenging, particularly for younger people. The research team designed a mobile application called Ticket to Talk to support these intergenerational conversations (Welsh et al. 2018).

In the Ticket to Talk example, the technology is used to reposition agency by redirecting the control of the conversation to the person with dementia; the younger person can listen to and discuss the stories shared, while at same time building confidence to interact with the person with dementia. In this research workshop, the technology was assessed in the homes of two families, a care home and at an expert critique workshop with nine older people who had an interest in and personal experience of dementia.

4.5.1.3 Touch Screen Ensemble Music model

HCI researchers (Favilla & Pedell 2013) worked in a collaborative setting with older adults with dementia, exploring how music therapy could play an active role in caring for people with dementia.

The group met at a community facility that was familiar to the participants, so the researchers could observe how the participants interacted with touch-screen technology. Before starting the activities, the researchers took time to get to know the group of paticpants. While not situated in YOD, what I took away from this study is that people with dementia can successfully particpate in workshop activitites (such as with touch-screen technologies) with little-or-no scaffolded instruction.

Overall, these examples outline valuable foundational work in technology design workshops within the context of dementia. However, in the first two examples—the Day Clock (2016) and Ticket to Talk app (2018)—the technology design did not involve people with dementia in the design process. In the third example—the Touch Screen Ensemble Music model (2013) people with dementia were included, and while, this work did not target the needs of people living with YOD, I found it beneficial in understanding the underlying principles of working in this sensitive setting.

From here, I will focus on the co-design methods workshop for my research, and how Dennis and Suzie introduced earlier were involved in each step: designing the workshop agenda, reviewing and designing probes and how to implement them in the YOD setting. The implementation included testing these new methods and approach before rolling them out

4.5.2 Starting with co-designing a workshop agenda

The aim of conducting a research methods workshop was to work alongside people living with YOD to find the most appropriate approach for conducting this research.

This collaboration between researcher and participant started with developing an agenda.

Prior to the workshop, an agenda was developed in collaboration with Dennis Frost and Suzie Dillon. They suggested the following four topics to address in our workshop discussions:

- **Research questions** How should research interviews be conducted with YOD individuals? What are the most appropriate preliminary questions to ask? What other items should we be mindful of when conducting interviews with people with YOD?
- **Reporting** How should we ask participants to capture or record their experiences? Through digital channels, non-digital channels or both?
- **Content** What needs to be captured? Experiences about dementia, families experience with dementia. Which moments have revealed something that affected you as a person with YOD? How did they make you feel?
- **Logistics** When should we ask participants to capture these moments? At the beginning or end of each day or both? Or in their own time?

The half-day session began with a review and discussion on the current research methods deployed in the dementia setting. This was followed by a more in-depth discussion on how to co-develop a suitable approach for people diagnosed with YOD—at a time where they have retained decision making rights, often still in the workplace, and wanting to play a role in shaping their future.

Dennis and Suzie were insightful on these topics because they had both been involved in medical research activities and understood the challenges first-hand of being a research participant when you have a diagnosis of dementia.

The workshop was held at Dennis's home; Suzie joined via FaceTime. The workshop was planned for two hours; however, the conversations were stimulating and informative between Dennis and Suzie and they asked for this to continue. The session extended for some 45 minutes past our planned timeframe. At several points, I checked in to ensure this extended time was acceptable to both.

I took notes and recorded the session. After transcribing and analysing the notes, these recommendations by Dennis and Suzie informed the design of the approach and probes used in the first empirical study.

4.5.3 Findings from the methods workshop

This section presents the findings of the workshop and offers preliminary insights on how the PAR model is a supportive methodology conducive for working closely with the participants.

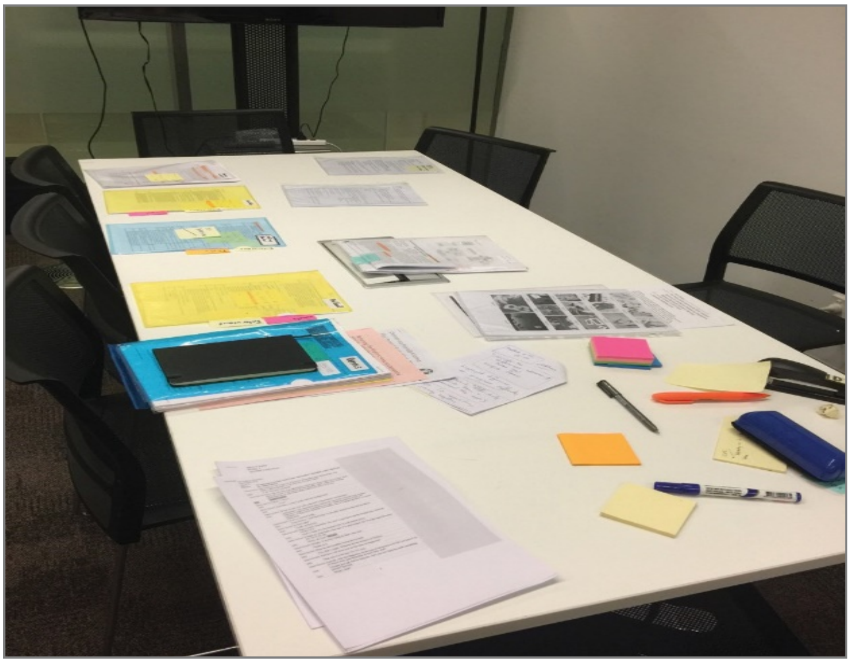


Figure 4.3 Designing the probe pack before rehearsing the implementation steps

4.5.3.1 Addressing stigma, flexibility and environment

In addition to tailoring the methods and probes for the next phase of this research, our discussions raised three important themes regarding ways of conducting research in YOD.

Stigma Both Dennis and Suzie suggested that researchers should be careful of the choice of language used in communications, presentations and interviews, to avoid reinforcing the stigma of dementia (e.g., not referring to people with dementia as 'sufferers' or 'suffering from' dementia or being 'demented').

Flexibility Dennis and Suzie strongly advised that the research should be flexible regarding the duration of interviews, and that the researcher should be aware of the pace of the discussions. That is, allow for more time (if necessary) for a person with YOD to share their story and accept as little or as much as they choose to reveal, even if this means extending the interview session time. *"It may be a rare opportunity for the person to* *disclose their experiences with YOD"* (Dennis Frost). It is also an opportunity to develop mutual respect and trust.

Environment Dennis and Suzie suggested first spending time in informal conversations before beginning the interview, 'warming up' the participants through exchanging information about families, friends and hobbies. They stressed the importance of a relaxed and flexible environment, and the exchange of stories, when building trust. While, at first, this appears to be a standard of ethics in research, it is imperative when working in the dementia setting. From the researcher's perspective, it allows time to understand, adapt and pace with the person being interviewed. In the dementia setting, communication styles can vary greatly, depending on the interviewee's retained abilities. The results of these conversations and interviews will be presented in Chapter 5, in which recruitment is finalised and the new tools and approach are tested in a three-week empirical study.

4.5.3.2 Co-designing and testing probes

Of great interest to me was Wallace et al.'s (2013b) study mentioned in section 2.7.2 suggests that probes need to work harder in sensitive settings, because users can have trouble articulating and communicating their thoughts and feelings. They need to enable deep reflection and gentle ways to give participants access to emotions and experiences.

During the workshop, I asked Dennis and Suzie what should be included in the probe pack. They suggested that the pack should contain elements to make the activities more enjoyable. However, beyond this, they stressed that the probes needed to be able to support the varying communication abilities of the people living with YOD. For example, stickers to help express emotions, colourful pens for visual stimulation, and provide labels so they could log the day/date and type of technology preferences.

They also suggested keeping the contents of the probe pack to a minimum and offer a series of written prompts to facilitate choice in the way they could 'record' their thoughts.

As such, the probe pack for this research contained a A5 lined diary, a selection of colourful pens, emoji stickers, researcher's contact information and instructions/guidelines.

It is worth noting here that while the contents of the probe pack (designed for this study) and the approach reflects that of others in HCI (e.g., Leong et al. 2010; Nassir & Leong 2017; Wallace et al. 2013a) may appear to be a repackaging of a diary study - the key difference is **the importance of self-selecting their own tools of inquiry and modes of communication,** as opposed to being given a diary to complete in a prescriptive way. In this study the (handwritten) diary entries were entirely optional.

While each participant was provided with 'instructions' in the probe kit, it was more important to have flexibility regarding how they wanted to communicate their YOD experiences back to the researcher, through various communication channels. That is, the participants were free to *choose* the tools that they felt would be the most effective and supportive based on their ability to communicate their experiences. More specifically, in this research, the participants could self-select their communication preference and relate their stories and experiences back to the researcher via text messages, phone calls, audio recordings, blog entries, emails and/or face-to-face visits.

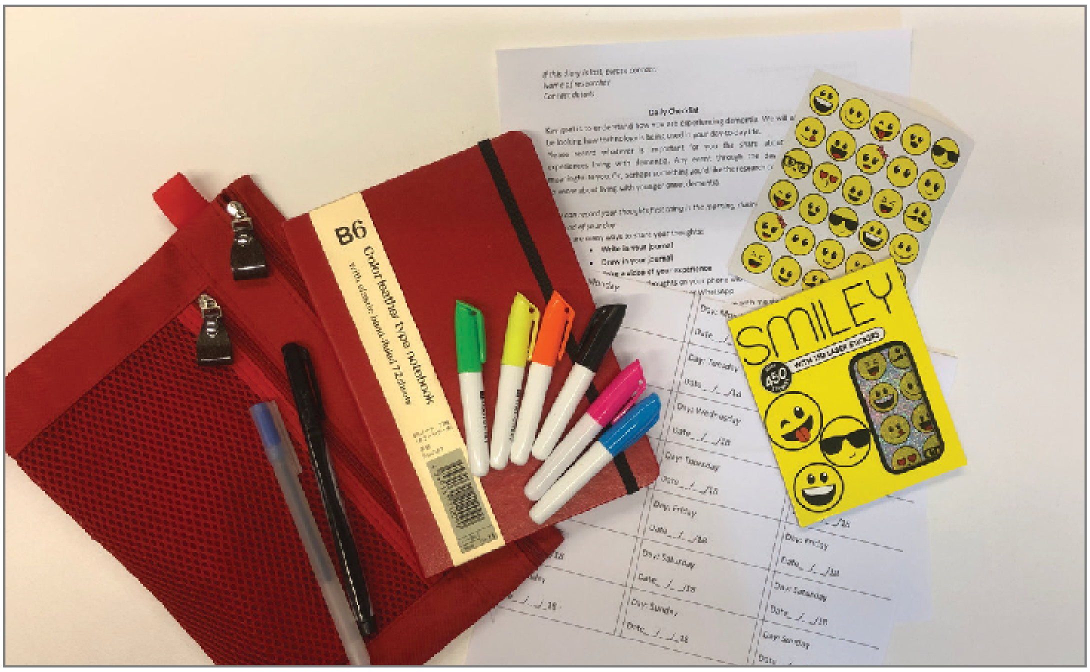


Figure 4.4 Dennis and Suzie recommended colourful pens and stickers during the Methods Design Workshop.

4.5.3.3 Co-developing Instructions and Guidelines

The discussion during the methods workshop revealed that having a prescriptive set of instructions may present some difficulties for a person with YOD, given their varying communication abilities and personal preferences. The overarching goal of the 'prompt' sheet (see appendix 3) that accompanied the probe kit was to respond to the request for 'flexibility' and 'choice' as part of the data collection process. This was of most importance to Dennis and Suzie, who made the following suggestions to add to the sheet.

- *Please start by sharing your personal story—as brief or as detailed as you would like.*
- *Please reflect on and share your experiences today. These can be experiences you would like the researcher to know about a person living with dementia.*
- *Please record daily entries using text, audio, photos/images or videos to express how you are feeling and why you feel this way.*

They both felt this would not only guide the participants, but also allow for self-expression and provide a choice of ways to communicate back to the researcher.

4.5.3.4 Testing the new methods before launching the empirical study

Denis and Suzie trialled the co-designed probes and guidelines 'prompt sheet' before I continued with the recruitment activities. We ran through each step of the study implementation together, paying particular attention to any untoward impact that this approach may have on a person with dementia.

After Dennis and Suzie validated the usefulness of providing both flexibility and choice in the procedure, I created multiple sets of the same probe pack for the participants. The probe packs were deployed in PAR Cycle 2: Study 1.

Providing the participants with a choice on how they would like to capture their experiences, went a long way to support agency for the participants involved in this research.

Following the co-design methods workshop with Dennis and Suzie, there was an opportunity to trial the interview questions and probes before rolling these out further. The goal was to assess if there was enough flexibility to respond to the research requirements in a way that supported their varying abilities to communicate the YOD experience and record their observations of technology use.

In addition to helping me set the early direction and approach to conducting the interviews and ways of offering probes to assist in their story telling in a respectful and inclusive way, Dennis and Suzie also provided holistic guidance on the research framework and how to continue to engage with people with YOD and their broader social networks.

These outcomes developed with Dennis and Suzie, resonated with the recommendations from Hammersley and Atkinson (1993) presented in section 3.3 of this thesis—albeit the following points were in context of ethnographic research principles:

- *Data should be collected using several different techniques with an emphasis on observation.*
- *Methods of data collection need to be flexible and unstructured, to focus on what people say and do.*

4.6 Discussion

PAR Cycle 1 was designed in two parts. First to spend time out in the field (12 months) to better understand the methodological and experiential gaps identified in the literature review. The aim was to explore more appropriate ways to conduct research and design into YOD and technology design. This is where I realised that most of what the public knows about YOD comes from popular media (television documentaries, magazine articles, etc.), rather than from the research literature. This validated the need for empirical research in this area, particularly if 'we' are to design appropriate technologies to support this emergent, more technically adept group of people who are living with dementia.

While there is valuable work in the technology and dementia space—with digital technologies available to support autonomy in daily routines, provide surveillance and socially engage those with dementia—I found no evidence of technology purposefully designed for, and with, people living with YOD. In fact, the findings from the scoping interviews revealed a creative use of existing technologies and devices by healthcare providers—primarily used to support those with LOD.

Regarding the previous technology design workshops reported in the literature (section 4.5.1), it was difficult to determine if these studies had representation from the YOD group. The researchers in these studies mostly relied on the families, researchers and designers to observe and reflect the needs of people with dementia in the final technology design. Nevertheless, I drew on the underlying principles from these workshops and examples from the more experienced researchers to conduct the methods workshop described in this chapter.

In summary, giving participants a choice of how they wanted to record their experiences and insights into YOD and technology use, was seen as going a long way to support a more positive approach to conduct YOD research. This became more discernible in PAR Cycle 2 where the recommendations and returns from Dennis and Suzie, were validated by the next wave of participants with YOD in Study 1.

Finally, the main point Dennis and Suzie wanted HCI researchers to understand is that the cognitive (sensory) characteristics of dementia needed careful consideration when designing the tools and artefacts to be used in a dementia research program. As a reminder, in both the major and minor forms of dementia, six cognitive domains are affected (APA 2013). These are outlined in chapter 2 (section 2.3.2).

From a researcher perspective this aspect raised the concerns about having a one size fits all approach when conducting research in the YOD setting, as each person may have varying strengths, preferences, and abilities. This will be highlighted further in Chapter 5 – findings from Study 1 (section 5.5).

4.7 Contributions

PAR Cycle 1 produced the following methodological insights for designing a research program that meets the needs of the participants with YOD and the goals of the research.

These insights are valuable in supporting those wishing to conduct research in YOD or a similar setting.

- The PAR model is an appropriate methodological framework to enable input from, and engagement with the participants with YOD
- The PAR model supports the agency of people with YOD.
- The PAR model creates an inclusive and collaborative environment for with participants and researchers to explore YOD and with an open mind as to the outcomes.
- PAR Cycle 1 (activities) enabled the flexibility to support the varying needs of people with YOD. For example, a key option that surfaced during the workshop was for participants in the empirical study to **self-select** probes, based on their personal preferences and abilities.

4.8 Limitations

The participants (with YOD) and I share similar cultural and ethnic backgrounds, and we were of similar age. The participants were well-educated professionals with sound socioeconomic status, who were motivated to advocate for others living with YOD.

On reflection, these points may be the reason they were more ‘visible’, thus allowing me to connect and recruit them into this research. Their backgrounds may also suggest why they have such a strong sense of agency and why they volunteer in public positions to advocate for people with similar experiences of YOD. Furthermore, their specific career backgrounds (IT, Science, Law, Business, Social Work) may suggest why the participants felt strongly about being closely involved in research activities. This may not always be the case, if recruiting from different professions.

4.9 Conclusion

The PAR Cycle 1 activities revealed that people with YOD want to participate actively in research so they can shape the narrative of their own experiences. It is a legal obligation—recognised by the *United Nations Convention on the Rights of Persons with Disabilities*—to include people with dementia in research or other similar activities. However, this option is rarely provided to people with dementia.

Regarding current methods used in dementia research, the practice of using a proxy to speak on behalf of the participant, as well as complete research activities for them, has implications for the YOD experience. People with YOD (and those in early-stage dementia) can communicate their own experiences; it is not necessary for another person to communicate their experiences. The YOD individuals who took part in this research expressed that they want agency—to be seen as a ‘whole person’, who is more than the dementia.

4.10 Looking ahead: Next steps

In Chapter 5, I will describe the first empirical study implemented in this research. This short study was designed with a three-week duration, which aimed to test the new methods and approach co-designed with Dennis Frost and Suzie Dillon during the co-design methods workshop.

In addition to testing the methods and approach, the study in Cycle 2 was designed to capture preliminary data on the lived experiences of people with YOD and the role of technology in their daily lives.

Chapter 5.

Cycle 2: Validating a New Approach for HCI Research in Context of Younger Onset Dementia

5.1 Introduction

This chapter presents Study 1, the first empirical study for this research program, and provides steps for study design, recruiting, testing, and implementing the new methods for sensitive HCI research into YOD. These fresh insights and recommendations were produced through open dialogue with Dennis Frost and Suzie Dillon during cycle 1. Armed with these new insights, we move seamlessly to cycle 2.

The focus in cycle 2 is to develop ways to build on the insights and recommendations that surfaced during the methods workshop. Working directly with two people living with YOD enabled me to take a co-operative and thoughtful approach to designing the activities and probes for this study; providing flexibility and agency to the all future participants who were not involved in the development process.

More specifically, the methods workshop (in cycle 1) produced a set of customisable probes and recommended a more flexible approach for researching in YOD. This approach forms the bases of the design of **Study 1.**

In addition to the study's methodological focus, and opportunities to gather preliminary insights into the YOD experiences; this chapter describes the natural evolution of roles on this journey. It may be because of the PAR framework, that our roles quickly developed from (the traditional) 'participant–researcher' to 'research collaborators', with the PAR model providing and environment of trust, and many opportunities for understanding the various ways we were contributing—personally, professionally, and academically.

5.2 Aims of Cycle 2: Study 1

In Cycle 2 it was important to finalise the recruitment, and further test the methods and approach to YOD research as proposed in the previous PAR cycle by Dennis and Suzie.

Aim 1: To test and validate the customisable tools and flexible approach designed in the methods workshop (Cycle 1) to support the varying abilities of individuals with YOD.

Aim 2: To collect preliminary data and insights on the lived experience of YOD and technology preferences. Before heading into a two-year ethnographic fieldwork to explore these experiences in more depth during Cycle 3.

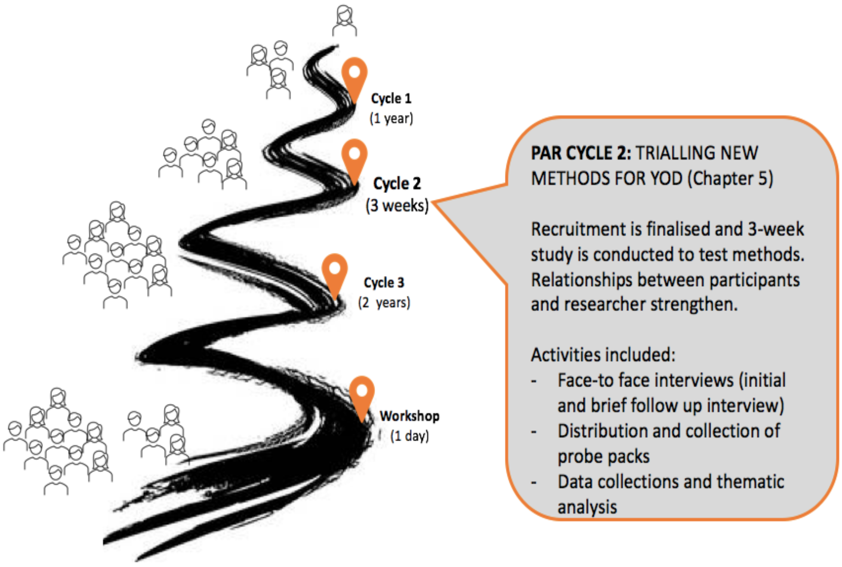
5.3 Research questions addressed in this chapter

RQ. How can HCI develop deeper and more nuanced understandings of the lived experience of people with YOD?

SQ 1. What methodological framework would facilitate a collaborative and trusting research environment to surface the unique first-hand experiences of people with YOD and their relationship with digital technology?

SQ 2. What research approach, methods and tools would best support the needs and wants of people with YOD?

PAR Cycle 2 (Figure 5.1) is where the methods workshop outputs (a customisable set of probes and flexible approach) were tested.



PAR CYCLE 2: TRIALLING NEW METHODS FOR YOD (Chapter 5)

Recruitment is finalised and 3-week study is conducted to test methods. Relationships between participants and researcher strengthen.

Activities included:
- Face-to face interviews (initial and brief follow up interview)
- Distribution and collection of probe packs
- Data collections and thematic analysis

Figure 5.1 The research journey gathers momentum: Study 1 begins, forming preliminary insights into YOD and role of technology.

5.3 Methods

The co-designed interviews, tools and approach helped to address the concerns (outlined in the literature) people with YOD have about stigma, independence, agency and choice, by building a respectful and collaborative research environment through the spirals of action research.

In this section, I describe Study 1's design, recruitment of participants and implementation steps.

5.3.1 Inclusion and exclusion criteria

Following approval from the University Ethics Committee (ETH17-1390) five individuals living with YOD completed the recruitment. The inclusion and exclusion criteria for recruitment are as follows:

5.3.1.1 Inclusion criteria

- A medical diagnosis of YOD (classified as the onset of dementia symptoms before 65 years of age).
- Able to provide independent informed consent to join the study.
- Comfortable with using technology; meaning that the participants enjoy engaging with digital technologies in their day-to-day lives.

5.3.1.2 Exclusion criteria

- Late onset dementia (diagnosed after 65 years of age).
- Late stages of YOD (classified as experiencing significant difficulties communicating).
- Physical conditions that impact being able to participate in this research.

5.3.2 Participants and recruitment

The YOD recruitment process was challenging. Locating people living with YOD is not easy, for several reasons. First, they are not living in settings where one would generally encounter people with dementia, such as aged-care facilities. Second, dementia has no visible physical characteristics. This is partly due to individuals with YOD retaining abilities and having high participation in everyday life.

Third, due to reported delays in receiving an accurate diagnosis, many YOD individuals are unaware of their condition. Finally, there is a lack of formal support services and communities to which researchers can turn for recruitment.

Organisations such as advocacy groups, conferences and local groups were helpful in connecting me with people with YOD. These organisations included:

- **Dementia Alliance International (DAI)** A forum in which individuals living with YOD establish public discussions and agendas. This setting allowed me to connect with people living with YOD.
- **Alzheimer's Disease International (ADI)** This is the world's largest and most important conference on dementia and Alzheimer's disease. Such conferences are of increasing interest for people with YOD who want to forge a presence at these international forums.
- **Local dementia organisations** These often have YOD research streams, which can be helpful with recruitment. However, these can also have several gateways and formalities before a researcher is introduced to potential participants.

Once five participants had joined this research, participant recruitment was stopped. Their names, career backgrounds and YOD diagnoses are shown in Table 5.1. The rationale for limiting participant numbers was based on the complexity of this area of research; the aim was to continue to work with the same individuals over the course of the research program (i.e., a period of two to three years).

After spending a considerable amount of time with the participants, I began to understand how important it was for these individuals to be seen as a 'whole person'—more than a dementia diagnosis. To support this desire, and with their permission and encouragement, I have not de-identified the participants in this research. Instead, their actual names (and photos and biographies) are shared in this thesis.

Name	Career background	Diagnosis
Dennis Frost	IT and Engineering	Frontotemporal dementia (FTD)
Suzie Dillon	Medical Science/Law	Vascular dementia
Phil Hazell	Business Consultant	Frontotemporal dementia (FTD)
Stephen Grady	Measurement Scientist	Vascular dementia
Jeff Thurlow	Business Manager	Posterior cortical atrophy (PCA)

Table 5.1 Demographics of the YOD participants, aged between 48 and 63 years of age at the time they joined this research program

Note: Navigating through the university ethics process was lengthy, with the application form assigning dementia research as a 'vulnerable' classification. This means that researchers are required to provide a great deal more information in the ethics submission, outlining the high level of support to be put in place. This level of support is not necessarily required for a person with YOD. This slowed the process down considerably and greatly impacted my efforts to network with recruitment gatekeepers -leading to delays in recruitment of up to six months.

5.3.3 Research timeline

The research timeframe for Study 1 was approximately two to three weeks, starting with an initial interview, where I spent time getting to know the participant, introduced the research aim and process, and collected the participants' consent.

Following the interview, each participant was presented with the probe kit (see Figure 5.2), which had been co-developed by the first two recruits in the Methods Workshop.

Throughout PAR Cycle 2, I maintained periodic contact with the participants through various means of communication. Each participant determined the level of contact and support that I would provide at the beginning of the study.

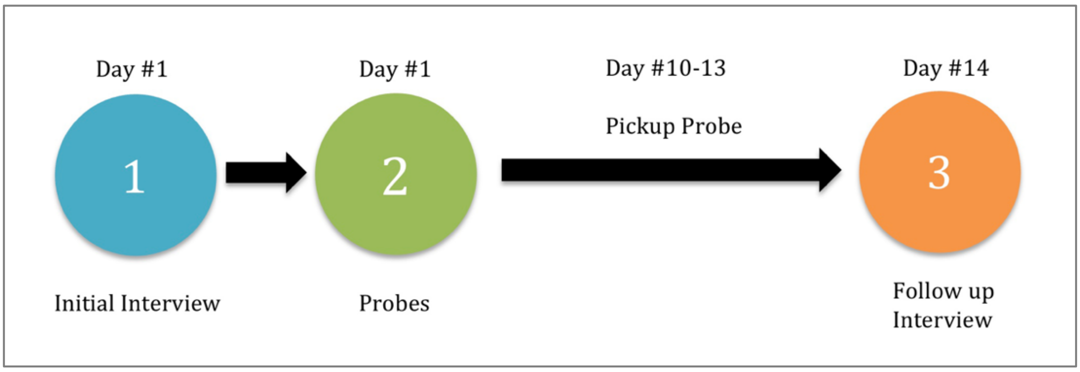


Figure 5.2 On Day 1, each participant completed the interview and was provided with a probe kit.

5.3.4 Conducting interviews

I conducted semi-structured interviews, each lasting approximately 60 minutes, with more time allowed if required. The interviews were designed to gather basic demographic data, as well as information related to the participant's diagnosis of dementia and use of technology in their daily life.

Carers and partners were not required to be present; however, they were welcome (at the participant's discretion). The interviews took place in the home of the participant with YOD. After each interview, I provided the participant with the probe pack, together with the accompanying instructions/guidelines, and explained how they could use the probes to provide accounts of their daily experiences with YOD during the study period.

5.3.5 Probe kit

In this study, the probe kit was not intended to be deployed or used in a 'prescriptive' fashion. What I mean by that tis, there was not a set of instructions provided that led to a predetermined way to use the kit. For example, the use of a paper diary to collect handwritten notes. While a diary was provided as part of the probe pack, it was not mandatory to make handwritten notes. This was to ensure that participants who did not enjoy copious handwriting could opt not to do so. Participants were provided a choice of how to record their daily experiences of YOD and use of technology.

The probe pack included the researcher's contact details, as well as colourful pens, labels and emoticon stickers. Dennis joined me (during a visit to the University) to shop for the journals, pens, stickers and labels (figure 4.4).

All participants were issued with the same probe kit described in the previous chapter (see section 4.3). A guidance sheet was included in this pack and contained examples explaining various ways the participants could self-select a preferred communication method. This 'guide' was an important inclusion in the probe pack (see appendix 3). Again, the reason for providing options, as opposed to a prescriptive set of instructions, was to introduce flexibility in how participants could communicate their experiences back to the researcher. This was a request from the people with YOD, so that their individual communication styles and strengths were supported in how the captured the events of the day/week.

The probe kits were dropped off at the beginning of the study and collected at the end, when a follow-up interview was conducted.

5.3.5.1 Sequence in the deployment of the probe kit

Dennis and Suzie be the first two recruits to trial the utility of the probe kit before it was rolled out to others who joined the study.

- **Day 1:** at the beginning of the initial visit (figure 5.2) - before the interview commenced - I explained the goal of the research, the purpose and scope of the interview, and the role of the **probe kit** in facilitating storytelling and capturing key information about the role of technology around the time of the diagnosis. This was an opportunity to establish a shared understanding of the activities to be conducted in the coming weeks and the type of information I was seeking.

  Prompts: I also had the opportunity to ask what level of support the participant would like me to provide; for example, the timing of prompts or reminders to complete the activity. For some, this was daily, while others did not require a prompt. This was also an opportunity to provide feedback and reassurance that the participants were making meaningful contributions (irrespective of how much or how little they chose to share on any given day/week).

  Probe kit contents: while the probe kit, was by no means 'novel', it did serve the purpose of signalling there was to be a recording of personal experiences and a duration of time to focus on the day-to-day activities for the person with YOD. It was also developed by the people who would be participating in the research (not preselected and handed out by me as the researcher).

- **Days 10 to 13:** check-in with participants to gauge their level of engagement, assess whether they need additional time, and to pick probes.

- Day 14: On the day I collected the probes, I also conducted a brief follow-up interview – to gather any information the participant would like to share that may not have been captured in the earlier activities. (Note: some participants wanted an additional few days to complete their activities).

5.4 Program level: data management and analysis

5.4.1 Data collection and management

While the data collection methods were open and flexible, the recorded experiences of YOD and the role of technology were analysed in depth using thematic analysis (Braun & Clarke 2012). This method of analysis continued across all studies.

Each participant was advised to self-select their means of communication, based on their personal preference and communication abilities. They shared information through the following communication modes: text messages, digital notes (iPads), emails, voice recording files and social media posts.

The varying response styles were processed as follows:

- **Text messages** Screen shots were taken of the text message and saved to file. The content of the text messages was entered into the coding spreadsheet.
- **Face-to-face meetings** Incidental observations were captured in field journals, and key points were transposed into the coding spreadsheet.
- **Emails** Key points were transposed into the coding spreadsheet.
- **Website posts** Key points were transposed into the coding spreadsheet.

5.4.2 Data Analysis of interviews

This complex and multi-layered research program included data on the lived experiences of YOD and their use of everyday technologies, which led to different thematic streams. From a methods perspective, an additional review on the uptake of probes was also conducted.

5.4.2.1 Thematic analysis of experiential data

Experiential data from the interviews: for this element of the research, a thematic analysis approach was taken over the course of the program. The source of these data came from interview responses, conversations (across the stakeholder networks), from the participants handwritten notes, texts, emails, voice recordings, blogs and workshops.

Given the personal and collaborative nature of this research program, the participants were actively involved at each step of the analysis. That is, the participants (as research partners) influenced the organisation and validation of themes, playing an active role in categorising themes; in adding reference materials (such as publications – see figure 5.3) to help bring perspective; and, in validating the themes as each category evolved into deeper insights.

To assist with this process, the data from the studies were organised in a **coding spreadsheet** with a tab for each study (Appendix 4). This enabled me to search and filter the text and trace key items/quotes back to the source. Once all data were available and ordered, I began coding as follows:

- **Open coding,** I performed a preliminary analysis, during which I read through the transcripts and highlighted key concepts. The commonalities (with the participant as the unit of measure) were mapped against themes; these were reflected in the coding spreadsheet.
- **Axial coding** Using the spreadsheet and highlighted transcripts, as well as listening to the voice recordings (many times), I identified items that were linked somehow (e.g., a quote or narrative from a transcript) and laddered them up into key themes and sub-themes.

Over time, referring to this spreadsheet revealed new understandings of events, which may not have been obvious at first pass. With these repeated viewings, opportunities emerged to validate or expand on the recurring themes. Towards the end of the analysis phase, the data were organised into a few key themes of most importance to the participants and of relevance for the HCI community.

5.4.2.2 Analysis of the uptake and use of probes

In terms of assessing the validity of the probe kit, the analysis plan was to map the various modes of communication chosen by the participants, and to assess if 'choice and flexibility' were beneficial in supporting communication in the YOD research setting, given the many challenges regarding cognitive processing of information.

While the duration of the data collection phase was two weeks, not all participants began the study activities on the same date. This staggered approach afforded me time to sort, review, and reflect on each participant's situation which sensitised me to my thematic analysis of the interviews.

Taking the time to examine the uptake of the probe kit, and the various communication approaches taken by the participants, enabled me to develop deeper insights about each participant's situation over the duration of Study 1.

5.5 Findings

In this section, I present the findings from analysis and reflections. As a reminder, this study’s primary objective was to implement and test the methods and procedures developed in the exploratory phase of this research, and it was designed to support individuals with YOD in the research setting.

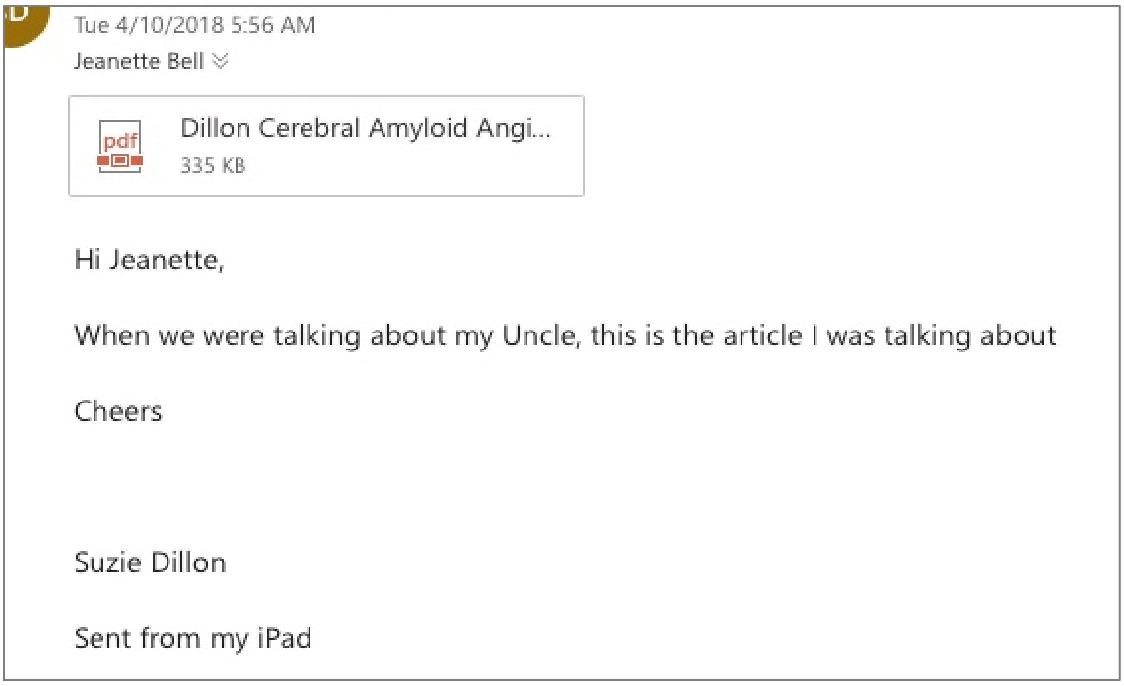
The secondary objective was to gather early insights into the experiences of people living with YOD and how they used technology in daily life. The participants offered thoughts and emotions on subsequent field visits during Cycle 2, which were also captured and integrated into the analysis.

I will begin with how relationships developed over the course of Cycle 1 and Cycle 2 of the PAR model.

5.5.1 The natural evolution of roles

While the individuals were initially recruited as participants, this conventional role quickly evolved into a collaborative relationship. Given the participants’ strong academic backgrounds in IT, medical science, law and social services, it became clear to me that, by looking beyond the condition of dementia to the person living with dementia, this research program would be enriched by a collaborative partnership. This resulted in the participants engaging in the research program as research partners. What this means is, while it was my responsibility to establish the research framework and ensure that an ethical approach was taken, I was open to a collaborative approach.

Some examples of the participants’ academic contributions to this research included sharing relevant and current research papers, links to related projects, insight into dementia-related technologies, and articles on medical and legal aspects of dementia research (see Figure 5.3).


Tue 4/10/2018 5:56 AM

Jeanette Bell

Hi Jeanette,

When we were talking about my Uncle, this is the article I was talking about

Cheers

Suzie Dillon

Sent from my iPad

Figure 5.3 An example of sharing literature on dementia.

5.5.2 Interviews—an exercise in building trust

During the methods workshop, the participants with YOD suggested that informal conversations would help people feel comfortable to share their individual experience. Indeed, these informal conversations (on hobbies, pets, families, etc.) helped and prepared me for what I might hear during the interviews. The participants' stories took many forms, which shifted from the medical/diagnosis stories to broader philosophical conversations about life.

In terms of structure, I began each interview with demographic questions such as age, type of dementia the participant was diagnosed with, time of diagnosis and so on. This was helpful in transitioning the interview to the more sensitive aspects of dementia, such as how they felt at the time of their diagnosis.

Asking questions about what led to a participant's YOD diagnosis provided greater clarity on the situation and allowed me to probe more deeply into their feelings regarding their dementia diagnosis. In the methods workshop, I was alerted to the need of being supportive of the pace and settings in which individuals shared their stories. This meant being open to the fact that the stories may be shared over time and, potentially, through follow-up meetings. Generally, the individuals appreciated the opportunity to tell their stories at their own pace.

One recommended technique offered from the first recruits with YOD was to use short technology-based questions to quickly shift the conversation's topic and mood. This provided some emotional relief and lifted the mood discernibly from the serious discussions that surrounded their diagnosis stories. All participants greatly enjoyed this part of the interview, and it was apparent that they all use and enjoy digital technologies daily. Dennis and Stephen, for example, had technical backgrounds and maintained a keen interest in technology. Suzie and Phil were avid fans of the iPad, while Jeff was comfortable with a smartphone. The enjoyment evident in this part of the interview may have been because they did not have to talk explicitly about dementia.

From a researcher perspective, I found that there were unexpected complexities to tackle during the interview activities in the participants' homes. Given the varying sensory impacts of dementia (which are different for each person), I needed to be mindful of how my personal style may or may not impact the person with dementia (voice tone and volume, facial expressions, body language, etc.) and become more sensitive to both verbal and non-verbal cues, adapting as required. This became more intuitive over time. I also asked for feedback.

5.5.3 Choice, flexibility and adapting to the environment

The findings presented in this section underscore the need to be flexible and adaptable (as a researcher) to the participants' varying abilities. Additionally, they argue the case for providing a selection of ways to communicate based on an individual's preferences. These examples are generalizable and could be applied more broadly, beyond research in the dementia setting.

While the probes used in this study are not at all revolutionary, this flexible, self-selecting method of using probes has not been previously reported in dementia research. Having access to the insights of people living with YOD led to exploring alternatives and more productive means of data collection for participants. This approach also addressed some of the methodological challenges faced simply by offering a variety of ways to diarise participants' experiences with YOD and their relationship with digital technologies.

5.5.4 Communication preferences

The study revealed that, when participants were offered a choice, they selected various communication methods, including text messages, emails, voice recordings, and electronic and handwritten diary entries. Providing flexibility and a choice of tools for the participants to share their stories was successful. It allowed participants to decide which way they felt most comfortable (and enjoyed) communicating, and to use different media to communicate their everyday experiences. Some of the participants' communication preferences are detailed in the following pages.

5.5.4.1 Voice recording diary entries—preferred by Stephen Grady

Stephen found it challenging to handwrite extensively. He was comfortable with using technology to record his thoughts: *'[it was] good to have the option of voice recording because I enjoyed the process of recordings.'* Throughout the study period, Stephen sent me his recordings daily (see Figure 5.4).

Steve

20180105 Jeanette

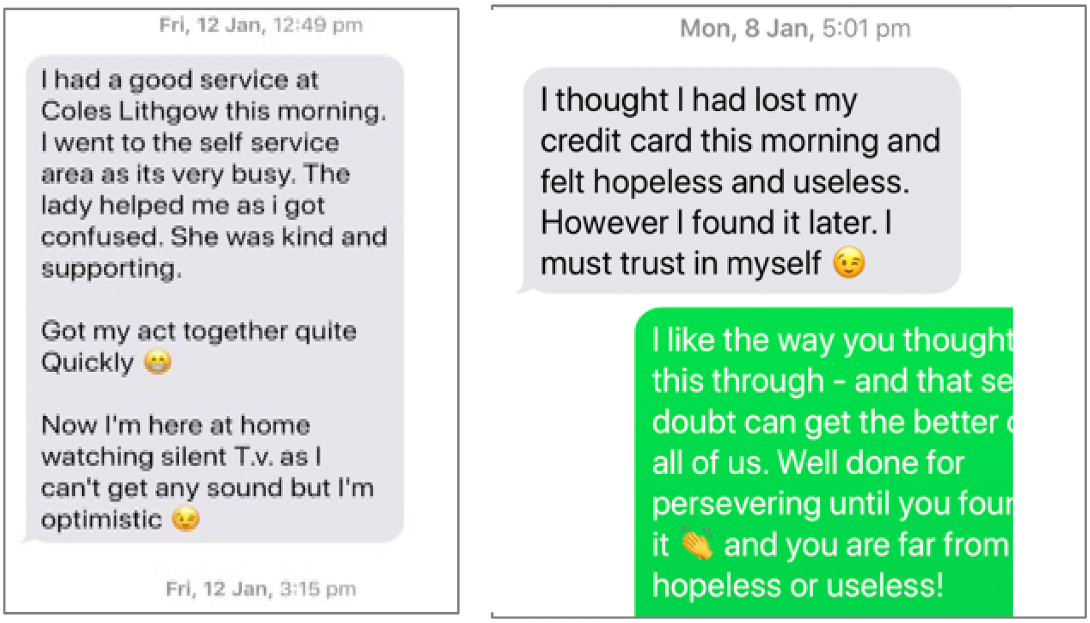
To:

7 January 2018 at 12:20 am

Figure 5.4 Voice diary entry—the form of communication favoured by Stephen.

5.5.4.2 Daily text messages—preferred by Jeff Thurlow

Jeff had some limitations with his handwriting but enjoyed texting and using emoticons (see Figure 5.5). Even though Jeff struggled with his handwriting, a symptom of his dementia, his short-form texts with emoticons were an effective way for him to express his day-to-day experiences of living with dementia.



Fri, 12 Jan, 12:49 pm

I had a good service at Coles Lithgow this morning. I went to the self service area as its very busy. The lady helped me as i got confused. She was kind and supporting.

Got my act together quite Quickly 😁

Now I'm here at home watching silent T.v. as I can't get any sound but I'm optimistic 😉

Fri, 12 Jan, 3:15 pm

Mon, 8 Jan, 5:01 pm

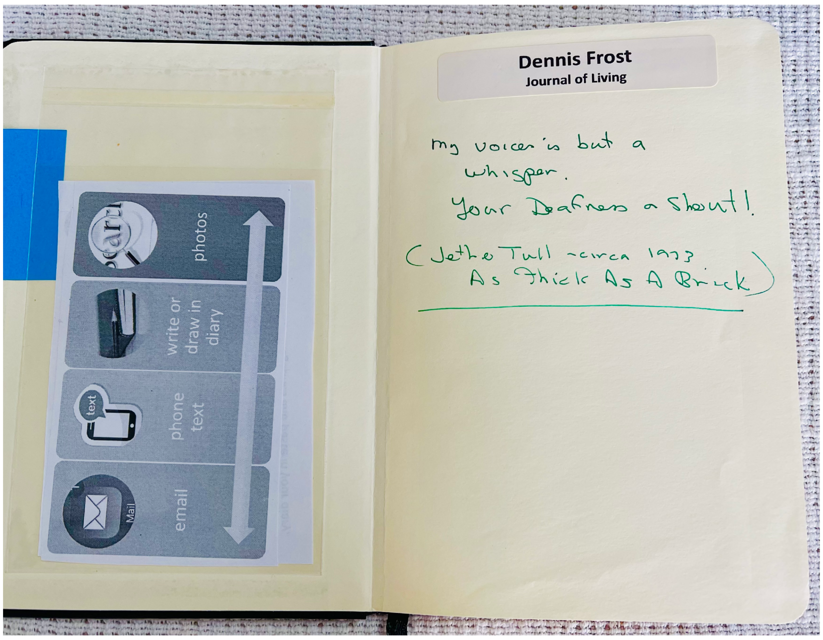
I thought I had lost my credit card this morning and felt hopeless and useless. However I found it later. I must trust in myself 😉

I like the way you thought this through - and that se doubt can get the better all of us. Well done for persevering until you four it 👏 and you are far from hopeless or useless!

Figure 5.5 Examples of texts and emoticons—favoured by Jeff.

5.5.4.3 Handwritten diary entries—preferred by Dennis Frost

Dennis could use various options to express his daily experiences with dementia. He was comfortable with handwritten notes and presented extensive accounts of his daily life events in the diary—Dennis always writes in green ink (see Figure 5.6).



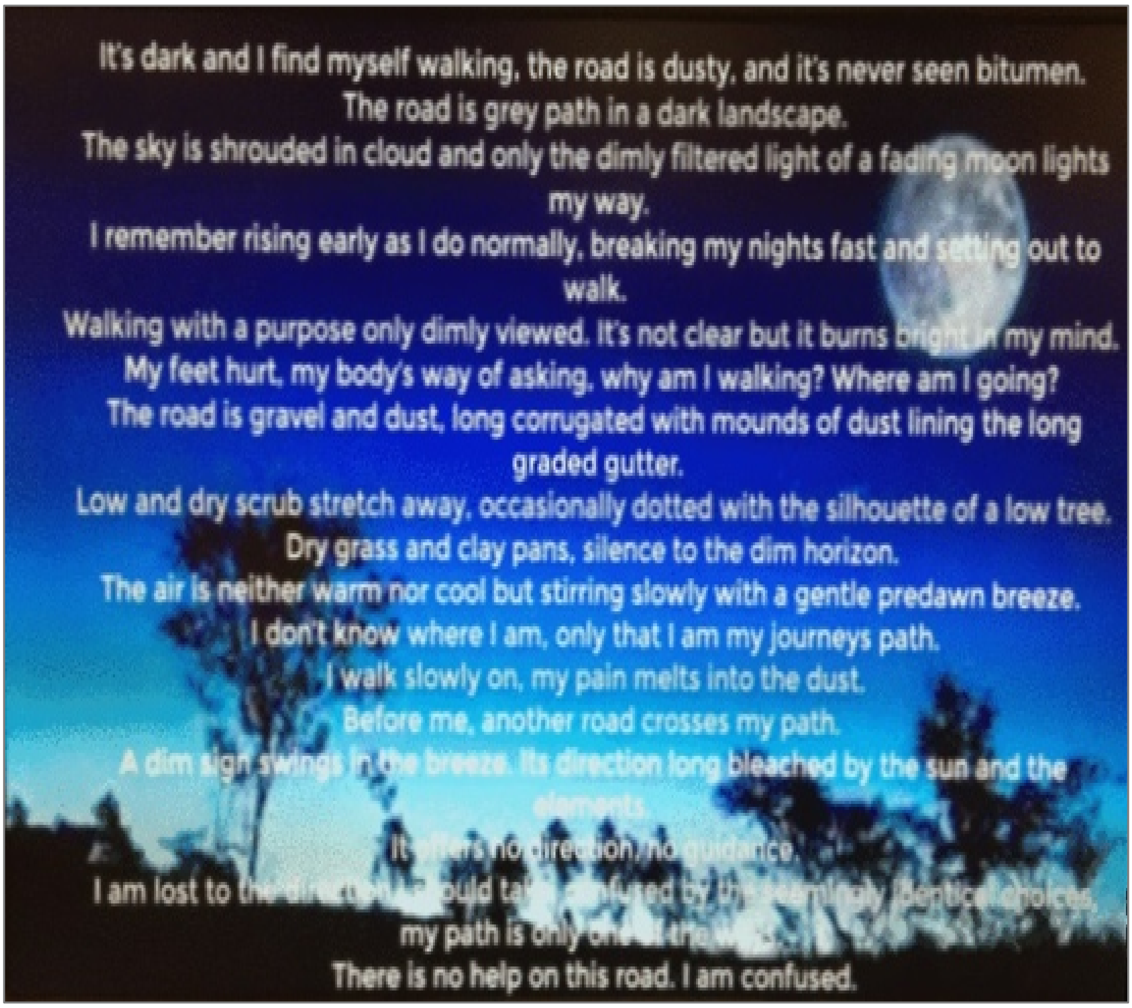
Dennis Frost
Journal of Living

my voices is but a
whisper.
Your Deafness a Shout!

(Jetho Tull - circa 1973
As Thick As A Brick)

Figure 5.6 Example of the diary from the probe kit, personalised by Dennis.

At the same time, Dennis created digital data. These included voice recordings of his thoughts, and poems he wrote about his experiences. He posted these materials on a website he developed specifically for this research (see Figure 5.7).



It's dark and I find myself walking, the road is dusty, and it's never seen bitumen.
The road is grey path in a dark landscape.
The sky is shrouded in cloud and only the dimly filtered light of a fading moon lights my way.
I remember rising early as I do normally, breaking my nights fast and setting out to walk.
Walking with a purpose only dimly viewed. It's not clear but it burns bright in my mind.
My feet hurt, my body's way of asking, why am I walking? Where am I going?
The road is gravel and dust, long corrugated with mounds of dust lining the long graded gutter.
Low and dry scrub stretch away, occasionally dotted with the silhouette of a low tree.
Dry grass and clay pans, silence to the dim horizon.
The air is neither warm nor cool but stirring slowly with a gentle predawn breeze.
I don't know where I am, only that I am my journeys path.
I walk slowly on, my pain melts into the dust.
Before me, another road crosses my path.
A dim sign swings in the breeze. Its direction long bleached by the sun and the elements.
It offers no direction, no guidance.
I am lost to the direction I could take, confused by the seemingly identical choices,
my path is only [illegible]
There is no help on this road. I am confused.

Figure 5.7 Poetic verse—written by Dennis for his website.

5.5.4.4 Electronic diary entries— preferred by Suzie Dillon

Suzie preferred to type up her experiences on an iPad, with a lined background. While she was very expressive, during this study, she did not enjoy handwriting to share her thoughts. Her profession as a lawyer is revealing in how she organises her thoughts and presents her data. Suzie also included personal photos and pictures to help illustrate her stories (see Figure 5.8).

Sunday 14 January 2018

Today started a bit slower as I was feeling very tired from the day before. Mum and I took Ruby down to CottonTree for a swim. While down there I met a fellow who went straight up to her and asked if he could pat her. He was seeking a "husky fix" as he used to live with one In Tasmania. He'd lived on the coast with his girlfriend for 6 months and seemed to be loving it here. He was a "sparky" and loving the climate and lifestyle. We spoke about the snow that had occurred in Tasmania the previous day as a contrast.

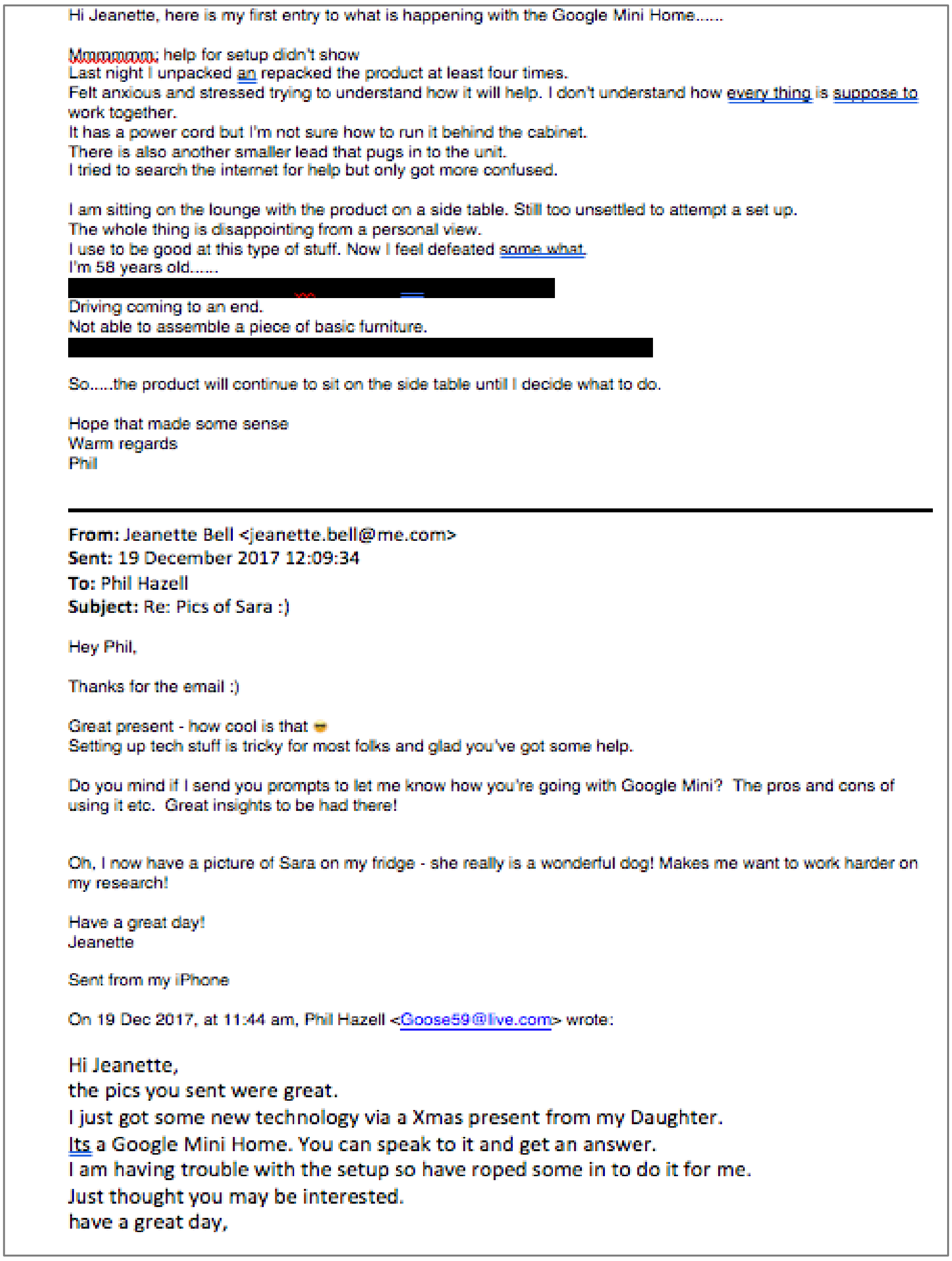
Back at home I found the energy to do a few jobs needs to be done outside in the garden, then just hibernated from the heat inside with the aircon for the rest of the day.

Nothing outstanding or different about this day. Below, me today with Jaspah!

Figure 5.8 Daily experiences recorded by Suzie on her iPad.

5.5.4.5 Emails—as preferred by Phil Hazell

Phil preferred to send daily emails (often late at night) to share moments in his day that he wanted me to include in this research (see Figure 5.9). These emails provided an insight into how Phil experiences dementia, and how he relates to technology. Writing notes by hand was becoming challenging and, in using digital technology, Phil could be supported with intuitive text, and spelling and grammar checks.



Hi Jeanette, here is my first entry to what is happening with the Google Mini Home......

Mmmmmm; help for setup didn't show
Last night I unpacked an repacked the product at least four times.
Felt anxious and stressed trying to understand how it will help. I don't understand how every thing is suppose to work together.
It has a power cord but I'm not sure how to run it behind the cabinet.
There is also another smaller lead that pugs in to the unit.
I tried to search the internet for help but only got more confused.

I am sitting on the lounge with the product on a side table. Still too unsettled to attempt a set up.
The whole thing is disappointing from a personal view.
I use to be good at this type of stuff. Now I feel defeated some what.
I'm 58 years old......
[redacted]
Driving coming to an end.
Not able to assemble a piece of basic furniture.
[redacted]

So.....the product will continue to sit on the side table until I decide what to do.

Hope that made some sense
Warm regards
Phil

From: Jeanette Bell <jeanette.bell@me.com>
Sent: 19 December 2017 12:09:34
To: Phil Hazell
Subject: Re: Pics of Sara :)

Hey Phil,

Thanks for the email :)

Great present - how cool is that 😎
Setting up tech stuff is tricky for most folks and glad you've got some help.

Do you mind if I send you prompts to let me know how you're going with Google Mini? The pros and cons of using it etc. Great insights to be had there!

Oh, I now have a picture of Sara on my fridge - she really is a wonderful dog! Makes me want to work harder on my research!

Have a great day!
Jeanette

Sent from my iPhone

On 19 Dec 2017, at 11:44 am, Phil Hazell <Goose59@live.com> wrote:

Hi Jeanette,
the pics you sent were great.
I just got some new technology via a Xmas present from my Daughter.
Its a Google Mini Home. You can speak to it and get an answer.
I am having trouble with the setup so have roped some in to do it for me.
Just thought you may be interested.
have a great day,

Figure 5.9 Phil preferred to communicate his experiences via emails.

While the participants were provided with clear directions on what to report (i.e., YOD experiences and use of technology), they were given a choice on 'how' to communicate and were free to use media that best supported their communication preferences and ability. This resulted in the participants selecting a mixed array of communication modes.

All participants expressed that they appreciated having the flexibility to communicate their experiences in various forms, including handwriting, texting, emails, blogs, audio recordings, and taking photos and videos. This flexibility, originally suggested by Dennis and Suzie, proved to be the most effective way to support the varying cognitive abilities of the study participants.

5.5.5 Adapting communication style: researcher's perspective

While the choice of communication approach was important for the individuals, for the researcher, it was equally important to be able to respond with flexibility and agility across a range of communication styles.

The way I communicated verbally and physically—my rate of speech, voice volume and body language—all became important areas to fine-tune during this early stage of the research.

During the three-week fieldwork study, I became more aware and mindful of my communication 'habits', such as my speech rate. I tend to speak at a fast rate, which may not always be best for a person with YOD.

I learned to check in with each person about my speech rate, content and pace of conversation—and adjust my style to support the individual. This became easier and more natural over time.

5.6 Discussion

In PAR Cycle 2, the aim was to test and validate the customisable tools and flexible approach in an empirical study, which were designed in the Cycle 1 methods workshop. The tools and approach were tailored by Dennis and Suzie, described in the Methods Workshop (section 4.5) to support the varying abilities of the participants with YOD.

Additionally, this first study was designed to surface preliminary insights into the lives of people living with YOD. These insights are critical for HCI to access, given the few documented first-hand accounts of the dementia experience and the need for HCI to better understand these lived experiences, before launching into technology design.

5.6.1 Methods: Work of others

In terms of related work, conventionally, designers maintain total control over how to design probe kits and how to interpret responses. This can mean that the probes might not be participatory enough to engage participants in the research project (Boehner et al. 2007). It can also mean that designer-led probes might not necessarily be the best fit for some participants; particularly for those with varying abilities in sensitive settings, such as dementia (Wallace et al. 2013a).

In other examples (Crabtree et al. 2002; Wallace et al. 2013a), probes were used as a supplement to interviews for gaining deeper and richer understandings into the participants' everyday lives. For example, researchers Crabtree et al. (2002) used 'informational probes' to identify the varying care and support needs of former psychiatric patients, and older and disabled people living at home. While their research was not conducted in a dementia setting the informational use of probes has 'proliferated widely in the HCI community', supporting engagement and addressing more intimate, idiosyncratic personal issues (Boehner et al. 2007).

Another example is seen in Tanner's (2012) research, which highlights the growing evidence that people with dementia want to participate in research and benefit from their involvement. However, there is little guidance on how to involve them as research partners. Tanner's aims to work with an older individual living with dementia (as a co-researcher) and conduct interviews with others living with LOD is a stark exception in dementia research. What was demonstrated by Tanner's research, however, is the potential of this approach to support agency and personhood for people with dementia.

5.6.2 Methods: Design input from those with YOD

While the approach discussed above, helped to guide which tools to select for this research, it was the input from people living with YOD that shaped the direction of the study design for Study 1, the approach for implementing Study 1, and the generation of insights for future HCI researchers and technology designers who wish to work in this field.

5.6.2.1 Insights to support future research into YOD

Research setting: To support a respectful environment in which to conduct the research, it was important to consider the approach and setting for the interviews. The participants taught me what to expect when conducting interviews, such as needing to carefully plan and consider the pace of the interview. I now understood the need for warm introductions and an informal lead-in before the more formal interview; stories were useful in soliciting richer accounts and shifting topics could help diffuse a somewhat serious mood when discussing life with dementia. Most importantly, when interviewing in this setting, it was essential to foster a relaxed ambience and focus on the individual's personhood.

Individuality: Each person will experience their dementia journey differently. All are at a different point on the trajectory: from the time before and after the diagnosis, to the many stages of adjustment and the physiological impact of dementia, as well as to the social adjustment—because friends and family also must come to terms with dementia. I learned to be aware of the sensitive nature of the stories being shared, as mentioned, particularly because individuals may still be coming to terms with their diagnosis. Recounting these stories to others can make an individual feel exposed as they revisit and reflect upon their particular circumstances. I needed to learn to look for signs of distress when participants recalled their experiences then respond appropriately, ensuring their pre-determined level of support was in place and called on when needed.

Time: It was also apparent that I needed to be sensitive of time in this setting; that is, 'dementia time', which involves finding out how each person experiences and prioritises their time. From the researcher's perspective, this has implications when planning interviews and workshops. As mentioned in the literature review, people living with YOD are most likely still employed and busily engaged in work and family life, while dealing with their diagnosis of dementia. Because of this, time is particularly precious to them, and to agree to be involved in research activities, they would need to see great value in giving up some of this time (away from their families).

Researcher vulnerability: The highly emotional nature of these interactions and being immersed in the lives of people with YOD (over prolonged periods of time) can be emotionally charged. Vines et al. (2013) alerted me to the fact that the researcher can also be vulnerable. Managing these moments requires great sensitivity, respect and empathy on the part of the researcher, who has assumed responsibility to provide a support system for participants under the code of ethics. It is advisable for the researcher to have a support network in place early on, perhaps through peers and/or more experienced researchers in this area of research.

To conclude, the aim of cycle 2 was to validate a new approach and methods for research in YOD. The contents of the probe pack (with A5 notebook, instructions, stickers, labels, and the coloured pens) was compiled based on discussions and input from Dennis and Suzie during the methods workshop conducted in Cycle 1. The key point they wanted the HCI community to understand was that each person with YOD will need several options and flexibility in how to use the items in the probe pack to communicate - based on their cognitive abilities and personal technology preferences. This approach allowed for the varying 'medical' characteristics (described in section 2.3.2) to be considered when assembling probe kits and capturing information.

The findings revealed that while the 'same probe pack' and instructions described in the previous chapter (figure 4.4) was distributed to each participant; each person chose something different, based on their cognitive abilities. I would like to highlight here, that all participants were encouraged and allowed to be creative which provided agency to choose how they can best contribute their voice to the research. It was only Dennis who wrote in the diary which he enjoyed to the degree that his diary entries went for an additional week. Dennis also created a webpage for voice files uploaded daily. While the other participants took the option to communicate via other modes: email, texts, voice recording (sending voice files) and iPad diarising.

The findings above also revealed noteworthy advantages in providing the choice to 'self-select' how to communicate to the researcher. I have little doubt that deploying the probe kits with a prescriptive set of rules on how to complete the tasks, would have failed as a methodological option in the YOD setting.

Finally, the benefits of choice and flexibility opened the communication channels up for the participants. The feedback from those with YOD suggested that while having been provided a probe kit, it was having a choice to self-select their means of communication based on their abilities and personal preferences that was most beneficial in supporting agency by recording their YOD experiences in their own style and on their terms.

5.7 Contributions

PAR Cycle 2 produced the following methodological insights, which reflect the key findings from PAR Cycle 1 and Cycle 2. These insights will be valuable to support researchers wishing to conduct research in YOD or a similar setting.

While some points are not novel—and will resonate with experienced HCI researchers and designers—the following points been co-developed by people living with YOD and as such are progressive. The hope is that the insights raised in the discussion and recommendations below will become a checklist for research in YOD (and other sensitive settings) to support a new researcher.

5.7.1 Checklist when planning research into YOD

Understand the uniqueness and complexity of dementia

YOD (cognitive decline) affects the abilities of each person in unique ways, requiring the researcher to spend time in the YOD community and with the participant to understand their unique requirements to participate in the research activities.

Design or adapt research methods

To support the varying abilities in YOD, providing options for selecting probes is needed when deploying research tools. Having a flexible approach support engagement in the activities and a more rewarding experience for the participant.

Pause before automatically assigning a proxy

Before assigning a proxy to speak and act on their behalf, invite the participant into the research program and ask what level of assistance they require.

Understand the recruitment challenges

People living with YOD fall outside the age limits of many services and systems, such as aged care environments, and are therefore not as visible as those with LOD, making it more difficult to recruit. This, coupled with the fact that they are often still in the workplace makes it challenging to identify specific places to connect with people with YOD. Time spent networking in their community helps with this recruitment challenge.

Adapting the pace

Individuals with YOD may have difficulty with specific tasks, because many have an altered perception of time (due to neurological changes) along with the varying functional challenges they are trying to manage. Again, this is different for each person. It is advisable to consider (and mirror) the pace of the individual during interviews and other interactions, and to offer a variety of ways to communicate.

Relationship-building

The nurturing of relationships over time and sharing relatable social activities (such as going to a movie or for coffee or travelling together) during fieldwork, can result in deeper and more nuanced insights. This requires some planning to ensure the emotional safety of the person with dementia and provide support and guidance from more experienced research supervisors.

Researcher authenticity

> People living with dementia often have a finely tuned intuitive sense. Maintaining authenticity while adapting to the varying communication needs of people with YOD is important to build and maintain trust.

5.8 Limitations

The demographics (e.g. age, educational background, socioeconomic standing, ethnicity) of the participants (and researcher) lacked diversity. In this research, the participants are highly skilled, scientifically trained, tech savvy, and well-versed on the impact and consequences of living with dementia. Two of the five recruits were especially tech savvy, due to their career backgrounds in IT and science.

Recruitment was intentionally capped at five people. This was because of the sensitive setting (YOD), and the intention to run this program over 3 years, which required deep level of commitment and emotional energy for all involved.

5.9 Conclusions

The learnings that surfaced from the time spent with Dennis and Suzie, during the early investigations in Cycle 1 informed the design of Cycle 2. The introduction of flexibility and choice in how to complete activities was a key feature of this study's design, particularly the option to self-select the mode of communication. This approach supported the individual strengths, retained abilities and personal styles of people with YOD.

When working directly with people with dementia, it is important to understand the various preferences and abilities that people have, and to support and adapt to these styles. I discovered that allowing some 'social' time to warm up and build rapport, through casual chats before and after the interviews, certainly made interviewing less stressful for the participants. In addition, it was useful to have a pre-prepared interview guide, including questions that were less confronting at the close of the interview. These questions helped to ease the mood of the interview. When approaching this study, as a researcher, I was required to be flexible in my communication style and adapt quickly to the various communication modes required to respond—such as via emails, phone calls, social media, texts, face-to-face visits and video calls.

Finally, there was a need to have (emotional) support mechanisms in place, both for the researcher and participant—this is a topic I build on in upcoming chapters.

5.10 Looking ahead: Next steps

Rethinking the methods and approach in a collaborative PAR setting (Cycle 1 and Cycle 2) facilitated the co-design of new methods and the flexibility to interact respectfully and creatively in the YOD research setting. The strengthening relationships also allowed us to move seamlessly into Cycle 3—a longitudinal ethnographic fieldwork. This next cycle of action research facilitated a deeper exploration, which continued to build on the learnings and insights of the previous cycles.

Chapter 6, study 2, includes additional examples of communication preferences based on the individuals' retained abilities and the various preferences for digital technology as reported on in study 1. Furthermore, chapter 6 provides detailed descriptions of developing friendships between researcher, participant, and community groups, and sets the scene a one-day Technology Design Workshop, which concludes the research program.

Chapter 6.

Cycle 3: A Deeper Exploration into Younger Onset Dementia and Role of Technology

'If you've met one person with dementia, then you've only met one person with dementia'.

—Professor Tom Kitwood (1997)

6.1 Introduction

Professor Kitwood's quote, which introduces this chapter, alerts us to the uniquely personal experience of dementia. Yet, these experiences are difficult for most to appreciate, given the few autobiographical accounts available to us. As HCI researchers (McCarthy & Wright 2004) point out, we don't just use technology, we 'need to understand the emotional, intellectual, and sensual aspects of our interactions with technology'.

Most of what is understood about dementia, however, comes from popular media and government-commissioned socioeconomic reports to assess service requirements. The socioeconomic research reveals that people living with YOD, and their families, face unique psychological and psychosocial challenges, which are even more impactful to those of their older counterparts (Brown et al. 2017; Sansoni et al. 2016b; van Vliet et al. 2010; Withall 2014).

To further confound this issue, living with dementia can render a person 'invisible' as those with YOD working with me on this research reported. This was also identified by researchers Greenwood and Smith (2016), who report, 'It can be difficult for other people to accept that a younger person can have dementia, particularly when no obvious physical changes can be seen'. This lack of 'visibility' may also contribute to the underrepresentation of YOD in research and design activities.

This chapter presents a case for taking a fresh approach to dementia research, one that supports agency and personhood though a two-year ethnographic fieldwork.

I have used a biographical style of reporting in Section 6.5 to afford a richer empathy and alternative way to look more deeply into YOD culture—'the culture' begin studied refers to the community, social networks (beliefs, rituals, interactions).

6.2 Aim of Cycle 3: Study 2

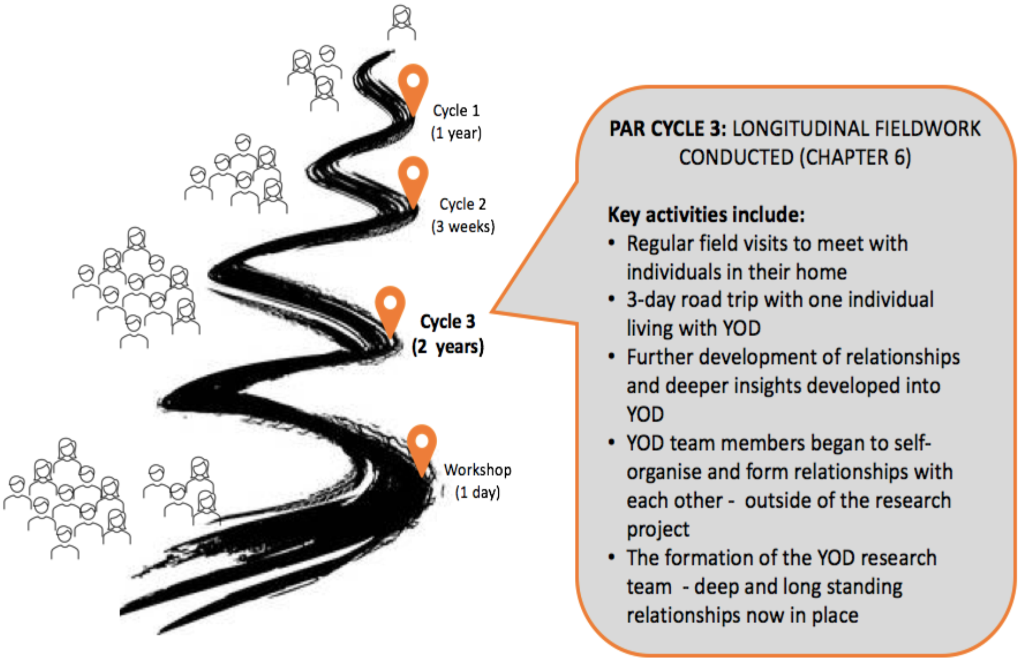
In cycle 3, the ethnographic fieldwork aims to better understand the unique life circumstances of people with YOD by spending time in the field (two years) to explore the culture (beliefs, rituals, interactions) of the YOD group as they live or coexist in their community and social networks. Additionally, this was an opportunity over time, to observe the unspoken communications and access stories that may not surface otherwise or cannot be clearly articulated in interviews, surveys or single workshops.

6.3 Research questions addressed in this chapter

RQ. How can HCI develop deeper and more nuanced understandings of the lived experience of people with YOD?

SQ 2. What research approach, methods and tools would best support the needs and wants of people living with YOD?

PAR Cycle 3 further explores the YOD experience as the community of collaborators continues to grow (Figure 6.1).



PAR CYCLE 3: LONGITUDINAL FIELDWORK CONDUCTED (CHAPTER 6)

Key activities include:

- Regular field visits to meet with individuals in their home
- 3-day road trip with one individual living with YOD
- Further development of relationships and deeper insights developed into YOD
- YOD team members began to self-organise and form relationships with each other - outside of the research project
- The formation of the YOD research team - deep and long standing relationships now in place

Figure 6.1 The research journey gathers momentum in cycle 3

6.3.1 Chapter structure

This chapter is structured in four sections:

- **Methodologies** The action research model concludes with cycle 3. This phase of the research incorporates a longitudinal ethnographic fieldwork.
- **Data collection and analysis** The thematic analysis approach continues in Cycle 3 and augments the data and in sights gathered in previous cycles of PAR.
- **Biographical reporting structure** To help channel the copious amounts of information and observations captured in this fieldwork, I created the following set of predetermined headings, which is repeated for each individual story presented in this chapter:

  Header—with name and photo
    - Background
    - Personal interests
    - How we met
    - Elements characterising our relationship
    - Our interactions in the context of YOD research
    - How [insert name] engages with digital technologies in day-to-day life
    - General insights offered by [insert name].
- **Reflections/Discussion** This section provides reflections on the relationship dynamics and includes a discussion about the importance of finding a role for the primary relationship partner – that is - if they ask to be more involved in the research. Particularly if there is a longitudinal element to the research program where the researcher may also build relationships within the network of the person with YOD.

In the next section, I briefly revisit the methodologies (PAR and ethnography) that underpin the research program. I outline the approach to data management and analysis for the longitudinal fieldwork, before presenting a series of biographies and insights in Section 6.6.

6.4 Methodologies

Cycle 3 of the PAR framework includes a two-year ethnographic fieldwork. Combining PAR and Ethnography for this cycle was inspired by Green and Kirk (2018) who combined methodologies in their study. In this work, Green and Kirk, argue for a renewed focus on "inclusivity" in HCI research.

As a reminder, in my research, choosing a combination of methodologies was to generate deeper insights, by examining the culture, community practices and use of everyday technologies. I also wanted to consider the work of Brereton et.al. (2014) who describe an "emerging paradigm" for HCI design, where engagement, reciprocity, and doing, are central to the ethnographic approach and remind us of how difficult in many settings it is for researchers to access the "privileged ethnographer position" – or in other words, working in a cultural setting that is not one's own.

6.4.1 Revisiting PAR and ethnography in the context of YOD

PAR and ethnography support collaboration, trust, reflection, relationship-building and storytelling (Dourish 2014; Duarte et al. 2018; van Maanen 2011). Ethnographic techniques such as writing style can help to provide a richer portrayal of what it is like to be diagnosed with dementia in an earlier phase of life.

> *Ethnographic writing—helps the reader to be in the field just as you were,*
> *and to feel and understand what it was like* Van Maanen (2011).

Different writing styles exist within the ethnographic framework. Van Maanen (2011) suggests that the type of writing is a major decision for an ethnographer to make. He describes three modes of ethnographic writing (realist, confessional and impressionist) by which to situate yourself in the ethnographic text, which forms the research report. Further to this:

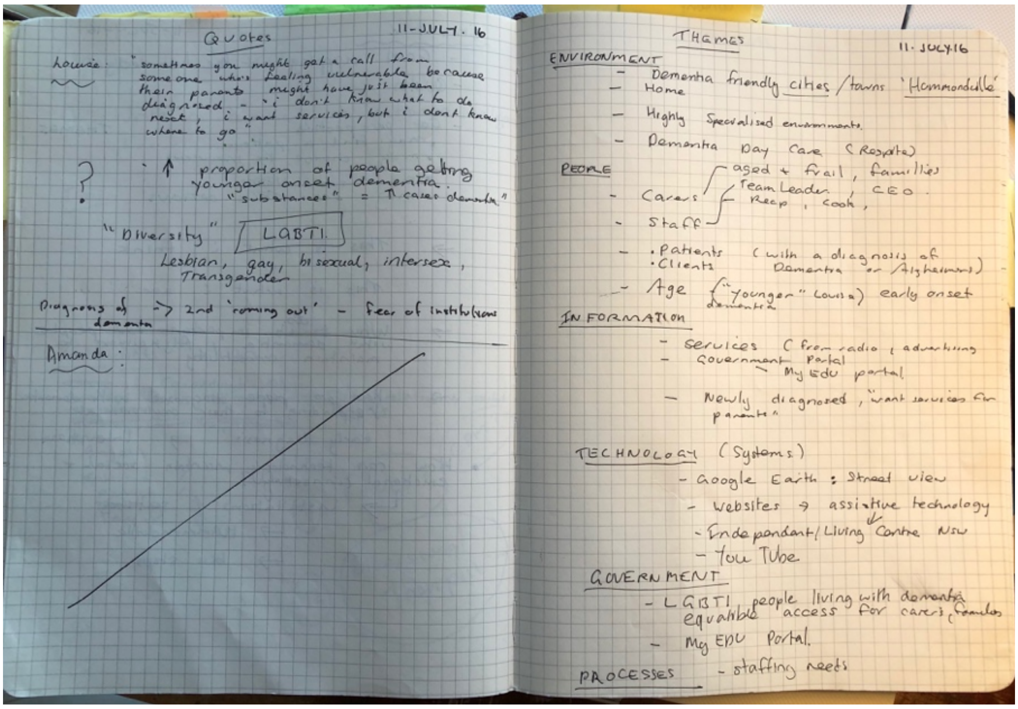
- **Realist writing** The researcher is absent from the analysis and text, and the aim is to present what happened in the field, realistically and objectively. Here, the researcher writes in passive mode without giving any personal accounts.
- **Confessional writing** The ethnographer opts for a personal style, presenting emotional reactions, unexpected occurrences, and one's own expectations and experiences of the fieldwork.
- **Impressionist writing** The researcher offers tales in which they have participated in the field. Here, the overall story of the research report makes visible both the culture being studied and the researcher's way of knowing the culture.

For this research, I selected the confessional and impressionist writing styles. The reason was to make the life experiences visible and facilitate the reporting of my reflections as a researcher. In this research, ‘culture’ refers to the YOD community—their social networks, attitudes, beliefs, spirituality, values.

Relationships: Central to conducting the ethnographic fieldwork over a two-year period was the intention to strengthen relationships, building trust and familiarity.

6.4.2 Data management and analysis

While the data collection methods were open and flexible, the experience of YOD and the role of technology were analysed in depth using a thematic analysis approach (Braun & Clark 2012). Furthermore, I kept detailed notes (during all phases of the research project), which I cross-referenced for key events and emergent themes. This notetaking assisted me in capturing our many conversations and my observations from cycle 1, with insights continuing to develop through the research program.



Quotes

11-JULY. 16

Louise: "sometimes you might get a call from some one who's feeling vulnerable because their parents might have just been diagnosed - "i don't know what to do next, i want services, but i don't know where to go".

?

↑ proportion of people getting younger onset dementia.
"substances" = ↑ cases dementia."

"Diversity" LGBTI

Lesbian, gay, bisexual, intersex, Transgender

Diagnosis of dementia → 2nd 'coming out' - fear of institutions

Amanda:

THEMES

11. JULY.16

ENVIRONMENT
- Dementia friendly cities / towns 'Hammondville'
- Home
- Highly Specialised environments.
- Dementia Day Care (Respite)

PEOPLE
- Carers — aged + frail, families
- Staff — Team Leader, CEO. Recep, cook,
- • Patients • Clients (with a diagnosis of Dementia or Alzheimers)
- Age ("younger" Louise) early onset dementia

INFORMATION
- Services (from radio, advertising
- Government Portal
  My Edu portal
- Newly diagnosed, "want services for parents"

TECHNOLOGY (Systems)
- Google Earth : Street view
- websites → assistive technology
- Independant / Living Centre NSW
- You Tube

GOVERNMENT
- LGBTI people living with dementia equitable access for carers, families
- My EDU Portal.

PROCESSES - staffing needs

Figure 6.2 An example of field notes—emergent themes early explorations in Cycle 1 continue to be reviewed and reflected on in Cycle 3.

This thematic method of analysis continued across all cycles, beginning in the early exploratory phase. Figure 6.2 shows the broader themes that emerged from cycle 1—during a pilot study in July 2016. These early insights helped to map out the complex stakeholder networks and validate the research design choices made during each cycle of this research.

As the research progressed through the PAR cycles, in addition the 'ecosystem' becoming clearer, the *types* of preferred technologies used to communicate their YOD experiences (listed below) became more evident and continued to be monitored in all cycles of this research. As newer, more nuanced themes emerged throughout the research via various modes of communication, deeper insights evolved.

The different modes of communication data were processed as follows:

- **Text messages** Screen shots were taken of the text message and saved to file. The content of the text message was entered into the coding spreadsheet.
- **Face-to-face meetings** Incidental observations, events, dates and quotes were captured in field journals, which were transposed into the coding spreadsheet.
- **Email messages** Key points were transposed into the coding spreadsheet.
- **Website posts** Key points were transposed into the coding spreadsheet.

Field Notes Extensive field notes were supplemented with voice recordings and photo images, which were collected and transcribed over the course of the two-year fieldwork. In this chapter, field data are recounted using direct quotes, which are italicised.

The data from Cycle 3 were organised in a coding spreadsheet (Appendix 4). As mentioned in the previous chapter, this enabled me to search and filter the text, and trace key items/quotes back to the source or ladder themes up to a key theme.

From the many sub-themes, the key themes were divided into 'YOD experiences' and 'technology'. The technology themes and associated experiences were carefully thought through (and validated by people with YOD), given the importance that HCI researchers place on understanding these areas before embarking on research and design practices.

Now that I have provided an overview of activities in Cycle 3—the aim, approach and underlying methodologies—I now move to presenting the Biographies. As outlined in the introduction of this thesis, dementia is complex, and the experience is unique for each person. Fortunately, as researchers, we are now enlightened by (Kitwood 1997) to the fact that dementia is more than a medical characterisation.

6.5 Findings: Biographies

This section offers five biographical accounts of people living with YOD. While there are some commonalties across their stories—such as the diagnostic pathway, life-stage circumstances, age, and social stigma—as Professor Kitwood reminds us—each person's experience with dementia is complex and unique.

Additionally, while the biographies aim to amplify the uniqueness of each person with YOD who worked on this research, I hope that by presenting these stories from the field I can also increase the visibility of the (YOD) group they represent—the environment, culture, community networks, and their relationship with technology.

This style of biographical reporting was inspired by the work of neurologist, Oliver Sacks (1990), and ethnographer, Van Maanen (2011). I trust the stories from the field will portray both the experience of the individual with YOD and shed a light on the environment and culture they have, and continue to develop.

For this chapter, I selected the confessional and impressionist writing styles described in section 6.4.1. The reason was to make the life experiences of YOD more emotionally accessible for readers of this thesis, not experiencing YOD.

Perhaps it also opens a window into the role of the research in this sensitive setting, for others who wish to follow this path.

6.5.1 Creating biographies

In his book *Awakenings*, Oliver Sacks presents several neurological case studies, in which he discusses the virtue of biographical accounts. Sacks summarises in the *Forward to his 1990 Edition* as follows; 'in addition to the medical accounts of the neurological condition—detailed and non-reductive narratives are required for explication and understanding of the 'whole' person' (Sacks, 1990).

Sacks goes on to say that 'two books are demanded by every clinical experience'. The first is purely 'medical' or 'classical', and includes an objective description of disorders, mechanisms and syndromes. The second is more existential and personal, 'an empathetic entering into patients' experiences and worlds. Dr Sacks took numerous daily notes, always had a camera to hand and provided diaries to those under his care, to allow them to capture how they were experiencing their neurological disorder. Like Professor Kitwood, Dr Sacks was most concerned with the lifeworld of each person, in addition to the medical perspective.

While not as vivid as the autobiographical form, the biographies presented here aim to go beyond the standard reporting of participant demographics to provide more detailed layers for each person, to build and bridge the theoretical gap in YOD research and design.

6.5.1.1 Structure of each biography

During the two-year fieldwork, I recorded YOD stories, key themes and observations. To help me manage the copious handwritten notes, audio recordings, videos and photographs collected over the two years—and channel them into the biographies—I created the following structure. The pictures and quotes included embody the YOD experiences.

6.6 Dennis Frost

6.6.1 Background

Dennis has a strong background in educat starting his career as a high school teac Following this, he spent time in the oil indu as a senior geophysicist. In this latter role, company he was employed by utilise research facility to evaluate informa technology (IT) systems. At that time, Dennis become involved in trialling 3D modelling, which has now become more mainstream. Dennis moved into IT as a computer system consultant and, later, became an IT trainer at a technology college. Dennis held an assistant registrar position for IT training and teaching support at a state business college, which continued for 25 years.

6.6.2 Personal interests

Dennis is a formidable advocate for dementia and has presented both internationally and locally. He is a member of Dementia Alliance International and various dementia advisory groups. Dennis presented 'Reframing the Rhetoric Around Dementia' at the 2017 Dementia Australia Conference, in which he discussed the appropriate use of language in dementia settings, to help remove the stigma associated with the disease. His key message was that the words we choose to talk and write about dementia can have a significant impact on how people with dementia are viewed in the broader community.

Dennis believes that, although people living with YOD have asked to be included in research, they still encounter stigma: *'having people with dementia involved in talking about dementia etc. takes a big attitude change'*.

6.6.3 How we met

Dennis and I met in Japan at the Alzheimer's Disease International (ADI) conference, where he was a featured speaker. ADI is the world's largest and most important conference on dementia and Alzheimer's disease and includes scientific and non-scientific content about the latest advances in dementia care. It was at this conference that I first became aware of YOD. Up until this time, my knowledge of dementia was limited to the medical characterisations and my own family's experience with dementia.

After I was introduced to Dennis, we talked briefly about my research on dementia and technology. Dennis was interested, given his background in IT, and agreed to meet me again to discuss the goals of my research further.

6.6.4 Elements characterising our relationship

Dennis was the first person recruited to this research and quickly became a valuable research partner, given his deep expertise and international dementia networks. Dennis worked with me on this project for more than four years. On occasions, he would take the opportunity to visit my university (University of Technology Sydney) and meet with other HCI researchers and my PhD Supervisor. We would often exchange research articles on dementia and technology. His dementia experience in the context of everyday life was central to our conversations.

Alternatively, I took regular day trips—on the train—to meet Dennis in his hometown. This was a three-hour train trip each way. Dennis would pick me up from the train station then it was a short 10-minute drive to his home, which he shared with his partner. We would generally spend half the day discussing this research program and other projects (government, private sector and institutions), in which Dennis was involved. The time on the train was invaluable—it afforded me the time to prepare for the visit, and to transcribe the recording from the visit and reflect on the content.

Dennis enjoyed baking and would have a loaf of freshly baked bread and tray of muffins ready when I arrived (Figure 6.3, Image 2). We began our sessions with a strong coffee and chat about our week. Dennis would also pack a sandwich for me to take on my trip back to Sydney. As our relationship developed, I was invited to the local Dementia Alliance Group BBQs—this was a close network of friends (with YOD).

Figure 6.3 Dennis has a strong background in IT—and enjoys baking.

6.6.5 Our interactions in the context of YOD research

Dementia is complex and manifests distinctive symptoms in each person.

With Dennis, one manifestation is face blindness or facial agnosia (prosopagnosia). This means that, when meeting a person for the first few times, Dennis cannot distinguish that person's facial characteristics.

Dennis and I spoke about this aspect of dementia for him before I travelled to his hometown to meet with him. While Dennis and I had met (once) at a conference, we needed to work out a way for Dennis to recognise me at the train station.

We agreed on using a colourful visual signal—my yellow gloves—which I wore for a few visits (Figure 6.4). When I alighted from the train, I would wave when I saw Dennis on the platform.

Figure 6.4 Yellow gloves—a bright visual cue to support facial agnosia.

Dennis helped me understand that, after a while, the non-facial cues develop. He can identify a person through their tone of voice, body language, gait, and even their hairstyle and laughter. These 'non-facial' cues only develop for the person with dementia when they get to know a person over time.

6.6.6 How Dennis engages with digital technologies in daily life

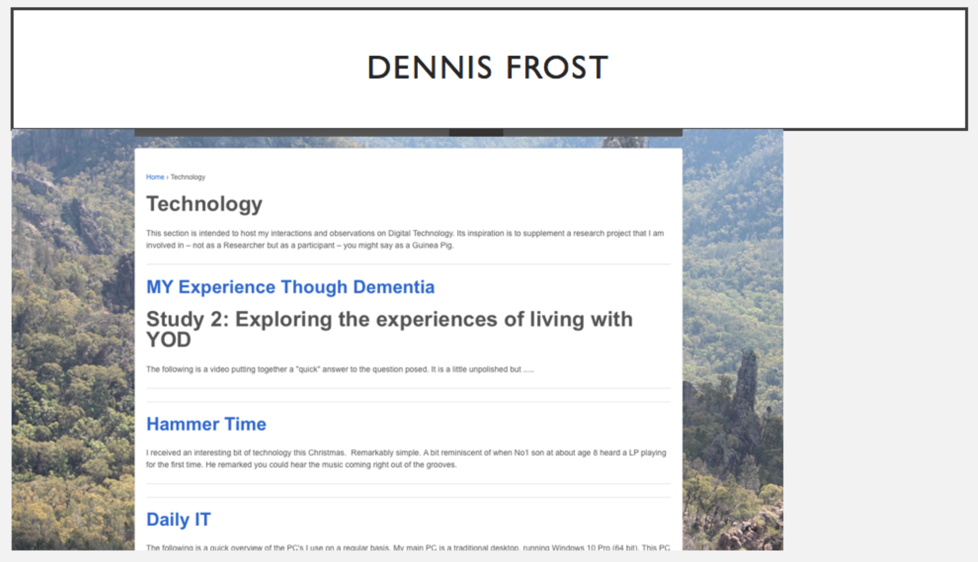
With his long career working (and teaching) in the IT sector, Dennis is a prolific user of digital technologies and various software. Dennis also has a strong interest in the potential for new and future digital technologies to support people living with dementia.

Currently, Dennis relies heavily on technology as a communication tool to connect him with others whose lives have been impacted by dementia (Figure 6.3, Image 1) by participating in global advocacy meetings.

Regarding this HCI research program, Dennis could speak with some authority with his background in IT. He could relate to the goals of the HCI community and would often send me academic articles that supported my research.

Physiologically, Dennis has a strong understanding of the how the brain processes information, and the neurological impact of dementia. With this, Dennis created media (booklets and videos) and published information on the implications of the neurological disruption that comes with dementia, using accessible language and style.

To help others with dementia, Dennis has created a website and 'YOD blog'. In support of this research, he added a web page (Figure 6.5) and would upload daily recordings (in addition to writing daily journal entries for Study 1 (Cycle 2), as discussed in the previous chapter).



DENNIS FROST

Home › Technology

Technology

This section is intended to host my interactions and observations on Digital Technology. Its inspiration is to supplement a research project that I am involved in – not as a Researcher but as a participant – you might say as a Guinea Pig.

MY Experience Though Dementia

Study 2: Exploring the experiences of living with YOD

The following is a video putting together a "quick" answer to the question posed. It is a little unpolished but .....

Hammer Time

I received an interesting bit of technology this Christmas. Remarkably simple. A bit reminiscent of when No1 son at about age 8 heard a LP playing for the first time. He remarked you could hear the music coming right out of the grooves.

Daily IT

The following is a quick overview of the PC's I use on a regular basis. My main PC is a traditional desktop, running Windows 10 Pro (64 bit). This PC

Figure 6.5 Website developed by Dennis to post daily journal entries of living with dementia (for Study 1).

Although Dennis is comfortable with technology, certain design elements create a high level of frustration. For example, Dennis finds the small interface of the digital phone frustrating: *'the biggest issue I have is actually physically manipulating the touch interface'*. For Dennis, this issue leads to unnecessary exhaustion when using technology.

Other challenges include lags in video conferences: *'I really have to use a lot of energy to try to connect the voice that is lip-synched'* and Windows updates, which are time-consuming and often result in a loss of structure and data.

Dementia is known to affect learning agility. Dennis provided some insight into what the meat for him. For example, installing a new 2D animation software *'proved too steep a learning curve'* and he had to revert to his previous software. Also, installing a Windows update '*took around five hours to get the basic structure and email configured properly*.

6.6.7 General insights offered by Dennis

On the diagnosis of dementia When asked about the moment of diagnosis, Dennis says it was a comfort: *'I was quite happy because it was, you know, a clear definitive answer'*. He did share some regrets, suggesting that he could have remained in paid employment for longer: '*I could probably have continued working a lot longer, but there was no history of that support in the workplace'*. The workplace support was *'painful'* and *'meaningless*. He says, *'I got a phone call about what support I would like, which was a bit late at that point—at the end of the course'*.

On stigma While addressing stigma is a major challenge for people living with dementia, this is amplified in YOD. Dennis states that '*dealing with people who assume I am 'incapable' due to dementia is amusing'*. He uses techniques such as humour and jokes to cope with his treatment due to the stigma. He recalls speaking to a former Australian prime minister, who was raising money for dementia, stating that he didn't realise people under 65 could have dementia.

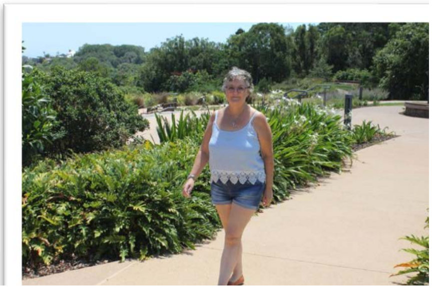
On anger *'the attitude from a healthcare administrator was that she didn't want to listen to anything I had to say; in a way, this is a loss of my outward identity—people are now seeing me only through the lens of dementia, rather than who I am as an individual'*.

On navigating IT application upgrades and new installations – the learning curve on these tasks was a key source of concern for Dennis. Words Dennis used to describe his apprehension are as follows: '*very frustrating', 'time consuming', 'upsetting'; resulting in a loss of structure and data on my computer*'. On the other hand, completing these tasks provided *'some satisfaction'* in having a clean install. *'When it takes about 5 hours to get the basic structure and email configured properly… it feels good'*.

Dennis suggested that it would benefit people with dementia if the HCI community considered the learning curve for people with dementia when designing new technologies, and provide a means of IT support – one suggestion was *'a dementia friendly 'IT support' system for computer upgrades and new application installations'*.

On maintaining a purpose and sense of self Dennis would like to share with the HCI community the importance of maintaining '*independence, personal interests, hobbies'* and 'a *sense of purpose'* – saying he has gained more friends (than he lost) once diagnosed with dementia, by participating in the Dementia Alliance International advocacy group: *'always interesting and enjoyable … it is quite empowering'*.

6.7 Suzie Dillon



6.7.1 Background

Suzie started her career as a biochem however, after leading a (successful) c action against her employer, she decided to study law. This led to a (second career) practicing law in child protection, until she was diagnosed with YOD at 55. As a lawyer, Suzie would manage hundreds of legal files, go back and forth to court, and negotiate multiple matters seamlessly. It was in the workplace that Suzie was having difficulties finding the *'right word'* and would have to describe the word she was searching for in great detail. She was initially told she was stressed, so the eventual diagnosis of dementia *'came as a relief'*.

6.7.2 Personal interests

Suzie has an active and independent lifestyle. She enjoys dancing and says, *'learning to dance keeps the brain and body working together'*. Suzie regularly attends square dancing events (Figure 6.8, Image 2). Suzie values the dance community and suggests that this style of dancing is beneficial for brain health: *'as a participant, you not only have to remember how to perform the steps, you also need to respond the caller's choreography'*. This requires firing up different areas of the brain. She also travels often, both locally and interstate, organising her own travel bookings, payments and accommodation requirements.

6.7.3 How we met

I first saw Suzie being interviewed by the Australian Broadcasting Corporation (ABC), during a news television report. Suzie was discussing her recent diagnosis of YOD. I contacted the reporter and asked for the details of my research to be passed to Suzie.

Suzie contacted me within a few days and became the second person to join this research.

6.7.4 Elements characterising our relationship

Suzie and I met regularly, facilitated by FaceTime, which Suzie preferred over other video chat options (Figure 6.6, Image 1). Typically, our conversations were broad and, at times, personal. We spoke of our families, our adult children and their careers, and of our own backgrounds and careers in medical science. Suzie and I share a love of pets and our virtual catch-ups often featured Jasper, Suzie's cat (Figure 6.6, Image 3).

Suzie has a great deal of insight into research practices, with her daughter being an academic, and from her own experiences in the medical and legal systems. Suzie and I always discussed the pros and cons of various digital technologies and software.

Figure 6.6 Monthly 'virtual' meetings. Suzie and I bonded through a shared love of animals—Jasper (the cat) featured in most video calls.

6.7.5 Our interactions in the context of YOD research

In our interactions, Suzie reminded me to be mindful of time—both the duration of our interactions and the time of day. This meant not taxing Suzie's energy with long calls, particularly, because we spoke about complex social, legal and medical issues.

Aside from this, one of the key challenges we had was geography, because Suzie and I lived in different states of Australia. Our meetings were supported through various technology platforms: Suzie preferred to use FaceTime and our meetings generally ran for about an hour. We also exchanged information (research articles and notes) via email, and communicated via phone and text.

6.7.6 How Suzie engages with digital technologies in daily life

Suzie has a positive relationship with technology and is skilled in using various apps and software for diarising and navigation. She is an advocate of 'life logging' for overall wellness (Figure 6.6, Image 4).

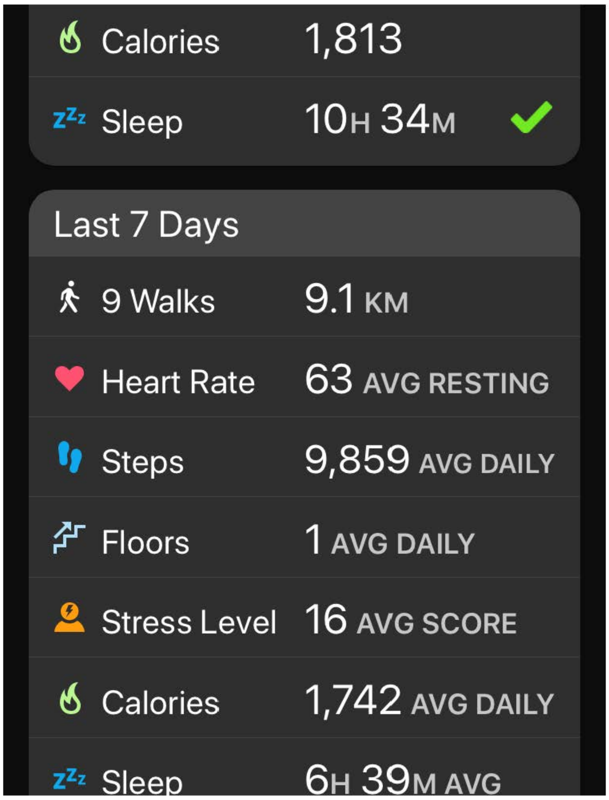
Some additional examples of how Suzie uses technology include:

- **Navigation** Suzie uses a smart watch, Waze (GPS navigation software) and digital calendars, which all helped to build her confidence and independence: *'everything automatically goes into my digital calendar'*.

- **Facetime** She says this is *'great for communication and keeping in touch with people'*. Suzie describes speaking to her daughter over FaceTime as *'the highlight of my day'*. She would find an alert feature useful for this technology, for example, to let her know that she hadn't spoken to her family in a while.

- **Facebook** Suzie stays socially connected to her family, friends and dance community through Facebook.

- **Health apps** Suzie also enjoyed the apps on her smart watch with reminders to take medication (while she is not using or needing it now, she is training herself for the future). The sports watch enabled Suzie to adjust her activities, based on a biofeedback mechanism (see Figure 6.7).



Calories 1,813
Sleep 10H 34M ✓

Last 7 Days
9 Walks 9.1 KM
Heart Rate 63 AVG RESTING
Steps 9,859 AVG DAILY
Floors 1 AVG DAILY
Stress Level 16 AVG SCORE
Calories 1,742 AVG DAILY
Sleep 6H 39M AVG

Figure 6.7 Suzie enjoyed the feedback from a smart watch to track daily activites.

6.7.7 General insights offered by Suzie

On the diagnosis of dementia Suzie recalls the time of diagnosis being a relief: *'I was lucky the GP took me seriously'*. Due to her experience as a lawyer, she understood the medical system; thus, she could navigate her way through the complexities of being diagnosed with dementia when in the younger demographic and while still in the workplace: *"What happens to those who aren't lucky?'*

On independence *'I must admit, I get very frustrated if people fuss over me too closely, and don't let me do things'* and *'I find a great sense of independence in learning from my own mistakes'*. Suzie and her children openly discuss options for care; however, Suzie is concerned with the reports of abuse in aged-care settings.

On humour Suzie finds humour in situations involving her dementia. She will joke, *'I thought I was the one with memory issues'* when a medical specialist forgets she has dementia. Suzie reminds us that she is more than this disease and says that making fun of 'it' strengthens (and maintains) her sense of identity.

6.8 Phil Hazell

6.8.1 Background

Phil was diagnosed with dementia while he was workin as a national business consultant. After his diagnosis, Phi was assigned one of the first dementia assistance dogs t be deployed in Australia. He continued to remain in th workplace for some time after his diagnosis with the hel of his employer, colleagues and clients, and his assistanc dog, Sara.

Phil became a dementia advocate and joined Dementia Australia while still in paid employment.

6.8.2 Personal interests

Dementia advocacy is a major interest for Phil. Currently, he holds the position as Chair of the Dementia Australia Advisory Committee. Phil expressed that this gives him purpose and this assignment ensures he is involved in many research projects related to dementia YOD.

6.8.3 How we met

A case worker from Dementia Australia introduced Phil to me. I worked with Phil for six months at the start of my fieldwork. Phil discontinued participating in this research after he had completed the activities for Study 1. This was due to the demands of joining Dementia Australia in a senior advisory position. The insights and comments collected during Study 1 from Phil were included in the thematic analysis.

6.8.4 Elements characterising our relationship

Phil and I would have meetings at his home, where his dog Sara was present (Figure 6.8). These visits to Phil's home were relaxed, yet structured. Our discussions were generally about dementia from the medical perspective. Phil was curious about my experience with dementia in my family. He asked me many questions about my father's experience with dementia and how the family felt about the more challenging aspects of dementia.

This was a sensitive topic for me, so I needed to answer with thoughtful, respectful and supportive responses.

I interviewed Phil in Study 1, where he diarised his daily experiences living with YOD and how he engaged with technology – and preferred to communicate with me via emails, and phone. While Phil and I did meet several times following Study 1, as mentioned, it was challenging for him to continue with this project (throughout the longitudinal phase), due to his other research commitments and the demands of his advocacy work.

Figure 6.8 Phil with Sara (dementia assistance dog). Once her 'work vest' was removed, Sara was able to socialise (Image 4).

6.8.5 Our interactions in the context of YOD research

As a reminder to the reader- regarding the findings of Study 1 (Cycle 2), Phil preferred to communicate via email. He would send daily reports about how he was experiencing his day with YOD and stories about his interactions with technology.

With Phil's permission, I needed to remind Phil about the goals of the project at each visit. This was helpful in supporting Phil's recall and assisted with the flow of activities in this project. For Phil, his ability to recall previous events was compromised due to the impact of dementia (in his case). At the beginning of the research, we agreed that I would send daily prompts to remind him of the goals of the research, and the activity for the day.

6.8.6 How Phil engages with digital technologies in day-to-day life

Phil has a great sense of humour regarding technology. For example, he had difficulty setting up his Google Home Mini. He just got 'fed up' with trying to set it up and decided to put it on the shelf in the fridge (Figure 6.9).

Oh yeah.....the Google Home thing is still on the dining room table.
I am going to move it to a new spot so it doesn't get board.
He he, check the photo. Hope the doesn't freeze!

Figure 6.9 Phil put his Google Home Mini in the freezer, after he 'got "fed up" with trying to set it up'.

On my next visit, I asked Phil, 'Why the fridge?' He explained that this was something he had always done with things he gets 'fed up' with - and this reaction was not related to his dementia. You can see other examples of Phil's (email) communication in Chapter 5, Section 5.5.4.5.

Phil enjoyed many forms of digital technology, including Skype and Zoom, working on his laptop and iPad, and using navigation and calendar apps: *'the calendar on iPad, that's essential for me now … to keep me on track'*.

Some of the technology insights that Phil offered include:

- **Technology end-user support** Phil would like to access more support with device settings. Because of his experience and frustration with Google Home Mini, he recommended that technology developers and marketers should provide the device with home-set-up support options. He shared that *'I only use the diary on my iPad'* and that he has not synched his calendar to his phone or laptop, because of a lack of support to help him set it up.
- **Technology design options** Phil struggles with spelling on his phone due to its small character size: *'sometimes, I'm getting it so wrong that I forget what the word is'*. Phil struggles with technology in that it is constantly evolving, which is challenging with his diminishing tech skillset. He suggests that minimising

the number of updates, having someone come to install the technology, providing a simple how-to for set-up, and having a 'simple' option (only including the essentials with a clean and clear layout) would be wonderful for a person with YOD.

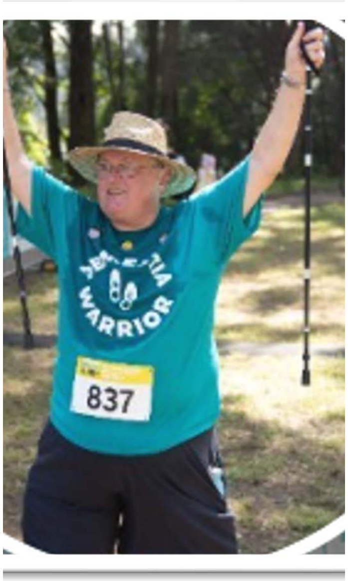
- **Time** Being on time is very important for Phil because it is one of his values. If he cannot maintain this, he can feel like he is losing control, losing a part of his identity. Planning alleviates his stress. Phil can rely on his digital calendar and trip planner to be on time while remaining independent: *'I am feeling much better when I have a plan'*.
- **Social** Phil expressed feelings of embarrassment when forgetting names and conversation topics while out for dinner: *'I had to put strategies into place really quickly … for example, writing down their names as I would meet people'*. Phil suggests designing an app in which the user selects a table, along with the number of guest seats, and inputs the names of each guest. This would act as a memory cue, so the person with dementia has a visual reminder of who they are sitting with.

6.8.7 General insights offered by Phil

On receiving a diagnosis while in the workplace:

- *'I was really nervous about doing all the (medical) tests'*. The doctor *'really put doubts in my mind and this shows there may needs to be a change in how doctors act around/treat people with dementia'*.
- The three main emotions Phil felt when he was diagnosed with YOD were depression (loss of work and memory equalled a loss of identity), anger (why me?) and confusion (denial): *'this couldn't possibly happen to me'*; *'I could see my working life coming to an end'*.
- Phil thinks he was fortunate in his workplace: *'they said, "We'll back you 100% of the way" … it was fantastic'*. Having a job that allowed Phil to stay on in the workplace, although working at a slower pace, meant he still had the satisfaction of work without the stress of completing tasks quickly.

6.9 Stephen Grady



6.9.1 Background

Stephen was employed as a measurement scientist with the National Measurement Institute, which is an organisation responsible for setting Australia's measurement standards. His expertise is in electrical measurements.

As Stephen began his story: *'Well, see the problem is that I was picked up in fairly early diagnosis—because of my wife's nursing background'*. Stephen recalled she noticed strange things going on: *'I lost my sense of smell … my executive decision-making wasn't good, I wasn't coping at work'*.

Stephen also recalled making mistakes in his job: *'I was starting to make mistakes. Mistakes are not bad, but mistakes that get out the door are! I was starting to do things like become very unsure of myself, having to repeat my measurements a lot more than I would, [having] less confidence in myself. My work was really suffering, to the point that they were putting me on a sort of a review to possibly, you know, to demote myself.*

'So, around about that time, we did get an MRI scan done of my brain and it showed that I'd had a vascular dementia … that was enough to give me a diagnosis of cognitive impairment and, from that point, I decided, well, it was time for me to go before they got rid of me. And so, I basically put my hand up to leave'.

6.9.2 Personal interests

Stephen has always had a great love of history. He loves the personal touch of history. *'I'm not so much, you know, interested in kings, wars, that sort of thing, [but] whatever sort of touches history—in other words, where current-day issues are steeped in historical connections.'*

Stephen also has a strong personal interest in IT: *'I used to do a lot of work in computers at work because that was part of my job of computerisation of measurement systems and so, you know, I could work in software and stuff like that. But I find software now is not as easy as it used to be because it's the logical processes involved that I just sometimes can't grasp. It's just, you know, I try to set up software systems, I can do it, but it just takes me a real lot longer than it ever did. And I'm finding myself having to go back to basics'.*

'I played with microcontrollers in my career. Recently, I set up a little weather station in the garden. I've got my own sort of interpretation of a Stevenson Box and, you know, I'm going to be sort of expanding upon that and putting wind vanes and the software interface to that.

'A lot of my dreams are still about work'.

Stephen is also very knowledgeable about the arts and enjoys gallery visits (with a support person) who provides support if required.

6.9.3 How we met

Dementia Australia connected me with Stephen through a key case worker. After initial introductions via email, I went to visit Stephen at his home (about an hour from Sydney) to discuss the goals of the study and gauge his interest in joining the research.

6.9.4 Elements characterising our relationship

Stephen Grady With Stephen's background as a measurement scientist and in information technology, Stephen is interested in the work that the HCI community is conducting. We often discussed the work currently underway by other researchers in HCI, and Stephen provided guidance on how this work may be seen through the lens of dementia.

Stephen also helped me understand the government systems he now found himself relying on, such as the National Disability Insurance Scheme (NDIS) among others. This was insightful, because he was navigating through interviews, forms, phone calls, websites and meeting people from various professional backgrounds. From this, I learned some important aspects about spending time with a person with YOD.

Ann Grady I also met Stephen's wife, Ann Grady. Ann has a nursing background in oncology and was always by Stephen's side during our interviews and meetings. Ann shared an interest in this research and quickly became an important 'voice' in this project. Ann had research skills and was a published author in the oncology field.

While not recruited as a participant (with YOD), Ann provided valuable insights over the years. Ann and Stephen were inseparable. I have included Ann's reflections on dementia (a personal letter) in Section 6.12.3 of this thesis—with Ann's encouragement and permission.

Ann also joined the YOD team for the Technology Design Workshop (see Chapter 7).

A feature of my visits to the home of Stephen and Ann was spending time in their beautiful garden. It was a vast mature garden, and a peaceful setting. We (Stephen, Ann and I) would begin my visits with a walk around the garden, and sit together to discuss things that were on their minds. Ann would always present me with one (prize) flower from the garden on each visit (Figure 6.10, Image 1).

Figure 6.10 The Garden: a feature of the home visits, the assembly of a 3D printer and a 3D printed 'Little My' (gift).

6.9.5 Our interactions in the context of YOD research

As requested, I would visit Stephen and Ann in the early afternoons, at approximately 2 pm. Stephen was mindful of his energy levels, both physically and intellectually, and this time of day best supported him. We started each visit with cup of tea, cakes and casual conversations. Stephen then diligently steered our conversations back to HCI technology and research. He was aware, had researched and understood the structure of the HCI community, and what this research was trying to achieve.

6.9.6 How Stephen engages with digital technologies in daily life

Stephen is extremely adept with technology. Most striking was his ability to assemble a 3D printer, which he had ordered online. This arrived in many parts (Figure 6.10, Images 2 and 3). While Stephen reported that it takes longer for him to work through instructions, he retains his 'ability' to complete the assembly work.

On one occasion, Stephen asked me, *'What is your favourite storybook character?'* I replied, *'Little My'* (a central character in *The Moomins*, by Finish illustrator Tove Jansson).

Several months later, over afternoon tea, Stephen put a 3D printed 'Little My' on the dining table (Figure 6.10, Image 4)—this was a gift from Stephen and Ann, which he had printed on his 3D printer. Apart from the kindness of this gesture, this activity was remarkable, given the patience and skill required to produce a 3D printed figurine. The tiny statue was delicate, with some parts printed separately—such as the hands—that were designed to clip onto the figurine. This further reminded me of the retained abilities that people living with YOD have, and the importance to recognise, value and work with this aspect of the dementia. It is different for each person.

A few technology-related insights offered by Stephen include:

- **Smart phone** Stephen uses a basic iPhone 5: 'I'm quite happy with the iPhone 5, don't feel I need to update it, you know, iOS 10.3.3 works quite well for us. I do all my internet banking, keep all my appointments and calendar things there'.
- **Music** Stephen likes to relax and listen to music: 'I have approximately 12 gigabytes of my music on this (iPhone), you know, so I carry around my music … If I'm going on the train, I'll sit down and listen to music. I like my music. So, in terms of those sorts of tools, that's very important because, you know, sometimes, I am affected by noise. I don't particularly like noisy environments and listening to music helps'.
- **Video sharing** 'Also, I love watching the YouTube channels, learning the way things work. If I want to know something … I will often turn to YouTube to try and … because they'll also, as well as giving me a written description, actually show me as well. So, the visual is becoming a little bit more important than what it ever was'.

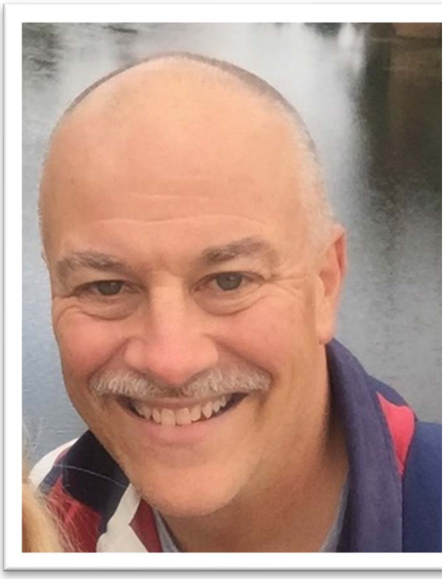
6.9.7 General insights offered by Stephen

On technology *'Well, I know in terms of … technology, I talk about the tracking apps like innersoles you can put in shoes 'cause a lot of people who have dementia will go out for a walk and not take their phone or not take their keys, but they'll always put their shoes on. So, if you put in an innersole and it's got a little GPS and radio, you know, it will track them.'*

On humour *'Humour has always been very important to me—you can become very quickly overwhelmed by the depression and the hopelessness of it all. If I can't maintain my sense of humour, I feel I've lost something essential about myself.'*

On identity Stephen's personal identity and his work life are closely linked. He describes no longer working as a measurement scientist was like losing part of himself: *'It was difficult for a long while, finding some sort of identity, and I think I still struggle with that. Who am I, outside of the workplace and my dementia?'*

6.10 Jeff Thurlow



6.10.1 Background

At the time he was diagnosed with YOD, J was employed as a Senior Manager ir government social services agency. In t role, he had a great deal of responsibil managing staff and had oversight for number of social cases. Being diagnosed w dementia while still in the workplace v '*stressful and confronting*'.

Jeff described the time prior to his diagnosi follows: *'I had a feeling that I just wasn't grasping things'; 'unable to adapt'; 'feeling a bit stressed'; 'relying more on Seb (Jeff's partner) for day-to-day things'*.

One of the first signs was *'I've always put my CDs in alphabetical order … that was one of the first signs I really picked up on that something was wrong with me … "Oh, this is strange. I can't find them there".'* Jeff blamed this, as he did with work, on stress. *'I just thought it was stress' … 'it wasn't just a temporary thing, it sort of recurred and then, gradually, I thought, "Oh, there seems to be a pattern here".'*

6.10.2 Personal interests

Jeff is a retro movie buff who idolises Marilyn Monroe. He recalls movie storylines word-for-word, as well as the names of actors. His home is filled with memorabilia from the bygone era of Hollywood. This interest brings Jeff much joy and his knowledge is exceptional: this era of Hollywood movies formed part of most conversations we shared.

Jeff takes one-day train trips frequently (often alone) or occasionally with friends for a few days. Jeff found that navigating the rail network and associated timetables was manageable—as was evident on a three-day road trip we took together (Figure 6.11, Image 2).

Being in nature is important to Jeff. He lives in a peaceful semi-rural setting. Jeff has two pet dogs, which are much-loved members of the family. On our three-day road trip, we spent a lot of time walking by the river, reflecting on the beauty of nature and what this means to him in the context of dementia (Figure 6.11, Images 3 and 4). It brings Jeff '*great comfort and renewal of hope*'.

Jeff seems to connect deeply with his environment; this is how he has positive experiences with his dementia. He often uses phases such as *'God's country'; 'I'm at peace today'; 'I drove to one of my favourite lookouts and I just sat there, savouring the view for ages.'*

Jeff is involved in a local historical society and enjoys learning about the history and indigenous culture of the area in which he now lives. Jeff is articulate on matters of local history and general politics.

6.10.3 How we met

Dementia Australia put me in contact with Jeff through a case worker. Jeff lives a few hours out of Sydney, with his partner Sebastian. Jeff and Sebastian are supported by their friend Kas Hilton, and the local rural community. Kas became an essential team member of the research activities; she is introduced in the Technology Design Workshop (see Chapter 7).

6.10.4 Elements characterising our relationship

Jeff and I would meet at his home to discuss this research, conduct interviews and share stories. It was a familiar and peaceful setting for us to discuss his experience of dementia, as well as his hopes and fears for the future; this was an element of his story that he felt comfortable to share with me.

During the longitudinal fieldwork, we established a safe and trusting relationship. With this, Jeff (with Sebastian's blessing) suggested that I join him on a three-day road trip, which was a five-hour train journey (Figures 6.11 and 6.12).

This time spent together was invaluable on many levels, particularly as a researcher. I was able to witness some of the experiences of YOD, both positive and negative, that the broader team were describing to me. Evident, for example, were the stigma, communication challenges and varying energy levels. One ability Jeff demonstrated was his strong sense of direction. He had no issues navigating to and from the accommodation and main road of the city (approximately 2 km walk). He also had no issues with the timetables for our train travel.

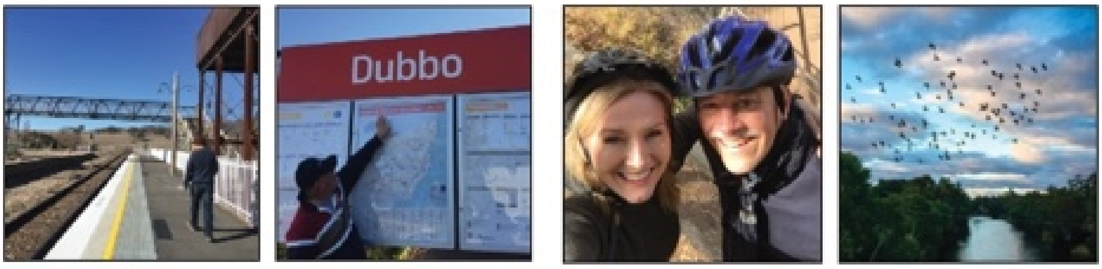


Figure 6.11 A three-day road trip to the country—and a shared a love of nature.

During our three-day road trip, we had a day out at the Western Plains Zoo in Dubbo, NSW (Australia). Here, Jeff and I hired bicycles to cycle around the precinct. While I was aware of some of the YOD challenges that Jeff was coping with, these were not visible to others. Jeff had been cycling for 20 years, and it took an incredible amount of will and determination for Jeff to master the bike ride—which he successfully managed—cycling 5 km around the precinct.

I regularly travelled to visit Jeff (about two hours from my home). Once I arrived, Jeff would often drive us to one of the local cafés for lunch. In these informal settings, I had the privilege to hear many stories of Jeff's life before dementia, and how he was adjusting to life with dementia.

He was optimistic and often spoke about where he finds inspiration (such as nature). While Jeff had a restricted driver's licence, he could still drive around the local area and I was happy to be a passenger and witness his joy of driving.

6.10.5 Our interactions in the context of YOD research

From a personal perspective, it was humbling to spend a few days in the life of a person living with dementia, out of the university and household settings.

As a researcher, spending time in shared accommodation (working through day-to-day tasks together) with a person with YOD afforded me with insights impossible to gain from conducting more structured research inquiries, such as interviews, workshops or observational exercises in a formal research setting.

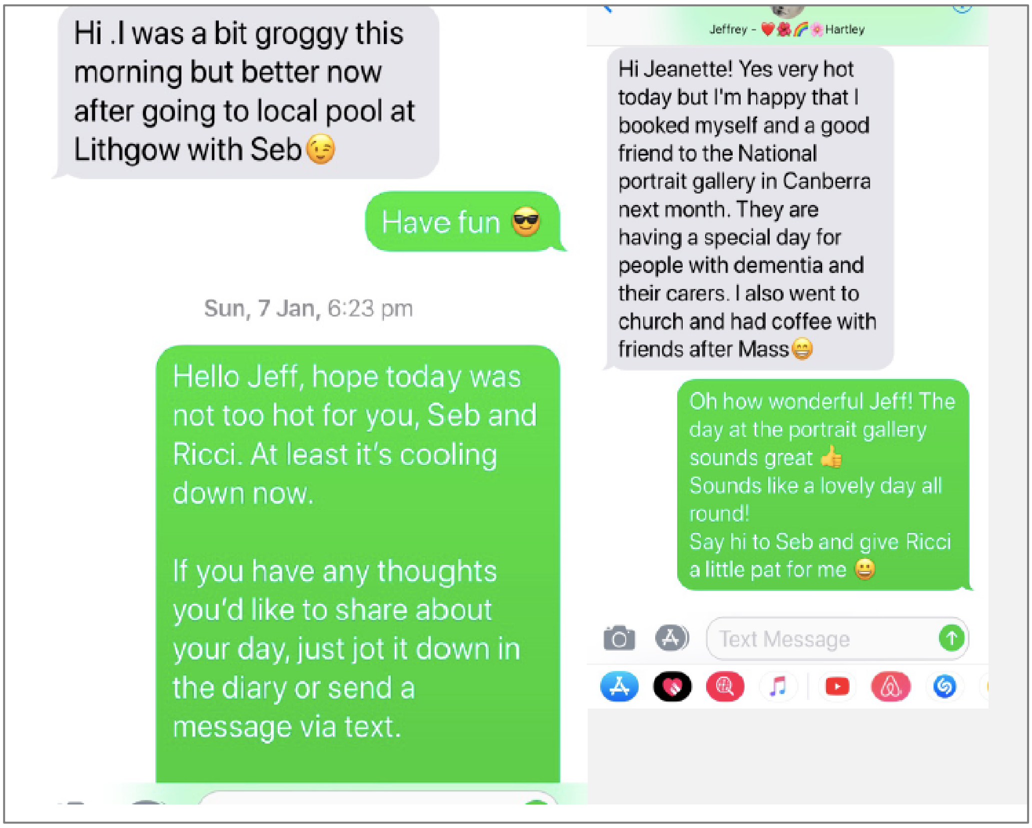
One example of developing deeper (more nuanced) insights was during a visit to the local café for breakfast. Because Jeff was paying for his meal, I noticed that he struggled to choose which payment card to use. This delay led to a line of people waiting behind him to pay for their meals. His confusion was not easily understood by the people waiting in the line. Jeff has no visible signs of dementia. This moment was triggered by not being able to visually differentiate between two payment cards.

While I saw his confusion, it was also important not to jump in and try to fix the situation. He just needed a little bit longer to work it out. We discussed this afterwards and Jeff suggested that it was because his two cards were both the same colour (red). This presents an opportunity for a technological solution to assist people with YOD with everyday financial transactions.

Figure 6.12 The three-day road trip included going to the movies and day travel to the Western Plains Zoo and local historical sites.

6.10.6 How Jeff engages with digital technologies in daily life

- Facebook: *'I'm linked into all the movie star sites'*; *'So, it's nice to talk—to communicate with people with that hobby.'*
- Jeff's ability to write was diminishing when we first met: '*my writing has really gone to pot*'; however, he has retained the ability to read and, as such, does not wish to move to audiobooks.
- Jeff expressed that he struggles with spelling and relies on autocorrect/word suggest for support.
- Jeff prefers communicating via text messages and enjoys using emojis (Figure 6.13): '*I deliberately chose sending texts because it's a good excuse for me to type, even though it's exasperating for me because I know which letter I want but I can't quite get it … I need to get that practice*'.


Hi .I was a bit groggy this morning but better now after going to local pool at Lithgow with Seb😉

Have fun 😎

Sun, 7 Jan, 6:23 pm

Hello Jeff, hope today was not too hot for you, Seb and Ricci. At least it's cooling down now.

If you have any thoughts you'd like to share about your day, just jot it down in the diary or send a message via text.

Jeffrey - ❤️🌺🌈🌸Hartley

Hi Jeanette! Yes very hot today but I'm happy that I booked myself and a good friend to the National portrait gallery in Canberra next month. They are having a special day for people with dementia and their carers. I also went to church and had coffee with friends after Mass😁

Oh how wonderful Jeff! The day at the portrait gallery sounds great 👍
Sounds like a lovely day all round!
Say hi to Seb and give Ricci a little pat for me 😃

Figure 6.13 Jeff asked me to send reminders for him to share stories from his day.

6.10.7 General insights offered by Jeff

Jeff mentioned to me that he had been invited to join many research initiatives (in addition to my project), which was becoming taxing on his energy. I recognised this drain on Jeff's energy and time, too, when visiting his home to set up a teleconference meeting for a government research project (not one that I was part of). At that session, the topics for discussion related to complex policy development initiatives. While Jeff was motivated to contribute to research—and had a background in social services—this was a challenging session. After this point, he also expressed to me how precious his energy and time had become. He felt that researchers should make their projects more visible because he saw repetition across research projects he was asked to join.

This concludes the biographical accounts of YOD. In this next section I summarise the findings from the field, before presenting study insights—including how to better include primary relationship partners if they express a desire to contribute to the research.

6.11 Summary of findings

Spending an extended period (over two years) developing relationships in the wider YOD community created an opportunity for those aspects of everyday life, that may be taken for granted, to be observed and documented.

Essentially, I found the people who joined me on this research journey, are highly attuned to their medical condition and deeply insightful on what this means for their future. Perhaps, having access to the internet has facilitated their level of insight into the medical and social implications of living with YOD.

Furthermore, the YOD group stay up to date with the latest research, policy development initiatives, and advances in technology. Some people with YOD on my research participate in government panel discussions and work with various dementia organisations (local and international) consulting on complex policy development. Such as: policies on palliative care, end-of-life planning, decision-making rights, human rights, and so on. Some have also become important contributors in media campaigns, often appearing in news reports, feature stories, and informing content of movie scripts.

While you may expect to witness a decline in cognition and hence a change in how those with YOD engaged with digital technologies; on this study, I did not witness any measurable change in their engagement with digital technologies from what has been reported in this thesis. For example, Suzie discussed how she was learning to use technology for 'later', such as a medication reminder, however this was not required at the time this research had finished. Also, at this study completed, Jeff was still driving on a restricted licence which he was tested for each year.

I also observed some life enhancements for the people with YOD, particularly as their level of acceptance increased, and they found a new joy in life. For some this was turning to nature and spirituality, for others it was in the new friendships and a greater sense of purpose in life.

6.12 Discussion and insights

The insights presented next are ethnographic insights, that significantly enrich and augment those resulting from the cultural probes developed in Cycle 1 and implemented in Cycle 2.

These insights and deeper understandings of the YOD community, have emerged from many conversations, social interactions, research activities, observations and reflections over the course of two years. While there are many more stories, key events and insights that warrant attention, the YOD group determined that the following areas were of most importance, and reflective of their broader YOD community. These are the key takeaways for the HCI community.

The four sections are:

1. Insights into the felt and lived experience of YOD
2. Insights into the role of technology in YOD
3. Unpacking the evolving relationship dynamics
4. Researcher insights: my reflections as a new HCI researcher working in YOD

6.12.1 Insights on the lived experience of YOD

Understanding the implications of the following recurring themes is important from an HCI research and design perspective. This understanding adds context to the 'needs and wants' of people living with YOD and can better inform technology design. While there were many incidences of stigma, loss of independence and freedom, the following examples were (communicated as being) the most impactful to people with YOD:

Stigma

Language is powerful. Labels such as 'sufferers', 'demented' and 'burdened' are amplified in YOD. There is also a sense of being overlooked and feeling invisible, constantly reinforcing the notion of fading away or losing identity.

Loss of independence and freedom (for example, the loss of one's driving licence)

Having your driver's licence taken away is a loss of independence and freedom. A YOD diagnosis affects the application requirements for a full driver's licence. To keep their driver's licence, people with YOD need to undergo a test then may be issued with a restricted driver's licence, which allows them to drive locally, within a defined radius.

Loss of employment

The supportive work environment that Phil speaks about is something Dennis and Suzie lacked in their workplaces, in which they weren't given the opportunity to work at a slower pace. Thus, they missed out on staying employed for longer post-diagnosis.

> *'I could probably have continued working a lot longer, but there was no history of that support.'*—Dennis

> *'It is frustrating when you know you're not coping at work but you can't afford to drop back your hours.'*—Suzie
>
> *'I've got better since leaving work. So, stress was definitely some of the compounding factor—working at a slower pace would have been beneficial to once I had received a diagnosis.'*—Suzie

Return to nature and spirituality

Making peace with life (e.g. religion, meditation, poetry) and a heightened spirituality were dominant in many conversations; this emerged as a primary theme throughout the longitudinal fieldwork.

Acceptance and getting on with life

Accepting a terminal disease diagnosis at an earlier stage of life helped those with YOD to find a sense of purpose. In this study, they described this as contributing to research and taking an advocacy role for YOD. Those with YOD shared a goal: to reject the stigma and to *'live well with dementia'*.

In summary, the key experiences that the people with YOD described to be of **most importance** to them relate directly to the impact of stigma, and loss of independence and freedom. Further, they can find great comfort in nature and with a return to spirituality. There was also an acceptance of their condition and a feeling of getting on with life.

6.12.2 Insights into the role of technology in YOD

Those with YOD described the following technologies as being essential to support positive experiences: navigation apps, social media platforms, healthcare and wellbeing apps, and communication technologies. They saw these technology-related themes as supporting their confidence, comfort and social connectedness.

- **Navigation software** Transport timetables and calendars support feelings of independence and freedom, which are highly valued by those with YOD.
- **Social media platforms** Facebook groups (personal interest groups), for example, promote social connectivity, maintaining identity.
- **Healthcare and wellbeing apps** These support health and wellbeing through life-logging their physical activity, moods, heart rate and stress levels, enabling notifications when self-determined limits are being compromised. This links to a sense of agency and self-control over one's body and mind.

- **Communication technologies** Zoom, Skype and FaceTime are channels used by key dementia agencies, such as DAI, ADI and Dementia Australia, to stream educational webcasts and event information. This facilitates activities and professional relationship-building among YOD peers globally.
- **Technology end-user support** There needs to be better access and IT support with home device settings. It is recommended that technology developers and marketers should provide the device with home-set-up support options for installations, software upgrades, and settings such as synching devices.
- **Technology design options** It has been expressed by those with YOD on this research that people living with cognitive decline struggle with technology that is constantly evolving, which becomes challenging with their 'diminishing tech skillset'. It is suggested that minimising the number of 'upgrades', having someone come to install the technology, providing a simple how-to for set-up, and having a 'simple' option (only including the essentials with a clean and clear layout) would be wonderful for a person with YOD.

The following section outlines my response to address the complex relationship dynamics that are not always evident in the early stages of research programs.

6.12.3 Responding to the emergent relationship dynamics

The work of Wallace et al. (2013) alerted me to the fact that couples may need to remain closely connected through research activities, because '*their lives and experiences of dementia were so tightly intertwined*'. This was an important insight from the more experienced HCI researchers in the dementia setting. I thus needed to move sensitively through this space.

Adjusting to the changes that come with a YOD diagnosis can be difficult and unexpected—not solely for the person with YOD, but also for their partner and friends. A partner who takes on the carer role, for instance, may now also have an additional responsibility of raising the children and managing finances. Sometimes, families and carers need to reduce or give up work altogether to care for the person with dementia (Sansoni et al. 2014). There can also be changes to a person's everyday way of life and their broader social relationships. These changes can be significant and unwanted.

Although I was aware of the importance of partners in this research, and I could informally observe and capture incidental insights, there were times that I wished I could have provided more structure around these (partner) conversations.

I spoke about this with my supervisor; we decided to create an activity for the partners, who were spending significant amounts of time on these research activities. This was a way to involve the partner without disrupting the aims and ethical parameters of this research program. This additional exercise added richness and context to the development of YOD experiential insights.

6.12.3.1 An optional activity—for the partner of a person with YOD

The goal of this exercise was to facilitate storytelling in a relaxed fashion, so the participant would have autonomy in selecting how and when they wanted to share their story in a safe environment. The instructions were as follows:

- Pick one photo from a selection of 50 random internet pictures, which I had compiled (Figure 6.14).
- Pick one photo from a personal photo album / collection [note: personal photos not posted in this thesis].
- Describe how the images you have selected relate to your experience of (your life) with dementia.

I had two key considerations to work through before I offered this exercise to the group:

- Would the people on this research journey be motivated to engage in an additional activity, which was introduced halfway through the research?
- If I was to work directly on an activity with partners and friends, was this going to be an imposition on the person with dementia, in ways that would undermine their position (agency) in this research?

For guidance on these points, I consulted with my PhD supervisor and the people with dementia, who were central to my research.

It was agreed that this optional exercise would not disrupt the overall research program; in fact, it added additional context to the broader impact of a dementia diagnosis to a family.

Figure 6.14 Optional exercise for partners: 50 images—select one and describe how this relates to your life in the context of YOD.

This exercise is a way to facilitate storytelling. Next, I will provide one response to this exercise, from Ann Grady (Stephen's wife). I wanted to find a way to include Ann in this research in a meaningful way. This was challenging in principle, because one of the study objectives was to not include a proxy for the person with dementia, so this needed to be considered carefully. Ann's personal and generous account of living with the impacts of YOD is profound—and reflective of others in this relationship position.

6.12.3.2 Ann Grady—reflections from a loved one

Ann selected the image of a garden (Figure 6.15) from the selection of 50 images (Figure 6.14). The garden image brought both Stephen and Ann great comfort during the more difficult moments of living with and supporting a person with dementia.

Figure 6.15 The garden image selected by Ann reflected the peace and calm experience of her own garden.

The image of the garden inspired the following personal response of how dementia was impacting their life. The first part references the internet-sourced image selected (Figure 6.15).

Ann selected two images, the second was from their personal photo albums. It was a picture of Stephen and Ann together in an earlier phase of their long relationship. Given the personal nature of the photograph it is not included in this thesis.

Next, with Ann's permission, I share her account of a 'life with dementia'. Ann wrote this letter in response to the internet image of the garden and the personal photograph - as a way to share her personal story with our HCI community.

Dear Jeanette,

I chose this image because of all the pictures; this is the one that would bring me the most peace & calm into my present life of uncertainty. Dementia seems to have robbed me not only of my husband of 20 years & my friend since the age of 16, of our future together, but also I have lost a large part of myself. My need for security, which has always been very heightened due to a difficult childhood & which Stephen has always been able to help me to feel secure & safe, are all in jeopardy again & I feel lost. I would like to sit in this chair in this beautiful garden, being still & breathing deeply, enjoying the serenity, 'lapping' up all the joy that colour brings to my world, the scents & textures of the garden, appreciating all that Nature can so wonderfully bring to help fill my emptiness. I would be in my 'safe place', able to recharge & take on tomorrow as best I can, with as much strength as I can muster.

Attached photo above is my chosen photo taken in happier times, back when on holidays in the Dandenong in 2005, pre-dementia, in a little quaint Tudor-style restaurant called The Cuckoo in Olinda, when we were so happy just spending time together. It was taken on our 8th wedding anniversary & we loved to take car trips through Victoria, stopping at places that were not only photographically beautiful, but food & wine meccas. We shared so much laughter & could finish each other's sentences. Our relationship was the envy of all our friends & family. It was about just being happy together & leaving the day-to-day stresses of life behind us, appreciating our love for each other & all that we shared together. I've gone through more than a few tissues putting my thoughts together, so I do hope it all make sense to you.

Looking forward to seeing you again on Friday.

Sincerely,

Ann.

6.12.4 Researcher insights

In this next section, I share my reflections on working on the two-year fieldwork in the dementia setting—or working in a 'sensitive HCI' setting, as characterised in the literature review (Section 2.5.3). These reflections are primarily in context of managing unconscious biases. I will go into more detail in the final chapter, in which I connect the observations made by other HCI researchers (Moncur 2013; Vines et al. 2014; Waycott et al. 2015) to my own experiences and observations.

One of the goals (and benefits) of working within the PAR framework is taking the time to develop and nurture relationship bonds. These bonds are based on trust, respect and a shared motivation to build knowledge on the dementia experience and how technology could provide comfort and support for people with YOD. We all wanted to find ways for technology to better support people with YOD—as a social mediator, digital navigator and as a source of information about their concerns with dementia and life in general.

Conversely, many unexpected situations emerged that I felt not only completely unprepared for but perhaps underprepared.

According to Vines et al. (2013), an HCI researcher needs to consider certain vulnerabilities:

> *Researchers are poorly prepared for stepping into these sensitive setting … one theme was the feeling that HCI training and education poorly prepares or sensitizes researchers to respond to the needs of vulnerable participants.*

After learning about 'researcher vulnerabilities', I was inspired to critically explore these sensitivities. In the next section, I unpack my inner biases—a legacy from my family experience with dementia—and discuss how I settled them.

6.12.5.1 Researcher vulnerability—stemming from unconscious bias

When I set out to research HCI and dementia, I was unaware of how my inner biases may have affected my approach and responses in this setting. On reflection, I realise that I was underprepared for spending a prolonged period in this setting.

As I was preparing for my first visit in the field, the following unconscious thoughts and the (unexpected) emotions started to surface. This surprised me. Even though I worked in medical science—and on dementia projects—this was my first experience as a HCI researcher in the field.

I found the following questions recurring based on my family experience of dementia—my only frame of reference:

- Would I be safe? *My father had moments where his emotions would quickly escalate.*

- Should I accept a lift in the car? *My father was unsafe as a driver, long before he gave up his driver's licence.*
- What would I do if the person in this research becomes disoriented, confused or disassociated? *This happened (often) with my father—how would I manage this without any prior knowledge of the person I was about to spend a considerable amount of time with, and no previous relationship experience to draw on?*
- What level of personal insight do people living with dementia have? *My father (in the advanced stage of Alzheimer's disease) had diminishing insight, which presented behavioural challenges that were extremely difficult and emotionally painful to manage.*

Fortunately, by acknowledging this thought pattern, I could address and settle these biases early in the fieldwork, often using the time spent travelling to and from locations (on public transport) to reflect and reframe my thinking. I also engaged the support of a counsellor to help me gain perspective.

I wish to note here, that my personal 'frame of reference' was quite limited with respect to dementia and how this affects a person. It did not reflect what I experienced in the field.

In fact, the level of optimism shared by the people living with YOD was palpable—and the concerns I initially held (based on my past experiences) were not of concern in this research. Having said this, the individuals with YOD did have their own challenges to manage, which I needed to understand and adjust to.

In terms of emotional health—and emotional responses—it was quite difficult to manage the personal stories being shared, especially as time went on and attachments had formed. I will discuss this issue in more detail in Chapter 8: Discussion and Conclusion and provide my recommendations for researchers wishing to work in this sensitive HCI setting.

6.13 Contributions

This ethnographic fieldwork produced the following insights into the everyday experiences of people living with YOD, their day-to-day activities, their communities, and the role of technology. Additionally, this extended time in the field strengthened relationships and provided a sense of purpose for the people with YOD (and the researcher).

While there were many examples on the use of technology produced in this fieldwork, the YOD team considered the following as the key areas to report back to HCI:

- People living with YOD are busy, engaged in all types of projects/work and family life, as well as dealing with their dementia. Be mindful of what activities we ask them to engage in.
- Digital technologies are firmly embedded in their day-to-day lives—much the same as people in this age group who do not live with dementia.
- Stigma is a barrier to being included directly in research and design activities; people with YOD want to be seen, valued and included ('nothing about us, without us').
- People with YOD are unique in the sense that they are prolific users of everyday technologies. They are also acutely aware and well-versed on all aspects of their dementia condition. Some have an interest (and experience) in research and design settings. This group is ideally positioned to make a major contribution, *if* they are included more closely in HCI research and design activities.

6.14 Limitations

Establishing boundaries: while the immersive period spent in the field galvanised relationships, there were inherent limitations associated with the PAR model. For example, when working through the interconnected PAR cycles, it can be difficult to identify where to stop and move to the next phase of investigations. There is no 'hard stop'.

While there was freedom to work within the PAR framework, there was also a blurring of roles and responsibilities. At times, I needed to disconnect as a researcher and assume the role of 'guest' at particular events. Furthermore, as trust strengthened, I became privy to personal conversations, and needed to set boundaries in terms of the more serious content. I would describe 'serious content' as information of a deeply personal nature that may be shared with me 'in confidence'. My approach in this situation would be to suggest that the person speak directly with their partner or support person. I would also seek advice from my supervisor on how to manage these situations.

Research reporting challenges: Being immersed in an ethnographic fieldwork, which included various social settings, made it difficult to determine which elements of the social interactions (and conversations) to report on.

This presented the question; what is research and part of the analysis (in) and what is excluded (out)? Regarding partitioning of conversations that were part of the social setting from the 'research related' conversations – I approached this as follows: If I was in a social setting and became aware that the conversation was research related content, I would ask the person if would mind if I captured the key points in my research notes. This was well received by the people who joined me on this journey, as they were able to vet what I was going to capture, and possibly use in publications.

6.15 Conclusion

Research in YOD is highly complex and requires extensive time in the field and a collaborative approach to access deeper learnings and understandings of the YOD community and the role of technology in this setting.

In methodological terms, collaborating through the PAR model and including an ethnographic fieldwork in this research plan increased the visibility of the people with YOD and surfaced insights and stories that cannot always be clearly articulated in interviews, surveys or single workshops.

The value to the HCI community in taking this combined approach is in the visibility and deeper insights into their lives of those with YOD, and the culture of the group to which they belong. This understanding that is particularly valuable in HCI research and design endeavours as asserted by HCI researchers (McCarthy & Wright 2004), who remind us to understand the lived experience before launching into technology design.

Theoretically, presenting the biographies, has showcased the YOD group, raised awareness on dementia in this younger group, their culture, and the community networks. These generous contributions and experiential insights are offered up for the HCI community to take forward into future research.

6.15.2 Introducing the YOD team

The people living with YOD had not known of each other before joining this research. Towards the end of the three cycles of the PAR model, 'we' (researchers, friends and family of those with YOD) had known each other for three years (or more, for some).

During this time, our emotional bonds strengthened and our motivation to contribute insights to HCI research was palpable. With our strong interest in digital technologies, we were optimistic that we could make a real difference and we were keen to find even better ways for technology to support people with dementia.

The team felt that HCI research and design practices would support this goal:

> *'it is often the technology that enables greater confidence in the face of dementia challenges'*—Stephen Grady

With this shared motivation and drive to make a difference, the YOD team (Figure 6.16) was ready to launch into the **Technology Design Workshop**.

Figure 6.16 The YOD team. Back row: Sebastian, Jeff, Dennis, Stephen. Front row: Kaz, Jeanette, Ann, Suzie.

6.16 Looking ahead: Next steps

Finally, the bonds formed during the PAR cycles and 'our' motivation to further explore how digital technology could provide support in YOD, which provided a wonderful opportunity for one more step in this research program—a **Technology Design Workshop**—presented in Chapter 7.

In the next chapter, I present the final stage of the research where the YOD team worked together to co-design the workshop agenda and map out the logistics on how to execute the one-day workshop in YOD.

In addition to offering guidance on how to run a one-day workshop in sensitive HCI setting such as YOD, we explored how digital technologies could be designed to support positive experiences for people living with YOD.

Chapter 7.

HCI Technology Design Workshop: Understanding Technology Design Requirements in YOD

> *"To design meaningful technologies, we first need to appreciate the emotional, intellectual and sensual aspects of our interaction with technology".*
> McCarthy and Wright (2004)

7.1 Introduction

The quote introducing this chapter reminds us that the HCI community should take time to understand what a person is experiencing when they interact with their preferred technologies. That is, to better understand what their desired experiences and design features are before launching into designing new technologies.

In this third study, I bring together the learnings (about the needs and wants of people with YOD) and technology insights (how they appropriate current technologies to support their needs) into one space. By this stage of the research program, the personal relationships had matured, and research collaborations were well established. We had formed trusted bonds and were all conversant on the current dementia (YOD) research and design activities underway in HCI and other research domains. The **Technology Design Workshop** thus benefited greatly from the culmination of knowledge, trusted relationships and collective insights, which had been built during the ethnographic longitudinal fieldwork discussed in Chapter 6.

Previous studies revealed that, while people with YOD use many available technologies —such as navigation, life-logging, and calendar-based apps—people with YOD have not informed the design. Essentially, people with YOD take existing technologies—and make do. For example, people use their camera, navigation apps and digital calendars to organise their lives and support them in the context of the challenges they face each day.

It was reported back by the team that while these readily available technologies go a long way in aiding people with YOD, there would be much benefit derived from user led design apps and platforms for YOD. This is because some technologies, when designed for dementia, may be stigmatising and not fit with the existing everyday technologies they are used to engaging with in their day-to-day life.

The Technology Design Workshop was not necessarily intended to design a new technology, device or an app; it was devised to bring people with YOD together in a supportive way to imagine how technology could best fit into their lives.

The rationale for conducting this one-day workshop was to explore the technological and experiential aspirations of younger people living with dementia. The workshop was designed to surface a series of pragmatic recommendations for the HCI community (from people with YOD who represent the YOD community) to inform future dementia technology development and research practices.

7.1.1 Chapter overview

This chapter describes the final step in the research (Figure 7.1), which is presented in three parts and arranged according to the steps in the planning process.

Part 1 (logistics) This section discusses the logistical complexities encountered during the *planning phase* of this workshop. The end goal was to deliver a co-designed workshop agenda for a one-day session, bringing together a team of HCI researchers and people with YOD for the event.

Part 2 This section provides the implementation steps (for two sessions: morning and afternoon) and reflects on the (preliminary) findings from these sessions.

Part 3 This discussion section offers insights and recommendations for the HCI community with:

- Recommendations for HCI researchers, including key requirements to consider when hosting workshops or meetings in similar settings.
- Recommendations for HCI designers, including a set of technology features and technical capabilities that would support people living with dementia.

7.1.2 Scope

The scope of the third study includes mapping out the complex logistical requirements of bringing a group of individuals with YOD together in a collaborative one-day workshop. This workshop included a fun/creative conversation about ‘future technologies’, which was informed by participants’ real-life experiences with dementia.

Please note: The workshop was intentionally designed to be an environment in which all contributors could exercise a great degree of imagination and creativity. It was not constrained by needing to develop final technology design solutions or working prototypes.

Setting the tone: While not downplaying the seriousness of dementia, the HCI team thought carefully about ways to bring fun and joy into the day.

7.2 Aims of Technology Design Workshop – Study 3

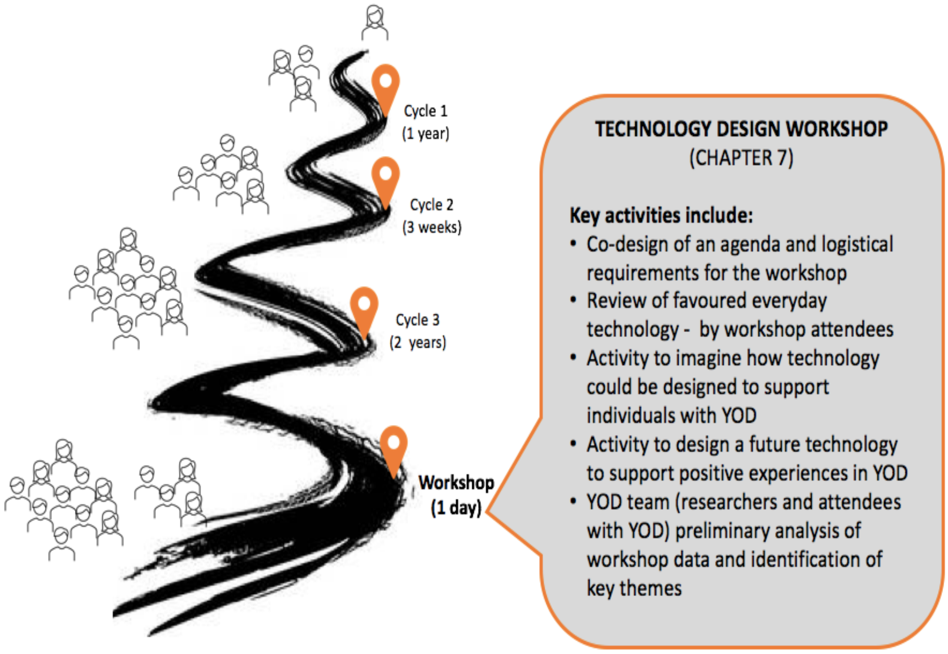
The one-day workshop aimed to bring the people with YOD and their supporters together—with the HCI research team—to imagine how technology could best be designed to fit into their lives in a supportive way.

Aim 1 Present back to the YOD team what I had learned about the dementia experience when diagnosed in an earlier stage of life. This was also an opportunity to validate the information gathered on their relationship with digital technology. In other words, to check whether the researcher analysis and insights were aligned and an authentic representation of people living with YOD.

gathered. In other words, to check whether the researcher analysis and insights were aligned and presented an authentic representation of people living with YOD.

Aim 2 Create a workshop setting (logistically) for people with YOD and their partners to imagine what possibilities technology could have for them in the future.

Aim 3 Produce a list of recommendations for conducting future workshops in the YOD or similar sensitive HCI settings.



TECHNOLOGY DESIGN WORKSHOP
(CHAPTER 7)

Key activities include:

- Co-design of an agenda and logistical requirements for the workshop
- Review of favoured everyday technology - by workshop attendees
- Activity to imagine how technology could be designed to support individuals with YOD
- Activity to design a future technology to support positive experiences in YOD
- YOD team (researchers and attendees with YOD) preliminary analysis of workshop data and identification of key themes

Figure 7.1 The research journey concludes with a network of those with YOD, HCI researchers, university peers and supporters

7.3 Research questions

RQ. How can HCI develop deeper and more nuanced understandings of the lived experience of people with YOD?

7.3.1 Sub-questions

SQ 2. What research approach, methods and tools would best support the needs and wants of people with YOD?

SQ 3. How can HCI use these theoretical and methodological insights to inform a fresh approach when designing digital technologies with, and for, people with YOD?

7.3.2 Two additional questions from the YOD team

As the workshop agenda was being prepared, two new questions surfaced from the individuals with YOD:

- What are the logistical considerations for conducting workshop with people living with dementia?

- What might a technology workshop 'look like' when the agenda is informed by people with YOD?

The individuals with YOD felt that these focus questions would help researchers drill down (even further) into their experiences, particularly regarding their participation in research and design activates.

7.5 Part 1: Workshop Logistics

This workshop was planned meticulously (with the people living with YOD, HCI research peers and my PhD supervisor), right down to the timing and location of the breaks to ensure that it was as successful as possible. In this chapter, I will provide the rationale behind each step.

The planning phase was conducted over a three-month period. In this section, I step through the logistics and extensive preparation required in hosting a one-day workshop in the YOD setting. It describes the challenges and opportunities of taking a collaborative approach for HCI research and design within the context of YOD. The deliverable of Part 1 was the **co-designed workshop agenda**.

Many considerations related to running the workshop surfaced during conversations with peers, supervisors and individuals with YOD. As part of the planning stage, the following questions needed to be addressed first:

- **Location** What type of environment (location) would best support the needs and wants of a person with YOD?
- **Agenda content** What types of activities would stimulate creativity and generate insights into the design process of YOD technology? How could the activities be designed to meet the workshop's goals? How could I structure the agenda (e.g. duration, topics, activities) to achieve the desired outcomes and support the needs of those with YOD?
- **Attendees** How many people should attend on the day? How many should be university staff (researchers)? Should peer researchers, who were interested in dementia but not familiar with the YOD team, be included? Should friends, partners and carers be involved? If so, to what level?
- **Assigning roles** What roles would the researchers and session facilitators play on the day?

Over some months with the YOD team, I discussed the location and date for the workshop. The preferred location was the university hosting my research—which offers meeting rooms, parking, lifts and an on-site cafeteria. The university is also in close proximity to major rail networks and a short distance from the airport.

Addressing the questions listed above took considerable thought and effort, to ensure they were incorporated into the planning adequately.

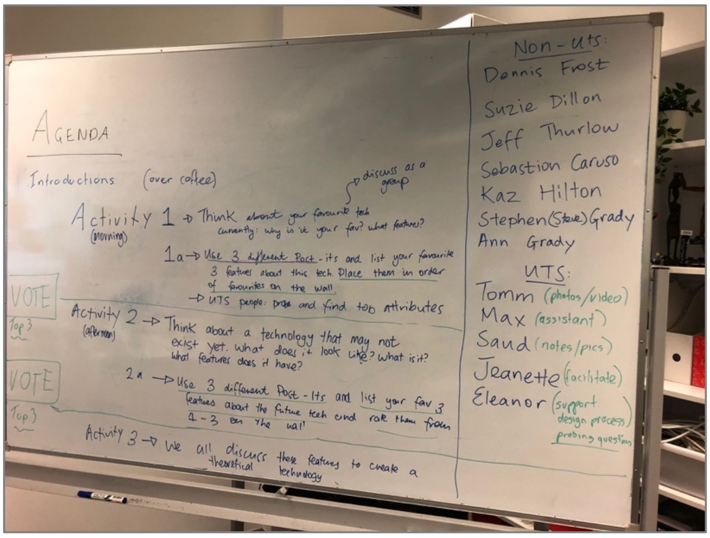
An important part of designing the agenda was to bring forward the insights formed throughout the earlier phases of this research program. The following points were carefully considered at every step of the workshop design and implementation planning:

- **Time** Be mindful and respectful of how a person with dementia perceives and values their time (dementia time). They may not remember the past in the order it happened. They are also aware of their cognitive decline and are explicitly choosing how they best invest their precious time.
- **Flexibility** Look for opportunities to be flexible in the design process and implementation of the research. This will support the varying needs and abilities of the individuals with dementia to communicate and engage in the most comfortable way for them.
- **Varying abilities** Be mindful of the varying abilities of a person with YOD. Individuals might find particular tasks challenge them unnecessarily. Provide options and workarounds.
- **Inclusiveness and collaboration** Find a way to be more inclusive in the research process and have an open mind when working in the area of YOD.

With these insights and considerations mentioned, in addition to consulting with the YOD team, the next step was to work on the agenda's content.

7.5.1 Developing the workshop agenda

In this section, I discuss the approach taken to develop the content and flow of the workshop's agenda. I also highlight the considerations taken to design an inclusive and creative agenda, which would support the goals of both the research and those contributing to the workshop. I mapped out the first draft of the agenda on a whiteboard with my HCI research peers, who were to join me at the workshop (Figure 7.2). My HCI peers not only joined me in planning the agenda but also provided practical support to facilitate the activities on the day. By this stage, they were familiar with this research and had already met the members of the YOD team.


AGENDA

Introductions (over coffee)

Activity 1 (morning) → Think about your favourite tech currently: why is it your fav? what features? → discuss as a group

1a → Use 3 different Post-its and list your favourite 3 features about this tech. Place them in order of favourites on the wall.

→ UTS people: [illegible] and find top attributes

VOTE Top 3

Activity 2 (afternoon) → Think about a technology that may not exist yet. what does it look like? what is it? what features does it have?

2a → Use 3 different Post-Its and list your fav 3 features about the future tech and rate them from 1-3 on the wall

VOTE Top 3

Activity 3 → We all discuss these features to create a theoretical technology

Non-UTS:
Dennis Frost
Suzie Dillon
Jeff Thurlow
Sebastion Caruso
Kaz Hilton
Stephen (Steve) Grady
Ann Grady

UTS:
Tomm (photos/video)
Max (assistant)
Saud (notes/pics)
Jeanette (facilitate)
Eleanor (support design process probing questions)

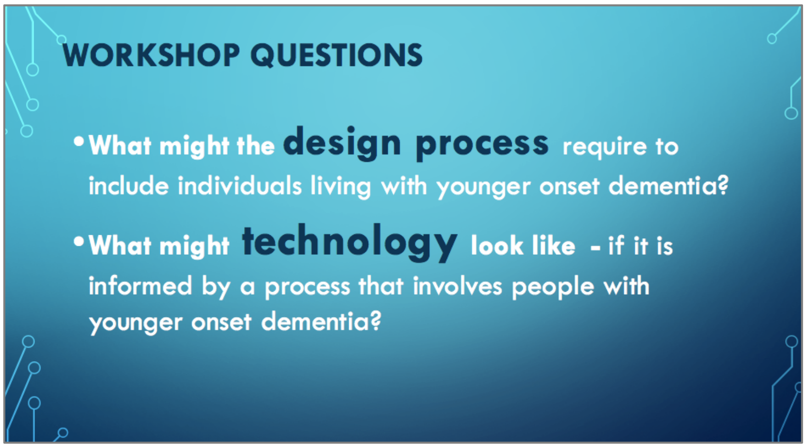
Figure 7.2 The draft agenda was created on a whiteboard in the university lab, where we assigned roles to HCI peers to support facilitation and data collection activities.

The activities for the workshop were split into two sessions: **Session 1** (morning) and **Session 2** (afternoon). Planning for the morning session involved figuring out how much time should be allocated for the following activities:

- Make individual introductions of all attendees.
- Talk about **one piece of technology** they could not live without (from the pre-work, see Section 7.6.1).
- List three attributes of their favourite technology, discuss with attendees and present back to the group.
- Group vote on the top design attributes for technology.

While working out duration times for workshop sessions may be a typical preparation step for workshop planning, when working in this YOD setting, a more thoughtful approach is required. For example, consider the participants' tolerance for time-consuming activities, their varying communication abilities, and how this impacts the facilitation (for example, giving instructions for activities).

Planning for the afternoon session involved a more flexible approach. With Session 2 following lunch, I had to be mindful of the group's energy levels. In this session, it was also critical for the structure and flow to foster uplifting and open discussions and stimulate imagination. This called for a less structured, more creative activity.



WORKSHOP QUESTIONS

- What might the design process require to include individuals living with younger onset dementia?
- What might technology look like - if it is informed by a process that involves people with younger onset dementia?

Figure 7.3 Two questions designed by individuals with YOD steered the workshop.

Two of the attendees with YOD reviewed the final agenda (Figure 7.3 and 7.4), before it was finalised and circulated prior to the workshop.

WORKSHOP OUTPUTS
CONSIDERATIONS FOR FUTURE RESEARCH

1) Improve the way technology is designed.
2) Share insights on how to design technology with, and for, younger people with dementia.
3) Influence how technology will end up looking and feeling in the future.

ACTIVITIES

In order to achieve our goals, we will be holding activities that are used in the design process and see how they work for our group.

- **Current focus:** Bring or describe one piece of technology you couldn't live without. Describe why you feel that way?
- **Future focus:** Think of a single technology. If you could have any technology designed, what would it be? Describe why you feel that way?

GOALS OF THE WORKSHOP

1)Implement a design process and understand what this looks like for our group.
2)Design a piece of technology to support living well with Younger Onset Dementia.

Figure 7.4 The agenda goals, activities and desired outcomes were presented at the beginning of the session

The agenda was thoughtfully co-designed to explore the aspirations of people living with YOD regarding digital technology design. It is worth noting again that we had two goals to work towards:

1. How to organise a HCI design workshop logistically within the context of YOD.
2. How to bring (amplify) the voice of a person with YOD into the technology design process. This is so they can offer first-hand insights for HCI technology designers and researchers.

As mentioned in the Introduction, producing a final design or prototype was out of scope for this research; however, the YOD team hoped to be part of an exercise to design a prototype in the future.

7.6 Part 2: Workshop implementation

The workshop was divided into two sessions—morning and afternoon—with an interval for lunch, providing for reflection of and adaptation to the agenda, if required. In this section, I will present the findings taken from the afternoon session. Where possible, all activities were offered to the broader group—those with YOD as well as their loved ones (whether a spouse, partner or life friend).

7.6.1 Pre-work (to bring to the workshop)

To optimise our time together on the day of the workshop, all attendees were asked to complete a pre-work activity:

- Think about one piece of technology you cannot live without. Bring this to the workshop (or bring a picture of it).
- Describe why you feel that way.

The rationale for asking the group to think about this ahead of time was to narrow the focus to one technology per person to discuss on the day. Each participant (apart from the HCI researchers) had an opportunity to discuss their favourite technology and the reasons behind their choice.

7.6.2 **Morning session – current use of technology**

The morning session was designed to build on insights from the previous studies in this program to understand how people with YOD use everyday technologies, and what this means with the additional challenges of dementia.

Aims of the morning session:

- Identify, discuss and prioritise the key experiences—in the context of dementia and their favoured technology.

- Take these prioritised experiences into Session 2 to inform a creative technology design discussion.

Before starting the introductions, I presented the agenda, research questions and goals of the day. I also introduced the HCI research support team and described the role they would play in the workshop. This was followed by a five-minute check-in with the attendees before beginning the workshop.

7.6.2.1 Step 1: Introductions

As mentioned earlier, Session 1 began with personal introductions. Although some of the team members already knew each other for some time. I was told early in this research that a few of the participants had 'self-identified' as being part of this research program (HCI, technology, dementia) during informal discussions at dementia related advocacy events. This was perhaps inevitable given the small number of participants, and the long duration of the research program.

During the opening introductions, each person spoke with candour about their personal experiences leading up to their YOD diagnosis and the impact on their lives post-diagnosis.

While these personal introductions were an important step to break the ice, the conversations took quite a serious tone when the participants began to share common frustrations with dementia. In hindsight, this was understandable and a natural process of storytelling, but it was a difficult point in the workshop for two reasons:

1. This sharing of personal experiences takes time and is difficult to steer 'conversationally'.
2. It was not supporting the (predefined) goals of the workshop.

7.6.2.2 Step 2: Discuss favourite technologies

Following the introductions, each person presented their favourite (and most important) technology to the group and shared why they selected this item. The YOD had predetermined that 'technology' would be defined as both digital and non-digital technologies. In terms of data analysis and having a method for capturing key comments, initially, the research team thought that a different coloured Post-It note should be used to identify those made by people living with YOD from those made by other attendees. However, during the workshop, we (people with YOD and researchers) spoke about this and decided collectively to take another approach, writing the names on the Post-It notes to help analyse the data post-workshop.

Step 3: Prioritise experiences

After discussing the various technologies, the group was asked to write down **three points or phrases** as to why each technology was important to them. These were put up on the meeting room wall for group discussion and thematic grouping below the large sheets of paper (see Figure 7.5).

After this, rather than asking the participants to vote for one feature/technology (because they all have different preferences and reasoning for why one is better than another), we asked them to select from one to three experiences regarding technology use that they valued most. These experiences were also added to the large sheets of paper in order of priority (Figure 7.5).

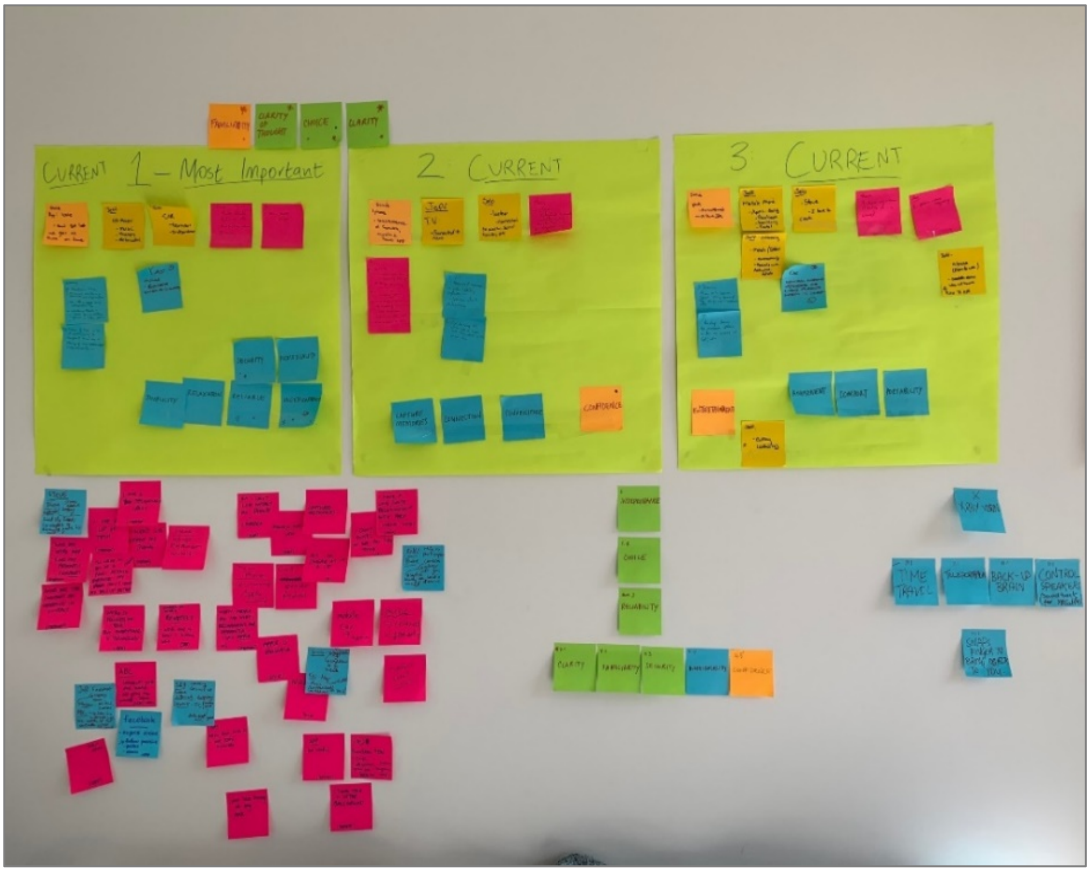


Figure 7.5 Experiences prioritised by the group: first, second and third most important experience in the context of YOD.

The final step in the prioritisation process was to vote on the features of the technology that could support positive experiences in YOD. The group as a whole discussed the various desired attributes and each participant voted by adding a small red sticker to the experience written on the post-it note (Figure 7.6).

Figure 7.6 Morning session: Voting on the most important experiential attributes of a favourite technology.

From this, the **top three experiences** (from a total of 19) emerged. These were **independence, choice and reliability**. The next tier included clarity (of mind), familiarity, security, individuality and confidence (see Figure 7.7).

Figure 7.7 Experiential attributes for technology design in order of priority.

It was advantageous to have my HCI research peers supporting the workshop session. In addition to conducting the voting and prioritisation exercise, they played a valuable role in identifying and recording (from incidental conversations throughout the day) the **experiences and emotions** of most importance to the attendees.

As we (the researchers supporting the workshop) dived deeper into the conversations, high-tech and low-tech items were linked equally to prioritised experiences. As for why the technology was considered to be useful, Sebastian made a statement that resonated: *'We're so focused on computer devices as technology, [but] when you think of it, everything is technology.'*

After this conversation, it was agreed that technology does not necessarily need to be high tech. It just needs to be useful. Certain traditional examples of technology were listed as favoured, such as a pen, oven, car, among others. The team did not need to limit their three choices to digital technologies; however, they were advised to include at least **one** digital technology in their responses.

Additional material related to the prioritisation of the experiences was captured:

- **Television** *'Sometimes when you're home alone you sort of go out of yourself, but I want to see what's happening in the world, so I watch the television'.*
- **Camera** *'I like the fact that it's always with you and easy to use. It captures a lot of memories'* … *'I also use pen and paper more now'* (reliability).
- **Fountain pen** *'the green ink is distinctive … it makes things a lot simpler for me because, if I sign something in green ink, I can always recognise it—supporting individuality and confidence'.*
- **Amazon Alexa** *'We had a look at that Alexa thing the other day, and Jeff goes, "Oh, could we change the voice to Marilyn?" Because he loves Marilyn Monroe'* (choice, familiarity and individuality).
- **Find My Friends app** Stephen calls this application *'Find my wife'*, because he feels he can always find Ann in an emergency and vice versa. Further clarification on this point revealed that he was not inferring a desire to be under surveillance, he saw it as a measure of security.
- **Waze navigation app** Suzie values the Waze navigation app, saying, *'It's the fear and the panic of being late, it's an emotional drive that makes [this app] most important for me—to be independent'.* On further clarification with Suzie, Waze offered her a greater level of confidence on the road; thus, she had a level of independence she would not otherwise enjoy (the YOD group voted both of these as priority experiences).

The attendees made specific comments on the constantly evolving nature of technology:

- *'Apps and software which change slowly over time would be useful.'*
- *'Minimising the amount of updates; having someone come to install the tech and provide a simple how-to would help'.*
- *'Having a "simple" option with only the bare essentials, and a clean and clear layout'.*

The importance for researchers to understand—and empathise with—the experiences of people with YOD is summed up in this group recommendation:

> *'The experiences are of greater importance than the technologies themselves when considering how to create a new technology in context of a life with YOD'.*

- This signalled the end of Session 1 and everyone moved to the café for lunch.

7.6.3 **Lunch break—**preparation for Session 2

Location We held lunch at the university cafeteria in a private dining area, which was chosen because it was easily accessible. Meal orders were easy to select and delivered directly to the table. The function room was small and relatively quiet—free from the usual (visual and auditory) distractions of university campus life.

These environmental features were critical in supporting the needs of those with YOD. As discussed in Section 2.3, people with dementia often experience sensory alterations as well as memory challenges, affecting sight, taste, touch, pressure, sound, smell, hunger and thirst.

Research team debrief The time over lunch gave the HCI team an opportunity to reflect on Session 1 and re-evaluate the goals for Session 2. The researchers sat together at one end of the lunch table, after those with YOD first self-organised, choosing to socialise together at the other end.

During the morning session, there were some serious moments when participants shared stories of living with dementia and their specific experiences. To shift the tone, I needed to consider how to foster a more imaginative and creative environment for the afternoon.

After some impromptu brainstorming, we (HCI peers) decided to reframe how to look at the role of technology; for example, if people with dementia could choose a superpower, what would that be?

The goal of this 'superpower' exercise was to elicit the feeling of endless amounts of choice. It was a deliberate attempt to abandon the deficit model (commonly seen in dementia and other disabilities) and adopt an additive model by focusing on a superpower. The following question was central to our discussions:

If you could have any superpower to counteract your negative experiences with dementia, what would this be?

This question would (in theory) elicit excitement about a technology that could support positive experiences and support the YOD goals of 'live well' with dementia. I checked back with the YOD team about this approach before moving to the workshop after lunch for Session 2. They were excited about this idea and ready to go. See Appendix 5 for an illustrative mind map of overcoming the roadblock.

7.6.4 **Afternoon session**—Future Technologies

The planned activity for the Session 2 was to discuss participants' preferences for a future technology design based on their top three prioritised experiences:

- **independence**
- **choice**
- **reliability**

7.6.4.1 Activity 1: Find your superpower

This activity was based on addressing the participants' prioritised experiences to imagine a future technology that would support YOD. I started the session by providing an example: having X-ray vision to find lost objects around the house. This example resonated with the participants, and a discussion about various useful superpowers ensued. Each person in the YOD team offered a suggestion. The energy in the room was positive, imaginative and spirited.

The superpowers that emerged were:

- **snapping your fingers to bring objects to you**
- **time travel**

- **teleportation**
- **back-up brain**
- **being able to control speakers with mind**
- **X-ray vision.**

The next step was for the YOD team to vote on their favourite superpower, with each person casting two votes. The most valued superpower was **snapping your fingers to bring objects to you**.

The least-valued superpower (with zero votes) was X-ray vision. The remaining four superpowers were: time travel, teleportation, back-up brain and being able to control speakers with mind. These received an even distribution of votes.

7.6.4.2 Activity 2: Design concepts created by people with YOD

We then split randomly into two groups—based on where people were sitting in the room—and discussed the winning superpower 'snapping your fingers to bring objects to you' regarding the top experiences voted on in Session 1—independence, choice and reliability.

This activity aimed to expand then contract the scope of the exercise. That is, to broaden thinking and imaginations to find a superpower—then contract back into a practical exercise, looking at creating a technology that can incorporate the superpower *with* the experiences identified as the most important to a person living with YOD.

The next step was to discuss how each team (Team A and Team B) could turn the superpower and experiences into a concept for a future technology (Group A shown in Figure 7.8).

The two design concepts are presented in the next sectoin.

Figure 7.8 Group A conceptualising a technology based on the superpower and top experiences.

7.7 Findings

Each group worked separately, and the discussions lasted for approximately one hour. During this time, the groups took short refreshment breaks. The final step was for each group to present their concept back to the broader team.

Two design concepts were created and presented back to the broader team:

- intuitive home system
- robotic animal.

7.7.1 Group A: Intuitive home system

Group A decided to design a concept based on the idea of an intuitive home system. They came up with the following key criteria to inform the design:

- Must be a personalised experience between user and technology to gain and maintain trust (i.e. customisable name and voice).

- Can both identify and differentiate similar objects.
- Can be controlled via voice/app.

The group described a system installed in the home that works with sensors. It is pre-programmed to know each object in the home. If the user purchases an item, they can easily program it into the system using an app. The sensors know where each item is located in the house.

The system would work with Google Home, Amazon Echo and similar devices, so the user can control it through voice, using either the home system (e.g. Google Home) or via a smartphone app. For example, if the user walks into the kitchen and cannot find the saucepan, they can ask *'Hey Google, where is the saucepan?'* Google would reply, *'There are two saucepans, are you looking for the large saucepan or the small saucepan?'* The user can then decide which saucepan, notifying the system via voice or through the app. The system would then tell the user where the object is located via audio instructions and/or map with visual directions.

The device must be fully customisable in terms of voice and name to enable the user a **personalised experience**, thus **building trust** between the device and individual, and encouraging use of the system.

7.7.2 Group B: Robotic care animal

Group B decided to build a concept based on the idea of a robotic care animal, which included the following key design criteria:

- Exhibits security-conscious behaviour.
- Able to evolve with the user over time, building trust and usefulness as the condition of dementia further develops.
- Able to be controlled in a variety of ways, which the user can customise.
- Comes in a variety of appearances/sounds.

This group described a robotic care animal, which is designed to locate/fetch objects and run through a checklist to ensure the user has everything they need before leaving the house. For example, the robot can check whether the user has their keys and wallet, locked the door, and that appliances such as the oven have been turned off. In this sense, the technology is designed for security-conscious behaviour. This could be extended to detecting if the user is in a dangerous situation, such as having had a fall, and alerting necessary contacts including the ambulance service and police, as well as close friends/family or other support persons.

The robot would also be able to learn behaviours so that it could evolve and adapt with the user. Such a highly personalised experience would build trust and increase the usefulness of the technology over time. Because the condition of dementia may worsen over time, the robot would be able detect (through AI) these changes and adjust its caring abilities to suit the user.

The robot must also be customisable, so the user can choose its appearance (dog, cat, unicorn, etc.) and how the animal communicates (barking, creating an alerting sound, emitting a flashing light, etc.).

It would be important for the user to access the robot through an app or other methods, depending on the ability and preference of the person with YOD. Some users may be able to use their voice, whereas others may not, which means physical cues would also need to be available.

Ideally, the technology would be a robotic animal in the form of the user's choice, which provides comfort (being soft and huggable), entertainment (by talking to the user, playing music, turning the TV on or playing games) and helpful (helping to locate items in the house; checking the house; and ensuring the user is safe when cooking, showering or before leaving the house, etc.).

To summarise, two design concepts were created based on the winning superpower of 'snapping your fingers to bring objects to you' and the priority experiences of independence, choice and reliability.

Note: The two design concepts are not necessarily about an intuitive home system, or a robotic care animal. Nor is this a team of technology designers. The value in these concepts is in the insights of the people with YOD, into what they need from a technology design and from designers of technology.

7.8 Discussion

This chapter presented on the logistical requirements of organising a Technology Design Workshop and the facilitation of a creative session to conceptualise a future technology item or system for YOD.

As mentioned in the introduction of this chapter, the rationale for conducting this one-day workshop was to develop a series of recommendations for the HCI community (from people with YOD who represent their community) to inform future dementia technology development and research practices.

By this stage of the research program the personal relationships and research collaborations were well established. Trusted bonds had formed, and we were all conversant on current research and design activities underway in YOD. As such, the workshop benefited greatly from a culmination of knowledge, trusted relationships and collective insights, built over many years.

While each step of the workshop was meticulously planned, I did not expect the morning session (which was designed to surface experiences of most importance to the YOD team) taking a serious tone. It was during the introductions, that conversations about the moment of diagnosis surfaced. These are confronting stories and I did not expect such a degree of disclosure in our workshop. In hindsight, those early moments in the day reflected a support group session, which I found challenging to facilitate without training in this area. These conversations set a tone for the morning session, that was difficult to shift.

Taking the time over lunch, to reflect on the morning session was invaluable. It gave me (and my HCI peers) time to brainstorm ways to reframe the activities to help people look creatively into the future and reflect on ways technology could support positive experiences. This approach was successful and the shift in mood and energy was evident from the beginning of session two.

This final study was not necessarily a workshop to design a technology, device or an app as such; it was a workshop to bring people with YOD together to imagine how technology could best fit into their lives in a supportive way.

As mentioned in the literature review, there have been other HCI design workshops and aims to design technologies through in the dementia settings—such as Wallace et al (2013)—where HCI designers were able to engage a person with YOD to bring them into the centre of the design process, and (Cohene et al. 2005) who reminds us of the limited ability to communicate with the primary end-user during the design process. However, in some ways, this workshop is unique.

To the best of my knowledge, this is the first time a group of people with YOD have collaborated on the design of a HCI workshop agenda, each logistical step, and then join the workshop as attendees.

7.9 Contributions

One aim (Aim 3) of the workshop was to develop a series of pragmatic recommendations for the HCI community that is reflective of the needs of the YOD community- and could be used to inform future dementia technology development and research practices. These are as follows:

7.9.1 Recommendations for HCI researchers

- **Be flexible in terms of the lives and abilities of the participants.** Researchers should look for opportunities to be flexible in the design process and implementation of the workshop activities. Take a collaborative approach to the workshop agenda, which will support the varying needs and abilities of the individuals with dementia to engage them in the most comfortable way for them.
- **Be mindful of the varying abilities of a person with YOD.** Ask for their input. Individuals might have particular types of tasks that challenge them unnecessarily, which researchers can avoid with prior and ongoing consultation. As with most workshops (irrespective of dementia), wearing name tags helps to identify people in the session.
- **Creative thinking is key to overcoming issues that may arise.** It was encouraging and engaging for attendees to think outside of the box, using the notion of a superpower.
- **Researchers must understand the people involved.** Spend time getting to know people, even if this means taking a few months to engage and understand the people they are inviting to the workshop.
- **Be mindful and respectful of time.** That is, how a person with dementia perceives and values their time (dementia time). They may not remember past events in the order they happened. They are also aware of their cognitive decline and are explicitly choosing how they best invest their precious time.

7.9.2 Recommendations for HCI technology designers

- **Have a deep understanding of who the technology is being designed for.** This can be achieved by involving the people in the process. PAR is a robust methodological platform that enables a fruitful collaborating and building deeper understandings.
- ***'Technology doesn't have to be digital'***—it just has to be useful.

- **The importance of building trust.** A point of interest emerging from the workshop (and in early interviews from PAR Cycle 1) was the participants' general distrust of technology companies. In terms of the technology itself, its design needs to evoke a sense of trust, providing people with YOD a reason to trust that it is reliable. The YOD team suggested that, if trust is not established, the end-user will feel less inclined to use the technologies and, therefore, the uptake would be negligible.
- **The personalisation of technology is important.** Interestingly, the group suggested that this attribute would aid in building trust for users, such as letting them customise the appearance of the device.
- **General interface/usability should be supportive of YOD.** This includes:
    - Apps and software that change slowly over time.
    - Minimise the number of updates.
    - Have someone come to install the technology and provide simple 'how-to' instructions.
    - Have a 'simple' design option with only the essentials on display, with and a clean and clear layout.

7.10 Limitations

While the success of this workshop can be attributed to the relationships that had formed over time, interpersonal relationship dynamics were also at play with the more dominant personalities in the group. This was not to the degree of a 'power imbalance' as described by Grant et al (2008) that the PAR model aims to offset.

On reflection, these different 'energies' could have been considered earlier, perhaps during planning. One approach would be to assign different tasks to participants to support their personality differences, such as nominating a more vocal participant as a group activity leader.

7.11 Conclusion

Planning the logistics of an HCI Technology Design Workshop in a sensitive setting is complex, requiring an environment that is supportive of the varying abilities and sensory needs of people with dementia.

Activities that foster creativity can be an effective tool to allow participants to emotionally break free of the constraints of dementia. We must remind ourselves, however, that this creative setting requires a great deal of sensitivity and care for all involved.

Regarding the two design concepts and recommendations, while some of the ideas may not appear novel, it is rare to have access to the personal insights of individuals who live with dementia to inform technology design features. It was a privilege to spend precious time with the YOD team—to understand their challenges and support their needs.

This signals the end of the research journey.

Next, I will present the final chapter of this thesis, with contributions from each PAR cycle and study. Chapter 8 provides the final insights from the people living with YOD for future HCI researchers and technology designers to consider, when working in the YOD and technology setting.

HCI researchers (Moncur 2013; Waycott et al. 2015b; Vines et al. 2014) have called for others in HCI to reflect openly about ethical challenges so we can learn from shared experiences. I thus share my contribution on 'reflexive practice' in the dementia setting to support future researchers, who are wishing to work in YOD or a similar 'sensitive HCI' setting.

Chapter 8.

Discussions, Conclusions and Contributions: The Importance of HCI Research and Design in the Context of Younger Onset Dementia

8.1 Introduction

Dementia is a complex, multidisciplinary field of research with stakeholder groups spanning the medical, government, commercial, healthcare and social sectors. All with varying views, approaches, policies and procedures for managing the far-reaching impact of this condition.

Most research efforts to understand dementia focus on addressing the condition's medical and socioeconomic impacts (Brown et al. 2017; Withall 2014), mainly in populations in a later stage of life with more advanced forms of dementia.

As HCI research and design communities continue to focus on pressing societal issues—and look at how technology can support people living with dementia—most of these efforts are in the late onset dementia (LOD) setting. As such, the methods and approaches are tailored for this setting; for example, assigning a proxy to speak and act on behalf of the person with dementia. As presented in chapters 2, 3 and 4, this approach is not suitable for people living with younger onset dementia (YOD) in an earlier stage of life where their needs are quite different.

The literature review revealed two key gaps: (1) methodological (how to approach research in the YOD setting), and (2) theoretical (understanding the lived experience of YOD). This thesis aspires to bridge these two gaps as follows:

1. **Methodological** Identifying (or designing) the most appropriate methodologies, methods and tools to support the varying needs and abilities of people living with YOD, by establishing a collaborative research environment in which relationships can develop and be nurtured. In this setting, the participants would feel supported, valued and empowered throughout the research journey.
2. **Theoretical** Understanding the uniqueness of the YOD experience by developing a long-range plan to spend time in the community and lives of people living with YOD. The aim was to collaborate on ways to document the

YOD experience, and their culture and community, as well as understand the role of technology regarding supporting positive every-day experiences.

Mapping the experiences with (and for) YOD individuals—in addition to understanding their exposure to, and aptitude for, everyday technologies—can inform the design of future technologies. First, however, I needed to find appropriate ways to work directly with YOD individuals in the research and technology design process, within a research framework that provides agency, autonomy and inclusion at each step of the way.

This is because, while not reflected in academic publications, there is a growing global movement by people living with dementia, who rally for greater inclusion in research practices and policy development activities. There is limited guidance, research protocols, methodologies and approaches available, however, for conducting collaborative research in the YOD setting.

8.1.1 Research framework

While the central research question tackled the theoretical gap, the first step was to find an appropriate methodological framework within which to build understandings and insights on the YOD experience.

Inspired by the inclusivity of Green and Kirk (2018), and Grant et al.'s (2008) definition of PAR as a methodology that includes research participants as co-collaborators of change, I selected Participatory Action Research (PAR) with three action research cycles co-designed and implemented over three years:

- **PAR Cycle 1** Exploring new ways to research in YOD
- **PAR Cycle 2** Trialling new HCI research methods for YOD
- **PAR Cycle 3** An ethnographic exploration into YOD and the role of technology to develop deeper more nuanced understandings, building on cycle 2

Theoretically, the aim was to surface first-hand YOD insights to inform technology design practices. Methodologically, the aim was to develop a more sympathetic, inclusive research and technology design approach for research in YOD—because there were still limitations in the PAR model regarding how to address the varying needs and abilities of people with YOD.

The final design of the research framework for YOD, key activities, methods and tools have been informed by people living with YOD and their community.

Each stage of this research has been inspired by previous work conducted in the HCI community.

The key influencers in the design and implementation of this research included McCarthy and Wright (2004), for their work on understanding experiences before designing technology; Brereton et al. (2014), Green and Kirk (2018), and Van Maanen (2011), for highlighting the benefits of conducting the ethnographic fieldwork to understand the YOD setting (culture and networks); and Kemmis et al. (2013), for stressing the importance of the action research model as a framework for collaboration, action and reflection.

I took great inspiration from HCI researchers. In particular, from the following: Wallace et al. (2013) who reminded me to focus on the 'whole' person and design for the person—not the dementia condition; and researchers Moncur (2013), Waycott et al. (2015b) and Vines et al. (2014), who alerted me to participant and researcher vulnerability; and finally, from Kitwood (1997), who reminds us all about the complexity, uniqueness and individuality of the dementia experience.

Finally, the value to the HCI community in combining methodologies, is the greater visibility and deeper insights it offers of people with YOD and the broader community / group to which they belong. This understanding is particularly valuable in HCI research and design endeavours, as HCI researchers McCarthy and Wright (2004) state, we should understand the lived experience before launching into technology design.

8.2 A brief look back on my research journey

While reviewing the literature at the beginning of this research, my immediate concern was how to approach the design of a study with people living with YOD. Early questions I needed to tackle were as follows:

- How do I work directly with people with YOD—who have requested agency and inclusion, and do not wish to be couched as 'vulnerable' in research systems and processes?
- How do I recruit individuals with YOD, given that they are not as visible as their counterparts with LOD?
- What methodologies can I apply to create a supportive environment—one that supports the unique experiences and varying needs of people with YOD?
- How are younger people with dementia currently using technology in their day-to-day lives?

- How can technology better support individuals with YOD (and their families) so they can 'live well' with dementia?
- What would people with YOD like the HCI community to 'know' about them, and their needs and wants from technology?

These early curiosities and explorations distilled into one central research question and three sub-questions, which have been addressed in this thesis.

8.3 Research Questions

RQ. How can HCI develop deeper and more nuanced understandings of the lived experience of people with YOD?

8.3.1 Sub-questions

SQ 1. What methodological framework would facilitate a collaborative and trusting research environment to surface the unique first-hand experiences of people with YOD and their relationship with digital technology?

SQ 2. What research approach, methods and tools would best support the needs and wants of people living with YOD?

SQ 3. How can HCI use these theoretical and methodological insights to inform a fresh approach when designing digital technologies with, and for, people living with YOD?

8.4 Discussion

In this section, I present the aim for each stage of the research followed by the insights, reflections and discussions in the order of implementation. This follows the flow of the PAR activities, insights and learnings as they developed from cycle to cycle.

While I can generalise about some aspects of this research program (e.g., PAR methodological approach, ethnography, probes), each cycle presented several nuanced observations for discussion.

8.4.1 PAR Cycle 1: Exploring new ways to research in YOD

At the outset of my research, I was somewhat aware of the sensitivities that lie ahead and the importance of not rushing to design the research of choose the environmental conditions in which to conduct this research. To guide me in these early deliberations, I reached out to people living with YOD to accompany me on this journey. Dennis Frost and Suzie Dillon were the first recruits to join this research program and provided invaluable guidance in create a setting that would be supportive of the YOD needs.

In this research setting, it was also important to establish the best environmental conditions in which to conduct this research. To guide this design, I looked to people with YOD for guidance.

> **Aim 1:** Design the actions for each cycle of the PAR framework and assess if this is an appropriate (and useful) research model for working in the YOD setting.
>
> **Aim 2:** To recruit people with YOD into this research program.
>
> **Aim 3:** Work with people with YOD to review current research methods used in the dementia setting and **co-design** new methods for YOD.

Cycle 1 presented a wonderful opportunity to co-design methods and approaches that best support the needs and wants of people living with YOD, dispelling preconceived notions about their capacity to contribute.

The one-year exploratory phase aimed to explore the dementia environment first, in order to understand the methodological gaps identified in the literature review for research into YOD, and the lack of research appropriate methods to for YOD. In hindsight, it was helpful to split the exploratory phase into two parts:

- Part 1: One-year exploration of the environment
- Part 2: Review and co-design of methods for YOD

8.4.1.1 Learnings from Part 1: Understanding the dementia environment

The Cycle 1 activities revealed that people with YOD want to participate actively in research, so they can shape the narrative of their own experiences. It is a legal obligation—as recognised by the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations 2010)—to include people with dementia in research or other similar activities. However, this option is rarely provided to people living with dementia. In the early fieldwork, I found that people with YOD were less visible than their older counterparts. In addition, their recruitment often depended on the dementia organisation's 'gatekeepers' which, in turn, depended on ethics approval. While I understand and respect the rigorous ethics application process in the dementia setting, the key challenge was dementia being classified as a homogenous group—this triggered many unnecessary procedural steps.

In response to these recruitment challenges, I contacted dementia organisations and attended dementia conferences to identify and recruit individuals with YOD into the research. Because dementia is such a complex and sensitive setting, it was important to take the time to understand the environment in which the research was being designed for, and to identify individuals with whom to collaborate with on the design and implementation of research activities.

8.4.1.2 Learnings from Part 2: Co-design methods workshop

In Cycle 1, the value of current methods in dementia research was closely examined, and the advice and insight of Dennis and Suzie led to developing a new more flexible approach. The half-day Methods Workshop aimed to co-design and trial new tools and a fresh approach, designed specifically for the needs of people with YOD.

I drew encouragement and instruction from previous technology design workshops (see Section 4.5.1). Overall, these examples outline the foundational work in technology design workshops in the dementia setting. In two examples—the Day Clock (2016) and Ticket to Talk app (2018)—the technology design did not directly involve people with dementia in the design process. In the third example—the Touch Screen Ensemble Music model (2013)—people with dementia were inlcuded; however, this work focused on the needs of people living with LOD, whose wants and needs are vastly different to those of people with YOD.

One of the current methods used in dementia research is to engage a proxy to speak on behalf of the participant, as well as complete research activities for them, which has implications for the YOD experience.

In the field, I found that people with YOD (and people in early-stage dementia) can communicate their own experiences; they do not need another person to communicate their experiences for them. The YOD individuals who took part in this research expressed that they want agency—to be seen as a ‘whole person’ who is more than the dementia.

In the Methods Workshop, Dennis Frost, Suzie Dillon and I determined how to approach the study design for the empirical research into YOD, after I first piloted the interview questions and probes with them. Providing flexibility and choice were paramount in supporting the varying abilities of people with YOD.

Ad mentioned earlier in this thesis (section 3.3), this resonated with the recommendations from Hammersley and Atkinson (1993) albeit the following points were in the context of ethnographic research principles:

- *Data should be collected using several different techniques, with an emphasis on observation.*
- *Methods of data collection need to be flexible and unstructured, with a focus on what people say and do.*

Dennis and Suzie also provided the final guidance on how to implement the study activities; this was carried into cycles 2 and 3 and the Technology Design Workshop.

8.4.2 PAR Cycle 2: Trialling new HCI research methods for YOD

Cycle 2 was designed further test the methods and approach to YOD research in the first empirical study for this research program.

In Cycle 2 it was important to finalise the recruitment, and further test the methods and approach developed in the previous PAR cycle by Dennis and Suzie.

> **Aim 1:** To test and validate the customisable tools and flexible approach designed in the methods workshop (Cycle 1) to support the varying abilities of individuals with YOD.
>
> **Aim 2:** To collect preliminary data and insights on the lived experience of YOD and technology preferences. Before heading into a two-year ethnographic fieldwork to explore these experiences in more depth during Cycle 3.

Study 1 revealed that, by co-designing and offering a flexible approach (designed in Cycle 1), in which participants could self-select their preferred communication mode(s), the varying needs of individuals with YOD were greatly supported.

This co-informed design considered the individuality of people's dementia experience and neurological considerations, as well as the probe design principles of openness/ boundedness (*how clear or vague a participant finds the question being asked by the probe*), materiality, and pace and challenge.

The YOD team made insightful contributions, which were evident in all phases of the project. They brought rich perspectives from several dementia organisations in which they were involved; for example, in which they were developing policies on palliative care, end-of-life planning, and decision-making rights.

By treating each participant as a research partner, we could share relevant findings and thoughts about the research with each other. This sharing ensured that the individuals with dementia were not only kept informed about, but had the opportunity to clarify and add to, the findings at each phase of the research program.

The results from Study 1 further revealed that, when offered, each person chose a different way to communicate; for example, using texts, emails, voice recordings and blogs. The study also highlighted the power of choice and flexibility to support agency, motivation and engagement.

8.4.3 PAR Cycle 3: An ethnographic exploration into YOD and the role of technology

The overarching aim of this ethnographic fieldwork study was to better understand the unique life circumstances of people with YOD by spending time in the field (two years) to explore the culture (beliefs, rituals, interactions) of the YOD group, as they live or coexist, in their community and social networks. This allowed access to both spoken and unspoken communications and build richer, more nuanced insights into the YOD experience and the role of technology.

The inclusion of an ethnographic fieldwork in this research plan aimed to increase the visibility of the people with YOD, as they live in their community. By taking the time to observe everyday life events, circumstances and experiences, I uncovered insights and stories that may not otherwise surface or be clearly articulated in interviews, surveys or single workshops.

Spending an extended period (two years) in the YOD community provided an opportunity to discover those aspects that some (the participants themselves and the broader community) may take as a 'given'.

During the fieldwork, I used both PAR and ethnography to support this collaborative journey. Without this extended exploration period, I would not have gained first-hand, deep insights into the experiences of YOD, nor would I have developed the context and perspective that underpin their real-world experiences, which is critical to the design of technology for individuals with YOD.

These deeper perspectives and context were gained from immersing myself in the YOD community: attending a variety of YOD social events (fundraisers), going on road-trips, and having many home visits. This enabled our conversations to have continuity over several years. These insights emerged from a foundation of trust, respect and the shared motivation to contribute.

8.4.3.1 Taking guidance from HCI researchers who paved the way

The relationships formed in this setting were strong, yet complex. The work of Wallace et al. (2013) alerted me to the fact that couples may need to remain closely connected throughout the research activities, because 'their lives and experiences of dementia were so tightly intertwined'. This was an important insight from these more experienced HCI researchers in the dementia setting. I thus needed to move sensitively through this space. Introducing an activity for the partners and/or carers was of great benefit in providing additional context to the YOD group experience.

Brereton et al. (2014) reminded me that, in many settings, it can be difficult for researchers to access the "privileged ethnographer position". Adding the ethnographic fieldwork to this research helped to build relationships and understand what was important to each person, which created reciprocity, as seen in the biographies in sections 6.5–6.10. The exchange of stories and small gifts and the sharing of meals were the most privileged and insightful moments of my research.

As the research progressed, each person self-identified as being a part of this PhD research group. Partly, this was due to the growing demand for the small number of people with YOD who rally for their peers to participate in research and policy development programs; and partly, to this research's novel topic of HCI, YOD and technology design. I also became easily identifiable as the HCI researcher to the group, given the narrow geography and novel area of this research.

8.4.3.2 Notes for those future researchers

It would be difficult for any researcher to fully understand what living with dementia is like at an earlier stage of age could be like. What we can ascertain is that their life circumstances, and lived experiences, are vastly different from that of their older counterparts—they are proficient and enthusiastic users of digital technologies, and thus require focus from the HCI research and design community.

It was suggested to me early in this research (by more experienced HCI researchers), that engaging as a researcher in the dementia setting, requires a great deal of tenacity, empathy and sensitivity, and a high level of insight and personal awareness. I am not sure I really understood this until now.

Theoretically, my hope is that by immersing myself in an ethnographic fieldwork and reporting back using biographies, and by sharing my personal reflections in Section 8.6, I can increase visibility of the YOD community and encourage others from HCI to join me in this rewarding research setting.

Next, I discuss the final study in this program—the Technology Design Workshop. By this stage of the research program, trusted bonds had formed, and we were all conversant on current research and design activities underway in YOD. The workshop thus benefited greatly from a culmination of knowledge, and collective insights, built over many years during the longitudinal fieldwork.

8.4.4 Technology Design Workshop: Study 3

The aim of conducing a one-day workshop was to bring the people with YOD and their supporters together, along with the HCI research team, to imagine how technology could best be designed to fit into their lives in a supportive way.

> **Aim 1** Present back to the YOD team what I had learned about the dementia experience when diagnosed in an earlier stage of life. This was also an opportunity to validate the information gathered on their relationship with digital technology. In other words, to check whether the researcher analysis and insights were aligned and an authentic representation of people living with YOD.
>
> **Aim 2** Create a workshop setting (logistically) for people with YOD and their partners to imagine what possibilities technology would have for them in the future.
>
> **Aim 3** Produce a list of recommendations for conducting future workshops in YOD or similar sensitive HCI settings.

This PhD research program concluded with a Technology Design Workshop (presented in chapter 7). The aim of this final event was to produce a series of recommendations from those with YOD, for HCI researchers and designers who wish to work in this setting in the future, or other similar settings.

Why conduct a technology design workshop? As a reminder, the relationship between YOD and technology is important to understand, because the next generation of people with LOD will have aged alongside the evolution of digital technology. Thus, they will likely have a greater aptitude for using new technology than most individuals who are currently living with LOD.

Allen (2016) points out that it is also important to ensure that individuals with dementia are able to use new technologies, by identifying and addressing the barriers to technology use. In the future, this could lead to a range of accessible and usable technologies (e.g. everyday ICT, assistive technologies, telemedicine) to support independence and agency (Allen 2016).

Related research Looking through the related research, there were several workshop activities situated in the dementia setting that **designed and assessed technologies.**

The examples of technology co-desgin workshops presented in Section 4.5 outline valuable foundational work. However, in the two examples—the Day Clock (2016) and Ticket to Talk app (2018)—the technology design did not involve people with dementia directly in the design process. In the third example—the Touch Screen Ensemble Music model (2013)—people with dementia were inlcuded; however, this scope of this project did not inlcude working with people living with YOD.

These workshop activities mostly focused on technologies in the more advanced stages of dementia—and were either conducted with a proxy, only the final steps included people with dementia, and some work did not include people with dementia. However, each project was critical in helping me understand the overall methodological structure, the challenges and the valuable contributions that these research teams made,

Extending the work of other's in HCI—why this workshop is different

This final study was not simply a workshop to design a technology, device or an app; the workshop aimed to bring people with YOD together to imagine how technology could best fit into their lives in a supportive way.

On reflection, while each step of the workshop was meticulously organised, not everything on the day went to plan. Unexpectedly, the morning session took a sombre tone very early, during the introductions. I had not provided a 'structure' for each introduction and assumed it would just be quick introductions with names, and goals for the session. While it is essential to stay in the moment, when people are sharing deeply personal and somewhat traumatic experiences like sharing the moment of the YOD diagnosis; this workshop was not the setting to support these conversations. That would be more reflective of conversations that would emerge in a Support Group setting.

Taking the time over lunch, to reflect on the morning session was invaluable. It gave me (and my HCI peers) time to brainstorm ways to reframe the activities—to help people look creatively into the future and reflect on ways technology could support positive experiences. The use of the Superpower question (see Section 7.6.3) turned the energy and mood around. This approach was successful and shifted the mood and energy in a more positive direction—and was evident from the beginning of Session 2.

As a reminder for the reader, the goal of this 'superpower' exercise was to elicit the feeling of endless amounts of choice. It was a well-considered attempt to abandon the deficit model (commonly seen in dementia and other disabilities) and adopt an additive model by focusing on a superpower. The following question was central to our discussions for the afternoon:

> *If you could have any superpower to counteract your negative experiences with dementia, what would this be*?

To the best of my knowledge, this is the first time a group of people with YOD have collaborated on the design of a HCI workshop agenda, each logistical step, and then be attendees at the workshop.

The value in these design 'concepts' to the HCI community, is in the accessing of first-hand insights of the people with YOD through these narratives, into what they need from a technology design and from designers of technology.

8.5 General Insights: ethics, stigma and human rights

8.5.1 Ethics

Before applying for ethics approval, I realised that dementia was a complex area to navigate, and that ethics would be a critical element of the research. This became even more evident during the early fieldwork and from what I was hearing from the YOD community about their challenges with stigma and their lack of visibility as people.

In this research, navigating through the ethics application process was prolonged. In part, this was because I had to demonstrate in detail how I planned to recruit participants. The constraints were borne from how dementia is generally understood and classified in these systems and processes. The ethical challenge has been characterised by the more aged and advanced person with dementia. While the literature recognises this challenge, it still relates to the aged dementia setting, in which people are described as having limited mental capacity, memory loss and communication difficulties (Hedge & Ellajosyula 2018). Even when this is addressed by assigning a proxy, it is important to recognise that this proxy may override the person's view. A person living with dementia does not *automatically* lack the capacity to consent for themselves. It may be possible for them to identify their wishes, even for those people in the later stages of the disease. When turning to the literature for guidance on how to approach ethics, I could not find information on working directly with the YOD group, who have asked to represent themselves in research.

Furthermore, in the ethics application, the automatic classification of 'vulnerable' means that researchers are required to provide a great deal more detailed information about their proposed research. This impacted recruitment, significantly slowing down the overall process and greatly impacting my efforts to liaise with gatekeepers (who act as a go-between for the recruiter and potential participants), leading to delays of up to six months. One approach I found to be of great benefit was reaching out to the ethics committee members for a one-on-one session to discuss the nuances of my research. This began a collaboration between me as a researcher and the ethics committee representative, who provided me with a level of support to navigate through this complex process.

8.5.2 Stigma

On so many levels, the stigma associated with a diagnosis of dementia is profound and impactful. In this research, for example, the impact of stigma was amplified due to living with dementia at a time of life in which you are still engaged in life, and have a high level of independence and autonomy. Dementia is not an expected health outcome.

At the global level, the stigma associated with dementia is being addressed. The first international survey to assess dementia-related stigma was implemented in 2012. In this report, titled *Overcoming the stigma of dementia*, ADI explored the nature of dementia-related stigma. The survey included 2,500 people living with dementia and their carers, in a small number of countries globally. The results of this report helped to define 'dementia-related stigma' and offered recommendations to address this stigma, forming a baseline understanding of attitudes to dementia.

This survey on global attitudes was then extended to better understand the role played by attitudes and set a baseline against which to measure future changes. The results on global attitudes to dementia and stigma were published in the *World Alzheimer Report 2019* (Alzheimer's Disease International 2019).

From the 2019 ADI report, it is evident that the understanding of and attitudes to dementia, and how stigma directly impacts people with dementia, are still maturing. In this research, there were moments when I saw the impact of stigma on the person with YOD.

Generally speaking, individuals with dementia do not want to be known as 'sufferers' or seen as a 'burden'. They fiercely reject the word 'demented', given its negative connotations. They are seeking opportunities to '*live well with dementia, not just die from dementia*' (Garnett 2017).

ADI's current and extensive inquiry into attitudes to dementia cautions researchers about the deeper implications of overlooking the stigma associated with dementia and, potentially, undermining the quality of the interactions and research outcomes.

8.5.3 Human rights

As mentioned earlier in this thesis (see chapters 1 and 2), people living with YOD have expressed that they want to be included in all work that concerns their future; they are keen for all researchers to adopt the philosophy of '*Nothing about us, without us*' (Alzheimer's Disease International 2017). To better understand this position, before I launched into the empirical research, I made appointments to follow up with keynote speakers (living with dementia) who had presented at the 2017 Alzheimer's Disease International Conference. I wanted to speak with them further on this issue of 'exclusion' and better understand their concerns and goals. These conversations reinforced the aspirations of inclusion and independence in this research program.

Dennis Frost from the YOD team reminds us the dementia has a *'beginning, middle and end'*. Not all people living with dementia are at the end stage and people living with YOD want to be seen as more than just the condition of dementia. They want to be seen as whole people—who they were before a diagnosis. HCI researchers have an opportunity to support these inclusion goals, particularly because interest in the area of dementia and the role of digital technology is growing (Alzheimer Australia 2017).

These five insights led to a more nuanced understanding:

1. The importance of collaboration and building trust.
2. How to overcome ethics and recruitment challenges.

3. How to invite collaboration in all activities—on the participants' terms.
4. How to co-develop design methodologies in sensitive settings.
5. How to take a respectful and inclusive approach by providing flexibility and choice about how an individual may respond, in a way that is most supportive of their abilities.

In the next section, I reflect on my journey as an HCI researcher, which I trust will support others researching in sensitive settings such as dementia.

8.6 Personal reflections—working in sensitive HCI

In the early stages of this research, I questioned whether I could stay immersed in the dementia setting (given my family experiences with dementia), and still maintain my own emotional wellbeing. On reflection, my pursuit to 'make sense' of dementia had a profoundly positive and healing impact on my life.

I was particularly struck early in my work by the insights from Vines et al. (2013), who addressed the notion of the 'researcher vulnerability'. At this point, I was alerted to the sensitivities of working in the dementia setting, over time.

Vines et al. (2013) raised concerns about the *vulnerability of the researcher* in sensitive settings:

> *one theme was the feeling that HCI training and education poorly prepares or sensitizes researchers to respond to the needs of vulnerable participants.*

Moncur (2013) and Waycott et al. (2015b) also raised these concerns. This encouraged me to pay more attention and record how I was experiencing being deeply immersed in dementia research activities, over a prolonged period. This level of awareness of my own mental health was invaluable.

8.6.1 The highs, lows and everything in between

Over the course of this research, there were many surprises, heightened emotions, unexpected encounters, deep learnings and moments of sadness. All of these challenged my deeply held beliefs about dementia. My beliefs had formed over the years by literature, case studies and stories—of other families, communities and cultures living with dementia. These stories have often been driven by stigma and fear of the dementia condition—seeing it as a deficit.

It was helpful knowing that there were ways to gain deep insights into the subjective world of dementia, such as described in *The Experience of Dementia* (Kitwood 1997). In this paper, Kitwood suggests that we look at the person as a 'whole', more than the diagnosis of dementia. This was an enlightening moment for me. And having a way to engage in a deeply personal way with the people who joined me on this research helped me on a number of levels.

Inherent tensions arise when conducting research in the dementia setting. For me, I needed to work through several notable challenges. Although these challenges were not the focus of this research project, I raise them here to provide context, in the hope that they will support future researchers and designers—as advised by more experienced HCI researchers who paved the way for me:

Confidentiality Over time, once trust has been established (between researchers and participants), you access very personal information—including secrets—and sensitive conversations. This requires a level of judgement about what to report. Here, the support of an experienced research supervisor was invaluable.

Boundaries At times, you need to balance the responsibility of taking a human rights approach to research—through inclusion and close collaboration—while maintaining a level of objectivity. This required establishing personal boundaries.

Exercising judgement I often needed to balance the level of support based on the varying abilities of a person with YOD to avoid imposing on their independence or sense of self by jumping in to help complete tasks (or sentences).

Empathy When working with people experiencing dementia, empathy is not always straightforward. I found I needed to resist making assumptions about some behaviours or stories, based on how I make sense of the world. The following advice from a friend—with background in psychiatry and experience in dementia care—served me well:

> *When you are hearing a story that you have trouble understanding, or is outside your frame of reference, accept it without judgement—it may make sense over time.*

With this advice, I could open myself up to new ways of listening, thinking and understanding how people with dementia engage with the world; as such, I developed deeper insights into the experience of dementia.

Sadness Over the five years of this research, sad stories, or stories that triggered sadness, would come and go. At times, these emotions were challenging to manage—particularly if I had unresolved feelings and memories of a family member with dementia. I found this aspect (sadness) quite impactful and somewhat unexpected. Over time, I developed personal strategies to 'lift' myself out of melancholic moods that lasted too long.

I maintained my emotional 'wellbeing' in this sensitive HCI setting by practising mindfulness and gratitude, and with regular physical exercise (running). I also gained immense joy from my pet dog (Timmy), who spent many hours by my side during the last two years of this research.

While, at the start of this research, I felt compelled to better understand dementia, I was also somewhat anxious about how I would manage the sensitive conversations and stories I would be reporting. On reflection, my personal investment was rewarding in ways I could not have imagined—including being able to resolve my pre-existing fears through a deeper level of empathy and sensitivity to dementia.

Towards the end of this research journey, I realised that there was true value in closing the conventional research gap (of observer and participant), immersing myself in a collaborative research journey with people living with dementia. I did not anticipate that the people I met through my research would become research partners—and friends.

8.6.2 I wish I knew then what I know now

In hindsight, this is what 'I wish I knew' before embarking on this research:

- 'Dementia is a deeply personal experience, affecting an individual in many ways' (Kitwood 1997).
- As researchers, we need to consider the 'whole' person—who is more than the disease. Some people may still be coming to terms with dementia; therefore, we need to proceed with care and empathy.
- It is important to take time to understand your unconscious biases with regards to the setting in which you are going to spend time.
- Meet the individual where they are on their journey, not where others (e.g. literature, families, communities, advocacy groups) tell you they should be. Be open to accepting their view of the world.
- Be comfortable with ambiguity—the next step may not always be obvious. Follow your instincts over the course of the research.
- It is okay to be researching in an organic fashion, guided by the grounded principles of ethical research. I raise this point because my background in medical science was (at times) a barrier to understanding the deeply personal aspects of an ethnographic fieldwork.

8.7 Benefits and opportunities for HCI

The YOD team suggested that, for the most part of their lives, future generations of people living with dementia will be highly exposed to digital technology. They will be more skilled at using a wider range of devices, which deliver music, pictures, social networking experiences, life-logging, smart home applications, AI and robotics.

In addition, the YOD team suggested that the uptake of these future technologies may be greater if individuals with dementia can influence design features and improve usability and learnability to support their level of cognitive function.

There is an opportunity for HCI and other research communities to collaborate more closely with the YOD community—particularly, in the development of processes and design of technology—to support their social and emotional needs of autonomy, agency and overall sense of self.

To achieve this, the YOD team advise HCI designers to work with them, being willing to understand their needs and translate them into the outcomes. Here are a few of their recommendations to HCI designers on the usability of technology:

- *'We can still learn, but learning is not as easy as it used to be. It requires a lot of repetition. We find it really difficult when faced with jargon. Keep it simple.'*
- *'The tool should be useful to its full potential with minimal training or familiarity with tech tools as a prerequisite. If something new is built on a familiar framework or way of doing things, not only will it be easier to adapt to, but the chances of being able to continually engage with it will also increase.'*
- *'Directions need to be short, simple and uncomplicated'* and *'Multi-step directions may not be remembered in the order they are given. Left/right, up/down, north/south can all be frequently reversed.'*
- *'It may be of great value if you can "componentize" your prototypes so each aspect can be tested by people living with dementia—both as a component and as a whole.'*

8.8 Limitations

This research presents rich insights into people with YOD and their use of technology. It also offers different ways to work directly with individuals with YOD. However, there are limitations to share, which may support future research in this area.

Diversity The individuals in this research (including myself) were from similar cultural and ethnic backgrounds, and age group. All participants with YOD were well-educated professionals with medium to high socioeconomic status, who were motivated to advocate for others living with YOD. On reflection, this may be why they were more 'visible', which thus allowed me to connect and recruit them into this research. Their backgrounds may also suggest why they had such a strong sense of agency and why they were volunteering in public positions to advocate for other people with YOD. Furthermore, their particular careers may have made them more visible for me to recruit.

PAR model While the action research model worked well in this YOD setting, with each cycle informing the next, I did experience some challenges. When working through the interconnected PAR cycles, for example, it can be difficult to identify where to stop and move to the next phase of investigations.

Ethnography I also faced ethical challenges through being immersed in the many different social settings—and lives—of the participants over many years. While there is value in the deep trust and strong relationships that ethnography fosters, it does become challenging (at times) to determine which elements of the interactions to report. Often, I needed to disconnect as a researcher, and assume the role of 'guest' at some events.

8.9 Contributions

This research contends that we, as HCI researchers, should pay more attention to the design of our research programs and include some discussion (or even negotiations) with participants before moving to the design of probes or other methods of inquiry.

The contributions that this research makes, undertaken with and for people living with YOD, goes beyond current HCI research in the context of dementia and role of technology.

The findings of the two-year fieldwork were reported in a biographical and pictorial format to strengthen the identity of each person with YOD. The aim was to increase the visibility of the YOD group—their culture and community networks who worked on this research, and to strengthen the insight into the dementia experience (a key theoretical gap).

This style of biographical reporting was created in the spirit of ethnographic writing principles, which portray the experience of the individual and also illuminate their everyday environment and culture. For this research, I selected the confessional and impressionist writing styles to make the life experiences visible and facilitate the reporting of my reflections as a researcher.

The experiential insights presented in this thesis are offered as a resource to inspire other researchers to take the time to explore the needs of the individuals at the heart of their project.

Through the course of this research, 'we' (the YOD team) make several contributions to the HCI community. These include productive approaches to research and design, which are sensitive, respectful and empowering to the individuals who join our HCI community on these important (and often long) research journeys.

8.9.1 In summary, this thesis:

- Offers the first description of a collaborative approach for how HCI researchers and ethnographic practitioners can conduct research, respectfully, sensitively and productively in the YOD setting.
- Adds to the understanding of how to use probes productively in HCI, providing a working example of probes co-designed with YOD participants, with participants free to select and personalise the probes used.
- Provides practical guidance on how researchers can successfully recruit and collaborate with YOD individuals as co-researchers.
- Describes a co-directed inquiry into the lived experiences of YOD. As such, it builds on the knowledge of the lived YOD experience, and the role technology plays in the lives of people with YOD.
- Contributes to the small but growing number of cases of PAR in HCI. This research provides the first account of how PAR can be used in YOD.
- Offers a series of methodological insights and practical recommendations for engaging with the YOD community in HCI research and design.

By working through the challenges of conducting HCI research in the YOD setting, I became more aware of and attuned to other areas where the HCI community could play a significant role. Adopting a bespoke approach is a relatively unexplored idea in HCI, especially for researchers who design digital technologies in dementia settings.

This bespoke approach goes beyond the current corpus of research methodologies that the HCI community use when researching and designing in dementia settings. Until now, the literature has focused primarily on the needs of older people. The approach used in this thesis could be applied in similar sensitive settings which comprise vulnerable and/or marginalised groups, communities or people.

In the next section, 'we' offer the following considerations for people wishing to work in this particular sensitive HCI area of research (YOD).

8.10 Future directions—suggestions from the YOD team

8.10.1 Managing recruitment challenges

There are fewer people with YOD than LOD, which creates a higher demand for their input into research programs. This therefore raises the need to better coordinate their time and input into research.

Currently, there is no connected, systematic, and inclusive way (in Australia) for people with dementia to express their interest in participating in research. For researchers, recruiting participants for dementia-related studies is time-consuming. These delays in finding the right people can result in studies taking longer to deliver outcomes, often requiring funding extensions. Delays are also hugely impactful and imposing on the precious time of those living with YOD- who have expressed a desire to participate.

One suggestion from the YOD team was a registration step (for the researcher to complete) for all dementia-related research. This is to address the 'competition for resources' as their time is precious and the same group are often invited into projects. They also suggested that this registration could be a step in the Ethics Application process. This would ensure researchers would be aware of a registration opportunity (early in their research).

Note: In the final months of my research, I became aware of an initiative to encourage researchers to register their research in dementia:

StepUp for Dementia Research[1] This is an inclusive Australian research hub, which gives everyone aged 18 and over the opportunity to participate in research. It is a research participation and engagement service—a 'one-stop shop'—that connects individuals, both with and without dementia, with researchers conducting studies into dementia prevention, diagnosis, treatment, care and cure. The philosophy behind the service is to make it easier for the brightest minds in research to connect with people, placing the value and potential of people with dementia at the centre of the solution. The

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[1] StepUp for Dementia Research (Australia) is modelled on a UK system.

service is free for researchers to use, with simple and flexible registration as well as opt-out options.

8.10.2 Focusing on the person, not the disease

The neurological and physiological aspects of dementia (degree of cognitive decline) and how this impacted the use of technology, over time, was out of scope for this research. As mentioned earlier in this thesis, living with dementia is a unique and individual experience. As such, this thesis is primarily concerned with the lived and felt experience of YOD, with a view of finding better ways for HCI researchers and designers to collaborate with people living with YOD, in future technology design.

While not in focus, of note, I did not witness a decline in cognitive abilities or any measurable change in the engagement with digital technologies over the course of this research.

This, however, does not mean that the abilities of the people on this research with YOD were not steadily diminishing. Perhaps in future work, surrogate measures could be integrated in the study design to capture physiological aspect of dementia. This could be mapped against technology aptitude, learning agility, and retained, enhanced, or diminishing ability in context of technology use.

Of note, I did observe many life enhancements for the people with YOD, particularly as their level of 'acceptance' increased; many found new joys in life. For some this was turning to nature and spirituality, for others it was in the new friendships and a greater sense of purpose in life.

8.10.3 Generalisability

HCI researchers have diverse backgrounds, and the formation of these multidisciplinary teams can help to tackle the complexity in HCI research and development by co-designing and working with people with dementia.

Many of the insights and learnings from this research journey can be extended to other 'sensitive HCI' settings. This research is based on an underlying principle of understanding the human experience at hand and addressing power imbalances through inclusive and immersive research designs—whether this imbalance is due to social, medical, neurological or socioeconomic factors.

8.10.4 Other sensitive HCI settings for future research

As I was nearing the completion of this research, and while writing this thesis, a few ideas surfaced that may be of interest for future HCI researchers. These are underexplored areas of research, for which digital technologies would provide tremendous support:

- Explore the rarer childhood dementia and role of technology.
- Understand the impact of dementia on women: safety, stigma and prevailing economic hardship.
- Study the experience of children becoming a carer for a parent with dementia and ways for technology to support this group.

8.11 To close the thesis

This research was an extraordinary privilege to facilitate. I am pleased to report that my PhD journey ends with cherished friends (some of whom happen to live with dementia).

I close this thesis with deep gratitude for the kindness, generous support and valuable contributions made to the HCI community from the YOD team. Thank you, Dennis Frost, Suzie Dillon, Phil Hazell, Stephen Grady, Ann Grady, Jeff Thurlow, and Sebastian Caruso.

I believe that this is the first immersive and inclusive research effort specifically designed with, and for, people living with YOD. To date, this highly collaborative, participant-centric approach to designing and using probes in an inquiry—and conducting a technology design workshop—has not been explicitly discussed in HCI publications.

In addition to producing rich and nuanced theoretical insights into the lived experience of YOD, this research has identified fresh ways for HCI to think about, and design, technology that supports positive experiences in YOD.

My job was to work out the following: *How do I thoughtfully and respectfully approach this work? How do I recruit? How do I conduct YOD workshops? How do I understand which digital technologies would work best with this younger group?*

In terms of *how much do we need to know as HCI researchers about the lived everyday experiences of YOD to design suitable technologies?* On reflection, a great deal more than we do now.

The hope is that the YOD stories, insights and recommendations to the HCI community presented in this thesis, will inspire and shape future technology design for YOD as well as other sensitive settings.

Appendices

Appendix 1. Pliot Study: Letter of Support from local respite centre

THE ELLA CENTRE
SUPPORTING THE COMMUNITY

14th August 2017

To whom it may concern,

I met with Jeanette Bell earlier this year and have discussed the research goals of her PhD.

I understand that this will be conducting research that will include working directly with and recruiting people with younger onset dementia (YOD). I understand the goal of the research is to conduct a study to gain an understanding of the first-hand experiences of living with YOD and the role of technology in supporting positive experiences.

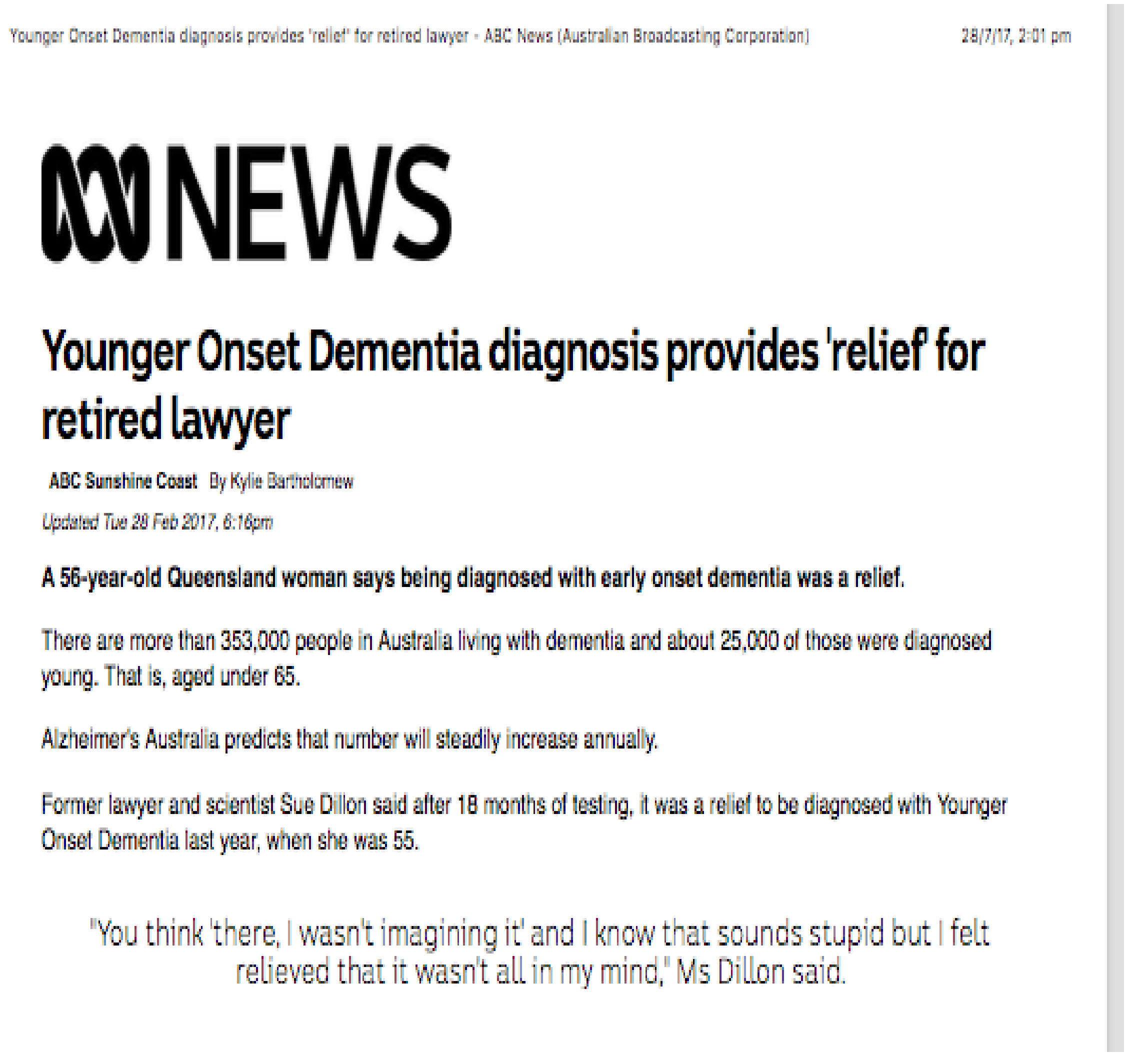
In my role at The Ella Centre we support people who live with YOD. The services and support available are limited and I believe this research will only benefit future generations.

I am supportive of this research and will work closely with Jeanette to identify suitable study participants based on an ethical and considered approach to research.

Kind regards,
Kathryn Cooper

Appendix 2. Sue Dillon (Suzie's ABC News story)

<https://www.abc.net.au/news/2017-02-28/younger-onset-dementia-diagnosis-provides-relief/8310356>



Younger Onset Dementia diagnosis provides 'relief' for retired lawyer - ABC News (Australian Broadcasting Corporation) 28/7/17, 2:01 pm

ABC NEWS

Younger Onset Dementia diagnosis provides 'relief' for retired lawyer

ABC Sunshine Coast By Kylie Bartholomew

Updated Tue 28 Feb 2017, 6:18pm

A 56-year-old Queensland woman says being diagnosed with early onset dementia was a relief.

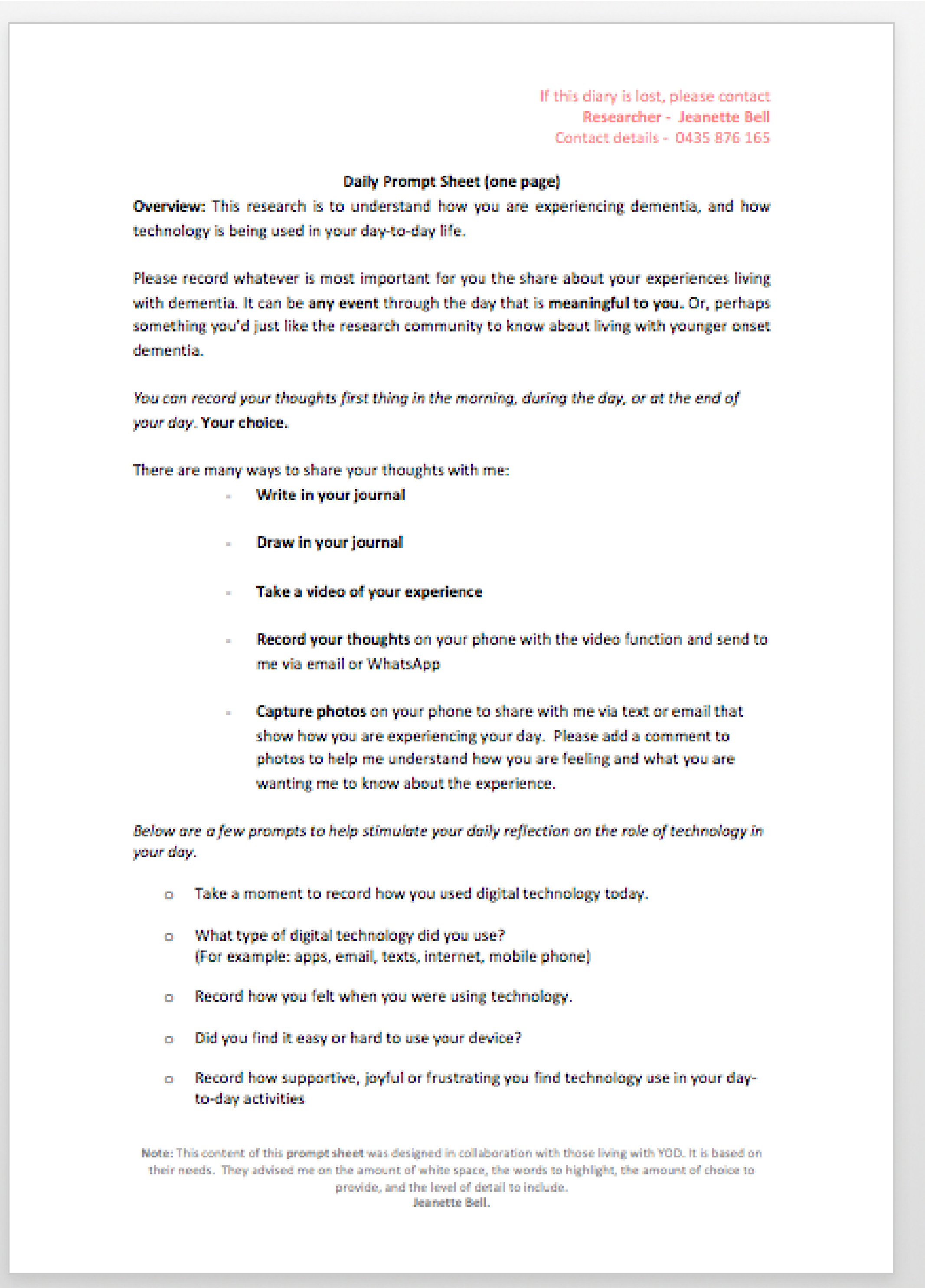
There are more than 353,000 people in Australia living with dementia and about 25,000 of those were diagnosed young. That is, aged under 65.

Alzheimer's Australia predicts that number will steadily increase annually.

Former lawyer and scientist Sue Dillon said after 18 months of testing, it was a relief to be diagnosed with Younger Onset Dementia last year, when she was 55.

> "You think 'there, I wasn't imagining it' and I know that sounds stupid but I felt relieved that it wasn't all in my mind," Ms Dillon said.

Appendix 3. Co-designed guidelines for completing probes, addressing stigma and providing flexibility



If this diary is lost, please contact
Researcher - Jeanette Bell
Contact details - 0435 876 165

Daily Prompt Sheet (one page)

Overview: This research is to understand how you are experiencing dementia, and how technology is being used in your day-to-day life.

Please record whatever is most important for you the share about your experiences living with dementia. It can be **any event** through the day that is **meaningful to you.** Or, perhaps something you'd just like the research community to know about living with younger onset dementia.

You can record your thoughts first thing in the morning, during the day, or at the end of your day. **Your choice.**

There are many ways to share your thoughts with me:

- **Write in your journal**
- **Draw in your journal**
- **Take a video of your experience**
- **Record your thoughts** on your phone with the video function and send to me via email or WhatsApp
- **Capture photos** on your phone to share with me via text or email that show how you are experiencing your day. Please add a comment to photos to help me understand how you are feeling and what you are wanting me to know about the experience.

Below are a few prompts to help stimulate your daily reflection on the role of technology in your day.

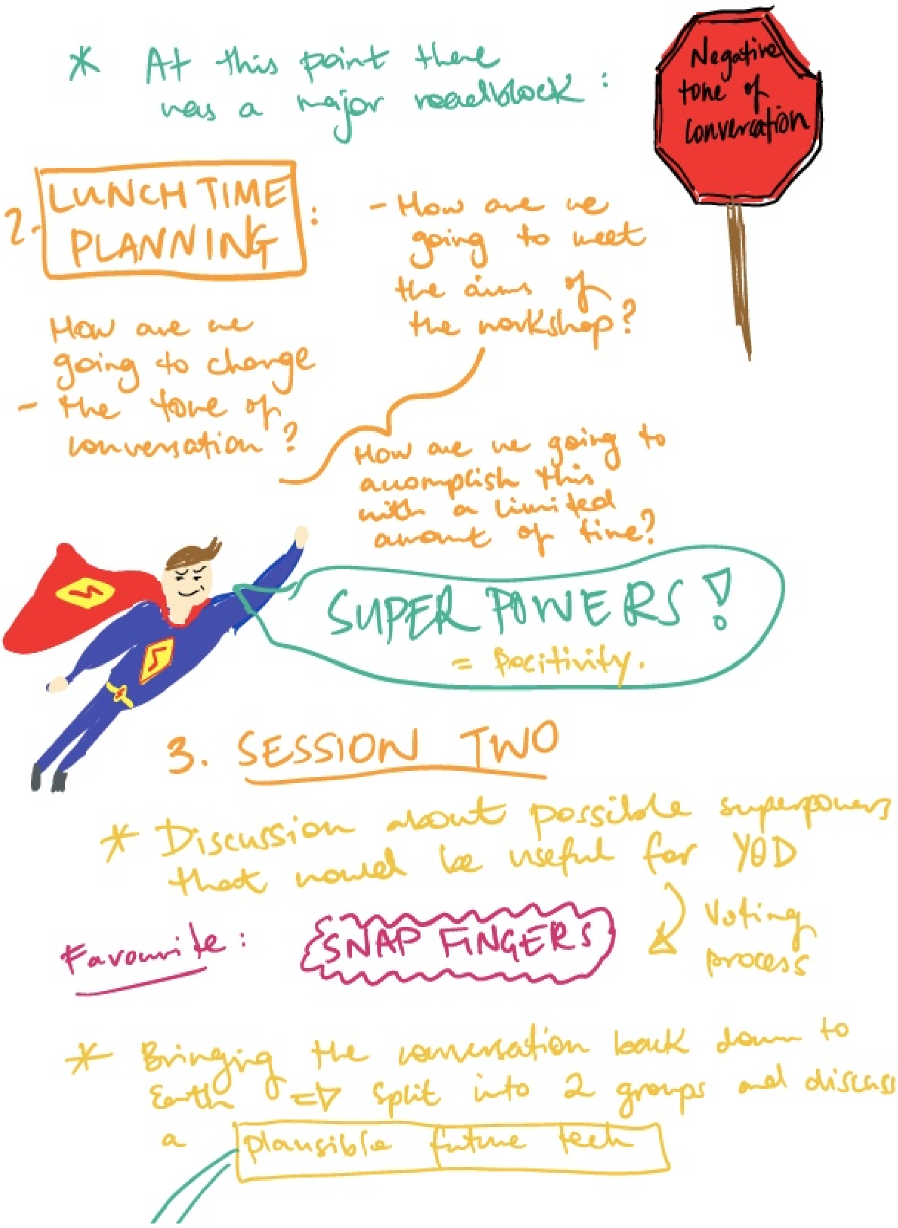
- Take a moment to record how you used digital technology today.
- What type of digital technology did you use?
  (For example: apps, email, texts, internet, mobile phone)
- Record how you felt when you were using technology.
- Did you find it easy or hard to use your device?
- Record how supportive, joyful or frustrating you find technology use in your day-to-day activities

Note: This content of this **prompt sheet** was designed in collaboration with those living with YOD. It is based on their needs. They advised me on the amount of white space, the words to highlight, the amount of choice to provide, and the level of detail to include.
Jeanette Bell.

Appendix 4. Coding Spreadsheet: The data from the studies were organised in a coding spreadsheet with a tab for each study.

Participant ID	Quote	preferred method of communication (email,, text etc.)	Environmental Factors	Emotion - as described	Subtheme	Theme
P1 - Dennis	• Burden of knowledge/secrecy for one week; attempting to live a normal life despite his diagnosis, waiting for the paper to say he's 'not fit for work': *** This may perpetuate a feeling of loneliness	diary entry, website	Early diagnosis:	Secrecy, burden	Loss of self	Fear? Loneliness?
P1 - Dennis	On workplace support: "painful", "meaningless"	diary entry, website	**workplace**	tokenism,	Self Worth	Dignity?
P1 - Dennis	Due to the stigma around Dementia, he was not taken seriously by medical professionals: ***"stressed" and concern for others experiencing his situation who would/could not make complaints***	diary entry, website	**Health care services**	Stressed concerned	Advocacy	Stigma
P1 - Dennis	"...the more I worked with and the more I engaged I became in getting something working, the better I understood what I was doing and the more rewarding it became." Fine line between tech that is too simple and too difficult, the median is where Dennis' satisfaction comes from.	diary entry, website	Early diagnosis:	Satisfaction	Self Worth	Identity (tech)
P1 - Dennis	Dementia Aus Form: "gave up" filling in the form, instead he "built a new document that was able to better meet my needs"	diary entry, website	Post-Diagnosis	Satisfaction	Empowerment	Independence/Identity
P1 - Dennis	"quite amusing", "[supervisor] was more surprised than I was"	diary entry, website	At the point of diagnosis/workplace	Disbelief, amusement	Self Worth	Identity --> unexpected change, who is he now?
P1 - Dennis	Dealing with people who assume he is incapable due to his dementia is amusing for Dennis. He uses humour and jokes to cope with people's treatment of him due to the stigma	diary entry, website	Post-Diagnosis	Amusement	Coping Mechani	Stigma
P1 - Dennis	Social engagement declined somewhat	diary entry, website	Post-Diagnosis	Sadness, rejection	Connection (or lack thereof)	Stigma
P1 - Dennis	"the attitude she had was she didn't want to listen to anything I had to say": in a way this is a loss of his outward identity: people are now seeing him only through the lens of dementia rather than who he is as an individual.	diary entry, website	Early diagnosis:	Anger, frustration	Self Worth	Identity
P2 - Suzie Dillon	While people close to P2 tend to give her space and some independence, "I wish everyone else would do the same"	iPad, emails,	Diagnosis	Frustration	Self worth/lack of independance	Stigma
P2 - Suzie Dillon	"I have digital cues just in case and I'd rather they ding than have Mum hover around me"	iPad, emails,	Diagnosis		Independence	Stigma
P2 - Suzie Dillon	Family struggle with trusting her, especially with young kids "frustration"	iPad, emails,	Diagnosis	Frustration	Lack of independence	Stigma
P2 - Suzie Dillon	"I must admit I get very frustrated if people fuss over me too closely, and don't let me do things" & importance in learning from own mistakes. Independence == identity	iPad, emails,	Diagnosis	Frustration, anger	Lack of independence	Stigma/Identity
P2, relates to P1, a	"I've got better since I come (sic) off work. So stress was definitely some of the compounding factor" & working at a slower pace would have been beneficial to P2		Workplace	Stress	Financial Security	Identity
P3 - Phil Hazell	Depression(loss of work, memory = loss of identity), anger(why me?) and confusion (denial) & 3 main emotions Phil felt when diagnosed. "this couldn't possibly happen to me", "I could see my working life coming to an end"	emails	Diagnosis	Depression, Anger, Confusion		Identity
P3 - Phil Hazell	• "embarrassment", forgetting names and conversation topics while out for dinner, "I had to put strategies into place really quickly" (writing down their names) • There could be an app where the user selects a table and how many seats and can then input the names of their company. That way they have a visual cue of who they're sitting	emails	Diagnosis	Embarrassment	Social	Stigma/Identity
P4 - Stephen (Stev	Loss of sense of smell, "executive decision making wasn't good", "I wasn't coping at work", Symptoms for up to 10 years before the diagnosis at 59	voice recording and email	Pre-diagnosis	Confustion, frustration		Identity
P4 - Stephen (Stev	"I could see myself declining; didn't know why". Like most of the participants, discovering a reason for their mental decline was comforting	voice recording and email	Diagnosis	Relief, comfort		Identity
P4 - Stephen (Stev	P4 struggled with acceptance at first, feeling very depressed and feeling as	voice recording and	Diagnosis	Depression -->		Self Worth

Appendix 5. Technology Worshop Overcoming roadblocks: Finding a Superpower



Bibliography

Alzheimer's Disease International 2017, *Alois Alzheimer,* Alzheimer's Disease International, UK, viewed 1 January 2018, <https://www.alz.co.uk/alois-alzheimer>.

Alzheimer's Disease International 2019, *World Alzheimer report 2019,* Analysis and Policy Observatory, viewed 2019, <https://apo.org.au/node/260061>.

Aldiabat, K. & Le Navenec, C.-L. 2011, 'Clarification of the blurred boundaries between grounded theory and ethnography: differences and similarities', *Turkish Online Journal of Qualitative Inquiry*, vol. 2, no. 3, pp. 1–13.

Alipour, A.P. & Khademi M. 2015, 'Alzheimer's disease detection using data mining techniques, MRI imaging, blood-based biomarkers and neuropsychological tests', *Research Journal of Recent Sciences*, vol. 4, no. 4, pp. 1–5.

Allen, R., Cook, S. & Hignett, S. 2016, 'How do people living with dementia use technology?'

Alzheimer's Australia 2017a, *What is younger onset dementia?* Dementia Australia, viewed 10 June 2017, <https://www.fightdementia.org.au/about-dementia/what-is-younger-onset-dementia>.

Alzheimer's Australia 2017b, *Dementia language guidelines,* Dementia Australia, viewed 10 June 2017, <https://www.fightdementia.org.au/resources/dementia-language-guidelines>.

American Psychiatric Association 2013, *Diagnostic and statistical manual of mental disorders, 5th edn (DSM-5),* American Psychiatric Association, Arlington, VA, USA.

Arntzen, C., Holthe, T. & Jentoft, R. 2016, 'Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers', *Dementia (London),* vol. 15, no. 4, pp. 646–62.

Arvanitakis, Z., Shah, R.C. & Bennett, D.A. 2019, 'Diagnosis and management of dementia: review', *JAMA*, vol. 322, no. 16, pp. 1589–99.

Astell, A., Alm, N., Dye, R., Gowans, G., Vaughan, P. and Ellis, M., 2014, July. Digital video games for older adults with cognitive impairment. *In International Conference on Computers for Handicapped Persons* (pp. 264-271). Springer, Cham.

Astell, A.J., Bouranis, N., Hoey, J., Lindauer, A., Mihailidis, A., Nugent, C. & Robillard, J.M. 2019, Technology and dementia: the future is now', *Dementia and Geriatric Cognitive Disorders*, vol. 47, no. 3, pp. 131–9.

Astell, A.J., Ellis, M.P., Bernardi, L., Alm, N., Dye, R., Gowans, G. and Campbell, J., 2010. Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers, 22*(4), pp.267-275.

Astell, A.J., Smith, S.K., Potter, S. and Preston-Jones, E., 2018. Computer interactive reminiscence and conversation aid groups—delivering cognitive stimulation with technology. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 4,* pp.481-487.

Bachurin, S.O., Bovina, E.V. & Ustyugov, A.A. 2017, 'Drugs in clinical trials for Alzheimer's disease: the major trends', *Medical Research Reviews, vol.* 37, no. 5, pp. 1186–225. doi: 10.1002/med.21434

Bakker, R. 2003, 'Sensory loss, dementia, and environments', *Generations: The Journal of the American Society on Aging*, vol. 27, no. 1, pp. 46–51.

Barbarino, P., Lynch, C., Bliss, A., Dabas, L. 2020, *From plan to impact III: Maintaining dementia as a priority in unprecedented times*, Alzheimer's Disease International, London, UK.

Basting, A.D. 2003, 'Looking back from loss: views of the self in Alzheimer's disease', *Journal of Aging Studies*, vol. 17, no.1, pp. 87–99.

Baum, F., MacDougall, C. & Smith, D. 2006, 'Participatory action research', *Journal of Epidemiology & Community Health*, vol. 60, no. 10, pp. 854–57.

Begum, M., Wang, R., Huq, R. & Mihailidis, A. 2013, 'Performance of daily activities by older adults with dementia: the role of an assistive robot', *IEEE International Conference on Rehabilitation Robots,* Institute of Electrical and Electronics Engineers, Piscataway, NJ, USA, No. 6650405.

Rudzicz, F., Wang, R., Begum, M. and Mihailidis, A., 2015. Speech interaction with personal assistive robots supporting aging at home for individuals with Alzheimer's disease. *ACM Transactions on Accessible Computing (TACCESS), 7*(2), pp.1-22.

Bell, J. & Leong, T.W. 2017, 'Collaborative futures: a technology design approach to support living well with dementia' *Proceedings of the 29th Australian Conference on Computer–Human Interaction*, Brisbane, Australia, pp. 397–401.

Bell, J. & Leong, T.W. 2019, 'Collaborative futures: co-designing research methods for younger people living with dementia', *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems,* Glasgow, Scotland, pp. 1–13.

Benton, L. & Johnson, H. 2013, ‘Designing technology with a vulnerable population: children with special needs and the role of the adult’, *Proceedings of CHI 2013 Workshop on Designing for—and with—Vulnerable People*, Paris, France.

Bharucha, A.J., Anand, V., Forlizzi, J., Dew, M.A., Reynolds, C.F., Stevens, S. & Wactlar, H. 2009, ‘Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges’, *The American Journal of Geriatric Psychiatry*, vol. 17, no. 2, pp. 88–104.

Blomberg, J., Burrell, M. & Guest, G. 2003, ‘An ethnographic approach to design’, in J. Jacko & A. Sears, *The human–computer interaction handbook: fundamentals, evolving technologies and emerging applications*, L. Erlbaum Associates Inc., Hillsdale, NJ, USA, pp. 964–986.

Boehner, K., Vertesi, J., Sengers, P. & Dourish, P. 2007, ‘How HCI interprets the probes’, *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. San Jose, CA, USA, pp. 1007–86.

Boger, J., Young, V., Hoey, J., Jiancaro, T. and Mihailidis, A., 2018. *Zero-Effort Technologies: Considerations, Challenges, and Use in Health, Wellness, and Rehabilitation. Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies, 8*(1), pp.i-118.

Boyd, H., Evans, N. & Harris, N. 2016, ‘A clock that does not tell the time: how the day clock meets the needs of people living with dementia’, in P. Langdon, J. Lazar, A. Heylighen & H. Dong (eds), *Designing around people: CWUAAT 2016*, Springer International Publishing, Cham, Switzerland.

Bradwell, H.L., Winnington, R., Thill, S. and Jones, R.B., 2020. Ethical perceptions towards real-world use of companion robots with older people and people with dementia: survey opinions among younger adults. *BMC geriatrics*, 20(1), pp.1-10.

Brereton, M., Roe, P., Schroeter, R. & Lee Hong, A. 2014, ‘Beyond ethnography: engagement and reciprocity as foundations for design research out here’, *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, New York, USA, pp. 1183–1186.

Brittain, K., Corner, L., Robinson, L. and Bond, J., 2010. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of health & illness,* 32(2), pp.272-287.

Brown, L., Hansnata, E. & La, H.A. 2017, *Economic cost of dementia in Australia 2016–2056*, report prepared for Alzheimer’s Australia.

Brown, M., Tsai, A., Baurley, S., Koppe, T., Lawson, G., Martin, J., Coughlan, T., Elliott, M., Green, S. & Arunachalam, U. 2014, 'Using cultural probes to inform the design of assistive technologies', *International Conference on Human–Computer Interaction*, Springer, pp. 35–46.

Bryden, C. 2012, *Who will I be when I die?* Jessica Kingsley Publishers, London, UK.

Craig, C and Fisher, H, 2020, Journeying through Dementia: the story of a 14 year design-led research enquiry. In: Christer, Kirstie, Craig, Claire and Chamberlain, Paul, (eds.) *Proceedings of the 6th International Conference on Design4Health. Lab4Living, Sheffield Hallam University*, 105-117.

Davies, C.A. 2007, *Reflexive ethnography: a guide to researching selves and others, 2nd edn*, Routledge.

Geertz, C. 1973, 'Thick description: toward an interpretive theory of culture', in C. Geertz (ed.) *The interpretation of cultures: selected essays*, Basic Books, New York, USA, pp. 3–30.

Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., Hagen, I., Holthe, T. & Jones, K. 2004, '"I know where this is going and I know it won't go back": hearing the individual's voice in dementia quality of life assessments', *Dementia*, vol. 3, no. 3, pp. 313–330.

Carrillo, M.C., Dishman, E. and Plowman, T., 2009, Everyday technologies for Alzheimer's disease care: Research findings, directions, and challenges. *Alzheimer's & Dementia, 5*(6), pp.479-488.

Chen, P.H., Lee, D.D., Yang, M.H. 2018, 'Data mining the comorbid associations between dementia and various kinds of illnesses using a medicine database', *Computers & Electrical Engineering*, vol. 70, pp. 12–20.

Cheng, B., Liu, M., Zhang, D., Munsell, B.C. & Shen, D. 2015, 'Domain transfer learning for MCI conversion prediction', *IEEE Transactions on Bio-medical Engineering*, vol. 62, no. 7, pp. 1805–17.

Chinner, A., Blane, J., Lancaster, C., Hinds, C. & Koychev, I. 2018, 'Digital technologies for the assessment of cognition: a clinical review', *Evidence-Based Mental Health*, vol. 21, no. 2, pp. 67–71.

Clemensen, J., Rothmann, M.J., Smith, A.C., Caffery, L.J. and Danbjorg, D.B., 2017, Participatory design methods in telemedicine research. Journal of telemedicine and telecare, 23(9), pp.780-785.

Coghlan, D. 2019, *Doing action research in your own organization*, SAGE Publications.

Cohene, T., Baecker, R. & Marziali, E. 2005, 'Designing interactive life story multimedia for a family affected by Alzheimer's disease: a case study', *CHI'05 Extended Abstracts on Human Factors in Computing Systems*, New York, USA, pp. 1300–3.

Cole, M.A. & Seabrook, G.R. 2020, 'On the horizon—the value and promise of the global pipeline of Alzheimer's disease therapeutics', *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, vol. 6, no. 1, pp. e12009.

Coradeschi, S.C., Cesta, A., Cortellessa, G., Coraci, L., Gonzalez, J., Karlsson, L., Furfari, F., Loutfi, A., Orlandini, A. & Palumbo, F. 2013, 'GiraffPlus: Combining social interaction and long term monitoring for promoting independent living', *6th International Conference on Human System Interactions*, Sopot, Poland, pp. 578–585.

Coughlan, T., Brown, M., McAuley, D., Baurley, S., Tsai, A., Koppe, T., Elliott, M., Green, S., Martin, J. & Lawson, G. 2014, 'Living with the user: design drama for dementia care through responsive scripted experiences in the home', *Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct Publication*, Seattle, WA, USA, pp. 35–38.

Crabtree, A., Hemmings, T., Rodden, T., Jeffe, K., Dewsbury, G., Hughes, J., Rouncefield, M. & Sommerville, I. 2002, 'Sore legs and naked bottoms: using cultural probes in dependability research', School of Computer Science and Information Technology, University of Nottingham, 11 January, 2019. <https://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.194.6823>.

Cutler, C., Hicks, B. and Innes, A., 2016. Does digital gaming enable healthy aging for community-dwelling people with dementia? *Games and Culture, 11*(1-2), pp.104-129.

Dai, J. and Moffatt, K., 2021, May. Surfacing the voices of people with dementia: Strategies for effective inclusion of proxy stakeholders in qualitative research. *In Proceedings of the 2021 CHI conference on human factors in computing systems* (pp. 1-13).

Dementia Alliance International 2017, *Dementia Alliance International: homepage,* Dementia Alliance International viewed 29 March 2019, <https://www.dementiaallianceinternational.org/>.

Davis, D.H. 2004, 'Dementia: sociological and philosophical constructions', *Social Science & Medicine*, vol. 58, no. 2, pp. 369–78.

Dementia Australia 2019a, *Types of Dementia,* Dementia Australia, viewed 23 November 2019, <https://www.dementia.org.au/information/about-dementia/types-of-dementia>.

Dementia Australia 2019b, *Dementia Alliance International*, Dementia Australia, viewed 24 November 2019, <https://www.dementia.org.au/resources/dementia-alliance-international>.

Derek, M.C., Chan, J. & Nejat, G. 2012, 'A socially assistive robot for meal-time cognitive interventions', *Journal of Medical Devices*, vol. 6, no. 1, pp. 6.

Derix, E.C. & Leong, T.W. 2019, 'Towards a probe design framework', *Proceedings of the OZCHI Conference*, Fremantle, Australia, pp. 117–27.

Dimirioglou, N., Kardaras, D. & Barbounaki, S. 2017, 'Multicriteria evaluation of the Internet of Things potential in health care: the case of dementia care', *IEEE 19th Conference on Business Informatics*, Thessaloniki, Greece, pp. 454–62.

Dixon, E., Piper, A. and Lazar, A., 2021, May. "Taking care of myself as long as I can": How People with Dementia Configure Self-Management Systems. *Proceedings of the 2021 CHI Conference on Human Factors in Computing System*s, Yokohama, Japan, pp. 1-14.

Dourish, P. 2014, 'Reading and interpreting ethnography,' in J.S. Olson, & W.A. Kellogg (eds), *Ways of knowing in HCI*, Springer, pp. 1–18.

Dourish, P. 2006, 'Implications for design', *Proceedings of the SIGCHI conference on Human Factors in computing systems*, New York, USA, pp. 541–50.

Dove, E. & Astell, A. 2017, 'The Kinect Project: group motion-based gaming for people living with dementia', *Dementia*, vol. 8, no. 6, pp. 2189–205. doi: 10.1177/1471301217743575

Downs, M. 1997, 'The emergence of the person in dementia research', *Ageing and Society*, vol. 17, no. 5, pp. 597–607.

Draper, B., Cations, M., White, F., Trollor, J., Loy, C., Brodaty, H., Sachdev, P., Gonski, P., Demirkol, A. & Cumming, R.G. 2016, 'Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study', *International Journal of Geriatric Psychiatry*, vol. 31, no. 11, pp. 1217–24.

Duarte, A.-M.B., Brendel, N., Degbelo, A. & Kray, C. 2018, 'Participatory design and participatory research: an HCI case study with young forced migrants', *ACM Transactions on Computer–Human Interaction (TOCHI)*, vol. 25, no. 1, pp. 1–39.

Enshaeifar, S., Zoha, A., Markides, A., Skillman, S., Acton, S.T., Elsaleh, T., Hassanpour, M., Ahrabian, A., Kenny, M., Klein, S., Rostill, H., Nilforooshan, R. & Barnaghi, P. 2018, 'Health management and pattern analysis of daily living activities of people with dementia using in-home sensors and machine learning techniques,' *PLoS One*, vol. 13, no. 5, pp. e0195605.

Eriksson, P. & Kovalainen, A. 2015, *Qualitative methods in business research: a practical guide to social research*, SAGE Publishing.

Erol, R., Brooker, D. & Peel, E. 2015, *Women and dementia: a global research review*, Alzheimer's Disease International, London, UK.

Favilla, S. & Pedell, S. 2013, 'Touch screen ensemble music: collaborative interaction for older people with dementia', *Proceedings of the 25th Australian Computer–Human Interaction Conference: Augmentation, Application, Innovation, Collaboration*, Adelaide, Australia, pp. 481–4.

Fetterman, D. 1998, *Ethnography step-by-step, 2nd edition*, Applied social research methods series (vol. 17), Sage Publications, CA, USA.

Fink, H.A., Hemmy, L.S., Linskens, E.J., Silverman, P.C., MacDonald, R., McCarten, J.R., Talley, K.M.C., Desai, P.J., Forte, M.L., Miller, M.A., Brasure, M., Nelson, V.A., Taylor, B.C., Ng, W., Ouellette, J.M., Greer, N.L., Sheets, K.M., Wilt, T.J. & Butler, M. 2020, 'Diagnosis and treatment of clinical Alzheimer's-type dementia: a systematic review', Publication No. 20-EHC003, Agency for Healthcare Research and Quality, Rockville, MD, USA.

Finkel, S.I., e Silva, J.C., Cohen, G., Miller, S. & Sartorius, N. 1997, 'Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment', *International Psychogeriatrics*, vol. 8, suppl. 3, pp. 497–500.

Forsythe, D.E. 1999, '"It's just a matter of common sense": ethnography as invisible work', *Computer Supported Cooperative Work*, vol. 8, no. 1–2, pp. 127–145.

Garnett, S. 2017, *Living with Dementia, not Dying from it*, Alzheimer's Australia, viewed 29 March 2019, <https://act.fightdementia.org.au/conferences/alzheimers-australia-2005>.

Gaver, B., Dunne, T. & Pacenti, E. 1999, 'Design: cultural probes', *Interactions*, vol. 6, no. 1, pp. 21–9.

Gaver, W.W., Boucher, A., Pennington, S. & Walker, B. 2004, 'Cultural probes and the value of uncertainty', *Interactions*, vol. 11, pp. 53–6.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K. & Robinson, L. 2016, 'The provision of assistive technology products and services for people with dementia in the United Kingdom', *Dementia*, vol. 15, no. 4, pp. 681–701.

Goeman, D., King, J. and Koch, S., 2016. Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action research. *BMJ open*, 6(12), p.e013064.

Grant, J., Nelson, G. & Mitchell, T. 2008, 'Negotiating the challenges of participatory action research: relationships, power, participation, change and credibility', in Reason, P. & Bradbury, H. *The SAGE handbook of action research*, SAGE Publications, pp. 588–601.

Green, D. & Kirk, D. 2018, 'Open design, inclusivity and the intersections of making', *Proceedings of the 2018 Designing Interactive Systems Conference, 2018*, Hong Kong, China, pp. 173–86.

Greenwood, N. & Smith, R. 2016, 'The experiences of people with young-onset dementia: a meta-ethnographic review of the qualitative literature', *Maturitas*, vol. 92, pp. 102–9.

Holtzblatt, K. and Beyer, H., 1997. *Contextual design: defining customer-centered systems*. Elsevier, pp. 46-61.

Holtzblatt, K., Jones, S., Inquiry, C. and Namioka, A., 1993. Participatory design: Principles and practices. Associates, C./. LE (ed.) *Contextual Inquiry: A Participatory Technique for System Design*, pp.177-210.

Hammersley, M. & Atkinson, P. 1983, *Ethnography: principles in practice*, Tavistock, London, UK.

Hammersley, M. & Atkinson, P. 1995, '*Ethnography principles in practice, 2nd edn*, Routledge, New York, USA.

Hedge, S. & Ellajosyula, R. 2016, 'Capacity issues and decision-making in dementia', *Annals of Indian Academy of Neurology*, vol. 19, suppl. 1, pp. S34–9.

Hori, M., Kubota, M., Ando, K., Kihara, T., Takahashi, R. and Kinoshita, A., 2009. The effect of videophone communication (with skype and webcam) for elderly patients with dementia and their caregivers. *Gan to kagaku ryoho. Cancer & chemotherapy, 36*, pp.36-38.

Houben, M., Brankaert, R., Dhaeze, E., Kenning, G., Bongers, I. and Eggen, B., 2022, February. Enriching everyday lived experiences in dementia care. *Sixteenth International Conference on Tangible, Embedded, and Embodied Interaction*, Daejeon, Republic of Korea, pp. 1-13.

Houston, A. 2018, *Talking sense: living with sensory change and dementia*, Hammond Care, Australia.

Institute of Development Studies 2019, *Participatory methods*, viewed 24 November 2019, <https://www.participatorymethods.org/glossary/participatory-action-research>.

Interaction Design Foundation 2019, *What is human–computer interaction (HCI)?* Interaction Design Foundation, viewed 23 November 2019, <https://www.interaction-design.org/literature/topics/human-computer-interaction>.

Ishii, H., Kimino, K., Aljehani, M., Ohe, N. & Inoue, M. 2016, 'An early detection system for dementia using the M2 M/IoT platform', *Procedia Computer Science*, vol. 96, pp. 1332–40.

Joddrell, P.H. & Astell, A.J. 2016, 'Identifying existing, accessible touchscreen games for people living with dementia', *Lecture Notes in Computer Science*, vol. 9758, pp. 509–14.

Joe, E. & Ringman, J.M. 2019, 'Cognitive symptoms of Alzheimer's disease: clinical management and prevention', *BMJ*, vol. 367, p. l6217.

Kensing, F. & Greenbaum, J. 2013, 'Heritage: having a say', in J. Simonsen & T. Robertson (eds), *Routledge international handbook of participatory design*, Routledge, New York, USA, pp. 21–36.

Kitwood, T. 1997, 'The experience of dementia', *Aging & Mental Health*, vol. 1, no. 1, pp. 13–22.

Launer, L.J. 2019, 'Statistics on the burden of dementia: need for stronger data', *The Lancet Neurology*, vol. 18, no. 1, pp. 25–7.

Lazar, A., Edasis, C. & Piper, A.M. 2017, 'A critical lens on dementia and design in HCI', *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, Denver, CO, USA, pp. 2175–88.

Leong, T.W., Wright, P., Vetere, F. & Howard, S. 2010, 'Understanding experience using dialogical methods: the case of serendipity', *Proceedings of the 22nd Conference of the Computer–Human Interaction Special Interest Group of Australia on Computer–Human Interaction*, Brisbane, Australia, pp. 256–63.

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales, H.C., Kivimäki, M., Larson, E.B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sampson, E.L., Samus, Q., Schneider, L.S., Selbæk, G., Teri, L. & Mukadam, N. 2020, 'Dementia prevention, intervention, and care: 2020 report of the Lancet Commission', *Lancet*, vol. 396, no. 10248, pp. 413–46.

Marasco, R.A. 2020, 'Current and evolving treatment strategies for the Alzheimer disease continuum', *The American Journal of Managed Care*, vol. 26, no. 8 (suppl), pp. S167–76.

Mathotaarachchi, S., Pascoal, T.A., Shin, M., Benedet, A.L., Kang, M.S., Beaudry, T., Fonov, V.S., Gauthier, S., Rosa-Neto, P. & Alzheimer's Disease Neuroimaging Initiative 2017, 'Identifying incipient dementia individuals using machine learning and amyloid imaging', *Neurobiology of Aging*, vol. 59, pp. 80–90.

Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F. & Goodman, C. 2017, 'Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review', *Aging & Mental Health*, vol. 22, no. 8, pp. 1–9.

McCarthy, J. & Wright, P. 2004, 'Technology as experience', *Interactions*, vol. 11, no. 5, pp. 42–3.

McKhann, G.M., Knopman, D.S., Chertkow, H., Hyman, B.T., Jack, C.R., Kawas, C.H., Klunk, W.E., Koroshetz, W.J., Manly, J.J., Mayeux, R., Mohs, R.C., Morris, J.C., Rossor, M.N., Scheltens, P., Carrillo, M.C., Thies, B., Weintraub, S. & Phelps, C.H. 2011, 'The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease', *Alzheimer's & Dementia*, vol. 7, pp. 263–9.

McNaney, R., Vines, J., Mercer, J., Mexter, L., Welsh, D. & Young, T. 2017, 'DemYouth: co-designing and enacting tools to support young people's engagement with people with dementia', *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, Denver, CO, USA, pp. 1313–25.

Mendez, M.F. 2006, 'The accurate diagnosis of early-onset dementia', *The International Journal of Psychiatry in Medicine*, vol. 36, no. 4, pp. 401–12.

Mihailidis, A., Boger, J.N., Craig, T., Hoey, J. 2008, 'The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study', *BMC Geriatrrics*, vol. 8, no. 1, pp. 28.

Moncur, W. 2013, 'The emotional wellbeing of researchers: considerations for practice', *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, New York, USA, pp. 1883–90.

Niemeijer, A.R., Depla, M.F., Frederiks, B.J. and Hertogh, C.M., 2015. The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. *Nursing ethics,* 22(3), pp.307-320.

Nassir, S. & Leong, T.W. 2017, 'Traversing boundaries: understanding the experiences of ageing Saudis', *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, Denver, CO, USA, pp. 6386–97.

National Disability Insurance Scheme 2020, *Understanding NDIS*, viewed 30 March 2020, <https://www.ndis.gov.au>.

Nelson, L.M., Longstreth Jr, W., Koepsell, T.D. & Van Belle, G. 1990, 'Proxy respondents in epidemiologic research', *Epidemiologic Reviews*, vol. 12, no. 1, pp. 71–86.

Orpwood, R. 2009, 'Involving people with dementia in the design process: examples of iterative design', *Dementia, Design and Technology*, vol. 24, pp. 79–95.

Orpwood, R., Chadd, J., Howcroft, D., Sixsmith, A., Torrington, J., Gibson, G. & Chalfont, G. 2010, 'Designing technology to improve quality of life for people with dementia: user-led approaches', *Universal Access in the Information Society*, vol. 9, no. 3, pp. 249–59.

Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost, D. & Hasan, H. 2019, 'Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project', *Dementia*, vol. 18, no. 7–8 pp. 2679–94.

Phinney, A., Kelson, E., Baumbusch, J., O'Connor, D. & Purves, B. 2016, 'Walking in the neighbourhood: performing social citizenship in dementia', *Dementia,* vol. 15, no. 3, pp. 381–94.

Prince, M.J. 2015, *World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*, Alzheimer's Disease International, London, UK.

Raz, L., Knoefel, J. & Bhaskar, K. 2016, 'The neuropathology and cerebrovascular mechanisms of dementia', *Journal of Cerebral Blood Flow & Metabolism*, vol. 36, no. 1, pp. 172–86.

Roach, P. & Drummond, N. 2014. '"It's nice to have something to do": early-onset dementia and maintaining purposeful activity', *Journal of Psychiatric and Mental Health Nursing*, vol. 21, no. 10, pp. 889–95.

Robbins, T.W., James, M., Owen, A.M., Sahakian, B.J., McInnes, L. & Rabbitt, P. 1994, 'Cambridge Neuropsychological Test Automated Battery (CANTAB): a factor analytic study of a large sample of normal elderly volunteers', *Dementia*, vol. 5, no. 5, pp. 266–81.

Robertson, T. & Wagner, I. 2013, 'Ethics: engagement, representation and politics-in-action', in J. Simonsen & T. Robertson (eds), *Routledge international handbook of participatory design*, Routledge, New York, USA, pp. 64–85.

Robertson, T., Durick, J., Brereton, M., Vetere, F., Howard, S. & Nansen, B. 2012, 'Knowing our users: scoping interviews in design research with ageing participants', *Proceedings of the 24th Australian Computer–Human Interaction Conference*, Melbourne, Australia, pp. 517–20.

Rossor, M.N., Fox, N.C., Mummery, C.J., Schott, J.M. & Warren, J.D. 2010, 'The diagnosis of young-onset dementia', *The Lancet Neurology*, vol. 9, no. 8, pp. 793–806.

Sacks, O. 1990, *Awakenings*, Harper Perennial, New York, USA. In Forward of 1990 Edition

Sampson, E.L., Warren, J.D., Rossor, M.N. 2004, 'Young onset dementia', *Postgrad Medical Journal*, vol. 80, pp. 125–39.

Sanjek, R. 1996, 'Ethnography', in A. Barnard, and J. Spencer (eds), *Encyclopedia of social and cultural anthropology*, Routledge, London, UK, pp. 295–302.

Sansoni, J., Duncan, C., Grootemaat, P., Capell, J., Samsa, P. & Westera, A. 2016, 'Younger onset dementia: a review of the literature to inform service development', *American Journal of Alzheimer's Disease & Other Dementias*, vol. 31, no. 8, pp. 693–705.

Sansoni, J., Duncan, C., Grootemaat, P., Samsa, P., Capell, J. & Westera, A. 2014, 'Younger onset dementia: a literature review', *University of Wollongong Australia*, viewed 11 January 2017, <http://ro.uow.edu.au/ahsri/373>.

Sari, D.W., Igarashi, A., Takaoka, M., Yamahana, R., Noguchi-Watanabe, M., Teramoto, C. and Yamamoto-Mitani, N., 2020. Virtual reality program to develop dementia-friendly communities in Japan. *Australasian Journal on Ageing,* 39(3), pp.e352-e359.

Shin, D.S., Shin, D. & Shin, D. 2014, 'Ubiquitous health management system with watch-type monitoring device for dementia patients', *Journal of Applied Mathematics*, vol. 2014, pp. 1–8.

Snyder, L. 2001, 'The lived experience of Alzheimer's—understanding the feelings and subjective accounts of persons with the disease', *Alzheimer's Care Today*, vol. 2, no. 2, pp. 8–22.

Sobral, M. and Pestana, M.H., 2020. Virtual reality and dementia: A bibliometric analysis. *The European Journal of Psychiatry,* 34(3), pp.120-131

Sposaro, F., Danielson, J. and Tyson, G., 2010, September. iWander: An Android application for dementia patients. *In 2010 Annual International Conference of the IEEE Engineering in Medicine and Biology* (pp. 3875-3878). IEEE

Sprint, G.C., Fritz, R. & Schmitter-Edgecombe, M. 2016, 'Using smart homes to detect and analyze health events', *Computer*, vol. 49, no. 11, pp. 29–37.

Stupar, M. & Moore, B. 2016, *Living well with dementia*, Discussion Paper 17, Alzheimer's Australia NSW.

Suchman, L.A. 1987, *Plans and situated actions: the problem of human–machine communication*, Cambridge University Press, New York, USA.

Swaffer, K. 2019, *Step up for dementia research*, viewed 20 December 2019, <www.stepupfordementia research.org.au/kate-swaffer>.

Swantz, M.L. 2008, 'Participatory action research as practice', in P. Reason & H. Bradbury (eds), *The SAGE handbook of action research: participative inquiry and practice*, SAGE Publishers, London, UK, pp. 31–48.

Swarbrick, C.M., Doors, O., Scottish Dementia Working Group, EDUCATE, Davis, K. and Keady, J., 2019. Visioning change: co-producing a model of involvement and engagement in research (innovative practice). *Dementia, 18*(7-8), pp.3165-3172.

Szebeko, D. and Tan, L., 2010. Co-designing for Society. *Australasian Medical Journal*, 3(9)

Tacchi, J., Slater, D. and Hearn, G., 2003. *Ethnographic action research.* pp. 2-4

Tan, L. and Szebeko, D., 2009. Co-designing for dementia: The Alzheimer 100 project. *Australasian Medical Journal (Online)*, (12), p.185

Tanner, D. 2012, 'Co-research with older people with dementia: experience and reflections', *Journal of Mental Health*, vol. 21, no. 3, pp. 296–306.

Thompson, D. 2011, *Service and support requirements for people with Younger Onset Dementia and their families*, Social Policy Research Centre, University of NSW, Sydney.

Tisher, A. & Salardini, A. 2019, 'A comprehensive update on treatment of dementia', *Seminars in Neurology*, vol. 39, no. 2, pp. 167–78.

United Nations 2010, *Convention on the Rights of Persons with Disabilities (CRPD)*, viewed 11 January 2017, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.

Van der Ploeg, E.S., Eppingstall, B. and O'Connor, D.W., 2016. Internet video chat (Skype) family conversations as a treatment of agitation in nursing home residents with dementia. *International psychogeriatrics, 28*(4), pp.697-698.

Van Maanen, J. 2011, *Tales of the field: on writing ethnography*, University of Chicago Press, Chicago, USA.

Van Vliet, D., De Vugt, M.E., Aalten, P., Bakker, C., Pijnenburg, Y.A., Vernooij-Dassen, M.J., Koopmans, R.T. & Verhey, F.R. 2012, 'Prevalence of neuropsychiatric symptoms in young-onset compared to late-onset Alzheimer's disease–part 1: findings of the two-year longitudinal NeedYD-study', *Dementia and Geriatric Cognitive Disorders,* vol. 34, no. 5–6, pp. 319–27.

Van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, R.T.C.M. & Verhey, F.R.J. 2010, 'Impact of early onset dementia on caregivers: a review', *International Journal of Geriatric Psychiatry*, vol. 25, no. 11, pp. 1091–100.

Vines, J., McNaney, R., Lindsay, S., Wallace, J. & McCarthy, J. 2014, 'Special topic: designing for and with vulnerable people', *Interactions,* vol. 21, no. 1, pp. 44–6.

Vines, J., McNaney, R., Clarke, R., Lindsay, S., McCarthy, J., Howard, S., Romero, M. & Wallace, J. 2013, 'Designing for—and with—vulnerable people', *CHI'13 Extended Abstracts on Human Factors in Computing Systems*, New York, USA, pp. 3231–4.

Wallace, J., McCarthy, J., Wright, P. C., & Olivier, P. 2013a, 'Making design probes work', *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Paris, France, pp. 3441–50.

Wallace, J., Mulvenna, M.D., Martin, S., Stephens, S. and Burns, W., 2010. ICT interface design for ageing people and people with dementia. In Supporting people with dementia using pervasive health technologies (pp. 165-188). Springer, London.

Wallace, J., Wright, P.C., McCarthy, J., Green, D.P., Thomas, J. & Olivier, P. 2013b, 'A design-led inquiry into personhood in dementia', *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Paris, France, pp. 2617–26.

Wan, L., Müller, C., Randall, D. and Wulf, V., 2016. Design of A GPS monitoring system for dementia care and its challenges in academia-industry project. *ACM Transactions on Computer-Human Interaction (TOCHI), 23(*5), pp.1-36.

Waycott, J., Davis, H., Thieme, A., Branham, S., Vines, J. & Munteanu, C. 2105a, 'Ethical encounters in HCI: research in sensitive settings', *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems*, New York, USA, pp. 2369–72.

Waycott, J., Wadley, G., Schutt, S., Stabolidis, A. & Lederman, R. 2015b, ‘The challenge of technology research in sensitive settings: case studies in “sensitive HCI”’, *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction*, Parkville, Australia, pp. 240–9.

Welsh, D., Morrissey, K., Foley, S., McNaney, R., Salis, C., Mccarthy, J. & Vines, J. 2018, ‘Ticket to talk: supporting conversation between young people and people with dementia through digital media’, *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, Montreal, Canada, pp. 1–13.

Willis, P. & Trondman, M. 2002, ‘Manifesto for ethnography’, *Cultural Studies—Critical Methodologies,* vol. 2, no. 3, pp. 394–402.

Wimo, A., Jönsson, L., Bond, J., Prince, M., Winblad, B. & Alzheimer’s Dementia International 2013, ‘The worldwide economic impact of dementia 2010’, *Alzheimer’s & Dementia*, vol. 9, no. 1, pp. 1–11.

Withall, A., Draper, B., Seeher, K. & Brodaty, H. 2014, ‘The prevalence and causes of younger onset dementia in Eastern Sydney, Australia’, *International Psychogeriatrics,* vol. 26, no. 12, pp. 1955–65.

World Health Organization 2019. *Dementia: key facts* , viewed 20 December 2019, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

Wright, P. & McCarthy, J. 2008, ‘Empathy and experience in HCI’, *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Florence, Italy, pp. 637–46.

Zubatiy, T., Vickers, K.L., Mathur, N. and Mynatt, E.D., 2021, May. Empowering Dyads of Older Adults with Mild Cognitive Impairment and Their Care Partners Using Conversational Agents. *In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (pp. 1-15).