

# Collaborative Futures: Co-Designing Research Methods for Younger People Living with Dementia

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## ABSTRACT

Designing new technologies to support the lived experience of dementia is of increasing interest within HCI. While there is guidance on qualitative research methods to use in areas such as dementia, there is a need for more appropriate ways to research in the younger demographic. In Younger Onset Dementia (YOD), the circumstances and experiences are markedly different from dementia in the later stage of life – requiring a different approach. This paper presents insights into the methods and approaches used in a fieldwork with five people living with YOD; where they engaged as co-researchers in a co-directed inquiry into their lived experiences. Through this, we make a number of methodological contributions to HCI and Participatory Action Research (PAR) for research in the YOD setting. This includes productive approaches that are sensitive, respectful and empowering to the participants. It also extends current approaches to using probes in HCI and dementia research.

## CCS CONCEPTS

• Human-centered computing → Human computer interaction (HCI)

## KEYWORDS

Methods; younger onset dementia; co-researcher; probes; co-design; participatory action research; ethics; stigma

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## INTRODUCTION

Dementia is not one specific disease. It is an overall term that describes a wide range of symptoms affecting the cognitive function of the brain. These symptoms vary from person to person, depending on the impact of the disease and the person's personality before the diagnosis. Dementia involves a slow deterioration in memory and altered sensory processing, impacting the ability to perform everyday activities [1]. Dementia is chronic and progressive.

In the past, impaired memory was thought to be a natural and expected part of ageing, with Alzheimer's disease being the most common cause of dementia symptoms [1]. However, the direct association between dementia and the ageing process, no longer holds true [1]. Dementia also affects younger people in their 30s, 40s and 50s [2]. Younger Onset Dementia (YOD) is an emerging trend and an expanding field of research [3, 4]. The medical classification of YOD is described as having symptoms of dementia under the age of 65 years.

Being diagnosed with dementia early in life results in vastly different experiences from being diagnosed with Late-Onset Dementia (LOD) [5, 6]. In fact, Greenwood and Smith suggest that the lived experiences of YOD are not only markedly different from LOD but often results in a greater negative impact on their lives, and that of their families [7]. At the time of a YOD diagnosis, the person is generally still employed and highly engaged in all aspects and demands of family life [2, 8]. Often a diagnosis of dementia is quite unexpected when a person is aged in their thirties, forties or fifties - making it difficult to diagnose. To date most research efforts (especially from the medical, economic and social sectors) have focused on late stage dementia in the elderly population [2, 3].

While this is undoubtedly valuable research and has contributed significantly to understanding the needs and experiences of living with dementia [9-11]; by comparison, there are very few empirical accounts of the experiences of living with YOD. Where the needs and experiences are markedly different - given this earlier stage of life.

The focus on late stage dementia in the elderly is also seen in the HCI community, with significant efforts in designing digital technologies to support individuals and their carers. This includes designing devices that foster joy through music and reminiscence [12] and technologies providing safety through surveillance measures [13-15]. These efforts provide great support for cognitive, physical, emotional and social well-being in the elderly population.

Similarly, we see a definite role for technologies to support those living with YOD. As such, this research specifically

investigates the experiences in the early stage of YOD. We suggest that if we were to design meaningful and appropriate digital solutions for these individuals, we first need to establish how to work directly with them - before we start to build deep insights into their lived experiences. This requires researchers to work more closely with these individuals in all phases of the research and design process.

This paper presents the inquiry phase of an ongoing research project seeking to understand the experiences of people living with YOD. It highlights unique challenges and considerations when researching in YOD. It contributes to HCI in a number of ways by presenting productive and inclusive methodological approaches and particular insights to collaborate with people living with YOD; as co-researchers. These insights emerged from ongoing researcher-participant dialogues and reflections about the research process of this inquiry phase. We hope that the understandings gained from this inquiry can be used to inform approaches to designing appropriate technologies to support positive life experiences for those living with YOD.

### **YOUNGER ONSET DEMENTIA**

Living with YOD differs considerably from dementia in older individuals [5]. In fact, people diagnosed with YOD are of employable age, with many being the main income earner and some will be a parent of young children [6]. They are generally fit and in good physical health. This, together with their marked age difference, makes the integration of those with YOD into mainstream dementia services extremely difficult [2, 16, 17]. This is because there are limited age-appropriate services available for people living with YOD. In addition to this, the carer or partner of a person with YOD will face higher levels of anxiety, depression and relationship problems than those partners or caregivers of older adults with dementia [16].

Furthermore, while there is cognitive decline in varying degrees, many individuals remain high functioning, independent and actively engaged in family networks, communities and life in general. While we acknowledge the overlaps, the trajectories and aspirations of YOD are vastly different from that of their older counterparts. Some researchers have highlighted that people with YOD are likely to be more digitally literate than those with LOD [18, 19]. We argue that technologies designed for, and adopted by individuals at the YOD stage may well continue to provide them with benefits as the symptoms of dementia progress - rather than asking them to adopt new technologies at later stages of dementia. However, in HCI we have yet to develop a nuanced understanding of the ways people with YOD are currently using digital technologies.

### **HCI RELATED WORK IN DEMENTIA**

As mentioned earlier, HCI has been engaged in designing for people's experiences with technology for some time [20]. However, when designing technology for people with dementia, HCI tends to focus on the impairments - predominantly providing support and independence for the person with dementia and carer through monitoring and surveillance devices [21, 22]. While such HCI efforts are highly encouraging and go a long way in supporting the more advanced stages of dementia - our research revealed that those living with YOD certainly do not need nor want surveillance or more intrusive technologies such as those used in LOD. Many individuals living with YOD have retained abilities, exhibit a strong sense of agency and independence - very different from those living with LOD.

Despite this, research efforts often conflate YOD and LOD [23] as a single group, with similar needs and experiences. When we began to design this inquiry, we did not find effective guidance in the literature as to how to conduct research specifically with individuals living with dementia in the younger age demographic. So, as a starting point, we followed the broader core principles for dementia research - written by The Scottish Dementia Working Group (a campaigning group of people with dementia influencing decisions about their lives) [24]. These core principles include taking a person-centred and inclusive approach, using appropriate language in research communications and understanding the notion of 'dementia time', which we discuss further in this paper.

### **APPROACHES AND TOOLS USED IN DEMENTIA SETTINGS**

Our search through various databases revealed that the majority of research in dementia focuses on people with advanced dementia. They offer guidance on appropriate and respectful approaches to working with this population. The most common method described is the use of a proxy to communicate for the person with dementia during the research process.

#### **Proxy**

Talking to a proxy is a well-established research approach when working with people with dementia. However, as [11, 25, 26] noted, this social science approach to research has tended to marginalise the experiences of those with dementia. Recently, social researchers such as Cahill et al., and Tanner [9, 27] have challenged the use of a proxy and sought to empower people with dementia by allowing them to be directly involved in the research and design process. For example, Tanner [27] engaged directly with older people with

dementia and undertook all interviews jointly with one of the co-researchers who was diagnosed with dementia. Tanner highlighted the ethical and practical challenges in this approach, but also the benefits derived for the participant, such as gains in self-confidence and self-esteem. While promising, Tanner also strongly urged further explorations of this approach.

On the other hand, individuals living with YOD are more independent. They have retained skills and abilities; some continue to work and many continue to contribute to society with input into the social policies on YOD. The YOD individuals we encountered also revealed their strong desire for all researchers to support their goal to 'live well' with dementia by maintaining as much independence and agency for as long as possible [28].

### **Probes, interviews and design-led inquiry**

In dementia research, interviews are the most commonly used method to elicit information. Yet, as explained above, most of these interviews are conducted in the presence of a proxy, such as a partner or professional carer [9, 16, 23, 29]. Similarly, we found literature on the use of cultural probes [23, 30] to elicit personal experiences of living with dementia. However, most researchers still relied on a proxy to complete the probe activities (e.g., [23]). Wallace et. al., [29] also used probes in their design-led inquiry into personhood in dementia, and found that not all the probes they designed were suitable for their participants – finding that most successful probes were those that resonated more closely with their participants' lives. While Wallace et al., [29] did not work with YOD participants, we were inspired by their inclusive approach which used probes in a co-creative, design-led inquiry into personhood in dementia. This paper presents our efforts to build on their inclusive approach [29] by exploring how we can involve individuals with YOD as co-researchers of their own experiences that include co-designing the probes that they would use.

We wish to reiterate that we did not find adequate methodological guidance from the literature as to how to best research with those living with YOD. Thus, when designing our fieldwork, we drew from the limited resources we found. More importantly, we relied upon the first author's preliminary work with YOD individuals to guide our approach in this fieldwork. We will introduce this preliminary work in the next section.

### **PRELIMINARY WORK**

This section describes the three phases of preliminary work that shaped and informed the overall approach taken to design the study and fieldwork; with each phase informing the next.

### **Phase 1: Reconnaissance work to build insights**

The first author began by conducting a number of reconnaissance activities to become sensitised into the world of dementia. She did this by observing and interacting with people with YOD in different settings where they were found to be actively engaged; this was to better understand their contexts and develop tacit knowledge about individuals living with YOD. The reconnaissance activities included attending international and local conferences on Alzheimer's Disease (where a large number of people with YOD attend and participate). Attending community BBQs with folks living with YOD. Visits to dementia respite centres and frequent meetings with professionals from dementia organisations. The first author also joined global online forums for YOD (e.g., Dementia Alliance International), connected with university colleagues working in dementia research and followed the social media advocacy groups concerned with YOD.

The reconnaissance activities at these public events also provided opportunities for recruiting participants. We advertised and recruited through the national Dementia organisation, through personal introductions at an Alzheimer's international conferences and through snowball sampling recruitment. Altogether, five people with YOD consented to participate (P1-P5). Their ages ranged from 55 to 63 years. While the number of participants might appear low, this gave us the opportunity to engage more deeply with each individual – over time.

This reconnaissance revealed that most of what the public knows about YOD comes from popular media; such as television documentaries, magazine articles and so on, and not from the research literature. Extensive conversations by the first author with people living with YOD revealed two primary methodological concerns when participating in research. First, they expressed the need for appropriate research methods that are inclusive and respectful of their agency and autonomy. Second, they want to be actively participating as co-researchers in research, because they want to shape the narrative of their own experiences with dementia. Upon discovering our interest in technology design, they also expressed the desire to have direct input and contribute to the co-design and development of any digital technologies that will ultimately be for their use.

### **Phase 2: Getting to know each other**

Early in this research, the first author took time to build relationships and trust with the participants and their partners. This is because she is aware of the sensitivity and complexity in YOD given her immersion and prior involvements in the many different YOD communities. This phase lasted 1 to 3 months depending on the relationship with the individual

participant. Instead of diving directly into research mode (conducting the actual fieldwork), the first author spent time with each participant. As mentioned earlier, this included regular visits to their homes, informal skype calls, phone calls, texts and some social activities (e.g., BBQs, lunches). Some of the participants also visited the first author's university, met with her research colleagues and got a sense of the academic setting and how formal research is being conducted in the field of HCI.

This valuable time was focused on getting to know the person and not their dementia. The types of conversations included topics on everyday activities, chatting about hobbies, pets, stories of their younger lives, their children, family, and partners. The first author also shared similar stories as well as her connection and experience with dementia in her family. As the relationships developed, the first author - without probing - began to hear about the darker aspects of their experiences, particularly related to dementia. This degree of familiarity was somewhat unexpected, yet in hindsight an essential part of sharing personal stories and building trust over time.

The first author also noticed the participants' prolific use of technology such as smartphones and digital watches. They used these technologies for a variety of activities including posting updates on social media, blogging, texting, scheduling and using GPS for navigation. As the involvement of the participants in this research grew, they indicated a wish for our work to surface opportunities for digital technology designs to support YOD.

### **Phase 3: Co-designing interviews and probes**

Once trust and familiarity (and friendships) were built, two of the participants began making recommendations about how we might collaborate on the upcoming fieldwork. This is because one person had a background in science/law (P2) and the other, an IT business professional/teacher (P1). So, we began working with P1 and P2 to co-design research tools that we could use, in addition to interviewing, that would be more appropriate to facilitate data collection of their unique and personal experiences of dementia. This involved adapting current tools used in qualitative research such as diaries, questionnaires, probes and so on. This co-design session took place within a formal 3-hour workshop.

### **Workshop to co-design the research approach and tools**

The agenda of the co-design workshop was co-created with P1 and P2. The agenda included:

- How should we conduct interviews? What are the appropriate things to ask? What are other things that we should be mindful of?
- How do we capture experiences - through digital channels or non-digital channels, or both?
- What needs to be captured? Experiences about dementia, families? Capture moments that have revealed something that affected you: made you happy, sad, angry, confused, joyful?
- When should we ask the participants to capture these moments - beginning and end of each day, or both?

We worked through this agenda and the outcomes of the workshop included protocols for interviews, co-designed probes and flexible guidelines.

*Interviews.* During the workshop, we piloted interview questions with P1 and P2. This was followed by a discussion on the interview approaches. With their input, we were reminded to be careful of the choice of language as to not reinforce the stigma of dementia, such as not calling them "sufferers" or "suffering from" dementia, or being 'demented'. We also received guidance regarding the duration of the interviews. We were advised to be flexible, be aware of their pace in conveying stories and allow for more time if necessary. P1 and P2 also suggested that we should spend time in informal conversations, 'warming up' through exchanging information about our families, friends and hobbies before we begin the interview. They stressed the importance of a relaxed and flexible environment, validated current methods and introduced the YOD perspective.

*Probes.* We co-designed a number of probes to capture their experiences with dementia. The probe pack contained a diary, a selection of colourful pens and a semi-structured questionnaire. We also included emoticon stickers and contact details. The instructions and guidelines were designed to introduce flexibility (as recommended by P1 and P2), for how participants could complete the probes to record their stories. This means that participants had the freedom to choose the tools that they felt were most effective and supportive to communicate their experiences. This was to support the varying retained communication abilities of individuals living YOD. For example, one person might find handwriting challenging and prefer to record audio or send short texts. Another might have difficulty with speech and prefer to handwrite. This flexibility allowed them to determine how much information they wished to share – in their preferred style.

Some examples of some of the 'co-developed' instructions for the study: *Please start by sharing your life story (as brief or as detailed as you would like) - Please reflect and share your experiences today. These can be experiences you would*

like the researcher to know about living with dementia - Record entries using text, audio, photos/images or videos to express how you are feeling and why you feel this way.

These co-designed probes were trialled by P1 and P2. After this, we created multiple sets of the probe pack to deploy. Before presenting the details of the fieldwork in the next section, we will explain our methodological approach.

**MOVING BEYOND ETHNOGRAPHY TO PARTICIPATORY ACTION RESEARCH (PAR)**

When completing our ethics application, we stated that we would use longitudinal ethnography as we thought that this would be an appropriate method. However, during our reconnaissance work, our participants expressed the desire to have greater agency and autonomy in the research process (i.e. to become co-researchers). This led to a realisation that we needed to evolve our methodological approach into a more inclusive one. We decided on a combination of ethnography and PAR. This combination offered a collaborative and inclusive approach - also used by others in HCI (e.g. [31, 32]). As the research progressed, it evolved more so towards PAR methods.

**THE FIELDWORK**

This fieldwork is the first stage of a larger project to explore how digital technologies can support positive experiences in YOD. Ethics for this fieldwork has been approved by the University of Technology Sydney, HREC committee.

**Participants**

Table 1 presents the details of our five participants (P1-P5). After spending time together, we understood how important it was for these individuals to be seen as the ‘whole person’, beyond the diagnosis of dementia. Hence the inclusion of the career backgrounds in Table 1.

**Research Design**

Once the participants were ready and the probe packs completed, we proceeded with the fieldwork.

**Table 1. Demographics of the participants**

**Overall timeline**

The fieldwork began with a two-week activity where we trialled the probe pack we co-designed with P1 and P2. We contacted the participants and arranged a time to meet in person to introduce ourselves. During this meeting, we provided information about the goals of the study and answered any questions the participants might have before consenting to participate. We then conducted an initial semi-structured interview (between 30-60 minutes) and a follow-up interview of similar duration at the end of the two-week intervention. After the interview, we provided each participant with the probe pack together with accompanying instructions

and explained how they could use the probes to provide first-hand accounts of their daily experiences with YOD during this period.

After the completion of this 2-week activity, the first author collected the probes and continued her data collection through regular contact with each participant. This included conversations and regular visits with each participant. She also used Skype and phone calls; exchanged text messages and emails. This regular contact went on for approximately 12 to 18 months. The aim was to capture information with as much richness and sensitivity as possible – as we tracked their changing experiences with the environment and digital technologies.

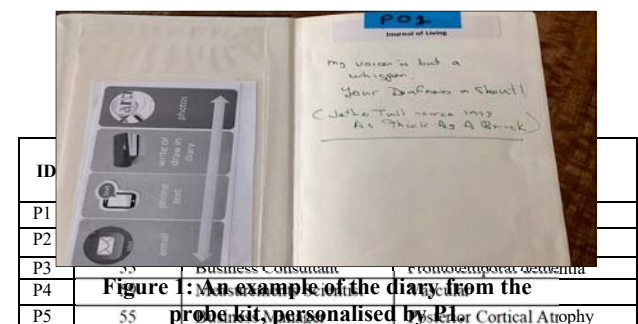
**Interviews**

Much like Tanner [27] and Magilvy & Congdon [33], we used minimally structured interviews, lasting approximately 60 minutes – allowing for more time if required. Carers/partners were not required to be present, however were most welcome (at the discretion of the person with YOD). The interviews took place in the home of the person with YOD.

**Probes**

As advised by P1 and P2, the probe pack was instilled with elements to make the activities more enjoyable and appropriate for varying communication abilities. For example, we included the colourful pens and fun stickers to help express emotions, and labels to log day/date or technology use. Figure 1 shows an example of the personalised introduction page of a diary from the probe kit. While the content of the probe pack reflects that of others in HCI (e.g. [29, 34, 35]) our participants wanted to ‘self-select’ their own tools of inquiry and mode of communication.

**REFLECTIONS ON THE FIELDWORK**



In this section, we present and reflect on the complexities of co-researching with individuals living with YOD. We also present methodological approaches we used to overcome these challenges. While what we present reads like ‘best practice’ in standard qualitative research, we wish to emphasise that our

practices would be considered the 'baseline standard' by the YOD individuals whom we engaged with in this research.

### **Recruitment**

The recruitment process was challenging. It is not easy to locate people living with dementia, especially YOD. This is because they are not living in settings where we generally encounter people with dementia, such as aged-care facilities. We had to take time to explore avenues where we might be able to meet people living with YOD. That is why we attended dementia-related conferences, sought contacts through journalists who write about dementia and went to dementia organisations.

As mentioned earlier, people living with YOD are most likely still employed and are busy, engaged in work and family life, as well as dealing with their diagnosis of dementia. With this, time is particularly precious to them. They would need to see great value in agreeing to give up some of this time (and time away from their families) to participate in research activities. Therefore, asking such individuals to make a long-term commitment to participate in research can be very difficult.

Finally, navigating through the ethics application process was prolonged, with dementia individuals automatically being labelled as vulnerable. This means that researchers are required to provide a great deal more (detailed) information. This slowed the process down significantly and greatly impacted our efforts to network with recruitment gatekeepers. For us, this led to delays in the recruitment efforts of up to six months.

### **Interviews**

While conducting interviews in participants' homes, we also discovered unexpected complexities when researching in YOD.

#### **Initial interview as an occasion to build trust**

We found that P1 and P2's suggestions to have informal conversations helped relax the participants. We also felt that these conversations relaxed us and prepared us to what we might hear during the interview. These stories can take many forms and can shift from a medical narrative to a somewhat philosophical conversation about life.

In terms of structure, we began the interview with demographic questions (as advised by P1 and P2) such as age, the type of dementia they were diagnosed with, time of diagnosis and so on. We found that this was helpful in transitioning to asking about the more sensitive aspects of dementia, for example asking them to tell us how they felt at the time of their diagnosis. Asking them to share this story of what led to the YOD diagnosis gave us greater clarity of their

situation and allowed us to ask them if they now felt differently regarding the diagnosis of YOD. We found that we had to be aware and supportive of the pace and settings in which individuals shared their stories. This meant being open to the fact that they might want to tell their stories over time with follow-up meetings. We found that finishing the interview with three short questions about technology, provided emotional relief and lifted the mood discernibly from the more serious discussions of their diagnoses.

We found all participants use and enjoy digital technologies. P1 and P4 had technical backgrounds and a keen interest in technology. P2 and P3 were avid fans of the iPad. Meanwhile, P5 is very comfortable with a smartphone. As such, all participants greatly enjoyed this part of the interview - perhaps not having to dwell on talking explicitly about dementia.

#### **Hanging out and sharing stories**

When working with our participants, we found that to learn about an individual's experience of dementia is not just something that you can walk straight into and walk out from. This is especially so because we are not interested in superficial snapshots of these individuals' lives. Our aim is to develop first-hand, richly layered understandings of YOD. To achieve this, we found that we needed to spend a lot of time gradually building rapport, and slowly establishing a working relationship with each individual. Our participants only began to gradually reveal their lived experiences with dementia when they felt that they trusted us enough. For example, P4 said that "*face-to-face visits helped build trust – more personable*", while P5 "*enjoyed the regular communication and the face to face visits/lunches*" and said it "*builds trust*". P5 also said that "*it was good to have an additional person to talk with about the experience*".

As we explained earlier, we quickly learned from our participants that we couldn't adopt a formal interviewing approach where we ask a series of questions that focus on their experiences with dementia. With this in mind, the first author's visits were primarily about 'hanging out', over many months, spending time with them and sharing stories. She felt privileged being granted access - to be there to observe and interact. This provided opportunities for her to clarify certain things with the participant. There wasn't a way to predict what might trigger particular stories about their dementia. Having developed a relationship allowed the first author to recognise signs as to when each individual is ready to confide and talk about his/her experiences.

Even when talking about such experiences, these emotionally-charged stories couldn't be forced or rushed.

They build over many different visits, with more dimensions and new layers of these experiences gradually appearing. We found that we simply had to be patient, and persevere; to allow our participants to share their experiences with us on their own terms and in their own time. Humour and positivity were evident throughout the research. We found that all individuals had developed a positive way of looking at life which was an uplifting aspect of this research for all involved.

**Probes**

While the probes used in this study are not at all revolutionary, our way of using them has not been previously reported. Our use of probes has led us to explore alternative and maybe more productive means of data collection. We found that the use of these co-designed probes allowed us to address some of the methodological challenges of working directly with a person living with dementia.

**Flexibility**

We found that providing flexibility and options, as well as the choice of tools for our participants to share their stories was really successful. For example, P4 has found it challenging to handwrite extensively. But he is interested in technology, so he was happy to be able to record his thoughts, *“good to have the option of voice recording because I enjoyed the process of recordings.”* In fact, P4 sent the first author his recordings daily throughout the study period.

The flexibility and options allowed participants to decide which way they felt most comfortable (and enjoyable) communicating. Our participants used different media to communicate their everyday experiences. Their choices were closely related to their symptoms of dementia. For example, P5 also some limitations with his handwriting but enjoys texting and the use of emoticons. The emoticons helping him express his moods and support his message (see Fig. 2).

On the other hand, P1 was able to use different options to express himself. He presented extensive hand-written notes in his diary (see Fig.1). At the same time, he created a number of digital data which he provided to us online. These included voice recordings of his thoughts (see Fig.2) and poems he wrote about his experiences (Fig.3). He also posted these materials on a website he developed. P2 was very expressive but did not enjoy handwriting to share her thoughts. She preferred to type up her experiences on an iPad. Her profession as a lawyer is revealing in the way she organises her thoughts and the way she presents her data. This is the only option she chose. P2 also included personal photos and pictures to help illustrate her stories (Fig.4).

All participants were very keen on having the flexibility of communicating their experiences in various forms, including

writing, texting, audio recording and taking photos/videos and through various mediums - including emails, SMS and blogs. The flexibility suggested by P1 and P2, was most effective in supporting the varying cognitive abilities of those in the study.

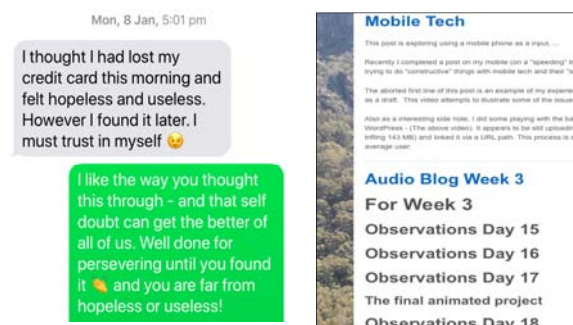
**Participants as co-researchers and collaborators**

Right from the beginning of the study, we were clear with our participants that we are open to them being co-researchers and collaborators. As such, they felt that they were able to provide open and unsolicited feedback on how they were experiencing being a part of the study. In fact, they were actively participating and contributing to this research throughout this study. Our participants actively research materials in the area of dementia. They try to stay abreast with advances in dementia. Besides research for personal interests, P1, P3, P4, P5 are also participating in different dementia organisations to develop policies on various issues such as palliative care, end-of-life planning, and policies on decision-making rights.

P1, P2, and P4 regularly forwarded links to relevant research papers and related projects as well as interesting technologies that they felt might be useful to this research. P2 also offered her legal expertise to the first author discussing the legal aspects of researching dementia. This helped the first author to continue learning about YOD and their situation, as well as helping to broker and broaden her network with different YOD communities. Treating each participant as a co-researcher also means that the first author would share relevant findings and thoughts about her research with the individual participant. This sharing is to ensure that they are not only kept informed but have the opportunity to clarify and add to the findings.

**DISCUSSION**

Our findings reveal the value of our research approach and the method and tools we used when conducting qualitative research with participants living with YOD. It demonstrates how HCI can support research with YOD individuals in sensitive, respectful and appropriate ways. Here we discuss and reflect on the research process to provide considerations



**Figure 2: Examples of texts and audio recordings**



and suggestions for HCI researchers wishing to work with individuals living with YOD.

### Reconnaissance and learning from participants

Most qualitative research of dementia provides guidance on how to research with older adults living with dementia, people who are classified as being in a vulnerable group. This is because a lot of the work is conducted with individuals living with more advanced stages of dementia and thus, requiring the assignment of a proxy in dementia research (highlighted in the literature review) as an ethical consideration. However, this is entirely at odds when researching with those living with YOD.

These younger individuals living with dementia are independent, often still working, engaged with life, live with less severe cognitive decline and very capable of providing informed consent. All of our participants are well educated and some continue to engage in demanding social roles. They are actively involved with their health decisions, reflective about their situation, fiercely independent and very vocal about their rights and agency. Given the lack of guidance on how to work with such individuals, we realise how beneficial it was to invest the time to build familiarity and sensitivity to the situation of these individuals.

First, it made us realise that the use of a proxy when researching with them is not only unnecessary but in fact, undesirable. This is not to say that we don't value the role of a trusted support person or partner in this research. We quickly learned though - with our participants - is that it is much more appropriate and productive for the research to involve them as co-researchers and collaborators. Second, we learned that dementia affects individuals very differently, affecting the abilities of the person in very individually-specific ways. That is why it was necessary to offer flexibility and options when designing data-capture tools for these individuals to use during research.

But here, we must also stress the need and benefits of collaborating with some of our more reflective participants to

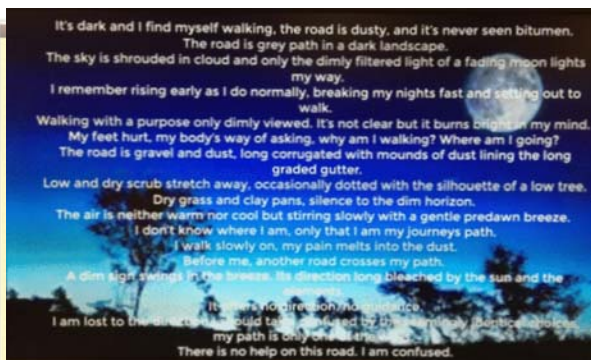


Figure 3: A screen capture of P1's video and poetry

adapt, trial and refine the tools they will use to collect data during the research. Having them work directly with the tools taught us about the need to consider the ethical and physical demands we might impose on our participants. This includes being reminded of using appropriate language in instructions, the difficulties that individuals might have with particular types of tasks due to unique changes in their brain and cognitive processes, the ongoing and unpredictable changes dementia has on the individual, and so on.

Having a few of our participants trial the tools meant that we more confident to offer options and flexibility for individuals. This allowed them to feel included; and able to contribute in ways that they felt most comfortable with and that best suited them at that particular point in time.

### Participants as collaborators

Deciding and inviting participants as co-researchers and collaborators taps into, and supports their sense of agency Working in health, Tanner [27], highlights growing evidence that people with dementia want to participate in research and benefit from their involvement. However, little attention has been given to date to the potential to involve people with dementia as co-researchers - not just participants. As we stress again, there is also no robust guidance on how to involve them as co-researchers. Tanner's attempt to work with an elderly individual living with dementia (as a co-researcher), helping him to conduct interviews with others living with LOD is a stark exception in dementia research. But what she demonstrated is the potential of this approach to support agency and personhood for those with dementia. While Tanner's approach will need to be reconsidered with YOD, it is certainly an affirmation on our approach and a definite call for others to explore this approach further.

### Recruitment

Recruitment of the elderly living with dementia is not a particular issue. Such research is very established and is generally conducted in hospitals, care homes and dementia care facilities. However, as we mentioned in our literature review and findings, people living with YOD fall outside the age limits of aged care services and systems. This, coupled with the fact that they are often still engaged with life (in family and work settings) makes it difficult to identify specific places to connect and recruit younger people with dementia.

People with YOD are difficult to identify as there are no visible physical characteristics of dementia. Many are still unaware of their condition due to reported delays in an accurate diagnosis. Participants self-identify only after a medical diagnosis. There is also a lack of formal support

Figure 4: an iPad journal entry by P2



services and communities where researchers can go to recruit. Many research disciplines are interested in researching YOD and individuals are asked to participate in more than one research project. This compounds the challenge of recruitment and engaging participants in longitudinal research. While it is generally good practice to respect peoples' time in research most people with YOD are aware of their cognitive decline and short-lived ability to contribute 'directly' to research. That is why it is paramount to invest in the relationships with YOD individuals when they offer to give up their precious time to support research. Researchers must also continue to find meaningful ways to engage them by supporting their desire for greater agency and autonomy in the process.

We learned that individuals who are more engaged with YOD social issues are often more likely to want to contribute and participate in research. Connecting with organisations where people living with YOD are seeking to establish public discussions and agendas, such as Dementia Alliance International (DAI) allowed us to connect with those living with YOD. DAI is a non-for profit organisation with membership exclusively for people with dementia from around the world. This organisation is widely accepted as 'the global voice of dementia'. Key conferences such as Alzheimer's Disease International (ADI) is the world's largest and most important conference on dementia and Alzheimer's disease with scientific and non-scientific content (including Technology) about the latest advances in dementia care. Such conferences are of increasing interest for those with YOD.

Local Dementia organisations often have YOD research streams that can be helpful with recruitment. However, we found that connecting with and recruiting individuals with YOD through such organisations can take a long time, as there are often many 'gate-keepers' that we had to move through before being introduced to potential participants.

### **Interviewing**

We learned a great deal from our participants about interviewing people with YOD. Our participants taught us what to expect when conducting interviews; such as the need to carefully plan and consider the pace. We understand now, the need for warm introductions and an informal lead-in before the more formal interview, the usefulness of stories in soliciting richer accounts and the need to shift to topics that can help diffuse somewhat serious mood of discussing a life with dementia. Most importantly, when interviewing in this setting, it is essential to foster a relaxed ambience and focus on the personhood of the YOD individual.

We learned to be aware of the sensitive nature of these stories, as individuals recount them. Many individuals may still be coming to terms with their own diagnosis of YOD.

Each person will experience this differently. We learned that recounting these stories to others can make the individual feel very exposed as they revisit and reflect upon their particular circumstance post-diagnosis. We had to look for signs of distress when our participants recalled their experiences. As we will discuss in the next section, researchers should always ensure that they have some support mechanisms in place – for both the researcher and participant. We found that allowing some 'social' time to warm up and build rapport, through informal chats before and after the interviews certainly made interviewing less stressful for our participants.

We also learned (from our participants), to be sensitive to time and to consider 'dementia time' which involves finding out how each individual keeps track of time. With regards to meeting people for the first time, there is one aspect of dementia known as 'prosopagnosia' (face blindness) which is a specific type of deficit that refers to being unable to recognise faces and is a perceptual problem. In this research, P1 experiences face blindness when meeting someone new. So, the first author would wear bright yellow gloves when they meet up at the train station, to help him recognise her. This visual cue helps with identification in crowded places. After a while, the non-facial cues develop, and one can be identified through voice tone, body language, hairstyle, smell and laughter. The 'non-facial' cues only develop for the person with dementia when they get to know a people over time.

### **Adapting the use of probes**

Cultural probes, initially developed by Gaver et al [36], were designed as a tool to elicit participants' ideas and thoughts and values. It 'valued uncertainty, play, exploration' and thrived on the designers' subjective interpretation of responses to offer inspirational insights into new ideas/opportunities for design. However, our use of probes in this study follows the examples whereby probes were used as a supplement to interviews to collect information and to gain deeper and richer understandings into their participants' everyday lives [29, 37]. For example, Crabtree et. al., [37] used 'informational probes' to identify the varying care and support needs of former psychiatric patients, elderly, and disabled people living at home. This use of probes has become common as highlighted in [38].

Traditionally, designers maintain total control over how probe kits are designed and how responses are interpreted. This could mean that probes are not participatory enough to engage participants in the research project [38]. This could also mean that designer-led probes might not necessarily be the best fit for some participants; particularly for participants with varying abilities (e.g. when working in sensitive settings such as dementia [29]). Just like [39-41] we agree that

participants should be involved in interpreting responses to design ideas. In fact, we extended this further in our study by co-designing the probe kit with our participants; allowing them greater control in the research design process. This has yielded fruitful results as our participants became highly engaged over the course of this longitudinal study. These researcher-participant conversations remain ongoing beyond the research period. To the best of our knowledge, co-designing probes with participants particularly in dementia settings have not been reported in HCI research.

Another aspect about probes that have not been explicitly discussed in HCI is the introduction of flexibility into the use of probes. In our research, participants could self-select the particular probes and reporting mediums. Our participants could also personalise their probes (see Figures 2, 3, 4). Again, one participant chose a diary because he is skilled in writing and writes extensively. He designed and used self-annotated labels on each page as a personal prompt. Another chose an audio recorder because his ability to write is diminishing. In contrast to common HCI inquiries our first two participants tested and validated the tools, structure and duration of each activity before we extended this to the next participants taking part in the study.

As for PAR projects, we have not come across reports where participants could co-design, self-select, test tools and provide feedback during the inquiry phase. Similarly, while co-design involves participants in the design of prototypes, we have not found reports where they were involved in co-designing and choosing their tools of inquiry.

### **Vulnerability and Managing Stigma**

It is important to discuss and reflect upon the notion of vulnerability in dementia research. As we mentioned earlier, when applying for ethics approval all individuals with a diagnosis of dementia are automatically classified as belonging to a vulnerable group. For our participants, and from what we learned when attending conferences concerned with dementia, most people with YOD are adamant not to be labelled as victims. Still, this is not to say that vulnerability should be overlooked.

Over the course of this study the researchers, the individuals with YOD and their families, were in a sense ‘vulnerable’, particularly when one is exchanging stories of a deeply personal nature. Managing these moments requires great sensitivity, respect and empathy on the part of the researcher. We mentioned earlier the need to be careful with the language choices used when conducting research in the dementia setting. During our reconnaissance work and throughout the extensive fieldwork, we continued to be

reminded of how strongly these individuals feel about particular terms and phrases. In our experience, people with YOD do not want to be known as ‘sufferers’ or be framed as a ‘burden’ to their loved ones or to society. This was also noted by others [42-44].

### **CONTRIBUTIONS OF THIS PAPER**

This paper makes a number of methodological contributions to HCI and PAR. To the best of our knowledge, this paper provides the first description of an approach for how HCI researchers can conduct research sensitively and productively with YOD individuals. In particular, it describes an example and provides guidance on how researchers can collaborate successfully with these individuals as co-researchers in a co-directed inquiry into the lived experiences of YOD. This paper also contributes to the small but growing number of cases showing how PAR can be used in HCI inquiry. In fact, it provides the first account of how we can use PAR in HCI research with YOD individuals.

Furthermore, we add to understandings on how probes can be used productively in HCI by providing an example of how probes can be co-designed with participants, and how participants freely select and personalise the probes. To our knowledge, this highly collaborative and participant-centred approach to using probes in inquiry has not been explicitly discussed in HCI publications to date. Individuals have particular preferences, abilities and styles where they are more comfortable expressing themselves. Given this, we would urge researchers to be more reflective in how we design probes to ‘communicate’ with us during an inquiry process – with discussions or even negotiations with participants before we design the probes. Additionally, it may be pertinent for researchers to consider whether it may be more effective if participants are given the freedom in how they choose to complete probe activities.

Finally, this paper provides an example of how probes can be used and applied in PAR. We argue that the learnings from this paper can be applied beyond YOD research settings, into research in the general population. In a way, this is akin to learnings that can be applied when working with lead users [46] or extreme characters [45].

### **CONSIDERATIONS FOR FUTURE RESEARCHERS**

Research in the field of dementia is highly complex, challenging and equally rewarding. To engage seriously in research in the area YOD requires a great deal of tenacity, empathy, sensitivity and a high level of insight and personal awareness. The reciprocity experienced by being open as a researcher to letting people into your life can be very emotionally satisfying and moving - despite the challenges.

With this in mind, we offer the following recommendations for research in YOD settings.

*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 and implementation of the fieldwork. This will support the varying needs and abilities of the individuals with dementia. The level of flexibility may best be negotiated with the participants early in the design phase.

*Varying abilities:* Be mindful of the variation in abilities of a person with YOD. Individuals might have particular types of tasks they prefer to undertake - due to unique and individual changes in their cognitive processing.

*Complexity:* It is helpful for the researcher to be aware of the unpredictable physical, emotional and intellectual changes that come with a diagnosis of dementia and be prepared to personally adapt and adjust to this over time.

*Trust:* Create opportunities for trust to emerge. This takes time. While it takes emotional fortitude to research in dementia over a prolonged period of time, particularly as the personal attachments form, it is deeply rewarding.

We stress here the explicit need and value of collaboration and co-design in trialling this methodological approach in HCI research for dementia and other similar settings.

## LIMITATIONS AND CONCLUSION

While this paper presents rich insights developed in collaboration with five individuals living with YOD, we must acknowledge that this study and the methodological recommendations we offer here, has its limitations. Our co-researchers are from similar cultural and ethnic backgrounds. They are well-educated professionals and have sound socio-economic status. On reflection, this may be the reason they were more 'visible', allowing us to connect and recruit them into this research. Their backgrounds may also suggest why they have a strong sense of agency and why they volunteer in public positions to advocate for those with similar experiences of YOD. Furthermore, their particular career backgrounds, some being academics, may suggest why they feel strongly about being co-researchers.

Future research that involves using this approach with different demographics and cultural backgrounds, will allow us to reveal further nuances and refine our methodological toolbox. In a situation where there is a lack of guidance, the collaborators in this research feel very much like von Hippel's [46] 'lead users' - the most advanced users in the field of

interest, who can help uncover innovative ideas to benefit and extend technology research into broader HCI settings and populations.

## REFERENCES

- [1] WHO. 2017. Dementia: Key Facts.
- [2] A. Withall, Draper, B., Seeher, K. and Brodaty, H. . 2014. The prevalence and causes of younger onset dementia in Eastern Sydney, Australia'. *International Psychogeriatrics*, 26. 1955-1965. 10.1017/S1041610214001835.
- [3] Laurie Brown, Erick Hansnata and Hai Anh La. 2017. ECONOMIC COST OF DEMENTIA IN AUSTRALIA.
- [4] Lenore J Launer. 2019. Statistics on the burden of dementia: need for stronger data. *The Lancet Neurology*, 18 (1). 25-27.
- [5] Janet Sansoni, Cathy Duncan, Pamela Grootemaat, Jacquelin Capell, Peter Samsa and Anita Westera. 2016. Younger Onset Dementia: A Review of the Literature to Inform Service Development. *American Journal of Alzheimer's Disease & Other Dementias*, 31 (8). 693-705. 10.1177/1533317515619481
- [6] Martin N Rossor, Nick C Fox, Catherine J Mummery, Jonathan M Schott and Jason D Warren. 2010. The diagnosis of young-onset dementia. *The Lancet Neurology*, 9 (8). 793-806.
- [7] Nan Greenwood and Raymond Smith. 2016. The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas*, 92. 102-109.
- [8] Deliane van Vliet, Marjolein E. de Vugt, Christian Bakker, Raymond T. C. M. Koopmans and Frans R. J. Verhey. 2010. Impact of early onset dementia on caregivers: a review. *International Journal of Geriatric Psychiatry*, 25 (11). 1091-1100. 10.1002/gps.2439
- [9] Suzanne Cahill, Emer Begley, Päivi Topo, Kristiina Saarikalle, Jurate Macijauskiene, Austra Budraitiene, Inger Hagen, Torhild Holthe and Kerry Jones. 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*, 3 (3). 313-330.
- [10] T. Kitwood. 1997. The experience of dementia. *Aging & Mental Health*, 1 (1). 13-22. 10.1080/13607869757344
- [11] Murna Downs. 1997. The emergence of the person in dementia research. *Ageing and Society*, 17 (05). 597-607.
- [12] Stu Favilla and Sonja Pedell. 2013. Touch screen ensemble music: collaborative interaction for older people with dementia. in *Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration*, ACM, 481-484.
- [13] Tira Cohene, Ron Baecker and Elsa Marziali. 2005. Designing interactive life story multimedia for a family affected by alzheimer's disease: a case study. in *CHI'05 extended abstracts on Human factors in computing systems*, ACM, 1300-1303.
- [14] Nam Tung Ly, Dominik Gall and Stephan Huber. 2016. Tangible interaction drawers for people with dementia: retrieving living experiences from past memories *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct*, ACM, Heidelberg, Germany, 157-160.
- [15] Nam Tung Ly, Audrey Serna and Samir Aknine. 2016. Towards Supporting Caregivers to Monitor the Whereabouts of People with Dementia *Proceedings of the 9th Nordic Conference on Human-Computer Interaction*, ACM, Gothenburg, Sweden, 1-4.
- [16] Cathrine Arntzen, Torhild Holthe and Rita Jentoft. 2016. Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. *Dementia*, 15 (4). 646-662.
- [17] Andrea Mayrhofer, Elspeth Mathie, Jane McKeown, Frances Bunn and Claire Goodman. 2017. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. *Aging & Mental Health*. 1-9.
- [18] Marita A. O'Brien, Wendy A. Rogers and Arthur D. Fisk. 2012. Understanding age and technology experience differences in use of

- prior knowledge for everyday technology interactions. *ACM Trans. Access. Comput.*, 4 (2). 1-27. 10.1145/2141943.2141947
- [19] Jeanette Bell and Tuck Wah Leong. 2017. Collaborative futures: a technology design approach to support living well with dementia. in *Proceedings of the 29th Australian Conference on Computer-Human Interaction*, ACM, 397-401.
- [20] John McCarthy and Peter Wright. 2004. Technology as experience. *interactions*, 11 (5). 42-43. 10.1145/1015530.1015549
- [21] Joanna Evans, Michael Brown, Tim Coughlan, Glyn Lawson and Michael P Craven. 2015. A systematic review of dementia focused assistive technology. in *International Conference on Human-Computer Interaction*, Springer, 406-417.
- [22] Karin Bendiksen. 2013. Dementia patients embrace GPS surveillance.
- [23] Michael Brown, Allen Tsai, Sharon Baurley, Therese Koppe, Glyn Lawson, Jennifer Martin, Tim Coughlan, Meretta Elliott, Stephen Green and Unna Arunachalam. 2014. Using cultural probes to inform the design of assistive technologies. in *International Conference on Human-Computer Interaction*, Springer, 35-46.
- [24] Dementia Working Group Research Sub Scottish and UK Group. 2014. Core principles for involving people with dementia in research: innovative practice. *Dementia (London, England)*, 13 (5). 680.
- [25] Jan Dewing. 2002. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1 (2). 157-171.
- [26] Theresa F Moore and Jane Hollett. 2003. Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nursing Science Quarterly*, 16 (2). 163-167.
- [27] Denise Tanner. 2012. Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21 (3). 296-306.
- [28] Jeanette Bell and Tuck Wah Leong. 2017. Collaborative futures: a technology design approach to support living well with dementia *Proceedings of the 29th Australian Conference on Computer-Human Interaction*, ACM, Brisbane, Queensland, Australia, 397-401.
- [29] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ACM, Paris, France, 2617-2626.
- [30] Tim Coughlan, Michael Brown, Derek McAuley, Sharon Baurley, Allen Tsai, Therese Koppe, Meretta Elliott, Stephen Green, Jen Martin and Glyn Lawson. 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*, ACM, Seattle, Washington, 35-38.
- [31] David Green and David Kirk. 2018. Open Design, Inclusivity and the Intersections of Making. in *Proceedings of the 2018 Designing Interactive Systems Conference*, ACM, 173-186.
- [32] Margot Brereton, Paul Roe, Ronald Schroeter and Anita Lee Hong. 2014. Beyond ethnography: engagement and reciprocity as foundations for design research out here. in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ACM, 1183-1186.
- [33] Joan K Magilvy and JoAnn G Congdon. 2000. The crisis nature of health care transitions for rural older adults. *Public Health Nursing*, 17 (5). 336-345.
- [34] Soud Nassir and Tuck Wah Leong. 2017. Traversing Boundaries: Understanding the Experiences of Ageing Saudis *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, ACM, Denver, Colorado, USA, 6386-6397.
- [35] Tuck Wah Leong, Peter Wright, Frank Vetere and Steve Howard. 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*, ACM, Brisbane, Australia, 256-263.
- [36] Bill Gaver, Tony Dunne and Elena Pacenti. 1999. Design: cultural probes. *interactions*, 6 (1). 21-29.
- [37] Andy Crabtree, Terry Hemmings, Tom Rodden, Karen Clarke, Guy Dewsbury, John Hughes, Mark Rouncefield and Ian Sommerville. 2002. Sore legs and naked bottoms': Using cultural probes in dependability research. *School of Computer Science and Information Technology, University of Nottingham* [http://www.mrl.nott.ac.uk/~axc/documents/DIRC\\_2002.pdf](http://www.mrl.nott.ac.uk/~axc/documents/DIRC_2002.pdf). 1.
- [38] Kirsten Boehner, Janet Vertesi, Phoebe Sengers and Paul Dourish. 2007. How HCI interprets the probes *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ACM, San Jose, California, USA, 1077-1086.
- [39] Alia K Amin, Bram TA Kersten, Olga A Kulyk, PH Pelgrim, Chih-Ming Wang and Panos Markopoulos. 2005. SenseMS: a user-centered approach to enrich the messaging experience for teens by non-verbal means. in *Proceedings of the 7th international conference on Human computer interaction with mobile devices & services*, ACM, 161-166.
- [40] Sami Hulkko, Tuuli Mattelmäki, Katja Virtanen and Turkka Keinonen. 2004. Mobile probes. in *Proceedings of the third Nordic conference on Human-computer interaction*, ACM, 43-51.
- [41] Eric Paulos and Tom Jenkins. 2005. Urban probes: encountering our emerging urban atmospheres. in *Proceedings of the SIGCHI conference on Human factors in computing systems*, ACM, 341-350.
- [42] Janet Sansoni, Cathy Duncan, Pamela Grootemaat, Peter Samsa, Jacquelin Capell and Anita Westera. 2014. Younger onset dementia: a literature review, Centre for Health Service Development, University of Wollongong.
- [43] Jacqui Allen, Jan R Oyeboode and Joanne Allen. 2009. Having a father with young onset dementia: the impact on well-being of young people. *Dementia*, 8 (4). 455-480.
- [44] AlzheimerAustralia. 2017. Dementia language guidelines.
- [45] J. P. Djajadiningrat, W. W. Gaver and J. W. Fres. 2000. Interaction relabelling and extreme characters: methods for exploring aesthetic interactions *Proceedings of the 3rd conference on Designing interactive systems: processes, practices, methods, and techniques*, ACM, New York City, New York, USA, 66-71.
- [46] Eric von Hippel. 1989. New Product Ideas from 'Lead Users'. *Research-Technology Management*, 32:3. 24-27. 10.1080/08956308.1989.11670596