# Chapter 1. Methodology

## Introduction

In the previous chapter, I have described the evolution of gerontology research in dementia that once questioned the biomedical view of dementia, towards now a political model of dementia that encompasses individuality, relationships, and supporting decision-making. Additionally, I discussed the relevant ways researchers engage with lived experiences of dementia by con- structing safe spaces that lean on creativity and long-term engagements to support relationships between the researcher and person with dementia. The literature then moved to HCI and de- mentia literature that has been inspired by the past 20 years of social research in the dementia domain. The literature highlights additional challenges in designing technology with and for people with dementia, resulting in HCI researchers forming a strong relational basis for design practice. These practices include involving the person with dementia in the research processes, understanding the individual’s individuality, and acknowledging that dementia is a complex experience that often includes social complexities, ageing, and multi-morbidities, which requires attuning to in design and research responses.

In this chapter, I describe the methodological approach taken in the thesis that stretches across the data chapters. Based on my understanding, I took a social constructionist approach to this research, in which the creation of knowledge is a collaborative process. Therefore, the way I structured the study and interpreted the data is significantly influenced by my relationship with the participants and my understandings of dementia ([Surr](#_bookmark49), [2006](#_bookmark49)). Further, social constructionism argues that the self is formed through language and interactions of varying kinds that are equally important in defining the person’s individuality ([Sarup](#_bookmark43), [1996](#_bookmark43)). Viewing the data this way recognises the non-verbal and actions of people with dementia with value and intention. I begin the chapter by introducing the primary design approach I adopted, Participatory Design, a methodology to design artefacts, systems or products while building relationships and engaging with the targeted population group ([Duarte et al.](#_bookmark12), [2018](#_bookmark12)). In this section, I describe its history in HCI. Following, I unpack participatory methods in dementia and HCI that emphasise the approach’s opportunities and pitfalls. I then discuss the ethical complexities of the thesis; an overview of the data collection of the four data chapters; and the qualitative data analysis method, thematic analysis and reflexive practice. This chapter closes with summarising the methodology for the thesis.

## Methodology

* 1. **Value in the lived experience**

For the past 20 years, it has been accepted that dementia is not solely reliant on someone’s cognitive abilities but rather made up of a set of bio-social-psychological factors that calls attention to centre the individual with dementia in research, practice and their care ([Dewing](#_bookmark10), [2008](#_bookmark10)). The shift in recognising the person with dementia’s individuality emphasised the value in engaging and understanding the lived experiences and stories of people with dementia and their care partners. Recently, [Bartlett and O’Connor](#_bookmark3) ([2007](#_bookmark3)) have moved beyond solely individual values through a citizenship lens that recognises the potential power relationships that will likely stem from a diagnosis of dementia. The authors argue that a lens that considers not only the power dynamics but also the relationships to the person and the unique nature of the individual are all connections we must consider when reflecting on the dementia context. Moving towards a citizenship model has empowered and promoted people with dementia to share their experiences to make themselves more visible to impact policymaking, practice and research.

[Ewick and Silbey](#_bookmark14) ([1995](#_bookmark14)) describe how narratives can be subversive, and to a degree, the stories we tell *"make visible and explicit connections between particular lives and social organ- isations"*. These stories that we tell of our respective worlds, open up new ways of being and may drive the lens that we view dementia, towards one that puts forth narrative, personhood, and citizenship where no lens overshadows another but instead work together in harmony ([Dupuis](#_bookmark13) [et al.](#_bookmark13), [2016](#_bookmark13)). Baldwin draws on these connections along with coining the concept as narrative citizenship ([Baldwin](#_bookmark1), [2008](#_bookmark1)). Still, for this to exist, it depends on the ability to tell a story through either:

"a) being able to express oneself in a form that is recognisable as a narrative, even if one’s linguistic abilities are limited. b) having the opportunity to express oneself narratively" ([Baldwin](#_bookmark1), [2008](#_bookmark1)).

The lack of involvement of people with dementia’s experiences in research has primarily come from the expectation that people with dementia do not communicate to ’social norms’ - promoting stereotyped narratives that have further excluded people with dementia. Returning to Baldwin, the researcher highlights the use of arts and creativity to provide alternatives to verbal communication that extends the importance of finding unique ways to offer people with dementia the opportunity to share their experiences. Through humour, dancing, acting, music, movement, and fashion, people living with dementia can evoke narratives and identity that can be particularly effective for those who may have their narratives’ dissolve’ as the condition develops [John Killick Claire Craig](#_bookmark24) ([2012](#_bookmark24)).

As the narrative of dementia continues to grow and change through the sharing of lived experiences, we must continue to explore ways to represent the voices of those who are continued to be underrepresented through creative ways to involve these individuals in the conversation and

## 1.3 Participatory Design

amplify their voices. [Swarbrick](#_bookmark50) ([2015](#_bookmark50)) argues research approaches should be more collaborative where people with dementia are recognised for their contribution. The following sections describe the growing interest in participatory design methods and their adoption in dementia research to enable participants to participate in the study actively.

## Participatory Design

Participatory design (PD) has been influential in various social research fields, including HCI ([Bannon et al.](#_bookmark2), [2018](#_bookmark2)). As the name implies, PD is about the *design* of systems, products, or knowledge through *participatory* methods to understand how users may interact or use an artefact or practice. These methods draw from ethnographic observations, interviews, focus groups, and qualitative content analysis. [Carroll and Rosson](#_bookmark8) ([2007](#_bookmark8)) articulate the importance of user participation from the following:

"The ’users’ – that is, the people who stand to have their activity and experience transformed – ought to have a direct say and a meaningful role in how that comes to pass at the very least because they know a lot about what is precious and what is annoying in their current activity and experience, but equally because they are morally entitled to have a say in anything that might change everything." ([Carroll](#_bookmark8) [and Rosson](#_bookmark8), [2007](#_bookmark8))

Through these participatory approaches, PD aims to create a collaborative space between developers and the population group that was often separated from the design stages due to different experience levels ([Duarte et al.](#_bookmark12), [2018](#_bookmark12)). Subsequently, PD has a significant political history where early PD work in the 70’s *"sought to rebalance power and agency among managers and workers"* ([Bannon et al.](#_bookmark2), [2018](#_bookmark2)). Although PD has radically altered from what it was in the 70’s, PD is still a popular approach to tackle communication barriers between different expertise levels.

Within the general structure of PD, [Halskov and Hansen](#_bookmark16) ([2015](#_bookmark16)) argue they are five funda- mental aspects of PD:

* + 1. politics - *"people who are affected by a decision should have an opportunity to influence it"*
    2. People - *"People play critical roles in design by being experts in their own lives"*
    3. Context - *"The use situation is the fundamental starting point for the design process"*
    4. Methods - *"Methods are means for users to gain influence in design processes"*

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* + 1. Product - *"The goal of participation is to design alternatives, improving quality of life"*

Halskov & Hansen review highlight that HCI and other fields are diversifying and rethinking what participation may be within their domains, resulting in a highly diverse set of studies that reconfigure methods to fit the needs of participants to provide participation - particularly those who are considered marginalised, such as children, older adults and those who have varying cognitive deficits. For instance, [Spiel et al.](#_bookmark46) ([2018](#_bookmark46)) conducted a series of PD studies with marginalised children that describe a set of ethical challenges of conducting PD within the space and the necessity to tailor participation for the children. The authors present detailed insights into tailoring PD processes to negotiate *"what the children can do and the desires they have"*, design safe and attuned spaces *"for the participation of children on their own terms"* and "*make ethical judgments"* that are attuned to kindness and learning. Furthermore, [Vines et al.](#_bookmark52) ([2013](#_bookmark52)) describe several issues that PD needs to address. These challenges centre on the shared control and agency between researchers and participants. For instance, the author’s highlight the need for transparency of participant and researcher’s roles; how researchers present and analyse participants contributions; and further examine how participants can take agency of the design process and reinvent methods to suit their needs.

As described above, while PD literature describes the flexibility in adapting to many different populations, communities that may be marginalised often come with complex, unforeseen tensions that require sensitive and personal consideration to provide collaborative engagement between the researcher and the marginalised community ([Harrington et al.](#_bookmark18), [2019](#_bookmark18)). With this in mind, the following section provides insight into the adaptation of PD approaches to fit the needs of people with dementia.

## Reconstructing participatory design methods for people with dementia

By tradition, early research in dementia has typically use focus groups, interviews, and involving stakeholders who are ’experts’ in the field such as care-partners to make design decisions on behalf of people with dementia ([Branco et al.](#_bookmark5), [2017](#_bookmark5)). This take on dementia research has often seen dementia as a cognitive problem, and in turn, constructed an assumption that people with dementia cannot participate due to verbal and communication issues. As we live in a society that places a high value on cognitive ability, a diagnosis of dementia can put significant strain on meaningful interactions, relationships, and activities. Authors have argued that when a person has dementia, their cognitive dysfunction erodes our being-in-the-world ([Hampson and Morris](#_bookmark17), [2016](#_bookmark17)), adversely affecting a sense of belonging and, therefore, a sense of self.

However, as our understanding of dementia has changed over the years, so have our methods of involving and presenting the lived experiences of people with dementia. [John Killick Claire](#_bookmark24)

## [1.4 Reconstructing participatory design methods for people with dementia](#_bookmark24)

[Craig](#_bookmark24) ([2012](#_bookmark24)) work in Creativity and Communication in Persons with Dementia, describe the importance of expression through the arts:

"Creativity is an expression of who we are, and when the arts form the vehicle or the means of channeling this creativity, the end result can embody something of the artist and their facets of personality" [John Killick Claire Craig](#_bookmark24) ([2012](#_bookmark24)) pg.17

The authors highlight alternative ways that people with dementia can participate and express themselves, such as - laughing, music, writing, and painting. [Ryan et al.](#_bookmark41) ([2009](#_bookmark41)) draw on creative methods for communication and expression through writing as a way to reclaim some sense of social identity, structure, and clarity on distinct thoughts and feelings. Furthermore, writing projects a sense of self to loved ones, helping family members see past a relative’s dementia and drawing attention to the creative potential for the person living with dementia.

Likewise, some HCI research has expanded to explore how new technologies can attune to the creative wishes of people living with dementia. [Lazar et al.](#_bookmark30) ([2017](#_bookmark30)) takes a critical dementia perspective to focus on how arts-based activities enable researchers to learn and draw from the experiences of people living with dementia. The author’s work into understanding the way art therapists configure the space for engagement noticed ways to encourage those living with dementia to express themselves by simply being in the moment. Taking part was noticed through *"subtle shifts in gaze, facial expressions, and verbalisation"* and highlights the importance of tailoring the environment such as the brush, canvas and colours to fit the individual. The individuality in approach, suggests an enable for *"connection between a person’s ’inner world’ and ’outer world’"*, where individuals can express, reflect and process thoughts and ideas that come to them. This embodied connection calls for methodologies that focus on bodily movement and action to learn from how people living with dementia configure their participation ([Morrissey](#_bookmark36) [and McCarthy](#_bookmark36), [2015](#_bookmark36)).

[Stenhouse et al.](#_bookmark47) ([2013](#_bookmark47)) resonate with the work above in engaging people with dementia in designing and creating their own digital stores. The study invited seven people with early-stage dementia to a workshop where they participated in a series of activities such as recording their voices, and approaches to telling a story. Through the participation, Stenhouse reports the necessary facilitation required in supporting people with dementia in the digital storytelling process. While this required facilitators to have knowledge of recording and narrating stories, the priority was building person-centred relationships with the participants to promote a safe space for sharing the stories. Additionally, people with dementia reported confidence in learning skills they felt they had lost through their diagnosis that was achieved through encouragement and support from the workshop group. Last, the authors argue that not only was the research meaningful for people with dementia, but the development of a diverse set of stories of dementia may support the change of perceptions people have of dementia - a particular challenge I describe in the background literature.

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Similarly [Lindsay et al.](#_bookmark32) ([2012](#_bookmark32)) adopted participatory design approaches to design for early stages of dementia through a series of workshops. The author’s draw on the KITE approach that prioritised fostering an empathetic relationship between people with dementia and designers. The use of empathy is described as an invaluable consideration when working with people with dementia because of a) the need to tailor PD activities on the needs of people with dementia, and

b) that care-partners or anyone who does not have dementia should not act as a replacement for the involvement of people with dementia.

[Lindsay et al.](#_bookmark32) ([2012](#_bookmark32)) highlight several complexities through their participatory design ap- proach that researchers should be aware of when working within the dementia space. For instance, while the team aimed to opening up participation through recruitment stages, structured workshops, and forming relationships with participants, the authors share uncertainty in how their analysis of the data *"could, inadvertently, disempower the participants and undermind [their] relationship with [the] participants" (pg.528)*. The authors highlight the construction of the relationship and bond between people with dementia and the designers, has a knock-on effect where people with dementia were hesitant to critique designs in fear of offending one of the designers. Additionally, while caregivers took part in meetings, their involvement was to assist their loved ones in taking part in the research and communication if needed. This initial work highlights that despite the flexibility of PD, to adapt the approach in dementia requires careful consideration of the relational approaches that researchers may want to engage with to provide involvement of people with dementia. Further, the requirement of care partners highlights an ecology of care that may be considered when conducting participatory design work.

These ethical and methodological complexities of participatory design with people with dementia are echoed by [Hendriks et al.](#_bookmark20) ([2014](#_bookmark20)). While the paper argues that PD has value in design work and can actively include people with dementia, the authors take the opportunity to highlight that they are several challenges that researchers may encounter during PD. These include the burden of PD on the designer that has been underexamined; activities may be too stressful for the person with dementia where they are doing the researcher "a favour"; and power relations can not be mitigated when research is very one sided through designers and researchers learning a lot from the person with dementia and not vice-versa. Last, the authors describe PD methods are difficult to be translated to a variety of stages of dementia.

While [Lindsay et al.](#_bookmark32) ([2012](#_bookmark32)) , and [Stenhouse et al.](#_bookmark47) ([2013](#_bookmark47)) describe the necessary needs to individualise and personalise PD approaches to fit the needs of people with dementia, the workshops they present in the work would be challenging to implement for those at later stages of dementia who may need creative, non-verbal activities. Researchers will also often recruit early and mid stages of dementia for ethical research and ease of working with reasons. This is not to say the work is inaccurate or unethical, more so that PD approaches are difficult to fit the varying needs of different stages of dementia. [Bossen et al.](#_bookmark4) ([2012](#_bookmark4)) points out similar challenges where providing a long-term engagement, a two-way process and tailored PD approaches is not

## 1.4 Reconstructing participatory design methods for people with dementia

necessarily sufficient. This mirrors [Hendriks et al.](#_bookmark20) ([2014](#_bookmark20)) argument that people with dementia are doing the researcher a ’favour’ where they get little involvement. Throughout the thesis, what people with dementia get out of taking part in research is a concurrent theme that runs the data chapters.

To describe the PD approaches I have adapted in the thesis, the following subsections describe two types of participatory design that I have explored during the PhD:

* First, I describe the adaption of interviews as ’walking-interviews’ where people with dementia and families take the lead in the direction of the walking route and conversations

- seen in chapter four.

* Second, I describe the ways people with dementia are participating online through Twitter, blogs and online forums that was an essential aspect in the participatory design approach implemented in the hackathon seen in chapter five.

### Participating in interviews

Interviews can be framed in multiple ways but will often be structured or semi-structured. While structured interviews provide a limited set of categories and are used to compare and contrast participants answers to the same set of questions, semi-structured offers flexibility from the interview guide where the opportunity to dive into people’s experiences, thoughts and ideas can be investigated in a more approachable way. Of course, this has drawbacks where the free-from method is unlikely to provide comparisons between participant responses. Still, for working with researchers, people with dementia, designers and developers, it is an applicable interviewing procedure to explore complex everyday experiences ([Horton et al.](#_bookmark23), [2004](#_bookmark23)).

However, while structured and semi-structured approaches have been popular in dementia focused studies, multiple researchers have adapted the process to fit people with dementia better. For instance, [Mayer and Zach](#_bookmark34) ([2013](#_bookmark34)) describe how people with dementia may find answering abstract questions difficult, suggesting that interviews may require approval through people close to the person and materials relating to the questions that may elucidate conversation. [Suijkerbuijk](#_bookmark48) [et al.](#_bookmark48) ([2019](#_bookmark48)) systematic review highlight the combination of interviews with observations was a popular approach when involving people with dementia in generative or evaluative phases of a study. In many person-centred approaches, researchers will explore the person with dementia’s interactions in an everyday setting. However, interviews become a challenge when working with later stages of dementia or those with verbal deficits, and the researcher will prioritise observational data instead. These explorations are often studied in care homes, the individual’s home, and activity centres [Keady et al.](#_bookmark26) ([2007](#_bookmark26)); [Wallace et al.](#_bookmark53) ([2012](#_bookmark53)). One space that remains overlooked is how people with dementia interact in outdoor areas and how methodologies can provide a sense of agency and fit into the needs of people with dementia.

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One alternative methodology in social research that has gained popularity is walking inter- views or ’go-alongs’ that provide meaningful engagements between the researcher and partici- pants and deepen an understanding of lived experiences outside. [Hein et al.](#_bookmark19) ([2008](#_bookmark19)) argue that sharing the ’go-along’ experience between the researcher and participants provides a richer set of data during the interviewing and observation process. Further, as Foley emphasises paying attention to the non-verbal for those at later stages, [Kullberg and Odzakovic](#_bookmark28) ([2017](#_bookmark28)) discuss walking interviews provides opportunities to explore the embodied interactions of people with dementia and that the approach puts less pressure on verbal communication. Additionally, by following the person with dementia on the walk provides a sense of agency within the study where the location is on their terms. As suggested by [Kullberg and Odzakovic](#_bookmark28) ([2017](#_bookmark28)), a walking interview approach provides a less stressful surrounding where participants may describe what they are seeing, how they are feeling and even the potential for memories and experiences to be triggered by varying triggers from their senses.

With this in mind, using walking interviews to work with families with dementia provides data-informed by experiences in the moments rather than relying on a participant’s memory for approaching meaningful experiences. Furthermore, providing an active activity as opposed to a sit-down interview promoted improvement in health and wellbeing. As such, chapter four engages with the use of walking interviews to build connections between myself and the families and provide an enjoyable and fruitful experience in partaking in the research.

### Participating through online platforms

As I described earlier, people with dementia’s lived experiences have been shared across research publications, keynotes, publishing books and blogs ([Bryden](#_bookmark7), [2020](#_bookmark7); [Shakespeare et al.](#_bookmark44), [2019](#_bookmark44)). These forms of engagement have provided a more accurate public portrayal of dementia that continues to tackle the misrepresentation, stigma and stereotypes of living with dementia ([Her-](#_bookmark21) [rmann et al.](#_bookmark21), [2018](#_bookmark21)). Additionally, people with dementia have started to broaden their engagement collectively through advocacy groups that stress the model ’nothing about us without us ([Oldfield](#_bookmark38) [et al.](#_bookmark38), [2021](#_bookmark38)). Within these advocate groups, members provide detailed resources for engaging and understanding a diagnosis of dementia; use online chat rooms to receive and share support; and build frameworks and ethics boards to provide researchers with feedback and insight into ways they may want to involve people with dementia ([Diaries](#_bookmark11), [2020](#_bookmark11)).

Over the past five years, particularly with the push of online interaction over the pandemic, people with dementia are engaging with Facebook groups, microblogging on Twitter and using online chat rooms or Zoom to share stories and maintain social interaction ([Lazar and Dixon](#_bookmark29), [2019](#_bookmark29)). For instance, [Talbot et al.](#_bookmark51) ([2020](#_bookmark51))describe people with dementia using Twitter as a platform to raise awareness, challenge stigma, and take part in online debates on topics of interest. [Johnson](#_bookmark25)

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[et al.](#_bookmark25) ([2019](#_bookmark25)) recent analysis of online forums for older adults describe challenges in ensuring safety, familiarity and decision-making that heighten hesitancy in adopting online technologies.

To support collaboration and engagement online, we need further consideration for platform users’ articulated needs and desires - particularly those within socially complex contexts. Chap- ter five explores the deployment of an online platform, Ideaboard, to engage with people with dementia and care partners in conversation with designers and developers before the in-person hackathon. As you will discover from reading the findings, this online platform lacked engage- ment during the study regarding how people with dementia appropriate technology was severely underexamined ([Lindqvist et al.](#_bookmark31), [2018](#_bookmark31)) . In chapter seven, we return to the challenges faced in our event by investigating how people with dementia envision their participation in online platforms.

## Ethics

Ethical approval was attained by Newcastle University Ethical Review Board, who reviewed the four individual ethics documents that the following chapters describe in more detail. Across the four studies, audio, video, photography and field notes were found to be the most suitable for data collection seeing that I anonymised the data during the data treatment stage. This stage consisted of anonymising names, blurring faces, transcripts of audio, and redacting specific quotes that may associate with the participant. As I describe in chapter seven, anonymity was an optional process for the designers, developers and people with dementia as there is a growing concern that institutional protection may hinder someone with dementia’s individuality and contribution to the work that came out of chapter seven’s findings that interviewed HCI researchers on the ethical challenges in working with people with dementia ([Hodge et al.](#_bookmark22), [2020](#_bookmark22)). While this thesis broadens the debate on dementia in HCI by inviting researchers, designers, developers to the conversation, this ethics sub-section will be about the ethical processes I introduced to involve people with dementia within the studies. Each data chapter describes any additional ethical procedures I followed to involve researchers, designers, and developers to attain ethical approval.

Within the area of dementia, ethical consent processes are a contested debate about the best ways to provide continued decision-making with people with dementia. As [Dewing](#_bookmark9) ([2007](#_bookmark9)) describe, traditional methods have often excluded the person with dementia by using a spouse or care partner to provide consent, and the consent process would never be revisited throughout the study. Instead, Dewing and others suggest a model where consent processes are a continuing consideration throughout the research project to provide informed flexibility and involvement from people with dementia ([Dewing](#_bookmark9), [2007](#_bookmark9); [McKeown et al.](#_bookmark35), [2009](#_bookmark35); [Slaughter et al.](#_bookmark45), [2007](#_bookmark45)).

Unfortunately, during our process of attaining ethical approval, we were unable to agree on a set of acceptable methods to mitigate risks for informed consent with people with dementia

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which caused several challenges for the involvement of people at the later stages of dementia. For instance, in chapter four, I invited three families to co-design family day’s out to capture meaningful moments through audio, photography, and 360-degree videos consisting of the family being at the beach or a National Trust site. For one of those families, Philip, living with late stages of dementia, could not provide verbal consent on the day of the study. Despite having his two daughters and wife to assist in the decision making, we could not provide an agreement to take part in the study at that very moment. Despite not being able to record or take part in the research, I still took the family on the day out as the trip had been planned, and the sole purpose was to provide an enjoyable day out for the family. Throughout the day, Philip’s interest in spending time with myself and his family became more apparent, and by the end of the evening, Philip started to take part in group conversations, tickle his daughters’ necks, and say to his partner, *"I love you"*. His family had rarely seen these acts from Philip over the past year. With this in mind, if the Ethical Review Board had more openness to alternative methods, an ethic of care procedure that acknowledges capacity is situational, where capacity can be strengthened through relationships proceeding the initial consenting procedure may have provided the opportunity for Philip and his family to be part of the research study ([Lloyd](#_bookmark33), [2004](#_bookmark33)).

Nevertheless, following the Mental Capacity Act 2005 ([Oyebode and Shickle](#_bookmark39), [2005](#_bookmark39)) and drawing on my main concern of duty of care to participants who were involved within this thesis, I provided a series of ways to support and inform people with dementia in the decision- making process. This consisted of receiving training and certificate to conduct Mental Capacity assessments to verify participants could participate; involving family members when necessary to provide additional explanations within the study; interview/workshop debriefs of the previous conversations we had prior to the next interview/workshop. Likewise, providing time before the study to get to know the participants to build an initial relationship, including understanding potential needs the person with dementia may need that I can accommodate throughout the study.

Additionally, navigating power dynamics within the studies required careful consideration to support people with dementia as equals who can meaningfully contribute through this work. To navigate such complex topics, I followed the works of [Foley et al.](#_bookmark15) ([2019](#_bookmark15)); [Lazar et al.](#_bookmark30) ([2017](#_bookmark30)); [Morrissey et al.](#_bookmark37) ([2017](#_bookmark37)) who describe the importance of recognition and adapting methods or interactions when necessary. For this to work, when working with people with dementia, I provided spaces that allowed for the person with dementia to lead the conversation or interaction. For instance, in the day’s out described in chapter four, I followed the families around, letting the person with dementia lead and make choices of what we do at that very moment. This also expanded into interviews and workshops where I provided a semi-structured interview that would flow depending on the nature of the conversation. Providing this type of agency also required that I would be flexible with my schedule where interviews or activities could be last-minute rescheduled by the person with dementia. Finally, while this was a process of learning and reflection, it was clear the need to guide expectations of what was possible within each study. Navigating these expectations was overlooked in the first study, which caused several frustrations

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between myself, participants and partnering charity. However, by the end of the thesis, I set out clear boundaries of what would be possible within the confinements of the study and thesis.

## Data Collection

Data was collected through various technologies and techniques throughout the PhD. To involve people with dementia, I adapted several data collection methods to fit the participants’ needs better. These adapted approaches are associated with chapters four, five, and seven. As I continued to learn from my successes and mistakes, the data collection evolved throughout the research. Here, I present an overview of the four phases of data collection, which I describe in further detail in their associated chapters.

### Phase One - Auto-ethnography about understanding my role as a researcher

A significant part of the thesis is understanding the different roles of others that influence the involvement of people with dementia. One particular role is the researcher’s role in conducting, analysing, and involving participants within their studies. Before taking on the PhD, I had begun my journey into HCI and dementia through an undergraduate dissertation that continued into my master’s project, which I finished in the first year of the PhD.

To provide the reader with an understanding of myself as a researcher and the influence these initial studies with people with dementia were on my perspective of dementia, the first chapter analyses a 20,000 thousand word auto-ethnography consisting of field notes, audio recordings, videos and photography that stretch the three years of work with families living with dementia. The auto-ethnography consists of the two following studies:

**Study one:** In 2017, as part of my undergraduate dissertation, I worked closely with a local dementia cafe called Silverline Memories, which had expressed an interest in virtual reality in dementia. The primary aim of this project was to explore, via collaborative workshops, the type of virtual reality environments and interactions people with dementia may want. Through these interactions with seven participants, a secondary aim was to design personalised VR experi- ences for couples with dementia to understand how VR could provide aesthetically meaningful experiences. The work was later published at CHI’18.

**Study two:** In 2018, through the master’s and first year of the PhD, I continued my col- laboration with Silverline Memories to explore the opportunities and challenges of designing enriched personalised multimedia experiences with people with dementia and their families. Adopting walking interview approaches to support wellbeing and provide the family with demen- tia agency in the interview, I designed a set of days out with all three families to create enjoyable or memorable moments, which I then sought to capture and document with audio recording,

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360-degree videos, and photography that followed with a series of workshops to consolidate the personalisation and to store of the created moments from their days out. This work was published at CHI’19. The combination of moments captured by the families and ideas from the workshops resulted in the first year of the PhD developing a set of ’moment boxes’ for the families consisting of dioramas; QR codes to access the 360-videos; VR tours of the days out; day out related sensory objects such as seashells, tree bark; and a set of edited photo’s of the families on their days out.

By revisiting the data collected through the two studies above and re-examining my field notes collected across 2017-2019, the auto-ethnography embeds frustrations and possibilities of involving people with dementia that I picked upon over the years. This data collection phase formed the basis for the rest of the thesis, where I recognised the importance of ethical challenges in dementia and the importance of broadening the conversation within HCI and dementia to invite designers, developers, and students.

### Phase Two - DemVR: A hackathon exploring public engagement with dementia

As the research evolved, I realised that it takes an extensive period for researchers to become aware of the challenges and opportunities within the populations they are working alongside. One area that I felt was underexamined was how inclusive design might function within the context of larger-scale community events. With this in mind, hackathons presented an exciting space to tackle where the events expect the same sensitivities (that I spent years learning) to be presented within a short amount of time - usually a weekend.

In 2019, I set up a design hackathon to invite designers, developers and people with dementia to develop prototypes of VR experiences that encourage shared experiences between people with dementia and others. Similarly to phase one, data collection continued to be field notes, pho- tography, video, WhatsApp conversations, and audio recordings that would be later transcribed. This range of data provided an extensive set of data to capture the participants design processes during the two-day hackathon.

Furthermore, to provide people with dementia and care partners an opportunity to develop ideas, I planned and arranged a six-week consultation period to be carried out via 1) an online participatory platform, and 2) in-person workshops with people with dementia and their care partners. The two activities intended to support people with dementia to engage in a set of design activities to illustrate their desired VR shared experiences and bridge the gap between designers, developers and people with dementia on the online platform. However, as chapter five unravels, my attempts to involve people with dementia and their care partners were significantly limited to one care partner’s involvement engaged through our online platform.

## 1.6 Data Collection

### Phase Three - semi-structured interviews with researchers to elucidate the ethical challenges in dementia co-design

Another thread of interest that came from phase one was better understanding the ethical challenges when working in dementia and HCI. Likewise, several conversations I was having at academic conferences with dementia researchers resonated with the problems I had been expressing such as ethical review boards blocking the involvement of people with dementia, the longevity of technology, and supporting growing relationships between the researcher and the person with dementia. As such, in 2019, I invited several dementia and HCI academics to collaborate on design ethics in dementia and HCI research, where we would reflect as a community of practice and elucidate broader concerns about ethics in HCI research.

Data was collected through a series of interviews with 22 self-identified designers and/or researchers who reported significant experience in working with people with dementia. Each participant was invited to a 45-60 minute interview which consisted of open-ended questions and prompts such as: 1) experience with institutional ethics processes, 2) technological ethics,

3) power relationships, and 4) research impact. Five of the authors carried out the interviews, which were carried out in person where possible, but were otherwise carried out over video calls. All interviews were audio-recorded and transcribed in full.

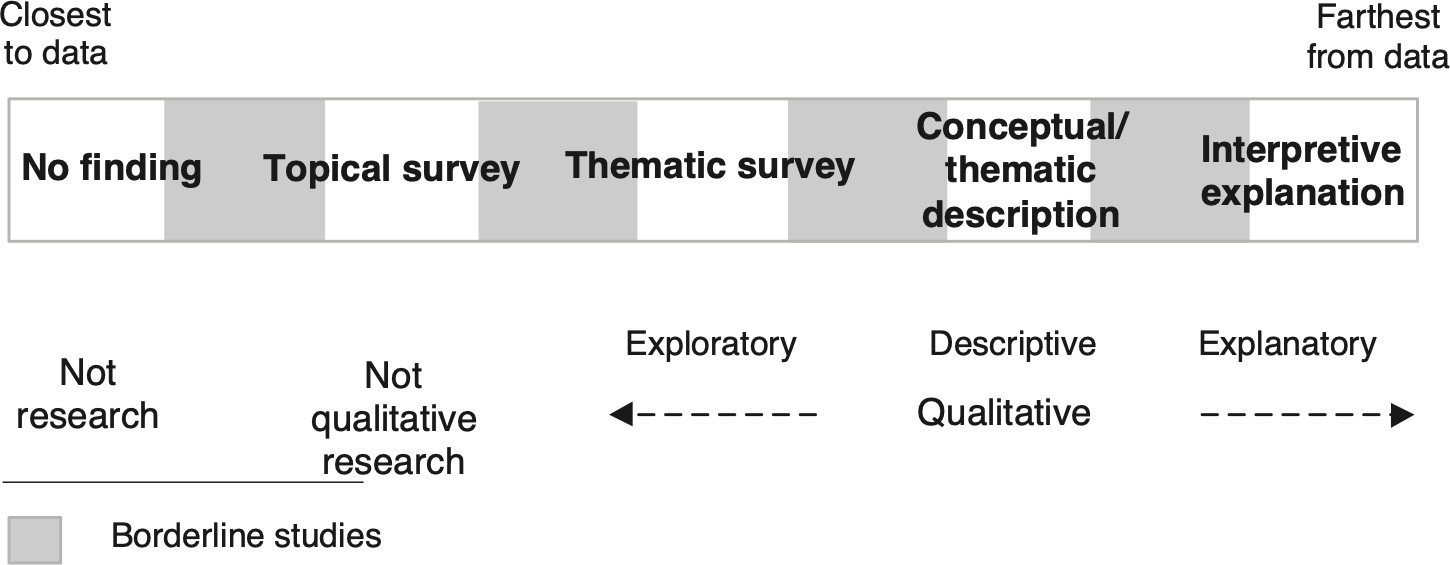
### Phase Four - Dialogical Dementia Design Toolkit: exploring the type of resources for educating designers and developers when designing for and with people with de- mentia

During the final phase, I built upon the reflections of the hackathon where it became apparent that interactions between those with dementia and others outside of the community remain sparse. With this in mind, this raises the question: How can toolkits and other creativity support tools foster dialogical engagement between people with dementia and designers and developers? To explore the work area, I invited 11 self-identified designers/developers and five people with dementia to examine the type of resources developers and designers need to design with people with dementia and investigate how people with dementia envision their potential participation within a toolkit.

Due to the study taking place over the pandemic, the workshops and interviews were all online and required inviting people with dementia who had access to the internet and had a reasonable function of their verbal communication. All data was collected via recording of workshops and interviews that I later transcribed.

Group workshops with designers and developers and one-to-one interviews with people with dementia were split across three stages of data collection. Stage one and two focused on gathering data to incrementally develop the dementia design toolkit. For the third stage, I

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**Figure 1.1** Typology of Qualitative Findings ([Sandelowski and Barroso](#_bookmark42), [2003](#_bookmark42))

presented the toolkit to participants to gather feedback and critique in its roughly ‘final’ stage. Interviews were carried out over Zoom as the preferred choice for participants with dementia. For the workshops, designers and developers joined a scheduled Teams’ meeting, with additional activities occurring on a shared online whiteboard space (a Miro board).

## Thematic Analysis

During the PhD, I primarily used thematic analysis to analyse the collected data as an approach to connect elements of the data to identify patterns within the studies. Since each study heavily relies on finding shared meanings between participants such as, researchers ethical challenges, or developers and designers workflows in sensitive settings, thematic analysis works well in examining these common connections between participants.

To situate thematic analysis to other analysis methods, I examined the framework set out by [Sandelowski and Barroso](#_bookmark42) ([2003](#_bookmark42)) that outlines the typology of qualitative findings. The typology in figure [1.1](#_bookmark0), highlights the different kinds of qualitative findings you may find as a result of an analysis and places them on a graph indicating how transformative the qualitative findings become compared to the data they originated. For instance, survey data remain close to the data. At the same time, methods such as phenomenology involve deeper interpretation of the data and will result in transformative moves away from the original data.

With this in mind, for the thesis, the aim of my analysis was to be a descriptive process of the participants’ experiences. In such a way, the aim of my analysis fits in the middle point of the qualitative ’poles’ in Sandelowski and Barroso figure where while I’m not engaging in data transformation to develop a theory, nor is my analysis purely descriptive of the original data. ([Kiger and Varpio](#_bookmark27), [2020](#_bookmark27)) suggest that thematic analysis is a proven approach that works well for providing highly descriptive and conceptual findings in their results. As thematic analysis

## Reflexivity

provides steps to organise the data through labels and themes, the process provides transformative approaches to understanding the meanings and experiences of the participants within the data.

The thematic analysis approach I followed was in line with the instructions set out by [Braun](#_bookmark6) [and Clarke](#_bookmark6) ([2020](#_bookmark6)). This process consists of seven steps: 1) preparing data through transcripts and additional data cleaning; 2) familiarising myself with the data while referring to the research questions. Following, using a whiteboard / Miroboard - order the data to make sense of the similar conversations between participants; 3) move onto the coding process to identify all relevant data by line-by-line coding, tagging and highlighting anything of interest; 4) organise codes into potential linking themes; 5) reviewing themes; 6) discuss the initial themes with supervisors to see if they fit with the original research questions and name the themes. Finally, step 7) is to finalise the analysis by writing and presenting it in the data chapters. Data was collected and analysed chronologically to the chapters that are set out in the thesis.

## Reflexivity

As described in the following data chapter, the work I did within dementia significantly impacted my experiences of dementia within my family. I relate the comparisons and connections between my research and my conversations with my Grandma about my Grandpa’s diagnosis. From early on, it was very apparent that my experiences during and outside the studies would influence the interpretations I made through my analysis. As such, Barbara Probst describes reflexivity as:

"Despite its "messiness," reflexivity remains a fundamental way, particularly in qualitative studies, to bolster credibility by parsing the research endeavor into its mutually affecting parts and documenting the pathways through which knowledge was generated." ([Probst](#_bookmark40), [2015](#_bookmark40))

Reflexivity offers a critical way to stay self-aware through the thesis. Still, more importantly, it is a way to acknowledge the emotional and often challenging experiences that a researcher may encounter when working within sensitive settings - like dementia. Throughout the PhD, I have made many relationships with participants I still talk to after finishing the study. For instance, Jim, a participant in my final study, will still email or occasionally Zoom to chat about dementia activist topics and general day-to-day conversations. This is often due to my early recruitment stages requiring openness from myself to get to know the participant and make them feel comfortable in my presence. Typically, participants would often ask my ***"why are you looking into dementia?"***Looking back at my reflexive journal - that researchers recommend for during the research process and coding stages, I found this excerpt from replying to the question above:

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**James**: Well, I’m not sure if you remember, but last year [2017] I worked with a couple of you to create some VR experiences that looked at ways to personalise the environments for members here [ at Silverline]. As I got to know the area more, I talked to my Grandma about my research. One of the reasons I thought about dementia research was because of her. My Grandpa had Alzheimer’s in his early 50’s. He sadly passed away when I was five. . . Of course, I didn’t get to know him that well, but through the circumstances my Grandma shares stories of him. She shared stories of before the diagnosis and many that of her relationship with him after his diagnosis too.

**Kate**: "are you close with your Grandma?"

**James**: "Very much so... I call her every few days and we talk about all sorts. . . To me, It’s been interesting to hear my Grandma’s side towards caring for my Grandpa too. The stories of her having to learn how to organise the bills, or mortgage – she had to take on so many social roles that he once proudly had. . . But also, she told me when she told him to get off his back-side and stop feeling sorry for himself. . . She would make alternations around the house to ensure he could do many of the roles he once felt like he lost – at least to the extent that he thought he could see fit.

## My reflexive journal comment:

"As I began to share stories of my family, Kate started to cry. Kate shared how much the story reflected her experiences too. We started to share stories from each family side. Kate had gone through similarities to my Grandma with having to change significant social and, even in their eyes, gender roles. I feel perhaps Kate and I have bonded over these stories. Maybe she trusts me more now she knows why I care for making some change in dementia? We both cried, laughed and smiled, listening to each other’s stories. It felt strange to me that this felt so wrong. A relatively common interaction among friends, maybe not so much between somewhat strangers, but what made me feel ’wrong’ was that my openness made me assume I was a bad researcher."

Although the reflective texts in my journal are not part of the data I analysed, they helped with the personal development of my role as a researcher and to deal with some of the difficult conversations and topics that were present in conversations I had with people with dementia. Some of the more difficult conversations I had, I was fortunate to share with the cohort I started the PhD with. The way the Digital Civics PhD programme was designed gave many of us who had similar difficult conversations in other sensitive settings the chance to share and reflect on the processes of being a researcher together. Finally, by taking a reflective approach throughout the data collection and analysis, has provided I have examined the growing relationships that I

## Summary

have made through the study, my positioning in the dementia context, and understanding how I fit into the research and the responsibilities that come with the role of a researcher.

## Summary

This chapter gives a detailed overview of the research approach I undertook to explore the research questions I set out in the introduction. At the start of this chapter, I describe participatory design and how it has been reconstructed to fit the needs of people with dementia, including the ethical considerations required when working in sensitive settings. From here, I describe ways I have adapted the participatory design to fit the needs of the thesis. I then introduce descriptions of the data collection within each data chapter that are described in more detail in their corresponding chapters. Finally, I conclude with my data analysis approach, thematic analysis, that I used to make sense of each chapter’s data supported by reflexivity. In the next chapter, I introduce an auto-ethnography of my initial insights into participatory design work with and for people with dementia, which is a source of motivation for the subsequent studies.

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