Design for dementia : a design-driven living lab approach to involve people with dementia and their context

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Design for Dementia

A design-driven Living Lab approach to involve people with dementia and their context

Rens Brankaert

Design for Dementia

A design-driven Living Lab approach to involve people with dementia and their context

Doctoral Dissertation

by

Rens Brankaert

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Design for Dementia

A design-driven Living Lab approach to involve people with dementia and their context

PROEFSCHRIFT

Ter verkrijging van de graad van doctor aan de Technische
Universiteit Eindhoven, op gezag van rector magnificus, prof.dr.ir.
F. Baaijens, voor een commissie aangewezen door het College voor
Promoties, in het openbaar te verdedigen op woensdag 2 maart 2016
om 16:00

door

Rens Gerardus Antonius Brankaert

geboren te Weert

Dit proefschrift is goedgekeurd door de promotoren en de samenstelling van de promotie commissie als volgt:

Voorzitter:	prof.dr.ir. M.J.W. Schouten
1e promotor:	prof.dr.ir. P.H. den Ouden
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	prof.dr. I.M.B. Bongers (Universiteit van Tilburg)
	prof.dr.ir. C.D. Nugent (University of Ulster)

Het onderzoek dat in dit proefschrift wordt beschreven is uitgevoerd in overeenstemming met de TU/e Gedragscode Wetenschapsbeoefening.

“Het leven is wat je gebeurt, terwijl je andere plannen maakt.”

John Lennon in *Beautiful Boy*

Vertaald door Acda & de Munnik in *Laat me slapen*

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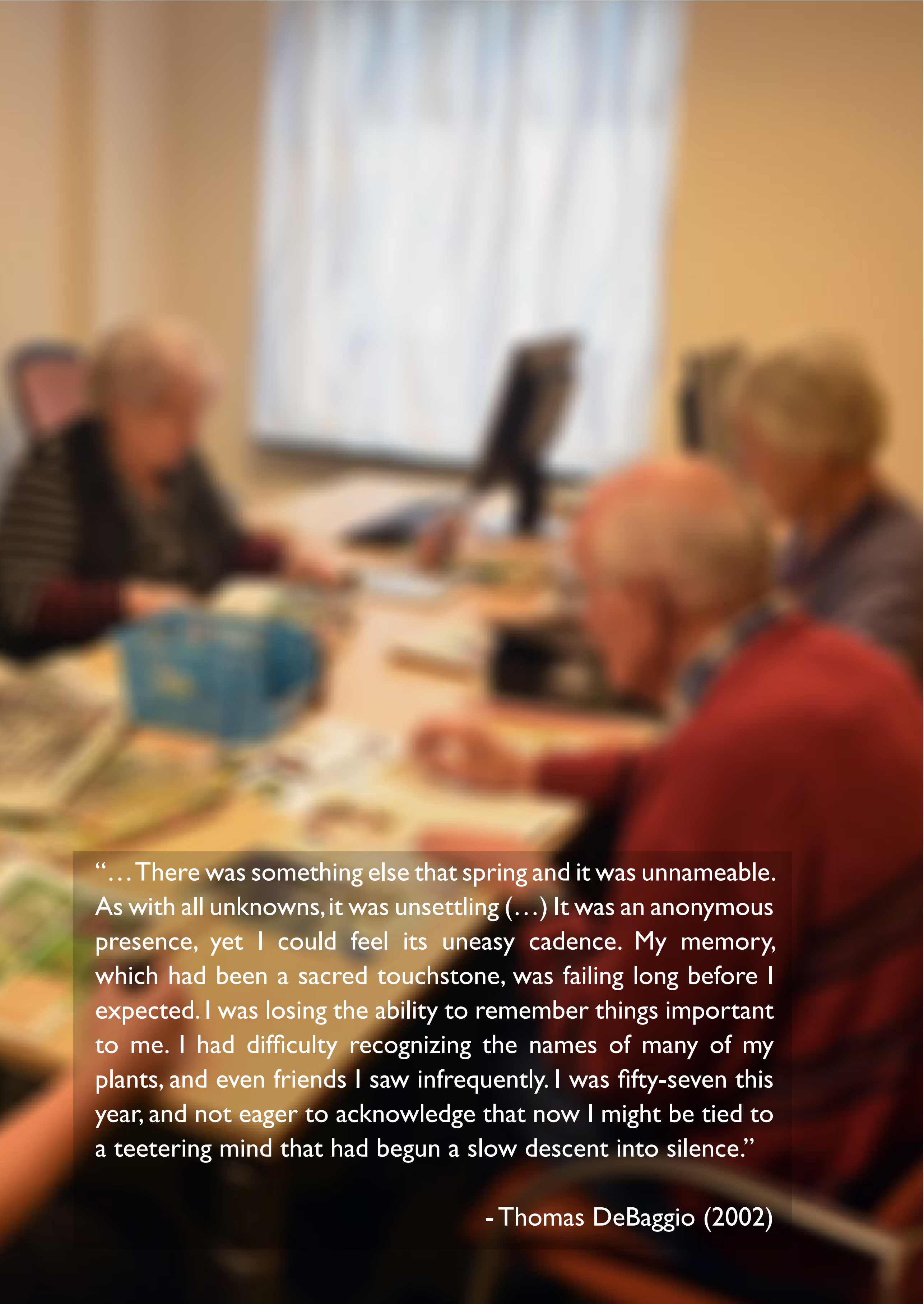

> "…There was something else that spring and it was unnameable. As with all unknowns, it was unsettling (…) It was an anonymous presence, yet I could feel its uneasy cadence. My memory, which had been a sacred touchstone, was failing long before I expected. I was losing the ability to remember things important to me. I had difficulty recognizing the names of many of my plants, and even friends I saw infrequently. I was fifty-seven this year, and not eager to acknowledge that now I might be tied to a teetering mind that had begun a slow descent into silence."
>
> - Thomas DeBaggio (2002)

Chapter 1:

Introduction

Most people I know are afraid of dementia. The quote (left), from an autobiography of a writer with Alzheimer's, shows this fear as he describes how he experiences the onset of dementia. However, there is a long road between the first symptoms of memory problems and the feared advanced state of dementia. In this dissertation we aim to examine dementia constructively and try to use design approaches to find new strategies and proposals to support those affected by the condition. In this Chapter we introduce our approach and formulate our goal of improving the quality of life of people with dementia and their caregivers.

1.1 What is dementia?

In order to improve the lives of people living with dementia through design and research we need to understand what dementia is. Dementia is the name of a group of diseases that affect the brain and impair cognition. The most common forms of dementia are Alzheimer's disease (>70%), Vascular disease (>20%), Lewy Body Dementia (<5%) and frontotemporal dementia (<2%) in descending order of occurrence (Prince, Albanese, Guerchet, & Prina, 2014). These diseases are progressive, and slowly but severely affect a person's brain, and thus affect his or her ability to live a normal life. Because Alzheimer's disease and vascular dementia together account for by far the largest proportion of the dementia population (>90%), and because the disease processes are relatively similar, we will refer to these when we use the term dementia.

Dementia affects one's behaviour and ability to live and enjoy life. In the early stages of the disease people will experience problems such as forgetfulness and difficulty executing complex tasks. In the mid-stage of dementia short-term memory is hampered, non-routine tasks are difficult and recognizing people and places becomes challenging. As the disease progresses into the later stages routine tasks are impaired, orientation in time and space is challenging and basic bodily functioning becomes increasingly limited (Timlin & Rysenbry, 2010). These are some general indicators of dementia. However, as every individual is different, the resulting challenges people face are different as well. In dementia care this personalization is also referred to as Person-Centred Care. This means that the personality, character and background of a person is taken into account during the care process (Clarke, Hanson, & Ross, 2003). This approach is seen as positive by nurses in practice; however, it is still not widely implemented as it challenges the still prevalent generalist approach to dementia care (H. Ross, Tod, & Clarke, 2015). In addition, dementia is seldom experienced alone. Often a spouse or other family members of a person with dementia are also burdened by care and worry (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). These informal caregivers, the non-paid and non-professional caregivers of people with dementia, are often mentally and physically burdened by the progressive deterioration of the dementia patient (Etters, Goodall, & Harrison, 2008).

Studies often refer to people suffering from dementia, but this target group is not continuously suffering; they are coping with the disease. That is why we use the term *people living with dementia*, relating to people with dementia *and* their informal caregiver network.

1.2 The societal challenge of dementia

In the United Kingdom, Prime Minster David Cameron described dementia as a national challenge, setting up three groups to improve care, creating dementia-friendly communities, and promoting dementia research (Lin & Lewis, 2015). In the United States, President Obama signed the National Alzheimer's Project Act, establishing an Advisory Council on Alzheimer's Research, Care, and Services (Lin & Lewis, 2015). In the Netherlands the government initiated the programme "delta-plan dementie" in 2013, referring to the delta-works constructed in response to the floods of 1953, to combat dementia. They formulated three pillars: academic research, improving dementia care and social innovations (Dutch ministery of Health Welfare and Sport, 2013).

The main reason for these countries to set up national programs to combat dementia is the appalling increase of people living with dementia globally (Wimo, Winblad, Aguero-Torres, & von Strauss, 2003). Owing to the continued ageing of our population, it is estimated that the number of people with dementia will double every 20 years, with an estimate of about 40 million in 2020 and 80 million in 2040 (Ferri *et al.*, 2005; Wimo *et al.*, 2003). In addition, national healthcare budgets per head of population tend to decrease, resulting in an even further retrenchment of care for people with dementia (Knapp, Iemmi, & Romeo, 2013). This places additional pressure on professional care and will result in an extension of care in the home environment, relying on informal caregivers (Knapp *et al.*, 2013).

The World Alzheimer Report (2010) shows that the cost of dementia care worldwide was more than US$604 billion, or 1% of aggregated global Gross Domestic Product. Reducing transitions into professional care environments and providing care at home for as long as possible is an important strategy for containing the costs of dementia care in high-income countries (Prince, Prina, & Guerchet, 2013). Whereas this strategy sometimes causes problems, it does generally align with older people's desire to live at home for as long as possible as well as with the global movement towards Person-Centred Care (Clarke et al., 2003). This trend, however, will put further pressure on informal caregivers who already provide ~60% of the accumulated care for people with dementia. This number is expected to increase majorly in western countries, and is already much higher in developing countries (Prince *et al.*, 2013). To conclude, there is a dementia 'flood' upon us and we see the world is already preparing for this. In this dissertation we aim to contribute to this global challenge from a design perspective.

1.3 Design for people living with dementia

In this dissertation we aim to aid in the global challenges of dementia by the design of new concepts to support them. We have seen there is need for political, social and economic changes to adequately address dementia; however, design should play a crucial role as well.

1.3.1 Design perspective

The department of Industrial Design at the Eindhoven University of Technology set out to educate a new kind of design engineer in 2001. This was a demand from major companies in the Eindhoven region such as Philips and DAF. As a student in this department I am educated as self-directed designer, capable of combining the competences of user-focus, technology and business to create (intelligent) products, systems and services to address societal challenges (Hummels, Vinke, Frens, & Hu, 2011). As technology keeps advancing at a staggering pace, we aim to consider the human aspects of this. This can involve the interaction with technology or a comprehensive solution for a social problem. The people we design for play a critical and eminent role in this. Throughout the design process they are involved actively at various stages of the design process through various methods (Tomico, Frens, & Overbeeke, 2009). In this dissertation we take this as a starting point for design, and investigate this approach further in the context of design for impaired users, in our case people living with dementia.

Traditional innovation processes can take several years; however, the world is moving much faster. Therefore, we need to take a more pragmatic approach in design. We aim to conduct more and shorter cycles to evaluate how our designs fulfil needs or address problems. We do this on a trial and error bases by creating prototypes that can be experienced by users. Therefore our design approach is highly iterative and pro-active, or as IDEO's former CEO Tom Kelley puts it, designers should "Fail often so they can succeed sooner" (Kelley, 2007).

Because we design for people with dementia we cannot take their perspective through empathy. People with dementia have a cognitive impairment and are therefore too distant from our own perspective. To address this we need to experimentally put our design proposals in the field as early as possible. The experiential design landscapes approach proposes such a method in the context of design (Peeters & Megens, 2014). By developing 'Experiential Probes' we can evaluate our design proposals in a real-life context while maintaining both a high level of control and a high ecological validity (Peeters & Megens, 2014).

In the context of dementia we see a resemblance between our design approach and the emerging trend of Person-Centred Care (Clarke *et al.*, 2003), which focuses on the individual persons behind the disease. In both care and design we should consider the individual perspectives and let this inspire our decisions. We can however, not grasp this by ourselves; we need to observe and harvest insights through our prototypes in the field to comprehend this perspective.

Another aspect in which designers excel is their capability to deal with complexity (Head & Alford, 2013). This can be both in a challenging goal (e.g. design for a societal challenge) and in a complicated context. And in order to achieve such high-level goals, as addressing the challenges of dementia, design proposals need to be supported by a complex network of stakeholders (Pol and Ville, 2009).

Living with dementia poses numerous challenges for both individuals and society at large. However, through design we can address these by developing appropriate design solutions. To develop these we need to create and probe design options that contribute to support people living with dementia.

1.3.2 Design research

In the context of research design plays a unique role. By definition, design is about opening up and creating, while research focuses on containing phenomena and investigating them. However, when we examine the etymology of the word 'research', we see that it comes from the Middle French word 'rechercher' (1590s), which means 'to seek for'. This is actually in line with what design does: Seeking new solutions and pursuing opportunities.

In the field of Human Computer Interaction research-through-design brings research closer to design practice. Design is used as a method for inquiry; however, this has not yet grown into a rigorous approach (Zimmerman, Forlizzi, & Evenson, 2007). More recent Koskinen and colleagues (2011) posed 'constructive design research' as the continuation of this work. This focuses not only on design for inquiry, but also includes the act of designing (construction of 'things') as part of design research. Design proposals then lead to questions and physical hypotheses (Koskinen *et al.*, 2011). When referring to design research in the field, the literature often uses the term design ethnography. This discipline involves gathering first-hand experience in the 'context' (the field) for product development and evaluation (Nafus & Anderson, 2009). In addition, design can give research a new perspective. It can propose radical new approaches over incrementally developing a certain body of knowledge. We thus aim to use design research for innovation in order to achieve significant impact (Verganti, 2008).

Design complements research when it comes to a difficult target group such as people with dementia. Designers often use empathy to take the first-person perspective of users (Postma, Zwartkruis-Pelgrim, Daemen, & Du, 2012). However, for people living with dementia this is not possible due to their cognitive deterioration, so we need to observe and capture their experience with our design proposals and inquiry tools (Peeters & Megens, 2014).

1.3.3 Technology in the field of dementia

In the field of computer science we can find several studies designed to develop technology for people with dementia. Bharucha and colleagues (2009) constructed a comprehensive overview of technological applications areas for people with dementia (Table 1.1). These are cognitive aids, physiological sensing, and environmental sensors/networks. In particular, research on the latter is growing rapidly in the sub-domains Ambient Intelligence (AmI) and Ambient Assistive Living (AAL).

Ambient Intelligence is a paradigm that envisions that computing devices will become widespread in our environment. This will enable us to design more intelligent and meaningful interactions in this context (Cook, Augusto, & Jakkula, 2009). This approach reveals numerous opportunities for enhancing quality of life. Based on this paradigm Ambient-Assisted Living (AAL) emerged as a tool that can be applied for people with specific needs. For example to allow people with dementia to live more independently (Queirós, Silva, Alvarelhão, Rocha, & Teixeira, 2013). In this regard, am example can be found in the COGKNOW project (Meiland *et al.*, 2007), which developed an ICT system that focuses on reminders, maintaining social contact, and supporting daily tasks and recreational activities. In this project three field trials have been performed with varying results. The continuation of this project, the Rosetta system, is designed to combine several support systems to offer a complete and holistic solution. Recent field trials showed that the system had some technical issues; however, users appreciated the direction in which the project was heading (Hattink et al., 2014). This shows, although promising, such holistic proposals take time and are difficult to develop.

Another example can be found in prompting systems, such as the COACH prompting system (Mihailidis, Boger, Craig, & Hoey, 2008). This enables the elderly with dementia to wash their hands by combining video analysis with voice feedback. Next to these two examples there are several more systems that are applying similar Ambient Intelligence principles to address challenges in dementia. These systems show there are a lot of different approaches to support people with dementia; in this dissertation we focus on design to enhance the capabilities of people with dementia and their context.

More background research concerning this topic will be covered in the specific chapters of this dissertation.

Table 1.1 Technology application areas for dementia (Bharucha *et al.* 2009).

Technology application area	Sub-areas
Cognitive aids	Prospective memory Retrospective memory Aphasia and Agnosia Visuospatial Dysfunction
Physiological Sensing	Vital signs and Metabolic Parameters Fall detectors.
Environmental Sensors/ networks	Single or multi-factor measurement Embedded intelligent networks

1.4 The Innovate Dementia project

> *"Innovate Dementia is a project (designed) to promote innovative care solutions for people living with dementia…Managing this potential threat to North West Europe (NWE) society in a cost-efficient way requires innovative approaches presenting opportunities for new businesses and employment as well as concerted action by business and policy makers at all regional levels.*
>
> *Innovative and sustainable solutions will be developed and tested in Living Labs and will take account of the socio-economic challenges concerned with ageing and dementia.*
> *The main sustainable effects of Innovate Dementia will include: increased focus on the benefits of innovative dementia care for people living with dementia which includes improved health and well-being and sustainable improvement for caregivers."*
>
> -Innovate Dementia Project website (2015).

1.4.1 The Innovate Dementia project

The Innovate Dementia project, which is funded by Interreg NWE IVB, started in 2012, with the goal of addressing the societal challenge of dementia. The ambition behind this project was to become a European expertise cluster in four regions *(Liverpool, UK; Antwerp-Geel, BE; Krefeld, GE; and Eindhoven, NL)* to develop and implement innovative solutions for people with dementia.

Each of the regions had their own network of partners to work on region-specific goals to address dementia related challenges. In the Netherlands we worked with four partners (*Geestelijke Gezondheidszorg Eindhoven (Mental Care Institute, GGzE), Brainport Development, Gemeente Eindhoven (Municipality) and us the University of Technology Eindhoven*). Together with these partners we built a strong stakeholder network to support business cases and share knowledge. Furthermore we built the Innovate Dementia User Platform (Lead by GGzE) with almost 150 active participants. These 'users' participated in focus groups, discussion sessions and tried our proposals at their homes. Most of the participants of studies in this thesis were gathered via this route. With the partners we defined three main challenges for the project, based on the Interreg program outline, these were:

1) Analyse the needs of people living with dementia (in care and support).
2) Develop new innovative solutions for people living with dementia.
3) Strengthen economic activity in the regions by these activities.

This dissertation is built on expertise and work from this project; however, the author conducted the work in the studies presented in this dissertation. Others are mentioned when they collaborated in the work.

1.4.2 The Innovate Dementia Living Lab

To achieve these goals we build and applied the *Living Lab approach* based on the Experiential Design Landscape perspective (Peeters & Megens, 2014). Many different kinds of Living Labs are described in the literature, we elaborate further on this in Chapter 3. To create our Living Lab we started with the five general principles formulated by Bergvall-kåreborn and Ståhlbröst (2009): Continuity, Openness, Realism, Empowerment of users, and Spontaneity. In this type of Living Lab there is room for different design and innovation activities. These range from early explorations of needs, to studies of several weeks with technology at home of our users. The role for us in this Living Lab was to design and evaluate new innovative proposals to support people with dementia.

Over the course of the project we defined a role for each of the partners in this Living Lab (Figure 1.1). Key to this approach is that people living with dementia are at the centre. Around them we created a virtual structure. This starts at the GGzE who focus on inquiry of needs and opportunities for people living with dementia, after this we (TU/e) take these insights and translate them into new proposals. Subsequently we implement and evaluate these in a real-life context. Following this, Brainport aims to build and support the business case and finally the municipality connects social organizations and manages communication.

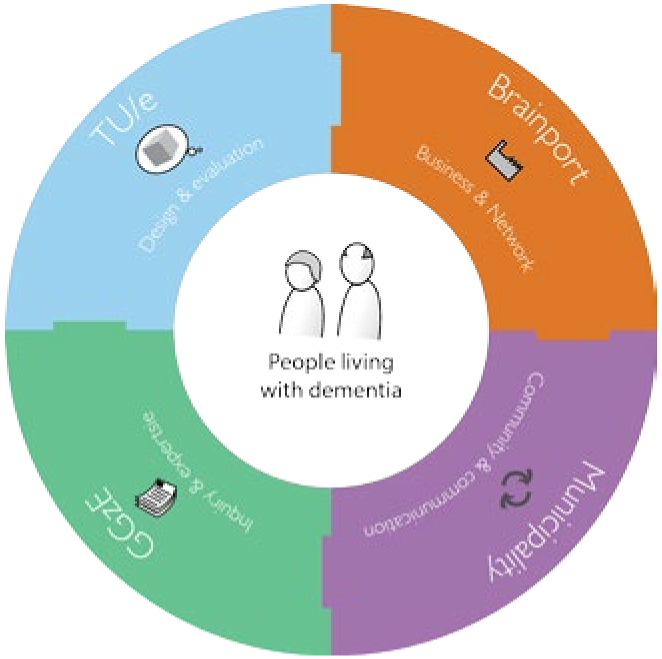

Figure 1-1 The Innovate Dementia Living Lab in the Netherlands.

1.4.3 Research approval and Informed consent

The internal approval committee of the mental healthcare institute approved the research activities as part of the Innovate Dementia project[1]. In addition to this we included several additional measures to obviate incidents.

First, we ensured participants are capable of participating. They are only selected if they are still able to live at home with a spouse, and are in the early stages of dementia. We did this in close collaboration with a mental care institute who made this decision based on their expertise.

Second, because the dementia condition changes over time, we continuously assessed capabilities with independent consultants during field studies. If a person loses capacity, the participant would be withdrawn from the study, and no further data would be gathered. In our studies both the care professionals (Mental care institute) and informal caregivers played this independent role and thereby protected the integrity of the people with dementia.

In addition, an informed consent for people with cognitive impairments has long been the subject of debate (Mahoney et al., 2007). Therefore, we handle the informed consent as a continuous dialogue (Coughlan *et al.*, 2013). While all participants signed a form at the start of the study, the participants were repeatedly asked to confirm its validity. Both participants and researchers experienced this as nice. With these general safety measures we aim to protect our participants, and, as a result, no abnormal events or incidents occurred during our studies.

Over the course of the dissertation you will find some images of participants in action. For some images we gathered an additional consent directly with the participants or the independent consultants, for other images were we did not get or ask additional consent we made the participants unrecognizable.

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[1] The Innovate Dementia Living Lab research activities have been approved by the interne toetsingscommissie (internal approval committee) of the Geestelijke Gezondheidszorg Eindhoven (GGzE) at 18 September 2012. This was consulted with the external Wet van Medisch-wetenschappelijk Onderzoekscommissie (Law of Medical-Scientific Research committee) of the Catherina hospital in Eindhoven. It was deemed unnecessary for a formal procedure due to the non-medical nature of the research and the precautions taken.

1.5 This dissertation

This paragraph portrays the research questions that are addressed in this dissertation. In addition, an overview of the chapters is provided with a short outline of the work presented in each of those chapters.

1.5.1 Research questions

The studies covered in this dissertation where conducted as part of the Innovate Dementia Living Lab. The Living Lab approach is relatively new, and interpreted in many different ways (see Chapter 3 for elaboration). Therefore, many of the methods and collaboration structures that can be used as part of a Living Lab should be explored further. In this dissertation we use the Living Lab as main method to address challenges in dementia by designing new innovative proposals for them and their caregivers. Because this field is relatively new, we aimed our research to be wide and experimental. Which leads us to the following main question for this dissertation:

> *How can we contribute to the societal challenges of dementia through design and innovation?*

To address this overarching question we have defined three sub-questions that each cover one of the three areas of research found in this dissertation. These are:

1. *How should we involve people living with dementia in design and research processes?*
2. *How should we construct the Living Lab to involve relevant stakeholders and cater for these design and research processes?*
3. *How should we design for/with people living with dementia?*

Because there is little work around design for people with dementia in the context of a Living Lab we aim to conduct several studies in a pragmatic way. This means we will go into the field and investigate these questions through several design cases with people living with dementia and other relevant stakeholders. Because we aim for this work to be explorative, our studies will be qualitative-based with a low number of participants. This allows us to perform more studies. As such we can cover many of the different aspects of a design-led innovation process to address challenges in dementia. Furthermore, this allows for holistic and broad insights into the application the relatively young Living Lab approach.

1.5.2 Dissertation outline

To guide you through this dissertation a visual outline of the sections and chapters is provided (Figure 1.2). This dissertation has three sections to elaborate on the work as well as a closing chapter covering Discussion and Reflection.

In section 1 we focus on unravelling the background of the goals set for this thesis to setup the Living Lab. In chapter 2: 'Dementia in review' we will explore the background of the condition for design and research purposes. Subsequently, in Chapter 3: 'Living Lab theory' we will explore what is know about the living Lab method and propose a Living Lab structure that will be used in this dissertation. Finally, this section is concluded with Chapter 4: 'Design process & pilot case' in which we will elaborate on the design process and methods used as part of the Living Lab structure. Additionally our first pilot study is covered in this Chapter. Based on insights from this study the scope for following sections is set.

In section 2 we cover two Living Lab cases, involving business stakeholders in the Living Lab structure. First, in Chapter 5: 'Involving people with dementia in context' we conducted a study with the Vitaallicht® lamp in which we focused on how to involve people living with dementia. Second, in Chapter 6: 'Design & evaluation with business stakeholders' the GoLivePhone® case is covered. In this case we focus went through the design process and the evaluation of the GoLivePhone® together with a business stakeholder.

In section 3 we aggregate the Living Lab cases to find more general results, these are covered in two chapters. First, in Chapter 7: 'Intervention Design recommendations' we focus on abstracting design recommendations from our Living Lab cases and some additional cases performed by students. Second, in Chapter 8: 'Design of a Living Lab protocol' we present insights gathered concerning our in-situ Living Lab studies, and conclude by proposing a Living Lab protocol.

Finally, in the closing chapter, covering Discussion and Reflection, the conclusions, limitations and insights from this dissertation are presented. These insights are put into perspective by looking at the future of this research work and a thorough reflection is provided.

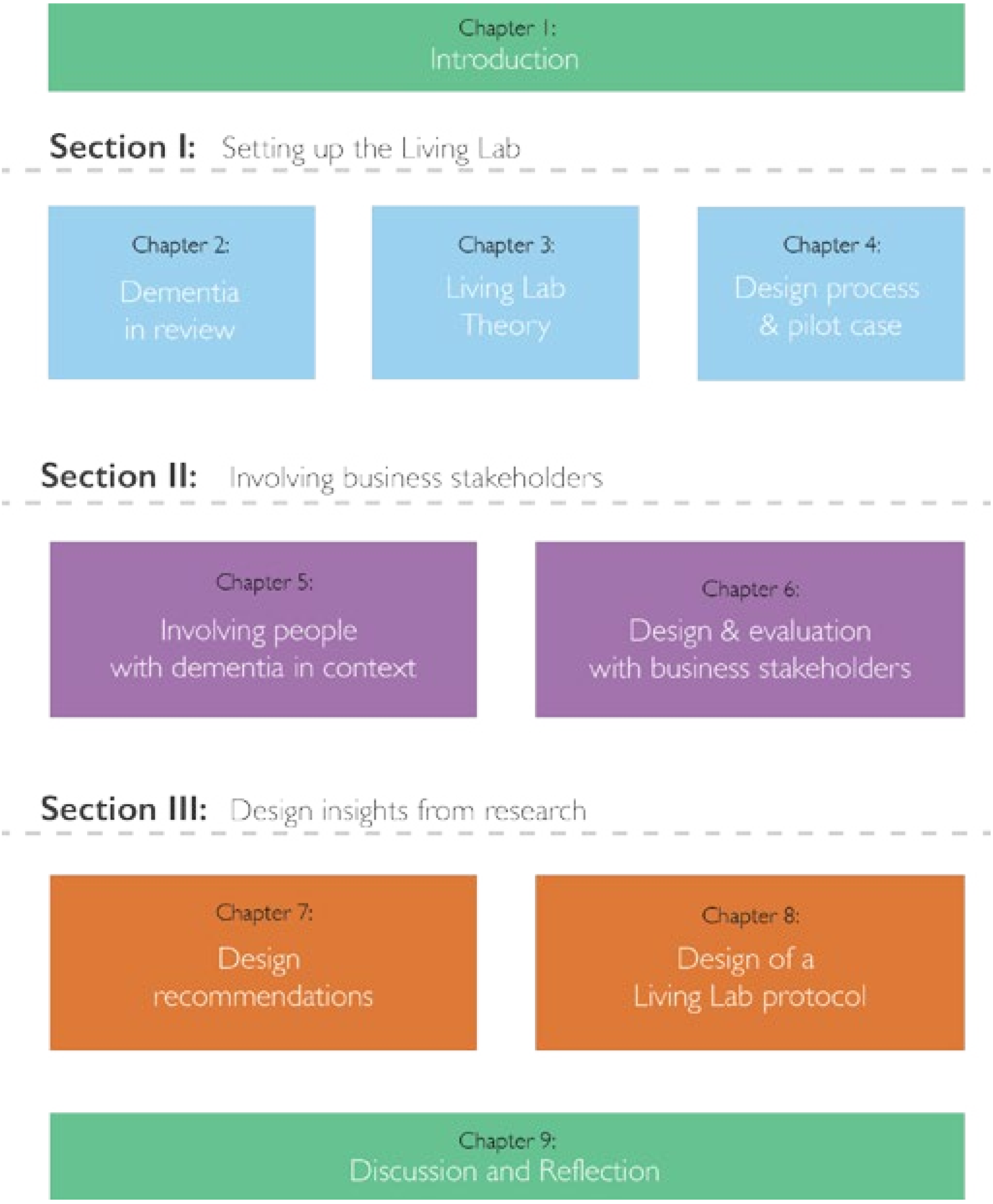

Figure 1-2 A visual outline of the sections and chapters in this dissertation.

Section I

Setting up the Living Lab

- Dementia
- Living Lab setup
- Design process

Chapter 2:

Dementia in Review

In recent decades various projects have used design to assist people with dementia and their caregivers. Involving people with dementia in such processes – and thoroughly understanding the condition is important, yet challenging.

Dementia is an umbrella term, and in this chapter we take a closer look at the diseases that are part of this condition. We explore what makes these diseases difficult to design for. We also present insights that need to be taken into account when we involve people with dementia in research and design processes. With this we better understand how to design solutions for and with people living with dementia.

2.1 Dementias

Dementia includes a range of diseases that cause cognitive functioning to deteriorate. In this chapter we take a closer look at these diseases and their implications in daily life. Furthermore, we examine the considerations that need to be taken into account when involving people with dementia in research and design.

2.1.1 Diseases that are dementia

In dementia general cognition and mental functioning are impaired. The most common type of dementia is Alzheimer's disease. Accounting for 50 - 70% of dementia cases (Prince *et al.*, 2014). The disease is named after Alois Alzheimer, a German neuroscientist, first described the disease in 1906 after discovering a "startling new pathology in the brain" of a woman who developed a clinically unusual dementia (Berchtold & Cotman, 1998). We now know that in Alzheimer's disease neuron plaques in the brain are no longer degenerated naturally, and this leads to a slow but progressive deterioration of the brain over time. This process can take from a few years to more than ten years. A diagnosis of Alzheimer's is still very difficult, and can only be done with 100% certainty post mortem (Thal *et al.*, 2013).

The second most prevalent form of dementia is vascular dementia, accounting for about 25 % of the cases (Prince *et al.*, 2014). Vascular dementia is caused by a diminished flow of blood into specific parts of the brain. This is induced by, for example, a stroke. This form of dementia is often more abrupt and is in general more progressive, so there is lower life expectancy, compared to Alzheimer's disease.

Another common type of dementia (accounting for 5 - 10 %, Prince *et al.* 2014) is frontotemporal dementia, in which the frontal and temporal lobes of the brain are affected. This often leads to uncontrolled behavioural problems and loss of emotional skills, such as for example empathy.

Slightly less common is Lewy body disease, which accounts for less than 5% of the dementia cases (Prince *et al.*, 2014). In this disease cognitive decline is combined with symptoms of Parkinson's disease. In Lewy body disease both motor and cognitive skills are impaired. This is for example shown in tremors, difficulties with walking or using your hands. Memory and other mental functioning are often maintained longer than in other types of dementia.

Furthermore, there are several other, rarer, types of dementia. For example Huntington's disease, a genetic type of dementia, which is caused by abnormalities in the Huntington gene (C. A. Ross & Tabrizi, 2011). In addition, there are also cases of HIV-related cognitive impairments and Korsakoff syndrome, which is often linked to alcohol consumption and causes cognitive impairment. In this dissertation we refer to these diseases as *dementia,* yet it is important to remember that this is not a single disease. Most *people with dementia* have Alzheimer's disease, vascular dementia or both. This adds up to 75-95 % of dementia cases, which is why we focus on these in this work. If the type of the disease is different this is specified.

2.1.2 Behavioural changes and dementia

Dementia has a different impact on individuals because everybody is different. Therefore, dementia is a very personal condition. The differences between people with dementia are mostly visible in the behavioural and social problems that occur in everyday life. However, some generalizations can be made and therefore an overview of general symptoms and implications of dementia are presented in this paragraph. This gives us a better understanding of the process people living with dementia go through.

In medical terms the Clinical Dementia Rating or CDR is often used to describe the disease progression of dementia (Morris, 1993). This rating describes dementia on a scale that ranges from 0 – 3, and covers the stages 0: no signs, 0.5 Very mild signs, 1 - Mild dementia, 2 - moderate dementia and 3 - severe dementia (Table 2.1).
The CDR scale describes the disease in terms of six key factors. These are Memory, Orientation, Judgement & Problem Solving, Community Affairs, Home & Hobbies and Personal Care (Morris, 1993). With a low score (up to 0.5) there are only slight impairments in each of these fields. Starting from a score of 1.0 people experience moderate memory loss, time orientation difficulties and more complicated tasks such as individual community efforts or complex hobbies are abandoned. For scale 2.0 the decline progresses further and assistance is required in physical orientation and hygiene, only very simple activities are preserved. With a score of 3.0 there are severe issues in all of the categories and basic functioning is hampered. At this stage, people with dementia can only relate to other people.

Table 2.1 Clinical Dementia Rating (CDR) phases (Morris, 1993).

Composite Score	Phase description
0	No signs of dementia
0,5	Very mild signs
1	Mild dementia
2	Moderate dementia
3	Severe dementia

Another measurement tool often used by clinicians to indicate the level of cognitive impairment is the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). This is a 30-point questionnaire commonly used to screen for dementia based on orientation, attention, memory recall and language. A score of 25 or above is considered normal; below 25 there is need for additional testing. A score of 10 – 20 indicates a mild form of cognitive impairment and a score of below 10 indicates severe impairment. It is however suggested in a follow up review that the MMSE should not be used as the only diagnosis tool (Tombaugh & McIntyre, 1992) and corrected for education and age (Galea & Woodward, 2005).

More recent, a more practical and design oriented description of the disease process is provided by Timlin and Rysenbry (2010) in line with more clinical descriptions. They simplify the disease to three stages: *early*, *mid* and *late*. The cognitive disabilities salient in the early stage are typically forgetfulness, social anxiety and the loss of concentration; what's more, people with dementia tend to disguise these impairments. In the mid-stage, we see impaired ability during daily activities, significant memory lapses, reduced people recognition and disturbed sleep patterns. As the disease progresses into the late stage, more basic human functions such as communication, decision-making and even basic motor skills become impaired.

Furthermore, a study showed that on average there is a period of 2.8 years between the first symptoms and a diagnosis of dementia (Brookmeyer, Corrada, Curriero, & Kawas, 2002). This means that the disease has often already progressed significantly before support is sought.
Moreover, the risk indicators of dementia can already much earlier be addressed by individuals. Factors such as high blood pressure, Body-Mass Index (BMI), Cholesterol, smoking and high alcohol intake are all associated with subsequent dementia (Mangialasche, Kivipelto, Solomon, & Fratiglioni, 2012). More protective factors are found as well such as high complexity at work, rich social network, mentally stimulating activities and regular physical exercise (Karp et al., 2009).

In addition, the earlier mentioned study also looked at the relationship between life expectancy and age. Brookmeyer and colleagues (2002) found that those who are diagnosed at 65 years have a median life expectancy of 8.3 years, whereas those who are diagnosed at 90 years have an expectancy of 3.4 years. This means that there is still a long period of time in which people can live a relatively normal life when suffering from dementia. In society this is generally not understood and leads to stigmatisation of people with dementia.

2.1.3 Burden on caregivers

Dementia does not only affect the person diagnosed with the condition; it also heavily burdens the people taking care of them, often referred to as informal caregivers. Informal caregivers are family members, neighbours or friends that provide care for a person with dementia. Butcher and colleagues (2001) conducted an interview study among 103 informal caregivers on the experience of taking care of a person with dementia. They take the following quote as most descriptive for their results:

> *"Being immersed in caregiving; enduring stress and frustration; suffering through the losses; integrating dementia[1] into our lives and preserving integrity; gathering support; moving with continuous change; and finding meaning and joy."*

Quote 2.1 – experienced care for dementia (Butcher *et al.* 2001).

This quote shows that the role of informal care should not be taken lightly. Thereby, it is found that the burden increases severely over the disease timespan (Langa *et al.*, 2001). For informal caregivers there remain significant challenges, which contribute both to current capabilities and coping with the loss of abilities. A recent survey found that 98 % of informal caregivers experience mental, physical and health problems by taking care of a person with dementia. In this study changes in behaviour of the person with dementia (77%) was found to be the most challenging aspect (Zwaanswijk *et al.*, 2013).

The role of an informal caregiver for a person with dementia influences everyday life as well as society at large. Such an intensive provision of care invokes economic effects because caregivers may be forced to quit work, cut back on work, or take less demanding jobs (Wimo & Prince, 2010). Which might result in loss of workdays, financial issues, and potential long-term problems.

It is not expected that the increasing population of people with dementia will be reflected by professional or formal care soon. Therefore informal caregivers will have a significant role in dementia care now and in the near future. And that is why supportive strategies for informal caregivers should be sought that cover the entire disease process (Zwaanswijk *et al.*, 2013).

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[1] Dementia replaces ADRD (Alzheimer's disease and related dementias) from the original quote used to describe the diseases in Butcher et al. 2001.

2.1.4 Non-pharmaceutical interventions

Non-pharmaceutical interventions are professional interventions that support people with dementia without the use of drugs or medicine. Across the world these are very different. Every country has its own unique care system and non-pharmaceutical interventions that are used. Also the success of these interventions is variable depending on local results. These interventions might have different effects in different cultures. In this section we cover the most important of these interventions.

In a systematic review Olazarán and colleagues (2010) found 18 non-pharmaceutical interventions for people with dementia, five interventions focused on supporting caregivers, and three other interventions, and compared them on successfulness. In particular, the interventions based on educating the caregivers scored well, as they were capable of delaying institutionalization at relative low cost. Other research confirms this and shows that education of caregivers ensures savings in healthcare (and for society at large), moreover this is also a wish of many people with dementia and caregivers (Long, Moriarty, Mittelman, & Foldes, 2014). Mittelman (2013) even found this intervention could delay the transit to institutionalized care on average with 329 days. These interventions, which are referred to as psycho-education, can combine curative and rehabilitative aspects in an education activity, this potentially changes unproductive thinking, attitude, behaviour and provides guidance for caregivers (Steyaert, 2014).

Another common intervention that is provided almost everywhere is a day-care service for people diagnosed with dementia (Figure 2.2). Such a programme enables informal caregivers to have one or two days a week off. This time can be used to recover, do chores and have time for hobbies. Literature on this topic is not extensive, however, results show that day-care facilities are capable of reducing caregiver burden to maintain cognitive ability, quality of life and nutrition levels (Kwok, Young, Yip, & Ho, 2013). On the contrary, improving behaviour was not noted due to this intervention. For those with dementia, however, a slight improvement on cognitive ability was measured (Kwok *et al.*, 2013).

Other examples of non-pharmaceutical interventions are the use of music, reminiscence, massage and multi-sensory stimulation. However, these are not studied sufficiently to gather conclusive results on the efficacy (Olazarán *et al.*, 2010).

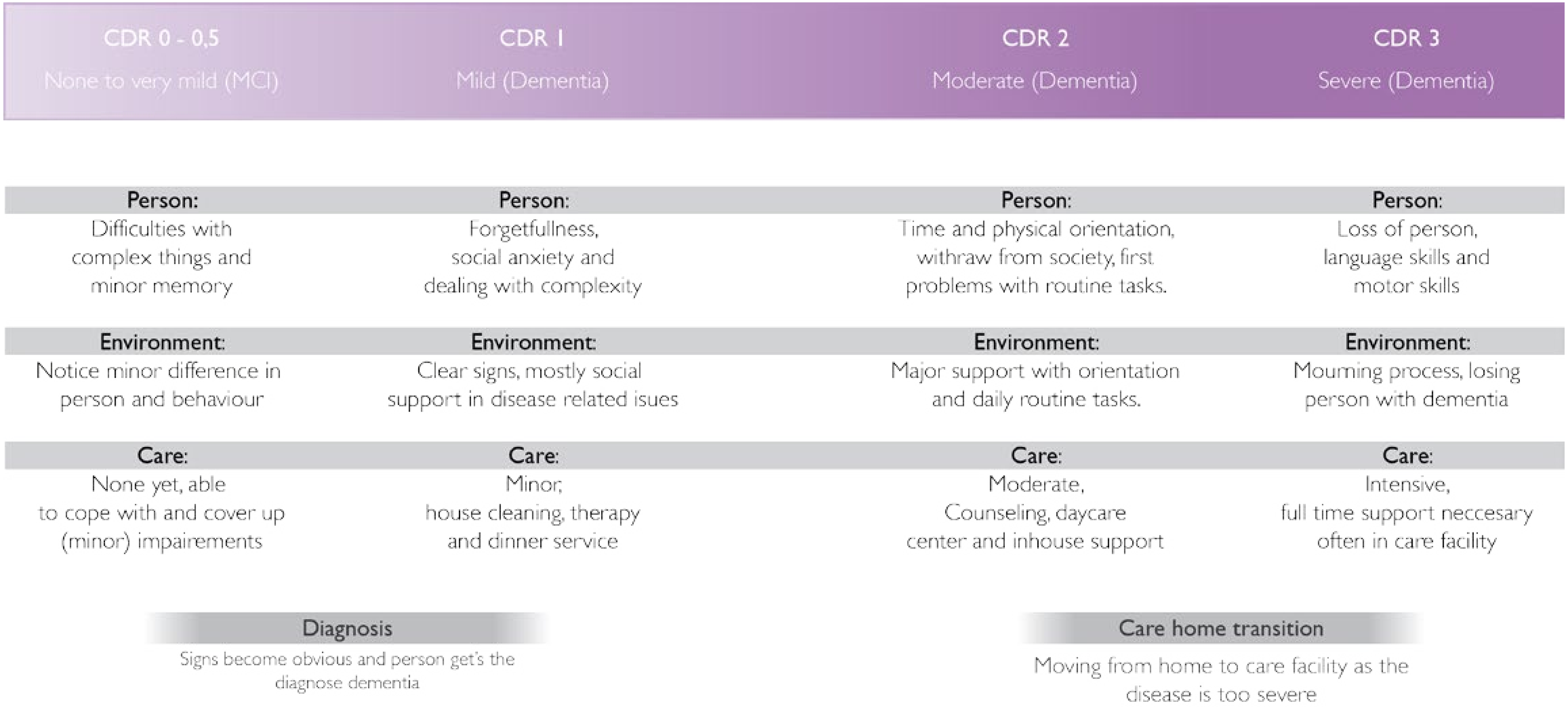
When the care burden is too high for informal caregivers a person with dementia can transit to a full-time professional care facility. This is both mentally and physically stressful. Also, due to the increasing costs of providing care in an institution, estimated at about 5000 euros each month (Nijhof, 2012), people with dementia have to live at home as long as possible, with all the risks this entails. In the Netherlands and most other European countries such care facilities are common, yet they also contribute to the high costs associated with dementia (Prince *et al.*, 2013).

There are many non-pharmaceutical interventions and some have produced promising results in studies over the past years. However, many of these studies are not conducted in a structured enough way to provide conclusive results. Nevertheless, they can inspire the design of new products, systems and related services, and show the potential of *care,* as long as *cure* is not possible.

Figure 2-1 Picture of a day-care facility for people with dementia.

2.2 A visual overview of the disease process

To provide a clear overview of the disease process an abstraction of the insights is translated into a single overview (Figure 2.3).



CDR 0 - 0,5 None to very mild (MCI)	CDR 1 Mild (Dementia)	CDR 2 Moderate (Dementia)	CDR 3 Severe (Dementia)
Person:	**Person:**	**Person:**	**Person:**
Difficulties with complex things and minor memory	Forgetfullness, social anxiety and dealing with complexity	Time and physical orientation, withraw from society, first problems with routine tasks.	Loss of person, language skills and motor skills
Environment:	**Environment:**	**Environment:**	**Environment:**
Notice minor difference in person and behaviour	Clear signs, mostly social support in disease related isues	Major support with orientation and daily routine tasks.	Mourning process, losing person with dementia
Care:	**Care:**	**Care:**	**Care:**
None yet, able to cope with and cover up (minor) impairements	Minor, house cleaning, therapy and dinner service	Moderate, Counseling, daycare center and inhouse support	Intensive, full time support neccesary often in care facility

Diagnosis

Signs become obvious and person get's the diagnose dementia

Care home transition

Moving from home to care facility as the disease is too severe

Figure 2-2 Visual overview of the disease process of dementia.

Based on findings in the literature we provide a process overview of he condition (Figure 2.2). This overview shows the impairment process and the issues people living with dementia are confronted with as part of it. Time is not included in this overview as it depends too much on other variables like age and additional conditions (Brookmeyer et al., 2002).

In the overview to moments have been added as transition points in the disease process. These are the *Diagnosis* and the *Care home environment*.
First, diagnosis is important as it makes it possible for professionals to get involved in the disease process. From a professional perspective the diagnosis is necessary as early as possible as the time window for support and education on the disease is longer. From a personal perspective this is different for each person. Some are willing to cope with the disease and act on first signals, whereas others remain in denial for as long as possible. This is also one of the reasons that makes the disease difficult and challenging to accept (Quayhagen *et al.*, 2000).
Second, a major transition in dementia can be found in moving from living at home to a professional nursing or care facility. This is a necessary step when care at home, often provided by informal caregivers, is no longer possible due to the heavy burden (Verbeek *et al.*, 2012). This naturally occurs earlier when there are no informal caregivers. There is no set time or phase of the disease for this transition; how much care they are able to provide differs per informal caregiver. This transition is very difficult, yet sometimes it's inevitable.

For this thesis we focused our design efforts on those with early to mild dementia (CDR 0.5 – 2.0). Approximately 30 – 40% of the people with dementia live in care homes (Prince et al., 2013), showing that the target group of our approach is significant.. This phase is particularly interesting because people with dementia then still have a couple of years to benefit from newly designed technology. However, this is also depended on their former experience people have had with technology. Docampo Rama and colleagues (2001) even found that there is a generation effect, referring to the dominant technology during a specific period in their life. Therefore, we do not exclude opportunities in other stages of the condition. In addition, we don't only focus on the person who is diagnosed with dementia. Others who are affected by the disease, such as informal caregivers, care professionals, etc. are an important focus for the interventions we design as well. This is why we speak of innovation for *people living with dementia,* including these groups. Hereby we don't focus specifically on people with 'early onset' dementia (under the age of 65) as the impact on everyday life is very different and the percentage is lower (<5%)(Prince et al., 2013).

2.3 Involving people with dementia in research

We have seen that there are several physical and emotional difficulties with dementia. In this section we explore why we should still pursue to involve people with dementia in research and what has been done so far in this field.

2.3.1 Person-centred care

In dementia care there is a global movement towards Person-Centred Care, often described as personalized care (Prince *et al.*, 2013). At the basis of Person-Centred Care lies the concept of personhood. Personhood contains elements of both individualisation and relationships that make up the self (Kitwood & Bredin, 1992). This concept relates to the experience of being, and in the case of dementia this is shattered over time. Kitwood and Breding (1992) argue that "personhood is not, at first, a property of the individual; rather, it is provided or guaranteed by the presence of others" suggesting that personhood can be preserved by external factors. An example approach which applies this for people with dementia is 'experience oriented care' (van der Plaats & Hazelhof, 2012); in this approach props and environments are used to trigger a familiar experiences of patients' younger years through reminiscence (Woods, Spector, Jones, Orrell, & Davies, 2005). Such an experience-centred view on dementia care is relatively new and has not yet been widely implemented; however, the first results of this approach in practice are promising (Ross *et al.*, 2014). We use this approach to steer and inspire developing innovative solutions for people living with dementia, and focus on taking the first-person perspective into account.

2.3.2 Involvement of people with dementia in design processes

Because there is no cure for dementia, there is a strong incentive to support people living with dementia in other ways. This is why we need to design and develop suitable interventions to improve the independence and quality of life for people living with dementia (Cahill, Macijauskiene, Nygård, Faulkner, & Hagen, 2007). Nevertheless, the full potential of such interventions has yet to be realized. Such assistive technologies have proved capable of contributing to a desirable living environment for older adults who require support in activities of daily living (Horgas & Abowd, 2004). However, we need to remain careful, as technological interventions cannot replace person-to-person dementia care. Supporting (technological) interventions will always be an addition to professional care. However, technology can contribute substantially by for example supporting autonomy and daily activities (Hoey *et al.*, 2011). Carefully designed interventions can answer unmet needs in various stages of dementia. Unfortunately, today, existing products, systems and services are often too difficult to be used by people diagnosed with dementia themselves (Astell *et al.*, 2010). The usability and adaptability (to the level of users) of newly designed concepts therefore deserves more attention. These interventions only become truly useful when individual needs are met *and* people living with dementia can use them.

In the literature interventions designed to enable people in their daily lives are called assistive technology. Still, when these assistive technologies target people living with dementia they seldom seem to consider their needs (Bharucha *et al.*, 2009). In addition, understanding their daily context is essential when developing new technologies to cater to their, often complex, needs.
Moreover, the first-hand perspective from the person with dementia itself is rarely sought in developing assistive technology (Topo, 2009), this has to change if we truly want to understand their context. Furthermore, such an experience driven approach is in line with Person-Centred Care. In addition, we need to consider that for cognitively impaired users, it's not only that the use of the proposed technology is challenging; it's also difficult to actively participate in research (Astell *et al.*, 2010). This could be one of the reasons for the absence of a first-hand perspective in developing technology for people with dementia. This is why we need to carefully consider the methods we use, and extend our efforts to include people with dementia (Lindsay *et al.*, 2012).

2.3.3 Involving people with dementia in research

We found three studies that describe in detail how to perform inclusive research with people with dementia. These are an adapted diary study (Bartlett, 2012) a focus group study (Qureshi *et al.* 1998, reviewed in Wilkinson, 2002, Chapter 9) and an interview-based study (Nygård, 2006). These studies were all ethnographical in nature, designed to broadly explore how to find the perspective of people with dementia. This deviates from the scope of developing and evaluating innovative interventions. Nevertheless, the insights generated in these studies are crucial when attempting to involve people with dementia.

Bartlett and Nygård both highlighted the importance of giving people with dementia a sense of control during research. Bartlett allowed users to select a specific type of diary input. In addition, participants were free to choose *when* and *where* they made an entry. Furthermore, the *context* in which the research takes place also needs consideration; Nygård (2006) stressed the importance of providing a meaningful context during the interview. She employed a strategy labelled 'reflection-by-doing' (capturing the insights and feelings as they occur), thus avoiding retrospection, which is particularly difficult for this user group. Moreover, Nygård deliberated that this 'reflection-by-doing' is more stimulating when other people are involved.

In addition, such a social aspect in a research activity increases the comfort for participants. The focus group studies of Qureshi and colleagues (2002) also provided a social setting during the inquiry. This was regarded as a positive aspect of the study.

Another important insight from each of these studies is the concept of segmenting the research activity into smaller parts. The studies show that this reduces the burden of participation for those with dementia. What's more, such a segmented research activity evokes the creation of a ritual. According to Qureshi and colleagues (2002), this ritual made the participants aware that something was going to happen and it was reminiscent of earlier focus- group sessions. This all contributed to a comfortable setting in which participants felt at ease, and in our project we included these aspects in our focus groups (Figure 2.4).

Figure 2-3 A focus group as part of Innovate Dementia with users.

2.3.4 Caregivers as spokespersons

The caregivers of people diagnosed with dementia should also be considered when conducting such research. They can play an important role in facilitating or supporting the research methods. However, care for people with dementia is already intensive, so we should not overburden them. When looking at research methods that require active participation, we see that they are often intensive for participants. Naturally, these would be even more difficult for people diagnosed with dementia. In the literature it is therefore often recommended that professional caregivers are spokespersons for people suffering from dementia in developing assistive technology (Orpwood *et al.*, 2004). In particular, in the later stages of dementia as care and contact becomes more frequent.

For this reason, informal caregivers might be useful as spokespersons for people in early-onset dementia. Baker *et al.* (2003) recommend involving the informal caregiver as proxies for those with dementia, to reduce the burden while maintaining a representative output. However, other researchers argue that people with early-onset dementia are perfectly capable of expressing *in situ* experiences and opinions (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007). This is why we need to continuously balance which perspective and user involvement is most desirable, with the least disturbance and burden.

2.3.5 Ethical considerations

When conducting research involving people with dementia ethics need to be considered throughout. Informed consent raises questions when people with a cognitive impairment are involved. So we have taken several precautions. Two actions were intended to protect those with dementia who participate in our project. First, we only chose people in early – mild stage dementia because they still have a sense of self and are capable of understanding what the research means (Ettema *et al.*, 2007). Second, we only involve people with dementia who have an informal caregiver taking care of them, at their home. Therefore, there is always another person nearby. These might present a potential bias in the population, however they also ensure a safe inclusion into the research. The main difficulty for research is that dementia is progressive, and the participant's perspective on the research might change. Therefore designated independent consultants must continuously assess the status of consent. In our studies, care professionals (mental care institute, GGzE) and informal caregivers performed that role to protect the integrity of those with dementia.

Therefore, when conducting studies with impaired users, informed consent could be seen as a continuous dialogue (Coughlan *et al.*, 2013). While all participants sign it at the start of the studies, the participants are repeatedly asked to confirm it to ensure continued consent. Both participants and researchers experienced this as a convenient way of working. In line with this, Mahoney and colleagues (2007) presents a layered ethical model for technology studies involving people with dementia (Figure 2.5). This model focuses on putting the human aspects (users) at the centre of the ethical considerations, and specifies; respect for the condition, individual differences, health, and family relationships. Research requires minimal invasiveness and clear boundaries as well as clear explanation of privacy and confidentiality. Thereafter the technology offerings (third layer) should be considered to ensure distributional fairness, and truthfulness. Much still needs to be added to this discussion, and perhaps it should become a family-centred approach, because the impact of home interventions also affects informal caregivers (Bauer, 2001). For this the Value Sensitive Design framework (Friedman, Kahn, & Borning, 2009) presents a wider value based tool based on a tripartite methodology including a: Conceptual, Empirical and Technical approach. In this conceptual refers to the starting point of value exchanges and conflicts in a specific design (ie. informed consent). Empirical presents the methods of inquiry used for a design (interviews etc.), and technology the features of the design itself that conveys values. Therefore this methodology is holistic and covers the perspectives from which ethical issues can be identified.

Figure 2-4 Ethical model used in technology studies (Mahoney *et al.* 2007).

2.4 Interactive Experience Flow

There are many different stakeholders who play an important role in the care process of dementia. To get an insight in these other roles, and the experience of people with dementia over the course of the disease we constructed an *Interactive Experience Flow*. This is an easy-to-use tool to get insight in the dementia care process and its stakeholders.

2.4.1 Design of the Interactive Experience Flow

The *Interactive Experience Flow* was created because there was a lack of a concise and complete overview into the disease process and the stakeholders involved. For this there were no direct sources available and information, In particular, about the various stakeholders, was fragmented. There are many sources available for people with dementia, but less so about people with dementia and their differences.

At the basis of the *Interactive Experience Flow* there are research techniques such as personas (Pruitt & Grudin, 2003)., customer journey (Zaltman, 2003) and our dementia disease process. Because dementia, and its accompanying care processes, is more complex than other care processes, these methods have been combined and extended create a more holistic overview. This resulted into, the *Interactive Experience Flow* (Figure 2.5).

The insights are derived from people with dementia, caregivers and various kinds of care professionals in the field of dementia care via interviews and reflection sessions (Alblas, den Ouden, & Brankaert, 2011). We found there are many differences among people and their 'journeys' through the care process. This is important as the disease affects individuals in a different way (Zwaanswijk *et al.*, 2013). This is why we selected three different stories to feature and provide a concrete context to the different stages in the *Interactive Experience Flow:*

Willem & Mien, blue line: First a very positive scenario of how a person would ideally flow through the disease, this doesn't mean they don't have trouble with the disease; however, they are able to overcome most issues.

Joop & Truus, red line: The second story line is a doom scenario, in this scenario almost everything that can go wrong, goes wrong for these (extreme) cases the care system has some protocols and facilities that are shown.

Toos, yellow line: The final scenario covers a person coping with the disease on their own, without informal caregivers, which brings its own challenges and care path.

In *Interactive Experience Flow* there are five stages. By selecting the stages more information can be found on: what happens in the stage, who is involved in the stage and a specific expert perspective. These stages are:

Realization phase: Awareness in society, and knowledge about dementia and the first sings of the condition.

Diagnosis phase: The phase of a formal diagnosis by a General Practitioner or other route.

Arrange phase: Process of preparing for dementia progression and coping with minor issues caused by the disease.

Informal Care phase: Living at home, using various care facilities, coping with moderate issues caused by the disease.

Institutional phase: Transition to institute, care in an institutionalized context, coping with severe issues caused by disease

Furthermore, two additional more peculiar stages are identified. These are *'Crisis'*, covering the process when an incident or emergency happens and *'Individual'*, which focuses on the care process when a person has no informal caregiver(s).

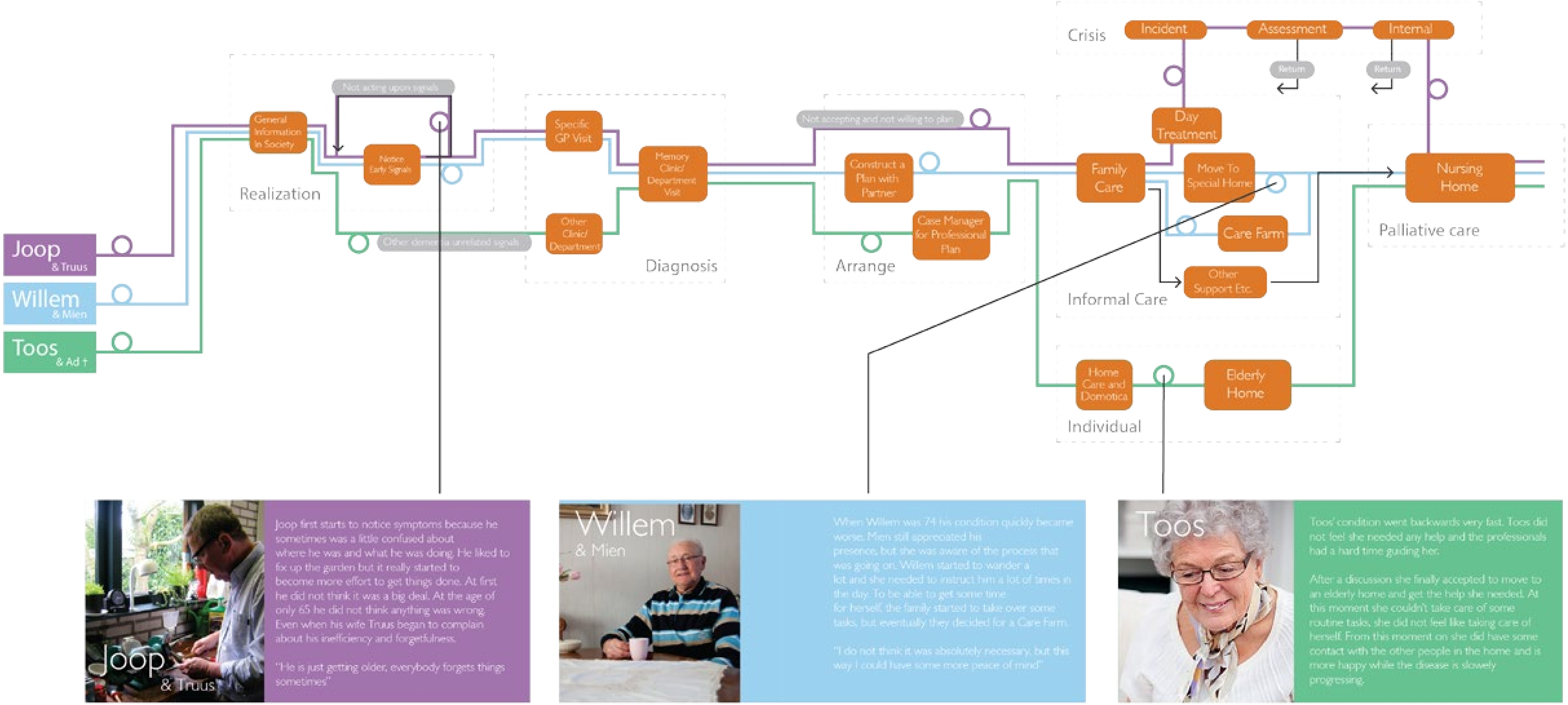
On top of the disease stages presented above the Interactive Experience flow provides more layers of information. Each of these layers can be selected from the main overview to get a deeper understanding of specific topics. Currently there are three of those additional layers included.

First is the finance layer, by selecting *'costs'* this layer is projected over the care process. The layer shows the costs of each phase (low early in the disease process, and rising as dementia progresses), next to this the layer shows how the finances are arranged between different stakeholders such as insurance, municipalities (WMO) and the government (Wlz).
The second layer that can be selected concerns the caregiver burden. By selecting *'care flow'* a graph is projected that shows the care burden over time for the person with dementia, their caregivers and their professional caregivers. In general the burden increases over time for both the person with dementia and their caregiver, however, at some point in time there is a cut-off point were professional care start playing a significant role in care as well.
Finally, in the third layer called 'opportunities' an overview of problems and opportunities are plotted on the care process. These are directions that might be interesting to pursue for designers or researchers.

These layers can be accessed in the online version of the *Interactive Experience Flow* and are not presented in the overview presented on the next page.

2.4.2 The Interactive Experience Flow

The flowchart overview (Figure 2.6) is a screenshot from the interactive online tool to be found at http://www.RensBrankaert.nl/flowchart.



Joop first starts to notice symptoms because he sometimes was a little confused about where he was and what he was doing. He liked to fix up the garden but it really started to become more effort to get things done. At first he did not think it was a big deal. At the age of only 65 he did not think anything was wrong. Even when his wife Truus began to complain about his inefficiency and forgetfulness.

"He is just getting older, everybody forgets things sometimes"

When Willem was 74 his condition quickly became worse. Mien still appreciated his presence, but she was aware of the process that was going on. Willem started to wander a lot and she needed to instruct him a lot of times in the day. To be able to get some time for herself, the family started to take over some tasks, but eventually they decided for a Care Farm.

"I do not think it was absolutely necessary, but this way I could have some more peace of mind"

Toos' condition went backwards very fast. Toos did not feel she needed any help and the professionals had a hard time guiding her.

After a discussion she finally accepted to move to an elderly home and get the help she needed. At this moment she couldn't take care of some routine tasks, she did not feel like taking care of herself. From this moment on she did have some contact with the other people in the home and is more happy while the disease is slowely progressing.

Figure 2-5 The interactive flow chart: Dementia.

2.4.3 Using the Interactive Experience Flow

The *Interactive Experience Flow* is created for designers and researchers to allow them to get a holistic understanding of the dementia care process. In this people with dementia their caregivers and other relevant stakeholders are included. The basic information is provided in the front layer (Figure 2.6) and specific information can be found through specific layers.

The most relevant of these specific layers is the *'opportunity'* layer, in which an overview of problems and new chances for dementia can be found. This is partly based on our expert interviews, or by what others have already identified as important needs in the dementia literature. The opportunities we presented are issues that are currently not yet addressed by technology or general care services. These opportunities can inspire designers or provides a new angles for researchers.

In addition, for design or research in this area, a single-perspective research tool would only have led to single-perspective solutions for people living with dementia. Furthermore, the *Interactive Experience Flow* makes it possible to explore different perspectives; in addition to the personas, the reader can see how caregivers and professionals view the disease process as well. This view might reveal new insights as well enabling them to achieve need-driven innovation (Verganti, 2008).

In the end, the *Interactive Experience Flow* is multi-purpose, and can be used to define a design scope, research proposal or to gain a better understanding of dementia. On top of that it also provides a common ground to create a shared perspective on opportunities, potentially resulting in products or services based on these shared values (Ballantyne, Frow, Varey, & Payne, 2011). Innovations based on such shared values have a better chance at adequately addressing the end-users correctly (Alblas *et al.*, 2011), which in turn is necessary to develop innovative solutions that can meet the societal challenge of dementia.

Currently the *Interactive Experience Flow* can't be fully personalised, however, due to the diverse personas and the variety of stakeholders included the dementia care process is covered in a broad way. One should be able to find perspectives that they can relate to, and this makes the tool potentially interesting for people living with dementia as well. At the moment there are not overviews for people with dementia or their loved ones that cover the entire disease process. This should be investigated further.

2.5 Conclusions

In this chapter we took a closer look at the diseases that are collectively referred to as dementia. We also found that there are some general characteristics that can be used to inspire design. Because Alzheimer's disease and vascular dementia are the most common type of dementia, we focus on these two diseases.
In addition, it is important to notice that not only the person with dementia is affected; the disease also heavily burdens informal caregivers, family members and friends. This leads us to the first key insights of this chapter:

Dementia is a name for several diseases that affect individuals in many different ways, so in designing for this group we have to take this into consideration.

There have been several research attempts to involve people living with dementia, yet very little to involve them in active role. We learned that we have to consider who we are involving, inspired by Person-Centred Care. In addition, the role of caregivers to become spokespersons for people with dementia is a possibility when the burden is too high. Several research methods can be used to gather insights from this population. This leads to our second key insight for this chapter:

When we involve people with dementia and their caregivers in research we need to adept the design and research methods to them, and respect their personhood, stage of disease and context.

Finally we have presented the *Interactive Experience Flow*, which was built as a tool for understanding dementia and its complexity from different perspectives. This tool can reveal new opportunities that would not have been discovered by focusing solely on the disease or a single stakeholder. This leads to the third key insight:

We need to build an understanding of the disease, the stakeholders and the different perspective before we can find adequate innovative solutions that contribute to the societal challenge. The Interactive Experience Flow provides a platform for doing this.

Chapter 3:

Living Lab Methodology

A Comparative Study

To address challenges in dementia we need methods that can cover the complexity of such a challenge. This means that no single or linear method will suffice. Instead, we need to examine an approach that is dynamic and adaptable to different stages of development.

The Living Lab approach accommodates both of these requirements. A Living Lab is an innovation method that allows for active user involvement in a realistic context. In this chapter we explore the method in detail, and examine how it evolved from a research method into an approach to innovation.

To build the Living Lab for our project we conducted a Comparative study of several Dutch Living Lab initiatives. This study ensured a more hands-on understanding of the differences and similarities between Living Labs.

This chapter is based on:

Brankaert R., den Ouden, E. and Grotenhuis, F. (2014). Identifying different living labs - development a typology framework. Proceedings of ISPIM Conference 2014, Issue 25. Dublin, IE.

3.1 Living Labs in the literature

The term 'Living Lab' became common in research about fifteen years ago. At that time researchers started to use the natural context of users in their interaction design studies (Markopoulos & Rauterberg, 2000). In one example, the Living Lab was envisioned as a reconstructed home environment that could be used to investigate human behaviour and experience. In the literature, these types of Living Labs are referred to as *'American'* Living Labs and represent research lab facilities that are designed to look like a natural context (Schuurman, Mahr, Marez, & Ballon, 2013). These early versions of Living Lab studies are attempts to increase the ecological validity of user-related research.

The Living Lab has gained more attention in recent years due to increased interest from Europe, and consequently European subsidiary programs. The European Network of Living Labs (ENoLL), which was founded in 2006, defines a Living Lab as follows: Living Labs are real-life research environments, used to tackle innovation challenges in all kinds of fields (ENOLL, 2013). Users, or people representing them, usually have a prominent role in these Living Labs as key stakeholders in the innovation process (e.g. Bergvall-Kåreborn & Ståhlbröst, 2009).

In recent years, the literature on Living Labs has expanded and many different definitions and approaches have become available. As such, it has become unclear what a 'Living Lab' means specifically as a method or as an approach to innovation . This ambiguity raises two main issues. First, it has become inherently difficult to adopt a Living Lab methodology for specific innovation purposes. And second, the Living Lab is becoming a fragmented field of methods rather than a focused research subject.

3.1.1 Living Labs in various fields

There are various research fields that apply Living Lab methods. One of them is Information Communication Technology (ICT). In this context, some Living Labs are used to expose users to new applications as innovation platforms to connect stakeholders (Følstad, 2008). Følstad (2008) describes nine characteristics of Living Labs. Of these four apply to most Living Labs. These are: Discovery (finding unmet needs and applications), Evaluation (of innovative proposals), Familiar Context (for the users) and the studies tend to be medium to long-term (more than a week). The other five are called diverging and only apply to some Living Labs: Investigate the Context (of use), Co-creation with the User (as part of the process), Technical Testing (does it work?), Real-world context (high ecological validity) and Large Scale. Følstad (2008) successfully describes the specific elements of a Living Lab, yet it does not attempt to describe the Living Lab as a method.

In innovation management Living Labs are also becoming more popular as a way to stimulate Innovation. Leminen *et al.* (2012) define the Living Lab method as a driving tool for innovation, and describe it as follows: *"Living Labs have been successful in providing networks that can help to create innovations that match with users' needs and have the ability to be brought to a market level".* They argue for differentiation of Living Labs based on who is the driver of the Living Lab. This results in four categories: Utilizer-driven (for business development), Enabler-driven (for addressing societal problems), Provider-driven (for promoting research and theory development) and finally User-driven (for solving users' everyday problems). This categorization provides insight into the goals that can be achieved by Living Labs with different drivers. Yet it remains ambiguous in describing the exact choices that are made related to the setup of the Living Labs involved in this study.

Various studies have been undertaken to define Living Labs. One example is work by Bergvall-Kåreborn and Ståhlbröst (Bergvall-kåreborn, Ståhlbröst, et al., 2009). They define Living Labs according to five key principles: Continuity, Openness, Realism, Empowerment of users, and Spontaneity.

Table 3.1 Living Lab key principles *(*Bergvall-kåreborn *and* Ståhlbröst, *2009)*.

Principles	Represented in questionnaire by:
Continuity	Collaborations build on long-term learning and trust, which both take time
Openness	The innovation process should be open to gather different perspectives and input
Realism	Necessary to get realistic use situations and behaviour for real insights into an innovation
Empowerment of users	As the users' needs and desires are fundamental for innovation, they need to be enabled
Spontaneity	Ability to detect, collect and analyse spontaneous users' reactions and ideas

Such principles are useful when describing the Living Lab phenomena, yet they seem difficult to use as a design or construction guidelines for Living Labs. For example on the key principle ‘Openness’, which mostly relates to open innovation (Chesbrough, 2003) and lead-user strategies (von Hippel & Katz, 2002), the following is stated: *‘The Living Lab should be as open as possible’*. Because when this process is open, it allows for input from users and other relevant stakeholders. This is inherently true for Living Labs, yet it doesn’t explain in detail how this is done and what the boundaries of the influence are. In order to successfully guide setting up a Living Lab a clear description, accompanied by examples, for a term such as ‘openness’ are necessary.

3.1.2 Experiential Design Landscapes

More recently a design-driven method called Experiential Design Landscapes (Gent *et al.*, 2011) has been founded to perform real-life experimentation in design. This method combines the strengths of ecologically valid context for research and an experimentation and design-driven approach to innovation . In user studies there is concession to be made on experimental control and realistic environment (Koskinen *et al.*, 2011). Yet this method involves altering this correlation and creating an environment where there is both a higher experimental control while retaining a high level of realism in design studies (Peeters, Megens, Hummels, Brombacher, & Ijsselsteijn, 2013). In addition, the focus of this type of experimentation is on facilitating an iterative design process, with reflective design cycles (ie. Hummels & Frens, 2011) and probing activities (Gaver, Dunne, & Pacenti, 1999). Experiential Design Landscapes provide a window for the rising complexity of society and the design for societal challenges within. Because the method is design-driven, it is designed to facilitate involving the real-life context as early as possible compared to traditional innovation processes. This provides stronger direct input from the ‘real-world’.

3.2 Living Labs – a comparative study

To gain a better understanding of the Living Lab method we investigated a number of Living Lab projects. In this paragraph the study setup is discussed.

3.2.1 Living Labs compared to other innovation methods

In the literature we can find attempts to compare Living Labs to other innovation methods. One example is the concept of Technology Experimentation Platforms or TEPs (Ballon, Pierson, & Delaere, 2007), which discuss Living Labs among several other experimentation methods. According to this overview Living Labs are strong in both a real-life context and active role for users. The overview shows that when research is performed in a non-real-life environment they are test beds, and when users have no active role in the research it is a field trial. Living Labs – and their variations – are therefore very suitable for a design-driven approach. Building on this, Pallot *et al.* (2010) constructed a methodology landscape for Living Labs. This work focuses on the methods that can be used in a Living Lab context. In this the diversity of a Living Lab approach is emphasised as it allows for many different studies. In a more recent study Almirall and colleagues (2012) extend this work by seeing Living Labs as a method (Figure 3.1).

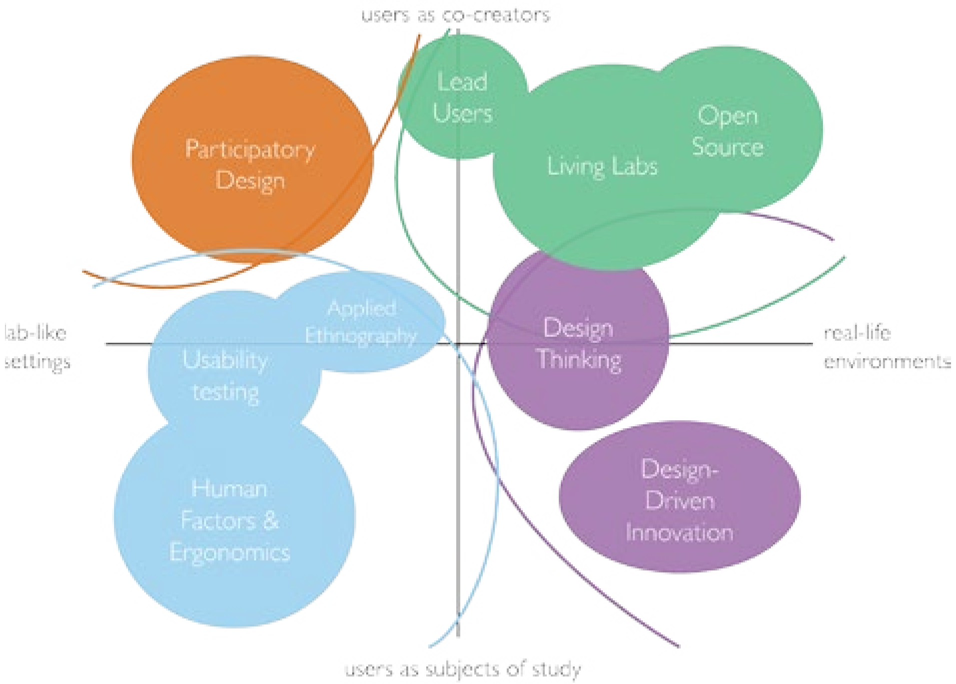


Figure 3-1 Mapping Living Labs in the landscape of innovation methodologies. Adapted from Almirall *et al.* (2012).

In this overview the researchers compare Living Labs to other innovation methodologies. This overview is based on two key aspects, the *user* and the *environment,* aspects we have seen in other literature as well. For this reason we selected this model to drive the study on Living Labs. The work sets the Living Lab method clearly apart from other methods, yet still lacks a clear description of a Living Lab. This is one of the reasons why the Living Lab research field is still fragmented, making it difficult to derive specific Living Lab guidelines. In our study we compare Living Labs to gain insight in the diversity in this field.

In general a Living Lab is positioned as a real-life environment where users are involved as co-creators (right-top, Figure 3.1). Co-creation means, users and designers develop innovations together at an equal level (Sanders & Stappers, 2008). Consequently, for the environment, real-life means seeing the innovation perform in a realistic context, rather than gathering research findings in a lab environment. To examine these Living Lab phenomena more closely we need to take a more detailed look at the variations in this field by comparing several approaches.

For this method we identified six Living Labs that were performing Living Lab activities as an innovation method. These Living Labs were selected in a pragmatic way, and we used a questionnaire method to gather their perspectives.

3.2.2 Differentiation factors: user and environment

To compare living labs we need to select factors that define the Living Lab approach, yet are different. Building on the work of Almirall and colleagues (2012) we selected the *user* and the *environment*. These aspects are recurring themes in Living Lab research (Ballon, Pierson, & Delaire, 2005; Bergvall-kåreborn, Ståhlbröst, et al., 2009; Leminen et al., 2012). However, we aim to specify these further.

First, concerning the environment, Følstad (2008) argues there is a need for a familiar context, following this Bergvall-kåreborn and Ståhlbröst (2009) describe a need for high level of realism. In addition Almirall *et al.* (2012) claim that the Living Lab 'field' is more like a real-life environment than a lab-like test environment. These descriptions seem similar; however, when we take a closer look we see some differences. There are Living Labs that use real-life environments, while others work with more simulated environments. This supports the notion that the environment is indeed a valid way to differentiate between other methods and between Living Labs when we examine how real an environment is. And therefore, we selected the factor of a *realistic environment* to examine the differences between Living Labs in this comparative study.

Second, the user is also mentioned as an important factor in the literature as well. We found different ways of involving the user, as well as different kinds of users who are involved. As is shown in Almirall *et al.* (2012), Living Labs are distinguished from other methods because they involve users in active way. This is a prerequisite for the method, and there should be no differences among Living Labs. Other authors also emphasize this (Bergvall-kåreborn, Ihlström Eriksson, Ståhlbröst, & Svensson, 2009). This shows that the way of involving the user is not a good way to differentiate between Living Labs.

We see, however, more differences in the kind of users who are involved in Living Labs. Some involve end-users and others involve people more pragmatically. Furthermore, there are Living Labs which do not just involve the user, but also a vast network of stakeholders. This is more apparent in the overview by Leminen *et al.* (2012) that differentiates between Living Labs based on its driving stakeholder. These emphasize the approach in which the network of stakeholders should also be strongly considered as part of the Living Lab. It is shown that the involving a network of stakeholders in Living Labs varies strongly. Some mention that the Living Lab is a network of stakeholders itself based on participation (Leminen, 2013) were others put minimal emphasis on this aspect (e.g. De Pessemier, Martens, & Joseph, 2013). This is interesting, and shows that the level of network engagement is a viable factor that can be used to differentiate among Living Labs. Therefore we selected 'involving the network of stakeholders' as a factor when analysing the Living Labs in our comparative study.

3.2.3 Questionnaire

For this study a questionnaire was developed, to investigate the different approaches. This questionnaire was used to analyse six Living Labs. From these Living Labs, the senior managers or responsible researchers were asked to fill it in. Subsequently, the respondents were invited for a semi-structured interview to motivate the answers provided.

We used the five key principles: Openness, Realism, Influence, Value and sustainability (Table 3.2) to check the Living Labs for eligibility (Bergvall-kåreborn, Ihlström Eriksson, et al., 2009). These are similar to the key principles presented earlier. These five key principles were translated into questions and evaluated as part of the questionnaire. The questions relating to the principles were rated on a 7-point scale, from Very Inapplicable to Very Applicable. Only the Living Labs that scored high (above 5) on at least 4 of the 5 principles were included in the study.

Table 3.2 Key principles for Living Labs *(Bergvall-Kareborn et al. 2009)*.

Principles	Represented in questionnaire by:
Openness	Sharing information and insight with parties.
Realism	Research in the natural context of the user.
Influence	Of users and stakeholders on the innovation process.
Value	For the prospected end-user and stakeholders.
Sustainability	The existing knowledge is captured and accumulated to build on further.

The second part of the questionnaire was designed to arrive at a general understanding of the Living Lab (goals & design) and more detailed questions about the differentiation factors. The following structure was used in the questionnaire:

1. Evaluation of the key principles (eligibility check).
2. Identify the general goal and design of the Living Lab.
3. Gathering in-depth information on the differentiation aspects.
   - Understand what kind of stakeholders are involved in the Living Lab.
   - Determine the 'realness' of the environment that is used in the Living Lab and the related level of experimental control.

The questionnaire contained both multiple-choice and open questions. The complete questionnaire can be found in Appendix A. In total four Living Labs participated in the follow-up Interview, as the answers were not entirely clear, and this eliminated ambiguity of the research terminology used. The interviews also provided additional information on some of the more detailed choices in the Living Lab design.

3.3 Comparison of study results

First we present the scores on the selection criteria for the Living Labs(Table 3.3). In total six Living Labs were included in this explorative study. For most Labs all five criteria were considered to be applicable, but for two one principle was considered inapplicable.

3.3.1 General results from the questionnaire

Via the questionnaire and interviews some general insights were gathered. Firstly, we found that the Living Labs were always used in the early stages of an innovation process. The participants selected in which phase their Living Lab was, with the options: Discovery, Exploration, Evaluation and Validation phase (elaborated on in Chapter 4). The Living Labs were either in the discovery (n=4) or in the exploration (n=2) phase. This is in line with the literature ,which suggests that the purpose of Living Labs is mainly for developing innovations early in the innovation process (Ballon *et al.* 2007).

Secondly, the questionnaire showed that four out of six Living Labs were publically funded, while only two living labs were privately funded. These privately funded Living Labs were the two labs that scored the lowest on the general key principles. In this small sample we see that Living labs with more financial autonomy adhere less to the Living Lab principles.

Table 3.3 Living Labs meeting the selection criteria

Living Labs	Openness	Realism	Influence	Value	Sustainable
Philips Exp. Lab	1	6	6	6	6
I3B Living Lab	5	2	7	7	6
SusLabNWE / Concept house	5	6	6	7	7
Sport park 'Op Noord'	7	7	7	7	7
Innovate Dementia LL	6	7	6	6	6
TU/e Living light labs	7	7	6	7	7

3.3.2 The Living Lab projects described

Below is a detailed description of the Living Lab projects that were in this study in detail, with a focus on the main goal and design.

Philips Experience Lab

Goal: 'An environment in which user-centred research and concept development can be performed for different domains, with the goal of ensuring speed in developing innovations that are meaningful to people.'

Design: 'The Living Lab contains a diverse offering of areas, objects and services to get to the right prototypes and environment quickly. Furthermore we have a 'knowledge group' for discussions with experienced researchers and developers.'

I3B Living Lab

Goal: 'An ecosystem for cooperation between knowledge institutes, high-tech companies and end-users with the goal to mutually develop new products and services.'

Design: 'The Living Lab i3B exploits a number of physical labs for research purposes through their network-oriented approach. There is a People tracking lab, a User experience lab and an Automotive lab.'

SusLabNWE / Concept house

Goal: 'A networked knowledge hub, that provides unique and novel testing facilities for industry, knowledge institutes and policymakers with actual users for (the development of) sustainable products and services.'

Design: 'Each location will be a public-private partnership set up to enable a three-phase approach to develop user-centred sustainable solutions. These are generating insights into the field, co-creation and prototyping of sustainable innovations in 'living laboratories' and field testing of new solutions in houses that are adapted to incorporate these solutions.'

Sports Park 'Op Noord'

Goal: 'An Experiential Design Landscape in which designers, users, analysts and other relevant stakeholders can design and create new disruptive proposals in an open and real-life context.'

Design: 'The Experiential Design Landscape takes place in a sports park with the possibility to introduce new concepts/proposals in a sufficiently instrumented way so they can acquire high value, multi-modal data.'

Innovate Dementia Living Lab

Goal: 'To cooperate with various stakeholders to develop assistive technology and services that contribute to the lives of people living with dementia. The aim is to allow them to live longer in the home environment, with an optimal quality of life.'

Design: 'A structure designed to develop, evaluate and validate new innovative products, systems and services for people living with dementia in their actual home context.'

TU/e Living Light Labs

Goal: 'A place in the real-world in which experiments can be conducted with new technologies to research the needs of users and how they can be addressed through technology, interaction and experience design. Stakeholders are involved to reflect on the results.'

Design: 'A diverse range of test beds are available for various projects. These include controllable light systems, with the possible extension of sensors. These are used to research how light influences the behaviour and experience of people.'

Figure 3-2 An overview of six Living Labs as part of our comparative study.

3.3.3 Comparing according to the differentiating aspects

We found that the context in which the Living Labs operated varied significantly. This already becomes apparent from the design descriptions (Figure 3.2). Some of the Living Labs use simulated environments while others position their Living Lab in the actual real-life environment of their users (Table 3.4).

The environment seems only to be different when we specifically asked if the Living Lab took place in actual real-life (Table 3.4). More general questions concerning realism or users were inconclusive. This shows that more specific questions are required to find out what is actually meant.

Some Living Labs use reconstructed or simulated environments for their innovation studies; others involve their users in their actual real-life situation. Most of these differences became apparent from the context input (Table 3.2, right column). For the differentiating aspect of *environment* this means that the description needs more detail than just asking for *realism*. In addition, we also asked for experimental control, because in the literature realism is negatively correlated with experimental control (Koskinen *et al.*, 2011). Interestingly most Living Labs position themselves having a high realism and high experimental control.

Table 3.4 Responses on the environment of the Living Lab.

Living Labs	Realism	Experimental Control	Real-life context
Philips Exper. Lab	6	6	Yes, but reconstruct
I3B Living Lab	2	6	Partly, lab and reconstructed
SusLabNWE / Concept house	6	6	Yes, reconstruct and real-life needs
Sport park “Op Noord”	7	5	Yes, active role
Innovate Dementia Living Lab	7	6	Yes, active role
TU/e Living Light Labs	7	5	Yes, passive role

The way users were involved varied minimally among the Living Labs. Sometimes envisioned end-users are involved (for example in the TU/e Light labs) in other cases a more pragmatic group is included (for example in the I3B Living Lab). In most of the cases the involvement was partly active, and a mix between observing and co-creation. Moreover, concerning the network of stakeholders we found differences in what kind of stakeholders were involved. Some Living Labs only included users in their Living Lab, while other living labs had a more network-oriented approach involving a wider stakeholder group. These Living Labs tended to aim for more high-level goals (such as the societal challenge of dementia). Some involve them actively (via discussion groups) and some are involved passively (remaining unaware throughout studies).

On the differentiating aspect ‘network involved’ there are again many variations in how this is used among the Living Labs (Table 3.5). On first sight, there seems to be a similar approach: most mention to operate in an open network. However, when questioned in more detail the differences become apparent. Some involve only users or people representing them, where others involve the entire network of stakeholders as part of their Living Lab process. This allows for a more clear distinction between Living Labs and therefore the kind of network involved could be a viable differentiator.

Table 3.5 Responses on involving the network of stakeholders.

Living Labs	Is it an open network?	Work together with other stakeholders?
Philips Exper. Lab	No, IP problem	Mostly users
I3B Living Lab	Yes, open	User (representatives) and network
SusLabNWE / Concept house	Yes, open	Mostly users
Sport park “Op Noord”	Yes, open	Mostly users
Innovate Dementia Living Lab	Yes, open	Users and stakeholders (separately)
TU/e Living Light Labs	Yes, open	User (representatives) and stakeholders

3.4 Comparative study conclusions

This explorative study revealed insights concerning the living lab phenomenon. Thereby, it provided concrete ‘hands-on’ examples of other Living Labs that can be used to define the direction of our Living Lab.

3.4.1 Discussion

The differentiating aspects used in the study were *environment* and *network of stakeholders*. These were valuable as both the environment factor (already familiar in Living Lab research) and the network of stakeholders factor (how and what) set Living Labs clearly apart from each other. Especially the network factor revealed the shift towards more networked and open innovation oriented Living Labs (Leminen *et al.*, 2012); however, it is not yet a common principle in the living lab literature yet. The comparative study showed that some of the Living Labs have taken this direction whereas others are more close to traditional research environments.

Moreover, some additional interesting insights were gathered. We saw that experimental control is considered high by the Living Labs included in the study. This is not in line with the literature; Koskinen *et al.* (2011) state, for example, that conducting research ‘in the field’ results in a compromise on experimental control. Hence, the Living Labs involved in our study did indicate that the realism of their research environment is overall high.

The discrepancy between realism and experimental control let to an altered, design-driven Living Lab approach: Experiential Design Landscapes. Peeters *et al.* (2013) show in this method that there is a need to challenge the experimental control/ environment relationship. Society is becoming increasingly complex and therefore we can no longer control all variables and perform ecologically valid research. If we want to address challenges in dementia we will have to take this perspective into account. And there is the ability to do so because technology is becoming more intelligent and reliable. Overall the Experiential Design Landscape approach shows a relevant perspective for the design of a Living Lab setup.

In the end we see the Living Lab as a structure, a way of working in a network of stakeholders to perform innovation activities. These can be different methods for user inquiry or design; these will be addressed in the following chapter. Therefore we don’t see the Living Lab necessarily as an entity, it is an innovation approach, which allows for different ways of involving end users or other stakeholders.

3.4.2 Limitations

Looking back at the comparative study we achieved our goal by getting a deeper and holistic understanding of Living Labs. Through the study we retrieved sufficient insights to design a Living Lab setup that suits our goals.

Nonetheless, some limitations should be addressed for this study. In the study we only included six Living Labs, in a pragmatic way. This questions the reliability of the outcomes and the relative distribution of results between the Living Labs. However, our main goal was not to investigate every aspect of the Living Lab phenomena, our goal was to explore Living Lab approaches to formulate our own Living Lab stronger. Therefore, we believe the low number of participating Living Labs is justified. Nevertheless, if we had included a higher number of Living Labs our research might have had more impact and would have contributed more to generalizing the Living Lab approach.

Thereby, we did not use a validated questionnaire to investigate the Living Labs. The research field of Living Labs, as mentioned before, is relatively young, and therefore there are insufficient validated research methods yet. To address this issue we translated leading Living Lab concepts (ie Bergval-Kareborn et al. 2009 and Koskinen et al. 2010) into questions. For the future we recommend to take more of such fundamental Living Lab studies as a starting point for a questionnaire it ensures a strong anchor in the literature.

Finally, it might seem conflicting to include an early version of the Innovate Dementia Living Lab in the study used to develop it future. However, from an explorative perspective this is no limitation, by looking at the results qualitatively we can distract values and insights from the individual Living Labs. Moreover, by including our Living Lab we can directly compare it to the results of other Living Labs and learn from this. In the end we gained many insights to develop our Living Lab further.

3.5 The Innovate Dementia Living Lab

Based on insights covered in this chapter, we developed the Innovate Dementia Living Lab further. Especially results concerning the environment, active role for users and the way of engaging with the stakeholder network supported this. The Living Lab is seen as a network structure that allows for several methods to be applied as part of it.

First, for the environment, we aim this to be as realistic as possible. As such the studies have a high ecologically validity and we learn faster how a certain innovation supports people living with dementia.

Second, the active involvement of users is essential in the methods we apply, this means users are co-creators in the innovation process (Sanders & Stappers, 2008; Wallace *et al.*, 2013). Hereby it is important that users are included in different stages of the development process (Figure 3.3) with stages like: co-creation, in context user involvement, stakeholder network evaluation and finally scaling up the innovation. This is not a linear process, but rather an offering of stages between which the project can move freely.

Finally, we aim to operate in a network of stakeholders and facilitate the Living Lab for both innovations from us as the stakeholder network. They can play a different role in each stage (Figure 3.4). In Chapter 4 we will elaborate on what methods we use to engage them.

The key aspect of our Living Lab is carrying out studies in collaboration, in the real-life environment of prospected users (people living with dementia), to develop our design proposals. This is challenging because people with dementia are cognitively impaired. On the other hand, a benefit of the home environment is that it is trusted and users feel more at ease while participating. In addition, by conducting studies at the homes of users we can increase the potential adoption and acceptance of our design proposals (Peeters & Megens, 2014). This is why our users are at the centre of our approach. In Figure 3.4 you can find a visualization of this structure.

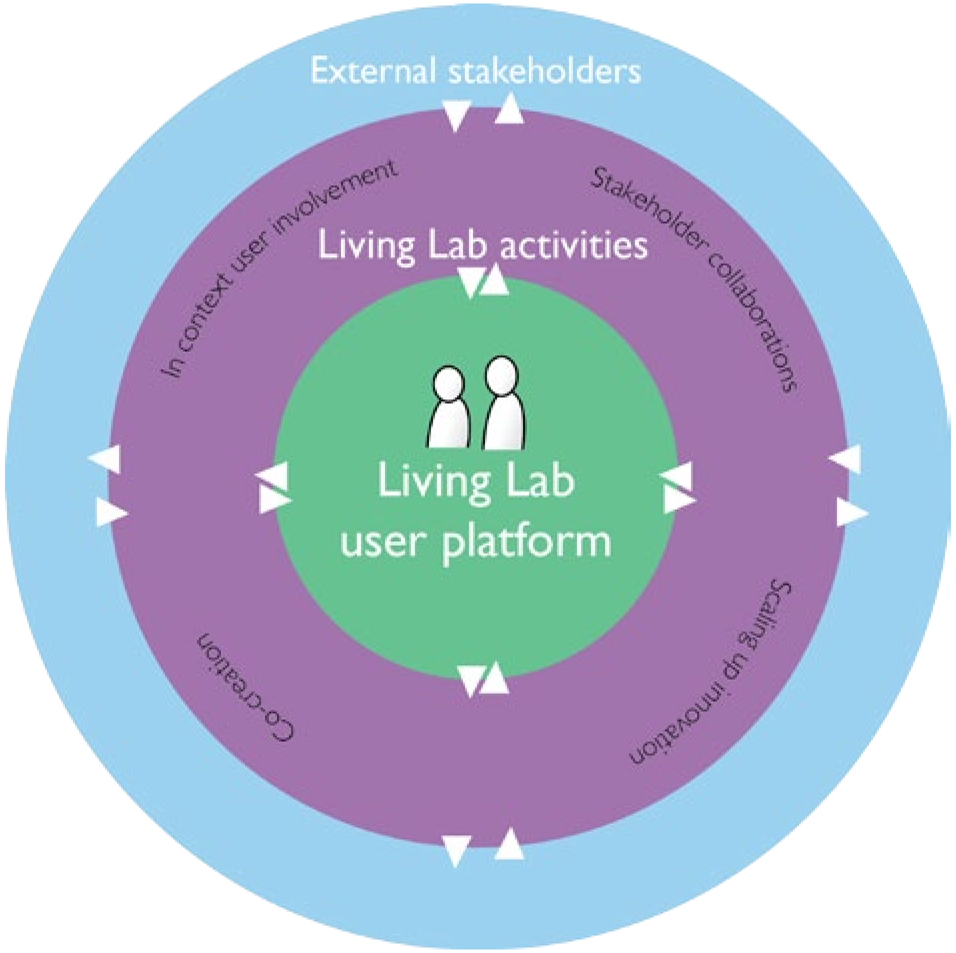


Figure 3-3 The Innovate Dementia Living Lab

Chapter 4:

Design Process & Pilot Case

In this Chapter we examine the approach and the process we use as part of the Innovate Dementia Living Lab. Before this we will review value creation within a societal business case in the context of innovation. Subsequently we have examined the innovation process and its specific phases.

To conclude this chapter we present our pilot study, the PhysiCAL concept, an intelligent planning tool, to support people with dementia. Based on insights from this pilot study the follow up cases were formulated.

This chapter is based on:

Brankaert, R. and den Ouden, E. (2013). Developing a design process to design for people with dementia and their extended care network - Learning from a case study. Proceedings of the International Conference on Engineering Design 2013, Seoul, Korea.

Brankaert, R. and den Ouden, E. (2013). Setting up a living lab for the dementia care chain, a case study of the PhysiCAL. Proceedings of the XXIV ISPIM Conference on Innovating in Global Markets: Challenges for Sustainable Growth, 16-19 June 2013, Helsinki, Finland.

4.1 Value creation

To create our design process we will take a closer look at open innovation and 'network of stakeholders' theory. These are approaches that are often considered to be essential parts of Living Labs (Chapter 3).

4.1.1 Open Innovation

Societal challenges, such as dementia, are complex and typically 'ill-defined' problems (Cross, 2006). The nature of ill-defined problems makes it impossible to predict all the relevant information and ensure its availability for the innovation process. It is also unlikely that all the information will be available to a single stakeholder or single company in a network (Lee, Park, Yoon, & Park, 2010). As a result the required innovation process needs to be much more of an 'open' kind, where various organizations collaborate to bring together complementary expertise and resources (Lee *et al.*, 2010).

In innovation management researchers often describe a company-centred view of networks (Ramirez, 1999). Such literature describes how and why companies seek collaboration to develop new products (Ledwith & Coughlan, 2005). Open innovation is mostly seen from the perspective of a single organization (Chesbrough, Vanhaverbeke, & West, 2006; Chesbrough, 2003). Companies embarking on open innovation should do so to make it possible ideas flowing into as well as out of the organization (Dahlander & Gann, 2010). However, this company-centric view is an inadequate basis for such exchange of value. The focus has to shift from the company itself to offerings for the customer. It then becomes clear that combining internal and external resources is a key issue for strategic survival (Ballon, 2007). It requires the replacement of the sequential, unidirectional 'value chains' by 'value co-production', where value creation is synchronous, interactive and involves the users. The focus is then no longer on the company, but on the co-produced offerings (Ramirez, 1999). The network becomes a means of creating more value by integrating offerings or competences from different organizations into better solutions for these users. Individual and collective interests need to be aligned and a 'win together' approach should be forged in connection with society at large (Marrewijk *et al.*, 2004). this innovation process needs to be open, and clear boundaries need to be defined to enable this. For the Innovate Dementia Living Lab this means we will need to seek collaborations and define shared goals with users and other stakeholders to steer our innovation process.

4.1.2 Towards a societal business case

For a network of stakeholders to operate, values should be shared by multiple stakeholders (Ballantyne *et al.*, 2011). Such a network should be balanced and represent the relevant stakeholders. The quadruple helix approach to innovation shows us which roles need to be fulfilled, these are industry, research, public organizations, and citizen – or users (Arnkil, Järvensivu, Koski, & Piirainen, 2010). In the context of health this should be extended with care institutes as it is a crucial provider of care (Leydesdorff, 2011).
Such a hybrid network and the concept of shared value blurs the line between for-profit and non-profit organizations (Porter & Kramer, 2011). Consequently, value exchange in the context of societal relevant innovation occurs on several levels between stakeholders in the ecosystem (Payne, Ballantyne, & Christopher, 2005). In dementia this is inherently more complex as there is not one single customer or customer chain. Due to this complexity dementia can be seen as a 'wicked problem' (Martin, 2009). To address a wicked problem a multi-perspective approach is necessary to contribute to the societal challenge. In addition, value proposals should address what customers really value and how the service or product offering will satisfy those needs (Teece, 2010). This supports their innovation process. Incrementally, these steps lead to the creation of a societal business cases, meaning the business case both addresses a societal challenge and is a self-proficient as a business. The Living Lab is a platform that can be used to launch such tracks and thereby, this platform develops over time as experience with successful cases is gathered. In Figure 4.1, this process is visualised. First a design proposal is evaluated with users, then other relevant stakeholders such as care professionals and finally the business case is crated based on these insights. This is conducted over several iterations, where the insights from previous iterations are taken into account.

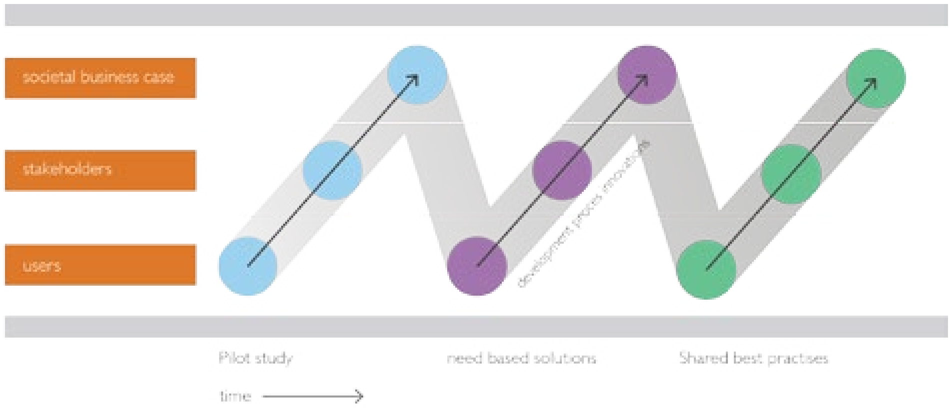


Figure 4-1 Moving towards a societal business case. Adopted from den Ouden & Brankaert (2013)

4.1.3 The value framework

The value framework (Figure 4.1) was developed to design transformational innovations that address complex societal challenges, such as for example dementia (den Ouden, 2012). The framework describes four levels of stakeholders: User, Provider, Eco-system and Society. In addition, it allows us to look at those roles from four different perspectives, these are: economic, psychological, social and ecological. This creates a complex, yet complete overview of the roles and motives in a certain innovation context. We used this to gather our stakeholders in the field of dementia, at different levels, and apply a process of zooming out, from users to society.

Concerning the user layer (centre) and people living with dementia (both people with dementia and their caregivers), the focus lies mostly on their *experience* and improving their quality of life through innovation. This is covered by value for money (economic), happiness (psychological), belonging (Social) and awareness (ecological).

On the organization level (second circle), different stakeholders play a role in the context of dementia. In the care context we have care professionals and institutes. However, also business-oriented stakeholders with an interest in introducing new technology or services to the market play a role. The value framework illustrates their efforts by looking at Profit (economic), core values (psychological), social responsibility (Social) and eco-effectiveness (ecological).

For the ecosystem (third circle) such a value proposition focuses on balance and an equal integration of the organizations and users. In particular, in the dementia ecosystem this layer is necessary, and mostly overlooked. Value gained in this context is not always with a single stakeholder or direct. The goals at this level are looked at from stability (economic), shared approach (psychological), Reciprocity (Social) and sustainability (ecological).

Finally, within the societal perspective (outer circle) we examine meaningful and lasting innovation in the context of dementia. These affect wealth (economic), wellbeing (psychological), meaningful life (social) and the environment (ecological).

Again the Value Sensitive Design framework (Friedman et al., 2009) presents a wider value based approach to capture the relevant perspectives in three steps: Conceptual, Empirical and Technical. This method provides input for the conceptual phase, and feeds into the Empirical (applied during the interactive experience flow design process as well as future studies) and the technical, core part of the Living Lab home studies covered in this dissertation.

The Living Lab approach will be used to develop and evaluate design proposals. The value framework (den Ouden, 2012) helps us to explore the potential network of stakeholders surrounding these designs. In addition, the framework aids in building a value proposition that is holistic, and that is designed for collaboration and sharing. By evaluating the proposition considering these different perspectives we can improve our design proposals and the value they have for the different stakeholders. The value framework provides insight into the different perspectives in the context of dementia, and helps us to developing a value proposition.

For dementia we found that the main user groups are: People with dementia, caregivers and care professionals. The main organisation groups are: Care, Business and research stakeholders. In addition, the ecosystem contains more distantly related partners. Society at large, naturally, covers the rest.

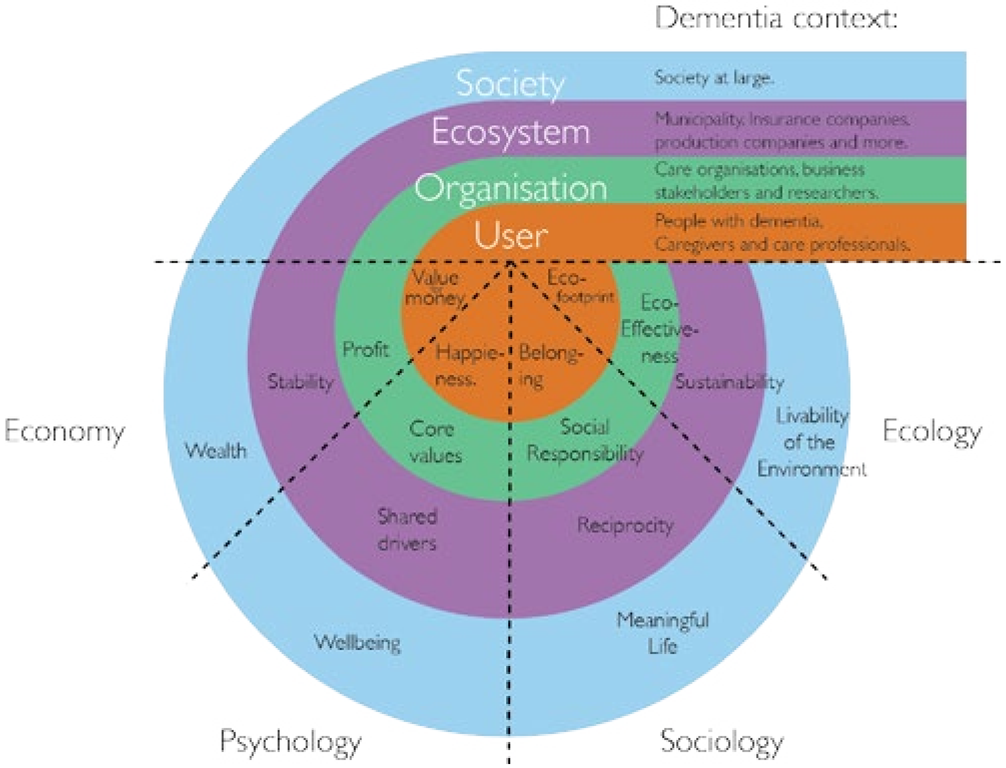


Figure 4-2 The value framework model with examples for dementia.

4.2 The design process

Based on our goal of building societal business cases we created a design process. Different methods are relevant in each of the stages of the design process. Moreover, it allows us to describe our Living Lab cases in a structured manner. This design process is built on existing processes and extended where necessary.

4.2.1 Design research approach

First we need to understand that the societal challenge of dementia has the characteristics of a "wicked problem" (Martin, 2009). This means that it is a marginally defined and complex problem that requires integrative multi-perspective thinking to get a problem understanding and possible solution space. This is why a linear innovation processes won't work. For example, a traditional engineering design process (e.g. B. Gagnon, Leduc, & Savard, 2012) puts a strong focus on feasibility and design characteristics, without including the critical development of a concept to adequately addresses an opportunity. In Innovation management, processes are often designed for a different purpose. For example, in the stage-gate innovation process (Cooper, 2001) often used for an idea-to-launch process with clear step-like stages. This approach is very much appreciated from a management perspective, due to its clear steps and boundaries. Yet, it doesn't allow for flexibility and jeopardizes learning and improving from the steps taken earlier in the process (Sethi & Iqbal, 2008), this affects market performance in a negative way.

Therefore, to address such a 'wicked' problem, Zimmerman and colleagues (2007) argue for a research-through-design approach. In this approach design research comes closer to design practice, with the goal of formulating novel concepts that are intended to transform society into a preferred state (Zimmerman et al, 2007). Building on this, we aim to generate knowledge through a process in which both the act of designing and the act of evaluating designs play an important role (van den Hoven *et al.*, 2007). This makes the process iterative by nature. Consequently reflection is a means of moving between these different acts (Hummels & Frens, 2011). With such an approach we can find design solutions that are able to fulfil needs and contribute to the societal challenge.

Therefore, our design process is of a qualitative and explorative nature to allow for insights to be gathered during the process. And therefore the design process is strongly iterative. Therein, we select the specific methods for the questions we want to address in each design case. These are, however, always for the purpose to develop the design.

We translated this design approach into several design phases by looking at the growth plan (Ross & Tomico, 2010), which builds on the notion of reflection. This process has three phases: *Exploration*; which is about gathering contextual insights, *Nurturing*; to translate these insights into design proposals and *Incubation*; allowing for these design proposals to become mature and suitable design offerings.

4.2.2 Design process stages

Based on these design processes we divide our innovation process into four phases: *Exploration*, *Design*, *Evaluation* and *Implementation*. The **exploration phase** focuses on gathering needs and opportunities, and does this via different analysis methods involving the user. The **design phase** is about synthesis and the iterative creation of proposals that address these needs or opportunities. The **evaluation phase** tests whether these proposals are sound and actually fulfil the envisioned goal in a real-life context. Finally we have the **implementation phase,** which is about strategies and approaches to getting the concept into the market. These phases are clarified in the context of dementia in the subsequent paragraph.

These phases are defined to clarify the methods and activities we perform as part of them, these are not linear. In a design process we move between these phases in an iterative way until a suitable and satisfactory design is found.

4.3 The design process in detail

In this part we take a more detailed look at the design process and the separate phases. We do this by covering the main method and activities that take place in these phases in the context of our Living Lab.

4.3.1 Exploration phase

The aim of this phase is to define a scope as starting point for design. This phase caters for need finding, offers freedom to explore and find creative perspectives. Several methods can be used to find a relevant need or opportunity.

One example already covered is the Interactive Experience Flow (Chapter 2), which provides an overview of the multiple perspectives of different stakeholders, examples of opportunities and general insights into dementia. Much of the overview is about the use of personas; these are fictitious users who give designers a strong insight into who they ought to design for (Pruitt & Grudin, 2003).

Building on such an approach, Sanders & Stappers (2008) argue for active user involvement, and the role of a designer changes from actor to facilitator. Via focus groups and creative sessions with our users we are able to find needs and to discuss our first ideas (Chapter 2). These participatory methods work In particular, with people living with dementia, as the group stimulates participation (Qureshi, 1996, reviewed in Wilkinson, 2002). In this way the collective creativity of users can be used to get better design and better designers. This approach enables a focus on achieving need-driven innovation that bypasses incremental improvements of existing products or services (Verganti, 2008). In the context of a multi-stakeholder approach these 'users' can be people living with dementia but also care providers, companies, social workers, etc.

For such active user involvement we have experimented with different methods to gain an understanding of which method works best in the context of design for dementia.

4.3.2 Design phase

When a clear scope is defined and its context is clear, the design phase will follow. In this phase we aim to address the defined challenge by iteratively constructing a concept (Martin, 2009). This is done with, for example, prototypes, models and storyboards that can be discussed and shared with relevant stakeholders.

In this phase several methods could be used to conceptualize ideas that potentially address the selected need or opportunity. These can be ideation methods (e.g. brainstorming, sketching, mind-mapping and more). Active involvement of people living with dementia is sought through co-creation (Sanders & Stappers, 2008) and can be seen as an extension of the focus group efforts. the design phase also functions as an integrator of the different perspectives in a design proposition, contributing to the process of 'making sense together' (Thompson Klein, 2004). In the context of dementia this is challenging; however, it still greatly contributes to the quality of the resulting design proposals.

Furthermore the involvement of other stakeholders is vital to the design process, especially in a complex field such as dementia care (Brankaert & den Ouden, 2013). For this stakeholder involvement we mainly use a co-reflection method (Tomico *et al.*, 2009) to have a dialogue concerning our proposals and their potential with relevant stakeholders. In this the design proposals are used to explore and develop the understanding of the problem context (Cross, 2006), the context and design co-evolve until a satisfactory proposal is found at the end of this phase.

4.3.3 Evaluation phase

The goal of the design process is a viable and suitable design to help meet the societal challenge. To gather insights into how suitable a design is we focus on in context real-life evaluations with people living with dementia. This is in line with the main philosophy of Living Labs (Chapter 3) and a prominent need in design of technology for dementia (Chapter 2).

In this phase we aim to evaluate and reflect on the proposed design that allows users to experience the potential via working prototypes. Bharucha and colleagues (2009) identify the fact that there is a need to evaluate concepts in a real-life context when developing assistive technology for people with dementia. The ecological validity of the study also improves (Koskinen *et al.*, 2011), as well as the likelihood the proposals will be adopted by business stakeholders (den Ouden & Brankaert, 2012). These evaluations take two to three weeks, which is selected to both overcome the short-term effect and to still make the research suitable for business stakeholders. This is sufficient to monitor acceptance and integration in daily life. In addition, Orpwood and colleagues (2004) mention the following: "Testing over longer periods of time with people with dementia needs to be carried out prior to any longer-term formal evaluations."

To monitor the use of our design proposals we have experimented with various methods to capture the experience of the users. These are covered in detail throughout the work. Initially we started with questionnaires (pilot study), yet these seemed too repetitive. This is why we extended this approach with a probe study (Chapter 5) and reflective interviews (Chapter 6).

Alternative evaluation methods are used when for example, the design case is too complex or the prototypes were not mature enough. In this case we apply a hybrid method in which we explore a design proposal for a limited time; however, still in context and with end-users (Chapter 7).

A similar approach can also be used with a wider group of stakeholders, and by for example, co-reflection (Tomico, 2009) a design proposal can be evaluated with entrepreneurs, care professionals, government bodies or other relevant stakeholders. This is in line with the need to include a network of stakeholders in the development and evaluation of new technologies.

4.3.4 Implementation phase

When a design is finished, and suitable to aid in the challenge there are possibilities for validation and implementation. This depends on application area of a specific innovation. For example, an ICT solution could have a more early market release due to limited cost; however venturing a physical product might need more investment, different expertise and more time. Furthermore, for healthcare products there is often need to conduct a validation study to get support from insurance stakeholders. Additionally, products in health have to comply with regulations for medical devices such as CE, FDA and PMA (McAllister & Jeswiet, 2003). Because there are so many additional factors, this phase is not a main focus in this dissertation. It is however important to understand that this is phase necessary to achieve impact. A common criticism is that design often ignores detailed economics associated with manufacturing, distribution, appropriate design for a product line, or effect on product identity (Zimmerman *et al.* 2007).

4.3.5 Resulting design process

The result is a design process to be used in the Living Lab. It should foremost be dynamic and adapt to the specific design cases. The phases are meant to be steps through which one can move freely in an iterative way, and not as a linear process. For example, in disruptive project without a strong network of stakeholders there will be more activity in the design and exploration phase (early). On the other hand, an existing concept could use an in context evaluation to steer future design iterations for a specific target group. In the cases covered in Chapter 5, 6 and 7 we describe several of such cases.

In Figure 4.3 you can see a visual representation of the design process used as part of the Living Lab. The process contains four phases with each of them having a different goal:

(1) *Exploration phase*, aims to set the design scope by defining the need or opportunity we are going to address, in this phase we use Questionnaires, interviews and focus groups to explore this.

(2) *Design phase*, aims to synthesise insights gathered in the exploration and uses methods alike Ideation, model making and co-creation to do this and find a suitable design concept.

(3) *Evaluation phase*, aims to evaluate the potential and acceptance of a design proposal. To do this we conduct co-creation sessions, in context field studies and co-reflections to evaluate these design concepts.

(4) *Implementation phase* is about validation and implementation. In this phase methods such as long-term testing, fundraising, building production lines and other activities needed to bring a design to market are applied.

The design process should be used as a point of reference for development and can thereby be used to steer design activities. When a design successfully addresses a societal challenge it can proceed to the implementation phase. From this point short-term iterations become more long-term.

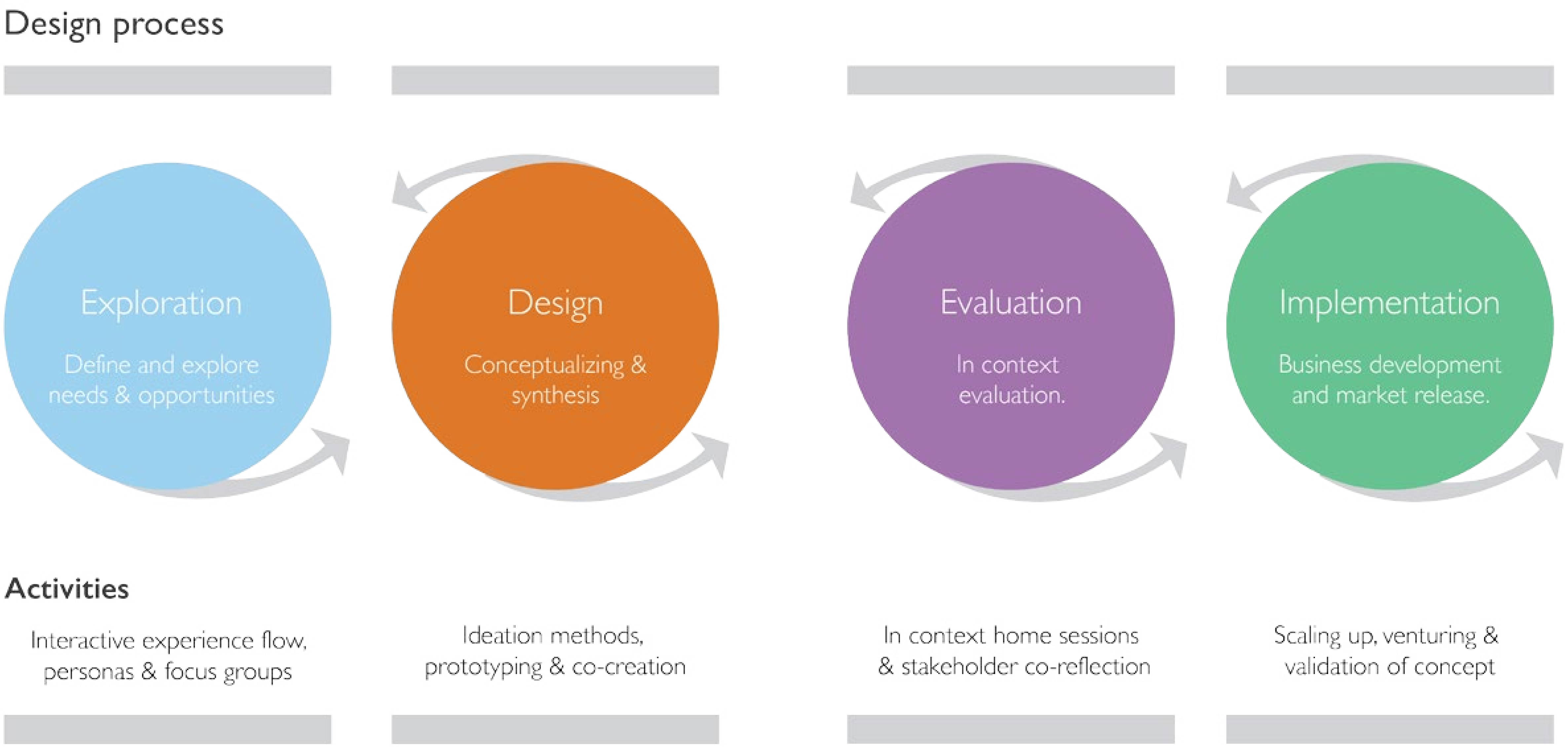


Figure 4-3 The design process as part of our Living Lab.

4.4 Pilot case study: PHYSICAL – a reminder system

In this pilot study insight is provided in the design case of the PhysiCAL, a reminder system for people living with dementia. The phases Exploration, Design and Evaluation are covered to position design process. In this pilot the various aspects of a Living Lab are used to guide future Living Lab cases.

First the exploration and design phases are covered to get to the final design of the system. After this the evaluations with people living with dementia, professional caregivers and two potential business stakeholders are covered. Because the concept is designed iteratively and evaluated on different levels this approach goes beyond single phase methods such as technology probes (Hutchinson et al., 2003).

The pilot study is covered as a design process in the stages: exploration, design and evaluation. For further reference concerning the PhysiCal design and evaluation please refer to the related papers.

4.4.1 Exploration

We used the Interactive Experience Flow (Chapter 2) to select an opportunity in dementia. We found that in the 'arrange' stage (Figure 4-4), in the early stages of dementia, supportive technology or services were rare. However, there are evident needs for users also in these earlier stages such as for example, orientation, dealing with complexity and memory loss (Rasquin, Willems, de Vlieger, Geers, & Soede, 2007). In addition, in this stage people struggle with accepting the disease, and have a desire to maintain their independence. Furthermore, there is a lack of suitable products in this stage to facilitate their needs. These needs were further explored via expert consultations provided by a local mental care institute.

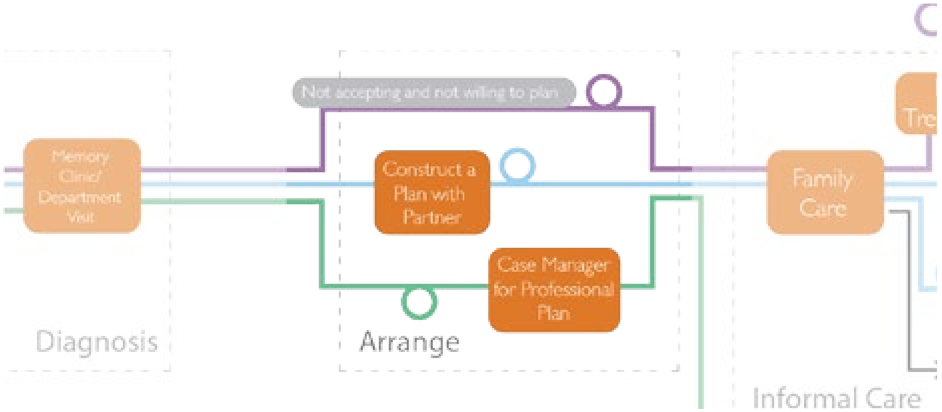


Figure 4-4 The arrange phase as screenshot from the Interactive Experience Flow.

4.4.2 Design iterations

Based on the selected opportunity space a design process was initiated to iteratively find a suitable solution. In iteration (I) we found more specifically that scheduling assistance is something people with dementia struggle with. We confirmed this in iteration (II), in which we also found that users need to understand what the purpose of supporting devices is when looking and operating the device. Finally we created a first prototype (iteration III); when discussing this prototype we found that it should be as simple as possible. This iterative design process can be found in more detail in Appendix B1. A summary of the results of this process is provided below (Table 4.2).

Over the three iterations, relevant stakeholders participated in co-reflection sessions to assess the design proposals. For example, in the first iteration the design proposition was a video prototype that showed how assistive technology could become part of currently available hardware (smartphones, tablets, etc.). This was however deemed to complex for many people with dementia. Subsequently in the second iteration, in which we presented concept scenarios, we found that people needed to recognize the device for its purpose of use. This defined the design scope further until we reached a first version of the physical Calendar, for more detail on this process please refer to Appendix B1. Over the course of these explorations and design proposals we came to the final design.

Table 4.1 The Innovate Dementia innovation process

	Type	Concept	Feedback
Iteration I	Video prototype	Monitoring of the elderly and suitable activities via tablet and smartphone interface	Tools not suitable for target group (yet), useful for supporting the elderly in daily activities
Iteration II	Scenario sketches	Calendar for activities to stay in control of daily tasks for independence	People need to see the purpose of a device before they use it. Concept in good direction.
Iteration III	Working prototype	Calendar scheduling system inspired by whiteboard to remind people of activities	There is a need for a working reminder system; interaction must be as simple as possible.

4.4.3 PhysiCAL: an activity reminder system for people with dementia

Over the past years there have been several inventions designed as reminder systems for people with dementia. These systems prove useful for people living with dementia in for example medicine intake (Kamimura, Ishiwata, & Inoue, 2012) or reminding people of everyday activities (Hartin et al., 2014). As touch-screens are not always suitable for this target group (Armstrong, Nugent, Moore, & Finlay, 2013) we aim to offer such reminder system in a tangible form.

The PhysiCAL calendar presents an entire week in one overview, with the weekdays visible to the user (Figure 4-5). On this calendar activity tags (RFID) can be placed, representing activities to remember. An automated arm moves vertically to indicate the current day. Horizontally a sensor reader moves to represent time and to read the activity tags. When this sensor passes an activity tag, the time indicator lights up, and an audio message is played when somebody is in front of the calendar. The design introduces a familiar shape, based on currently used whiteboards, and adds technology to it. The device supports people with dementia by providing a tool to maintain independence by allowing them to schedule their everyday activities for a week and be automatically reminded when they occur. The system operates as a platform, and those living with dementia can decide for themselves for what purpose they would like to use the system.

Figure 4-5 The PhysiCAL calendar

4.4.4 Evaluation structure

In this pilot case study we aimed to evaluate the prototype of the PhysiCAL with three different stakeholder groups: The potential users, care professionals and potential business stakeholders.

Potential users:

A prototype of the PhysiCAL was evaluated with four couples. For one week the four couples, each one person with dementia and one caregiver could use the PhysiCAL at their home. Subsequently, the participants were jointly interviewed to provide a reflective perspective on the technology. Among individual anecdotes about the PhysiCAL we found some interesting aspects that related to the potential of the product. Because this was a pilot study designed to explore home studies as part of the Living a limited number of participants and a short period of time were sufficient.

The protocol for this home evaluation had the following setup:

1. **Introduction session:** In this session we explained how the calendar works and performed an initial baseline need assessment (Interview).

2. **Experiencing the design***:* Home experience, in which users could experience the concept in their own context for a period of a week.

3. **Reflection:** After a week we held an interview with both person with dementia and spouse to gather insights into the product and protocol.

Care professionals:

To get insight from other relevant stakeholders several care professionals were involved through co-reflection sessions (Tomico *et al.*, 2009). The care providers play an important role in the acceptance, recommendation and adoption of innovative solutions in dementia care (Gagnon, Orruño, Asua, Abdeljelil, & Emparanza, 2012). The concept was evaluated with three groups of care professionals: *1) Case managers,* people who coordinate care for people with dementia, found the concept potentially viable to improve independence. *2) Mixed Care professionals,* mainly doctors and nurses, mentioned it would be interesting if there were more interoperability with devices or an online platform. And finally, *3) Client advisory board,* a board of user representatives from a regional mental healthcare institute participated because they were interested in the potential.

Potential business stakeholders:

Finally, to gather insights from a business perspective two workshops were organized with companies that were potentially interested in the PhysiCAl as a product (referred to as potential business stakeholders). During these sessions we aimed to get insight in the business potential of the reminder system. We started with a discussion on the company's main drivers. For this step we used the four perspectives from the value framework (den Ouden, 2011).

Overall the evaluation with three different stakeholders allows us to explore the different facets of a Living Lab and thereby transcends innovation methods that only involve potential end-users.

4.4.5 Evaluation results

The evaluation results are presented for each of the three stakeholders: potential users, care professionals and potential business stakeholders.

Potential users:

The interviews and data collected were analysed, and feedback was gathered in three areas. More details on this process can be found in Appendix B2.

First, were comments concerning the product appearance: the actual size of the product would need to be reduced for common households. Also the white color was deemed stigmatizing. Second, the participants reflected on their need for the product: all people with dementia mentioned they didn't need the device, yet half of the caregivers mentioned they thought it actually was valuable. Furthermore three out of four caregivers in the home environment mentioned they could relate to the goal of the PhysiCAL and judged it as possibly relevant for people with dementia. This highlighted that the target group for such a product might be the caregiver rather than the people with dementia themselves. Finally, based on the qualitative results, we found that the focus on physicality was appreciated and strong. Also including reminiscence, the theory of recalling memory by diverse sensorial input (Woods *et al.*, 2005), supported the ability of users to interact with the design.

Concerning the protocol, the response was in general positive and all participants were willing to participate again. What could be improved was the introduction of the concept.

Care professionals:

The insights from the care professionals was gathered and analysed collectively. These insights proved useful for the care perspective.

The case managers thought the concept was potentially valuable. The pratical implementation of the Living Lab could however be improved. The mixed care professionals thought the concept was very interesting, and they started to add features to the concept on the spot. The client advisory board was positively surprised by the concept and were interested in trying it at home, some were immediately convinced of the potential benefit.

In general care professionals evaluated the concept positively. Improvements suggested that the interaction should be as simple as possible, and the device should also consider the family members and other informal caregivers. Overall we did not receive many new insights from this evaluation.

Potential business stakeholders:

Results from the two workshops were of a qualitative and anecdotal nature. The first potential business stakeholder (1) is a company that has developed and launched a successful product/service combination in healthcare. They didn't really saw potential in their current business for the PhysiCAL as it was not developed far enough and also different from their current offering. However, the approach of involving people living with dementia is really interesting for them and many other companies with an interest in developing products, systems or services for this target group.

For the second workshop, potential business stakeholder 2 was involved. They run an informal care management service that started around 10 years ago. They are still struggling with the complexity of the business environment in healthcare, and the challenge to implement innovations. The stakeholder believed in the concept, yet sees limited value in a Living Lab approach, as the biggest challenge seems the implementation and scaling up of innovations in healthcare (for the Netherlands).

In general, the insights of the potential business stakeholder provided an interesting perspective on the living lab approach and the PhysiCAL reminder system. Despite the perspective being somewhat contradicting. However, to allow this perspective to influence the design this should be included earlier in the design process.

4.5 Conclusions

The pilot study with the PhysiCAL reminder system allowed us to conduct a design process. Insights were gathered concerning the involvement of stakeholders and the Living Lab approach. Based on these insights we can reflect on our approach and adjust were necessary. Overall the approach was useful and supported us to design as part of our Living Lab in the field of dementia.

4.5.1 Involving people with dementia

Involving people with dementia in design processes presents challenges. These are described in the literature (Chapter 2), yet this was also confirmed in our pilot study. Often the involvement of people with dementia is avoided because it is too challenging (Topo, 2009), yet it is evident that this is very valuable for the quality of research and design. The pilot showed that the at home evaluation, in the actual real-life context, provided most valuable feedback concerning the concept. Also, this concept of early in-context evaluation is one of the goals of the Living Lab, and is an acceleration of the innovation process compared to traditional processes (Chapter 3). The reflection with users proved useful, however more direct insights from the person with dementia and their caregivers concerning the technology were not found. This should be investigated further so that the Living Lab can cater for different innovation insights, and different ways of involving users.

4.5.2 Involvement of the stakeholder networks

Co-reflection with both care and business stakeholders provided insights from these different perspectives. The care professionals reflected most on the effect on and integration in healthcare. For the business stakeholders most responses related to viability of a business case. However, involving the professional caregivers didn't seem that different from the feedback from the users in context.

Moreover, we found that a business perspective should be taken earlier in the design process. Living Lab literature is not explicit about this, yet it seems important they can influence the design, so integrating the result into their own businesses is more likely. Now the post-study evaluation with potential business stakeholders did not provide sufficient value to accelerate the adoption or implementation of the concept.

By focussing stronger on the individual stakeholders more impact might be achieved. Thereby a more thorough methodology contributes to a higher effectiveness of the evaluation results.

4.5.3 Design guidelines for people with dementia

Designing within an opportunity frame revealed a new and promising approach to design for people living with dementia. The subsequent iterative development, of design and design scope, also proved effective and we were able to construct a promising design proposal. This worked especially well thanks to the early involvement of users and other stakeholders. Yet the concept still had some design flaws that could have been overcome. For example, the appearance and the sensors need to be improved. Some positive aspects of the design were also found. The physical aspect and the interaction with activity tags were evaluated as positive. These positive and negative aspects could lead to a more general understanding of design for dementia by creating guidelines.

4.5.4 Limitations

Concerning the study two limitations should be addressed. First, concerns the design of a reminder system. The system provide a reminder for activities, however does not monitor if the activity is actually performed which might limit the potential of such systems (Hartin et al., 2014). In addition an opportunity for reminder systems might lay in their awareness of their context. By this these systems could predict, based on behavior, when reminders ought to be provided such as in the CoReRa system (Hua, Seung Jin, Kawanishi, & Morikawa, 2007).

Second, related to the pilot study setup. This pilot was performed to explore the potential of a design process to go through the different stages of the Living Lab with different stakeholders. This resulted in an ad-hoc and pragmatic approach to conduct each of the stages, in this we might have failed to capture the full richness of each of them. Therefore, in follow up studies more attention is given to the methodology and the execution of it.

4.5.4 Resulting direction

The pilot case provided insight into three important areas: 1) User involvement, 2) Stakeholder involvement and 3) Design guidelines for people with dementia. These topics are briefly addressed in the pilot study. Each of these aspects needs more in-depth research; yet focusing on only one of these aspects in a vacuum would defy the purpose of the Living Lab. They have to be addressed in an integrated way. Therefore, the follow-up Living Lab cases (in section 2 and 3) each focus strongly on one of these three aspects without neglecting the other two. And by doing this we aim for integral insights into the application of a design-driven Living Lab.

In Figure 4.6 a schematic overview of this approach is provided. It shows how the follow-up Living Lab cases each have a stronger focus on one of the above-mentioned areas. In the end, these will be integrated and analysed to build our understanding concerning Living Labs to design for people living with dementia.

First, for the area: *Involving people with dementia* we focus on gathering direct input from people with dementia and their caregivers. In this study we evaluate the 'Vitaallicht®', for which we developed an evaluation game (Chapter 5). Second, for the area: *Involvement of the multi-stakeholder network*, we focus on the benefit of Living Lab research for business stakeholders. In this case we investigate the 'GoLivePhone®' to find suggestions for redesign (Chapter 6). Finally, in the area: *Design for people with dementia* we aim on finding general design insights for how to appropriately design for people with dementia. In this the Homing Compass case is included, a way finding solution, as well as some design work conducted by students (Chapter 7).

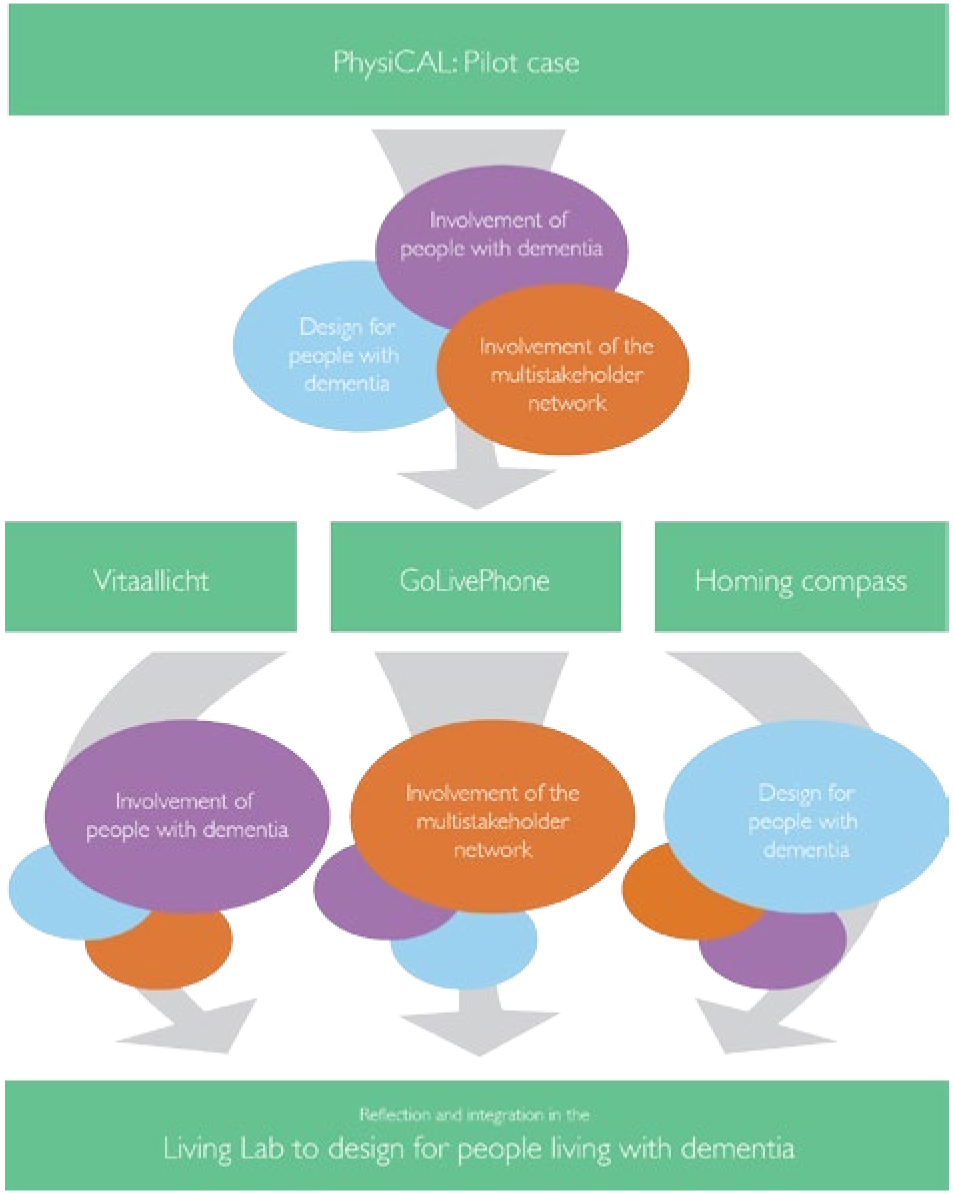


Figure 4-6 Focus on key aspects in follow-up cases.

Section II

Involving business stakeholders

- Probing in context
- Stakeholder collaboration

Chapter 5:

Involving people with dementia in context

In this chapter we take an in-depth look at the ‘Vitaallicht®’ Living Lab case in which we focus on the active involvement of people living with dementia. In Chapter 2 we argued for the importance of such an active role for people with dementia, yet not much research has been done in this field. We have therefore developed our own method, the evaluation game method, to understand that first-person perspective.

This chapter is based on:

Suijkerbuijk, S.[1], Brankaert, R. [1], Snaphaan, L.J.A.E., de Kort, Y.A.W., and den Ouden, E. (2014). Seeing the first-person perspective in dementia: a qualitative probing game to evaluate assistive technology for dementia patients in the home context. *Interacting with Computers*, 27(1), pp 47 – 59.

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[1] First two authors contributed equally to the work.

5.1 Actively involving people with dementia

In the design process of supportive technology for people living with dementia, we need to understand how to involve them. For this, we propose a living lab structure (Chapter 3) and a design approach (Chapter 4). In both, the involvement of users is key.

In our Living Lab proposal users should not merely be involved; they should play an active role in developing and designing proposals for them. Participants thus contribute to the design directly and consciously (Björgvinsson, Ehn, & Hillgren, 2010). However, such active involvement is more challenging for people with dementia, because an active attitude demands initiative and participation (Astell *et al.*, 2010). We therefore need to adapt our involvement approaches so that they are suitable for people with dementia.

Due to the active role of users the resulting design proposals match their needs better and in this process of co-creation the designer becomes more of a facilitator (Sanders & Stappers, 2008). Users are seen as equal actors in the design process. The advantage for the designer is that the users give extensive feedback, provide creative input and support decision-making. In addition, Topo (2009) suggests that people with dementia are seldom involved in such an active role in design and research processes. We therefore take a look at adapting these to the dementia context.

5.1.1 Co-creation in focus group sessions

There have been some attempts in the literature in which co-creation is explored with people with dementia, for example Wallace *et al.* (2013) conducted an intensive design process in which a 'design probing' method was used together with users to generate useful concepts for individuals with dementia. In addition, work by Lindsay and colleagues (2012) shows that if participatory methods are tailored to people with dementia, and are facilitated, participants are perfectly capable of taking part. In the case described below you can see an example of how we applied this approach. The co-creation approach goes beyond a focus group session approach, which just involves group discussion. However, because these discussions have been conducted with people with dementia, we can learn from them. For example, in a focus group study (Qureshi *et al.* 1998, reviewed in Wilkinson, 2002, Chapter 9) the authors found that a social setting is regarded as positive during the inquiry. Therewith, they also found that splitting up the research activity into smaller parts works well because this reduces the burden of participation for those with dementia. In addition, such a segmented research activity leads to the creation of a ritual. According to Qureshi and colleagues (2002), this ritual made the participants aware that something was going to happen and it was reminiscent of earlier focus group sessions. This all contributed to a comfortable setting in which participants felt at ease.

CASE 5.1 - Co-creation in the Innovate Dementia project

As part of active user involvement of the exploration phase we conducted several co-creation sessions. These could either focus on finding new needs, giving feedback on concepts or contributing by design.

In Figure 5.1 one of these sessions is portrayed. In this session people with dementia and their caregivers were asked to make a mood board that depicts their current wishes for their future.

Some insights could be extracted from the mood board, but most interesting results originated from the process of constructing it. Discussions were held, in a casual manner, on the important things of life, what is difficult when dealing with dementia and what we could contribute through design.

Figure 5.1 - A co-creation session with people living with dementia

5.1.2 Studies performed in the home context

The in-context evaluations, as part of the evaluation phase, are the main asset of our Living Lab. The goal for these is to get insight into how people living with dementia use a certain design in their natural context. This supports both design for a difficult-to-relate-to user group and person-centred design.

Attempts in the literature to design by involving people with dementia are marginally successful. Instead, the technology is often only discussed with the informal or professional caregivers. Also, such studies are often conducted in a lab setting and do not include people in their natural context. While the study can be better controlled in this way, the ecological validity is compromised (Koskinen *et al.*, 2011). This means that these studies do not show what the effect would be when implemented in real life.

Nevertheless involving people with dementia in studies remains challenging because of impaired cognitive abilities (Astell *et al.*, 2010). This is why we need to carefully consider the methods we use to involve people with dementia in context. Bharucha *et al.* (2009) argue, however, that such user involvement and related design processes are needed to design technology that better addresses the needs of people with dementia and eventually contributes better to the societal challenge.

5.2 Vitaallicht®: study set-up

In this study we aim to include people living with dementia in the evaluation of assistive technology. The aim is not only to assess a design proposal (Chapter 4), but also to gather general insights about the methods we can use when involving people with dementia. This is why the research question for this study is:

How can we successfully design a qualitative research method for collecting first-hand evaluative data on the assistive technology from individuals with (early) dementia in the context of the home environment?

The term 'success' in this question pertains both to the quality of data collection and the experience of the participants. This should be one of fulfilment rather than being burdened. This is why we formulated three main criteria for the qualitative research method of this study:

1. The method should extract first-hand experiences and perspectives from people diagnosed with dementia and their caregivers. Therefore the method should be sensitive to the specific needs and cognitive limitations of this particular user group.

2. The method should be attractive, appealing and fulfilling for the participants in the study. Because the study is taking place as part of the Living Lab structure, we want to keep our participants motivated and involved. It is imperative that the method places a minimal burden on the participants.

3. The method should generate useful evaluative data on the design. This data should provide insights for improving the intervention. Furthermore, it should facilitate the surfacing of additional unmet needs for the development of innovations and research in the future.

Reflection on the pilot case with the PhysiCAL showed us that we need another evaluation method that would better suit the user group. These three criteria are used to evaluate our method and the technology, and are designed to help understand the first-person perspective.

5.2.1 Evaluated technology: a Dynamic Lighting System

As intervention for this study we used a dynamic light system called Vitaallicht® (Dutch composition of 'Vital' and 'Light'). Fundamental to this design is the integration of a positive light effect into a home-friendly light armature.

The lamp uses a bright bluish light that has a positively influence on the sleeping/waking cycle by supressing the hormone production of melatonin. If this is suppressed through the day sleep is positively influenced. There is evidence that this effect is beneficial for people living with dementia (Riemersma-van der Lek *et al.*, 2008),. The effects are, however, still in process of being researched (Hanford & Figueiro, 2013). Thereby does the lamp improve the quality of light in the home environment of its users.

The lamp has a lot of potential in improving the sleeping/waking cycle of its users. Deteriorated sleep patterns are a common problem among people with dementia, which places a heavy burden on informal caregivers (Bell, Araki, & Neumann, 2001). This is even one of the main reasons for moving someone from a home context into a nursing home environment.

Unique about this design is that the lamp provides this light dynamically. The stimulating light effect is 'active' during the day and in the evening it functions as regular lighting providing a cosy light atmosphere.

Figure 5-2 The Vitaallicht©, an intelligent lighting system.

5.3 Design and cultural probing

To construct a new first-person perspective qualitative research tool we examined other similar approaches. Bartlett's diary study (2012) captured insights for a couple of weeks without the direct influence of the researcher. It also showed that, when gathering data over a longer period of time, it is necessary to think about ways to create a holistic view of the entire period and context. Photographs can enhance data through their contextualized and rich figurative nature. Taking photographs does not require language skills, a common problem for people with dementia and thus helpfully complements verbal feedback. Furthermore, photographs can be used for elucidating and communicating textual research findings. Bartlett also found that audio could serve as a convenient and informative way to collect user input as well, since it reveals insights into the aural aspects of the participant's life (Bartlett, 2012). In addition, it can enhance understanding of the language difficulties of people with dementia, more than written text can. An audio recorder provides flexibility and places the participant in control of what is said and when. Finally, writing is described as an activity that is beneficial in helping people with early dementia to retain language skills as it also helps them to rediscover the self.

Flexibility and being in control should be the hallmarks of a new research method for people with dementia. In 'cultural probing' as a method for non-intrusive research these aspects are evident (Gaver *et al.*, 1999). Cultural probe approaches have been used in research with older people to facilitate the co-production of technologies (Wherton *et al.*, 2012). Wherton and colleagues (2012) found that their probes were most effective when used as a tool to facilitate communication and to develop a deeper understanding of older users' needs.

Cultural probes (Gaver *et al.*, 1999) provide flexibility to participants because they typically provide several options for input. The flexibility of a probe method provides an opportunity to combine different types of answering options in a single method. In our method, we therefore aim to integrate several options to encourage flexible and longitudinal input collection, providing holistic insights into the participant's life, in our case with a light intervention. Boehner *et al.* (2007) elaborated on the use of probes in Human–Computer Interaction research and concluded that there are two ways to work with probes in this field; inspiration-oriented or information-oriented. The initial use of cultural probing (Gaver *et al.* 1999) was intended as a means for inspiration and for opening up the design space. Wallace and colleagues (2013) used this method in a similar way to design for people with dementia, showing that by focusing on the individuals involved such an approach can indeed achieve this. For the current study, however, getting inspirational data was not the main purpose because the design of the assistive technology was already well advanced. Instead, we wanted to explore how to gather insights concerning the intervention and those with dementia directly.

The choice of selecting elements of probing is grounded in the flexibility that it creates; probes typically provide several options for giving input. Bartlett (2012) points out the possible benefits of including such options for people in the early stages of dementia. Another important aspect of the probing method is that it can substantially enhance the active involvement of people with dementia in research (Wallace *et al.*, 2013). This is why the key elements of cultural probes are maintained; it is qualitative rather than quantitative and it produces responses from users rather than numeric data (Boehner *et al.*, 2007).

Playful probes are a variation on the probe method that allow users to participate based on game principles (Bernhaupt, Weiss, Obrist, & Tscheligi, 2007). A study by Bernhaupt and colleagues (2007) shows that, by adding a playful aspect, a research tool could generate more interesting and relevant responses. We felt that a game ambiance would contribute to an informal setting, which is important for our user group. In addition, having the informal caregiver and the person with dementia play a game together would add a social aspect that could further encourage discussions. Moreover, this could lower the burden on participants and engage them more with the home study.

5.4 Method and study set-up

For this study we developed a personal evaluation game method, named ‘Aangenaam’ (Dutch for both ‘Nice to meet you’ and ‘Pleasant’) which is inspired by probing approaches and is question-based. In this section we will have a detailed look at the development of this method.

5.4.1 Method development

For the type of questions and wording used in the method we applied suggestions from Nygård (2006) to ensure clear, unambiguous and few retrospective questions. Open questions were used in the personal evaluation game to encourage further discussion. Asking questions about detailed knowledge, such as time or sequences, was avoided. Instead, concrete questions that capture direct experiences were used.

The question cards in ‘Aangenaam’ were divided over four categories: (1) experiences related to daily activities; (2) the social and physical context; (3) personal goals and events; and (4) a set that could be developed for the study at hand, in our case to evaluate the light intervention. These different categories were chosen to generate insights concerning the context in which the light intervention was placed. Besides, the categories were intended to be flexible, allowing us to explore what type of questions participants preferred.

The personal evaluation game had three answering options: written answers in a notebook, spoken input via an audio recorder and photographs taken with a disposable camera. The question cards gave one of these three options as a suggestion, although the participant was free to select any alternative. Since this study focuses on people in the early stage of dementia, we did not want to eliminate the options of using language completely.

The personal evaluation game itself did not have strict rules, since it was important for the participants to be in control of the activity (Bartlett, 2012; Nygård, 2006). We did decide to present it as a game, with the remark to take turns and to play it together. In addition, the appearance of the box and the categorized cards created a *game-like* appearance. This created an informal setting and relaxed experience, without upsetting the person with dementia by adding a competitive element. To evenly spread the research burden over the measurement period, the participants were requested to use the method every day and to answer only a couple of questions per session.

5.4.2 Study design

In the study we used two research methods: the newly developed personal evaluation game and a tablet-based questionnaire already used in the PhysiCAL pilot. We used two devices to examine the difference in the quality of data between the two methods. Participants were assigned to one of the two methods in a pragmatic way, based on the time of recruitment. As the main interest of the study was the experience of the personal evaluation game and its answering options, a ratio of 2:1 (game:questionnaire) was chosen.

In the analysis, we examined the experience participants had with both methods. The advantages and disadvantages of each of these methods concerning the value for evaluating assistive technology were also considered. The entire evaluation period was 3 weeks: one baseline week without an intervention and 2 weeks with the assistive technology. After the baseline, the lamp had to be installed and this was also a moment of contact between the researcher and the participant. A semi-structured reflection interview on the final day of the study (after three weeks) covered additional insights concerning the method and the assistive technology.

5.4.3 Participants

In total fourteen households participated in the study. Professional caregivers from the Eindhoven mental healthcare institute (GGzE) recruited the participants and ensured they were able to participate.

Three households withdrew from the study after the first week due to worsening health. Only one of these three households provided enough data to be included in the analysis, since they actively played the personal evaluation game during their first week. This household is not included in the technology evaluation data, as they did not receive the ‘Vitaallicht®’ lamp.

Eventually five females with dementia and seven males with dementia were included in the sample. They were aged between 66 and 87 (M = 74.92, SD = 6.17). In total, eight households received the personal evaluation game and four households worked with the tablet-based questionnaire. Research took place in the homes of the participants, all located in or near Eindhoven in the Netherlands. All participating couples lived independently.

5.4.4 Measurements and procedure

In this study, we explored the possibilities of the personal evaluation game and whether it succeeded in capturing the user experience related to light intervention. The participants received either the personal evaluation game 'Aangenaam' (Figure 5.4) or a tablet with a pre-installed questionnaire.

For the tablet-based questionnaire, iPads (generation 4, Wi-Fi Cellular, 16GB, Black, 9.7 inch) were configured in a way that the number of apps on the home screen was reduced to keep it simple for the participant. This app was a direct link to an online questionnaire. Two separate questionnaires were used, one for the baseline week and one for the 2 weeks of evaluation of the light intervention. Both questionnaires contained multiple choice questions and statements with six response categories. With the questionnaire we aimed to evaluate the lighting intervention. To do this, a question could, for example, be: 'How many hours did you spend today near the lamp?', i.e. gathering insights into how the lamp was used. Other questions concerned the subjective perception of sleep quality and energy level of the person with dementia. To provide more freedom, a comment box allowed for additional input. After the baseline week the light intervention was placed and they received a new set of questions, both in the personal Evaluation Game and the questionnaire.

5.4.5 Data analysis

We used manual methods to analyse the responses (Rose & Webb, 1998) to get insights from the generated data. A thematic analysis was used as the main method (Braun & Clarke, 2006). In this form of analysis, we included the written and audio data from the personal evaluation game, input data from the iPad questionnaire and comments made during the final interview. A theoretical approach was used in extracting themes from the data, led by the three key goals stated earlier: the level of engagement of the person with dementia, how they judged participation and what type of evaluative data was generated. In addition to the thematic analysis, a content analysis of participants' answers in the written vs. audio data was conducted. The focus lay on choice of words, prosody, repetition of words, extensiveness of answers and unanswered questions. This way, the latent preferences in how to use the method (questions, categories, answer option etc.) could be identified by looking at the exact behaviour of the participants. The photographs from the personal evaluation game were compared within subjects to identify whether there were any differences in types of photos in relationship to questions.

Figure 5-3 A picture of the personal evaluation game as presented to participants.

Throughout the results section of this paper we use a code to identify the supporting quotes. This code consists of [fictive name of participant] – [IC (informal caregiver)/ PwD (person with dementia)], [source]. For example:

"This is an example quote of Beatrice, who suffers from dementia, using an audio recorder." (Beatrice-PwD, audio)

5.5 Findings

The personal evaluation game 'Aangenaam' and the tablet-based questionnaire generated data that varied substantially between participants. Table 5.1 shows an overview of the input from both methods and how people handled the flexible answering options and question categories. Furthermore, we present the extracted themes from these results. These are structured according to the three main goals: the degree of involvement of the participants, the importance of the participant–researcher relationship and the evaluative outcomes concerning the assistive technology. Furthermore, special attention is given to the three ways of answering in the newly developed method.

5.5.1 First-hand experience of people with dementia

In this study, we focused mainly on avoiding marginalization of dementia patients in research. To make the method suitable for this user group, characteristics of the disease have to be considered. We evaluate whether we succeeded by taking a closer look at whether people with dementia were able to participate and how the interaction between informal caregivers and dementia patients worked.

In the personal evaluation game, we aim to achieve a higher level of participation of the people with dementia. We saw both in audio and written data that people with dementia contributed to the research directly. Some even explained that they experienced this as important, for example:

"I am a considerate person, kind in interacting with others. I am a bit reserved, but I do want to have my say." (Beatrice-PwD, audio).

Experiencing and evaluating together is beneficial to supporting dementia patients' performance. Couples indicated that some questions evoked discussions. However, the involvement of the dementia patient in these discussions appears to depend on the attitude of the informal caregiver. Some informal caregivers regarded this involvement as more important than others. One partner in the personal evaluation game, for instance, explicitly mentioned how she enjoyed the fact that her spouse was easily involved in the research activity:

"Usually I have to do everything myself, and friction might arise as he doesn't understand it. Now he showed initiative by himself. (Geraldine-IC, final reflection" (Aangenaam)))

Table 5.1 Overview of methods applied in this study.

Method name	Data type	Feedback
Evaluation Game (Ratio 2:1)	Output	We received 425 answers: 125 answers in the daily activities category, 124 answers in the environment category, 84 answers in the personal category and 92 answers in the dynamic light armature category. 345 answers were written down, 65 answers were audio taped and 15 answers were given via the disposable camera. This resulted in 4580 written words, 52 min and 32 s audio data and 26 photographs. One accidental audio recording of 3 h was not included in the analysis.
	People Involved	One of the informal caregivers worked individually on the evaluation game, three people with dementia worked individually with the evaluation game and four couples actually played the evaluation game together. One of these couples reported that they played the game with a couple of friends once.
	Answering options	Three participants only used the notebook to answer the questions. Another one used both the notebook and the photo camera. Two participants used all answering options. One of the individuals with dementia did not answer any of the questions in the personal evaluation game. The related informal caregiver delivered the answers digitally via a computer.
Tablet-based questionnaire (Ratio 1:2)	Output	We received 81 entries creating 927 answers to all questions. The remarks box was used 65 times and a total of 1629 words were written down. Two participants were very elaborate in their remarks, explaining the activities of the corresponding day.
	People involved	The informal caregivers made all entries in the tablet-based questionnaire. Two couples reported having discussed all questions and answers throughout the study. One informal caregiver indicated having had only minor discussions with the individual with dementia when filling in the form. Finally, one informal caregiver did not have any discussions with his spouse about the questionnaire.
	Answering options	Two households made all entries via the tablet, one household just used a paper version and one household used the tablet, the paper version and their own laptop.

In addition, we learned that it took participants extra time and effort to partake in a research activity together. For the informal caregivers it was sometimes easier to just fill in the answers to the questions themselves. Whether they did seemed to depend partly on how important they felt it was that they elicited input directly from their partner with dementia, but also how demanding they felt it would be for their partner. Moreover, some felt that their intimate relationship enabled them to validly respond instead of their spouse:

"I've known him for 55 years, so sometimes I answered the question myself." (Harriet–IC, final reflection (Aangenaam)

It is especially in the audio data that the role of the informal caregiver becomes apparent. The audio data provide detailed insights into the interactions between the dementia patients and their partners. We found that informal caregivers applied several strategies to help the patient to actively participate. Such strategies could, for example, be supporting the structuring of an answer, breaking a question into smaller questions or reminding the dementia patient by suggesting the answer. For example:

[The question is: Do you listen to music often?] 'Well, not that often. Maybe on television - a music broadcast.' ***But you do listen to the radio very often?*** *'Yes, I do listen to the radio'*
That's music too, isn't it? You always search for the music channel; never for a talk show. *'No? Then I listen to music often'*
*(**Geraldine** and George, Audio, (Aangenaam)*

This data shows that the relationship between the two spouses is influential on different levels. One is an exact understanding of the needs of the partner, since everyday life together generates knowledge about someone's difficulties and how to overcome these. Another aspect is that the dementia patient accepts this help, because it comes from a familiar person.

Evaluating and experiencing together requires substantial time investments from the informal caregiver. They appear to balance the value of their partner's personally voiced input against the extra time and effort it takes them to elicit this first-hand input. The informal caregiver's role is therefore crucial in involving the dementia patient.

5.5.2 Involvement and motivation

Participants should not be or feel needlessly burdened by a research method. The method should therefore be designed to create feelings of involvement and long-lasting motivation for both the informal caregiver and the person with dementia. For this reason, we paid extra attention to factors that might indicate or illustrate these feelings of involvement and create motivation.

We started by examining the direct answers people gave when they were asked how they experienced participating in this research. During the final reflections, none of the participants reported any discomfort while participating in this study, regardless of the method. Several aspects appeared to influence their feelings of involvement and motivation. First, participating in research sometimes seemed to remind participants of their loss of abilities due to dementia, which potentially caused discomfort. Nevertheless, a feeling of fulfilment was achieved by being able to contribute and help future generations with dementia. Secondly, the evaluation game was in general regarded as a fun activity that enhanced the motivation of the participants. A third factor influencing feelings of involvement and motivation was the participant–researcher relationship.

5.5.3 Reminder of loss of ability

We expected that one of the aspects of keeping people motivated in a research activity was how much time it would take to participate. During the final reflection, none of the participants indicated that the study had been too time intensive. Nevertheless, two informal caregivers (both in the personal evaluation game) did indicate that 3 weeks of participating was enough for them. This comment was attributed to the confrontational experience of seeing their spouse fail to understand and answer questions:

"It confronts us yet again with the disease."
(Evelyn–IC, final reflection (Aangenaam))

Besides their own perspective, the informal caregiver often considered the effects of participating in the study on their spouse. They have learned to protect their spouses, and know what upsets them, which can result in reluctance to adopt a new research method. This is, for example, shown in the following quote:

"I do not want to affect her with those questions; she will be out of her comfort zone, and I do not want that."
(Dick–IC, final reflection (Aangenaam))

The people with dementia themselves do not specifically mention feeling reminded about their loss of ability when participating in the current research. They are keen to be successful in participating, when they participate. For example:

"At first we practiced the answering to the questions before actually recording the verbal account."
(Beatrice + Bernard, final reflection (Aangenaam))

This might mean that they wanted to provide the researcher with something useful, which indicates a good participant-researcher relationship. However, we expect that this may also have served to cover up their inabilities and thus not embarrass themselves or their partner. For example, one dementia patient did not deliver any data, as he indicated that he was afraid of failing:

"I have troubles with concentrating and am not sure that I can contribute to this research in a useful way."
(Charles – PwD, final reflection (Aangenaam))

The importance of carefully constructing the questions and research guidelines – to avoid the feeling of being tested – is evident.

5.5.4 Fun to participate

We aimed to enhance the motivation of the participants by creating a joyful experience. Aspects that are regarded as fun in both research methods are elaborated on here. A few participants explicitly indicated how enjoyable the experience had been for them. One informal caregiver in the personal evaluation game condition explained that this shared involvement was an added value of the game over regular questionnaires:

"In any case it is more enjoyable then a plain questionnaire."
(Geraldine-IC, final reflection (Aangenaam))

People who liked to play games were very suitable participants. The two couples that were most elaborate in their answers (and used all answering options) reported enjoying playing games in general. One of these couples even 'played' the game with friends, which is an indication that it was actually experienced as a game. The use of humour in answering the questions is regarded as clear evidence that participants enjoyed participating. Four participants used some humour in their answers by laughing during an audio recording, making silly remarks or jokes with a double meaning. Also, in the picture option some humour is shown, as there was a picture showing one of the participants and a friend laughing (Figure 5.5).

Figure 5-4 Participants having fun with the personal evaluation game.

5.5.5 Participant: researcher relationship

The level of involvement of participants is reflected in their behaviour towards the researcher. This is why the attitude of the researcher in interaction with the participants is crucial for a good participant–researcher relationship. Participants wanted the interviewer to be more than just a distant researcher:

"When you left after your first visit we thought: finally somebody who can interact with people." (Vivian and Victor, final reflection (Tablet))

A good balance between talking about the objectives of the project and showing interest in the participants as human beings (and not just as participants) is relevant in the interaction. It is sometimes difficult to keep this balance. The final reflection, with one of the informal caregivers, illustrates this. The informal caregiver was so overwhelmed with all the events of the past weeks that it was impossible for the researchers to properly discuss all topics during this session. Instead, the researchers talked about problems and so forth. This shows that finding the right balance between talking about the project and about the people's everyday life is crucial. The researcher should accept that discussing the project is sometimes not possible. This must be expected, and over-structuring the research would be unwanted in such a situation. Eventually a good participant-researcher relationship can motivate the participants to contribute more.

5.5.6 Generated evaluative insights

In this section, we reflect on the type of data we received. The generated data should be rich and give sufficient evaluative insights for the development of the assistive technology. Along these lines, the input might potentially inspire new design directions.

Reflection on input

We sought to gather data from a first-person perspective of people with dementia. The personal evaluation game provided a more dynamic understanding of the lives of the participants, not only through written text, which in itself was already more vivid than the digital input received via the tablet, but also from the audio and photographical data. The data from the personal evaluation game offered more contextual richness, allowing the potential for new, unsolicited insights. For example, one user tried to support the designer of the lamp by indicating how the lamp could be used:

"People who get headaches from the lamp might try using sunglasses or a sunshade."
(Geraldine-IC, notebook (Aangenaam)).

[Note: This of course would defeat the entire purpose of the lamp, and thus points to an important misunderstanding about the lamp's use.]

Written, audio and photographical input options

In the personal evaluation game three different answer formats were provided, each with their own benefits. In general, all types of data contained more information than just the answer to the question. For example, the written data clearly illustrated the language difficulties some dementia patients face. In the written and audio data, it was therefore easy to identify who made the entry. For the photographical input this was more difficult, and it was impossible for the digital data. This was important since we wanted to know what the dementia patients contributed directly.
Furthermore, the audio data provided rich insights into the interaction between the dementia patient and the informal caregiver. These data also showed the possibilities of using a voice recorder to capture events in the home context, unaffected by the presence of a researcher. In addition, the photographical data in this study showed the richness of pictures compared to plain text. For example, the photos of the current light situation in the home environment of the participant immediately showed that the look and feel of the dynamic lighting armature is incongruent with the interiors of many participants (Figure 5.6).

Lastly, the pictures also supported input from the other options and contributed to a better understanding of what the participants meant. The digital data in the current study did not provide more insights. The participants require self-motivation to use the remark box, especially since the data could not be reviewed later on. Despite that, there were some benefits as well. The data is already digitized and very clean, and so there is no need to decode any handwriting or listen to a 3-hour audio recording. The final reflection revealed that some participants liked the ease of correcting errors:

"What the informal caregiver also liked was that the errors could be recovered quickly on the iPad in contrast to a paper questionnaire."
(Vivian –IC, final reflection (Tablet))

Figure 5-5 The home environment with the incongruent light armature.

Evaluative insights

In both methods, insights were gained into the dynamic lighting fixture. The specific evaluation areas that are covered were different for the tablet-based questionnaire and the personal evaluation game. The personal evaluation game seemed to reveal more information on the aesthetics and context of use. The questionnaire gave more functional insights, for example whether they noticed the effects of the light on a daily basis. Both these areas are relevant for the evaluation process, yet very different. The various input formats each provided a different kind of value for the lamp. The audio data revealed insights into the interaction between the informal caregiver and the dementia patient. The photos provided more insights into the current lighting solutions and the aesthetical requirements of armature design in this domain. In contrast, the tablet-based questionnaire generated less qualitative data and none directly from the dementia patients themselves. The questionnaire did provide very concrete user input concerning the light armature, yet was limited for developing the design.

5.5.7 Sleep quality measurements

In addition to the qualitative evaluation with the personal evaluation game we also examined the effect of the lamp. There is evidence that such light interventions can slow down the cognitive deterioration of dementia (Riemersma-van der Lek *et al.*, 2008), making it especially interesting to pursue. To evaluate the 'Vitaallicht®', the subjective sleep quality was measured through a questionnaire (Appendix C). This was an adaptation based on the Karolinska sleep diary (Akerstedt, Hume, Minors, & Waterhouse, 1994) and the Pittsburg Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). The questionnaire was administered at three points in time: as a baseline at the start and after the 1st and 2nd week.

The results show the development of the subjective sleep quality over a period of two weeks (Figure 5.7). In the Figure the horizontal axis reflects the three measurement moments of the questionnaire. The vertical axisd shows the score from the questionnaire on a scale from 0 (no sleep) to 5 (sleep very well). The lines represent the individual users and reflect their progressive scores. Based on these results there was no significant improvement of the sleep-wake cycle. Nevertheless, based on the averages, a slight increase of the mean sleep quality over two weeks is visible.

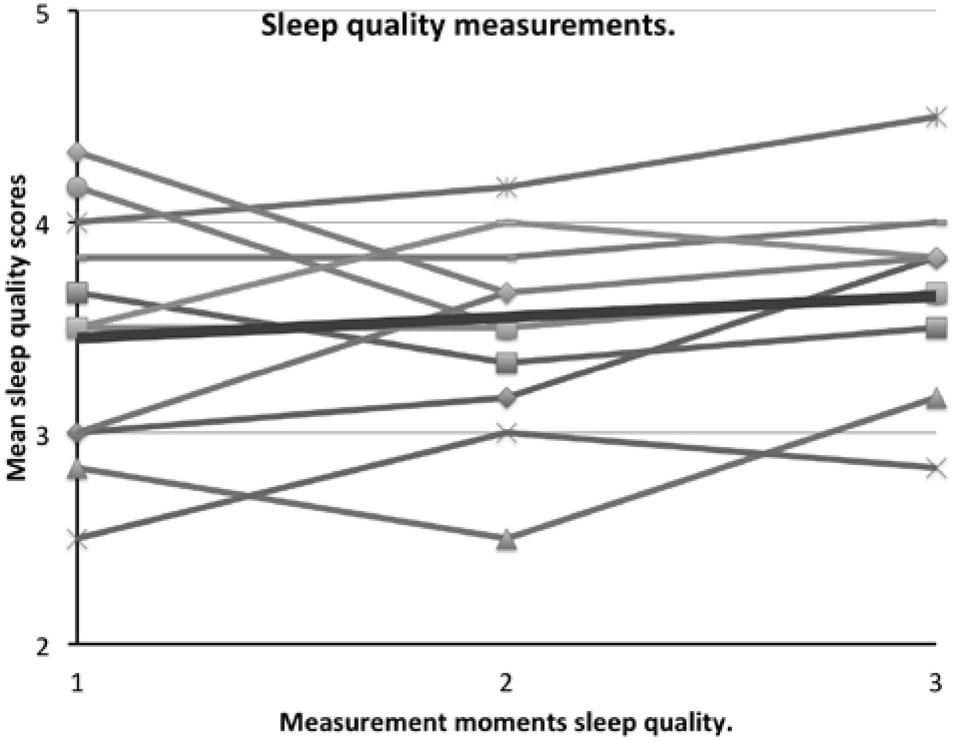

Figure 5-6 Mean sleep quality improvement.

5.6 Conclusions

The goal of this study was to explore the potential of the personal evaluation game method to capture first-hand experiences from people with dementia directly, in addition to a caregiver-oriented questionnaire. The probing-inspired method is applied to evaluate the 'Vitaallicht®' assistive technology in the home environment for several weeks. We were well aware of the differences between qualitative and quantitative data, and we therefore specifically focused on the experiences of the participant in using our newly developed research method. The questionnaire method was also applied, as a different method in the same context. For this we expected to give valuable insights into both pros and cons of the methods used when evaluating assistive technology with people living with dementia at home.

In this study we had three main objectives. First, we wanted to make the dementia patient's voice heard in the research when taking into account the aspects of dementia such as memory deficits, language difficulties, and a reduced capacity to concentrate. Secondly, we focused on the experience of the participants. They should not be burdened by the method and we therefore carefully considered the factors that might influence feelings of involvement and motivation. Finally, the generated data should be rich and give insights for improving or developing new assistive technologies. We should be able to draw evaluative conclusions on the assistive technology and find unmet user needs as inspiration for future developments.

5.6.1 Findings from the study

Some participants, both those with dementia and their informal caregivers, experienced problems working with the tablet and therefore the involvement of those with dementia was limited using this method. The questionnaire did provide specific insights, yet these were limited to functional parameters. The comments box allowed for additional input but participants were not often inclined to do so.

In the personal evaluation game, we succeeded in gathering first-hand input directly from those with dementia. Clear evidence for this could be found in both the audio and written input. In addition, we found that real enjoyment in the research activity could be accomplished when the method was experienced as an informal and social activity. The shared involvement of both the informal caregiver and the person with dementia made participating pleasurable and at times even resulted in participants involving others in the research. The experience of playing a game also compelled users to try multiple answering options and to give answers that were more extensive.

In particular, the audio data from the personal evaluation game provided insights into the interactions between the dementia patient and the informal caregiver to an extent that would not have been possible otherwise. The study showed the capabilities of a voice recorder to capture events in the home context without the researcher's influence.

Some questions in the personal evaluation game were left unanswered without any clear reason; these should be carefully adapted for future studies, where wording and syntax is further simplified. As preferences differed among participants, perhaps a greater variety of types of questions could be provided (open-ended/closed, with or without gradation and so forth).

Others in the field of conducting research with people affected by dementia have already pinpointed the importance of establishing a proper researcher–participant relationship (eg. Lindsay *et al.*, 2012; Wallace et al 2013). The insights gathered during the current study corroborate these conclusions. Importantly, both the newly developed research method itself, as well as our research protocol supported this relationship substantially; this is elaborated on in Chapter 8. A decent introduction by the recruiters; meeting the participants three times in their own home environment; and discussing with the participants afterwards all contributed to trust in the researcher. The user's home environment is a private, secure place, which means that the research conducted in this domestic domain must be sensitive and respectful. In addition Ogonowski *et al.* (2013) emphasize the importance of a relaxed, friendly and social attitude from the researcher for enhancing this relationship. Furthermore, the research-participant relationship is especially important when conducting research in a real-life context because the home environment will be disturbed by both the research activity and the technological intervention (Coughlan *et al.*, 2013).

5.6.2 Limitations

The set-up of the current research was a compromise between an evaluation of the technology and the method. While investigating potential methods, it was inevitable to carry out these two studies at once; there was no method available that fulfilled our needs. Thus, in order to see whether the new method could generate evaluative insights, there was a need for something to evaluate. Since one of the goals was finding a method that does not burden participants, doing two studies at once seems contradicting. However, by continuously checking the burden with the participants we were able to overcome this. Thereby, was the focus put on the evaluation game method, the intervention itself was non interactive and put to the background of the study.

The crucial role of the informal caregiver during our study raises questions about their exact influence on the answers given by those with dementia and their motivation to participate individually. In both methods, the informal caregiver appeared to play the role of an interviewer. This might not be easy for everyone. Some informal caregivers took charge of the questions, while others gave full responsibility for participation to the person with dementia. We do not know whether more interaction between caregivers and people with dementia would result in more biased or less valid answers. It could even be that these answers represent the opinion of people with dementia more accurately because of the long-term relationship and intimate familiarity between both participants. This is why we recommend that this should be investigated further in future research.

Finally, the limited number of participants questions the validity of our results. The study provided ample input for a qualitative reflection of the evaluation game; however, concerning the effects of the intervention the numbers were too little for conclusive results.

5.6.3 Implications

In this study, the user group 'people with dementia' is diverse in terms of abilities, interests, relationships and ways of dealing with the disease. It is questionable if you could even define them as one user group. As Nygård (2006) puts it: 'Big differences between people make it important to know WHO has the disease rather than just WHICH disease'. This was reflected in the great variety of input we received from the participants in both methods. Some liked to play with the game; others had great difficulties with it. Some were happy to have the tablet; others were not interested in the device. We are not only dealing with a dementia patient and an informal caregiver, but with people that have their own preferences and personhood (Wallace *et al.*, 2013). How they experienced participating in the current study was therefore different for everyone. Accordingly, we cannot state that either the tablet-based questionnaire or the personal evaluation game is more suitable for people with dementia.

However, the results of the current study do provide insights into the tools that researchers can use, and what they need to pay extra attention to, in order to involve people with dementia and informal caregivers in research. A flexible solution is important for this diverse user group. One strategy could be to allow people who participate in research to offer as much or as little as they desire, while still letting them feel they have contributed sufficiently (Vines, Clarke, Wright, Mccarthy, & Olivier, 2013). However, it is important to keep the balance between flexibility and letting the person with dementia be in control, as we found in our study that the stacks of question cards can already cause problems.

In both methods, the informal caregiver is crucial for conducting successful research with this user group. Experiencing and evaluating together with a spouse is indeed increasing the involvement of dementia patients in research. The relationship between the two spouses is beneficial for the research activity. The informal caregiver has a complete understanding of the needs of their partner and is therefore capable to provide help where needed. On the other hand, the dementia patient seems to accept this help from the informal caregiver more easily because of the familiar relationship. As a researcher, it is important to not underestimate the time and effort that is requested from the informal caregiver. We even found that some informal caregivers experienced participating as more burdensome than the dementia patients did. It is therefore important that special attention should be paid to how to include informal caregivers as well.

Input from the personal evaluation game provided different insights concerning the assistive technology. The tablet-based questionnaire provided more feedback on functional aspects, and the newly developed method showed how the dynamic lighting armature was used in context. Thus, the new answering options (for example, the camera) show a very different perspective on the technology. For future research these can be adapted towards the specific requirements of a study.

To conclude, the personal evaluation game method showed the possibilities of including dementia patients with their first-person perspective in research. The new method might not be suitable for every household, and several factors influence this, such as abilities of the dementia patient and the attitude of the informal caregiver. In addition, the personal evaluation game will only be suitable for qualitative evaluations in which the personal perspective of participants is important. If the focus lies on evaluating functional parameters of assistive technology one might still use alternative methods. However, the personal evaluation game can be a method that delivers more surprising insights concerning the assistive technology and thus opens up the design space, and above all increases enjoyment for the participants.

CASE 5.2 - Vitaallicht 2.0

A few months after evaluating the high-fidelity prototype of the Vitaallicht® lamp with our personal evaluation game, the company behind the intelligent lamp initiated a redesign process to improve their concept. Among other inputs the company used insights gathered in our study to design a new version of the lamp. In reflections with the company, there were some communication issues and a conflict between the results and their expectations. They would have liked us to focus more on their product, and less on our method. From this we learned that for future cases we should aim to balance research and industry interests stronger.

In the new version, the Vitaallicht® 2.0 (Figure 5.8), there are three main improvements: the interaction design, the aesthetics of the lamp and the evening light setting. First, for the interaction design a delicate rotating switch replaces the main switch. By rotating the switch users can select modes for the lamp. This can be a setting or an automated natural light pattern that allows the lamp to follow the natural day-night rhythm. Users can, if they want, deviate from this and set the device to their preferred state. Second, concerning the aesthetics, the design of the new lamp has undergone a major improvement. The new lamp looks friendlier and more elegant because of well-rounded edges and curves in the armature and the lampshade. Furthermore, the smaller base makes the lamp look smaller overall. Third, the evening light setting was improved based on feedback from the study. The warm LED lights were not sufficient to mimic a cosy light setting; instead other LEDs with a higher colour temperature were added.

In addition to the new prototype students from the department of industrial design have contributed to the communication and long-term perspective of Vitaalicht®. By applying design methods they have constructed a smartphone application, extended the product family and proposed ways to contact specific users groups that might benefit from the Vitaallicht® lamp. These steps are, however, still in the early stages and there might be further extensions over the next year.
These improvements show how Living Lab research in context contributes to the design of new intelligent systems. In addition, the Living Lab is not a single study but the entire process of step-by-step refining innovative technology on different aspects. Our care partner, the Geestelijke Gezondheidszorg Eindhoven (GGzE), even purchased a number of lamps based on the responses from participants in this study. Overall we think this is a very successful case, despite the communication errors early in the process, and we can learn from this for future cases.

Figure 5.7 - The Vitaallicht 2.0 design

Chapter 6:

Design & Evaluation

With business stakeholders

In this chapter we focus on how design contributes to the business perspective of business stakeholders. This will be exemplified by another case as part of our Living Lab. In this case we evaluate the GoLivePhone®, a software interface for smartphones specifically designed for older people. We do this in the home context of people living with dementia.

This chapter is based on:

Brankaert, R., Snaphaan, L., & Ouden, E. Den. (2014). Stay In Touch: An in Context Evaluation of a Smartphone Interface Designed for People With Dementia. In *IWAAL 2014* (pp. 288–295).

Brankaert, R., & Ouden, E. Den. (2015). (Re) Design of a mobile interface : Reflections on an in-context evaluation. In proceedings of *Participatory Innovation Conference 2015*. The Hague, NL

6.1 Role of design in the Living Lab

We have seen that a network of relevant stakeholders is key to our Living Lab approach (Chapter 3). By involving the relevant stakeholders we are able to generate the impact we envision for our design business stakeholders through design.

6.1.1 Stakeholder roles in our Living Lab

A traditional way to define stakeholder roles is the triple helix model, in this model it is suggested that industry, government and university collaborate for innovation (Arnkil *et al.*, 2010). In an evolution of this model the user is added as a fourth key stakeholder role; this is the basis for the quadruple helix innovation model (Afonso, Monteiro, & Thompson, 2012). In this approach the four stakeholder categories are: business stakeholders (e.g. firms), public organisations (e.g. municipalities or care stakeholders), research (e.g. universities), and citizen (e.g. users). In such a Quadruple-Helix network each of these stakeholders can take a leading role and steer the innovation approach that fits best with their innovation goals (Arnkil *et al.*, 2010). Similarly, Leminen and colleagues (2012) propose four different kind of Living Labs based on what kind of stakeholder is driving the innovation, these are: utilizer-driven for R&D activity, enabler-driven for strategy development, provider-driven for operations development, and finally user-driven for problem solving. This clearly shows how the driver of a Living Lab influences what kind of research is conducted in the Lab. This aids understanding the mechanisms of Living Lab networks so we can position design among them.

In our Living Lab we emphasize addressing the societal challenge of dementia. To achieve this our Living Lab is partly utilizer-driven to support the R&D from companies as we have seen in the Vitaallicht® case, but also user-driven as we aim to address the problems people living with dementia have through design.

6.1.2 Design in Living Labs

The multi-disciplinary nature of design inherits several roles in the innovation processes of our Living Lab. For instance early in the design process, when exploration and discovery are most important, design can facilitate user involvement methods such as co-creation or focus group sessions. Subsequently, later in the evaluation phase (Chapter 4) designers can collect the insights gathered from the studies and translate these into new concepts.

Designers perform well in such a context as they are typically capable of dealing with unclear boundaries and vaguely defined problems (Cross, 2006). In addition, in innovation networks not all information lies within a single stakeholder, and design can operate as a facilitator to gather the shared perspective and encourage stakeholders to learn from each other (Baha, Sturkenboom, Lu, & Raijmakers, 2013).

Design thus provides new perspectives for the stakeholders involved in the Living Lab. However, the kind of Living Lab needs to be considered strongly (Chapter 3). The Living Lab method can be offered to gather insights from users to either develop new concepts or gather insights to improve an existing offering. In this chapter we focus on the latter, and aim to enhance the business offering through in-context evaluations and design reflections.

This is what we have done in close collaboration with Gociety©, the case study covered in this chapter. We evaluated their business offering at the homes of people with dementia and their caregivers. We thus contributed to both assessing their technology and inspiring them to come up with new design proposals.

6.2 Evaluation of the GoLivePhone®

The assistive technology used in this Living Lab case study is the GoLivePhone®. This is a smartphone application developed by Gociety© that runs as a Google Android® skin. The smartphone interface and functionality are specifically designed for older people. We evaluated this in the home context of people with dementia to determine whether the product would be suitable for them. And if not, how we could improve the design of the concept to make it more so.

6.2.1 GoLivePhone® concept

The smartphone interface is specifically designed for older people. It has sizable icons, high contrast, limited scrolling and a simple menu (Figure 6.1). In addition, new features are added. First, is a 'guide me home' function (E), it guides users to their destination step by step. This is easier than conventional navigation as a clear arrow guides users in combination with a picture of the neighbourhood. Second, is a help button (A), this is designed to alarm caregivers. When it is pressed, a push message (email or text message) is sent to caregivers with the coordinates of where the person is. Regular functionality of a phone is available as well; these are contacts (B), calling (C) and messages (D). Furthermore a settings button (F) is available for caregivers. In addition, the menu structures of the smartphone are kept simple as well. Also, caregivers are able to control and look into the smartphone of their spouse via an online tool: GoLiveAssist®.

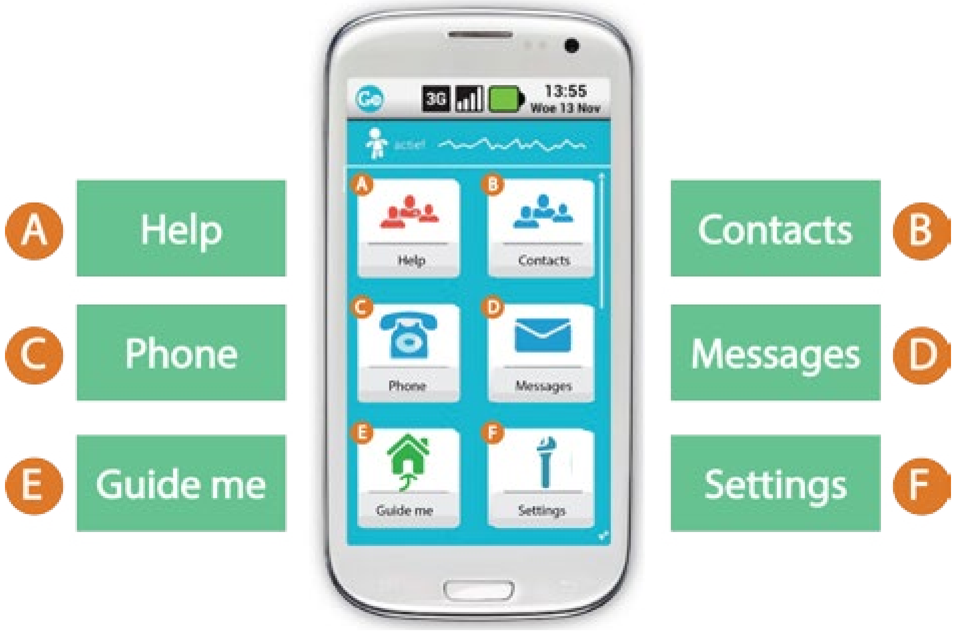

Figure 6-1 The GoLivePhone® interface menu tree.

6.2.2 GoLivePhone® study set-up

The main goal of this study is to explore the potential benefits of the smartphone interface and find suggestions for a redesign. In general the interface offers three main functionalities: (1) communicating with caregivers and family, (2) providing support when in a public space through personal navigation and (3) sending out an emergency signal to caregivers.

In total ten people with dementia, and their informal caregivers, participated in the evaluation. These were selected on an ad-hoc basis. A mental healthcare institute (GGzE) selected the participants from their caseload of people with dementia. From these one dropped out after a week due to inability to operate the phone (by both the patient and the caregiver). The people with dementia were scaled at CDR 1.0, except for two, those who were scaled at CDR 2.0 and CDR 0.5 (Chapter 2).

In this study we aimed to explore the experience of users with the concept and look for development opportunities, therefore we did not compare the smartphone with other assistive technologies. The study took place at the homes of the participants to have a study with high ecological validity.

We conducted a similar home study approach as our previous studies with three home visits. During the first visit we introduce the project and the intervention, during the second visit we bring the smartphone device and start the evaluation, and finally during the third visit we collect the device and reflected with the users on their experience. New in this study is the inclusion of in-between checks, twice, with the users by phone. By this we evaluated if everything was still ok, and the participants had room for questions. In total the home study was schedule to take 2 to 3 weeks. Next to this we allow participants to offer as much or as little information as they desire (Vines *et al.*, 2013). The participants joined the study voluntarily and were instructed to use the smartphone as they desired.

6.2.3 Data collection

Over the course of the study, three different types of data were gathered. These were data logs, questionnaire data and reflection data.

Data logs

To gather objective data on the home study we monitored two aspects; the main goals for these data logs were to make a comparison with the qualitative data, and to spot deviations. The following aspects were collected from the smartphone:

- GPS data, to see how far and how often users took their device with them.
- Activity levels, to see how often and how intensively the phone was used.

Questionnaire data

To evaluate the experience and perspective of the users during the study we issued a twice-daily questionnaire for both the caregiver and the person with dementia (Table 6.1).

Table 6.1 The questions and goals for these questions in the questionnaire

Questions	Goal:
Open questions:	
What functionality did you use most?	To find out what the users used most.
How long did you use the phone?	To get an indication of estimated use.
Which function gave trouble?	To find out what was most difficult to use.
Closed questions:	**Fully Agree to Fully Disagree on a 5 point scale**
Today the device was useful:	Perceived benefit
Today I had no problems:	Perceived issues
With this I feel more safe:	If it contributed to the feeling of safety
It increases my communication:	If it led to more communication with family/friends
Additional comments:	Record additional comments users want to make

Reflection insights

During the reflection sessions (final visit to participants) we reflect with the persons with dementia and their caregivers on the technology, the study and the method. These sessions took about 1 hour. From these sessions quotes were extracted and qualitatively analysed to find common insights (Braun & Clarke, 2006).

For the reflection session we set four topics to discuss: Mobile Interaction (e.g. touchscreen and menu structure – designed by Gociety©), Device Hardware (e.g. battery and exterior buttons – not designed by GoCiety©), dementia related issues and research method and protocol. The participants themselves provided the content for these discussions and thereby decided what they wanted to discuss most intensively. As a result, not all users commented on all aspects of the design. Because we wanted our users to participate actively, we gave them the role of a test explicitly and this resulted in some users providing additional text and even some images; these were also included. The results from these reflection sessions were translated into quotes (with the use of MAXQDA software) to be clustered.

During the reflection sessions we noticed that some questions could be overwhelming for the person with dementia. This was expected, as complex social situations and discussions are often experienced as to burdening. In these cases the caregiver usually took the lead and answered for both of them. This resulted in a 2 (caregiver): 1 (person with dementia) ratio for the resulting statements that have been included in the analysis.

The result section uses quotes to exemplify the thematic clusters, and their contents. These are formatted as follows:

"[Example quote from a participant]"–[PwD or CG]

In this format *PwD* refers to a person with dementia, and *CG* to caregiver.

6.3 GoLivePhone study results

In this section we cover three levels of results. First, the data measured from the device, second the questionnaires distributed and finally the reflection sessions at the end of the study. For the participants (n=9) an average length of 17.9 days (with a min. of 13 and a max. of 21 days) was registered of using the smartphone at home.

6.3.1 Data logs

The accelerometer was used to measure the activity of the participants over the test period; the application presents this data in terms of energy expenditure by the user (Aguiar, Silva, Rocha, Carneiro, & Sousa, 2014). The following graphs show the average results, with standard deviations, for each day, for those with dementia (Figure 2). The data of the informal caregivers is not presented as it showed significant lower use of the phone, mainly because they often already had phones and did not want to change.

In general we can see that the participants used the phone over the test period, however, very irregular. The data shows that almost all users enthusiastically started using the smartphone when they received it. However, after the first week (from day 7, Figure 6.3) we see a drop in average use. Thereafter, after approximately two weeks of use a nadir was reached for smartphone usage. This shows that a re-engagement of the user with the system is necessary. Nevertheless, some users continued to use it after this first period and these users also indicated they experienced the smartphone as beneficial. From the day 13 participants started to drop (orange boxes, Figure 6.3), and the data is no longer representative from day 18 when there were only 3 participants left.

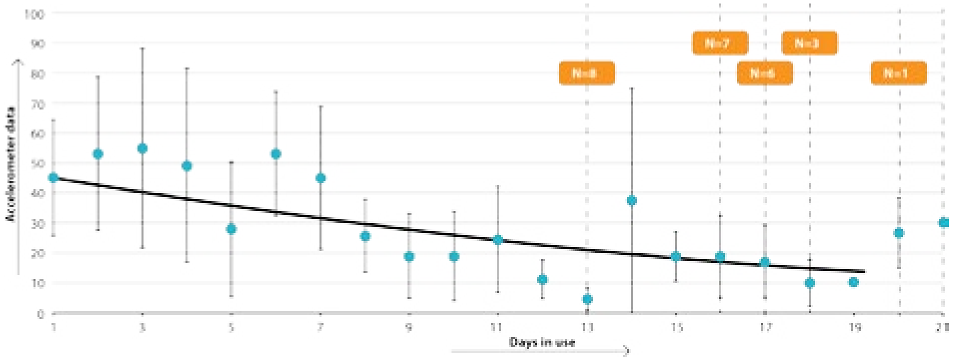

Figure 6-2 The average accelerometer data of participants with Dementia.

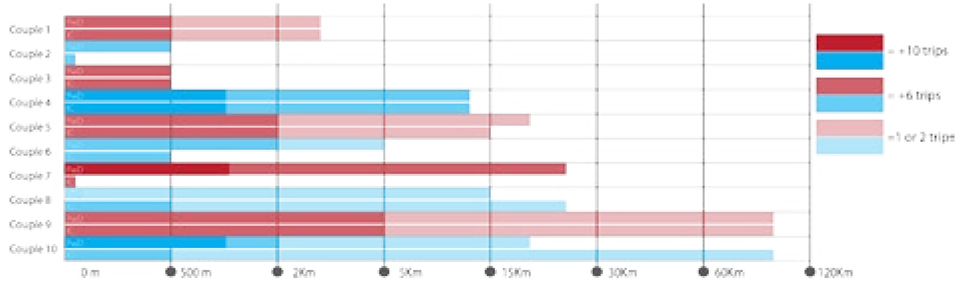

Figure 6-3 The GPS data from People with Dementia and Informal Caregivers.

The GPS data (Figure 6.4) shows – for each couple – their distance from home, the upper bar represents the person with Dementia (PwD) and the lower bar the Informal Caregiver (IC). Red and blue colours are added for readability. Almost all participants tried the phone around their house in an area of +/-500 meters. Moreover, some users took the phone on larger trips (i.e. Couple 9). In addition, some users took it almost everywhere they went showing intensive use. Couple 7 – PwD – took it almost everywhere everyday, Couple 9 – both – experimented a lot on near, mid-range and long trips almost daily, Couple 5 – both – showing near to mid-range trips uses and Couple 10 – PwD – showing mid-range trips.

6.3.2 Questionnaire

The participants did not adhere well to the questionnaire in general. We aimed at 7 questionnaires per person, yet an average of 3.3 questionnaires were completed per couple (with a minimum of zero and a maximum of 7). However, some of these users provided their experience by email or text file.

From this data we found that about half of the participants had a positive experience with the device (Table 6.2). Two of them were very active users of the phone and three participants felt they didn't need the phone yet. The other five participants experienced many difficulties with the system, including one dropout, and indicated they could not use the smartphone interface and did not want to use it. The calling and navigation features were used most by the participants.

Table 6.2 The results of the twice-daily questionnaire

Questions	Goal:
Open questions:	
Most used functionality	Calling each other (N=7), Navigation (N=4),
Average time phone used (that day):	0 – 10 min (N=5), 10 – 30 (N=3), 30 – 60 (N=2)
Which function gave most trouble?	General use (N=5), Help (N=3), Navigation (N=2)
Most common issues:	
Forgetfulness	Users often forgot their phone, difficult to integrate in routine of dementia patients, use menu (N=5)
New functionality: HELP	help button is difficult (N=4), or not used (N=6), although caregivers think this is nice (N=3)
Guide me home application	Very positive (N=3), and Ok (N=2)

6.3.3 Reflection session

In total 108 quotes where gathered via the reflection sessions, from informal caregivers (n=73) and from people with dementia (n=35). These quotes were divided in different categories based on the topics we set for the reflection session (Table 6.3). These were: mobile interface, mobile device, dementia related and other comments among which the research protocol is discussed. In the next section we describe the insights gathered from these quotes. Finally we also reflect on the general experience of our participants.

Mobile interface

The mobile interface cluster is the most sizable from the four main cluster themes. The new functionalities were also a part of this cluster. Most comments related to the 'Guide Me Home' navigation application. Most comments pertained to a positive experience of the new feature, as the following quote exemplifies:

"I could use the [Guide me Home] Application after some tries on my own, and it worked very nicely." – PWD1

Some difficulties occurred as well, mostly related to technological errors. Some users also mentioned that it was not suitable to be used on a bike. In general we could say the 'Guide me Home' application was considered a welcome addition to the device. And from the reflection sessions we found participants experimented a lot with this feature. However, the technological issues need to be solved as some of these participants put it away after the first uses.

Table 6.3 An overview of the quotes provided by participants in the reflections.

Cluster themes	Sub-theme	N	Explanation of theme:
Mobile Interface	Guide me home app	18	Describes experiences with the 'new' guide me home application.
	Help button	8	Covers comments concerning the help me button, almost all comments are critical about functionality.
	General phone use	9	The general phone functions such as calling, texting and adding contacts is covered here.
	Menu (complexity, readability)	6	This is a cluster of comments that pertain to the difficulty to understand the (often too complex) menu structures.
	Other (language, functions, speech)	11	These are other, software related issues such as language, agenda functions, text to speech and keyboard.
Device Hardware	Interaction with device	10	In this cluster mostly comments concerning the touchscreen interaction are made, such as for example scrolling.
	Physical product (size)	8	This section describes comments related to the physical (non-button) part of the smartphone device.
	Physical buttons	7	This cluster contains comments concerning the external buttons on the device (volume, on/off and home).
	Battery	6	This cluster concerns complaints about the battery life.
Disease-related	Addressing a need	8	Contains more general comments concerning a reflection on the general need or benefit of the mobile interface.
	Familiarity	4	Comments that are related to the concept of familiarity and recognition are clustered here.
Other	Opportunities	5	Contains new functionalities suggested by the users.
	Method	3	Contains comments related to the research method.
	Other comments	5	Other (reception, pre-paid, glove interaction, multi-use case challenges with phone and pricing.

Concerning the ‘Help’ feature, most of the comments were critical. Participants mentioned that it did not add value, the icon was unclear, and mostly that it was often pressed by accident. We felt this functionality would have most potential, as it is simple and deemed essential in several assistive technology studies (Topo, 2009). However, the study revealed that this functionality should be improved significantly.

The participants offered several solutions; for example, it could be pressed twice, ask for a confirmation or add a telephone number to the message caregivers receive. Finally, one participant contributed a new icon suggestion for this feature (Figure 6.4).

Related to the general phone functionality (dialling, text messaging and managing contact) the texting functionality was not used often. For dialling we received mixed results, for some this was fine, whereas others couldn’t use it. Additional issues concerning these features came up as well such as erasing numbers, contacts and missed calls. It is challenging to redesign these functionalities, as they are a must for a mobile device. However, some of these items could also potentially be hidden. The general interface and menu structure were considered to be too complex; however readability was very good. This means conceptualizing a menu was an issue rather than reading and understanding text. This problem occurs when too much functionality is presented at once. The next quote, from a caregiver, shows this:

“The menu was a little bit too complex for [PWD10], for example the message and call functionality were unnecessary.” – CG10

Finally, several other software issues were mentioned. Two participants mentioned that the online environment to control the phone was appreciated. Furthermore, some language issues were found. Finally, the backlight went off too quickly for one participant. These comments are all very relevant and can be implemented relatively easy.

Device hardware

The second largest thematic cluster is the hardware cluster it contains four sub-categories. These comments pertain to the physical aspects of the device.
Concerning size participants mention it was too big, yet some thought it was fine, and one even mentioned that it was too small for typing due to his visual impairment. Related to the material, the users preferred a casing that ensured a good grip.


De help app is onduidelijk. en zou
een andere ~~App~~ plaatje moeten zijn

Figure 6-4 An alternative icon for the help functionality, provided by the user.
It says: “The help app is unclear and should use a different image”.

Most participants expressed that they did not have any difficulties with the touchscreen interaction. And indeed during the first introduction session the researchers experienced that most could perform basic tasks after a short introduction. However, some participants did have difficulties, and one person mentioned that the person with dementia pressed the phone rather than touched it.

“When I called my wife, sometimes my wife pressed the phone rather than touched it; in such a case she would pick up the phone and also hang up the phone in one action.” -CG7

Concerning the physical buttons some participants experienced difficulties related to size. However, in general, the participants did not often use the other buttons, apart from on/off, much. Finally, the battery needs to be improved significantly. Charging was challenging, and participants thought the device should ideally work for a week. The following quote refers to this:

“Calling went ok, yet sometimes the battery wasn’t properly charged (empty after half a day) and it still would not work.” -CG6

Disease-related issues

Participants told us in the reflection sessions that the touchscreen and smartphone are something people with dementia do not recognize as such. This could be one of the reasons it is so challenging to use for some. One person mentions that his own mobile device, an iPhone© 5, is easier because he is familiar with it. As elderly people start using smartphones more and more for themselves this might change. However, this was an exception, and still many people struggled with this, as can be seen in the following quote:

“My Husband [PwD] does not want to try the mobile interface; it is too challenging, and he does not recognize it.” –CG8

Furthermore, related to whether the phone addressed a need it was mentioned several times that it ‘might in the future’. One person specified that it needed to be simpler. In another case the caregiver could not use it, which made using the device challenging for the household. However, they were interesting in trying the help feature. This shows that only a need is not sufficient, the intervention should adequately address it in a way that fits the needs of a certain user.

Other insights

Concerning the protocol, a few participants thought the introduction should have been longer and optionally given twice. The learning curve differs a lot for each person, and perhaps this could become part of a dynamic protocol. In addition, the communication could have been stronger between researchers and healthcare workers. Sometimes users were not adequately informed what our research would entail, making the introduction even more overwhelming.
In addition, some explicit opportunities were found that did not fit with specific features of the mobile interface. It was for example, mentioned twice that the functionalities should be provided in a different way. One person mentioned that there should be a feature that supports the localization of device and charger. Another user recommended this to be on the other phone (of the informal caregiver):

“It’s a pity you cannot see where the other phone is on your own phone, this would have been useful.” –PWD5

It is very interesting to see that the participants actively thought about improving features, and even sought new opportunities for the device.
Almost all participants found contributing to meaningful and rewarding while having a cognitive impairment such as dementia.

6.3.4 Redesign suggestions

Especially in the reflection with the participants plenty of redesign suggestions emerged. One contains direct translatable improvements, the second entails more challenging improvements that need to be discussed and considered carefully.

Easy to improve, for example, are the general phone features. For some users these were too complex, whereas others could use them after some practice. Making these functionalities (optionally) hidden solves this.
Another improvement that is often mentioned is battery life. While battery performance is on a par with other similar devices, it empties quicker due to continuous wireless GPS communication and activity monitoring (key features of the GoLivePhone®). This results in a smartphone battery life of 15-17 hours per cycle; the participants experienced this as much too short. Battery technology should therefore be further developed, so that over time such devices might become more suitable for people living with dementia.

Views on smartphone size and appearance were divided; however the solution might be straightforward. Because it is personal, the smartphone device could be offered in a variety of shapes and sizes. In this the exterior buttons of the mobile device should be considered and must not be too small.

Furthermore, some specific issues need to be discussed, for example in the ‘Guide me home’ application. It was appreciated by half of the users, but sometimes confusing for others. Some of the couples discarded this feature because they had a bad experience during first use. The technology could therefore be improved to compensate more for errors by users (Mäki & Topo, 2009). Nevertheless, this feature was appreciated and is very suitable for people in early dementia.

Some users also had issues with basic touch screen interactions. For these users we need to reconsider whether we want to offer a mobile interface device at all. And if so, we need to look at alternative ways to offer them the functionalities. Similar issues arose from the disease-related reflections. However, this inability was not related to the level of the disease (CDR) and differed significantly per person. For this group of users other opportunities might be sought.

6.4 Conclusions

In this study we evaluated a smartphone interface designed for elderly users. This evaluation was conducted as part of the Living Lab at the homes of people with dementia for a period of 2 to 3 weeks.

From the data logs we found that all participants actively started using the smartphone, but only a few kept using it. The data graphs show how the usage of the smartphone dropped over time with the lowest point after two weeks. This suggests that a reintroduction of the system and related services might be necessary for a successful introduction of such solutions.

From the questionnaire data we learned that interacting with the system was challenging, especially touch screen usage (Armstrong et al., 2013). Also integrating the device in a daily routine proved difficult, a known issue with mobile phones for people with dementia (Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009). However, some participants were capable of using the smartphone to its full extent and enjoyed it.

Furthermore, the study showed that for some users some minor improvements could enhance the experience already, such as consistency in the interface and language. However, for other users this technology was not suitable at all. This was for example apparent for the couple that dropped out after seven days because the informal caregiver could not even use the device. This shows that the disease is not the only factor that determines the usability of assistive technology.

Additionally, in the context of familiarity it was mentioned that some users did not recognize the mobile interface as an object to use. And, because of this, the users lacked initiative to use it (Jones, Kay, Upton, & Upton, 2013). This suggests that the current format, a smartphone device, is simply not always a suitable solutions. Moreover, this might guide the design of other solutions; in particular for the navigation functionality and communication with family, as these were most appreciated by the participants.

We recommend for future studies to put technology 'in the wild' as soon as possible, as this generates reflective insights that cannot be found otherwise. In addition, the business stakeholders appreciated this very much as well as the research approach was pragmatic and rapid enough to be relevant for their own development processes. For them the reflection sessions, and subsequent thematic analysis, provided plenty of insight for development of the smartphone interface and how to position the smartphone.

6.4.1 Involving people with dementia

Overall, those with dementia had no issues whatsoever with participating in this study. This was mainly due to two reasons. Firstly, we allowed the participants to decide by themself how much they would like to contribute. By positioning them as co-designers they provided input freely. This resulted in some participants contributing more and from different perspectives. In particular, content such as the new icon suggestion shows this. . This role contributed to an informal setting for the participants. Second, because the study took place at the homes of the participants they felt more comfortable as well (Wherton *et al.*, 2012).

Furthermore, the home context contributes to insight into how technology is integrated in everyday life, an important factor for technological interventions (Robinson et al., 2009). For example, during the introduction meeting we noticed how some participants could use the touchscreen and mobile interface when instructed how to do so. Yet, in the reflection session, some of these participants did not use the system over the course of the study, lacking initiative and guidance on how to do so (Jones *et al.*, 2013). On the contrary, this also happened the other way around. This shows that a lab set-up based on short-term evaluations, in which people with dementia are asked directly to perform an action, does not say anything about how they would perform and actually use the device at home.

Thereby, we suggest for future studies the inclusion of a reflective approach and a freeform setup. Especially when dealing with vulnerable people, like people living with dementia.

6.4.2 Stakeholder collaboration

In this Living Lab case we focused on the role of the stakeholders more. Different insights were found concerning the care stakeholder, a mental healthcare institute, and the business stakeholder, provider of the GoLivePhone© services.

For the care stakeholder this collaboration resulted in the introduction of new assistive technology for an active group of participants from their dementia community. The role of professional caregivers from this stakeholder was very important, and supported the gradual introduction of the technology. Thereby, it also allowed these professionals to get acquainted with new kinds of technology. In addition, from a Living Lab perspective the involvement of care professionals is important for scaling up such studies. By integrating technology evaluation in the daily practise of care professionals higher number of participants can be achieved with relatively low effort in the future.

The main contribution of this study was a stronger involvement of the business stakeholder. By involving the Business stakeholder early in the process they had influence on the approach and method. This resulted in a shared ownership and a more active engagement in the study. In addition, from a design research perspective collaborating with business stakeholders resulted in high-quality technology to do research with, and therefore there were little technical issues. Currently improvements found in this study are being considered for inclusion in the next generation of the GoLivePhone©.

In a closing session with Gociety®, the business stakeholder, we reflected on their role. Overall they were very happy with the collaboration and found the re-design suggestions helpful for their business development. They stressed to have no influence on the design of the hardware and that they are at the mercy of third-party suppliers to provide alternatives. As long as they don't design suitable smartphone devices for people with dementia, or older people in general they can only use the best option available.

Unfortunately, the results of the study were not as promising for them as they hoped, many participants with dementia were unable to use the device. However, the product was not specifically designed for older people with dementia and therefore this target group is slightly out of scope. In addition, participants were involved on a pragmatic basis. This sometimes resulted in very non-technical users (for example the couple who dropped out after seven days) and people with more complex issues such as depression. This might negatively influence the results.

They learned that for future studies we should look into extending the introduction session as it might have been too short for some users, and additionally it should be adapted to the level of the users. They suggested a 'buddy' system might work. In this a buddy operates as a go-to person for small issues and tech support. They noticed, also in other studies, that participants are very reluctant to contact a helpdesk, and a buddy might bridge this gap. Overall, our business stakeholders were very content with the insights gained from this study and these will be take into account in the redesign of the product and thereby have a significant impact.

6.4.3 Limitations

Some limitations of the study should be addressed. In particular, the twice-daily questionnaire was not well adhered to and should be reconsidered. Little results were found from this.
Furthermore, we decided not to use the personal evaluation game method (Chapter 5) as the primary goal was to gather specific design insights for improvements, as opposed to gathering results concerning the participants. However, we felt that the personal evaluation game would facilitate a more diverse evaluation of the smartphone with pictures, sound fragments and written feedback. In addition, adherence might have been higher with this method as compared to the questionnaire.

Furthermore, the data logging should be improved. Some conclusions could be made about the accelerometer and GPS data, but a more in depth analysis of the software would have enriched the study results. For example, logging what functionalities are used most often could easily be done in a smartphone.

Finally, similarly to our previous studies, we chose the number of participants to be low. The questions we had concerning the device related strongly to finding suggestions for redesign, and to have an explorative insight in how users would integrate the device in their daily lives. In addition, our questions concerning collaboration and the Living Lab focused on engaging with the business stakeholders, and making the evaluation fruitful for them. These questions could be addressed with a low number of participants. Nevertheless in a follow up studies with this device the number of participants should be higher to be able to formulate conclusions concerning the effectiveness of the device and the related services.

Section III

Design insights from research

- Design recommendations
- Protocol design

Chapter 7:

Design Recommendations

For improving design for people living with dementia.

There are several design cases in this dissertation in which we have designed for and with people living with dementia. In this chapter we reflect on these and some additional design proposals.

First we introduce student design and the Homing Compass case. Subsequently we conduct a thematic analysis of the design aspects of these and our previous cases to propose design recommendations. In this way we aim to contribute to design for people with dementia.

This chapter is based on:

De Jong R. & Brankaert R. (2015). A point in the right direction: A simple navigation device for people with dementia. In proceedings of design 4 health conference 2015. Sheffield, UK.

7.1 Design for dementia

In this part we examine the role of person-centred care to support design. Finally, we describe the thematic analysis methodology we use to analyse the design qualities of our design cases.

7.1.1 Technology design for people with dementia

We have seen that technology can play an important role in supporting people living with dementia. However, in the field of assistive technology we see that studies often ignore the real-life context. Topo (2009) only found five of a total of 66 studies in which assistive technologies for people with dementia were designed in a way that took the real-life context into account.

A more recent review shows that in Ambient Assisted Living (AAL) – an application area related to assistive technology in the home context – 87% of the studies focus on the capabilities of technology (technology push), and only 13% (132) take the user and their context into account (Queirós et al., 2013). The study suggests two ways to address this issue. First, they suggest further developing the integration and interoperability of systems, and second – similar to our proposal – they suggest adopting Living Lab-like methods to experimentally evaluate early versions of technology in a real-life context. Both of these activities need to take place in parallel to encourage the development and implementation of assistive technology for people with dementia. Technology development should therefore not only focus on pushing the boundaries of technology; it should also invest in matching technology with human factors through real life experimentation.

In this dissertation we discussed examples of technological solutions that are beneficial for people living with dementia in various ways. Such design proposals can target people affected by dementia, their informal caregivers, and professional caregivers. All of these people are different, each with their own perspective, which should be considered in the design process. Person-centred care can inspire us on how to do this.

7.1.2 Person-centred care enabled by design

In dementia care we see person-centred care as a care strategy that focuses on personhood (Kitwood & Bredin, 1992). This approach focuses on the individual perspective of people with dementia as the starting point for care. Kontos (2005) argues for the body being an integral part of selfhood – to extend person-centred care – and introduces the idea of 'embodied selfhood', which stresses knowledge of the body's 'natural intercourse with the world' (Kontos & Martin, 2013). These advancements of person-centered care and embodiment have contributed significantly to improving the quality of dementia care (Dupuis, Wiersma, & Loiselle, 2012). 'Bodily knowledge' - the idea that the body knows how to respond without cognitive deliberation (Kontos & Naglie, 2007) – can also be used in technology design for people with dementia. This is for example shown in the design of VIGOUR (Brouwer, ten Bhömer, Tomico, & Wensveen, 2015), a smart cardigan that motivated people with dementia to move. The designers demonstrated how bodily knowledge could be used to assess both tangible and intangible aspects of the design.

Despite these advances in person-centred care, there is still a need to increase the quality of dementia care in practise based on this concept (Dupuis et al., 2012). Trends such as staff shortages, high workloads and insufficient time are related to this deficiency in quality of care (Hall & Kiesners, 2005). An extensive literature review concerning quality of life for people with dementia explicitly reveals the importance of experience. Various studies elaborate on the fact that the experience of impairment, e.g. needs, support received and the concept of agency, affect quality of life and thus reliance on others (O'Rourke, Duggleby, Fraser, & Jerke, 2015).

By considering individuals and their experience of the design of their environment and care approach we can improve quality of life (van der Plaats & Hazelhof, 2012). Moreover, technology and design can play an important role in supporting person-centred care (Figure 7.1). For example, in the Land van Horne case (P.136) we can see how technology enables a person living in a dementia residence to still cycle to his work every day. This case shows that person-centred care, in addition to improving quality of life, is also capable of lowering the cost of dementia care. This is especially important in a time of budget cuts and reduced resources.

CASE 7.1 - Person-centred care at Land van Horne

In care for dementia, examples of person-centred and experience-based care have increased in recent years; however, this approach has yet to be implemented widely. A promising example is that of the care home Mariënburght in Budel in the Netherlands, which is run by the Land van Horne care organization.

Although the architecture is not conducive to a therapeutic environment, the nursing staff have done everything possible to make the dementia ward feel like home. When walking along the hallway you come across a café, a chapel and a comfortable living room. But the interventions designed to enable person-centred care go much further than a friendly environment. For one person, band practice takes place on the ward and chickens are kept in the garden to provide for the specific daily routine of one resident. In Figure 7.1 you can see an example of how technology can enable this person-centred approach. A home trainer is connected to a video, which is synchronised with the resident's pedal movements, so that he can still 'cycle to work and back' each day.

The nursing staff, too, had to change some of their practices. For example, for the night shift, nurses dress in pyjamas (or something that looks like pyjamas). This might sound strange at first sight, yet they argue that residents associate sleep with pyjamas, whereas the regular uniform is associated with activity. The nursing home introduced these changes early in 2013 and continues to improve them all the time. The results are clear. Staff absenteeism has decreased from 12.8% to 2.14% and the incidence of aggression has been reduced significantly from 34 cases per 29 clients in 2012 to 10 cases per 56 clients in 2014. This shows that there is a lot of merit to this approach, so the question is: why is this not implemented more widely?

Figure 7.1 - A resident with dementia is enabled to still cycle to work everyday.

7.1.3 Additional design cases

In this chapter we analyse our design cases to find out which aspects are important to facilitate usability and adoption by people living with dementia. Before presenting this analysis we introduce some additional cases from the project and students. With these we enlarge the data set of design cases we can analyse.

Over the course of the project design students contributed by applying the Reflective Transformative Design process (Hummels & Frens, 2011). In this process they identified needs of people living with dementia and developed design proposals to match these. These cases are often only evaluated with only a few participants; however, the resulting concepts offer additional insights into design for dementia. In the subsequent paragraph (7.2) these student cases are covered.

After briefly covering these student cases a final case is introduced: the Homing Compass, which is a way finding device for people with dementia. This design process was initiated as we identified a need for way finding support in a more suitable form based on results from our smartphone study. The design process, concept and in-context evaluation (with eight participants) are covered in paragraph 7.3. After this final case a thematic analysis is presented in paragraph 7.4.

7.2 Student design cases

During the project several student designers have been involved. Three of these cases are included in this part as they contributed to design for dementia. These students were all from University of Technology, department of Industrial Design. The cases are covered briefly to identify relevant design aspects of these concepts.

7.2.1 Student case: Discover Dementia experience pillow

Concept: A strong example of person-centred care enabled by design is the Discover Dementia experience pillow, designed by Eriano Troenokarso (Bachelor's graduation project, Industrial Design). The pillow (Figure 7.2) has twelve patches. By touching these patches sound fragments can be played. The sound fragments are personal and selected together with family members to elicit memories and responses from the person with dementia. The pillow can be used individually or together with these family members to explore the personal sound fragments.

Evaluation results: The design was created through an iterative design process, in close collaboration with Land van Horne. This ensured that person-centred care values (Case 7.1) were strongly present in the concept. Results from an informal evaluation with four residents with late-stage dementia were very promising. Some of the residents responded very emotionally to the sound fragments. For example, one person, who did not respond in 1-on-1 conversations, was enlivened by a piece of music and sang along with it. The evidence base for music interventions is significant for its therapeutic effect on agitation and anxiety (Spiro, 2010).

Reflection: The pillow shows how people, even in the later stages of dementia, can be included in an iterative design process. Thereby, does the focus on reminiscence of experiences benefit the design (Woods et al., 2005). Furthermore, the fabric sensors are very suitable for people with dementia. Overall the pillow is not only designed for people with dementia, but also carefully considers the role of caregivers and family members in the use of the pillow.

Finally, we want to remark that the design's potential is recognized outside this project as well. In December 2014 the experience pillow won the prize for the 'Best care idea of the Netherlands 2014' (Beste zorg idee van Nederland, 2014). The pillow is currently being developed further and a formal evaluation of the design is scheduled for 2016.

Figure 7-2 The Discover Dementia experience pillow design in practice.

7.2.2 Student case: A personalised design

Concept: In this design research project Martijn Roza (Master's project, Industrial Design) developed a personal activity for a person with advanced dementia. The first probe – a cushion with ten small 'activities' – delivered the insight that personal history and a mirror worked very well for this person as an activity. These were subsequently integrated in a booklet shaped design (Figure 7.3).

Evaluation results: As the design was specifically created for one individual, the booklet is only evaluated with this person. The booklet provided a personal activity for this person that occupied him for a while. This relieved the burden of the caregiver as more time became available due to this design.

Reflection: In this concept tangibility and familiarity proved to be important aspects to engage the person with dementia. Moreover, the process showed that personalisation increases adoption of the design. Because many options were included in the first iterations, the second iteration allowed for maintaining those that were successful for this person. Through this process a suitable design was found in a relatively short amount of time.

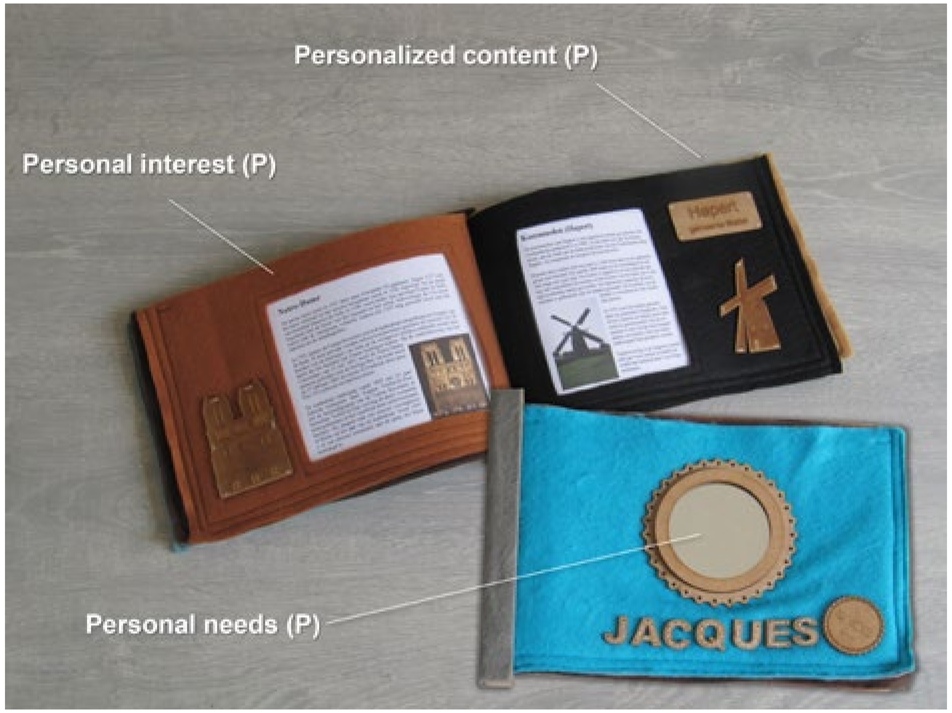

Figure 7-3 Personally designed activity probe for a person with dementia.

7.2.3 Student case: Stay-tuned Radio

Concept: The Stay-tuned radio is a communication system designed by Marjolein Wintermans (Master's graduation project, Industrial Design). The device integrates WhatsApp® (a popular messaging application) with a familiar 60s radio shape exterior (Figure 7.4). Family members, portrayed by small pictures on the front of the radio, can record voice messages and send them directly to the radio. The person with dementia can listen to these messages by selecting one of these pictures. The interaction is kept simple and familiar, one knob for volume and one to select a person's photo, in this way a person with dementia is ought to be able to interact with it for a longer period of time.

Evaluation results: In a ten day, in-context evaluation, the radio was evaluated with two people with dementia and their caregivers. It was found that communication improved, and the messages were percieved more directly by the person with dementia. The people with dementia enjoyed this way of keeping up to date with the activities of their family.

Reflection: The system allows people with dementia to Stay in control and thus improves their self-reliance. The interaction is kept simple, as Orpwood and Colleagues (2007) show that a common cd-player interface can already be problematic. In addition, the interface and appearance is kept physical and familiar in terms of interaction (buttons), aesthetics (radio) and appearance (pictures), supporting usability and adoption by people living with dementia.

Figure 7-4 The Stay-tuned radio for communication.

7.3 Case study: Homing Compass

In this design case we cover the design process and in-context evaluation of the Homing Compass. The Homing Compass is designed to provide personal outdoor wayfinding support for people with dementia.

7.3.1 Background research

The Homing Compass was designed to support people with dementia in finding their way. Wayfinding problems can already appear early in the development of dementia. The severity of these spatial disorientation problems increases as the disease progresses. In the early stages they may only get lost in unfamiliar areas, yet later people with dementia even get lost in well-known places (Passini, Rainville, Marchand, & Joanette, 1998). In order to find their way people with dementia start to increasingly rely on outward cues. Sheehan, Burton, & Mitchell (2006) suggested that traditional methods and designs such as visual aids and signs might help.

However, in the study by Passini et al. (1998) it was shown that people living with dementia were more likely to get confused by such aids. We therefore think that new solutions should be sought with more potential. Silverstein and Parker (2002) emphasise the fact that the quality of life among elderly increases significantly if the ability to get out is maintained, increasing the incentive to pursue new directions.

Several attempts to design GPS systems for people living with dementia and their caregivers are described in the literature (Landau, Auslander, Werner, Shoval, & Heinik, 2010; White & Montgomery, 2014). In one study it was found that 2 out of 3 participants were able to increase their outdoor activity significantly, as well as increase the feeling of safety for the caregivers by using such devices (Olsson, Engström, Asenlöf, Skovdahl, & Lampic, 2014). However, these systems often focus on localization rather than increasing self-reliance, and are designed for use by informal caregivers. In this case study we describe the design process of a GPS navigation system intended to empower people with dementia using a simple and easy to use system.

7.3.2 The Living Lab design process

Before we elaborate on the design, we cover the design process. In the design process we aimed to design, together with users and experts, a more suitable navigation solution for people with dementia. We initiated this design-led process to find new angles to approach the issue from (Wallace et al., 2013). Ideally, the solutions proposed should aid people with dementia directly and provide reassurance. It should guide them home in a safe manner free from moments of fear. Also, a device for people with dementia should not look too technical, such as for example, a smartphone as we have seen in Chapter 6 (Robinson et al., 2009). This was why we wanted to find something recognizable for wayfinding, and we found that a compass matched this prerequisite. In addition the appearance of a compass might suggest bringing you home.

Iteration I (Exploration phase): Expert interviews

The main purpose of this first iteration was to find if this was a suitable way to support people with dementia. Second, we focused on the look and feel of the device. Many different prototypes were created and then evaluated using co-creation with experts. We didn't want to involve users yet because this phase was still very conceptual. The direction of the design was well received, but often caution was expressed as to whether it would work for people with late-stage dementia. Other concerns related to people with dementia having difficulty learning new things.

"They have taught themselves how to use technology, but when they get dementia it's the late-learned skills that disappear first." -Geriatrician

Nevertheless, in general the experts saw potential. Their main message was that the design needs to be simple and yet recognizable. The learning curve should be very short. Furthermore, it should be introduced as early as possible in the disease, because as such a trustful relationship could be built with the device. In addition the experts felt that the users would be more self-reliant if it enabled them to get out and about by themselves.

Iteration II (Exploration phase): Focus group

Based on expert input from 'iteration I' a simpler more recognizable design was proposed. The design maintained the look and feel of a compass. A small display was added to provide feedback about where the compass was pointing. Finally we also added a central button, with a home icon. This button was included to provide auditory feedback and add a visual reference to 'home'.

In this second iteration people with dementia where involved via a focus group method. This is considered a successful method for this target group (see Quereshi et al., 1998, reviewed in Wilkinson, 2002). We wanted to find out if the target group would see a need for the device and if they would be able to understand such a simple way of navigating. Four people with dementia and three informal caregivers participated. In the focus group we used a schematic drawing and an interactive prototype. In general they responded positive, there was a general desire for simplicity and extra buttons were deemed to be confusing. Moreover, they emphasised that the technology should work better than current GPS systems, which generally do not take small streets into account, which are important for walking. Related to sturdiness it was remarked that the device should be weather and impact proof, as the risk of accidents increases with dementia. In addition, most participants preferred a smaller size (about 10 cm). Finally, the home icon we added was confusing; it suggested that the device was pointing away from home.

Iteration III (design phase): Final Design

Based on the expert interviews and the focus group session with users a final design was proposed. The main functionality of the 'Homing Compass' is a simple navigation system that points homewards via an arrow. The physical arrow's look and feel support improved usability. Additional features such as a map, auditory feedback and alternate route selection were removed from the device to maintain this simplicity. The design's look and feel resembles a compass by using familiar materials such as wood and metal. The prototype (Figure 7.5) was built using the Arduino® platform with additional sensors and actuators attached so that users could experience the device.

Figure 7-5 The Homing Compass.

7.3.3 Design evaluation: Set-up

Until this stage our design decisions were based on expert and user assumptions. We aimed to embark on these in a field test with a working prototype with end-users in their natural context (Figure 7.5). Eight couples participated, each consisting of an informal caregiver and a person with dementia. Each participant with dementia was in the early stages of dementia (CDR 1.0). The field experiments adhered to the principles of Living Lab research i.e. conducting the research in a realistic context with real users (Chapter 3). However, the prototype was not mature enough to conduct a long-term evaluation. We therefore designed a study that could be performed in about 2 hours.

The study was set up as following: The person with dementia was instructed to use the device to find a set location in their neighbourhood (A). After that they were pointed to a second slightly more difficult to reach nearby location (B), and from this location they were pointed home. For comfort the informal caregiver would walk together with the person with dementia; however, they were instructed not to help. The researcher walked behind them as a non-participatory observer. The device pointed directly towards a location and therefore they still had to make their own decisions. A semi-structured interview was then held at home lasting approximately 20-40 minutes.

7.3.4 Design evaluation: Results

Seven out of eight participants managed to successfully find their way home. Three participants very positive about this, and expressed a desire to use the design in the future. Two found the device too simple and reported no need for it, two participants saw a benefit but still had many remarks to add to the device and would not use it as is and, finally, one user experienced a lot of trouble. Because almost all participants reached their destination, we can say that with limited directional support people with dementia can be supported in wayfinding by a simple, physical navigation solution. However, caution needs to be expressed with this statement. During walking confusing moments did occur, especially when the device seemed ambiguous in its navigation direction, or when it was moving uncontrollably in random directions (technical issues). Furthermore, some caution should be expressed about usability. The participants could use it very well, but were sometimes distracted too much from their surroundings by the device. Overall, the participants were positive, especially when they were aware that the device was pointing home (final task). We saw some users only occasionally checking the device at this stage, to assure themselves of their direction. This final observation is key to how the design should work, and confirms that there is potential for further developing the concept.

7.3.5 Discussion of Homing Compass evaluation

This case study addresses the design and field evaluation of the Homing Compass. Current navigation solutions are often solely used as a tool for the caregiver and they focus on localization. This is dehumanizing and reduces the self-reliance of people with dementia. With the Homing Compass people can use this technology to empower themselves. In this study we have seen that people with dementia are very capable of using such a solution on their own. These results are promising and should be investigated further.

Caution should be taken with extrapolating some of the results. Apart from direct observations during walking, this study consisted mostly of self-reporting with a researcher present. This influences what is said, because the participants are eager to aid the researcher, they might be embarrassed about their performance or they want to please the researcher. Nevertheless, the presence of others during the field study also has a positive influence. People with dementia might feel more at ease and more people could observe how the device is used. However, this is a step further away from reality compared to our previous Living Lab case studies because the concept is in an earlier developmental stage.

In future studies long-term patterns of use should be investigated to find out how users deal with issues such as battery charging and taking the device with them on their journey. Furthermore, people with dementia can still partly rely on their regular navigation skills, e.g. using landmarks (O'Malley, Innes, & Wiener, 2015) and the relationship of such strategies to the compass should be further investigated. In addition, some technological improvements are needed for future iterations. More accurate localization technology is required as well as an Internet connection so that the device can be located in case of emergency. Thereby, we have to be careful when launching such the Homing Compass in a real-life context. Users might be distracted by the device and pay less attention to traffic, which may cause dangerous situations. For these additional elements the hardware needs to be redesigned, and software should be developed further. However, these should not hamper the main functionality of the device, which is to allow a person with dementia to find their way home safely.

7.4 Thematic analysis

In this part we cover the thematic analysis of our design cases. First we distracted the design aspects from each of those cases. Second, we clustered the aspects. Finally, from these clusters themes of interest emerged. Based on these resulting themes nine design recommendations are formulated.

7.4.1 method

For the thematic analysis we pursued an inductive approach, we use the design cases to formulate a theoretical perspective. This research is performed in a qualitative and explorative way to allow design recommendations to emerge from our past work.

The design cases, the data set, are analysed and design aspects, the data codes, are extracted from the student design cases covered in this chapter and our previous cases covered earlier. These codes are clustered using a thematic analysis approach to find commonalities between the design aspects (Braun & Clarke, 2006). This process involves two levels of clustering: the first level to reflect on the codes as part of the theme, and the second to reflect on the themes as part of the overall data set (Braun & Clarke, 2006). Based on the themes that emerge we formulated design recommendations. In addition, we support these themes with findings in the literature. Many of the recommendations are already touched upon in literature and we extend some of them with our findings. The aim is for this analysis to be explorative, allowing common themes to surface from our data set, and thus add to existing knowledge on design for dementia.

7.4.2 Data set

In total nine cases are included in the dataset, these are: PhysiCAL, Vitaallicht®, GoLivePhone®, Discover dementia, personal activity, Stay-tuned radio and our final design case the Homing Compass. In each of these design cases we found 3 to 6 design aspects that are beneficial for the usability and overall quality of the design. These were found by analysing the study results from these cases in retrospect, for more insight into this analysis see Appendix E. The student cases were smaller and thus had in general fewer design aspects, whereas the other cases included had a more extensive evaluation and therefore more detailed design aspects. This resulted in a dataset of 32 design aspects, which we clustered in our analysis to find patterns and identify themes. In total 38 participants with dementia were included in these design evaluations, thereby at least the same number of informal caregivers were involved.

7.4.3 Thematic analysis result

Based on a thematic analysis (Braun & Clarke, 2006), we first conducted an initial cluster exercise. By reflecting on the first level we related the individual codes to each other and related these back to the emerging themes to find nine distinctive themes. Thereafter, at the second level, we reflected on the relationship between the themes and the overall dataset and we found several reciprocal relations between some of the themes, in addition, we found two main overarching themes (Figure 7.6). Therefore we will refer to the nine themes as sub-themes.

The two overarching themes were identified because five of the sub-themes reflected on the *artefact*, referring to its form, clarity and impression on the user. The other four themes reflected on the *function* of the design, referring to the goal, usage and overall context.

These two overarching themes cover the following nine sub-themes: Familiarity, Non-stigmatizing, Personalisation, Physicality and Simplicity, these are *artefact* aspects. Empowerment, Flexibility in use, Reliability and Social Context, these are *functional* aspects. In the next paragraph (7.4.4) these will be covered in detail.

In an overview of the thematic analysis we visualized the themes (Figure 7.6). The two overarching themes can be found at the top of the overview and show which of the *sub*-themes they cover.

Subsequently, the relationship between the sub-themes is visualized as well. A blue line shows this. In this overview personalisation and familiarity are related, Simplicity and Physicality are related, and Social context and Empowerment are related. In the next paragraph (7.4.4) these relationships will be clarified.

Finally, a distinction in colour is made between the nine themes to distinguish between their current role in the literature. First, purple means the themes are already defined in the literature and familiar topics there. In our studies we revalidated these. Second, green means that the themes are less familiar in the Literature and we provide a new perspective by our research, therefore these are an advancement of the literature. This distinction will become more apparent in the following section in which we describe the nine sub-themes in detail and relate these to the literature.

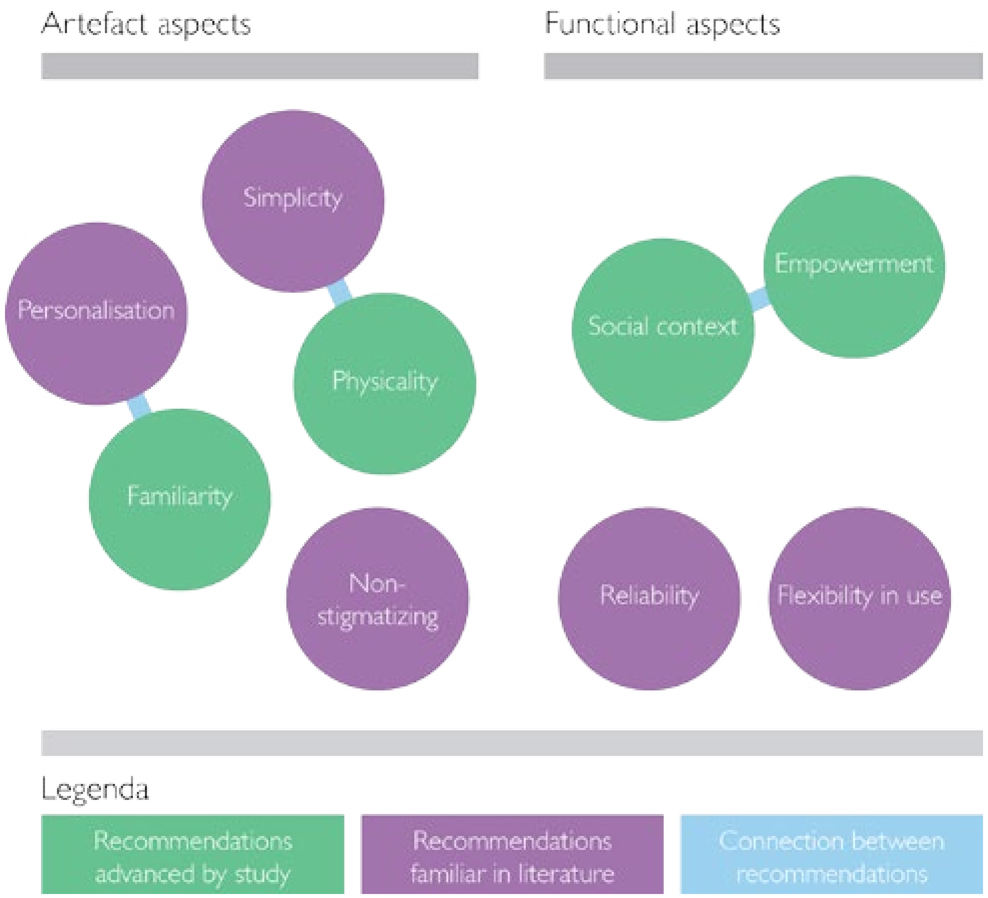

Figure 7-6 Thematic clusters emerged from thematic analysis.

7.4.4 Sub-themes in detail

Artefact aspects

As sub-themes of the artefact aspects we found elements that are known in the literature (Simplicity, Personalisation and Non-stigmatizing) as well as aspects that contribute to the literature (Familiarity and Physicality).

Simplicity in technology for people with dementia is often mentioned as an important consideration. Devices should be easy to learn and require little interaction (Orpwood et al., 2004). In addition, chains of action should be avoided (Rosenberg, Kottorp, & Nygard, 2011). Because people with dementia are impaired, these aspects need to be taken into account.

Concerning stigma, caregivers in particular do not want assistive technology to be very visible or to communicate old age (Rosenberg et al., 2011). We noticed this for example in the calendar. It was large and completely white, which communicated too strongly that the participants were impaired. This is why design proposals should be as non-stigmatizing as possible.

Personalisation is another familiar concept that works well for people with dementia. We have seen that the person-centred care approach is built around this quality (Kitwood & Bredin, 1992). In technology, however, this is challenging and we see only few examples in electronic health (e-Health) (Greenhalgh et al., 2015). From our own cases, both the GoLivePhone® and the personal activity probe (booklet) showed how personalisation can become part of a technology design for both early and late-stage dementia care solutions to increase usability and encourage adoption.

Personalisation is related to familiarity, as what is known and recognized by somebody differs per individual. In the literature recognisability is considered important in technology for people with dementia (Orpwood et al., 2004; Rosenberg et al., 2011; Woods et al., 2005). We aim to elaborate on this aspect, and go beyond recognition. In our thematic analysis we found familiarity contains three aspects. We illustrate these with the example of the Homing Compass.

First, familiarity through appearance supports adoption of and trust in a technology. In the Homing Compass study the compass design supported this. Second, familiarity contributes to usability, and with the Homing Compass people knew to look at the arrow and follow it as the main interaction. Finally, familiarity contributes to the experience. With the Homing Compass the hybrid user technology reminded users of wayfinding, enabling them to use the design for this purpose.

Finally the artefact aspect of physicality was found, as a quality that supports clarity of both use and appearance. So simplicity is related to physicality, making interactions more direct. In the literature we can find arguments for making information visible (Mäki & Topo, 2009) and in the design of the Homing Compass we found that physicality enables this. In addition, in the PhysiCAL concept and the Discover dementia pillow we found that the aspect of tangibility contributed to the ability of people with dementia to interact with the systems directly. This suggests that the use of touchscreens only should be avoided in the design of assistive technology for people with dementia (Armstrong et al., 2013).

Functional aspects

The sub-themes among the functional aspects are Reliability and Flexibility in use. These are common themes in the literature. In the additional functional aspects Empowerment and Social context we made contributions to the literature.

In the GoLivePhone® case the adaptability of the interface was appreciated by both users and caregivers
; this flexibility is needed to make a piece of technology work for dementia (Rosenberg et al., 2011). In addition, this design quality supports adaptability to the different levels of the disease process (van Hoof, 2010) and thus supports usability and longer term integration in the lives of people living with dementia.

The theme reliability was voiced explicitly during the focus group on the design of the Homing Compass; users and caregiver felt that technology should be free of errors and designed to be both fall-proof and weather-proof. Topo (2009) also explicitly mentions that for meaningful technology evaluations in context, devices should operate well and without errors. Also in more recent work it was confirmed that people with dementia need to be able to rely on technology and that an evaluation is seriously hampered if errors occur in operation (Hattink et al., 2014).

The theme empowerment contributes to the recommendation to improve the independence of users by the technology we design (Mäki & Topo, 2009). In addition, people should also become more self-reliant through technology design proposals. The Homing Compass clearly portrays this, whereas other GPS solutions often try to localize people with dementia, which is rather dehumanizing. The Homing Compass enables people living with dementia to control the technology themselves directly to find their way home. The Stay-tuned radio is another example. The radio enables people with dementia to directly keep up to date with the activities of their family. In this regard, we should not consider the impairments of people living with dementia, but rather the abilities they still have.

Finally, we found that the social context should be included in design proposals. The involvement of caregivers and family members in the development of assistive technology is often recommended so as not to burden people with dementia with these processes (e.g. Hanson et al., 2007). However, this involvement can be extended and become an integral part of the functionality of technology proposals as well. This is a delicate balance, as overburdening of caregivers is also a concern to be considered, and for this reason this theme is related to empowerment.

In the GoLivePhone® case we saw that caregivers could monitor their spouse using an online tool and only take action when an emergency occurred. They appreciated this and felt safer due to this system. This also counts for other, more distant, family members. In the Stay-tuned radio we see how we can design the contribution of other family members to be low effort (WhatsApp©) and in this way increase their engagement with people with dementia.

7.5 Conclusions

Based on the thematic analysis of our design cases we found nine themes with four recommendations contributing a new perspective to the Literature. In this section we summarize and propose these four unique design recommendations we found for future designers and researchers to consider in design for dementia.

7.5.1 Design recommendations

Recommendation 1: Empowerment
A design proposal should empower people with dementia and increase their self-reliance.

Through design we can enable people with dementia to do something they could not do before and increase their self-reliance. It is important that we design our technology in such a way they can directly use it, and benefit from it.

Recommendation 2: Social context
A design proposal should consider and balance the role of the social context, which can include caregivers, family members, neighbours and friends.

People in the social context of a person with dementia can play an important role in the functionality of a concept as well as increase its effect. This should be carefully considered, as overburdening might become an issue.

Recommendation 3: Familiarity
A design proposal should promote familiarity in appearance, interaction and experience to increase usability and trust.

Including familiar aspects in the design of a design proposal increases the trust of people with dementia in these solutions while promoting a better experience and increased usability.

Recommendation 4: Physicality
A design proposal should include physicality to increase the ability to interact directly and allow users to better conceive information.

Physicality is important in the appearance and interaction ability (tangibility), which both increase the likeliness of understanding (and therefore using) a design concept by people with dementia.

7.5.2 How to use the design recommendations

The design recommendations are intended as an addition to existing design principles in design for people living with dementia. The five design qualities we found that were more common topics in the literature (Simplicity, personalisation, flexibility in use, reliability and non-stigmatizing) contribute to design for dementia as well and should also be considered. The nine design recommendations might, however, not provide a complete overview as we extracted them from a specific type of project. In, for example, long-term (>4 weeks) evaluations or more technology-oriented project other recommendations might surface.

Nevertheless, we think these recommendations can be used in the exploration, design and evaluation phases of design and research processes for people with dementia. In the exploration phase they are useful to generate ideas and find new opportunities. In the design phase these recommendations could be used to enhance the experience and interaction of a device or servicce. In addition, these recommendations could be used to reflect on a design proposal to find areas of improvement.

Finally, these recommendations could also be used to assess the quality of design for other challenging user groups. In genetic cognitive disorders such as Down syndrome, or in acquired brain injury caused by for example physical trauma these design recommendations might contribute to acceptance and usability as well. Especially empowerment and considering the social context play an important role to increase the functionality of design in general.

7.5.3 Design for impaired users

Through the dissertation we have seen how the concept of person-centred care and the need to probe our design proposals in the field. Only by experimentally probing our design proposals we can find adequate solutions for impaired users. Some of the cases demonstrate a very direct translation of these concepts, such as the Discover Dementia pillow with which a personal soundscape is used to evoke a response, and seeing people with dementia to experience this allows us to reflect on the design and make decisions accordingly.

Moreover, other cases show the importance of focussing on the impaired user directly. Both the Homing Compass and the Stay-tuned radio, for example, enable a person with dementia to perform certain tasks they could not do before and thus increase their self-reliance. This is person-centred, as these design proposals are designed for being used by people with dementia themselves.

The perspective of person-centred care and in context evaluations allow us to focus more on the experience people have rather than the characteristics of the disease. This contributes to the quality of life as indicated by people living with dementia themselves (O’Rourke et al., 2015). In such design proposals there are two main themes that should be considered. The design and its purpose (Molin, Pettersson, Jonsson, & Keijer, 2007). Our overarching themes also emphasise these two elements. Furthermore, other researchers argue that both the need and usability should be explicitly addressed by a design proposal for it to have potential (Olsson, Engström, Skovdahl, & Lampic, 2012) and should be continuously reflected on during in context evaluations. Our design recommendations support this reflection process, which enables us to improve the quality and increase the impact of design proposals we create for impaired users.

Chapter 8:

Design of a Living Lab protocol

In this chapter we generalize our insights concerning performing in-context studies and relate these back to findings in the literature. We propose a protocol that was designed for in-context Living Lab studies when involving fragile or impaired users and a complex stakeholder network. We do this by reflecting on past Living Lab cases and discuss the limitations and insights that need to be taken into account in future studies.

This chapter is based on:

Brankaert, R., den Ouden, E., & Brombacher, A.C. (2015). Innovate dementia: the development of a living lab protocol to evaluate interventions in context. *Info*, *17*(4), 40–52.

8.1 Setting up a reflective framework

The literature promotes the active involvement of impaired users in design and research (Chapter 2 and 3). Over the course of our Living Lab cases we developed our understanding of how to approach this. In this chapter we look at these cases from a reflective point of view and propose a protocol based on this reflection. In addition to the users, the 'quadruple' helix innovation approach prescribes the involvement of all relevant stakeholders in innovation processes (Arnkil et al., 2010). This has been an important aspect of the Living Lab approach (Chapter 3). Through our Living Lab cases the importance of these stakeholders became more evident as they each contribute their own unique expertise and role to the innovation process. Therefore, we also take an in-depth look at the role of these stakeholders and weave it into our protocol proposal.

Over the course of several Living Lab cases we have seen that users should play an active role in the design process (Almirall et al., 2012). However, this is inherently challenging with impaired users such as people with dementia. All kinds of ethical issues play an important role (Chapter 2). Hence, this reflective exercise provides insight in how to involving vulnerable users. The protocol evolved over the course of three Living Lab cases: The PhysiCAL, Vitaallicht®, and GoLivePhone® case studies, because in these cases we involved users in their real-life context. These evaluations are an essential part of the design process as they show how a design proposal operates in real-life.

In this chapter we therefore aim to address the following question: How can we design and develop a Living Lab protocol, including relevant stakeholders, to evaluate design solutions for impaired users, in context?

8.1.1 Method

In this chapter we aim to answer this question by reflecting on our previous living lab cases. By looking at the different iterations inductively we can learn from our past protocols and formulate a protocol proposal.

To structure the reflective development, we structure the analysis for each Living Lab case as following: First the protocol is explained, then the experience with the protocol is addressed and finally suggestions for improvement are formulated. The content of the study can be found in earlier chapters and will not be covered in this chapter. In addition, to aid in the readability of the protocol we present the protocols in a similar visual layout for each of the three cases (Figure 8.1).

The protocol is a dynamic tool that evolves over time, continuously adapting to new insights and developments based on experience gained with previous applications. Therefore the focus of this research will lie within the implications for the Living Lab protocol.

8.1.2 Initial protocol

The initial protocol is based on the literature in this field (Chapter 4). This protocol (Figure 8.1) starts with the "Prepare" phase, which entails a selection of intervention, evaluation method and participants. Following this, during "Home visit 1" the intervention is introduced and the in-context study begins. After a set number of weeks, the intervention and results are collected during "Home visit 2". In addition, the researcher discusses the experience of participants with the protocol. Finally, in the results phase, the researchers process the results and provide these to the stakeholder network.

In the case of dementia care and business stakeholders are of vital importance in design evaluation as referred to often throughout the dissertation. The care stakeholders had a similar interest as the end-users and supported us with gathering participants. Business stakeholders have an interest in implementation of the design. Finally, we fulfil the research stakeholder role. The role of these stakeholders, at each step in the protocol, is indicated with dark grey boxes. These roles change and intensify over the course of the Living Lab cases.

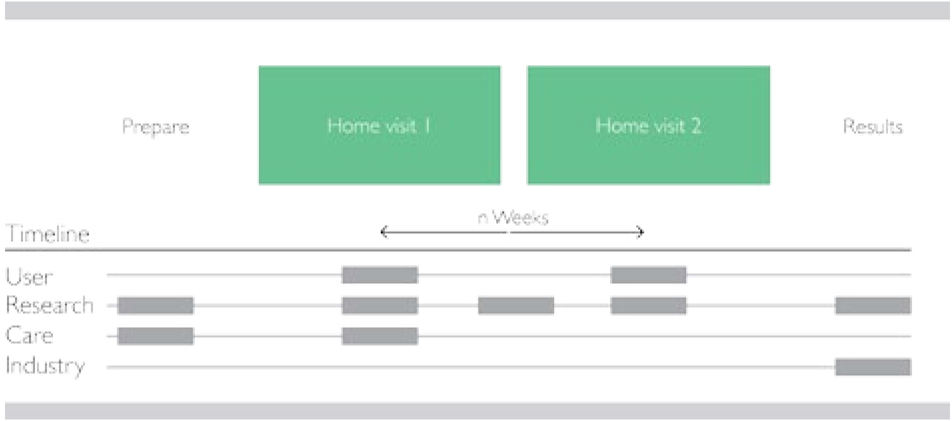

Figure 8-1 The starting point for our first protocol.

8.2 Reflective Development

In this part we reflect on the three in-context Living Lab cases in order to learn from our experiences and development of the protocol. Based on this reflection we propose a final protocol.

8.2.1 Living Lab case 1: Pilot *('PhysiCAL calendar')*

During the pilot case we had too many objectives for the introduction session ('Home session 1', Figure 8.2). The researcher had to introduce the project, introduce the technology and introduce the evaluation method. For future evaluations the research introduction should be done in smaller steps. This would also provide more time for the participants to get acquainted with the study and better consider participation.

At the stakeholder level, we found, firstly, that the care stakeholder did not really benefit from the results, as the set-up was research-focused. Secondly, concerning business stakeholder involvement we had a similar experience, because they were only involved post-hoc in this pilot study.

On the other hand, the reflection session proved to be really successful, as the researcher could discuss detailed insights and the users could ask questions and provide comments freely ('Home session 2', Figure 8.2). The users felt comfortable with this and provided additional insights related to the protocol, the intervention, and the project in general. Finally, the test time was considered too short, as users had only just got used to the technology.

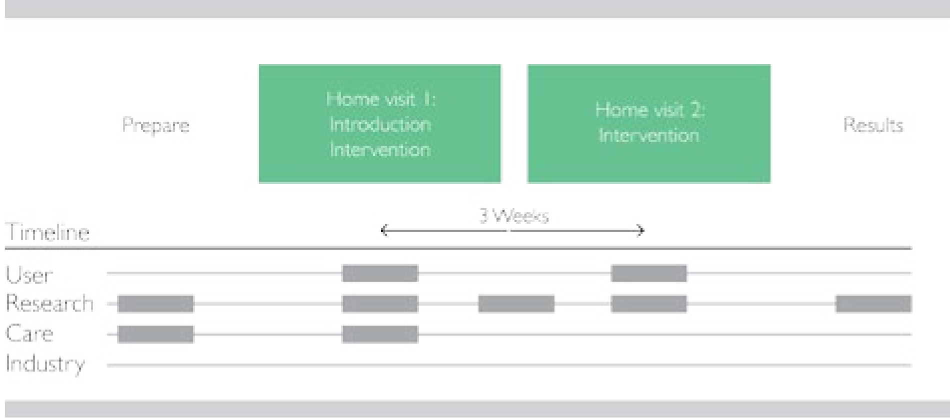

Figure 8-2 The pilot protocol used during the first Living Lab case.

To conclude, we have found several aspects that need to be changed based on this pilot case. Firstly, we should add an introduction meeting so that users can get acquainted with the project and the workload is spread more evenly. Secondly, stakeholders should be more involved. Finally, the evaluation period should be longer, and the reflection sessions should be maintained in the protocol.

8.2.2 Living Lab case 2 ('Daylight lamp')

For this case study, we included an introductory visit so that users could get acquainted with the technology and the workload was more spread. The additional visit would than be conducted by the care stakeholder ("Home visit 1", Figure 8.3). To make this visit efficient, it was combined with a regular visit already scheduled by the care stakeholder. This also prevented burdening the users too much.

Furthermore, we let the same person join the second home visit as well. In this way the couple would already be familiar with one person, making them feel more comfortable. In addition, we expanded the inclusion of the Living Lab stakeholder network. We involved our business stakeholder for this case, from the start of the study. They provided the daylight lamp prototype and supported carrying out the study. In return, they were curious how their lamp operated in the homes of people with dementia. Finally, the test time was extended to three weeks, as one week proved too short in the pilot.

In Figure 8.3 the changes in the protocol are marked with light grey boxes.

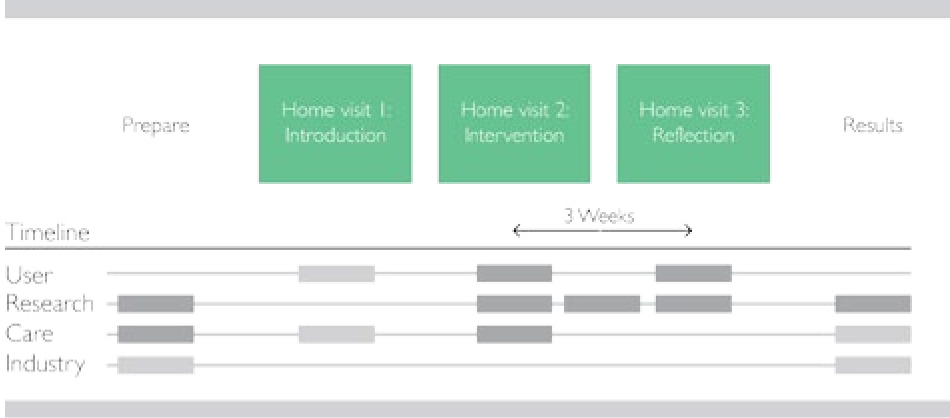

Figure 8-3 Visual of protocol used during the daylight lamp evaluation.

By conducting the study (Chapter 5) we gained new insights into the protocol. First, the additional introductory meeting was appreciated; it gave sufficient time to consider participation. However, communication was still not optimal. Sometimes, the care stakeholders were insufficiently instructed to convey the project. This was revealed when participants were unfamiliar with the intervention, and subsequently didn't want to participate, during Home visit 2 (Figure 8.3).

Secondly, another positive improvement was the extension of the test period: users could experience the innovation more extensively (Chapter 5). However, a side effect was that the users sometimes felt "left alone" during the evaluation at home, as some reflections during home visit 3 revealed.

Finally, the stronger involvement of business stakeholders was partly positive. They liked results which directly affected their product, yet they were slightly disappointed because there was a misunderstanding about the aims and results of the study.

8.2.3 Living Lab case 3 ('GoLivePhone®')

In the adapted protocol for the GoLivePhone® case (Chapter 6), we added two additional contact moments ("Check via phone call", Figure 8.4). With these we aimed to avoid communication issues. The first "Check via phone call" was positioned before the second visit ("Home visit 2"), which prepared the researchers better. The second phone check was added to support the participants during the evaluation of the intervention at home, in order to prevent the feeling of "being left alone" which users experienced.

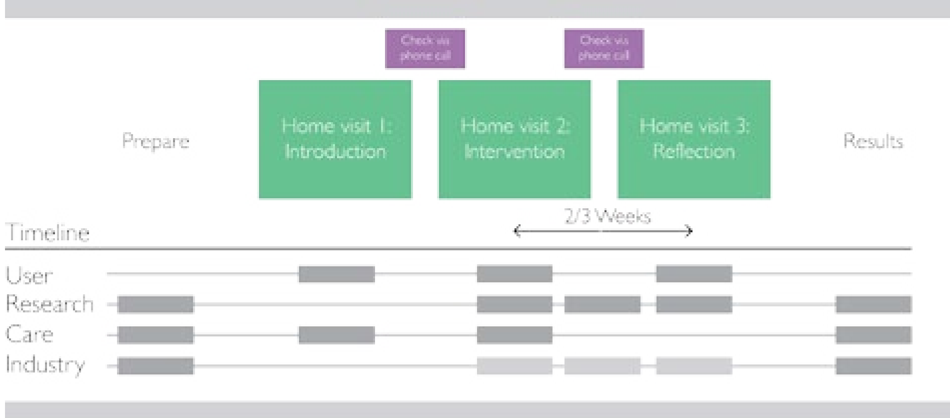

Figure 8-4 Visual of protocol used during the 'GoLivePhone®' evaluation.

Finally, the business stakeholders' role was improved. They had a say in what aspects of the intervention we would evaluate (light grey boxes, Figure 8.4). In this way the business stakeholders would know better what outcome to expect and feel more ownership of the study.

Based on the application of the new protocol during the GoLivePhone® study (Chapter 5) we found that the addition of the phone calls to the protocol proved useful. This contributed to a feeling of involvement among the participants. Furthermore, it improved the efficiency of the protocol; users were better informed and could opt out prior to the study, over the phone.

Also, the more intensive involvement of business stakeholders was appreciated; the results were novel and relevant, for example, this evaluation outcome showed that the alarm feature needed to be improved (Chapter 5).

Nevertheless, two other issues came up. First, some users felt involved during the evaluation and wanted to continue collaboration, even after the study was finished. However, that option was not always available.

Second, feedback from the care stakeholder showed that the selection of interventions should be conducted together as well, as users could be better matched with an intervention. We already noticed this during the Vitaallicht® study (Chapter 5); some users didn't match well with the concept. It would, for example, not make sense to give a daylight lamp to somebody who does not have any sleep issues. This biases the results negatively.

Another aspect that came up during this case was the need for an "exit strategy". In our studies, the users could not keep the products, even if they experienced them as beneficiary. This was made clear to them during the introduction visits and the users agreed, yet they have memory problems and might easily forget about this.

To conclude, many of the issues we experienced during the first two Living Lab cases have been solved in the third iteration. Based on these results we were able to propose a protocol for other Living Labs as well. We even found two opportunities for such a protocol. First, we have found that users would like to be involved more, which could be facilitated by us to build a community. Second, using such a community could lead to a pre-selection of participants with evident needs so that they could be matched with specific interventions.

8.3 Living Lab protocol proposal

The cases described in the previous section illustrate how the Living Lab protocol developed over the course of three Living Lab cases. Table 8.3 provides a summary of the insights gathered over these three iterations.

Based on these insights, we propose a new in-context evaluation protocol (Figure 8.5) to be used in design-driven Living Labs for impaired users. This protocol is based on three home visits, each with a specific goal: introduction (Home Visit 1), intervention (Home Visit 2) and reflection (Home Visit 3). Thereby, we propose additional steps for a safe involvement of users, and the engagement of users through a community structure. These are covered in Figure 8.5.

In addition to the protocol phases we suggest a strong involvement of all relevant stakeholders throughout the process (User, Care, Industry and Research). In this way the different stakeholders feel involved and responsible in each of these stages.

For designers this protocol enables a holistic, safe and efficient way to engage with people with dementia and their context. By this they can evaluate their design proposals in a real-life context and gain insights for adjustment or redesign through this. Therefore such an evaluation should be seen as part of an iterative process, which will most likely be preceded or will be succeeded by additional iterations.

Table 8.1 Development of the protocol through three iterations.

Iterations:	*Iteration 1*	*Iteration 2*	*Iteration 3*
Cases:	**PhysiCAL**	**Vitaallicht®**	**GoLivePhone®**
Key insights:	- More intense role for care stakeholder. - Studies should be longer. -Need for business stakeholder. -Reflection session was appreciated by the users	-Should be a more influential role for business stakeholder. -More streamlined communication. -Additional home visit was appreciated.	-Stronger involvement of business stakeholder was appreciated. -Need for community opportunities. -Added communication by phone was appreciated.

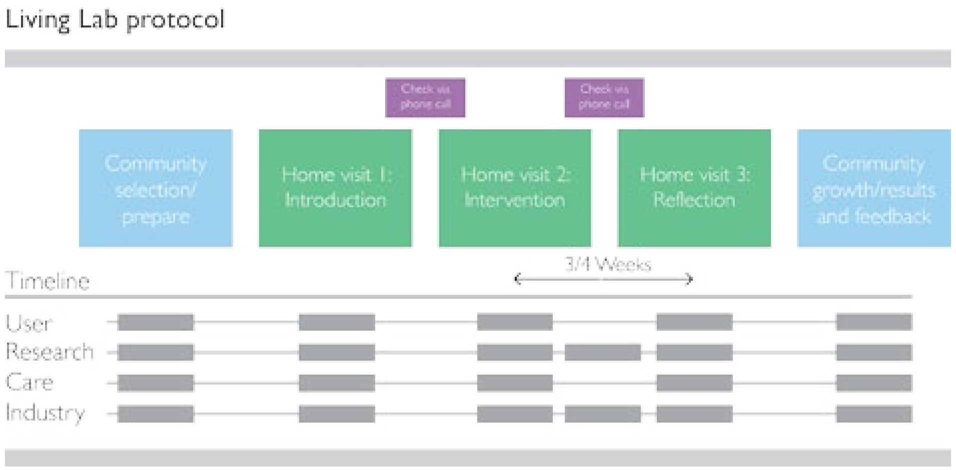

Figure 8-5 Protocol proposal for future involvement of impaired users.

8.3.1 Community selection/preparation

In this phase the study is set-up and prepared. We recommend that all relevant stakeholders are already included from this phase onward. In this way they might feel more ownership in selecting an intervention, the evaluation method and the context. Finally, when a community is built, it could support a selection of users who match a certain intervention. In this way, needs are better matched with interventions, and the results for stakeholders might improve.

8.3.2 Home visit 1: introduction

During this phase the users are visited with the main purpose of introducing the project and the rationale behind it. Depending on the abilities of the users, the intervention could also already be explained. Key in this phase is to allow users to get acquainted with the project and the process step by step.

8.3.3 Home visit 2: intervention

During this visit the intervention is brought and (re-) introduced; the users should already be familiar with the project. We advise that at least one familiar person (from Home visit 1) joins this visit. In this step the research method is explained as well, and from this moment the users can use the product or system for a limited period of time as they wish. Thereby, it has to be made clear that users cannot keep the intervention after the test period if this is not possible in the specific case.

8.3.4 Home visit 3: reflection

During the final home visit the researchers (and potentially the care or business stakeholder) collect the prototype used for the intervention and the data from the research method (again we recommend that one familiar person is present). They also reserve sufficient time (~ 1 hour) to reflect with the users on their experiences and address queries related to the research method and the project in general. The agenda for this meeting has to be set together with the relevant care and business stakeholders, so that these partners gain reflective insights that are of particular interest to them.

8.3.5 In-between checks

To streamline communication, we added additional checks in between the home visits. One of these checks is set before the second home visit to improve protocol efficiency and communication. The second check, which should be scheduled during the intervention study, is designed to address issues that might have come up so far. However, we can also anticipate other purposes, or a higher quantity, for the checks depending on the specific user (and their impairment), the complexity of the research method, and the length of the study.

8.3.6 Community growth/results and feedback

We added community building to the proposed protocol. This is new; however, it has been experienced as positive so far in our project after the GoLivePhone® study. The users feel engaged with the project because their efforts go beyond a single research project. They are asked during "Home visit 3" if they want to join the community and, if they do, are added to the community list. In our case, the members of the community get updates concerning developments and publications via a newsletter. In addition, they are invites for focus groups that are organized twice a month. The first indications suggest that users feel involved and connected, and they even recruit new users from their own communities (via sport clubs, hobby associations, etc.). Finally, the results of the Living Lab cases are processed in this phase and provided to the relevant stakeholders. We discuss with these stakeholders how to continue the collaboration.

8.3.7 Roles of Stakeholders

In the protocol proposal (Figure 8.5) each of the four stakeholder types should be included in each of the protocol steps as indicated by the grey blocks.

Initially end-users only participated in the field studies as participants or co-creators. However over the course of the Living Lab cases we found value in involving them earlier to also support in the study setup, and later to reflect with us on the results. Over time this active involvement of participants grew into a community. This allows for users to be involved beyond a single Living Lab case. Additionally, the Living Lab benefits as a community ensures participants are more easily available.

For the care stakeholders their role initially was solely to prepare and select participants during the evaluation. This grew over the course of the Living Lab cases to a more engaging role in which they as care stakeholders take interest in the reflection (Home Visit 3) and results to improve their own services and research. In addition, they benefit most from the community structure and therefore take responsibility to maintain this through meetings and newsletters.

For the business or industry stakeholders the implementation and evaluative results of the design are most important. This still fulfils their primary purpose. However, by involving them early in the process, during the preparation and introduction of the intervention, they gain ownership of the evaluation and have influence on the study design. As such the results are more valuable for them and their expectations match better.

For the role as researcher, in our case as design researcher, the study allows for a direct engagement of users with a design proposal in context. By this the design researcher gains insight into the usability and successfulness of a design proposal and the factors that influence this. Naturally the design researcher takes the leading role in such design-driven Living Lab studies and enables the involvement of the other stakeholders to benefit the design and from the design.

In the end, there are contradicting interests between these different stakeholders. For example, between business stakeholders and care stakeholders concerning the importance of value versus revenue. Or between researchers and business stakeholders related to objective research and a positive outcome of the research. We recommend that in such stakeholder collaborations it is the role of the (design) researcher to balance these interests. And to ensure a balanced gain in value for all of the stakeholders to make the collaboration beneficial for everyone.

8.4 Discussion

The protocol proposal is based on the insights gathered by conducting our Living Lab cases and reflecting on them accordingly. In the literature there is a lack of such in-context studies, and related protocols, especially when concerning people living with dementia. Issues found concerning such studies are willingness to participate (Astell et al., 2010), safety and security (Meiland et al., 2007) and adequately addressing needs (Topo, 2009). Our protocol proposal provides several suggestions for overcoming these.

By allowing impaired users to experience an intervention in context we are able to reflect on our design, spot opportunities and make design decisions. As a result we can better address the needs of people with dementia. The protocol we propose prescribes to involve stakeholders and participants as early as possible in the process, which contributes to solving these issues. Also, concerning the involvement of care stakeholders, we have seen these contribute to user selection and introducing the project to the participants.

The participants are, in the end, the most important stakeholders in such in-context studies. And in this regard, insights were gathered on how to involve cognitively impaired users carefully and safely. For this specific elements need to be considered: First, the users' needs should be adhered to at all times. Second, more home visits (and contact moments) are needed to reduce the burden and allow for a gradual introduction of project, intervention, research method and (other) stakeholders.

With this protocol we can also encourage other (design) researchers to perform in-context studies with impaired users more early in the design process. Which allows an observation of design proposals as experienced by people directly. This path is often not chosen when involving impaired users in research (Topo, 2009), whereas there are clear advantages concerning quality of such an approach (Bharucha et al. 2009). Therefore, this protocol improves the quality of a design-driven Living Lab approach and thereby the quality of the design studies performed as part of it.

Chapter 9:

Discussion & Reflection

In this chapter the general conclusions are formulated and positioned in the literature. Furthermore, the findings concerning the involvement of impaired users and the stakeholder network in our design-driven Living Lab approach are discussed. In addition, conclusions are formulated concerning our overall findings related to design recommendations and the Living Lab protocol proposal. Finally, future research areas are proposed based on this work and I reflect on personal insights gained throughout this work.

9.1 Conclusions

In this part we provide an overview of the insights gathered during the Living Lab cases. In the following paragraphs we will cover a more in depth discussion concerning these conclusions.

9.1.1 Approach

At the start of this project we set out to contribute to the understanding of how to design for people living with dementia. The design cases covered in this dissertation target people living with dementia (Chapter 2) to aid in the societal challenges of dementia. To achieve this we developed a Living Lab structure, based on conducting real-life studies and involving the stakeholder network (Chapter 3). As part of this Living Lab we elaborated on our design process and approach with the phases Exploration, Design, Evaluation and Implementation (Chapter 4). In each of these phases different methods can be applied. The focal point of this dissertation is the real-life evaluations and the involvement of impaired users as part of it to be able to design for them. When people have a condition like dementia, they are too distant from ourselves to apply empathy methods. Performing real-life studies is challenging with such impaired users, and not practiced sufficiently in design and innovation research (Bharucha et al., 2009; Hattink et al., 2014; Topo, 2009). In this the role for design as part of such a Living Lab setup allows us to accelerate innovation and involve relevant stakeholders. In this setup we conducted a pilot study (Chapter 4) and three subsequent Living Lab cases (Chapters 5 – 7), each with a slightly different focus. Through these cases we developed insights concerning involving impaired users in their own context, our design approach and the inclusion of a complex stakeholder network. The application of a Living Lab to design for impaired users is an unexplored area and therefore this research was set up to be holistic and explorative to cover the various aspects.

9.1.2 Living Lab Cases and results

From each of the cases covered in this dissertation we gained different insights. In the pilot study, conducted with the PhysiCAL calendar, we explored the different facets of an in-context Living Lab evaluation. Based on these results we set the goals for subsequent cases. Firstly, we found that it is insufficient to gather the first-person perspective of people with dementia through general methods like a questionnaire. Secondly, it was challenging to link a design proposal post-study to a business stakeholder; these stakeholders need to be included earlier and more prominently. Finally, we found insights related to design for people with dementia as we found encouraging and discouraging aspects.

After the pilot study we conducted the 'Vitaallicht®' case study and for this developed the personal evaluation game method. Results showed that this method was a much better way to capture the first-person perspective of participants. The evaluation game method provided rich data thanks to the various types of input it offered. We also gathered additional insights into how people with dementia live and what they thought about the assistive technology. Moreover, we found that the method and study must be dynamic and adaptable to the level of users, and that business stakeholders need to be more closely involved in the entire process.

In the subsequent case, the GoLivePhone® evaluation, the benefits of involving business stakeholders early in the process became evident. We collaborated more intensively and this resulted in the study being more useful for them. During this study we also experimented with several data gathering methods. We collected GPS locations, activities, questionnaires and reflective data. In particular the data from the reflection sessions, post-evaluation, proved valuable and it is recommended for future studies. In this session we could freely discuss both the design and the study together with the participants.

Thereafter, based on the Living Lab cases, and some additional design cases, we were able to extract design recommendations for future designers and researchers. In particular, these additional cases, by students and ourselves, show the strength of enabling person-centred care through design, and the need for in-situ involvement of participants as part of the design process. There are few principles available in literature of design for dementia (Mäki & Topo, 2009; Orpwood et al., 2004), and we contribute to these by advancing four design recommendations: Empowerment, Physicality, Familiarity and Social context.

Finally, we found that the Living Lab approach, build on experimental probing and in-situ evaluation, allows us to design for impaired users where empathy methods do not suffice. These user groups are too distant from our own perspective and by this we cross the boundaries of empathic design. We propose to rethink our inquiry tools, and work with methods, such as for example the personal evaluation game, that allow researchers and designers to construct an experience based on gathered data. In addition, working in the field as part of the design process, as early as possible is essential to this as well. This is for example shown in the Homing Compass case. By observation we can retrieve the experience of impaired users with our design proposals. Therefore we need to embed real-life experimentation in our Design and Living Lab approaches as much as possible.

9.2 Living Lab protocol and design recommendations

The Living Lab cases generated insights related to the development of our Living Lab and the protocol for in context evaluation. In this protocol proposal the inclusion of impaired users as well as external stakeholders are most important. In addition, we formulated design recommendations based on an analysis of our design cases to be considered in design for dementia.

9.2.1 Living Lab protocol

The Living Lab protocol proposal (Figure 9.1) is created for the inclusion user, care, research, and business stakeholders in an in-context evaluation to further develop design proposals.

The protocol contains five steps. The first step includes the preparation of the in-context evaluation by selecting participants, an intervention, and a method suitable for the participants. If a community has already been established, this step can be accelerated, because the participants are reached more easily. In addition, a community allows for a pool of participants that can more easily be matched with specific interventions.

After the first step, three steps follow in the form of home visits. During the first step the research and project are introduced (Home visit 1), at the second step the intervention is initiated (Home visit 2) and finally, during the third step, there is a reflection session with the users on the design and the research (Home visit 3). It is important that users have time to accommodate to the research before starting in the intervention. It is also important to adapt the overall method for evaluation and choice of intervention to the level of the participants.

After these steps there is the rather broad fifth step. In this the results from the study are analysed, processed and shared with both the care and business stakeholders. Finally, the participants are invited to become part of the community to engage in future activities.

An essential part of the protocol is to include additional communication with the (impaired) participants to ensure safety and security, depending on the length and complexity of the study. Furthermore, the community accommodates not only for the in-context evaluations; it also allows for other Living Lab activities such as focus groups or design sessions.

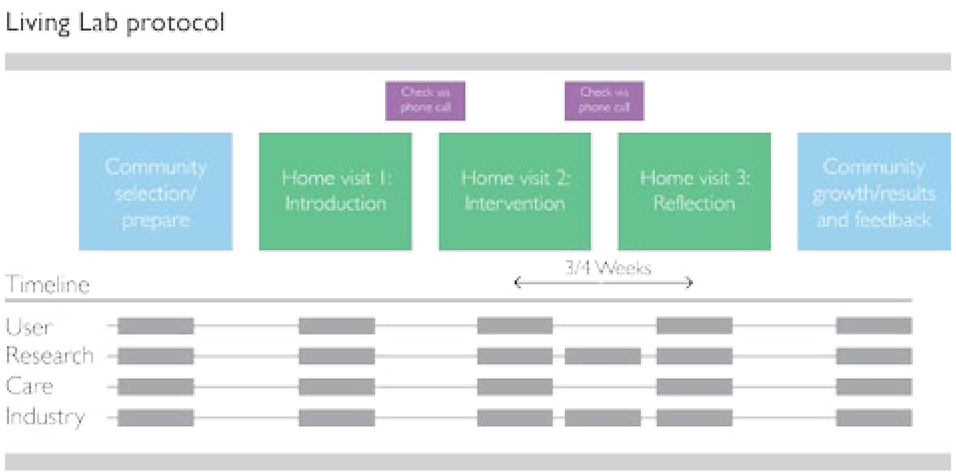

Figure 9-1 Proposal for future involvement of impaired users in Living Labs.

In summary the Living Lab protocol proposal contains five sequential steps as part to accommodate for in context evaluations, these are:

1. Community selection/prepare
The study is prepared and participants are selected from the user community.

2. Home visit 1: introduction
The project is introduced as well as the study setup and the intervention.

3. Home visit 2: intervention
Start of in-context intervention study (the research method is introduced).

4. Home visit 3: reflection
Reflect with users on their experience with the study and intervention.

6. Community growth/results and feedback
The community grows and results are returned to the relevant stakeholders.

In each of the five steps all four of the stakeholder types (User, Research, Care and Industry) play a different, yet important role in the process. It is the responsibility of the design researcher to balance the interests of these stakeholders. In this each of the stakeholders should feel responsible to carry out the design and research work.

9.2.2 Design recommendations

The design proposals from our Living Lab cases and some additional cases were analyses to gain insights into their design qualities. Based on a total of seven cases we found nine design recommendations in design for dementia. From these four are an advancement of the literature. These four design recommendations are:

- **Design recommendation 1:**
  A design proposal should empower people with dementia and increase their self-reliance.
- **Design recommendation 2:**
  A design proposal should consider and balance the role of the social context, which can include caregivers, family members, neighbours and friends.
- **Design recommendation 3:**
  A design proposal should promote familiarity in appearance, interaction and experience to increase usability and adoption by users.
- **Design recommendation 4:**
  A design proposal should include physicality to increase the ability to interact directly and allow users to better conceive information.

Thereby, the other five design considerations should also be taken into account. However, they could already be found in the literature and were revalidated through our studies. These were: *Reliability, flexibility in use, simplicity, personalisation and non-stigmatizing.*

These design recommendations are not intended to become requirements in design for people living with dementia. They rather contribute to existing frameworks. The recommendations can be used in several phases of design or research processes to achieve higher quality in the resulting design proposal.

In each of the different design process phases the recommendations could be of value. In the exploration phase they are useful for inspiring idea generation and finding new opportunities. In the design phase these recommendations might be used to enhance the experience or interaction with an intervention. In addition, these recommendations could be used to reflect on a design proposal to find areas for development or improvement in the evaluation phase.

9.3 Discussion

In continuation of our general conclusions we discuss our detailed results in this part. The insights are grouped in three themes, referring back to our research questions. These themes are: (1) involving impaired users in a design-driven Living Lab, (2) design for impaired users, and (3) design in a complex stakeholder network.

9.3.1 Involving impaired users in context

In the pilot study we found that we need a different research approach when involving people living with dementia in their context. Results from the personal evaluation game method, as part of the 'Vitaallicht®' case, showed us that this method is able to capture the experience in the moment and suitable for people living with dementia, but not for everybody. *People with dementia* are a diverse group on several levels (age, interests, ways of dealing with the disease, etc.). Too often people with impairments are clustered based on their impairment rather than on their ability (Nygård, 2006). This is why it is important that the personhood of impaired users is maintained. In dementia care this is addressed by the concept of person-centred care, arguing for addressing the person behind the disease to achieve higher quality and efficiency in care (Ross et al., 2014). Based on our Living Lab cases, and especially our design recommendations, we see a need for this perspective to also be adopted in research and design to create person-centred inquiry methods and design proposals. In the literature a design-led inquiry approach (Wallace et al., 2013) has potential for exploring personal design solutions; however, this can be applied more widely. This perspective also needs to be taken into account in the more advanced stages of design such as for example our in-context evaluations.

We found that we must conduct mid to long-term evaluations in context; only then do the actual usability and adoption of a design proposal become clear. This was clear from the GoLivePhone® case. Some people with dementia could use the device during the introduction meeting, yet not during the following evaluation period. On the contrary, some users could not use the smartphone during the introduction meeting, but did well during the home evaluation that followed. This shows that we cannot generalize the results of the potential of a design proposal based on a single measurement. This also shows that we cannot generalize research that is based on such a short-term intervention.

Putting our design solutions in a real-life context for a longer period also aids to overcome the newness effect (Peeters & Megens, 2014) and allows us to gather insights into how users would integrate a piece of technology in their daily life (Robinson et al., 2009). In the Homing Compass case, for example, we only conducted an in-context study lasting a couple of hours with a number of set tasks. This is why we could only formulate conclusions on the interaction and form, and not concerning acceptance or integration in daily life. Therefore, we must be very careful not to generalize from these results.

Conducting evaluations at the participants' homes has additional advantages. For users this is a familiar environment where they feel safe and more comfortable (Wherton et al., 2012). Moreover, by conducting research in the home context we can increase the ecological validity of the outcomes (Koskinen et al. 2010) in which the person-environment fit is integrated and examined (Gitlin, 2003). These are especially important because we involve impaired users. They might be more anxious and self-conscious because they or their spouse are challenged by the research. Therefore it is also important to establish a trustful participant-researcher relationship as we have found in the Vitaallicht® case.

Involving impaired users in research raises the requirements for the methods we apply. It should be possible to adapt the methods to the participants' level. The personal evaluation game method shows this. In this method different kinds of input can be provided and the participants decide the amount of contribution. As such the burden is kept low and allows for surprising input. This puts participants in control of what they contribute, which is recommended when conducting research in the home context (Coughlan et al., 2013). Therefore this is integrated into the protocol proposal. As long as users have the role of active contributors they will provide interesting output and in turn support decision-making in the design process (Sanders & Stappers, 2008).

It is, however, challenging to capture the entire experience with such an open approach. This is why the role of the caregiver is crucial; input from the person with dementia can be both discouraged and encouraged by this external influence. And therefore additional attention should also be paid to the researcher–caregiver relationship (Chapter 5).

To further ensure the safety of participants we involved a mental healthcare institute in selecting participants for our cases. They, together with the informal caregivers, performed the role of gatekeepers during the evaluation. The gatekeeper protects the participants from a high research burden and continuously evaluates whether the person with dementia is still able to participate. This worked out very well. And only having few participants drop in our studies reflects this. This is why we recommend such a gatekeeper role for future Living Lab studies, especially when impaired users are involved.

9.3.2 Limitation of in context studies

Overall, we need to be careful when generalizing from these results. First, because participants are asked to participate we might involve only a certain type of user. It is known that older adults who want to participate in research tend to be more trusting (Ybarra & Park, 2002). Such users assume that the combination of research and a researcher makes them feel they are in good hands, which might reduce their vigilance (Diane Feeney Mahoney, 2003). However, when conducting explorative studies such as our Living Lab cases this could be beneficial; they are not afraid to voice their opinion and freely contribute to the research.

Second, we decided to only involve people with early to mid dementia who have a caregiver living with them at home. Only by this we could guarantee a safe involvement in our studies. This, however, resulted in a convenient sample of the populations as opposed to a random sample (Marshall, 1996). This only represents a sub-group of the dementia population. For example, people living alone at their homes with dementia, or people living in a care home (later stages) are not fully represented in our studies. The influence of this bias on the results should be investigated further.

Third, we chose to only include a small number of participants in our studies. This is considered a limitation for all the studies included in this dissertation. However, for the purpose of our studies, to explore and learn for design, these numbers where sufficient. Nevertheless, we can therefore not formulate conclusions about the long-term effectiveness of our interventions. This is an opportunity for future Living Lab studies.

9.3.3 Design with and for impaired users

In empathic design designers aim to draw information from users and their everyday lives to inspire the design process (Leonard & Rayport, 1997). Empathic design is driven by four principles: 1) balancing emotional and rational aspects in user experience, 2) involving users as partners, 3) engagement of designers in multi-disciplinary research, and 4) using empathic abilities to see the first-person perspective of users (Postma et al., 2012). These principles are not possible when designing for impaired users such as people with dementia. When users are too distant from our own view on the world, as with older adults (Keates & Clarkson, 2003), it is no longer possible to make reliable interpretations of what these people think and feel (Lindsay et al., 2012). Therefore we prescribe such impaired users need to be involved and recorded in real-life studies to inform and confirm our design decisions.

One approach is to use suitable inquiry methods, such as for example the personal evaluation game method, to gather the first-person perspective in context. The resulting data from such a method can inform the design process as users directly voice their perspective. It is important that these methods are conducted in context and over a longer period of time to overcome the bias of short-term inquiry (Koskinen et al., 2011).

More importantly is experimentation and design in the field, one of the main contributions of this dissertation. By conducting such in-context activities we were able to confirm our assumptions in the cases when empathic design is no longer a suitable method. This can be done on several levels in the design process. For early phase prototypes, such as with the Homing Compass (Chapter 7) we see that real-life experimentation informs the design of interaction and form. For more mature technology, as for example in the GoLivePhone® case, such studies provide insights for redesign (Chapter 6). This is why we need to embed this perspective in Living Lab approaches, and encourage inquiry methods and experimentation in context even more. Especially when we design for impaired user groups.

Thereby we can define the boundaries of empathic design over the course of our Living Lab cases. When it comes to aging, empathy on a physical level might be possible by for example an empathy suit such as the MIT Age Lab's old-age suit AGNES (MIT, 2014). In this example designers physically impair themselves in order to better understand the physical challenges associated with ageing. This is however the limit of what we can achieve through empathy in context of design for elderly. Dementia naturally adds another level of complexity. Therefore, these target groups don't allow for a first-person perspective view by empathy, we cannot mimic the complexity of such a condition.

Therefore, for impaired users such empathic approaches are not possible. There are approaches, such as for example, the Into D'mentia dementia simulator (Hattink et al., 2015), in which researchers attempted to replicate the experience of having dementia. However, these don't succeed in achieving their goal as they interpret a scenario (Hattink et al., 2015). In future design research with cognitively impaired users we therefore have to be careful with empathic design methods and position our design proposals in a real-life context as early as possible in the design process. We propose this in design for users who we cannot relate directly to, and for whom we need to construct their perspective by field experimentation and carefully considered methods of data collection.

9.3.4 Stakeholder network in a Living Lab

In addition to involving impaired users, the stakeholder network is another key element of a Living Lab. For this we involved the four types of stakeholders defined by the quadruple helix approach (Arnkil et al. 2010), which are public (care), business, research and citizen or user stakeholders.

The care stakeholders played two main roles as part of our Living Lab cases. First, they focused on engaging the users and inquiring about needs. As such they played an important role in the exploration phase. Second, they supported our real-life evaluations by gathering participants and continuously monitoring the ability of people with dementia to participate from a professional perspective. In general care stakeholders want the same as the users from the designs we create, this already became apparent in the pilot study. They benefit from an improvement of the quality of life and efficiency of care for the people with dementia, which could indirectly support their work, providing care.

Concerning the business stakeholders we gathered insight in terms of collaboration in the design-driven Living Lab. In the pilot study we found that involving business stakeholders post-hoc is insufficient (Chapter 4). This is why we involved the business stakeholder earlier in the subsequent 'Vitaallicht®' case. In this study there were, however, still some issues concerning collaboration. They felt they were not part of the decision-making process in terms of the research method and evaluation goals. This resulted in incongruence between expectation and results. Nevertheless, the business stakeholder did gain insights and used this to influence the design of their product.

In the following case, the evaluation of the GoLivePhone®, we involved the business stakeholder even more intensively by involving them in the decision process in anticipation of the home evaluation. We found that this influenced the collaboration in a positive way. In this way the business stakeholder got more ownership of the evaluation and the results. This is why the expectations matched stronger with the overall outcomes. This feeling of ownership contributes to the stakeholder's engagement and willingness to put effort into the Living Lab collaboration (Budweg, Schaffers, Ruland, Kristensen, & Prinz, 2011).

However, focusing too much on supporting business stakeholders as opposed to innovation based on fundamental needs might stifle innovation and only lead to incremental improvements. To address such needs which are not, or could not be, addressed by current technology or service offerings we need to design from an original and creative perspective. However, in these cases it is more challenging to find business stakeholders who are willing to collaborate from the start of the process, as the design might not fit into their core business or is not mature enough to do so. This showed, for example, after the Homing Compass evaluation (Chapter 7). We contacted several companies that had worked on GPS way finding solutions. Yet, they had no interest in solutions for people with dementia for diverse reasons. Nevertheless, it is essential to also pursue cases with a more disruptive perspective to be truly innovative in a certain market (Verganti, 2008). This is why we propose that both of these approaches, industry-driven and need-driven should be pursued simultaneously to provide a balanced innovation output as a Living Lab. As such both in the long-term and the short-term needs can be addressed. These approaches should, however, both be design-driven, to develop incremental and disruptive innovations that coherently address societal challenges.

9.4 Future outlook

In this section we discuss some of the findings in our studies and, based on this, propose future research. We thereby aim to support designers and researchers working in similar areas.

For our Living Lab cases we argue for a mid to long-term involvement of participants to overcome newness and get insight into the adoption of a concept. For this reason we recommended an evaluation period of 3 to 4 weeks. This is sufficient because our goal is explorative and focused on design. However, to validate a certain intervention or assistive technology a different study setup is necessary. The study could be more long term and, for example, be setup as a randomised controlled trial with a random sample (e.g. Leroi et al., 2013). Naturally, this was outside the scope of this dissertation that aimed for exploration and design. Nevertheless, it would be very interesting to pursue such a route with the design proposals we developed. This would open up opportunities to generalize our results and formulate conclusions related to subjective wellbeing, cognitive decline and overall effectiveness. This would also change our pragmatic approach concerning the involvement of people with dementia. With long-term interventions user involvement should be reassessed. Nevertheless, we already mentioned this as a logical next step in the validation phase (Chapter 4) as such results might improve both implementation and market success.

Related to the design-driven Living Lab provided earlier in the dissertation (Chapter 3) further research would also be required as well. Living Lab literature is growing at a rapid pace and all sides of the spectrum we proposed are being investigated. In our proposal we positioned our Living Lab between active involvement of the stakeholder network and the research itself taking place in a real-life context. Moreover, our Living Lab cases and protocol proposal portray how to practically achieve this. However, to expand the literature of Living Lab research we would suggest a comparison of more Living Lab initiatives, on a European level to derive generalizable insights in the phenomenon. We think that eventually there would be a need for a strong and sharp definition of what kinds of Living Labs there are, with clear design guidelines on how to implement each of them. Sometimes the Literature concerning Living Labs was insufficiently described, especially concerning Living Labs with a design perspective. This could be a role for the network organisation European Network Of Living Labs (ENoLL). However, they have a conflicting goal. They benefit from more Living Labs as opposed to a high-quality selection of Living Labs. Whereas the strength of the network benefits from a more defined selection of which initiatives are actually Living Labs. We recommend them, and other Living Lab researchers, to critically assess the definition of a Living Lab, and take a position in the network.

Over the course of the project we found that person-centred care (focus on personhood) as a care concept can be supported strongly by design and technology (Chapter 7). The design cases, Discover Dementia experience pillow and the personal activity (both student cases) show strikingly how personalisation supports wellbeing. Furthermore, concepts such as the Homing Compass and the Stay-tuned radio also benefit from the inclusion of a person-centred perspective as both the familiar appearance and the direct interaction increase self-reliance and overall usability. Concerning person-centred care opportunities for design we have only revealed the tip of the iceberg. There are many more possibilities, for example, in the context of maintaining one's identity or creating very personal solutions. Therefore we recommend this perspective to be included more in design.

This approach might be extended to other impairments as well. In for example Mild Cognitive Impairment (MCI) – often a precursor of dementia (Gauthier et al., 2006) – our approach might also inspire technology design. Another advantage of design for MCI is that we can rely on more advanced technology and a smartphone might be, for example, much more suitable. Furthermore, also in such other cases where cognition is impaired our design recommendations might support usability and adoption as well. These could be in for example genetic disorders such as Down syndrome, which is characterized by cognitive disability, or in acquired brain injury. These extrapolations need to be investigated further and recommendations might differ for each of these conditions. Nevertheless, the provided perspective might reveal new opportunities.

Not only person-centred care or the design recommendations could be used in these cases. Also the Living Lab setup and protocol proposal illustrated in this dissertation could also be applied to develop design proposals for different kind of target groups.

Finally, we have seen that it is difficult to take the first-person perspective, as part of empathic design approaches (Postma et al., 2012), of users groups that are so different from us. This is why we recommend the application of in-situ methods and early interventions with prototypes being more widely applied in the design process. The boundaries of such methods should be investigated further.

9.5 Reflection

Looking back at the project, we have addressed the research questions and achieved our main goals. We managed to set up a design-driven Living Lab and use this approach to develop innovative solutions for people living with dementia. In this chapter I reflect on the collaboration and design process.

Overall, I think we have conducted two different types of Living Lab cases in this dissertation. First, one type focused on collaborating with business stakeholders to redesign and develop proposals. These were the Vitaallicht® and GoLivePhone® cases. These were interesting for me as a designer. The prototypes were more reliable and the business stakeholder collaboration provided a new perspective that enriched the research.

Second, we conducted a type of cases in which we designed more disruptive proposals based on needs we found: these were for example the PhysiCAL and Homing Compass cases. In these cases I felt more freedom to create a solution that matches the needs of people with dementia adequately. However, it was much more challenging, initially to my surprise, for these cases to find suitable stakeholders to collaborate with.

As concluded in the previous part, I think that both approaches are needed to move forward and to contribute effectively to societal challenges. And it is interesting to speculate which of these two approaches would achieve more impact. Collaborating with industry stakeholder is faster and they have the ability to put something on the market through their existing channels. However, concepts based on eminent needs might contribute more to users' wellbeing in the long term and eventually support resolving societal challenges stronger. In the dissertation we therefore propose a hybrid approach, however there might be a delicate balance between disruptive and incremental innovation that could be investigated further.

When reflecting on the work itself the joint effort should be specified. This dissertation is the result of collaborating with many different people and organisations, hence the use of *we*. The composition of we differed for each of the Living Lab cases and research activities. Sometimes these were the care or business stakeholders, and sometimes students or co-workers. From my perspective this collaboration brought the work to a higher level. It would have taken much more time to for example find participants or develop prototypes for all the cases. Thereby, the multi-disciplinary nature of the collaboration brought new perspectives on the work, which enhanced the quality as well. For future researcher I therefore recommend to seek for collaboration as much as possible. We live in a connected world, and this should be taken to full advantage.

Additionally, what really liked about the project is that we were able to take the Innovate Dementia Living Lab beyond the project deliverables. Currently the user community is still maintained by the GGzE and the strong collaboration between the stakeholders continues. With this we are working towards a sustainable Living Lab structure, something that is often a criticism of Living Labs as commented on in Chapter 3.

Overall, in the project we developed and improved a number of innovations, our activities contributed to increasing awareness of dementia, and, especially in the regions, we have become a known entity. There are still request for collaboration coming in, months after the closure of the project. This is particularly interesting, as the Living Lab approach might in this way become a vehicle for creating revenue and become a service for different kinds of stakeholders. In the end it might not have been a sustainable starting point to rely on public funding, but it certainly allowed us to achieve goals that could not have been achieved easily in another way.

Next to the positive results of the studies conducted as part of this dissertation, there were some discrepancies as well. In the end these were all resolved during the project, but they provide interesting reflection topics. That we still collaborate shows the vigilance of the stakeholder network. There are two striking examples from Living Lab cases that I want to elaborate.

First, in collaboration with business stakeholders, we gathered many additional insights from the project. The collaboration with business stakeholders was experimental and especially in the Vitaallicht® case, there was a misalignment between expectations and results. For me as a research this was surprising. Over several reflections with the company we discussed this. We settled it and we still continue to collaborate now. I learned that different disciplines do not talk the same language, and even when things seem obvious within your own discipline they might not be so for others. Thereby, if this is resolved, the additional perspective is extremely valuable. This is why I still strongly promote collaborating, as opposed to performing design research in a vacuum (and yes, only involving users is still a vacuum). I do recommend that researchers and designers approach such collaborations deliberately but carefully.

Second, collaboration with the care stakeholders was strong throughout the project. Right from the start of the project we worked together and without them we would never have been able to conduct so many in-context evaluations. However, from their perspective, as well as the user perspective, the development process of technology is not transparent, and the road from product to the market is not clear. The expectations are very high, and when they feel a prototype works well, they do not understand why it is not on the shelves a year later. As designers (and researchers) we should make this very clear to them by communicating roadmaps and ambitions of the research and design more clearly.

In the end there will always be contradicting interests between stakeholders, as we concluded in Chapter 8. It is important that these interests become explicit so a middle ground can be found. The research perspective can forge this common ground by adapting the process to accommodate for most needs. In this the pros and cons need to be weighed.

We applied an iterative approach regarding the design process as explained in detail in Chapter 4. The Living Lab cases presented in this dissertation often only cover one or two iterations in the early phases of its design process. Therefore these cases have to be viewed in context of this greater picture for its generalization and eventual design outcome. In addition, to complete these cases the implementation phase should become a part of the design process as well. However, in the light of this dissertation this phase was outside the scope, we focused on exploration of the Living Lab method and design work.

By reflectively looking at the design-driven Living Lab, as illustrated in Chapter 3 (page 66), the central position in the Living Lab could be seen differently. The work is described from a design perspective, and perhaps the design perspective should be considered central instead of the Living Lab users. Nevertheless, the user is central in the Interactive Experience Flow, the methods applied as part of the design process and the design work in general. Also in the concept of person-centred care the users perspective is constantly taken first. Therefore the design researcher or the design research perspective could also be considered an invisible layer in the Living Lab. This layer connects the different stakeholders and activities, and guides the design process. This could be investigated further.

Overall the main goals set at the start of this project have been achieved and I have provided new and in my opinion interesting perspectives to the different facets of the Living Lab. Moreover, we have successfully used this Living Lab approach to research and design innovations by involving impaired users and their context. And as we have shown we can use this to contribute to societal challenges now and in the future.

English Summary

English Summary

Design for Dementia: A Design-driven Living Lab to Involve People with Dementia and their Context

Introduction (Chapter 1)

Most people are afraid of dementia. However, there is a long road between the first symptoms of memory problems and the advanced state of dementia. In this dissertation we aim to examine dementia constructively and try to use design approaches to find new strategies and proposals to support those affected by dementia.

Dementia is seldom experienced alone. Often spouses or other family members are also burdened by the condition through providing care and experiencing worry (Zwaanswijk et al., 2013). Moreover, informal caregivers are often mentally and physically burdened by the progressive deterioration of the dementia patient (Etters et al., 2008). Therefore the context of people with dementia has to be considered when we design for them.

Because we design for people with dementia we cannot take their perspective through empathy. People with dementia have a cognitive impairment and are therefore too distant from our own perspective. To address this we need to experimentally put our designed proposals in the field as early as possible.

Additionally, in the context of dementia we see a resemblance between our design approach and Person-Centred Care (Clarke et al., 2003). The focus of this type of dementia care focuses on the persons behind the disease. In both care and design we should consider the individual perspectives and let this inform our decisions. We can however, not grasp this by ourselves; we need to observe and harvest insights through our prototypes in the field to comprehend this perspective.

To achieve these goals we build and applied the Living Lab approach. This Living Lab is based on the Experiential Design Landscape perspective (Peeters & Megens, 2014) and builds on five general Living Lab principles as formulated by Bergvall-kåreborn and Ståhlbröst (2009): Continuity, Openness, Realism, Empowerment of users, and Spontaneity. In this Living Lab there is room for different innovation activities to design for people living with dementia. It is the role of the researcher in this Living Lab to design and evaluate innovative proposals to support people living with dementia. For these design activities the involvement of the people with dementia in a realistic context is important.

We wanted to ensure a safe involvement of people with dementia in our Living Lab. Therefore, we only selected participants if they are still able to live at home with a spouse and are in the early stages of dementia. We collaborated in this with a mental care institute (Geestelijke Gezondheidszorg Eindhoven or GGzE). They supported the selection of participants from their patient networks and they protect those patients from overburdening in the research.

Overall, in this dissertation we use the Living Lab as main method to address challenges in dementia by designing new innovative proposals. Because this field is relatively new, we aimed our research to be wide and experimental. Which leads us to the following main question for this dissertation:

How can we contribute to the societal challenges of dementia through design and innovation?

With three sub-questions:

1. How should we involve people living with dementia in design and research processes?

2. How should we construct the Living Lab to involve relevant stakeholders and cater for these design and research processes?

3. How should we design for/with people living with dementia?

There is little work conducted in the area of direct and active involvement of people with dementia in the context of a Living Lab. Therefore, we aim to conduct several studies with each a slightly different focus to cover all the facets of the Living Lab. This means we will go into the field and investigate the posed questions through several Living Lab cases. In each of these cases we involve people living with dementia and other relevant stakeholders. Because we aim for this work to be explorative, our studies will be qualitative-based, with a low number of participants and will be of a pragmatic nature.

Dementia (Chapter 2)

In this chapter we zoom in on dementia and how to involve people living with dementia in research processes. The deterioration process is described in a design oriented way by Timlin and Rysenbry (2010) in the stages: early, mid and late as follows:

In the early stages typical symptoms are forgetfulness, social anxiety and the loss of concentration. In the mid-stage, we see impaired ability during daily activities, significant memory lapses, reduced people recognition and disturbed sleep patterns. As the disease progresses into the late stage, more basic human functions such as communication, motor skills and decision-making become impaired.

Carefully designed interventions can answer unmet needs in various stages of dementia (Astell et al., 2010). However, the usability and adaptability of newly designed concepts deserve more attention. These interventions only become truly useful when needs are met and people living with dementia can use them. This is what we aim to do in this dissertation. Moreover, when we involve people with dementia and their caregivers in research we need to adept the design and research methods to them, and respect their personhood, stage of disease and context.

Finally we have created the Interactive Experience Flow as a platform to do this (Http://www.RensBrankaert.nl/Flowchart). This overview allows for understanding the process of dementia from different perspectives. Moreover, this tool can reveal new insights and opportunities.

Living Lab (Chapter 3)

In this chapter we look at the Living Lab approach developed to design for people with dementia. A Living Lab is an innovation methodology in which users are exposed to innovation to develop the innovation further. Living Lab research takes place in a real-life environment where users are involved as co-creators. Co-creation means that users and designers develop innovations together (Sanders & Stappers, 2008).

To gain a deeper understanding of the Living Lab phenomena six Living Lab projects in the Netherlands were studied. This explorative study provided insights into the Living Lab approach and supported the construction of the Living Lab approach we use at the basis of this dissertation.

The study confirmed that Living Labs orient more towards a networked structure and open innovation (Leminen et al., 2012). Moreover, it revealed that experimental control and realism are considered high and very important by the Living Labs included in the study.

Based on the insights from this study we developed our Living Lab structure. In this the Living Lab is seen as a network structure that allows for several innovation methods to be applied as part of it. For the environment, we aim this to be as realistic as possible. As such the studies have a high ecologically validity. Thereby, the active involvement of users is essential. Hereby it is important that users are included in each of the different stages of the development process.

In the end, the key aspect of our Living Lab is carrying out studies in collaboration with our stakeholder network to iteratively develop innovative design proposals.

Design process and pilot study (Chapter 4)

In this chapter we elaborate on the design process and its separate phases: Exploration, Design, Evaluation and Implementation. In this dissertation the focus lies on the first three phases. In each of these phases different methods can be applied to iteratively develop design proposals. The focal point of this dissertation is the evaluation and the involvement of impaired users in their real-life context.

In this setup we conducted a pilot study with the PhysiCAL calendar. This is an intelligent physical calendar designed for people with dementia to remind them of their weekly activities. In this pilot we explored the different facets of an in-context evaluation as part of our Living Lab. As such we evaluated the calendar with users, care professionals and business stakeholders.

Based on these results we set the goals for the subsequent cases of Chapter 5 - 7. Firstly, we found that it is insufficient to gather the first-person perspective of people with dementia through a questionnaire. This will be focused on in Chapter 5. Secondly, it was difficult to deploy a design proposal in a stakeholder network; especially the business stakeholders need to be included earlier and more prominently. This will be addressed in Chapter 6. Thirdly, we found insights related to design for dementia. There are no clear overviews and both encouraging and discouraging design aspects were discovered. Based on our Living Lab cases we formulated design recommendations in Chapter 7.

Involving people with dementia in context (Chapter 5)

In this chapter the Vitaallicht case is covered. In this case we focused on the involvement of people with dementia in home context research. For this purpose we developed a new method: the personal evaluation game. This method, based on cultural probing (Gaver et al., 1999), allows users to decide in which way (written, audio or pictures) or amount they contribute to the study in a playful way.

In the study we also used a tablet-based questionnaire to compare our newly developed method with. The study period was 3 weeks: one baseline week without an intervention followed by 2 weeks with the vitaallicht lamp. This lamp stimulates healthy sleeping patterns. On the final day of the study a semi-structured reflection interview was held with the participants.

We used manual methods to analyse the responses (Rose & Webb, 1998) to get insights from the generated data. A thematic analysis was used as the main method (Braun & Clarke, 2006). In this analysis, we included the written and audio data from the personal evaluation game, input data from the tablet-based questionnaire and comments made during the final interview. In the analysis we focused on the following three topics: the level of engagement of the person with dementia, how they judged participation and what type of evaluative data was generated.

Results showed that the evaluation game was a much better way to capture the first-person perspective of participants during an in context study. The evaluation game method provided rich data thanks to the various types of input it offered.

We also gathered insights into how people with dementia live and what they thought about the assistive technology. In this study we found that the method and study must be dynamic and adaptable to the level of users. Nevertheless, the method is not suitable for all types of users and this should be investigated further. Thereby, we also found that business stakeholders need to be more closely involved in the entire evaluation process.

Design & evaluation with business stakeholders (Chapter 6)

In this chapter we cover the GoLivePhone® case. During this case we aimed to improve the evaluation process and collaboration with business stakeholders. Hereby we focused on generating useful output for them to improve their product and achieve a higher level of impact with it by the results of our study.

The GoLivePhone is smartphone software designed for elderly, with specific functionality for independent living. We evaluated this with people living with dementia, in total ten couples participated in this Living Lab evaluation study. We aimed to explore the experience of users with the GoLivePhone and provided them with the device for a period of 2 to 3 weeks. The study took place at the homes of the participants to evaluate the device with high ecological validity. Over the course of the study, three different types of data were gathered. These were data logs from the device directly, questionnaire data as evaluation method and reflection data from participants after the study.

From the data logs we found that all participants actively started using the smartphone, but only a few kept using it. The lowest use was registered after two weeks. This suggests that a reintroduction of the system might be necessary.

From the questionnaire data we learned that interacting with the system was challenging, especially with the touch screen (Armstrong et al., 2013). Also integrating the device in a daily routine proved difficult, a known issue with mobile phones for people with dementia (Robinson et al., 2009). However, some participants were capable of using the smartphone to its full extent and enjoyed it.

We recommend for future studies to put technology ‘in the wild’ as soon as possible, as this generates reflective insights that cannot be found otherwise. In addition, the business stakeholders appreciated the process. The approach was pragmatic and rapid enough to be relevant for them. For them the reflection sessions, and subsequent thematic analysis, provided plenty of insight for development of the GoLivePhone. By involving the Business stakeholder early in the process they had influence on the approach and method. This resulted in a shared ownership and a more active engagement in the study. In addition, from a design research perspective collaborating with business stakeholders resulted in high-quality technology to conduct research with. This resulted in less technical issues as compared to the use of self-constructed prototypes.

Design recommendations (Chapter 7)

In this chapter we analyse the design proposals of our past Living Lab cases. Thereby we introduced some additional cases: three student cases and the Homing compass case. Together these are seven cases which we conducted a thematic analysis on to extract design recommendations (Braun & Clarke, 2006). Some of these additional cases show the strength of enabling person-centred care through design.

In the study we identified nine design recommendations. In the literature there are few overviews of principles or recommendations available on design for dementia (Mäki & Topo, 2009; Orpwood et al., 2004), we contribute to these by advancing four design recommendations:

Design recommendation 1: Empowerment.
A design proposal should empower people with dementia and increase their self-reliance and independence.

Design recommendation 2: Social context.
A design proposal should consider and balance the role of the social context, which can include caregivers, family members, neighbours and friends.

Design recommendation 3: Familiarity.
A design proposal should promote familiarity in appearance, interaction and experience to increase usability and adoption by users.

Design recommendation 4: Physicality.
A design proposal should include physicality to increase the ability to interact directly and allow users to better conceive information.

Thereby, the other five design considerations we found should also be taken into account. However, they could already be found in the literature and were revalidated through our studies. These were: Reliability, flexibility in use, simplicity, personalisation and non-stigmatizing.

These design recommendations are not intended to become requirements in design for people living with dementia, they rather contribute to existing frameworks. The recommendations can be used in several phases of design or research processes to achieve a higher standard in product, system and service design for dementia.

Design of a Living Lab protocol (Chapter 8)

In this chapter the in context Living Lab cases performed in this work are reflectively analysed to propose a new evaluation protocol. This protocol is designed for in context Living Lab studies with impaired users and the stakeholder network.

The resulting protocol contains five steps. The first step includes the preparation of the evaluation by selecting participants, an intervention, and a suitable method for the target group.

After the first step a series of three steps are proposed as home visits. The research and project are introduced to the potential participants (Home visit 1), following agreement on participation the intervention with a design proposal is started (Home visit 2), and after this we reflect with the users on the design and the research (Home visit 3). It is important that users have time to accommodate to the project and the research before starting in the intervention.

After this there is the fifth step in which the results from the study are analysed, processed and shared with the relevant stakeholders. Finally, the participants are invited to become part of the community to engage in future activities as well.

Overall, an essential part of the protocol is the inclusion of the stakeholder network. Over the course of the studies we found that each of the four different stakeholder roles: Care, Business, User and Researcher (Arnkil et al. 2007) should be included in each of the five steps. There might be contradicting interests between these different stakeholder roles, and it is up to the (design) researcher to balance these.

Discussion & Reflection (Chapter 9)

In the final chapter the work and results are discussed and reflected upon. We found that the Living Lab approach, build on exploration and in-situ evaluation, allows us to design for impaired users where empathy methods do not suffice. These user groups are too distant from our own perspective and by this we cross the boundaries of empathic design. We propose to rethink our inquiry tools, and work with methods, such as for example the personal evaluation game, that allow researchers and designers to construct an experience perspective based on gathered data. In addition, working in context as part of the design process is essential to this as well. By observation we can retrieve the experience of impaired users with our design proposals. Therefore we need to embed real-life experimentation and stakeholder collaboration in our Living Lab research. And with this we can use design and our Living Lab approach to aid in societal challenges such as dementia.

Nederlandse samenvatting

Nederlandse samenvatting

Introductie (Hoofdstuk 1)

Veel mensen zijn bang voor dementie. Echter, is er een lang weg te gaan tussen de eerste symptomen van geheugenverlies en de latere fases van dementie. In deze dissertatie kijken we naar de aandoening dementie en trachten we middels een ontwerp gedreven aanpak om nieuwe strategieën en ontwerpvoorstellen te vinden om mensen met dementie te ondersteunen. Hierbij is het belangrijk te erkennen dat dementie zelden alleen wordt ervaren. Vaak zijn er partners, familieleden of vrienden, die zijn belast met zorgen voor en over de persoon met dementie (Zwaanswijk et al., 2013). Bovendien, ervaart deze zogenaamde mantelzorg vaak zelf mentale en fysieke last door het achteruitgaan van de dementie patiënt (Etters et al., 2008). Daarom is de context van mensen met dementie van belang als we voor hen willen ontwerpen.

Omdat we ontwerpen voor mensen met dementie kunnen we ons niet in hun perspectief plaatsen door empathie. Mensen met dementie hebben een cognitieve beperking en zijn staan hiermee ver af van ons eigen perspectief. Om dit te adresseren dienen we experimenteel onze ontwerpvoorstellen in het veld te zetten om te kunnen zien hoe deze functioneren (Peeters & Megens, 2014).

Daarbij zien we in de context van dementie een overeenkomst tussen ontwerpen voor mensen met dementie en belevingszorg (Person-Centred Care, (Clarke et al., 2003). Belevingszorg is een vorm van zorg die zich richt op het individu en de persoon achter de ziekte. In zowel zorg als design dienen we ons in dit perspectief te plaatsen om keuzes op te baseren.

Om dit te bereiken hebben we een *Living Lab aanpak* ontwikkeld gebaseerd op de vijf algemene Living Lab principes zoals geformuleerd door Bergvall-kåreborn en Ståhlbröst (2009): *Continuïteit, Openheid, Realisme, Empowerment van deelnemers* en *Spontaniteit*. In dit type Living Lab is er ruimte om verschillende design activiteiten te verrichten om ons doel van ontwerpen voor mensen met dementie te bereiken. Dit gebeurt vooral samen met de mensen waar we voor ontwerpen: Mensen die leven met dementie, in hun directe context. De rol van de onderzoeker in dit Living Lab is om nieuwe innovatieve ontwerpvoorstellen te ontwikkelen en deze te evalueren. Mensen met dementie staan aan de basis van dit proces en worden actief betrokken middels verschillende methodes.

Om een veilige deelname van mensen met dementie in ons Living Lab te garanderen betrekken we enkel mensen met dementie die thuis wonen en een partner hebben. Met betrekking tot deze selectie van mensen met dementie voor deelname aan het Living Lab hebben we intensief samengewerkt met de Geestelijke Gezondheidszorg Eindhoven (GGzE).

In deze dissertatie gebruiken we de Living Lab methode om uitdagingen rondom dementie te adresseren middels het ontwikkelen van nieuwe ontwerpvoorstellen. Dit leid ons naar de volgende onderzoeksvraag:

Hoe kunnen we bijdrage aan de maatschappelijke uitdaging van dementie door design en innovatie?

Deze vraag heeft drie sub-vragen:

1. *Hoe kunnen we mensen die leven met dementie betrekken in design en onderzoeksmethodes?*

2. *Hoe kunnen we de Living Lab aanpak opbouwen zodat we de relevante partijen betrekken en het design en onderzoeksproces ondersteunen?*

3. *Hoe zouden we voor en met mensen die leven met dementie moeten ontwerpen?*

Omdat er nog maar weinig werk is gedaan rondom ontwerpen voor mensen met dementie in de context van een Living Lab richten we ons op het pragmatisch uitvoeren van een aantal zogenoemde Living Lab casussen. Dit betekent dat we vooral de thuisomgeving (context) opzoeken en samen met mensen met dementie en andere partijen deze vragen gaan onderzoeken. Omdat we ons richten op exploratief en kwalitatief onderzoek zullen de studies lage gebruikersaantallen hebben. Echter, kunnen we op die manier wel alle belangrijke facetten van ons design-gedreven Living Lab behandelen.

Dementie (Hoofdstuk 2)

In dit hoofdstuk zoomen we in op de aandoening dementie en kijken we hoe we mensen met dementie het beste kunnen betrekken in onderzoeksprocessen. Het ziekteverloop is op een design georiënteerde manier omschreven door Timlin en Rysenbry (2010) in de fasen: Vroeg, Midden en Laat.

In de *vroege* fase van dementie zijn typische symptomen vergeetachtigheid, angst voor sociale gelegenheden en gebrek aan concentratie. In de *midden* fase zien we problemen rondom dagelijkse activiteiten, hiaten in het onthouden van momenten, verminderd herkennen van personen en gebroken slaap patronen. Als de ziekte vordert naar de *late* fase dan zien we problemen rondom basaal menselijk functioneren zoals communicatie, motoriek en keuzes maken.

Zorgvuldig ontworpen voorstellen kunnen onbeantwoorde behoeftes vervullen in verschillende fases van dementie (Astell et al., 2010). Echter, de gebruiksvriendelijkheid en aanpasbaarheid van nieuw ontwikkelde concepten vergen meer aandacht. Ontwerpvoorstellen kunnen alleen echt bruikbaar worden als behoefte worden vervuld en mensen met dementie ze zelf kunnen gebruiken. En dit is precies wat we willen bereiken in dit werk. Verder, als mensen met dementie worden betrokken in onderzoek moeten we de ontwerp en onderzoeksmethode aanpassen aan hen, hierin dienen persoonlijkheid, fase van de ziekte en de context mee te worden genomen.

Tenslotte hebben we de *Interactive Experience Flow: Dementie* ontwikkeld om hierin te ondersteunen (http://www.RensBrankaert.nl/flowchart). In dit overzicht kan men inzicht krijgen in het ziekteproces vanuit verschillende perspectieven. Verder kunnen ontwerpers nieuwe kansen en inzichten verkrijgen.

Living Lab (Hoofdstuk 3)

In dit hoofdstuk kijken we naar de Living Lab aanpak en ontwikkelen we deze dusdanig om te ontwerpen voor mensen met dementie. In Living Labs wordt de doelgroep van een bepaalde innovatie blootgesteld aan die innovatie om deze verder te ontwikkelen. Living Lab onderzoek vind plaats in het 'echte' leven bij de mensen thuis waar we voor ontwerpen. Zij worden betrokken middels co-creatie, wat betekent dat toekomstige gebruikers en ontwerpers op gelijke voet samen innovaties ontwikkelen (Sanders & Stappers, 2008).

Om een dieper inzicht te krijgen in de Living Lab methode onderzochten we zes Living Lab projecten in Nederland. Deze exploratieve studie gaf inzicht in de Living Lab aanpak en draagt bij aan het ontwerpen van ons eigen Living Lab.

De studie bevestigt dat Living Labs zich tegenwoordig meer oriënteren naar een netwerk structuur en open innovatie (Leminen et al., 2012). Verder, laat het onderzoek zien dat experimentele controle en realisme als hoog worden gezien in alle Living Labs en als erg belangrijk wordt ervaren door de Living Labs.

Op basis van de inzichten van deze studie hebben we onze Living Lab structuur opgebouwd. We zien het Living Lab als de netwerk structuur van verschillende partners waarin allerlei innovatie methodes kunnen worden toegepast. We richten ons op een zo realistisch mogelijke omgeving, dan blijft de ecologische validiteit van de studies hoog. Daarnaast is het actief betrekken van eindgebruikers van groot belang. Hierbij is het belangrijk dat de eindgebruikers betrokken zijn in de verschillende fasen van het ontwikkelproces.

Uiteindelijk is het belangrijkste onderdeel van ons Living Lab het uitvoeren van studies in samenwerking met belanghebbende partijen, waaronder ook de zorg en de zakelijk kant van innovatie. Op deze manier kunnen we in samenwerking ontwerpvoorstellen ontwikkelen voor mensen met dementie.

Design proces en pilot studie (Hoofdstuk 4)

In dit hoofdstuk behandelen we het ontwerp proces met de fasen: **Exploratie, Design, Evaluatie** en **Implementatie**. De focus van deze dissertatie ligt op de eerste drie fasen. In iedere van deze fasen kunnen verschillende innovatie methodes worden toegepast die uitgebreid worden behandeld in dit hoofdstuk. De belangrijkste methode is de evaluatie van ontwerpvoorstellen bij mensen met dementie en hun mantelzorgers thuis.

In deze opzet hebben we een eerste pilot studie uitgevoerd rondom de PhysiCAL, een intelligente kalender ontworpen voor mensen met dementie om hen te ondersteunen met activiteiten plannen en herinneren. In deze pilot hebben we geëxploreerd met verschillende facetten van in-context Living Lab onderzoek. Om deze reden is de kalender geëvalueerd met eindgebruikers, zorgprofessionals en zakelijke partijen.

Op basis van deze resultaten hebben we de doelen voor de opvolgende studies van Hoofdstuk 5-7 gebaseerd. Ten eerste, hebben we gevonden dat het ontoereikend is om het eerste-persoonsperspectief van mensen met dementie te vangen met conventionele evaluatie methodes; hier gaan we op verder in Hoofdstuk 5. Ten tweede was het moeilijk om het ontwerpvoorstel te laten landen in het partner netwerk, vooral de zakelijke partijen moeten eerder en prominenter in het proces worden betrokken; dit wordt behandeld in een vervolg studie in Hoofdstuk 6. Ten derde, we vonden inzichten omtrent hoe te ontwerpen voor mensen met dementie. Er zijn momenteel geen toereikende overzichten, en we vonden zowel bevorderende als belemmerende aspecten in het ontwerp. Op basis van onze Living Lab casussen zullen we een aantal ontwerp aanbevelingen doen in Hoofdstuk 7.

Betrekken van mensen met dementie (Hoofdstuk 5)

In dit hoofdstuk behandelen we de Vitaallicht casus. In deze casus richten we ons op hoe mensen met dementie te betrekken in thuisstudies. Om dit te beantwoorden hebben we een nieuwe evaluatie methode ontwikkeld, de '*personal evaluation game*'. In deze methode, gebaseerd op cultural probes (Gaver et al., 1999), kunnen eindgebruikers kiezen op welke manier (geschreven, ingesproken of met beelden) en hoeveel ze willen bijdragen aan de thuisstudie op een speelse manier.

In deze studie hebben we ook een tablet-gebaseerde vragenlijst ingezet om de nieuwe methode mee te vergelijken. De totale studie duurde 3 weken, hiervan was week 1 de 'baseline' (grondslag) en vond de interventie in de opvolgende 2 weken plaats. Dit was met de Vitaallicht lamp; een lamp die het dag-nacht ritme van haar gebruikers positief stimuleert. Op de laatste dag van het onderzoek hebben we een semigestructureerd reflectie interview georganiseerd met de deelnemers.

We hebben handmatige methodes gebruikt om de reacties te analyseren (Rose & Webb, 1998) en zo inzicht te krijgen in de gegenereerde data. Vervolgens hebben we een thematische analyse gedaan (Braun & Clarke, 2006). In deze analyse hebben we de geschreven en auditieve data meegenomen uit de *'personal evaluation game'* , data uit de tablet vragenlijst en opmerking uit het reflectie interview. In de analyse hebben we ons op de volgende drie onderwerpen gericht: Het niveau van toewijding van de persoon met dementie, hoe zij de deelname beoordeelde en welke type evaluatieve data werd gegenereerd.

De resultaten laten ons zien dat de *'personal evaluation game'* een goede en juiste manier is om het eerste-persoonsperspectief te vangen tijdens studies in context. De nieuwe methode verschafte rijke data dankzij de verschillende manieren om input te leveren. Daarnaast hebben we ook inzichten verworven met betrekking tot hoe mensen met dementie leven en wat zij van de ondersteunende technologie vinden. In deze studie vonden we ook dat een evaluatie methode voor thuis in context aanpasbaar moet zijn aan het niveau van de gebruikers. Desondanks was de methode niet geschikt voor iedereen, dit dient verder onderzocht te worden. Daarbij hebben we ook gezien dat de zakelijke partner sterker moet worden betrokken in het proces.

Het betrekken van zakelijke partijen in onderzoek (Hoofdstuk 6)

In dit hoofdstuk richten we ons op de GoLivePhone casus. Tijdens deze casus kijken we naar hoe de samenwerking en betrokkenheid van zakelijke partijen te verbeteren is. Hierin ligt de focus op het behalen van studieresultaten waarmee het bedrijf achter de GoLivePhone haar product kan verbeteren en meer impact kan krijgen op de maatschappelijke uitdaging van dementie.

De GoLivePhone is een smartphone interface ontwikkeld voor oudere gebruikers met specifieke functionaliteiten om langer zelfstandig thuis te kunnen wonen. We hebben deze oplossing geëvalueerd met tien mensen met dementie en hun mantelzorgers volgens onze Living Lab aanpak. We richten ons hier op de exploratie van de ervaring van gebruikers en hebben de participanten 2 tot 3 weken een GoLivePhone gegeven om uit te proberen. Deze studie vond wederom plaats in de thuisomgeving van mensen met dementie om de ecologische validiteit te verhogen. Tijdens de studie hebben we drie verschillende vormen van data verzameld. Ten eerste waren er data logs direct uit de smartphone, ten tweede was er data uit de evaluatie vragenlijsten en ten slotte reflectieve data van de slot sessie.

Resultaten van de data logs leerde ons dat de interactie met het systeem uitdagend was voor mensen met dementie, en dan vooral de touch screen interactie (Armstrong et al., 2013). Maar ook het integreren van het toestel in de dagelijkse routine was moeilijk, dit is een bekend probleem van smartphone gebruik door mensen met dementie (Robinson et al., 2009). Desondanks waren een aantal deelnemers na een tijdje erg bekwaam met de GoLivePhone en konden het volledig gebruiken en vonden het prettig.

Andere onderzoekers die thuisstudies willen verrichten raden we aan om dit zo vroeg mogelijk in het ontwerp proces plaats te laten vinden. Vooral de resulterende reflecties brachten inzichten die op geen andere manier te verkrijgen zijn. Daarbij vond het bedrijf de gang van zaken tijdens deze studie erg prettig. De aanpak was pragmatisch en snel genoeg om relevant te zijn voor hen. Voor hen was de reflectie sessie en de daaraan gekoppelde thematische analyse het meest waardevol. Hier hebben ze veel inzichten verworven om het systeem te verbeteren. Doordat we de zakelijke partij vroeg hadden betrokken hadden ze invloed op de aanpak. Dit resulteerde in een gedeeld gevoel van eigenaarschap over de studie en een actievere houding gedurende de studie. Daarnaast, was het vanuit een onderzoeksperspectief prettig om met bedrijven samen te werken omdat de technologie een stuk volwassener was dan zelfgemaakte prototypes. Dit resulteerde in veel minder technische mankementen.

Ontwerpen voor mensen met dementie (Hoofdstuk 7)

In dit hoofdstuk analyseren we de Living Lab casussen die zijn behandeld in dit werk. Daarnaast introduceren we nog drie studenten casussen en het 'welthuis kompas' (Homing compass). Samen zijn dit in totaal zeven casussen die we thematisch analyseren om ontwerp aanbevelingen te doen (Braun & Clarke, 2006). Een aantal van de nieuwe casussen laten zien hoe belevingszorg kan worden gebruikt in design.

In deze studie hebben we negen ontwerp aanbevelingen gevonden. In de literatuur zijn er maar weinig design principes bekend omtrent ontwerpen voor mensen met dementie (Mäki & Topo, 2009; Orpwood et al., 2004), en we dragen hier aan bij door vier ontwerp aanbevelingen uit te breiden.

Ontwerp aanbeveling 1: Empowerment
Een ontwerpvoorstel dient mensen met dementie in staat te stellen om iets te doen dat zij voorheen niet konden om zo zelfstandigheid te bevorderen.

Ontwerp aanbeveling 2: Sociale context
Een ontwerpvoorstel dient de sociale context mee te nemen en in balans te brengen. Hier vallen bijvoorbeeld verzorgers, familieleden, en vrienden onder.

Ontwerp aanbeveling 3: Herkenbaarheid
Een ontwerpvoorstel dient herkenbaar te zijn op het gebied van voorkomen, interactie en ervaring om de bruikbaarheid en adoptie te bevorderen.

Ontwerp aanbeveling 4: Tastbaarheid
Een ontwerpvoorstel dient tastbaarheid en tactiliteit mee te nemen om zo de directe interactie en het bevatten van informatie in een ontwerp te bevorderen.

Verder dienen de andere vijf ontwerp aanbevelingen die zijn gevonden in onze studie ook mee te worden genomen. Deze zijn al bekend in literatuur en zijn dus bekrachtigd in onze studie. Dit waren: *Betrouwbaarheid*, *Flexibiliteit in gebruik*, *Eenvoud*, *Personalisatie* en *Niet-stigmatiserend*.

Deze negen ontwerp aanbevelingen zijn niet bedoeld als eisenlijst voor ontwerpers, ze dragen juist bij aan bestaande overzichten. De aanbevelingen kunnen worden gebruikt in de verschillende fasen van een ontwerp- of onderzoeksproces om een hogere standaard te bereiken in het ontwerpen van systemen, producten en services voor mensen met dementie.

Living Lab onderzoeksprotocol (Hoofdstuk 8)

In dit hoofdstuk kijken we naar de Living Lab casussen van deze dissertatie, analyseren deze en stellen een nieuw onderzoeksprotocol voor.

Het resulterende protocol heeft vijf stappen. De eerste stap is de *voorbereiding*, dit houdt in het selecteren van participanten, de interventie, en evaluatiemethode passend bij de doelgroep en de interventie.
Na deze eerste stap volgen de drie volgende stappen in de vorm van huisbezoeken. Tijdens *huisbezoek 1* wordt het project en het onderzoek geïntroduceerd aan potentiële deelnemers, tijdens *huisbezoek 2* wordt de interventie met een ontwerpvoorstel gestart. Na de interventieperiode vindt *huisbezoek 3* plaats waar samen met de participanten wordt gereflecteerd op het ontwerp en het onderzoek.
Na deze drie stappen is er de vijfde en laatste stap waar de *resultaten* van de studie worden geanalyseerd en gedeeld met de relevante partijen. Uiteindelijk worden de deelnemers gevraagd om onderdeel te worden van de community (gemeenschap).

Uiteindelijk is een essentieel onderdeel van het protocol het betrekken van het partner netwerk. In onze studies hebben we gevonden dat het belangrijk is om alle relevante rollen te betrekken: De zorg, onderzoekers, eindgebruikers en de zakelijke kant (Arnkil et al. 2007). Deze dienen vertegenwoordigd te zijn in ieder van de vijf stappen. Er zullen mogelijk conflicterende interesses zijn tussen partijen, maar het is aan de (design) onderzoeker om hier een balans in te vinden.

Discussie en Reflectie (Hoofdstuk 9)

In dit laatste hoofdstuk worden het werk en de resultaten bediscusseerd en op gereflecteerd. We hebben gevonden dat de Living Lab aanpak, gebouwd op exploratie en in-situ evaluatie, ons in staat stelt om te ontwerpen voor een cognitief beperkte groep waar empathiemethodes niet voldoen. Deze doelgroep is te ver van ons eigen perspectief en voldoen empathie methodes niet meer. Daarom stellen we voor dat onze onderzoeksmethodes moeten worden aangepast, zoals bijvoorbeeld de '*personal evaluation game*', zodat ze onderzoekers en ontwerpers in staat stellen een ervaring te reconstrueren op basis van de onderzoeksresultaten. Daarnaast, is het uitvoeren van onderzoek in context als onderdeel van het ontwerp proces hiervoor ook van essentieel belang. Dit dient zo vroeg mogelijk in het proces te gebeuren. Door de doelgroep te observeren kunnen we hun ervaring met onze ontwerpvoorstellen achterhalen. Hiervoor dient ook het belanghebbende partner netwerk onderdeel te worden van het onderzoek. Tenslotte, kunnen we hiermee dan middels design en onze Living Lab aanpak bijdragen aan maatschappelijke vraagstukken zoals dementie.

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Appendix A: Living Lab questionnaire – comparison study

PART I Living Lab setup

Q1: What is the name of your Living Lab?

Q2: What is your definition of a Living Lab?

Q3: What is your role in the Living Lab?

Q4: What is the name of the company you work for?

Q5: What is the role of this company in the Living Lab?

Q6: What is the goal of your Living Lab?

Q7: What facilities does your Living Lab have?

Q8: What kind of party does fulfill the leading rol in the network surrounding your Living Lab? The Living Lab is a….

A8.1 … Network, with the leading role for a business/private party
A8.2 … Network, with the leading role for a public party
A8.3 … Network, with the leading role for a knowledge institute
A8.4 … Network, with the leading role for the user/a user group
A8.5 … It is no network, my party/employer is the only party.
A8.6 … Other, [ ]

PART II Living Lab integration

Q9 What is the most important source of income for your Living Lab?

A9.1 It is financed as part of one company
A9.2 It is financed from a public funding
A9.3 It is financed from a network of business/private parties
A9.4 It is financed as part of a knowledge institute
A9.5 It is financed from a network of public parties
A9.6 It is financed from income generated by the Living Lab
A9.7 Other, [ ]

.

Q10 Do you work together with business/private parties in your Living Lab? Yes, in what way? No, why not?

A10.1 Yes, comments
A10.2 No, comments

Q11 In what way do you work together with (potential) end-users of new innovations?

A11.1 They give feedback on innovations (in a lab)
A11.2 They give feedback on innovations (in their natural context)
A11.3 They participate in focus group sessions
A11.4 They fulfill a questionnaire (about a particular innovation)
A11.5 They participate passively, their data is being monitored
A11.6 We don't work together with our (potential) end-users
A11.7 Other, [ ]

Q12 What kind of innovations do you evaluate in your Living Lab?

A12.1 Products
A12.2 Systems
A12.3 Services
A12.4 Applications
A12.5 Data collection
A12.6 Other, [ ]

Q13 For which phase of the particular innovation do you use your Living Lab?

A13.1 Discovery (Seeking directions)
A13.2 Exploration (confirming directions)
A13.3 Evaluation (Insights about an innovation)
A13.4 Validation (Affirm an innovation)
A13.5 Confirmation (Insight in existing innovations)

Q14 What kind of data do you collect in your Living Lab?

A14.1 Data about the user (ea. Profiles)
A14.2 Data collection through retrospection of the users (ea. Questionnaire or interview)
A14.3 Data collected through external researchers (ea. Observation)
A14.4 Data collected within an innovation (ea. Logging)
A14.5 Data collected in the context about the innovation (ea. Sensor network)
A14.6 We don't collect data in our Living Lab
A14.7 Other, [ ]

Q15 What is the average time of sessions in your Living Lab?

A15.1 A couple of hours
A15.2 An entire day
A15.3 Between two days and a week
A15.4 Between a week and four weeks
A15.5 Between a month and six months
A15.6 Between six months and a year
A15.7 More then a year

Q16 Can you indicate for the following concepts (on a scale from 1: Very much not applicable to 7: very much applicable) if it applies to your Living Lab?

A16.1 Openness (To what extend do you share insights and results)
A16.2 Influence (To what extend do users and partners influence the innovations through the sessions?)
A16.3 Realism (How realistic is the context in your sessions?)
A17.4 Value (how much value is created for the participants)
A17.5 Sustainable (The results are developing knowledge and our understanding about the innovation or Living Labs)
A17.6 Experimental control (Is high for the sake of the research)

Q17 How far is your Living Lab developed as a structure or method?

A17.1 Start-up phase (beginning)
A17.2 Explorative phase (searching for a role)
A17.3 Development phase (with a clear goal)
A17.4 Mature phase (healthy and self-sustainable)
A17.5 other, [ ]

Q18 Other remarks concerning the questionnaire?

Q19 If you wish to be contacted concerning the questionnaire put your e-mail here:

Appendix B1: The iterative design process of the PhysiCAL

2.2.1 Design from an opportunity frame

With a reflective transformative design process involving the different stakeholders (including end-users) the design process is need-centered, while maintaining a realistic perspective.

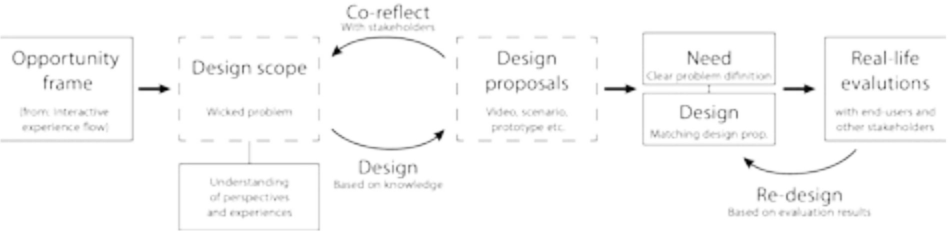

Figure B.1: Visual overview of the design process methodology.

2.2.2 Shared perspective co-reflection

Based on the opportunity frame gathered from the interactive experience flow the design scope (problem definition) is defined and iteratively developed through design proposals (see figure B.1). The design scope has the characteristics of a “wicked problem” (Martin, 2009) a marginally defined problem which requires extra attention to the problem understanding. The design proposals, being evaluated with stakeholders, are used to explore and develop the understanding of this problem context (Cross, 2006). A co-reflection methodology (Tomico, 2009) is chosen to achieve a user-driven design, as well as an effective way to generate new input in evaluating the design propositions.

2.2.3 Design evaluation

To finalize the design process the resulting design proposition (described in the case-study) is evaluated within the home environment of people living with dementia. In the development of assistive technology for people with dementia there is a need to evaluate new concepts in a real-life setting (Bharucha et al, 2009). The evaluation is used to verify the resulted design scope and design proposition, but also the methodological approach. The evaluation step contains three steps: 1) A need assessment with people living with dementia in their home environment, 2) Experiencing the concept at home (real-life) and 3) A reflection session to find indicators for redesign and opportunity.

From:
Brankaert, R. and den Ouden, E. (2013). Developing a design process to design for people with dementia and their extended care network - Learning from a case study. Proceedings of the International Conference on Engineering Design 2013, Seoul, Korea.

B2 - Results of clustering and interviews physical study.

During the evaluations the PhysiCAL is evaluated through a prototype. In these sessions (n=4) a qualitative approach was used to generate results in context.

Step 1: *Introduction to evaluation process and need assessment*
The need assessment showed regular problems that occur in the early-phases of dementia at all four couples. Which are forgetfulness, struggle with accepting the disease and worries about the near future concerning safety and planning. Other needs that were found related mostly to individual physical problems related to general aging, for example impaired sight and hearing.

Step 2: *Experiencing the prototype in the home environment*
For the evaluation of the prototype in these home sessions, the couples were asked to use the product at home as they desired. All couples participated, yet number of days varies. The caregiver was asked to conduct a daily questionnaire to capture the shared perspective. The daily questionnaire was short and focused on usability and desirability. The results (table 5) show the most important differences and similarities found in these questionnaires. One couple was unable to use the interface and didn't conduct the daily questionnaires, in this case (couple IV the questions were asked during reflection).

Step 3: *Reflective session to evaluate the design.*
As the tests were of an explorative nature this reflective session allows for an open conversation. In this open interview a questionnaire was used to support the researcher to capture insights. This questionnaire contained three sections: General innovation, re-design opportunities for the PhysiCAL and a final reflection on the overall evaluation process. Most important results (Table 5) show an interest in the prototype while there are many desires for redesign, the overall prototype was assessed positively.

Table A.1: Results from the home evaluation session with the end-users.

	Couple I	**Couple II**	**Couple III**	**Couple IV**
Need-assessment (prominent issues)	Problems with hearing, and cycling in the area due to memory.	Problems with hearing and moving in and outside the house.	Personal trouble with forgetfulness (rely on others), trouble with walking.	Trouble in marriage because forgetfulness. Hearing trouble.
Home sessions	Positive about conceptual design. Not applicable yet.	Logos on activity tags too small. Design not fitting in homes	If sound is better, product smaller perfect in home. Too expensive.	Too big to fit in home. Already useful during first day.
General reflection	IEF based – In further stage of dementia would like to use it.	IEF based – Longer test would give more insights.	CANE – Cane is too long. Future interest in more likewise tests.	CANE – Tablet daily assessment difficult. Not so suitable yet.

From:
Brankaert, R. and den Ouden, E. (2013). Developing a design process to design for people with dementia and their extended care network - Learning from a case study. Proceedings of the International Conference on Engineering Design 2013, Seoul, Korea.

Appendix C: Sleep quality measurement questionnaire (Dutch)

Hoelaat bent u deze week gemiddeld naar bed gegaan 's avonds? ___________________
Viel u moeilijk/gemakkelijk in slaap? *Erg moeilijk/Moeilijk/Gewoon/Gemakkelijk/Erg gemakkelijk*
Hoelang duurde het deze week gemiddeld voordat u in slaap viel? ______________________
Hoelaat bent u deze week gemiddeld uit bed gegaan 's ochtends? ______________________
Werd u moeilijk/gemakkelijk wakker? *Erg moeilijk/Moeilijk/Gewoon/Gemakkelijk/Erg gemakkelijk*
Hoeveel uur per nacht heeft u deze week daadwerkelijk geslapen? ______________________
Wat vindt u van deze hoeveelheid slaap *Absoluut te weinig/Te weinig/Genoeg/Veel/Absoluut te veel*
Hoe rustig heeft u gemiddeld geslapen? *Erg rusteloos/Rusteloos/Gewoon/Kalm/Erg kalm*
Hoe uitgerust wordt u wakker? *Absoluut niet/Niet/Gewoon/Wel/Helemaal*
Bent u van de week 's nachts wakker geweest? Zo ja, wat was de reden?

____

Heeft u deze week gebruik gemaakt van slaap medicatie? Zo ja, wat was de reden?
____

Heeft u deze week overdag geslapen? Hoe vaak?_____________________________________

____

Heeft u deze week moeite gehad met wakker blijven tijdens bepaalde activiteiten? Zo ja, welke activiteiten?

____

_

Hoe fit voelde u zich deze week gemiddeld? *Helemaal niet/Niet/Gewoon/Wel/Helemaal wel*

From:
Karolinska sleep diary (KSD; Akerstedt, Hume, Minors & Waterhouse, 1994)
Pittsburg Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman & Kupfer, 1988)

Appendix D: Design recommendations related to the specific cases.

	PhysiCAL	Evaluation Game	Vitaallicht	GoLive-phone	Homing Compass	Discover Dementia	Personal activity	Stay - tuned Radio
Physicality	In appearance and interaction the tangible aspects support use.	The input options supported physical aspects.	-	-	Enabled both usability and understanding.	Tangible sensors.	Promoted interaction.	Improved interaction.
Familiarity	Design based on existing calendars.	The input options were mostly familiar.	-	The smart - phones use was often not understood.	Of the shape supported understanding navigation functionality.	-	Promoted engage-ment.	Ensured acceptance.
Simplicity	-	-	-	Complex menu structure exemplifies this.	Striping down features based on expert and user input.	Direct input-ouput connect-ion.	-	In interaction promoted usability.
Personalisation	-	Ability to provide input as desired.	-	Adapting the interface to the level of user was appreciated.	-	In music selection.	Strongly improved engage-ment of user.	-
Stigma	The white and sizable design did not support acceptance.	-	The lamp did not fit with interior design.	Prevents stigma as everybody has a smartphone.	-	-	-	-

	PhysiCAL	**Evaluation Game**	**Vitaallicht®**	**GoLive-** phone	**Homing Compass**	**Discover Dementia**	**Personal activity**	**Stay tuned Radio**
Empowerment	Increased the feeling of independence of some users.	-	-	Increased self-reliance of users.	Supported independence and self-reliance of users.	-	-	Enabled users to stay up to date of their families lives.
Social context	-	Designed for both caregiver and person with dementia.	-	Feeling of safety and role for caregiver is strong.	-	Provide sound.	Designed so caregiver could have time.	Family members integrated in core of the concept.
Flexibility In use	As a platform the users could use it as they whished.	People could select input method and amount.	-	The interface is adaptable to the level of the user.	-	Individual or multi-user use.	Several options to chose as an activity.	Up to users and family members when to interact.
Reliability	Errors in sensor reading decreased trust in the device.	-	The technology of the lamp was far developed and caused no flaws.	-	Some technological issues caused confusion for users.	Technology operated well which increased appreciation in staff.	-	-

Curriculum Vitae

List of Publications

(Scientific - English)

- De Jong R. & Brankaert R. (2015). A point in the right direction: A simple navigation device for people with dementia. In proceedings of design 4 health conference 2015. Sheffield, UK.

- Brankaert, R., den Ouden, E., & Brombacher, A.C. (2015). Innovate dementia: the development of a living lab protocol to evaluate interventions in context. Info, 17(4), 40–52.

- Suijkerbuijk S., Brankaert R., Snaphaan, L., de Kort, Y., and den Ouden, E. (2015). Seeing the first-person perspective in dementia: a qualitative probing method to evaluate assistive technology for dementia patients in the home context. Interacting with Computers, (25,1), pp 57-68.

- Brankaert, R., Snaphaan L., and den Ouden, E. (2014). Evaluating the Experience and Use of a Personal Smartphone Design for People Affected by Dementia. Accepted for IWAAL 2014. Belfast, UK.

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(Public – Dutch)

- Innovate Dementia: Slimme oplossingen thuis. In Zorgvisie, Juli 2014.

- ‘Deze samenwerking mag niet stoppen’. Over hoe GGzE en TU/e samenwerken onder Innovate Dementia. In GGZE magazine jaargang 10, nr 2.

- Innovate Dementia of ‘Dementiezorg van morgen’. In Thuis in Eindhoven, Augustus 2013.

- Empatisch ontwerpen voor mensen met dementia door middel van techniek. In RDO nieuwsbrief van Zet Brabant, November 2012.

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Profile

Hello, my name is Rens Brankaert. I'm an enthusiastic design researcher who is always looking for collaborations and opportunities to create and investigate innovation in the context of health. I'm highly motivated, team oriented, able to take necessary actions in new or unfamiliar situations and have a strong instinctive sense.

Profile last jobs

Currently I work for Optistaff B.V., a company that works in close collaboration with Brainport Development and Corporation Slimmer Leven 2020 on Health innovation in the region of Eindhoven. The focus lies on innovation for independent living and ageing. In this regard I work as a project lead in several European oriented programs like Helicopter, Cross Care and ENSAFE. And my main activities are: multi-stakeholder collaboration, Living Lab design and implementation, user-centered innovation and the application of my generic design skills.

Before this I worked at the University of Technology, department of industrial design, as a PHD and project lead in the Innovate Dementia project. In this project I developed an expertise concerning needs inquiry, conducting Living Lab research and design for elderly.

Education

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For my portfolio, publications and design skills please have a look at: http://www.RensBrankaert.nl

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