Homes for Life & Other Stories

The Use and Evaluation of Design Fiction as a Means to Understand Sensitive Settings: a Case Study of Exploring Technologies for Dementia Care

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I, Britta F. Schulte confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
Abstract

Design fictions are used in HCI to position emerging technologies in fictional future worlds, through which the complexities of our relationships with technologies can be represented, explored and experienced. They promise to stimulate discussions about sensitive topics, such as the future of technology-enabled care, a complex area with contrasting emotional, social and practical views and wishes. However, the term design fiction is currently associated with a wide range of uses, and artefacts. It is also linked to contrasting philosophies and frameworks, which are often not made explicit, as I show in an initial survey with practitioners. This makes it difficult to identify what makes a design fiction good or effective for different purposes.

This thesis aims to answer the research question: **How can design fiction be used and evaluated in understanding sensitive settings?** I turn to the Constructive Design Research framework and adapt it to classify how design fiction is used in HCI. I outline how design fiction can be used in the showroom approach, where it is most commonly placed, but also how it can be used as a lab and field approach to gather insights into the responses to design fictions. I developed design fictions and explored how they can be used to further discussions around the use of monitoring technologies in dementia care: an area challenging to research because of ethical issues associated with deployment studies of prototype technologies.

The contribution of this thesis is threefold: first, a methodological contribution into the use of design fiction in HCI and an evaluation of the Constructive Design Research framework as a means to classify research through design fiction. Second, insights into participants’ views and wishes about technology-led care in regards to dementia. Third, a design contribution of artefacts that can be used to stimulate further debate around the topic.
Impact Statement

Technology is becoming smarter and is applied to all areas of life, such as the support of caregiving. As the technologies hold promises, but also dangers of replacing human properties, skills and labour, a debate is needed to shape which technologies are needed and how they can be fitted into people’s realities. My thesis project turns to smart technologies for people living with dementia as a case study, to understand how these debates can be held around complex and sensitive issues, such as illness and health care. It furthers the debate about these topics in three ways:

In this thesis I mainly discuss design fiction as a method. Novel methods are needed to develop technologies that fit into sensitive, everyday contexts. Design fiction is a method that promises to do so, but its terms are unclear, leaving to a lack of clarity of how it could be applied and how it could be useful. The studies and reflections in this thesis provide insights and clarities about the use of the method that can benefit both designers who are familiar with the method, but wish to expand their understanding of it as well as those designers or developers who are tasked with a complex and sensitive situation they wish to design for. To share my insights with this group, I chose suitable outlets, such as the NordiCHI 2016 conference design fiction panel that deliberately encouraged reflective papers.

The secondary contribution of this thesis project lies in the insights my work generated about people’s wishes, needs and expectations that can support the development of technologies to be used in the support of people living with dementia. To reach people interested in the broader questions of HCI design, I published at the prestigious CHI conference.

Another, tertiary contribution of this thesis project lies in a wide range of artefacts it generated about future technology use in care. These have not only been developed and are collated here, but have also been performed at public events, such as the Bloomsbury festival. Some of these performances are available through platforms such as youtube.com to carry the debate about the potential ethical implications of future technologies into the general public.
My thesis projects sheds light on both a promising design method and a complex topic for which timely solutions are needed by stimulating debate both within an academic audience and beyond.
Acknowledgements

‘Begin at the beginning,’ the King said gravely, ‘and go on till you come to the end: then stop.’

Lewis Carroll, Alice in Wonderland

Many good novels draw the reader in with their complex characters and their intriguing and delicate networks, relationships and entanglements. A good thesis I have been told only has one protagonist: knowledge and its contributions take centre stage. While knowledge will take over soon enough, here I want to acknowledge the networks, relationships and entanglements that have helped to bring out these contributions.

I had the pleasure of working with an extremely talented supervisory team. I thank Paul Marshall for curbing my enthusiasm when I was about to run away with ideas and for dealing with all the crises that occurred over the years with kindness, calmness and unfailing advice. I thank Anna Cox for her patience when my thoughts ran faster than my words could, for calming me down and for many lessons that I now find myself passing on to others. I thank Shaun Lawson for asking all the critical questions and bringing in many new perspectives.

Beyond this close supervisory team, it is my absolute pleasure to acknowledge a much wider network at UCLIC without whom this work would not be what it is today. I think it is safe to say that neither would I. I am grateful to have been able to ask all the stupid questions, share and receive advice and have had many conversations around lunch, drinks and cake that always made me feel welcomed, especially with Katarzyna Stawarz, Marta Cecchinato, Amid Ayobi, who I met on the first day and whose advice I still cherish; Giulia Barbareschi the star knitter, who always has an open ear and a helping hand; Susan Lechelt and Aneesha Singh for productive distraction when it was needed; Dilisha Patel for kindness and grumpiness; Roxanna Ramirez Herrera for enthusiasm and her attempts to convince me to go to karaoke; the A-team for daily motivation when it was needed; the CUDDLE group and TIPPS session for all the things I learned along the way. By the way, folkx: I do not like ice cream. Nicolai Marquardt gave constructive and kind feedback in my first year and upgrade viva and pushed my work further. Chris Evans has supported me in becoming a better teacher and together with Duncan Brumby has given time in their busy schedules for my studies. Sarah Turnbull,
Louise Gaynor and Jo Pearson have done an excellent job in helping me with countless queries, concerns and forms, thank you.

Renee Noortman was only at UCLIC for a short time during her internship, but it fills me with joy and pride that she worked alongside me and gave time, talent and enthusiasm to build on my work and take it much further.

Many other people have given their time, enthusiasm and intriguing insights by taking part in my studies. Without these people the work would clearly not be what it is. Participants took time out of events they attended, classes they took, their working day and even their everyday life to help out with my research and I hope to have been able to represent them in a respectful and honest manner.

During my studies I reached out many times for help and the IoT meetup, led by Alexandra Deschamps-Sonsino and The Cube, represented through Anne, helped out. They gave practical help by giving me space to undertake some of my studies, but even more so by giving support, making contacts and staying in touch even after the work ended.

I would not have even started this project without the support of my partner, who helped in all the ways mentioned above and even many more. Without my parents who have unfailingly supported my seemingly never-ending student life. It might come to an end finally.

A special acknowledgment needs to go out to the EPSRC who funded this work through their generous support and enabled me to tell this story. Without this much needed support none of this would have happened. Further regards go to the Ubihealth network that allowed me to widen my horizon and meet even more people along the way.

It is never as easy to find the beginning and end of a story, and also this selection has to be exactly this, a selection. This page cannot hold all the gratefulness I carry with me, there will be more on the way when our paths cross. Thank you.

Now, let’s come to an end. Lights off on this stage. Only one spotlight remains. And so it begins.
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Related Publications

Thesis chapters:

An introduction to Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies has been presented at Dementia Lab 2017 as a personal story. In print.

Reflections on the development and use of the Homes for Life design fiction, presented in 7.2 The Artefacts have been published at NordiCHI 2016 in collaboration with Paul Marshall and Anna Cox, in [Schulte et al. 2016].

An introduction to Chapter 10 Evaluation of HawkEye with HCI Experts and 11.2 The Deployment of HawkEye in the Field has been presented at Dementia Lab 2018 as an introduction to design fiction for the dementia research community in collaboration with Renee Noortman. In print.

A detailed version of the development of HawkEye and initial findings of 11.2 The Deployment of HawkEye in the Field has been presented at CHI 2019, in [Noortman et al. 2019].

Further academic publications resulting from this project:

A design fiction on wearable dementia care technologies reflecting on autonomy has been presented at Designing, Developing, and Evaluating the Internet of Personal Health, UbiComp 2016, in [Schulte 2016].


A reflection on the use of design fiction to assist participatory design in collaborative design has been presented at NordiCHI 2016. Not archived.

The use of design fiction in a collaborative project on autonomy and air pollution has been presented at DIS 2018 in collaboration with Susan Lechelt and Aneesha Singh, in [Schulte et al. 2018].
A Word on Pronouns

Throughout the thesis I refer to the participants who have kindly given their time and insights to aid my studies by the gender-neutral singular they. In most instances I refrained from collecting data on how people self-identify as it was beyond the scope of my thesis. With my choice I acknowledge that people hold power over their identity and to some part define their role. This thought is picked up in some of the study results.

In most of the thesis I refer to myself in the first person to emphasise my role as a reflective practitioner. Exceptions are in Study 6 and Study 7 which involved a collaboration with a visiting MSc student, Renee Noortman, who was inspired by my previous work. In these chapters I use the term ‘we’ to emphasise the collaborative nature of our work.

Ethical Clearance

All studies presented in this thesis have been cleared in advance through the departmental or UCL ethics committees. All participants were informed about the aims and design of the study in advance and informed consent was recorded through a signature on a consent form.
Chapter 1. Introduction

In this chapter I:

- Motivate and present the research question of this thesis
- Outline the contribution of this thesis
- Present the structure of the thesis

1.1. Motivation & Research Question

Technologies offer opportunities to enhance people’s lives and support them, but the context they are set in is often messy and complicated. Their use can encompass many stakeholders and contrasting values and emotions. The experiences are situated and cannot be easily explored through conversations or experimental studies in the lab. Many of the technologies are not yet available and cannot easily be tested. Nonetheless, an early intervention might not only make them more accessible, but one could also argue that we – as designers – have a responsibility to consider the ethical implications of the technologies we develop. In addition, research into sensitive settings is notoriously hard to do and might not be possible in all projects – or suitable in all phases. Is there a method that is forward-looking, ethically motivated and rich that could be useful in these contexts?

Design fiction has been successfully applied as a means for communication, exploration and research. It has made its way into the HCI vocabulary and it has shown promise to be useful in certain ways, such as in smart city planning [Baumann et al. 2018; Forlano and Mathew 2014], supporting ethical responsibilities towards data collection [Elsden et al. 2015; Luu et al. 2018] or exploring the uses of novel technologies [Heibbeck et al. 2014; Wong et al. 2018]. As it draws on the extrapolation of existing trends and observations, fictional prototypes can be as critical as the maker wants them to be. The settings can be as rich and futuristic as the skill of the maker allows, without the constraints or effort that physical development demands. But where does the skill of the maker lie and how do we evaluate an artefact when everything is possible?

Beyond its promise, design fiction has encountered criticism. It is currently not clear what is meant by design fiction and its rigour is not widely understood. Design
Chapter 1 Introduction

fiction is caught between two approaches: one that links it with speculative and
critical design approaches that ground it in a humanist philosophy and one that is
based in an empirical framework. Both approaches try to establish design fiction as
a means to generate or elicit discussions around emerging technologies but both
interpret this in contrasting terms. It is neither clear who is to be addressed by the
design fiction artefacts nor what suitable measures for the quality of a design fiction
are. Design fiction is increasingly used in HCI, but it is still unclear what the term
entails. Design is notoriously hard to define. This should not be seen as an inherent
flaw of the approach, but could be attributed to its novelty [Lindley 2015a]. Instead
it opens up the opportunity for researchers interested in design fiction to examine
and shape it. This PhD project adds to this effort by offering a new perspective on
design fiction.

Design fiction is mainly discussed from a theoretical, humanist and literary
perspective. Even though design fiction is increasingly used within HCI, few
authors add their distinctive definition to what design fiction is. Instead, design
fiction is often explained through taxonomies [Hales 2013] or typologies [Knutz et
al. 2014], as one approach to speculative design [Auger 2013] or through literary
theory (e.g. [Blythe 2017]). Going beyond this theoretical approach, I describe
within this thesis how I elicited insights relevant to design in sensitive settings by
using design fiction in an empirical manner. In this PhD project I explore how
design fiction can be used to support research in sensitive settings. I do so focusing
on technologies for dementia care, which often do not fit well into the context they
are developed for and pose ethical concerns. In addition to this particular use case,
I discuss how the insights gained about design fiction as a method can be
generalizable to other similarly sensitive settings. I furthermore develop an
empirical practice-based approach to the making and use of design fiction. I add to
the understanding of how design fictions can be made by adding extensive
preparatory work that preceded the development of the design fictions.

In this thesis I present a nuanced view on the futures of technologies for dementia
care. The position has been drawn from responses to design fictions I shared with
others. This has helped me to draw out insights about design fiction that go beyond
this individual case, but instead offer clarity to the different assumptions
surrounding design fiction. This is further supported by the structure of this thesis
that builds on the Constructive Design Research framework [Koskinen et al. 2011],
which classifies three ways in which design fiction can be used: showroom, lab and field. By using this established framework, I have been able to identify and emphasise the similarities and discrepancies of design fiction with other design methods which has helped to strengthen this promising approach. The project was guided by the research question: **What can we learn about technology use in sensitive settings through research through design fiction?**

### 1.2. Contribution

This thesis contains three main contributions: a methodological one, a contextual one and a range of artefacts:

Its **primary contribution** is methodological. I show that design fictions can be classified into three types based on the Constructive Design Research framework: in the showroom framework it can be a useful means for self-reflection by the maker that can be shared through mediums such as annotated portfolios or implications for design. In controlled settings, comparable to the lab approach it can be used as a method to elicit personal discussions that are critical about the technologies presented. In the field approach is can be used to elicit comparable results that carry fictional narratives or worlds into the mundane, everyday world and enable situated reflection over time. I further present extensive work that shows how different types of research can inform and inspire design fictions.

As these insights have been derived from employing design fiction in the context of technologies for dementia care, the empirical evaluation of the artefacts has also led insights into participants’ fears and wishes about smart home technologies for care that I present as the **secondary contribution** of this thesis.

As the title Homes for Life and Other Stories suggests, the thesis further contains a range of stories, or more specifically design fictions (also referred to as artefacts) that have been developed during the duration of this PhD project that I consider to be the **tertiary contribution** of this thesis. Homes for Life is the main design fiction that has been empirically evaluated. The other design fictions are referred to as the portfolio that I share and discuss in Chapter 7 In the Showroom. The stories are collated in the appendix, following the structure of the thesis. They can be read in two ways: following the narrative of the thesis (e.g., see the reference to the interlude on pg. 23) or as a companion to Chapter 7 In the Showroom. Within the
thesis I included references to the stories to enable reading alongside the narrative of the thesis.

1.3. Thesis Structure

To address the research question, this thesis contains

- Design artefacts
- Research into the use of technologies in dementia care to explore sensitive settings
- Research into the development and use of design fiction.

To structure this extensive work, the thesis follows an unusual structure. In the first part I describe how I derived at the research question, by narrowing the field down from critical design generally to design fiction specifically. I further describe extensive work undertaken to understand the domain area of technology-led interventions in dementia care to inform and inspire the design fiction on many levels. In the last part I turn to the Constructive Design Research framework and the research activities that have been done in each paradigm. The structure has been derived iteratively to give information where needed and the deviation from the standard structure is deliberate. The thesis is structured into three parts, which break down into the following chapters:
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Appendix II
In the introduction I motivated my research question: **What can we learn about technology use in sensitive settings through research through design fiction?** The two chapters presented in this part explain how I arrived at the question by narrowing down the research field. I outline how I moved away from critical design generally towards design fiction more specifically and what motivated this decision. I further outline how design fiction is placed within HCI and which open questions remain.

First, in Chapter 2 Understanding Critical Design I present a survey with practitioners of critical design to gain insights both into the theory and practice of design fiction, answering the question: **How is critical design used in HCI?** Instead of clarifying how design fiction and critical design are related, the study results work further towards problematizing the relationship. They reveal that opinions of what critical design is vary widely. They further show that design fiction has an elevated position within the HCI community as it was highlighted by many participants but its relationship with critical design is not unanimously understood.
Following this insight, I narrowed the focus of my thesis down to design fiction more specifically than critical design.

Second, in Chapter 3 Understanding Design Fiction I present the results of a literature review to answer the question **How is design fiction used in HCI?** in which I describe how design fiction is currently used in HCI and which open questions remain. The review indicates ambiguities between the way design fiction is described in theory and how it is used in practice. I outline why this is problematic. I conclude the literature review with open questions about the use in design fiction in HCI, specifically how to make and evaluation the use of design fictions. These are addressed in the remainder of the thesis as I explain the extensive research I undertook to inform and inspire the design fiction in part Prepare and the work I undertook to evaluate the use of design fictions in the last part: Evaluate.
Chapter 2. Understanding Critical Design

In this chapter I:

- Describe a variety of ways in which critical design is understood, discussed and applied in HCI
- Introduce the concept of critical design and its problematic relation to design fiction
- Motivate my decision to focus on design fiction above other critical approaches

2.1. Introduction

My first contact with design fiction was through critical design. At first I did not recognize it as something special. Reading Auger’s classification of speculative methods [2013], I understood it to be one approach among many for which critical theory is applied to contemporary culture and expressed through (material) artefacts. My interest in the topic therefore started with an exploration of critical design in general, before I narrowed it down to design fiction. In the study presented in this chapter, design fiction is only described within this larger context. I nonetheless decided to start the exploration of design fiction in HCI in this thesis with this study, which hints at many of the issues, questions and definitions described in the remainder of the thesis. Through the exploration of critical design in the views of practitioners I explore tensions in the way both critical design and design fiction are defined, lack distinction from each other and are used in a variety of ways.

The most quoted definition of critical design by Dunne & Raby is deliberately open-ended and ambiguous and mainly contrasts critical design with “affirmative designs” as something that “challenges the status quo” [Dunne and Raby 2013]. Bardzell et al. [2014] expand on this and suggest a matrix to “read” critical designs. This gives more detail to the understanding of what critical design aims to achieve. It is, nonetheless, still based in the humanist understanding that the literature review indicates is not shared by all. In addition, it lacks any insights of whether critical design achieves the goals it sets. The usability for design fiction for research has been addressed by
a range of authors, as a means to add to the theory of design fiction (see e.g. [Blythe 2017; Grand and Wiedmer 2010]), but these offer little insights of how to evaluate design fictions in the context of research. As a result criteria are not well-understood (see e.g. [Lindley and Coulton 2016a]). But it is to be expected that practitioners have an understanding – maybe tacit rather than explicit – of what constitutes ‘good’ or even ‘critical’ design.

Instead of turning to the theory of critical design, I undertook a survey with practitioners of critical design, mainly from academia, but also from commercial design backgrounds, to answer the research question: **How is critical design used in HCI?** The survey consisted of open questions to understand how they use CD, how they define CD and where its strengths and limitations lie. Using discourse analysis, I was able to clarify where opinions and positions differ. I outline differences in the way CD is discussed that highlight implicit biases and conceptions about its use. The main contribution of this study is a rich description of the way CD is understood by practitioners that highlights discrepancies. In addition, I suggest a range of terms that could be used in the description of CD projects to aid clarity.

2.2. Method

2.2.1. Design

To explore what practitioners, who have an interest in critical design, consider to be critical design, what they expect from critical design and how they evaluate it, I undertook a survey with mainly open-ended questions to gather rich, qualitative data. The survey was conducted online to enable quick and wide distribution without geographical limitations. While an in-person survey or even expert interview might have led to more structured results, we decided to pose the questions via an online survey to give higher anonymity and distance to the researchers. The questions enabled participants to respond freely.

2.2.2. Participants

To recruit participants, I contacted people with an interest in CD, mainly in academia, but also with an interest in responses from the commercial sector. While I placed the focus on HCI practitioners, I did not limit the survey to this field. Participants were recruited first through personal emails and secondly through
social networks via snowball sampling. Potential respondents were identified through publications with keywords ‘critical design’, ‘speculative design’ and ‘design fiction’ in the ACM Digital Library. Using SCOPUS with the same keywords, identified further publications from The Design Journal and Design and Culture, as well as one from Fashion Practice.

Overall, 74 responses to the survey were recorded. I excluded those (n=17) who did not provide any data or did not give consent to use their data. From those filled in partially (n=57), I included those who at least explained their interest in CD even if they did not respond to all the questions, which left 36 responses for analysis, of which 10 were only partial, i.e. more than 1 question was skipped.

Participants’ experiences and backgrounds varied widely. As would be expected from our recruitment approach, the majority of participants currently worked in the academic sector, either doing research (n=22) or education (n=7). Additionally, three participants who identified as ‘other’ explained that they were working in academia and therefore engaged both in research and education. Nonetheless, the survey was answered by four participants with an interest in CD in the commercial sector. Most participants declared that their current work was located in design (n=18). The second largest field was engineering (n=4). Most participants who chose ‘Other’ also worked in Engineering or Computer Science departments, but highlighted the multi-disciplinary nature of their work (n=8). Four participants identified as social scientists and two as working in the arts & humanities. Not only did a large number of participants emphasize their multi-disciplinary approach, but a large number had also changed their careers. About half (n=15) of the participants were educated in a different area to the one they were currently working in. While participants’ backgrounds and experiences varied widely, the study results indicate that a high number of CD practitioners have an interdisciplinary background and are reflective about this part of their work.

I did not gather any demographics from the participants apart from their experience with CD and educational and professional background, as other information was considered beyond the scope of the survey.

2.2.3. Materials
The survey was conducted online to be able to contact all first authors of publications on critical design in the ACM Digital Library who were not only
numerous but also distributed widely geographically. It was divided into three parts: first I asked participants about their background and their experience with CD. Participants who said that they had undertaken CD projects, were given prompts to support those who did not know where to start: “e.g. what topic they addressed, how you used CD or for how long you have been working in this area”. To enable participants to articulate what was of importance to them, I chose a free text entry field for the question regarding the experiences participants had with CD. While I was mainly interested in the views of those who were actively involved in CD projects, I gave participants the opportunity to explain why they were interested in the topic if they were not active designers. The inclusion of participants who had an interest in CD, but no practical experience, was done to learn if the understanding of CD would vary with concrete experience of using CD in design work. I also asked participants to define CD and to suggest an example of it. I left it open to participants to describe their own work as an example or present someone else’s. Following this I asked participants whether they considered the project they presented to be ‘good’, what makes the project they chose ‘critical’, how it relates to ‘more traditional design’, as well as what is lacking in ‘bad’ CD projects. Finally, I asked participants to respond to Dunne & Raby’s definition of CD, as quoted above, to learn how their understanding of CD was grounded.

2.2.4. Procedure
To ensure that questions were clear, I developed the questionnaire by iteratively testing it with both practitioners of CD and those who had only a passing interest in it. These results were not included in the analysis. Study participants were recruited as described above and had the opportunity to fill in the questionnaire for 30 days after the first participant was approached.

2.2.5. Analysis
Responses were collated first by participant and second by question to enable independent analysis as well as one that provides context and individual views. I read and annotated these responses in three rounds. While the process followed the approach to thematic analysis as outlined by Braun and Clarke [2006], I also paid particular attention to the way participants talked about critical design, inspired by the approach to Critical Discourse Analysis as described by Paltridge [2013]. This lens enabled me to not only find common themes in the data collected, but also
identify terms and phrases that were commonly used and explore their history and meaning. This initial and open annotation led to the development of a coding scheme based on the question of where participants placed the focus of critical design mentioned by participants as outlined below. Once the initial dimensions had been decided on from the annotations, the responses to each dimension were coded iteratively until codes were established for each. Memo writing was done throughout to investigate and discuss the relationship between the codes. Questions about codes and their relationships were resolved through discussions within the research team.

2.3. Results
As most questions were deliberatively open-ended and the survey contained many free text fields, I had rich data to use for this analysis. Overall, 36 responses were analysed, even though not all of them were completed. I focus on four aspects: First, I describe who responded to our survey to introduce the participants and especially their experience or expectations about critical design. Second, I describe the examples of critical design participants chose to present about critical design. Third, I highlight that participants did not describe critical design in a holistic manner, but rather focussed on elements that were important to them: either what critical design aimed to achieve, how it was done or who the audience might be. Through this lack of shared vocabulary, the results highlighted the underlying discrepancies of theoretical and methodological frameworks. Lastly, I report the different criteria and modes of evaluation participants chose to judge the quality of critical design.

2.3.1. Critical Designers
In this section I provide an overview of the insights gained about who uses critical design in their work and what expectations people have about critical design. I do so by discussing which interest participants had who had not done critical design projects, before I describe the context in which participants have done critical design projects.

Regardless of their own experience with critical design, participants had strong views on what to expect from using critical design, even though not all were sure about the concept. Eight participants indicated that they had not done a critical design project themselves. Of these, one participant expressed the wish to use
critical design in a specific context and one argued that their interest was in design fiction, but that they did not consider that critical in itself: “While the two can frequently overlap my initial interest is not to be critical of technology any more than romantic fiction is critical of love” (P12). Others highlighted advantages they saw in critical design, e.g. “how it blends creative and computational practice” (P36) or why they thought it might be a useful tool: “analytic lens and vocabulary to assess realities” (P23). One participant argued that they considered critical design to be an “embodied argument” and therefore was interested in the “rhetoric semiotics of CD products” (P26). Those who had not engaged in critical design or related approaches had nonetheless a strong idea of what they expected from using them.

However, the question of whether participants had conducted critical design projects was not necessarily clear cut, as many participants either specified that they do not normally consider their own work to be critical design, or outlined that they were not sure whether it would be considered to be critical design by others, e.g. “critical design specialists” (P29) As has been outlined in the literature, the question of critical design compared to related design methods are not yet clearly defined and this survey mirrors this. Throughout the survey, some participants suggested a wish for, or a need for an approach to design that went beyond critical design, but was nonetheless critical (of) design, e.g. P35 who describes the approach to design as follows: “I have always been interested in critical design/speculative design and more general ‘critical’ approach to interaction design”. Others acknowledged the variability of what critical design can mean and argued that whether the example of critical design they gave would be considered critical design was “(d)epending on the definition of critical design” (P10). Throughout the survey, participants mentioned speculative design or design fiction when making distinctions either from their own words or generally. P7 for example argues that they “does not characterise my work as CD”, but instead “work[s] with notions of speculative and/or design fiction”. The link to design fiction was the most prominent, even though the relationship between critical design and design fiction does not appear to be clear-cut. P19 argues that “design fiction has a strong connection to CD”, while P16 tries to make sense of the relationship himself: “my focus on CD evolved more (or specialised?) into design fiction”. This indicates not only a lack of a shared understanding of what critical design is, but also a lack of clear evaluation and quality criteria with which designers can evaluate and critique their own work.
Participants’ responses went beyond the prompts included in the survey. The results indicate that the participants had a wide range of experience ranging from “just one project” (P15) to the “past 8 years” (P9). Also the contexts varied widely: from university projects at different levels, e.g. “masters course” (P4), or as part of a PhD (P21; P28; P31) to a “little side project to my main work as HCI researcher” (P16). Most people who had done critical design in a PhD project had moved on to different subjects afterwards, and only one wrote that it was “used […] as a research method” (P17), which I mean to indicate that it was the main project. One participant highlighted that critical design was part of “my design exercises” (P5) and part of their curriculum. One participant who worked in the commercial sector (P32) explained that they had “used CD in non-commercial concept work”. One participant indicated they made it part of his everyday work to “approach unforeseen impacts of design of new technologies in transcendent UX and IOT” (P14), indicating that they used it in commercial work. Participants also had varying views not only of the context in which critical design should be made, but also how it should be distributed. This could, but did not have to be the same mechanism.

Overall, I distinguished two modes of distribution participants mentioned: academia and art. Throughout, the responses refer to academic papers, through which participants distributed their work, but also how they learned about it: “I recently read a new paper from CHI 2018 …” (P17). Participants also considered distribution through art outlets, but their opinions whether that was acceptable varied widely. One participant argued that critical design projects are “exhibition pieces aimed to stir people’s imagination and make them reflect” (P5) or that they are “suitable for public/art spaces” (P33). Others were more critical and argued that “it would have been nice if it could have existed outside the gallery sphere” (P3) or that “I am not particularly fond of many examples of CD that live in art galleries or exhibition [sic]” (P31). Participants had varying backgrounds and experiences with CD and used it in many contexts. They also encountered it through a range of channels, some of which were perceived as more acceptable than others. The variability of what CD can and should do can further be seen in the examples of CD participants chose, as I describe in the next section.
2.3.2. Examples of CD

Out of the 36 responses, seven did not give an example of a critical design project when prompted to do so. One participant explained that they did not have an example yet, as “the concept is still unclear” (P33). Out of the remaining six, half had previously undertaken a critical design project themselves, half had not, indicating that this was not linked to their experience with critical design. Other participants gave at least one example each, but many named more than one, leaving a total of 42 examples. Instead of focusing on the content of these examples, I describe the way participants talked about the projects. Three aspects stood out in particular: the frequency with which participants mentioned specific projects, the way in which they described the examples they discussed as well as whether they presented their own work or other people’s examples.

Some projects are more prevalent in the HCI discourse than others as a couple of examples were named more than once, e.g. the “After-Life” or the “Audio Tooth Implant” project by Auger & Loizeau (P3; P5; P16; P28) or work by Superflux (“Drone Aviary”, P16; “Uninvited Guests” P30). While participants overall disagreed what CD is and how it should be identified, these examples appear to be accepted in their ‘critical’ nature. This hints at discrepancies in where this criticality lies as participants placed the focus differently when describing the examples.

Participants highlighted different aspects of the projects. In some instances, the project was named or explained, while in others it was more clearly linked to a specific artist or set of artists, e.g. “the microchip in the tooth. Don’t remember the designer anymore” (P28), compared to “speculative fictions by Blythe” (P20). The “Menstruation Machine” was named a couple of times without the mention of the author or maker (P5; P10), while Dunne & Raby were named once without a specific project (P29). The identifier chosen to describe a project appeared to be personal. But most examples given by participants were specific projects or artists. However, one example was commercial, as one participant named the “iPhone” (P8). Two participants did not name a concrete project, but named “design fiction” (P14; P24) as an example of what critical design is. Examples went beyond individual projects, but show that participants have idiosyncratic ideas of what CD is.

Only five participants named their own work as examples, either as one of many “more central” works (P20) or as the only example (e.g. P4). One participant gave an
often cited example, Dunne & Raby’s Faraday Chair, but explicitly stated that they did not consider their own work to be critical design (P7). Another participant discussed in detail the critical approach to design that their lab takes and explained that it is critical by, “making space for voices that are especially underrepresented in privileged technology design conversations” (P20) which they contrast with “material, aesthetically-pleasing or provocative technological design artefacts” (ibid.). This last example in particular goes beyond the other examples presented and implicitly critiques them.

In this section I compared the examples participants chose to explain what CD is. This has not only given an overview of what was considered to be critical design, but has also shown that participants highlighted different aspects of the work. I identified participants who focused on the artist, while others were more interested in the topic of the project. Another distinction lies in the question of whether participants described their own work in detail or turned to others designer’s work, the discussion of which often pointed to the lack of confidence of whether it would be considered CD by others. In the next section I further unravel the similarities and differences by analysing in more depth how participants talked about CD in more general terms. As the aspects participants’ chose to describe their work varied so widely, I present the results in the three categories participants used to describe what CD focusses on: Outcomes, Audiences or Methods.

2.3.3. Focus of Critical Design

In the survey I gathered responses of what the outcome of CD is, i.e. the intention of the designer or the aim of the project, from both participants’ descriptions of their own work and from examples of what makes CD ‘critical’ or ‘good’. As a large number of participants of the study referred to the iconic definition of CD by Dunne & Raby that CD aims to “challenge the status quo”, but extended on this in their explanations, I chose this as the basis to structure this section. Here, I first describe how participants referred to the definition by Dunne & Raby, before presenting three interpretations of this definition: understanding, action and critique.
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<table>
<thead>
<tr>
<th>Classification</th>
<th>Question</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcome</td>
<td>What should CD achieve</td>
<td>“As a means to criticize phenomena in contemporary society” (P5)</td>
</tr>
<tr>
<td>Audience</td>
<td>Who should be addressed by CD?</td>
<td>“But it definitely makes everyone stop and think how they would feel about something like that.” (P28)</td>
</tr>
<tr>
<td>Method</td>
<td>How should CD be done?</td>
<td>“This is often done by designing some sort of diegetic prototype which carries one's message” (P5)</td>
</tr>
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Table 1: Comparison of where the participants placed the focus when describing critical design

2.3.3.1. Outcome

The designer duo Dunne & Raby have been widely recognized as an inspiration behind the recent uptake of CD (see e.g. [Bardzell and Bardzell 2015]). Even though not without debate (see e.g. [Malpass 2013]) this predominant view might be one of the driving factors why their definition was widely used by participants in our study. Two participants referred explicitly to the Dunne & Raby definition: “I would define Critical Design as what Dunne & Raby used to define it” (P7) or linking to their website and quoting verbatim (P16). Ten other participants used the term “challenge” in their definition without the direct link. Some nonetheless were close to the definition by Dunne & Raby that critical design is used to “challenge narrow assumptions, preconceptions and givens about the role products play in everyday life” [Dunne and Raby], e.g. when stating that critical design projects “challenge assumptions and preconceptions made in everyday life” (P12). Especially the notion that critical design is a means to ‘challenge assumptions’ was picked up by participants eight times throughout the whole data. Others built on the definition and extended it as they saw fit, partly through small changes, for example that critical design is a means to “challenge the power structures of the status quo” (P20), partly when describing their own projects and describe the individual aims: “challenge householders [sic] perceptions on suitability” (P15). This participant argued that the “topic that was being challenged” (P15) not only stood out about the project they chose as an example, but also that the project was critical “because of the topic they chose to challenge” (P15). The critical nature of design here is not placed in the artefact itself, but comes from the subject area it addresses. But critical design was not only considered to be a challenging to “thoughts” (P9), “narrow designs” (P3) or these specific projects, but also more
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structural goals, such as “design education” (P31), “existing consumptions practices” (P11) or “traditional research” (P1). Another participant brought in an element of time, arguing that the term did not refer to “common beliefs or assumptions” (P16), but rather that it should extend to “existing or upcoming norms” or “emerging norms” (P29). In most of these examples, the ‘challenge’, be it personal, structural or behavioural, appears to be the main aim and intended outcome of critical design. But throughout the responses, I further identified participants that described “challenging assumptions” as a means to achieve a greater goal, in particular: understanding and action.

Many participants’ responses indicated that CD could be used to generate knowledge and gain a deeper understanding about a subject. I identified this theme by looking into descriptions participants chose and collated a wide range of descriptions under the theme ‘understanding’, e.g. “investigate” (P25 & P27), “to understand” (P17) or “surface” (P27). Participants often emphasised that critical design offered novel tools to generate knowledge, e.g. by stating that “CD was used as a method to expand conventional ways of Knowledge [sic] production” (P22) or “to understand a phenomenon in a new way” (P17). One participant highlighted that critical design has the advantage that “we can gather more honest and deep opinions about the topic” (P4). Participants not only used CD as an extension of methods that stemmed from a humanities background, but also as a tool that delivered specific – and preferable insights. ‘Challenge’ in this context is interpreted as a nudge to enable reflection.

Many participants highlighted that reflection is the most important aspect of CD. One way to generate knowledge was either as “design that is self-reflective” (P24), or as a tool that “guides users/participants to reflect upon [existing assumptions/beliefs/attitudes]” (P15). This is distinguished from other types of design, as “Critical designs are not meant to be used, but to spur reflection” (P5). One participant argued that in a specific project, an online game: “The player is forced to reflect …” (P9), indicating that the design inherently leads to reflection. Others even more explicitly argue that this is the main aim of critical design, when e.g. discussing one particular example: “Most people interpret it in a functional sense, assuming that it’s a device meant to serve a purpose, rather than thinking about as a provocation for reflection [sic]” (P10). Not only does it not “seek to be functional”, but it also “proposes an alternative which cannot be ‘scaled up’ but that instigated discussions” (P31). One participant for example argued that it led to “better discussions with possible stakeholders” (P14), even though this is not contrasted with any other method or tool. The participant went on to outline that this use of critical design
was useful within the bounds of their project: “In that it created discussion and friction ... it was successful. No actual product has been developed yet but stakeholders are now aware of paths that cannot be ethically chosen now.” (P14). Instead of the artefact, reflection was the most valued outcome of a critical design project. In addition, participants specified the type of reflection generated through critical design.

Some participants used the term “discussion” generally. Others instead offered a narrower view, for example to “generate critical and reflective discussion” (P27). This distinction appears to be important to participants who used this not only as a means to distinguish CD from other approaches to design, but also to highlight that this distinction is often misunderstood by others. Few of these references to understanding were made in the definition of CD, but were rather stated when describing practical applications of CD. This suggests that the practice of CD differs from what is shared in the current theoretical frameworks. This leads to the question of whether understanding is part of “challenging the status quo” or whether it constitutes a different aim that might need more explicit description and novel criteria for evaluation. Viewed through this lens, CD is a means to “critique” (e.g. P11; P27; P31) or “critically envision the future” (P23). Throughout the responses 13 mentions of critique (including derived forms such as “critiquing”) appear. This use and outcome of CD has been used most predominantly in the definition of CD, but also has been highlighted as a means to make design critical and also of high quality, e.g. “but more importantly the very clear critique and message of how we look at work and productivity” (P6). Nonetheless, critique does not always imply that a viewer is forced into action, as critique can be “inherent” (P6) and does not have to be explicit: “It does not explain how or why it encourages critique” (P9). Only one participant suggested a means to evaluate the critique, by arguing that “The object should offer some insight into the link between ‘how things get designed’ and the things that we live with” (P9). This implies that the intention of the designer plays a large role in the development of CDs. But understanding was only one aim mentioned by participants: another was the interpretation that CD should lead to action.

In addition, participants also suggested that critical design should be actionable or lead to actionable changes. Some participants used critical design in their own work with a motivation to not only make people reflect and learn, but to take further action, as one participant stated explicitly: “for the purpose of generating reactions, actions or discussions” (P31). Participants argued that the design should include a ‘question’
or ‘critique’ that would “make people think” (P4) or even “reconsider their choices” (ibid.). P10 used two similar descriptions, which nonetheless place the focus somewhere else: they first emphasise the active role of critical design as “critical design is about asking questions”, before later stating that critical design is “meant to provoke questions”, indicating that the question is not inherent in the artefact itself, but made in collaboration with the viewer. Another participant described the role of the object as “to point at something worth discussing or questioning” (P5). Therefore, an artefact developed during a critical design project is a means to another end, e.g. “it questions to create another future than in which everything is maintained in status quo” (P21) or to “trigger audiences into questioning issues and power hierarchies” (P25). The relationship between the artefact, the designer and the audience was interpreted differently by participants.

Asking questions implies an audience; critical design’s ability to generate discussion was often seen in one specific context: it was often described as a participatory tool. For example, one participant described it not only as a means to “help workshop participants envision, understand” (P5) but also to “prepare for their future in their rapidly changing field of operations”. A similar aim of supporting participants was also voiced by P2 who argued that their objects were used to “encourage my audience/participants to create their own representations of the future” or “to support changes in the participating families’ practices” (P21). In contrast to focus groups or comparable HCI methods, critical design promised to lead to actionable outcomes for the participants, not only knowledge generation for the researchers. Other participants highlighted the use of critical design not only for research, but as a means of “advancing any design solution at hand” (P13). These responses hinted that design is not only seen as a tool for reflection, but that it also leads to practical outcomes. Reflection can be done as self-reflection, by designers about design. But, he examples here further indicate a shared view in which the critical designer works together with others towards a shared goal.

In addition to the way critical design was described, I also asked participants about the history of critical design and examined their views on the influence of Dunne & Raby on the field. The results confirmed my expectation that their work was widely known. From those who answered the question only two were unaware of Dunne & Raby’s definition. However, views were divided on the importance of their work and when looking deeper into the descriptions participants gave about their relationship to the definition, differences became more clear, depending on
where participants saw the beginnings of critical design. While some participants considered Dunne & Raby to be the ‘founders’ of critical design and aligned themselves closely with their definition, others were much more tentative, or distanced themselves completely from this definition. P2 argued that designers should also “[explore other] ways to frame criticality through design”, while others specified other researchers, such as “the Bardzell” or “Malpass” (P5) or even designers from other time frames, such as “radical design, the Situationists, Archigram etc” (P11). The range of views on the history of CD led to a range of interpretations of what critical design should aim to achieve.

Participants’ views could be seen as three interpretations of the term “challenge”: a challenge inherent in the artefact that is a suitable outcome of a critical design project or the critical design project as a means to an end, particularly a means to stimulate reflection and generate discussion or even beyond that, the critical design project as an impetus for change. In the next section I describe in more detail how participants thought about the viewers or audience of critical design.

2.3.3.2. Audience

To categorize the way participants discussed the (expected) audience of critical design, I distinguished three aspects: the degree to which the audience was described, the reach of the artefact and the position of the designer themselves.

Participants described the potential outcomes of critical design in a variety of ways as reflection or discussion, but few specified who the actors of this discussion and therefore the audience of critical design should be. A few avoided the question altogether, e.g. by referring to abstract groups such as “people” (e.g. P7; P20) or “audiences” (P25) or argued that a piece “facilitated discussions” (P14). Others were more specific and for example indicated that they referred to their “users/participants” (P15) or the “reader of the paper” (P21). But not only the type of audience, also the size of the audience was discussed.

Many participants argued that a large audience would be a preferable outcome for critical design projects, not only in terms of their number, but also their diversity, e.g. as one participant commented: “I think they are good examples in that their output is very visible” (P2) or that “it definitely makes everyone stop and think [my emphasis]” (P28). This is contrasted with art exhibits that are “probably only accessible [sic] to particular audience” (P11), which others refer to as the “gallery sphere” (P3). The art world was
considered to be limiting. Positive examples of critical design instead “made it to the media” (P28) or received “lots of public engagement. Lots of discussion from academics as well as journalists and interested public” (P9). The quality of critical design was judged in relationship to audience reach, but this also extends to the question of where the critical design project is placed in regards to design itself.

The question of reach is related to where the participants positioned themselves in relation to the critical design project. Another group of participants placed the audience more in relation to the design world, e.g. by positioning it as a means to explore alternatives that “standard product process development tools, like lean and design thinking, cannot or will not examine” (P14). This, comparable to the response from another participant that “CD is design that is self-reflective” (P24), implies that the design world itself is the audience of the critical design. But the relationship between the participant and the audience was not always as clear-cut. One participant placed themselves outside the design world and argued their artefact “question[ed] the way, I imagine the designers would think” (P21). Another argued that critical design is used “to make people think about current developments or situations that we take for granted [my emphasis]” (P4), placing themselves in with the audience, even though they are more abstractedly referred to as “people”. One participant saw critical design as a connector between design world and “others” (P30) as “it becomes part of a wider discourse”. Participants took different stances of whether critical design should address designers or comment on design or whether it should reach beyond the design world.

Within this section I described three ways in which participants discussed who the audience of critical design should be but also highlight that many participants did not mention audience at all. A topic that was raised more widely was the question of which methods or strategies should be used to reach these audiences as I discuss in more depth in the next section.

2.3.3.3. Method

By enabling participants to discuss critical design in their own words, I was able to extract not only what participants considered to be a desired outcome and who should be involved, but also how one might be able to do critical design projects. I distinguished two ways in which that could be conducted: either as a general description of how critical design is done or by providing strategies that make
design critical. In general terms, many participants emphasized the role of design in the process. Two ways of using artefacts can be distinguished: making artefacts or using artefacts, e.g. “designing some sort of diegetic prototype” (P5) or that in their own work they “use designed objects” (P2). One participant combined the two points and specified that it encompasses the “making and displaying of a prototype” (P28). This is most often referred to as “artefacts” (e.g. P9), which also encompasses non tangible designs, such as “scenarios” (P4) or “speculative visualisations” (P31). Participants highlighted the role of the artefact, but remained vague about what makes the artefact or the critical design project as a whole critical.

Other participants were more specific in pointing out properties that made the artefact critical. Participants’ responses indicate that finding the correct level of criticality is not easy. When discussing negative examples of critical design, participants warned that a tension exists between “subtlety and the extreme case” (P4). Even though one participant lauded an example of critical design that was “uncomfortable, unexpected and challenging” (P26), another warned that “overuse of dystopian fictions” could lead to “metaphors shutting down discussions rather than balancing complications of human choices within complexities of nature” (P14). While these are properties of artefacts, other participants framed it more as strategies used in critical design.

A third strand of responses indicated that the designer could use specific strategies to make design critical. Participants for example referred to “transgression” e.g. “it transgresses against conventional design principles” (P17). In addition, they described the effect it might achieve, such as that viewers would be “surprised” (P4) or that the design is “absurd and polarises people to some extent” (P28). This quote suggests that humour might be another strategy, but participants also warned that bad critical design “lacks a seriousness” (P30). Transgression was also described in varying levels of abstraction: one participant described a critical design project as one that explored how in-game events could be translated into the real world by using blood as an interaction design” (P6), which I classified as transgression, while another participant who had a more abstract interest in critical design, argued that one example of critical design is “about pushing the semantic meanings” (P26).

In this section I described methods suggested by the participants that made design critical. Not only did participants have different ideas what was important to critical
design, they also varied in their evaluation of the strategies used. Some referred to the process of developing or using an artefact. Others went beyond this and highlighted specific strategies, such as transgression that were important to the criticality of the artefact or made good critical design. Following up from this question what makes critical design good or bad, I describe in the next section how critical design should be evaluated.

2.3.4. Evaluation

In this section I present participants’ views on the evaluation of critical design. This was rarely done explicitly but more often when stating what makes good – or bad - critical design. I interpreted these suggestions as criteria that were important to critical design, i.e. those that critical design should be measured against. In this section I focus on the granularity of the evaluation, the intention of the designer and the rigour of critical design.

I observed a distinction between specific properties vs. specific outcomes of critical design. Some participants evaluated the projects they chose with reference to specific outcomes, e.g. by arguing that it led to “lots of public engagement” (P9) or as “it makes the reader of the paper reflect on previously ‘hidden’ aspect of women’s lives” (P21). These types of evaluations were mainly surfaced when participants were asked to reflect on what makes a critical design project ‘good’. These varied widely and were often highly individual to the project, e.g. “Because it redefines what a chair is and what it means to live in an electromagnetic space of wirelessness” (P7), which could hardly be used to evaluate critical design in general, one can assume that participants have their individual interest in projects and personal criteria that are important to them. Neither the individual evaluation of own projects nor those of others have been given much attention. Nonetheless, it seems to have an impact on how participants perceive the designs. Other participants highlighted specific properties, e.g. “I would say bad CD is something that is not new”, which is often also linked this to an outcome: “and therefore doesn’t invite to that much reflection” (P28). The participant took the role of a critic, which implies that critical design can be judged from the outside. But this view was not unanimously shared.

From participants’ responses I identified three positions of where the criticality of critical design lies: in the intention of the designer, the artefact itself or in the interplay with or reaction from the viewer of the artefact. These different positions
can also be observed in the responses gathered into the theme of evaluation. One participant argued clearly, that “it’s [sic] intention makes it critical design” (P25). Criticality in this view is not linked to a specific outcome or response, nor does it lie within the work itself, but is linked exclusively to the designer. This poses the question of how the intention is communicated to others to make it recognizable or whether this matters at all. This poses the question of whether the audience for critical design is the designer who produces the piece or a wider audience. Other participants argue that the designer might have an intention with the design, e.g. “it seeks to critique” (P31). Here the intention is less direct as the work does not seem to be inherently critical, but aims to achieve something. Considering the discrepancies in opinion, it is unclear how to ensure the quality of critical design. Participants’ responses further imply that critical design is judged through varying frameworks.

Another tension lies in the relationship between humanism and empirical evaluation. One participant outlined that they knew of only one project in which “the author … talks about empirical evidence about whether this kind of work can support the claims it makes (which I find very important)” (P2). Another participant expressed a similar criticism of specific designers, by arguing that “they don’t interrogate their own designs as scholars” (P7). While this lack of empirical, or scholarly evaluation of critical design was criticised by these two participants, another participant had strong concerns about using critical design in an empirical way: “I think that research that employs critical design often misplaces effort when it employs traditional ‘user studies’ or ‘user deployments’ as a means to generate knowledge from the design” (P17). They go on to explain that CD does not solve a particular problem and therefore “it’s not clear to me what insights are to be gained from having ‘users’ interact with a critical design, unless those ‘users’ are directed to perform some kind of critical reading and have some expertise or motivation that enables them to do this” They further link the design to art, by arguing that “A poet doesn’t conduct a focus group or user test to understand a poem better! But the poet might attend a writer’s workshop or have the poem read by a literary critic”. This is strong argument against empirical evaluation, but instead places critical design clearly within a humanist framework in which the artefact would be ‘read’ and its audience would be a group of other designers, rather than a general public.

These two positions appear to be contrasts: one humanist, the other empiricist, but it can be noted that they address two positions: whether critical design itself should be evaluated through empirical means or whether research through it should be
done in an empirical way. Only one participant mentioned rigour specifically, when critiquing that a specific project did not have “a thorough grounding in critical theory”, which made it “not very rigorous” (P29). They go on to say that: “We all like to think of ourselves as being well-intentioned, but that doesn’t mean that all our work is CD”. This quote links critical design with “good intentions”, i.e. a wish for change for the better, but this in itself does not imply that the intention is enough to make critical design. This view contradicts the suggestion that the criticality of a design lies in the intention of the designer, highlighting another discrepancy of how critical design is perceived.

This section has revealed a lack of clarity even between critical designers of how critical design could and should be evaluated. A minority of participants are interested in an empirical evaluation of critical design. Others instead argue that the criticality is inherent in the design if the designer has the intention, which would make any type of formal evaluation useless. Additionally, participants not only hold the critical design projects against abstract values, but highlight particular outcomes that are specific to the project and to them. Overall, the study results have revealed a wide range of discrepancies of what critical design is and what is important about it.

2.4. Discussion

For this study, I undertook a survey with participants who self-identify as practitioners of critical design to learn how they understand the term and how it relates to other design methods. The study results have shown that critical design is done in a range of contexts, but the results suggest that it might be favoured by practitioners with an interdisciplinary background and research interest. The study results further indicate that it is not yet agreed on what constitutes the criticality of critical design and participants drew on many different projects and methods to explain what it meant to them. While the study was not as useful as expected to present a classification of the use of critical design – and by extension to learn where design fiction is situated – it further problematizes the use of critical design in a wide range of meanings. The following discussion is divided into three parts: first I frame the lack of distinction between key terms. Second I discuss the idea of criticality and where it sits in relation to the artefact and the audience. Third, I discuss what the study results reveal about design fiction and its relationship with critical design.
2.4.1. Interpretations of Key Terms

The lack of agreement on definitions of critical design has been acknowledged by a range of authors (e.g. [Auger 2013; Swan and Boehner 2013; Ferri et al. 2014]), who, among others, have responded by developing taxonomies [Ferri et al. 2014; Malpass 2017; Hales 2013] or by adding to the theory behind critical design [Bardzell and Bardzell 2013]. For this study I turned to practitioners, rather than theory to learn how designers and researchers who view their work as critical design understand and define it. As the results have shown, understanding varies widely, which is mainly due to individual interpretations of key terms. Here I look into two points: first, the varying definitions of the term Critical Design and second, the variety of interpretations of the Dunne & Raby definition. The impact Dunne & Raby had on CD as a field and on making it widely known is undisputed, but the literature is divided on how they relate to it. Swan and Boehner [2013] link CD directly to Dunne & Raby, while Bardzell and Bardzell [2013] for example link it to the Frankfurt School and Critical Theory, while others [Malpass 2017; DiSalvo 2012] link CD to Italian Radical Design. Participants’ views mirrored this distinction. While I could not find any direct link between the way participants talked about CD and their understanding of its history, it might have an impact on the understanding of CD as each of these schools has varying aims and agendas.

In the call for the study and within the survey questions I used the term critical design throughout. I deliberately chose this ambiguous term and refrained from giving my own interpretation, but instead asked participants to provide their views. With this strategy, I was able to elicit responses that show that the term is not unanimously understood even by those who consider themselves to be critical designers. This lack of clear distinction is not in itself problematic, as for example [Swan and Boehner 2013] point out that it enables critical designers to respond to the variety of contexts it is used in. But the study results have shown that some participants were unsure whether they themselves considered their work critical or whether it would be accepted by others as critical design. As Lindley and Coulton [2016a] have pointed out, this lack of clarity is problematic for scientific methods such as peer review. What is needed therefore is a way to describe and distance critical design clearly from other approaches, without the need to “codify it” [Swan and Boehner 2013:22], i.e. to be too prescriptive and thereby limit the creativity of design.
Current examples of proposed mechanisms of judging or ‘reading’ critical design, such as the matrix suggested by Bardzell et al. [2014] are intended for trained and experienced members of the critical design community. Nonetheless, it is unclear whether lay participants encounter critical design as such. These survey results also show that some practitioners themselves do not approach critical design in this way. Another problem with the current attempts of clarifications is that the authors themselves often highlight that their classifications are neither complete, nor prescriptive in the attempt to allow for creativity in the field (see e.g. [Swan and Boehner 2013; Bardzell et al. 2014]), which leaves room for interpretation, but interpretations drawing on these are often not made explicit.

Dunne & Raby have an ambiguous relationship with art as they mainly exhibited in art galleries, but pointed out in the FAQ published on their website that critical design “is definitely not art” [Dunne and Raby]. The boundaries between art and design are blurry, as for example pointed out by Cross [1982] and they seem even more vague in regards to critical design. The relationship between art and design was one item that divided the participants of this study. While some argued that critical design is made for exhibition, others pushed back and specifically made the critique that design exhibited in galleries is divorced from its intended context. Not only the type of distribution of artefacts, but also the role of artefacts was disputed as some participants considered critical design objects without function as just art. One question arising from this that has previously been given little attention is what makes critical design not only art, but also design. This becomes especially relevant with regards to design fiction, which often does not even result in an artefact. I come back to this question in the reflection in section 7.2 The Artefacts when describing my own design fictions. In the next section I discuss the results in relationship to where the discrepancies between participants are situated and how they could be grounded in the way critical design is discussed in the literature.

The results have shown that Dunne & Raby’s definition of critical design is widely used to communicate what critical design is, but that the term is interpreted in a variety of ways. Critical design – and related approaches – have been pulled in many directions, depending mostly on the related fields it has been aligned with, such as activism [Markussen 2013; DiSalvo 2010], prototyping [Lindley 2015a], research methods [Grand and Wiedmer 2010], or humanist exploration [Bardzell and Bardzell 2013]. I suggest four criteria to describe the aims of critical design based
on the results of our survey and the literature on the topic: **challenge, critique, call to action and change.** All of these could be considered critical, but the level of what they aim to achieve varies.

A **challenge** is provocative, but ambiguous. It challenges the audience to engage with a topic, but leaves it open which steps to take, if any. The “Menstruation Machine” by Sputniko, mentioned by some participants in this study, could be seen as an example. Not only did the participants themselves provide a range of different readings of the artefact, so did Bardzell, Bardzell and Hansen [2015].

A **critique** in contrast is directed at one or more specific problems that are explicitly addressed. The work by Superflux, especially the Uninvited Guests video, highlights contrasting aims and wishes between those whose health status might be monitored and those who do the monitoring and falls within this category. While critical, it is still ambiguous and does not include any suggestions of how to resolve the situation.

A **call to action** builds on the critique, but openly advocates for change, e.g. by presenting implications for design or for action. While participants in this study did not give examples of this explicitly, the paper on sustainable HCI [Wakkary et al. 2008] could be considered an example for this type of use.

**Change** not only uses the critical design to critique, but as a means to generate real-life change. While explicitly not defined as critical design by the participant themselves, the example by P20 who empowers others in their everyday work might be seen as an example for this.

It is understood that creative projects are open and exploratory in nature and often do not follow one aim, but rather explore a multitude of nuanced possibilities. Therefore, these terms are not meant to be prescriptive. Instead, they are suggested as discussion points for authors to make their position more visible to others. Especially following the debate that arose around the use of probes in HCI (e.g. [Boehner et al. 2007; Gaver et al. 2003; Hemmings et al. 2002]), this could be understood as an attempt to classify critical design as a means to work towards making it accountable. It is supposed to be understood as a means to trigger constructive discussion about the different ways in which critical design – and its
related approaches – is and could be beneficial to HCI. Instead of aiming for a new framework, this goes towards a “shared vocabulary” as e.g. suggested by Ferri et al. [2014] The study has shown that some practitioners themselves are unsure about the nature of their work and these suggestions go towards focusing this debate. As do the reflections on criticality that I address in the next section.

2.4.2. Audience, Artefact & Designer

Participants discussed critical design in a variety of ways and few patterns could be observed. Nonetheless the lack of clarification of who the intended audience is stood out. When describing the results of where participants placed the focus, audience did play a role, but it was the least talked about. The literature shows a similar picture, as the audience is given little consideration in descriptions such as “critical design projects are meant to raise questions and encourage dialogue” [Swan and Boehner 2013:17]. In a field that is centred around the concept of a ‘user’, as debated as that might be (see e.g. [Blythe and Dearden 2009]), this lack of classification is surprising. The choice of audience might be specific to each project and cannot easily be generalized. One specific point stands out nonetheless: in many participants’ contributions is was unclear whether the audience was supposed to be the designers themselves or someone else. This is related to the question of what the contribution of the critical design project is: insights about the process of designing, the artefact itself or the responses it generates. A framework specific to critical design could be a useful means to make these distinctions clearer and easier to describe by practitioners. While a widely accepted research-through design framework in HCI, the Constructive Design Research framework, by Koskinen et al. [2011] puts critical design squarely in one type of research, the showroom approach, the results of this study suggest understanding its use in other types of approaches, such as lab and field could be a useful extension. I follow up on this in the third part of the thesis: Evaluate. Considering how debated the term critical design currently is, it has to be decided whether design that acts in a different framework or epistemology should still be called critical design or whether a novel label might be useful. The relationship between design approaches, such as speculative design and critical design is debated. It furthermore remains unclear how to distinguish between design that is critical and that which is not. While a range of authors have attempted to classify design that is critical, be that critical design or related approaches [Malpass 2013; Swan and Boehner 2013; Auger 2013],
little consideration has gone into the reflection of what makes other types of design non-critical. Design that is affirmative in the sense that it “reinforces the status quo” [Dunne and Raby] is the main distinction used.

However, the dichotomy between affirmative and critical design has been called into question, at a workshop at DIS’18 [Forlizzi et al. 2018] and beyond [Blythe et al. 2018]. One of the questions that this survey set out to understand, but failed due to the complexity of the answers, is the question of where the criticality of an artefact sits. Bardzell and Bardzell [2013:3305] draw heavily on critical theory and examples to “tease out a number of critical concepts”. In this survey participants argued that criticality was either in the critical thoughts or actions it evoked, or in the intention of the designer or artefact. This could be related to the framework participants place critical design in, either as research-through design, in which the artefact is a research outcome or as design-through research, in which the artefact is a means to an end [Fallman 2007]. These considerations are mostly implicit in the description of what critical design is. But as both are clearly visible in the survey results, both are equally valid. Nonetheless, they should be made more explicit. In addition to a debate about what makes design critical, I encourage practitioners to highlight where they place the criticality of their projects. I suggest the three talking points: why is critical design a useful strategy, what makes the project critical and what does it critique?

To make the concept of critical design more concrete for participants, I asked participants to give examples. This method is common in theoretical descriptions of critical design (see e.g. [Swan and Boehner 2013; Ferri et al. 2014]). Instead of suggesting them as a canon [Ferri et al. 2014] or by other means trying to classify or analyse the examples themselves, I described in more depth how participants talked about them. Some of these give insights into the way of how people not experienced in ‘reading’ CDs think about them, e.g. when describing a project in more depth. In addition, it has shown that some participants linked CD to specific designers or methods, such as design fiction, which again poses the question of where criticality sits.

2.4.3. Critical Design, Design Fiction & Beyond

In this study I asked participants about their experience with and understanding of what critical design is. I chose this term not in spite of the discrepancies surrounding
its definition, but instead as a deliberate attempt to learn what participants understood to be critical design. While in the survey the term critical design was used throughout, I reached out to practitioners who were interested in the related fields. For example, authors of publications with related keywords, such as speculative design or design fiction were included into the call. With this I wanted to learn how practitioners related to the term and whether they included their work. The results both show that not all participants were sure of what constitutes critical design, as I outlined in the section 2.3.1 Critical Designers, but also that participants were aware that the borders of critical design are not well-defined and areas overlap (see also [Auger 2013; Swan and Boehner 2013]). Current classifications of design approaches that are critical include e.g. “adversarial design” or “speculative design” (see e.g. [Malpass 2013]), which were rarely commented on in this survey results. Design fiction instead, was mentioned by a range of participants specifically, either as a type of critical design or specifically contrasted to it. This indicates that design fiction is of significant importance to critical designers in HCI.

Nonetheless, few examples presented in this study were projects that were classified by the makers as design fictions, with the exception of the work by Mark Blythe, who was named specifically by P20. While this might have been influenced by the explicit call for the study to do with critical design, it also poses questions about the visibility of design fiction. Design fiction, that is explicitly advertised as such, is rarely visible in the popular media. Even within the academic literature design fiction is often not as prominent as critical design, due to its immateriality. It might blend with non-fictional papers, such as for example the Drone project [Lindley and Coulton 2015a] or the Fit4Life paper [Purpura et al. 2011], in which authors deliberately hid the message of the fiction within a paper that looks non-critical at first glance. As a result, design fiction does not appear to be as ‘provocative’ related to related methods and therefore might not be the first reference. This begs the question whether design fiction needs different criteria to judge its quality than other critical designs.

The results nonetheless indicate that design fiction is not unanimously understood. In particular, the question of whether design fiction is inherently critical was raised by the participant who compared it to “romantic fiction”, which does not critique love. This poses interesting new questions about the inherent value of design fiction and the motivation for using design fiction as a method, compared to other design or
research methods, but also contrasted to other critical approaches. A classification of design fiction projects in HCI might highlight comparable relevant discrepancies as this study reveals for critical design. As the field is constantly developing at the moment, I refrained from presenting such an overview in this thesis. Instead, I follow up on the underlying question how design fiction is used in HCI and which types of insights it can contribute to HCI.

2.5. Conclusion
In this chapter I presented a preliminary study for which I approached participants who had published in HCI and self-identified as having an interest in critical design to learn about their understanding of the term critical design. The study has led to three key insights about critical design:

- Interpretations of key terms vary, but definitions are often kept vague
- Neither the role of the audience, nor that of the artefact is explained regularly, which poses questions about accountability of critical design as it is unclear what designers aim to achieve with critical design
- Different strands within the approach lack distinction from each other

The study offers many points for future work in the context of critical design. In the remainder of this thesis I will look at design fiction, its definitions in relation to critical design and its position within HCI. I decided to follow up on design fiction more specifically for two reasons: First, I acknowledge its predominance in the HCI arena. Not only within this study, but also beyond exists a strong interest in design fiction and its opportunities. This can be seen for example through a steady rise in publications on the topic. Second, design fiction in its variety of uses seems to be at the heart of the conflict between humanist evaluation and empiricist rigour that the participants in this study described. With the results of the study in mind, in the following chapter, I present a literature review on how design fiction is used in HCI.
Chapter 3. Understanding Design Fiction

In this chapter I:

- Give a working definition of what design fiction is, based on the current literature
- Motivate the use of design fiction in HCI research as a tool to undertake research in complex settings as a means to address sensitive topics.

3.1. Mapping the Use and Evaluation of Design Fiction in HCI

In the last chapter, Chapter 2 Understanding Critical Design, I explored the views of researchers in HCI on critical design. The study revealed tensions in the way this approach to design is discussed. I narrowed down the focus of this thesis to design fiction and describe here in more depth how HCI defines and uses design fiction. In this chapter, I describe how design fiction has developed in HCI, how it is currently used and which strategies are attributed to it. Following these observations, I outline ambiguities in the way design fiction is discussed. Design fiction is used both in the design process and as a research tool. I give examples of how it can be used in the design process, but focus on the research process, particularly its use in design research within HCI.

When turning to the literature about design fiction, three types of paper can be identified: those that are design fiction, those that contain one or more design fictions and those that are about design fiction. The first group contains two types of paper, based on how realistic they appear. Some are clearly fictional, e.g. when providing a look back from the year 2082 to current HCI research from the perspective of the robot overlords that will have taken over control by then [Kirman et al. 2013]. The paper has a strong inherent critique of current practices in HCI through its dystopian outlook. But the paper does not contain any text that explains or clarifies the author’s perspective. But other papers in this group are not as obviously fictional, but instead mimic traditional research papers, with the exception that the research proposed is entirely fictional. The Game of Drones paper
Chapter 3 Understanding Design Fiction

[Lindley and Coulton 2015a] contains the outline of a research project in progress and its fictional nature is only apparent through the use of the keyword ‘design fiction’ and a short explanatory text in the conclusion in which the authors explain that the paper is fictional and explain their reasoning for creating it. These could be considered extreme examples, but the presentation of design fictions in academic papers itself is not unusual. Out of the 105 publications in the ACM Digital library with the keyword ‘design fiction’ I reviewed, 68 either contain or describe a design fiction artefact. The remaining papers are more theoretical in the sense that they discuss design fiction by comparing already existing artefacts, e.g. of real-world projects to provide a taxonomy of design fiction [Knutz et al. 2014], discussing games that were announced but not produced to learn more about the future of gaming [Coulton and Lindley 2016] or commercial concept videos to learn more about the future of computing in general [Wong and Mulligan 2016]. Other papers do not give any examples but explore design fiction as a “toolbox” for research [Grand and Wiedmer 2010] or discuss design fiction as a means for specific aims, e.g. to discuss adoption [Lindley et al. 2017b]. As these examples have shown, the use of design fiction is manifold and it is easy to feel overwhelmed by the variety of examples. This makes it complex to define design fiction and explain the benefits of a method that is moving towards the mainstream of HCI. The following literature focusses on publications in the ACM Digital Library, but also turns to examples beyond HCI, e.g. from design research or futures studies to provide a fuller picture of the approach. Within the ACM Digital Library that covers many of the main conferences of the HCI community, such as CHI and NordiCHI as well as related conferences such as CSCW or DIS, the author keyword ‘design fiction’ was first used 4 times in 2012, increasing to about 20 publications in each of the last three years. In addition, design fictions have moved from being a topic of special sessions (such as the panel on design fiction at NordiCHI’16 I took part in) to being presented as a tool for research in other sessions (such as the ‘Values & Ethics’ track at DIS’18). The method has gained popularity in HCI in recent years, probably as a response to the changes in complexity and responsibility that new ubiquitous and automated technologies bring with them [Heidt et al. 2014; Zeller 2011]. However, the fact that design fiction is becoming more mainstream, does not yet mean that its tools, terms and aims are clear and universally agreed on. In the upcoming sections, 3.2 to 3.7 I present my own definition of what design fiction
is before describing some of the similarities and differences of design fiction to
outline the use of design fiction in HCI. In the last section 3.8 Criticism & Open
Questions I outline which open questions remain, which is followed up in the
remainder of the thesis.

3.2. History & Definitions
Descriptions of design fiction in the HCI literature often start with a sentence
similar to this: “Bruce Sterling has defined design fiction as ‘the deliberate use of diegetic
prototypes to suspend disbelief about change’” (here taken from [Tanenbaum et al. 2016b]).
Bruce Sterling has been widely attributed to coin the term “design fiction”, by
reflecting on its own practice and contrasting it with science fiction [Sterling 2013].
The term has further been attributed to Bleeker, who wrote a short essay about this
novel practice [Bleeker 2009]. Another often referred to source is an article by Kirby
[2010], which explains the term “diegetic prototype” as an artefact that exists in a
fictional world, which gives context to the use of the prototype and therefore makes
its use believable, or suspends disbelief as quoted above. Few authors add their own
definition of what design fiction is. Lindley and Coulton summarize the references
as follows: “So a design fiction is (1) something that creates a story world, (2) has something
being prototyped within that story world, (3) does so in order to create a discursive space” [2015b].
They critique that this summary glosses over what that ‘something’ is, which leads
to a lack of clarity, even within the community of makers of design fiction.

While the three sources presented above remain the main explanation of what
design fiction is, some definitions go beyond that and hint at other important
factors about design fiction. One aspect that is only hinted at in the definition above
is the political nature of design fiction. Wakkary et al. [2008] emphasise the
importance of design and highlight that design fiction is a “designerly response” that
enables “designers” to “engage in a material reflection”. While the term “designerly” was
first used to distinguish design from both science and art, when it was coined by
Cross [1982], Wakkary et al. [2008] contrast the term to “social analysis and policies”.
Markussen [2013] contrasts design’s disruptive power with “a boycott, strike, protest,
demonstration or some other political act”, but instead argues that it is “a designerly way of
intervening in people’s lives”. While both of these statements hint at something
undefined when using the term designerly, they link design fiction to activism and
empowerment. Prost, Mattheiss and Tscheligi [2015] emphasise this dimension of
design fiction and highlight that it can help to shift social practices “from awareness to empowerment”. Adding these two considerations to the definition above, I derived at the following working definition for design fiction:

**Design fiction uses design methods to discuss technologies and their societal consequences within a world in which these technologies can plausibly exist with the aim to elicit debate of such technologies from the audience of the design fiction.**

My definition places more emphasis on the role of design methods in the process. But the relationship between design fiction and design is not yet fully clear. I expand on design in the next section 3.3 Design Fiction in Relation to Other Research Methods, before analysing the role of fiction in more detail in section 3.4 Design: Fiction & Narrative.

### 3.3. Design Fiction in Relation to Other Research Methods

While design fiction is relatively new to HCI research, design research is an established method in HCI. In this section I look into some of the discrepancies and relationships between design research in general and design fiction. One of its major discrepancies is the medium of the design fiction. Even though design fiction can be visualised through physical artefacts, such as extensions for mobile phones to measure empathy [Sturdee et al. 2016], catalogues [Brown et al. 2016] or cameras that need to be destroyed to work [Pierce and Paulos 2014], it has been emphasized that “its focus is never a material end product” [Lindley 2015a:4]. In addition, it is not “medium-specific” (ibid.), in contrast to other types such as industrial design or graphic design.

Video is a common communication tool for design fictions. Nonetheless, the aims and motivations between the development of videos vary. One reason given to use design fiction is the role of prototyping, especially prototyping not only of an artefact, but rather of the future [Lindley and Potts 2014]. Video can be a means of communicating the design fiction to the outside, e.g. as a means to “demonstrate” the outcomes of the design process [Van Allen et al. 2013:2251]. In the Data Economy project [Luu et al. 2018] this communication seems to have been twofold, both within the design team as a means to explore the topic, but also beyond, after finishing the project as a means to communicate the results. Gilardi et al.
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[2016:1399], describe the production process in detail and argue that: “Films are perfect tools for conveying fictional worlds to an audience and elicit reactions from them”. This motivation is shared by Hauser et al. [2014:32] who describe the use of video as a “deliberate choice” because it can easily be shared with participants both online and offline and has the ability to “capture attention through rich media content”. A similar motivation seems to have been behind the decision by Heibeck et al. [2014] to post a video online in addition to a blog post, because the authors emphasise the reach they achieved through this type of communication.

There is no agreed upon medium that design fiction should take and it might depend highly on the project. Suggested forms are “everyday artefacts, such as product catalogues, newspaper articles, technical manuals and so forth” [Rostami et al. 2017]. In contrast, other design fictions are simply presented as stories, narratives or snippets [Ylipulli et al. 2016; Lyckvi et al. 2018; Prost et al. 2015; Edwards et al. 2016; Derboven and Vandenberghhe 2016; Dalton et al. 2016; Baumer et al. 2018; Pargman et al. 2017; Buttrick et al. 2014]. Within HCI, these two strands have been merged into a type of narrative familiar to HCI researchers, which is fictional or imaginary abstracts [Blythe and Buie 2014; Blythe 2014; Encinas et al. 2018] These in turn have been extended to full research papers [Lindley and Coulton 2015a; Fields 2016]. This selection of artefacts suggest that familiarity plays a role in the development of design fictions. Like critical design, design fiction “leverages design itself” [Bardzell and Bardzell 2013] and is therefore directly linked to the design world. Videos for example often mimic crowdfunding calls that are often presented in the shape of videos (see for example [Søndergaard and Hansen 2016; Sturdee et al. 2016]). In other cases the stories take the shapes of fictional research papers [Blythe 2014; Fields 2016; Lindley and Coulton 2015a], job adverts [Fuchsberger et al. 2017] or fictional entries to existing internet forums [Wong et al. 2018]. In these cases, the shape is not deliberate but instead is part of the story, hinting at events only, rather than spelling them out. This goes beyond the practical motivations expressed beyond, but instead moves towards the aim of speculative design to blur the boundaries of what is real, possible or plausible (see also [Dunne and Raby 2013]). Designs are often indistinguishable from ‘real’ or existing artefacts, as a means to question the artefact itself and ask the audience if it is real and how they feel about it [Swan and Boehner 2013].
Even though design fiction might look indistinguishable from ‘real’ design objects, different aims are attributed to it: “If the goal of design is, as Herbert Simon has written, to devise courses of action aimed at changing existing situations into preferred ones [...], then the goal of design fiction is to use speculations, metaphors, and explorations of desired futurities to explicate and inform material design practices” [Tanenbaum et al. 2012a]. Posing questions, rather than providing solutions, design fiction has been suggested as a means to overcome “solutionism” in HCI (see e.g. [Blythe et al. 2016; Blythe et al. 2015]). Solutionism, a term coined by Morozov [2013], has been described as “solving problems that don’t exist or proposing technological quick fixes for complex social, political and environmental problems” [Blythe et al. 2015:1]. By not only describing a possible prototype as would be done for example in a scenario, but by placing it in a life-world in which people interact with it, design fiction makes technological outcomes debateable.

In summary, like Interaction design, which can be completely digital, tangible or ubiquitous, design fiction comes in many shapes and forms. In contrast to other design areas, the materiality or medium does not appear to be a useful category in distinguishing between design fictions and other types of design. Drawing on the literature published in the ACM Digital Library, I turned to the author keywords instead to understand how authors position their work. I observed a link to both research-through design as well as to other design approaches, in particular critical design and speculative design that I follow up in more depth below.

3.3.1. Research through Design

Papers about design fiction are often linked to design research methods, e.g. through keywords such as “design methods” [Edwards et al. 2016], highlighting that the contribution lies in the method rather than the artefact presented. One keyword stands out through its frequent use: research through design. Many authors claim to use design fiction as a method to do “research through design fiction” [Blythe 2014; Sturdee et al. 2016; Lindley and Coulton 2016b]. Encinas et al. [2018:2] argue that research through design in itself is not a means to find solutions, but rather “seeks to better understand problems in order to question them”. Design fiction in many instances shares this aim as I outlined above. Used in this way, it links design fiction to other methods of “building new prototypes in Research through Design (RtD)” [Blythe and Buie 2014:227]. Nonetheless, it is rarely specified whether design fiction is used like any other prototype or whether it offers distinctive advantages. Furthermore, it is
unclear how design fiction relates to two other design paradigms it is often linked to: critical and speculative design.

### 3.3.2. Critical & Speculative Design

The main body of this literature review is built on publications in the ACM digital library with the author key word “design fiction”. Further publications have been identified through the snowball-technique. In many instances the papers also include the key word ‘speculative design’ or ‘critical design’. I therefore looked further into the relationship between the three types of design approaches to highlight how they differ and where they overlap.

Many design fiction papers include the keyword ‘critical design’ and many design fictions appear to be critical. Critical Design is another approach that has recently gained attention in the HCI literature. Understanding the relationship is important because critical design provides design fiction with a theoretical framing, based in a critical and humanist stance. Critical design, speculative design and design fiction are often linked, but the terms are themselves not well defined and their differences are subtle [Auger 2013]. It has yet to be settled how these disciplines relate to each other [Lindley 2015a]. Some argue for a hierarchical model in which critical design – or sometimes speculative design [DiSalvo 2012]– contains all other design disciplines [Lindley and Potts 2014; Malpass 2013]. Others instead argue that all disciplines are somewhat “related” [Duggan et al. 2017:3]. This link between design fiction and critical design implies that design fiction is always “critical” even though it does not yet give insights into what criticality means in practice. The most commonly used definition of critical design, contrasts critical design with “affirmative” design [Dunne and Raby 2013:34] and therefore identifies it as something that “challenges the status quo” (ibid., see [Bardzell and Bardzell 2013] for a discussion). Some artefacts are provocative to stimulate discussion, such as the PeriodShare artefact that combines a wearable technology embedded in a pair of underwear with an app to reflect on the relationship between woman’s health and the quantified self [Søndergaard and Hansen 2016]. In addition, this approach has been used in a more goal-oriented manner as a means to critique existing technologies. Purpura et al. [2011] for example did not develop a physical prototype, but wrote a design fiction in the form of an academic paper which was used to reflect how self-tracking technologies might develop, followed by a critical
evaluation of why this approach may be problematic. Nonetheless, it is not clear yet, whether design fiction is supposed to be critical, even though some authors such as Wong and Mulligan [2016] suggest that it is, stating that: “corporate concept videos differ slightly from design fictions with critical ends”. The relationship again is complicated as a design object can be both critical and affirmative at the same time (see e.g. [Bardzell and Bardzell 2013]). One distinction is that critical design often sits outside the commercial market and is not developed for monetary gain (see e.g. [Auger 2013]). The presumed tension between affirmative design and critical design is also apparent in regards to design fiction:

“The relationship between design fiction and the (perhaps better known in HCI) critical design illustrates this issue. It is not that design fiction is without critique, and critical design is all about critique — nor is it that organizations (commercial and public) are unable to deal with critique as part of projects they work on. Rather what matters is the form that critique takes, and how it can contribute to a collaboration, rather than seeming as an ‘academic privileging’ that steps outside a specific situation” [Brown et al. 2016].

The authors hint at the empowering nature that critical design often takes. Critical design, is related to political [DiSalvo 2010] or activist [Markussen 2013] design as its aim is to enable “social emancipation” [Bardzell and Bardzell 2013:3298]. In this text, the authors suggest that critical design should draw more explicitly on critical theory to ground its varying approaches. As design fiction is often implicitly linked to critical design, this theoretical grounding might extend to this approach, but it is rarely done so explicitly.

Design fiction has also often been linked to speculative design, but the relationship between the two is not clearly defined. It has “links between design and the speculative” [Morrison et al. 2013] or “occupies a space among the wider miscellany of speculative design approaches” [Coulton et al. 2016]. This lack of distinction is understandable as design fiction and speculative design share comparable aims: “Speculative design practices have no direct interest in producing a finished article for production, sale or implementation. These speculative designs aim to challenge assumptions, be critical, and stimulate conversations” [Lindley et al. 2015]. While the aims may be comparable, understanding what distinguishes the two might be an important step towards the rigour of design fiction – and speculative design for that matter – especially to understand whether design fiction inherits the implicit critical tone of both critical and speculative design.
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3.4. Design: Fiction & Narrative

Design fiction comes in a variety of shapes and is linked to a variety of frameworks. This leads to the question of how a distinction between design fiction and other design approaches can be made. The most explicit statement can be found in Tanenbaum [2014], who identifies “narrative” as the most important distinction between design fiction and more speculative or critical approaches. Even though this distinction has been widely cited, few authors expand on it and explain how the term is understood in the context of design fiction.

The terms ‘narrative’ and ‘story’ are often used interchangeably within the literature and therefore I do not make any distinctions between them myself. Tanenbaum, for example uses the term ‘story’ to explain what sets design fiction apart: “The logics of the story are what gives design fiction its power and I would argue that in the absence of these logics a design fiction ceases to operate” [Tanenbaum 2014:22]. Blythe [2014:7] warns that narrative has a broad meaning, but identifies two important factors in terms of shape and content: “This equates to beginning, middle and end but includes, conflict, struggle and resolution”. They further expand on this in a following paper, by reflecting on the term ‘plot’, which links the different elements in the story together. Blythe further goes on to use the type of plot as a distinction between design fiction and scenarios. While scenarios often include a plot in the sense that a conflict is overcome through the use of technology, design fictions go beyond this and place the conflict in a “story-world”.

As I outlined in the section on the historical background of design fiction 3.2 History & Definitions, design fiction not only draws on narrative, plot or storytelling, but also on the element of “diegesis”, i.e. the creation of a story world, which also has been named the “factor that differentiates and distinguishes design fiction from other approaches” [Sturdee et al. 2016:1]. By including references to the world in which technologies will be integrated, the technologies can be critiqued. According to Coulton et al [2017] referring to world-building is a more useful means to think about design fiction as it removes the approach from the literary critique. Instead it enables the audience of the design fiction to focus more clearly on the relationship with the reality. Nonetheless, the two concepts narrative and world-building do not have to be mutually exclusive as narratives may emerge through the process of developing of world in which the artefact belongs. The two strands of storytelling
and world building have been brought together by Luu, van den Broeck and Søndergaard [2018] who argue that the craft of design fiction lies in combining the literary world with design methods to bring a point across. Design fiction not only contains linked story elements which span a narrative arc of beginning, middle and end, but also include some type of artefact that is placed within a world in which its use can be considered to be normal. Often, but not always this story is placed in the future and in the upcoming section 3.5 Design Fiction & Future, Past and Present I reflect further on the role of temporality in design fiction.

3.5. Design Fiction & Future, Past and Present

Design fictions often address a specific type of technology and mostly those who have not yet been established, as a means to let the audience reflect on the “desirability” of emerging technologies and “their effect on society” [Coulton and Lindley 2017:46]. Examples are drones [Lindley and Coulton 2015a], artificial intelligence [Lindley and Potts 2014] and digital personal assistants [Søndergaard and Hansen 2018] or virtual realities [Colombo et al. 2018; McVeigh-Schultz et al. 2018; Wood et al. 2017; Ylipulli et al. 2016]. Design fiction is used to explore and evaluate the potential outcomes of a technology that does not yet exist [Sanders and Stappers 2014; Tanenbaum 2014]. It offers the opportunity to “raise awareness of technologies before they become public concerns, not afterwards” [Lawson et al. 2015:9]. Because technologies and their outcomes can be explored through narrative, rather than the building of functional prototypes, design fictions can be introduced at any stage during the design process.

Design fictions are often compared to science fiction (see e.g. [Ylipulli et al. 2016; Blythe and Buie 2014; Baumann et al. 2017; Wong et al. 2017b; Wakkary et al. 2015]) and as such carry an implicit expectation to take part in the future. Often, design fictions are placed in an unspecified, near future to explore the “long-term consequences” of technologies [Lawson et al. 2015:3]. Other projects specify what near-future they refer to, but the time range varies widely: from 2025 [Derboven and Vandenberghe 2016] to 2331 [Markussen and Knutz 2013] in the examples I reviewed. Other projects are set in relation to the present, e.g. “before the end of another two decades” [Fields 2016:1]. This future-oriented perspective is not without criticism, as it has been suggested that it might create a barrier for participants when relating to the topic [Gonzatto et al. 2013] or “cultivate unrealistic anticipatory relationships”
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[Harmon et al. 2017:1]. Researchers who use design fiction in their practical work argued instead that it is a useful tool to make the future tangible (e.g. [Tsekleves et al. 2017; Ylipulli et al. 2016]). Most design fictions extrapolate existing trends in technology design and place them into a future scenario. As such, it has an accountability in the present [Franke 2010], that is sought after in some research projects, especially when co-designing (see e.g. [Vavoula and Sharples 2007; Slaughter 1997]).

But some papers are also explicitly set in the present or describe a world indistinguishable from ours (e.g. [Encinas et al. 2018; Muller and Erickson 2018]). This poses the question whether the turn to the future is an essential part of design fiction or more specifically what it is used for. The turn to the future is often a means to “suspend disbelief” (e.g. [Lindley 2015a]) about the suggested changes through technology implementation. Nonetheless, it is only one means of “making strange” [Bell et al. 2005] or “defamiliarization” to “upsetting things in a productive way” [Bleeker 2009:9]. Another strategy for example is to disrupt the experience of using technology by creating speculative digital agents that talk back when harassed [Søndergaard and Hansen 2018] or using erotica writing to reflect on the relationship between technologies and the user [Buttrick et al. 2014]. Defamiliarization can be achieved through extrapolation of current trends (see e.g. [Blythe and Encinas 2016]) or by imagining “design of technologies under different circumstances in a near future” [Søndergaard and Hansen 2016:3]. Therefore, design fiction should not be understood as a way of imagining the future, but rather a means to observe, analyse and potentially critique the present.

With its main aim to disrupt, rather than to predict, design fiction is different from future studies or scenarios (see e.g. [Pargman et al. 2017]). Instead, design fictions often describe outcomes that are not necessarily desired, but are rather used in a critical way, as a means to question and warn. It is often highlighted that design fiction is not about the future, but about a “plurality of possible futures” [Grand and Wiedmer 2010:10] or the question of “what kinds of (everyday) futures” could be created through technology [Wong et al. 2018:1359]. By providing alternative views design fiction not only poses the question whether the viewer wants this future to happen, but it further also disrupts the techno-determinist discourse within the HCI academic literature. Related to this, it also disrupts the “solutionism” (e.g. [Blythe et al. 2016]) of conventional scenarios, by providing alternatives or questioning
whether the proposed changes are desirable. This also becomes clear when analysing the topics that are mainly addressed in design fiction as I show in the next section 3.6 Topics & Strategies.

### 3.6. Topics & Strategies

Design fictions cover a wide range of topics, covering fields as diverse as animal-computer interaction [North 2017], women’s health [Søndergaard and Hansen 2018] or bitcoin mining [Lindley 2015b]. In this section I describe in more detail the strategies of design fiction and do so by classifying design fictions into three categories, depending on the topics they address: first, breaking taboo topics; second, addressing complex ethical and societal topics, e.g. around sustainability, data and privacy as well as urban planning; and third, a turn to the arts to gain a more holistic and embodied point of view.

#### 3.6.1. Breaking Taboos

Many design fictions could be considered shocking as they address intimate topics, such as BDSM as a means to question the relationship between people and their artefacts [Buttrick et al. 2014], porn as a means to learn more about virtual reality as an emergent technology [Wood et al. 2017] or menstruation as a means to discuss how feminine health is underrepresented in HCI [Søndergaard and Hansen 2018]. Design fiction has been highlighted as a means to discuss sensitive issues, such as urinary tract infection [Nägele et al. 2018]. This turn to the extreme and the “*perverse*” [Buttrick et al. 2014] might appear to be either a provocation or a fringe case of HCI research, but provocation is not a means in itself. It has been argued that design fiction should not be done as a “provocation solely for provocation’s sake” [Swan and Boehner 2013:17], but rather as a means to “build discursive spaces” [Lindley and Potts 2014:1082]. While expanding on the topic of sexuality in HCI that might have been mainly ignored [Kannabiran et al. 2011], it also touches on wider topics of wellbeing and situated, embodied interaction that are acknowledged topics of HCI research. Design has been criticised for providing a sterile view on human behaviour. Dunne and Raby [2013:38] observe that: “Dark, complex emotions are usually ignored in design; nearly every other area of culture accepts that people are complicated, contradictory, and even neurotic, but not design. We view people as obedient and predictable users and consumers.” By turning to the arts and design, design fiction – like comparable speculative and critical approaches – makes these topics tangible and debatable.
Often humour is used alongside the taboo breach within these projects to manage the immersion of the viewer and to suspend both disbelief and belief [Helms and Fernaeus 2018]. The defamiliarization of design fiction, at times criticised for creating a distance as discussed in the last section (see 3.5 Design Fiction & Future, Past and Present), provides a useful means to do so, as it creates a safe space for participants to engage with topics. Nägele et al [2018:11] for example describe that participants in their workshops could “cathartically enjoy speaking about their unspoken concerns and futures”. A similar effect has been observed by Lyckvi et al. [2018] who observed that providing fictional future scenarios enabled participants to take a step back and reflect on their practices. While not necessarily about the dark sides of human nature, design fiction promises to be a suitable means to discuss taboo topics that are harder to breach with more traditional research methods, such as interviews and focus groups. In addition, design fiction methods not only offer means to address the human body, but also often involve an embodied experience.

3.6.2. Embodied, Immersive Futures

Immersive [Heibeck et al. 2014; McVeigh-Schultz et al. 2018; Skirpan et al. 2018] approaches are used to discuss a wide range of topics, such as futures of design work or possibilities of emerging wearable, affective technologies. Increasingly, these approaches go beyond the written narrative to provide a more embodied experience, such as by using Virtual Reality [McVeigh-Schultz et al. 2018] , performance [Baumann et al. 2018] or enactments [Elsden et al. 2017]. But even beyond these participatory, immersive approaches, design fiction offers opportunities to engage with sensory experiences [Heibeck et al. 2014] or prototype for experience [Gilardi et al. 2016]. In addition to the strategy outlined above in which design fiction is used to create safe spaces for engagement with sensitive topics, design fiction also enables speculation and an engagement with technology before it exists. Blythe et al. [Blythe et al. 2016; Blythe and Encinas 2016; Encinas and Blythe 2016] link this type of speculation to “magic” and argue that it enables participants – and designers themselves? – to look beyond the abilities of technology, but instead enables them to articulate their needs and wishes more freely. Make-believe is used in a variety of HCI methods, such as user testing that uses the ‘Wizard of Oz’ technique in which a researcher takes on the role of the device, sometimes without the knowledge of the user [Turner et al. 2014]. Design fiction goes beyond this technique as it not only presents the user with the artefact,
but also a world in which this artefact would fit. In many of the examples given in this paragraph it also extends many traditional HCI methods as it not only focusses on usability and efficiency, but instead turns to a more embodied and holistic experience.

### 3.6.3. Complexities & the Long-Term

A seemingly different strand of design fiction discusses complex topics such as urban planning [Baumann et al. 2017; Forlano and Mathew 2014; Smyth et al. 2015; Stals et al. 2014], data and privacy [Blythe et al. 2018; Elsdon et al. 2015; Lindley and Coulton 2015a; Luu et al. 2018; Skirpan et al. 2018; Søndergaard and Hansen 2016; Wong et al. 2017b] or issues around nature and sustainability [Hauser et al. 2014; Pargman et al. 2017; Wakkary et al. 2008]. While these issues may appear more serious than the ones mentioned above, they are related in two ways: complexity and lack of visibility. In addition, all of the examples share that their outcomes, both intended and unintended, will most likely be only visible in the long-term. Issues around sexuality might appear more personal and of less social importance than for example sustainability issues. But they are often complex, complicated and shaped by social discourse. In addition to the last two strategies presented - creating safe spaces and speculation- design fiction also offers the opportunity to embed technologies in the social context and observe them. Authors highlight the importance and opportunity to discuss “community context” [Baumann et al. 2018], “future technologies in context” [Ylipulli et al. 2016:6], “social, political and cultural dimensions” [Prost et al. 2015:1] or even “elicit rich, contextualized and intimate data” [Stals et al. 2014:737]. Both the speculative nature and the narrative element of design fiction are useful to address these complex topics. Certain trends, technologies or societal impacts can be observed in detail and over a long period of time when turning to the future. Design fiction enables designers and researchers to look beyond the short term consequences normally addressed in HCI research, but instead turn towards potential long-term consequences [Swan and Boehner 2013; Lawson et al. 2015; Linehan et al. 2014; Lukens and DiSalvo 2011]. This might open up design fiction to the critique that this speculation limits the accountability of the futures or alternative realities. But its aim is not to describe a ‘correct’ outcome, but to describe one that can be discussed and acted upon by viewers.
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In this section I described three different topics that design fictions repeatedly discuss: taboo topics, such as intimacy, embodied experiences and complex topics with long-term consequences. This distinction enabled me to outline three strategies that are deployed to address these topics: first, using defamiliarization to create ‘safe spaces’ in which technologies and their outcomes can be more easily discussed because they are fictional; second using embodied and immersive approaches to move beyond usability and towards an embodied and holistic experience and third, using narrative to make complex long-term outcomes tangible and debatable. In the next section, 3.7 Aims & Contributions, I describe in more detail the motivations behind using design fiction. I do so by providing categories of when it is used within a design or research process.

3.7. Aims & Contributions
In the last section, 3.6 Topics & Strategies I discussed which topics are addressed through design fiction and expanded on the strategies used to do so. Here I describe in more depth what aims and contributions are generated through design fiction. The section is structured into three parts, depending on which stage of a project the design fiction is used in: the first aim is to develop research questions or outline a research or design area which often happens at the beginning of a project. The second aim is to elicit data in a probing way, either for design or as a research tool, which happens during the project. The third aim is to communicate research or design outcomes, which happens mainly at the end of a project. This classification is done in the understanding that neither design nor research projects follow this strict linear structure, so stages might overlap and artefacts might follow more than one goal throughout, but this simplified structure has been used to emphasise the different aims. I further link to the way the contribution of the design fiction is made in the different types of stages.

3.7.1. Exploration
Design fiction is often provocative and aims to enable a novel perspective on a topic. This can be linked to the concept of exploration, e.g. as design fiction “can help articulate and explore problem spaces” [Blythe et al. 2016:4977] or provides “methods of story-telling and world building to explore and externalize a data obsessed future set in 2036” [Luu et al. 2018:1]. Looking deeper into the language used, this use of design fiction is often expressed through metaphors of travel and exploration, as design fictions
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Furthermore, even “illuminate and explore” [Lindley et al. 2015]. Another description is “opening up” [Hanna and Ashby 2016]. Design fiction has been used as a means to open up a wide variety of options, such as “new questions and unfamiliar opportunities” [McVeigh-Schultz et al. 2012:226], “open a discussion” [Lindley et al. 2017a:23] or “sociocultural questions and design ideas opened up by the fiction” [Ylipulli et al. 2016:1]. This has even been described as one of the principal aims of design fiction [Hanna and Ashby 2016]. Design fiction thereby often takes a Foucauldian perspective that aims to make biases visible and enable discussion about the values inherent in and attributed to technologies [Franke 2010; Tanenbaum et al. 2016a; Ylipulli et al. 2016].

One reason behind this is that design fictions are not limited by the restrictions of existing technologies: “design fictions are excellent means to open up space for critical conversations about the future” [Lindley et al. 2015:79]. Franke [2010:89] even calls it “a form of philosophical inquiry” and offers the following explanation: “By rendering alternatives to the present world possible, they question our current material landscape and the values, which our artefacts embody. It can also open a space in which alternative forms of existence, values, or political systems can be negotiated through fictional design objects.” The language used links design fiction to aesthetic and philosophical enquiry, rather than empirical research. Design fictions have also been called “ambiguous” [Bardzell and Bardzell 2013] or “poetic” [Markussen and Knutz 2013; Morrison et al. 2013], but are increasingly valued beyond their aesthetic properties, e.g. within research projects as means to elicit knowledge.

3.7.2. Data Collection

In other examples, the use of design fiction appears to be more applied, when this approach is used as a means to elicit data, which can be done either to support the design process or as a tool for research. As critical design artefacts are mainly made outside of the commercial mainstream design, their gain is not monetary, but their “primary intended outcome is knowledge” [Bardzell and Bardzell 2013:3298]. Design fiction is discussed in similar terms as it has in addition been considered a useful tool in design research as it not only critiques the existing solutions, but presents alternatives, which can then be evaluated [Grand and Wiedmer 2010]. Two types of design fictions can be distinguished: those that are “normative” and those that are “exploratory” (see [Wright et al. 2014]). Normative design fictions suggest an
outcome of a technology, e.g. by describing its outcome in utopian or dystopian terms [Tanenbaum 2014; Wright et al. 2014; Mancini et al. 2010]. Depending on the use case, utopian [Hauser et al. 2014] or dystopian [Dalton et al. 2016; Barik et al. 2016] visions can both offer advantages. Nonetheless, many design fictions are deliberately more open-ended and speculative (see e.g. [Dunne and Raby 2013]).

Instead of describing design fiction with the colourful metaphors of journeys and exploration, design fiction in this second use case is presented as a tool, e.g. when the authors describe that it “helped us to collect real-life project insights beyond the speculative scenarios” [Lyckvi et al. 2018]. Used in this way, the artefacts are not the main outcome, but are “a means for reaching project goals” [Pargman et al. 2017:774]. Increasingly design fictions are shared with participants, e.g. business partners to start a discussion about changes in the technological landscape [Lyckvi et al. 2018], pet owners to elicit discussion about tracking and monitoring [Lawson et al. 2015] or alternative urban maps to generate discussion about the opportunities of this technology [Stals et al. 2014]. As ambiguous designed objects, design fictions share characteristics with probes.

Here I differentiate the two methods to sharpen the definition of what design fiction is and to motivate future research. Probes are artefacts given to participants, which enable them to select the focus of what they share. A wide range of probes have been developed to date (see [Mattelmäki 2005] for an overview). ‘Technology probes’ [Hutchinson et al. 2003] are the most related to critical design objects, as they rely not only on creative tools for data collection, e.g. diaries and cameras, but on tangible prototypes. One important fact that distinguishes probes from design fictions currently though is the lack of narrative or world building elements, as probes are usually provided without a fictional backstory or setting, but clearly as research or design tools. A more empirical approach to critical design and speculative artefacts is emerging in HCI. This has a historical analogue in the development of probes. The original ‘cultural probes’ were supposed to inspire design rather than be analysed systematically (see [Gaver et al. 1999]). However, the move towards a more empirical evaluation through ‘informational probes’ [Crabtree et al. 2003] changed the way probes were perceived. As a result, Gaver, Beaver & Benford [2003] argued that probes were in danger of losing their ambiguity, which can be considered to be a useful tool in the design process. A similar critique can be observed with design fictions. Morrison et al. [2013], as well
as Markussen and Knutz [2013] emphasise the relevance of “poetics” in design fictions. The “aesthetics” of design fiction might be ambiguous, but they are not without focus, as they “ability to open up the relation between people’s behavior and emotions—between what they do and what they feel about this doing” [Markussen 2013:39]. A move towards a more empirical understanding of design fiction might therefore take away from the critical and political nature of design fiction. From the beginning on, probes have been labelled to show their distinct properties: from “cultural probes” [Gaver et al. 1999] to “empathy probes” [Mattelmäki and Battarbee 2002], who were made specifically to elicit empathic responses or “technology probes” [Hutchinson et al. 2003], which always contain a physical artefact to be deployed.

In addition to presenting participants with design fiction artefacts, design fiction artefacts have been developed collaboratively, e.g. with people who have been diagnosed with dementia [Tsekleves et al. 2017], people with urinary tract infection [Nägele et al. 2018] or to connect designers, researchers and bee-keepers [Edwards et al. 2016] as a means to enable participants to describe their needs and wishes for technology freely. In this case it is used in a structured, goal-oriented manner, rather than the previously mentioned explorative manner. In addition, its narrative and open, exploratory nature offers advantages for more traditionally used empirical research into user needs and wishes.

### 3.7.3. Communication & Visualisation

Above I outlined how design fiction has been used to stimulate discussion or elicit data. Both cases share that the design fiction is used as a means to an end. However, design fictions can be contributions in their own right. A range of design fiction papers are written around the explicit contribution of the artefact. Authors for example, “presented a number of ‘imaginary abstracts’” [Blythe and Buie 2014:234], “describe the story” [Lindley and Potts 2014:1081] or even “offer this design fiction to stimulate a conversation” [Dailey et al. 2018:230]. This conversation is often structured around the values that surround the technologies or potential outcomes that might arise from their use. One example that is explicit about this type of intended contribution is by Wong et al. [2017a] who use design fiction as a means to further ‘privacy by design’. As such, design fiction is closely related to methods such as value-sensitive design [Friedman 1996] which take on responsibility for the potential outcomes of technologies and aim to minimise negative impacts. While
value-sensitive design foregrounds reflection though, design fiction is a more practical, hands-on approach.

While in these examples the design fiction might not be the only contribution of the paper, its role as one of the contributions is clearly emphasised. Pierce and Paulos [2014:131] for example contrast that their contribution should not be seen as “design process documentation”, but instead as “a type of visual-textual design artefact”. As has been seen above, this is often done with a turn to the future, e.g. “present[ing] one possible future application of today’s research” [Skirpan and Fiesler 2018:267]. Even though the goal of a design fiction such as this is to “help ground debates around” technology use [Skirpan and Fiesler 2018:267], this is not always done within the scope of the project, but instead the design fiction work is presented in its own right.

In this section I distinguished three types of contributions that can be made through design fiction: creative exploration of a research project or design space for scoping, empirical data collection using the design fiction as a probe or communication in a “designerly” way [Cross 1982]. While the language around these differ as the literature review has shown, all refer to the term design fiction. This term in turn becomes less clear. In the next section, 3.8 Criticism & Open Questions I describe which open questions remain and why the current use of design fiction might be problematic.

3.8. Criticism & Open Questions

In this literature review I defined design fiction for the purpose of this thesis and have outlined how it is used within HCI research. I described the language used to describe design fiction and its possibilities. I have shown that design fiction is introduced through positive terms of exploration and discovery into HCI research. Concluding the literature review I point out criticism surrounding the term as well as reflecting on the open questions that remain, some of which I address within this thesis project.

3.8.1. Using Design Fictions

Without an explicit understanding of what design fiction is and how it could or should be used, how can we evaluate the rigour or value of this promising method? What framework or theory should we use to classify, test and judge the quality of design fiction? As Lindley and Coulton [2016a] point out, this leads to the bigger
question of what the nature of contemporary HCI research is, what types of insights it could or should generate and which topics it should address. Instead, in HCI a “current, intense discourse on forms and values of design fiction” prevails [Fuchsberger et al. 2017:581]. Creative methods, such as design fiction, have been said to “not sit well” [Blythe 2014:1] within HCI research and the question of understanding why and where it fits in or where its limitations lie will not only be relevant to the rigour of design fiction itself, but to HCI research more generally. Within this thesis I expand on the suggestion that design fiction can be used within a research-through-design framework and more specifically how it can be used within the three categories of the Constructive Design Research framework [Koskinen et al. 2011]. Drawing on the framework I describe how one specific design fiction can be used within the showroom (Chapter 7 In the Showroom), lab (Chapter 8 In the Lab) and field (Chapter 11 In the Field) approaches and present study results and discussions on the different types of insights it can generate. Before I do so, I describe in more depth the problems of making design fiction artefacts.

3.8.2. Making Design Fictions

As I outlined in section 3.3 Design Fiction in Relation to Other Research Methods, design fiction can take many shapes, from stories only, e.g. in the form of snippets [Lyckvi et al. 2018], short stories [Ylipulli et al. 2016] or even poetic fragments [Morrison et al. 2013], while others can be only physical and tangible objects, e.g. the counterfunctional camera, an object that needs to be broken to be used [Pierce and Paulos 2014]. But within these two extremes lies a whole world of tangible or intangible artefacts. As many of these artefacts are presented as a bundle, it becomes complicated to understand where the ‘design fiction’ itself is positioned. The range of artefacts is wide and makes it complicated to find common factors. In many instances a project that works with or through design fiction leads to a range of artefacts, e.g. “sketches, renders, prototypes, and videos” as a means to “create glimpses of possible future scenarios enabled by emerging technologies” [Colombo et al. 2018:368]. Videos often contain fictional prototypes (see e.g. [Heibeck et al. 2014; Luu et al. 2018; Søndergaard and Hansen 2016; Sturdee 2017]), some of which are also presented as artefacts and outcomes in their own rights in academic outlets. Others place the video higher in the design process as other artefacts, such as prototypes and collages are seen as a step towards this final outcome [Baumann et al. 2018]. The relationship between these artefacts is often not specified and it is therefore unclear whether
they can exist independently from each other or whether they together form the
design fiction. The motivation behind using a specific form or object often remains
unspecified.

Design fiction furthermore draws on other types of videos, such as commercial
Other examples appear to draw more from the world of art and exhibition and
present design fictions on the style of video installations [Ota 2013; Smyth et al.
2015]. Through this variety of examples, it is unclear whether an object can be a
design fiction in itself and if so how it differs from speculative artefacts in general.
By leaning on other examples and the design world more generally, it also blurs the
boundaries between design fiction and speculative design as neither the fictional
aspect nor the narrative can easily be identified. This might become problematic
when one approaches making a design fiction.

One of the problems with the current landscape of design fiction research is that
the focus is too often on the outcome, than the process (see also [Sturdee et al.
2016]). Shared insights of how a design is made are rare (with laudable exceptions
including [Sturdee et al. 2016; Gilardi et al. 2016]). Wider reflections on design
fiction, e.g. [Blythe and Encinas 2016] are often built on a specific understanding
of what design fiction is, without making this explicit. The last sections of this
literature review have shown that design fiction is used in a variety of ways with
varying aims, therefore this is not without its problems.

As the review above has shown, design fiction is used in a variety of ways. One of
the problems is that it is linked implicitly, e.g. through the use of keywords, to a
variety of frameworks and contrasting design methods, as I outlined in section 3.3
Design Fiction in Relation to Other Research Methods. This poses the question of
whether design fiction should be evaluated or judged by the standards of any of
these or if it provides its own new set of quality criteria. The question is not only
how to define design fiction, but even how it could or should be classified (see
section 3.2 History & Definitions). The lack of clarity of what design fiction is
shines through all sections of this chapter. This is not helped by the link to sub-
groups, such as fictional abstracts (see [Lyckvi et al. 2018] for a discussion).

What is even more problematic is that the term is used in a variety of ways without
clarifications: “The words and constructs used to describe and communicate about design fiction
mean different things to different people, depending on context and existing knowledge” [Lindley 2015a:2]. Even though the method of critical design promises to lead to a more critical stance in design – and in HCI – this approach has been criticised. Critics question whether it actually reaches beyond an audience that is already critical and mainly consists of designers themselves (see e.g. [Malpass 2013]). A similar claim has been made about design fiction, e.g. by [Nägele et al. 2018]. One problematic aspect lies in the way design fiction is made. Like design, design fiction carries an element of quality and craft in it, which shines through its descriptions, such as “weaving participant narratives” [Cheon and Su 2018] or “crafting a sci-fi narrative” [Nägele et al. 2018:10]. One view in design is that ‘everyone is a designer’ and that design takes part as an everyday activity [Stead and Coulton 2017; Morrison et al. 2013]. Expanding on this, as the output is supposed to be a narrative or fictional world, design fiction begs the question if everyone is a writer. Researchers have chosen a wide variety of strategies to develop design fictions. Many design fictions have been crafted by the researchers themselves (see [Lindley and Potts 2014; Fields 2016; North 2017; Heibeck et al. 2014; Søndergaard and Hansen 2016; Stead and Coulton 2017] and many more). Others have engaged writers in the process (e.g. [Wood et al. 2017; Ylipulli et al. 2016]) with the explicit aim of enhancing the quality of the writing. This expert-driven approach to design fiction has led to a concern that design fictions present a biased view on the dangers of technology design (e.g. [Nägele et al. 2018; Prost et al. 2015]). As a result, methods for developing and discussing design fictions with participants have been developed. A range of projects wrote or used design fiction collaboratively. Currently their means and aims again vary widely. Design fiction has been used as a means to enable collaboration and shared decision making [Baumann et al. 2017; Edwards et al. 2016] or as a means to create a safe space in which participants could explore ideas [Nägele et al. 2018; Lyckvi et al. 2018]. The variety within these and other projects adds to the confusion around what design fiction can do and how it relates to the literature. Participatory design fiction offers promising insights to make the field of design fiction more diverse. As participatory design might not be applicable to all settings, this is only a solution in part. It further contributes to the lack of clarity about how to use design fiction.
3.9. Conclusion

In the last two chapters I narrowed down the potential research space from critical design in general to design fiction in Chapter 2 Understanding Critical Design and to specific questions within the use of design fiction in HCI in Chapter 3 Understanding Design Fiction. I have given a preliminary definition of design fiction and outlined areas that lack exploration. Chapter 2 Understanding Critical Design has already indicated that I chose a practice-oriented approach to my research question **What can we learn about technology use in sensitive settings through research through design fiction?** But to do so I address two current limitations. First, little is known on how on goes about developing a design fiction. In the next part, Prepare, I therefore describe in detail the steps I undertook to inform and inspire design fictions in the area of monitoring technologies for dementia care. I outline what types of insights could be gained through which research activity which might be useful for other researchers who want to use this approach. Second, to learn whether design fictions can be a useful tool to explore sensitive topics in HCI, I first need to set criteria for evaluation, which I do in the last part of this thesis: Evaluate.
In the literature review in Chapter 3 Understanding Design Fiction, I outlined that design fiction promises to be useful to address technology use in sensitive settings. But the literature lacks insights on how one goes about developing a design fiction. The three chapters presented in this part go towards a better understanding of how one can inform a design fiction. This goes towards answering my overall research question - **What can we learn about technology use in sensitive settings through research through design fiction?** - by distinguishing different types of insights that can be gained through different research activities and exploring what insight might be needed to explore sensitive settings.

First, in Chapter 4 Understanding Technologies for Dementia Care I present the results of a literature review to learn more about the technologies available in dementia care and why they might be problematic, answering the question: **How are monitoring technologies currently developed for dementia care?** The review indicates that monitoring technologies in dementia care could benefit from the application of design fiction. The use of these technologies might be
Chapter 3 Understanding Design Fiction

problematic due to ethical concerns about their impact on autonomy and privacy. It further highlights the lack of insights into the lived experience of these technologies, that hinders the development of such a design fiction.

Second, to build on these insights and test whether they can be extended, in Chapter 5 Dementia & Privacy – A Survey with Privacy Experts I present a study with privacy experts to gain a deeper understanding of the concerns surrounding the technologies. The study answers the question: What are the views of privacy experts on the ethical, social and emotional implications of monitoring technologies in dementia care? The study results indicate that the impact on privacy might be much more individual than the literature suggested. It further situates the technologies as elements of power. But the results remain quite theoretical and little is known about the mundane experience of using the devices in the everyday.

Third, to address this lack, in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies I present a self-study of selected monitoring technologies to gain insights into the mundane experience of using such devices. This study answers the question: What is the lived experience of non-mutual tracking tools? It indicates that the problems go beyond those currently addressed in the literature. The studies gave insights into the everyday life with these devices that sensitized me to issues about their use, which were later translated into design fictions.

These chapters add to the methodological contribution of this thesis by addressing a question that has received little attention so far, of how design fictions can be made.
Chapter 4. Understanding Technologies for Dementia Care

In this chapter, I

- Outline the current problems with monitoring technologies in dementia care
- Outline why design fiction could be a useful tool to address the wicked problems that exist in this domain
- Specify to which extent a literature review can be useful to inform design fiction

4.1. Mapping the Development & Use of Technologies for Dementia Care

My decision to start this review on the technologies currently developed to support people living with dementia was based in my previous experience of giving care to my grandmother who lived with dementia in her later years and the experience of the resulting design work I undertook for my MA and BA projects. Care is an essential part of human life: parents supervising the first steps of their children, partners taking on new responsibilities after a diagnosis or children taking over tasks from their elderly parents. Even though it is an essential part of our biological and social life, it comes at immense costs: of time, to finances and to emotions. Transitions between stages can be both emotionally painful and physically demanding and involve a wide range of negotiations and re-arrangements. In some cases, such as advanced dementia which might hinder communication, these negotiations are not possible and people have to make decisions on behalf of someone else. Safety and privacy, autonomy and dignity are just some of the values at stake that need to be understood, evaluated and acted upon. Often, these can contradict each other as it might be necessary to infringe on someone’s privacy to keep them safe, and people’s values can contradict each other, which can lead to conflict.

Care has many dimensions. For example, it includes the care of different ages of people (e.g., children or elderly care), different illnesses or chronic conditions, and
also reaches across different contexts, such as institutionalised care in care homes or hospitals, and that offered in everyday contexts by paid or unpaid carers. All of these settings lead to different expectations and needs for technology therefore differ. The academic literature is widely spread over specific medical and nursing publications, that often outline the need for technology, technical publications that focus on the feasibility and use of specific technological solutions, or papers in social science venues that outline ethical problems or document the use or acceptability of new technologies. A complete review of technology for care is therefore neither possible, nor would it be particularly useful. Instead, I focus on dementia as one specific illness and monitoring technologies as one specific technological response. While those can also be deployed in institutional settings, the main focus here is on the home and the interactions with informal carers, i.e. next of kin or partners. This decision has been motivated by the focus on monitoring technologies, which are often used in the home, e.g. as a means to avoid the move into care homes (see e.g. [Boger et al. 2005]) Many people have expressed the wish to stay in their home for longer and this is also seen positively as a move towards reducing the rising costs in the care sector due to demographic changes (e.g. [Patterson et al. 2015]).

In this chapter I give an overview of dementia symptoms, what types of technology have been developed to respond to some of the challenges of dementia, and why these technologies can be problematic. The chapter closes with a review of design approaches which might offer new insights and methods for development of more suitable technologies. I conclude with an evaluation of why design fiction might be a useful method in this area.

4.2. Dementia

Dementia is considered to be one of the main challenges in future care, due to the number of people it affects and the individuality of symptoms. Currently 50 million people worldwide live with dementia and the number is expected to double by 2030 and triple by 2050 [World Health Organisation 2017]. Dementia is an umbrella term for a range of progressive illnesses that affect the brain and lead to changes in memory, reasoning, behaviour, mood and communication as well as other symptoms [Batchelor et al. 2012; Skillen et al. 2012; Donnelly et al. 2010]. Alzheimer’s disease is the most common form of dementia for people over 65
Other types such as frontotemporal dementia, dementia with Lewi bodies or vascular dementia often affect people at a younger age [O’Rourke et al. 2011]. Symptoms differ between different types of dementia and individually (see e.g. [Batchelor et al. 2012]). All types of dementia are progressive in nature, which impacts the relationship between the caregiver and the person with dementia as the caregiver takes on more complex tasks over time [McHugh et al. 2013]. These challenges have led to a range of technological solutions in the area.

### 4.3. Technologies for Dementia Care

Technologies for dementia care address both caregivers and people diagnosed with dementia. To classify these technologies, I decided not to question who benefits from technology, as benefits and risks are intertwined. Instead I focus on use. Some technologies are intended to be used by people with dementia directly as a means to gain access to or participate in public life (e.g. [Brankaert et al. 2014; Savitch and Zaphiris 2006]) or take part in leisure activities (e.g. [Lazar 2014; Astell 2006; Astell et al. 2010; Alm et al. 2009]). However, most technologies are intended to be used by caregivers to support everyday tasks, such as dressing or cooking (e.g. [Mahoney et al. 2014; Wherton and Monk 2010; Hoey et al. 2011]) or to keep the person with dementia safe (e.g. [McKenzie et al. 2013; Ganyo et al. 2011; Doughty and Dunk 2009]). In this instance, the caregiver is tasked with setting up and maintaining the technology, while the person with dementia is a passive user of the technology.

I focus here on technologies that are intended to be used by the caregiver and in particular those that monitor people with dementia and alert caregivers to critical events. A wide range of data is monitored to infer critical events, such as behavioural, environmental or health data [Altendorf and Schreiber 2015]. The topic is of particular interest as it has already received much academic attention, but has not led to commercial technologies that meet the need of potential users. In the coming sections of this literature review I outline problems associated with current technologies and discuss issues underlying the development process.

### 4.4. Problems with Technology Use

As I outlined in the last section, 4.3 Technologies for Dementia Care, a range of technologies has been developed to support those living with dementia, with a strong focus on the needs of the caregiver and less so the needs of the person living...
with the condition. Overall few accounts are available of how these technologies are used in the care environment – partly because many are still in the development phase and partly because of problems with access to the user group (see section 4.5 Problems with Technology Design for Dementia Care below). Market data about this type of technology is not readily available. The consensus view however is that few technologies are useful to the user group (see e.g. [Rosenberg and Nygård 2012]). In this section I focus on some of the problems that might arise from technology and how they relate to the problems technology sets out to solve.

4.4.1. Autonomy
Autonomy is loosely defined as “the capability to act on the basis of one’s own decisions and to be guided by one’s own reasons, desires, and goals” [Friedman 1998:26]. For dementia care this becomes problematic as people with dementia may not be able to clearly communicate their wishes and therefore may be hindered in acting on them. In the medical model of dementia, the symptoms may lead to a loss of autonomy as they indicate a lack of capability to make decisions [Behuniak 2010]. As a result close caregivers or formal guardians are normally put in charge to make decisions on behalf of the person with dementia [Livingston et al. 2010]. However, a dementia diagnosis does not in itself constitute a loss of autonomy: lack of mental capability needs to be established through other means [Haberstroh 2015]. Furthermore, technologies can also augment the autonomy of people with dementia: for example, through ethnographic observations Morrissey [2015] highlighted how people with dementia use existing technology, such as music players and televisions to express their wishes in a community setting.

In situated use, issues of autonomy become more complex and go beyond the question of whether consent is given or a technology is used at all. Technologies can affect autonomous behaviour in many ways as outlined by Friedman [1998]: they can be overly complex, not accessible as their functions are unclear to the user, or the capabilities of the software can be misrepresented. In addition, autonomy, i.e. the ability to exert one’s free will, is influenced by a range of outside factors, such as cultural norms [Stoljar 2006]. Current devices rarely reflect these subtleties.

4.4.2. Caregiver Roles
Care settings are varied and individual and I do not cover all aspects in this thesis. I distinguish between the two most common types of settings: formal and informal.
Decisions about care and the use of monitoring technologies are often taken by those caring for people living with dementia, either formally in institutionalised care or informally by next of kin or loved ones [Martins et al. 2014]. Formal or institutional caregiving entails caregiving in settings such as care homes, by professional home care providers or in hospitals. Informal caregiving on the other hand is done by non-trained persons, often without reimbursement. These individuals are mostly close to the person with dementia such as partners, spouses, or next of kin. Care can – and will in many instances – be undertaken by a mix of formal and informal caregivers.

The process of becoming an informal caregiver may cause tensions between the individuals affected. Decision making on behalf of a family member or partner can be conflicting and stressful for those involved [Livingston et al. 2010]. Roles and existing power structures can influence how dementia care is done [Wan et al. 2016]. Conflict may exist in the family prior to the diagnosis and it is important for HCI researchers to acknowledge that roles evolve and change [Yarosh 2014].

### 4.4.3. Caregiver Conflicts

Both formal and informal caregivers are to a large extent aware of their responsibilities towards people with dementia and aim to decide in their best interests [Robinson et al. 2007]. However, caregiver wishes and needs may differ not only between caregivers but also from the opinion of the person with dementia; particularly regarding the question of what constitutes risk and what level of risk is acceptable [Landau et al. 2010; Robinson et al. 2007]. Caregivers may feel compelled to keep people with dementia safe, even though this might impact on their autonomy [Wan et al. 2014]. This can lead to people living with dementia being coerced into the use of devices, without feeling like they benefit from their use directly [Gibson et al. 2015; Berridge 2015]. Nonetheless, giving caregivers this peace of mind could benefit people indirectly by delaying institutionalisation [Boger et al. 2005]. The resulting question is whether people living with dementia should accept infringement of their privacy rights to benefit from these positive effects. Hughes [2008:48] argues that there are “no right or wrong answers” to the debate around these monitoring devices, making their use a ‘wicked problem’ [Rittel and Webber 1973] for which no general solution can be found.
Adding to the complex decisions caregivers are faced with, technology can also create new dependencies and workload, which has been observed both by informal [Saborowski and Kollak 2015] and formal caregivers [Engström et al. 2006]. The constant possibility to monitor someone might lead to a perceived increased responsibility and burden, the so-called “Big Brother” effect (see [Casas et al. 2006:779]). Caregivers raise concerns that technology can lead to a lack of human contact [Engström et al. 2006]. While technology could supplement care, critics fear that it might lead to a reduction in staff numbers due to the financial pressure on the health system and the potential cost reduction through the technology [Kenner 2002; Bail 2003].

Keeping technologies simple to make them easily usable by people living with dementia is an often declared goal (see for example [Donnelly et al. 2008; Orpwood et al. 2008]). As the dementia care setting is complex, concerns are raised that these simple solutions may not be adequate [Rosenberg and Nygård 2012]. One of the questions that surround the adoption of technology is at which stage of dementia the technologies can and should be introduced. Stigma or lack of perceived need might reduce engagement in the early stages of dementia, while in the later stages symptoms might be too advanced for successful implementation (see [Nijhof et al. 2013; Perry and Beyer 2012]). In addition, caregivers may be hesitant to introduce a new device before an actual problem has arisen [Starkhammar and Nygård 2008]. Technology is often seen as a means to compensate for the lost needs of someone with dementia, rather than a supportive aid [Rosenberg et al. 2012], for which the medical model of dementia can be seen as an explanation.

4.5. Problems with Technology Design for Dementia Care

In the last section 4.4 Problems with Technology Use I outlined reasons why current technologies do not fit in well within the setting they have been designed for, particularly questions around autonomy and privacy and the wide variety of settings and stakeholders, as well as the conflicts that might arise from conflicting values. Looking beyond the technologies as such, in this section I describe systemic issues that have led to the mismatch between user goals and technology applications.
4.5.1. The Medical Model

The recognition of dementia as a specific sets of illnesses is still relatively new. Alouis Alzheimer first observed the illness in 1906 as a separate condition and not a normal sign of ageing [Bond 1992]. The process of labelling symptoms can be described as “medicalization” (see e.g. [Bond 1992]), which generated a medical model of dementia, foecussing on the symptoms a person displays.

Inherent in the medical model is a division between what is ‘normal’ i.e. healthy and that which is deviant. Members of the medical profession – and to some extent those who develop technology interventions in this context – are enabled to “dictate others how they should behave” [Lupton 1997:96]. This can be observed in technologies designed for people with dementia, for example in GPS trackers that set a geo-fencing area and send out notifications when the person with dementia leaves the area.

The medical model and technology design have influenced each other, as technology design focusses increasingly on health and health providers are increasingly reliant on technologies in their everyday tasks (compare [Clarke et al. 2003]). In dementia care this can be observed through the turn to monitoring technologies that “have the potential to reduce the costs and burdens of caregiving while increasing safety and autonomy in old age” [Kenner 2002:2]. The avoidance of risk is at the heart of the medical model and people with dementia might be “infantilized” in having the capacity to make decisions taken away from them [Bond 1992:402]. Technology is a means to do that. Commercially available GPS trackers for example often target both people with dementia and children (as well as dogs!) as user groups.
(see e.g. Figure 1, the package of a GPS tracker used in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies). The medicalization of dementia has implications for care. The management of dementia becomes a personal rather than a societal problem. Technological interventions then become more urgent as the responsibility is placed on the person with dementia themselves and their next of kin.

For dementia the medical model has been challenged for example by the personal model introduced by Kitwood and Kitwood [1997] which assumes that even though the dementia symptoms may hinder the expression of it, a ‘self’ remains that needs to be catered and cared for. This model has led to changes in the care of people with dementia, such as the introduction of reminiscence therapy and other sensory stimuli. Most dementia care is based in this model (see also [Behuniak 2010]). Technology development lags behind this current model of care, and so arguably does not fit well within either private or institutionalised care environments.

4.5.2. Problems with Recruiting Users

Disability, care and illness are sensitive issues that are not easily accessible for researchers. Activities often take part in the home or in care facilities to which access is not easy and researchers need to tread particularly carefully as to respect the needs and wishes of both staff or carers and potentially vulnerable populations. As a result, people with disabilities have for a long time been excluded from user research [Sears and Hanson 2012]. Comparable practices can be observed when elderly people or those with dementia are meant to be the recipients of technologies. Alternatives to direct user-involvement of people with dementia include involving actors [Boger et al. 2005], dramatic performance [Coughlan et al. 2014] or testing a navigation app with children [Kaminoyama et al. 2007]. An extreme example can be found in Helal et al. [2003], who used a movable “test dummy”- made from PVC pipes, moving on a remote controlled car and dressed with wig, make-up, glasses and dress - for the initial usability study of a smart home.

More generally, caregivers have been involved in the design process as proxies. As those who are close to people with dementia either as partners, next of kin or professional caregivers, it is expected that they have a good understanding of the everyday impact of dementia symptoms and the requirements of care. The
involvement of caregivers in participatory design has been debated, as a caregiver may support the person with dementia [Orpwood et al. 2004], but also may also take the lead and influence the process too strongly [Hendriks et al. 2013]. Focusing on caregivers might have skewed developers in the development of technologies (e.g. [Rosenberg et al. 2012]). As outlined above, care involves a wide range of stakeholders who might have contrasting views, as can be seen for example in a study by Fauconau et al. [2009] who tested a GPS tracker with a married couple where the husband had been diagnosed with dementia; they found that the device was not able to fulfil the requirements of either user. To develop technologies useful to people with dementia, it has been claimed that it is essential to include them in the design process [Fligkos and Xanthidis 2013; Adlam et al. 2004] but it is not regularly done.

Here I explained how dementia affects the use of technologies and how its progressive nature makes it problematic to develop technologies that fit into the complex settings that dementia care brings with it. This problem is further exacerbated through the focus on dementia itself and its symptoms as well as a lack of engagement with the people who are most directly affected. In the next section I outline why this makes it an interesting area to apply design fiction to.

4.6. Dementia, Technologies and Design Fiction

As the literature review has shown, dementia leads to decreased independence as symptoms increase. While there is a strong interest in using technology to relief the burden of caregiving and support those affected to live independently for longer, the review has also shown that few of these solutions work well in the complex settings they are introduced to. Design fiction has been applied to complex areas, in which consequences might only become visible over time (see section 3.6.3 Complexities & the Long-Term), which makes it promising for an area such as dementia care. In the context of monitoring technologies, it seems particularly suited as the ethical debates did not have much impact on technology development. New discourses are needed to reframe the problem and develop alternative solutions. Design fiction has been lauded as a means to show up alternatives (e.g. [Tanenbaum et al. 2016a]), which are currently needed in the debate about monitoring technologies Lindley and Sharma [2015] argue that changes in technology design in care are often incremental and suggest that design fiction can
be a useful way to develop more ‘radical’ and maybe more ethical solutions. A comparable incremental approach is taken in dementia care which makes design fiction a potentially suited method to further technology development in this area.

Design fiction is further useful as it enables the exploration of technologies that do not yet exist. As the miniaturisation of technologies moves on, the potential of smart home solutions, embedded into the fabric of the house, is currently explored. Design fiction might be a means to further the development of such technologies alongside the technical advancement (e.g. [Orpwood et al. 2007; Boger et al. 2005]), work with caregivers or elderly people (e.g. [Wan et al. 2014; Lindsay et al. 2012; Wild et al. 2008]). This might be particularly relevant to not only those who live with dementia now, but also as a means to involve those who might in future live with these technologies. But this opportunity also raises relevant questions about whose voices get to inform the design fiction and what can be the base for the speculation. The current discourse about monitoring technologies is mainly led between those who have experience with care (e.g. [Wild et al. 2008; Bail 2003]) and those who build technologies (e.g. [Paiva and Abreu 2012; Boger et al. 2005]). To provide alternative views, a new perspective might be needed. One approach might be to involve people with dementia themselves in the development process. Design fictions have been written with people living with dementia themselves [Tsekleves and Darby 2016] and people living with dementia have been involved in the process of developing scenarios. As their views are starting to emerge (e.g. [Lindsay et al. 2012; Tsekleves et al. 2017; Wan et al. 2014]), I turned to another group of experts for the next study: privacy experts.

4.7. Conclusion

While a wide range of publications discuss monitoring technologies for people with dementia, many discuss the topic in the abstract. The position and experience of those who are being monitored is underrepresented as dementia is often seen as a medical, isolated issue and access to people with dementia is complicated in the academic context.

The literature review highlighted a strong predominance of monitoring technologies in dementia care and a resulting debate about autonomy and privacy. To widen the discourse and my understanding of the issue, I turned to experts previously neglected in the debate: privacy experts. From this turn, I hoped to gain
new arguments and views on the issues that might inform and inspire a design fiction that went beyond the discourse in the current dementia literature that placed monitoring technologies in regards to privacy and autonomy.
Chapter 5. Dementia & Privacy – A Survey with Privacy Experts

In this chapter, I

- Add nuance to the arguments surrounding monitoring technologies for people living with dementia
- Establish monitoring technologies as situated and tools of power
- Establish probes as a useful means to elicit rich data to inspire design fictions

5.1. Introduction

The literature review about monitoring technologies for people with dementia has shown that the impact these technologies might have, has been debated for a while. Two positions currently prevail: developers emphasise the potential benefits of technology use, while caregivers raise concerns about the autonomy and privacy of people living with dementia. Technological solutions are often sought to enhance the acceptance of these devices with a focus on cost [Paiva and Abreu 2012], or the accuracy of the signal and time to find missing persons [Milne et al. 2014]. To overcome concerns that the device itself may be considered to be stigmatizing, their functions are increasingly transferred to mobile phones [Beauvais et al. 2012]. While this may reduce the stigma and cost, compliance may be a concern for a user group not used to these devices [Doughty and Dunk 2009]. A main interest expressed in the academic literature lies in enhancing the efficiency of the devices, while the emotional and ethical impact has received little attention.

To widen the perspective, I undertook a study with privacy experts, a voice also previously neglected in this debate. The study addresses the research question: **What are the views of privacy experts on the ethical, social and emotional implications of monitoring technologies in dementia care?** The study engaged visitors of the Chaos Communication Congress, which according to their own website is “an annual four-day conference on technology, society and utopia”, with a “critical-creative attitude towards technology” [32C3]. Then in its 32nd year, the Chaos
Communication Congress (32C3) took place in Hamburg, Germany in December 2015. It has an open agenda of exploring the role of technology in everyday life, with a traditional focus on data security, hacking and open software. Talks about hardware and software hacking are as much part of the conference as talks from political interest groups about surveillance by governments and businesses. It was expected that this group would have a good understanding of challenges and benefits of technologies which would enable them to give more nuanced views than healthcare staff. Their strong views on privacy nonetheless were expected to lead to more critical perspectives than those held by developers working in the field.

As the topic touches on sensitive issues, I developed ‘probes’ to gather responses from participants that were designed to match the informal, collaged style that predominates at this event, and further enabled participants to respond in a way they preferred. The study results confirm that views on current monitoring technologies are more nuanced than presented in the academic discourse and indicate important considerations for potential users of the technology.

5.2. Method

5.2.1. Design
This qualitative study aims to gather participants’ responses towards the social, technical and emotional impact of current technologies in dementia care. To enable participants to express their views in their own words, a set of worksheets was developed, based loosely on the concept of ‘informational probes’ [Crabtree et al. 2003]. The exploratory nature of the materials was considered useful to gather a wide range of participants’ responses. Worksheets with scenarios that described technology use have been placed for participants to work on in their own time and return to the researchers. Data collection took part over the first three of four conference days. Most talks at the conference are held in English, even though the conference is in Germany. I therefore decided to design the worksheets in English to enable a wider group to take part.

5.2.2. Participants
The study took part at the 32C3 conference to recruit participants who have an interest in privacy and the implications of technology use. It is unknown how much understanding about dementia the participants brought into the study. Eight
audience members at the conference decided to take part and returned their study materials in time to be included in the analysis.

The study was conducted anonymously and no personal data was collected. This was out of consideration for the participant community who were expected to hold strong beliefs about the appropriateness of data collection and security of the data.

In 2015 13,000 people attended the sold-out conference [Wikipedia 2019]. The conference audience at the 32C3 is very diverse demographically and geographically. Even though the majority of the audience is still male, the number of female participants is constantly rising. The conference has no lower or upper age limit and prices are kept low to support the attendance of younger visitors. While the first conferences of this series were hardware focused, the conference now attracts a wide audience of people with an interest in the social impacts of technology.

One participant expressed interest in the study but did not feel confident to take part in English, therefore I translated the questions for them. Replies by this and another participant, who did not discuss his choice of language with the researcher, were given in German. I translated these for analysis. All other responses were given in English.

5.2.3. Materials
The probes included an information sheet, 5 scenario sheets, a privacy living will sheet, a debrief sheet, two pens and a number of coloured stickers, packed into a see-through wallet.

The information sheet gave an introduction to the project, introduced the researchers and explained that the participants gave informed consent when returning the filled in envelopes. It was placed on top of the other sheets and could be read before opening the pack.
The five scenario sheets described current use cases of monitoring technologies in dementia care as they are described in the literature (see Figure 2 for an example). Each scenario used fictional names to generate an empathetic connection with users of the technology. The five scenarios were:

“Camera surveillance in Laura’s care home”,

“Peter wearing a GPS tracker”,

“Motion sensor tracking at Jane’s home”,

“RFID tags in Doris and her friend George’s care home” and

“Camera surveillance of John’s father at home”.

The scenarios contained one paragraph describing the situated use of the technology, giving a short overview of the function, the situation and stakeholders. A collage of pictures was added to evoke emotional responses. Each sheet also contained three questions: “What do you think about this technology?”, “Who benefits?” and “Are there any issues?”.

On an additional sheet participants were given a multiple choice questionnaire in which to indicate their personal preferences when using these technologies. Short introductory paragraphs outlined why these technologies were used in a care setting which were taken from the academic literature. Different options about the data collected by the monitoring technologies were given, e.g. under which circumstances it could be recorded and who should have access to the data. In the following result and discussion sections this is referred to as the privacy living will.
5.2.4. Procedure
A set of envelopes were arranged on a table with a locked box next to it, into which participants could return envelopes after working on them. The envelopes were left out for the three first days of the four conference days around the clock, with a sheet next to them explaining that conference visitors were free to pick them up and return them in their own time. In addition, the main researcher at times attended the desk, informed passing visitors and invited them to take part.

5.2.5. Analysis
As the aim was to get novel views on the topic, iterative thematic analysis [Joffe 2012; Braun and Clarke 2006] was used to analyse the data. Data was transcribed from the sheets and responses to each scenario were gathered. Data was initially divided into ‘social’, ‘technical’ and ‘emotional’ codes to reflect the research question, which were further refined. The data was coded in multiple steps of reading, refining the codes and writing. Data analysis took part shortly after the data collection ended and took about one month.

5.3. Results
Eight envelopes were completed and returned in time. All sheets were filled in in all the envelopes, but levels of engagement varied. Even though the information sheet specified that participants could respond in the way they preferred, all participants chose writing to express their thoughts. The only other marks were
made by one participant who erased words in the description of the scenario in two cases. These marks were considered to be too ambivalent to be included in the analysis (see Figure 3).

By comparing commonalities and discrepancies between the codes in each of the three blocks - ‘social’, ‘technical’ and ‘emotional’ – five themes were developed from the data. All theme titles were chosen from participants’ expressions in their own words:

‘Wonder what happens with the data’, a theme about technical and social implications of the data,
‘Humans are no clocks’, a theme about the relationship between humanity and technology,
‘Other means possible with fewer data’, a theme about the adequateness of data collection,
‘Looks like policing’, a theme about power structures, and
‘Then again’, a theme about sense-making.

5.3.1. Wonder What Happens with the Data

“Wonder what happens with the data” is a comment made by P1 in response to the GPS tracker scenario and this question can be traced throughout all results. Abuse of the data was one prevalent subtheme, particularly in regards to the motion sensor scenario: “Not good – abuse possible by people who do not mean well” (P2). The participant further highlights that the threat may not only be towards the individual and their data, but may also be material: “Can someone unlock the front door with his fake RFID? (Mr. Burglar)”. This underlines the strong conviction that technologies can be exploited if not secured correctly. A response to the RFID tag scenario for example explicitly poses the question: “How well protected (it security) [sic]?” (P4). The potential exploitation of these technologies was a strong concern for participants.

Connections that require data transfer via the internet have been especially mentioned by participants as possible threats. In regards to the webcam used at home P2 for example writes: “Never ever use a fucking webcam. PERIOD. Just don’t”. The strong language used here indicates a strong personal conviction behind this statement. Another possible point of exploitation mentioned by the participants is data storage. Whether or not data is stored is seen as a critical point to decide whether the data collection is appropriate or not: “Only acceptable if, … and the videos
“are not / will not be stored” (P5 [translation BS]) The acceptance of the data depends on a range of options, e.g. the medium with which it is collected and under which circumstances data is stored.

How the data collected can be acted upon and by whom has been questioned throughout the results. P8 for example asks in regards to the camera in care home scenario: “Do the cameras really help? Watching trouble may not be enough.” Many participants questioned whether help would come in time or at all when observed through the technology. One participant wrote: “Not obvious that anybody benefits” (P1). Technical issues also play a role in the discussion. P2 observes in response to the motion sensor scenario: “What happens during power outages? NO MOTION DETECTION.” No clear adequate response to the data collection has been identified by the participants of the study.

Many participants discussed potential emotional responses the caregiver might have to receiving the data. Worried and (perceived) safety were mentioned most often. These contrasting emotions were mentioned throughout all scenarios, though normally by different participants. While two participants argued that perceived safety might be a good outcome because it increased the autonomy of the people living with dementia, two other participants expressed concerns that caregivers might be more worried after having been given this level of control. The relationship between worries and the use of devices was also criticised by P2, who wrote: “It is not a good idea to violate the right to privacy because you are worried”. Remote monitoring via camera or motion detection gives reason for this concern: “But again when he doesn’t find him on the screen, what’s next? A lot of worries for no reason?” (P6). While the use of the technology can be seen as positive, its benefits are also questioned.

All sheets posed the question: “Who benefits?”. It has often been picked up by participants who outlined who they think the beneficiary is. I refer to the camera in care home scenario as an example here as four participants expressed three different views. Two participants argue that the benefit lies with the “caretaker” (P2) or with the “operator” (P8) as these stakeholders can reduce cost through the introduction of the technology. P7 argues that the benefit lies with the patient. P1 in contrast asks whether there are benefits at all. This range of opinions can be seen throughout the data set. Participants raised a range of possible consequences of the technology
which can be both positive and negative. Technical issues as well as social issues were highlighted as influencing the impact of the technologies.

5.3.2. Humans are No Clocks

“Humans are no clocks” is a theme, which consists of social and emotional responses that explore the difference between human contact and the use of technology in a care setting. Participants often showed hesitation to accept these technological solutions as care in the traditional sense, by stating: “even when it is not clear what means ‘caring’ in this case” (P1 in response to the webcam at home scenario). Going even further P2 argued that: “If you cant [sic] take care of a demented [sic] relative, get professional assistance”. In the motion sensor scenario P5 actively contrasted care and the use of smart technology and described it as “Just a substitute for real care and human interaction”. Participants argued that these technologies might lead to staff reduction and might be employed as a means to reduce cost: “less costs for care for care companies / substitute for persons” (P3). It can be inferred that this is a negative outcome because participants expressed a wish for human contact: “It would be nicer if there was an actual person by the door, checking if Doris wanders off” (P6). Participants also expressed personal preferences: “I’d rather have someone check in regularly” (P6). These responses imply that technology is not a suitable response to the care needs of the persons with dementia.

But there is another view on human surveillance compared to machine surveillance. While it is considered more controversial to ‘replace’ personal care in institutions with technology, it seems to be more ‘freeing’ in the home. In the webcam at home scenario P8 remarked that:” Such an arrangement would, anyway, be preferable to one in which John has to stay home and his father cannot escape his watch at all”. In the motion sensor scenario P4 argued that “[s]elforganised living may be possible”, underlining the positive, freeing aspects that technology might bring. P7 describes the “big advantage” of the GPS tracker as follows:” having the device Peter (and his wife) feels more free [sic], because he is also able to leave the house”. In contrast to the negative responses above, participants also considered these technologies as empowering.

In response to this scenario P5 argues that “If it is a person close to him, I guess it is a huge benefit”. This closeness of the relationship seems to make the difference when behavior is not observed personally, but mediated through technology. Especially the motion sensor and the RFID scenario evoked responses in this direction. P4 hints towards the “danger” of “not considering the very special circumstances” in the motion
sensor scenario. Without the emotional connection, the use of technology is seen much more negatively. P1 states: “A society with one single idea of reality benefits because there is no need to deal with people who have different demands and needs”. P1 makes two references to sexual practices in the responses as examples of behavior that may be considered inappropriate that might be exposed through the sensors. Depending on the context in which the technology is used, it has been considered both negative and empowering by the participants of this study.

5.3.3. Other Means Possible with Fewer Data

One consideration with which participants decided on the adequateness of the data collection was “other means possible with fewer data”. Gathering consent was seen as one requirement for data collection: “Legitimacy depends on: … consent” (P4). Participants did not reflect on the nature of dementia symptoms and whether they might impact on informed consent. Other limiting factors were raised: “Does the father agree and did he agree on free choice?” (P7). It is unclear from the response who might attempt to influence the choice but this answer suggests that consent might be influenced by a range of factors.

Participants established type of data as a criterion to decide whether data collection was adequate. “Other means possible with fewer data” has been a response by P3 to the webcam at home scenario. Participants negotiated the use of these technologies considering themselves: “This is better” (P5), “… I guess I could live with the tracker” (P8), “Only acceptable to me, if…

Figure 4: Privacy Living Will, filled in by P1, 2015, own scan
Participants expressed a range of considerations in regards to these technologies based on their own values.

Comparing the privacy living will sheets, responses became even more individual. All eight responses differed and ranged from participants’ rejection of all technologies to people who agree to be monitored very closely. While some participants preferred monitoring from care staff, others preferred family members or added “good friends” (P1) to the list (see Figure 4). Participants gave a range of responses of what was considered acceptable not only in regards to people living with dementia, but also themselves. The acceptance of the monitoring technologies was individual for every participant.

5.3.4. Looks like Policing

“Looks like policing” became a theme that covers codes of oppression, power and violence. It has been developed from the strong or negative language used by some participants. “[P]olicing” (P6), “reminds me of prisons” (P6) and “Where is the difference from a prison?” (P2) are responses to both the RFID tag scenario and the camera in care home scenario. These kinds of comparisons are limited to care institutions and have not been applied to people living at home. While the mention of prisons might be a response to the fact that people living with dementia are physically confined in the motion sensor scenario, the connotation of “policing” is a response to the camera scenario. It evokes images of oppression, prosecution and possibly criminalization of people living with dementia. It is an expansion on the “Humans are no clocks” theme, implying that people are not only classified but also ‘punished’ for their deviating behavior. P1 writes “Camera surveillance is the last (technical) solution to take care of people who are not part of a community”. The view on technology is here is one of a tool used to exert power and control.

People with dementia, in contrast, are seen as “helpless dementiapatients [sic]” (P2), which underlines the perception of them being victims. Participants who named people living with dementia as “helpless” or “demented” – a word not currently used anymore in care circles because of its negative connotations – expressed much stronger views on the use of technologies. Participants who attribute a more active use of the technology to the people with dementia, found the technology more acceptable.
Technologies were described as a “violation” (P1) of privacy and as “a massive invasion” (P6) of privacy. P4 introduced the word “Danger” while the worksheets used the more neutral word ‘issues’. This use of language described the use of RFID chips in care homes as a “horror-scenario regarding what reality is” (P1). Even though the examples on the worksheets were introduced as current practices, P1 used the term ‘scenario’ distancing it from reality. Two references to movies were made in this participant’s responses, indicating a further distancing from reality. Strong language was used throughout the worksheets, introducing an element of power and indicating that the people subjected to these technologies may be victimized.

5.3.5. Then Again
Taking the form of the responses, i.e. how the responses were arranged on the paper, into account, it was decided to declare “then again” as a theme from the data. It gathers elements of sense-making by the participants who seemed to respond spontaneously, making sense of their replies while they went along. P6 was particular articulate about the thought process, arguing and comparing arguments while going along (see Figure 5). P6 added short statements, just bullet points, after longer explanations on the page, which appear to be an afterthought. In addition, P6 added a long statement on the last page to voice very negative emotions, explaining that taking part in this study had changed existing points of view. P3 used plus and minus signs to rate the comments and alternated between them,
These additional thoughts and alterations indicate that participants expressed their thoughts spontaneously and made sense of the questions while they went along. It underlines the individuality of the responses, the emotionality with which the participants responded and the complexity of the topic.

5.4. Discussion
Using a probing method, I was able to confirm that opinions of what is acceptable varied widely, even though the group of participants was expected to be highly conscious of their privacy. The results give practical insights into the development of monitoring technologies that support a wider user group by giving participants needs and wishes about potential modalities. The work furthermore supported the reframing of the topic by introducing an element of power and control that has influenced the writing of the design fictions presented in this thesis. In the upcoming discussion I first talk about the way participants linked data collection with individual benefits, before discussing how they reflected on the power exerted through the technologies. In the last two sections I discuss the method of the study, first by considering the role empathy played in framing participants’ responses before discussing the strengths and weaknesses of this study in more depth.

5.4.1. Data Use & Benefit of Technology Use
Little is known about how common these monitoring technologies are, neither in personal nor professional use. Efforts have been undertaken to reveal market data or study on this subject, but none could be found. Insights into the use of these technologies came from case studies, such as observations into how people living with dementia and other cognitive impairments relate to it by Niemeijer et al. [2010] or a comparison between two care homes by Wigg [2010]. Personal use has only been researched in short-term studies in which devices have been given to people living with dementia who did not use the devices before the study began (see for example [Milne et al. 2014; Faucounau et al. 2009]. While these studies show beneficial results, the longest study lasted three months. No long-term effects have yet been observed. These studies often show high number of drop-outs, which Altendorf & Schreiber [2015:44] attribute to “[e]thical controversies and concerns”. As was to be expected from the main framing and the audience of the study many of
the comments questioned the use and benefit of data collection. But acceptance of the devices varied and showed a range of underlying motivations.

When discussing consent to data collection, one participant questioned whether it would be given out of ‘free choice’. Gibson et al. [2015:4] report from their interview and observation study with people living with dementia in regards to assistive technology that: “One person with dementia accepted a range of potentially intrusive DIY technologies including CCTV cameras set up by her husband because she felt it made his life easier”. This underlines tensions around the question who benefits from the use of monitoring technology. Study participants had no clear response as opinions differed. Godwin [2012:131] set up an ethical checklist for the use of assistive technologies in general which starts with the question “Who is the real beneficiary?” Power relations in the use of this kind of technology have not yet been highly researched but could have a strong impact on the acceptance of the technology.

Participants argued against the storage of data and in particular the development of movement profiles. Products currently do not match these requirements. The trackimo tracker for example is advertised with “complete device path history for up to 5 years” [Trackimo 2019]. This data could potentially be used to develop a movement profile. Study participants also brought up the topic of technical data security to prevent exploitation. This has been given little consideration in the existing literature. Overall there seems to be a mismatch between concerns potential users have and the products offer. While the importance of maintaining or at least negotiating the privacy of the user of the device has been discussed both by the participants of the study and researchers such as Solanas et al. [2013] or Hughes [2008], only one out of nine providers of GPS trackers mentioned the security of their tracker as a functionality on their website.

Participants held different opinions about observation by family members in contrast to care staff. Participants responded differently to the use of technology by institutions, which indicates a latent mistrust against the health care system behind them. People close to someone with dementia in contrast are expected to be more likely to make decisions in their best interests. Landau et al. [2010] set up focus groups with both family and professional caregivers and found differences in the way both groups define their caring role. The tools currently available though
do not yet make any distinction in regards to who uses them, which might influence whether or not their use will be considered appropriate.

5.4.2. Individuality
Responses to the study were more varied than the specialist audience suggested. Throughout the data emotional language was used. This implies that participants were nonetheless engaged with the topic and held strong beliefs.

The scenarios deliberately gave very limited insight into the use of the technology. Only use in specific moments was shown without discussing the adoption of the devices or future consequences. This was done deliberately to elicit responses from the participants on how they imagined the process to be and what matters they found relevant beyond the actual use. It also mirrors the tone of the academic literature when development projects are presented, which also often focus on use, leaving out acquisition, maintenance or end of use. Participants questioned how the use of the devices would be integrated into a larger context and how it could be adapted to individual circumstances. Even when the general usefulness was not rejected, participants questioned the context or set out conditions with which to evaluate the situation.

Participants were critical about the possibility to not only observe, but also to classify behaviour through the use of technology, which might lead to self-censoring. Berridge [2015] has given one example of how technology might influence behavior. They researched the reasons behind non-use of a sensor-based care package, called QuietCare, for elderly people and reports that: “The most common reasons cited [behind non-use] was that the expectation of routine built into the system disrupted their activities and caused them to change their behavior to accommodate QuietCare…” Kenner [2002:262] observes that monitoring technology is not only used to “identify and evaluate risky behavior, but also work to normalize what is acceptable”. Classification of behavior can lead to a categorization into ‘right’ and ‘wrong’ behavior, forcing people to adapt their behavior as to not stand out or to avoid judgement.

Dahl and Holbo [2012:577] apply the concept of value-sensitive design to safer walking technologies and find that existing technologies lack “granularity” of choice. Suppliers of commercially available tracking devices offer the same or very similar devices to track children, the elderly, pets or possessions, showing little or no adaptations for the individual needs of people living with dementia.
5.4.3. **Power & Surveillance**

Power structures imposed by monitoring technologies have been given little thought in the academic literature on the topic so far. Discussions around the negative connotations are mainly avoided, as seen for example by the neutral term ‘monitoring’ chosen to describe the kind of technology described. Kenner [2002:253] makes the point that those technologies can also be understood as ‘surveillance’, which “raise[s] critical questions about caregiving, quality of life, and how technological design engages with everyday individual rights”. The technologies can be used in a variety of ways as observed in the literature. Wigg [2010] discusses the use of RFID chips in care homes based on their own observations and compares two approaches: one care home in which doors are locked so that residents cannot leave and one in which a caregiver is notified when a resident leaves. The caregiver then accompanies the person with dementia. They conclude:

> “By comparing the technologies of locked doors and motion detectors in context, this paper shows that distinction exist between surveillance technologies that chiefly engage in social control and surveillance technologies that encourage greater independence and interpersonal interaction between staff and resident” (ibid, 299).

Participants’ expressions imply that they are more worried about the control that these tools can exert. Reports from current practice show that a better approach is possible, but this was not taken into account. This quote underlines that these technologies can be embedded in a humane and dignified way, but anxieties that they may not shows strongly through participants’ negative expressions. Participants of this study questioned whether the use of the technologies introduced in the scenarios constituted caring. Trust – both towards the technologies and institutions using them - has not much discussed in the literature so far. Its understanding could be beneficial to improve the technologies. Participants in this study might held stronger views than the general public, as the study took part close to the ‘Anarchist Village’ of the conference. Nonetheless, a mistrust towards the technology and the people using it can be found throughout the responses.

5.4.4. **Empathy**

People living with dementia at retirement age today do not seem much concerned about privacy issues (compare. e.g. [Lindsay et al. 2012]). This study implies that coming generations are more aware and might feel more strongly about privacy in
regards to the devices they use. Understanding the impact of these concerns and addressing them in a way that is acceptable to future generations might be an important contribution to technologies that are usable for coming generation.

The use of the fictional characters worked well to elicit empathic responses from the participants. In technology development projects the users are often called ‘people with dementia’, thereby distancing the developers from the intended user group. The producers of the ‘Stray Star GPS tracker’ for example use the slogan: “Know when THEY wander, and where THEY are” ([Stray Star Ltd], emphasis BS). This use of terminology could be considered dehumanizing as it emphasizes that people living with dementia are different. Nonetheless, the study materials might have suggested a particular image of people living with dementia. People living with dementia have twice been described as “old” (P2 & P4). This reveals another perception about dementia, though this might have been influenced by the use of images in the scenarios.

Even before the privacy living will which asked participants specifically to imagine themselves as users of the technology, participants expressed their own views about the technology. This shows that the method chosen worked well to elicit empathic responses, but is also an indication how emotional this topic is. This might have an impact on the development of technologies that might be ‘unusable’ if participants do not feel that they match up with their values.

5.4.5. **Strengths & Weaknesses**

Limitations in the study setup, such as a lack of advertisement, led to a small number of participants. Nonetheless, the engagement of the participants who participated and the resulting depth of data makes this a valuable pilot study which informed my further PhD work. It also added nuance to the big ethical problems outlined in the literature review which can be useful to develop nuanced design fictions.

In a focus group study Wild et al. [2008:7] found that it “was difficult for many of the focus group participants to see themselves as persons with deteriorating cognitive function and the consequent need for monitoring of their activities”. Participants in this study on the contrary have given varied and reflected responses to the question how they would feel about the devices, which implies that the open study materials and the scenarios have been useful for this kind of study.
Little is known about the participants’ level of knowledge about dementia. Language use shows differences in the understanding. While one participant used the word ‘demented’ which is not widely used anymore due to its negative connotations, another participant uses “stages” showing at least a minimal understanding about the progressive nature of dementia. It has been a conscious decision to leave out particular information on the worksheets to avoid leading participants’ thoughts. This could have led to uninformed remarks. The differentiated answers give the impression that participants understood at least some of symptoms dementia and the resulting behaviours. Sense-making when participants were unsure also gave valuable insights. One consideration to challenge this limitation is to undertake a second study with the same materials at a dementia-related conference and compare the results.

5.5. Conclusion

In this study I gathered expert opinions on the use of monitoring technologies in dementia care. In contrast to previous studies I engaged privacy experts, rather than those engaged with dementia care or people living with dementia themselves. The study results show more nuance and personal preferences than many previously published studies and opinion pieces. It shifts the focus from the question of whether these technologies are to be used to the question how they are deployed. In addition, the results brought the view to the forefront that these technologies are not neutral, but instead can be used to hold power of those who are monitored. This provides a useful insight for a nuanced design fiction. It also opens up the question how to evaluate whether the design fiction will the “successful” in communicating these tensions. I will follow this up in the last part of the thesis Evaluation.

While the results were more nuanced than the positions I presented above in the literature review, they still remain mostly theoretical and abstract. Participants argued about which types of data they might feel confident with, but gave little insights into how the technologies might affect everyday life. In addition, I still took a step back and drew on other’s people experience. To immerse myself into the topic and gain insights into the everyday use of monitoring technologies I undertook a self-study using some contemporary devices that I present in the next chapter.
Chapter 6. Mundane Tracking – A Self-Study of Monitoring Technologies

In this chapter, I

- Provide a rich description of the everyday experience of living with monitoring technologies
- Reframe the debates surrounding the impact of monitoring technologies
- Outline how a self-study can be useful to inform the development of design fictions

6.1. Introduction

The literature review presented in Chapter 4 Understanding Technologies for Dementia Care revealed that monitoring technologies form a large part of the developments to support dementia care. In the last chapter, I added to the understanding of how these might affect people living with dementia by undertaking a study with privacy experts. This study added nuance to the opinions presented above, but still remained quite abstract. While I gained a good understanding of the ethical concerns surrounding these technologies, I lack the mundane experience of these devices. I could draw on the experience of caring for my grandmother to draw a clearer picture of the experience of caring for someone with dementia. Nonetheless, I have no experience of what the use of technologies feels like in the everyday. Little has been written about what is needed to develop a design fiction and what type of insight to draw from. Design fiction offers the advantage that technologies do not have to be fully developed to explore potential outcomes (e.g. [Blythe et al. 2018]), therefore speculation is clearly part of the process. Nonetheless, design fiction also explores the story world beyond the technology and is often based in rich descriptions and mundane experiences (see e.g. [Wong et al. 2018]). Still, little research has been undertaken in this area that provides rich data and insights. Addressing this gap I focus on the question: How does being monitored with non-mutual tracking tools affect everyday experience?

Choosing a self-study enabled me not only to inform the development of design fictions, but also to sensitize myself to the issues that might arise. By using existing
technologies, I was able to learn more about the everyday impact of these devices. Self-study and auto-ethnography are first person qualitative approaches in which the researcher records, reflects upon and writes about aspects of their personal experience. While anathema to many HCI researchers, who have been trained according to the dictum ‘you are not your user’, and still rare, self-studies are increasingly being used in HCI in a wide range of circumstances and settings. Researchers have tested both self-made prototypes [Harrison and Cecchinato 2015] and commercially available products [Pearson et al. 2015]. Studies have been undertaken to inspire and inform design, e.g. by drawing from the experience of horseback riding to inspire interaction with technology [Höök 2010] or to explore the design space around ubiquitous technologies [Bakker and Niemantsverdriet 2016; Dourish et al. 1996].

Much of the existing literature discusses people who are monitored - children, elderly people or people with long-term conditions – as ‘Other’, i.e. presents them as distinctly different from the group of developers [Dourish et al. 1996]. A self-study can help to develop an empathic connection with the potential users of technologies [O’Kane et al. 2014] and to understand how issues around privacy and autonomy might play out in everyday life. A self-study supports the researcher in drawing on the knowledge they already have and thereby gaining deep, situated understandings of the topic at hand [Neustaedter and Sengers 2012; Uotinen 2010]. It has been suggested that this method enables the researcher to draw out details that other participants might not think about mentioning as they are considered “unremarkable” [Neustaedter and Sengers 2012:519], which I considered to be particularly useful to overcome the limitations and abstract discussions of earlier studies. In the upcoming results section, I present highly personal observations, that participants might not be comfortable sharing with researchers, which nonetheless are essential in understanding the potential issues arising from the use of monitoring technologies. Furthermore, a self-study can also be used to unpack “technology-related agencies” [Uotinen 2010:172] and to learn how technologies impact on the autonomy of the user and the wider network, which I consider to be of particular importance in this area in which questions of autonomy, consent and benefits are highly debated.

The study covers the use of three tools that are currently used in dementia care that can have an impact on the autonomy and privacy of those who are using it. I
describe the results of all studies collated, referring to individual parts of the study when presenting the results, as themes that arose were common to most studies. The study implies that data collection is highly individual and that the tools could benefit greatly from a more person-centred design.

6.2. Method

6.2.1. Design
The study was undertaken as an exploratory self-study in three parts. During the first part, my partner was given access to my phone and asked to set reminders. During the second part, my partner received access to location data via an online platform and mobile notifications from a GPS tracker I wore for 31 days. During the third part, my partner and I installed a house sensor in my bedroom, through which my partner received notifications about environmental data and movement in the room.

6.2.2. Participants
Even though I was the main participant in the study, two other people were involved as participants as well. My partner TK (male, mid-thirties, self-employed) played a role not only in setting up the technologies, but also as the one who received notifications and therefore monitored me. For part 2, during which the GPS tracker was used, I gave access of my location data to my supervisor to be able to compare how tracking by different individuals felt.

6.2.3. Materials
When starting this study, I was confronted with the task to select and buy the technologies used. I set three criteria to decide which devices to test: first, I decided to use commercially available products to get a comparable experience to those of other users. Exploratory prototypes may have been too different to what is available to users outside of the research community. Second, I chose technologies that could be personalized to some extent to enable learning about the process of setting up and maintaining the technology. Third, the devices had to support tele-health or independent living as I do not share a household with my partner. This last issue was not complicated to fulfil as remote care is a common motivator for these kinds of technologies. A reminder app, a GPS tracker and a house sensor were selected for the study.
Chapter 6  Mundane Tracking – A Self-Study of Monitoring Technologies

Figure 6: Screenshot during the installation process of Alzminder, 2015, own illustration

Figure 7: Picture of myself wearing the GPS tracker, 2015, own photography

Figure 8: Setup of home sensor, 2015, own photography

For part 1, I selected Alzminder (see Figure 6), a reminder app I had been aware of before the study and installed it onto my phone (Huawei ALE L-21). When I showed it to my partner, he considered the functionalities too limited. I therefore changed the protocol and asked him to choose one he felt more comfortable with. We tested two other dementia-specific apps (Nudgu Reminders & Memory Angel), which did not work reliably on my phone. In the end we decided to use a non-dementia specific app, called Wunderlist, which enabled remote setting of reminders.

For part 2 I selected a GPS tracker that was advertised as being designed for care – e.g. for children, the elderly or people with dementia – but also for the tracking of pets, valuables or cars (no brand name, available on amazon.co.uk, online). The device was chosen from a range available online that all offered similar functionalities using criteria that are commonly used by online shoppers: online ratings and price. The device enabled access to location data on command or a notification when the wearer left a ‘safe’ zone, via a geo-fence. Further functionalities involved an SOS button which was placed predominantly on the front of the device which automatically established a phone call with the emergency contact. In addition to the device itself, the package consisted of a charging cradle, and a screwdriver for maintenance as well as a keyring and lanyard which could be
used to carry the device (compare Figure 7). Access to an online portal to view and manage the collected data was also available. To enable the call and SOS button functionality as well as the communication with the device via SMS, a SIM card was needed; as none was provided a pre-paid SIM was purchased.

For part 3 I selected a tele-care device, the SeNCit Plus Home Care monitor (see Figure 8). It sensed motion as well as temperature and CO₂ levels in the room it was installed in. Additionally, it notified the caregiver, in this instance TK, about problems with the device such as power cuts and a tamper alarm was triggered when the device was opened. An external door alarm was included in the package, but was removed after the first day as it did not give useful information. A SIM card was included in the package. Additional materials used were a paper diary (reminder & GPS tracker) and my laptop (house sensor) to record reflections.

6.2.4. Procedure

Before each phase I selected and bought a tool to be used in the study (see last section 6.2.3 Materials).

For part 1 I selected the Alzminder app and installed it on my phone. I instructed my partner to set reminders from three areas: reminders to do household chores, reminders to drink water and reminders to contact him, friends or family members. These have been adapted from McGee-Lennon, Wolters and Brewster (2011, 4f) mirroring the main areas for which people generally set reminders but making them more applicable to the context of the study. The reminders were set within the coming month. He was instructed not to tell me how often and at which times the reminders were to be received, to simulate the disruption that the reminders may cause when they remind of events forgotten through dementia. Due to the limitations with this app and technical limitations of the other apps, the process took a couple of days during which I reflected on the experience in a paper diary whenever issues arose. After the app had been defined, set-up and the reminders started, I reflected on the experience whenever a reminder arrived or when outstanding issues arose.

For part 2 my partner and I set up the device (Day 1) together and agreed on the following notifications:
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- Using the online portal, a geo-fencing area was set, covering the area around my home, workplace and the connecting route. A notification was sent to my partner when I left this area.
- A notification was sent to TK when the battery ran below 15%. This percentage was a device default.
- Online data collection was set to gather location data every five minutes. The current position was constantly available online. Additionally, it could be queried by sending a text message to the device.

For the following 30 days I carried the device with me and kept the device charged to ensure it was working. At the end of the 31 days of the study, data collection ended and I switched off the device.

For part 3 my partner and I set up the device (Day 1) together and agreed on the following notifications:

- A notification was sent when the room temperature dropped below 16° C.
- Movement was measured in the morning and evening, but not during the day. After each time period a notification was sent when movement had been detected.
- The device sent a status notification every day.

It was planned to install the device for the following 30 days in the bedroom of my shared flat, but it stopped sending notifications to TK after 24 days. Data collection was interrupted for nearly 2 months until both of us tried to resolve the issue on day 81 and failed, as the device indicated that movement was detected, but instead of sending a notification started ringing TK’s mobile phone continuously. The device was then uninstalled and data collection ended.

The study phases did not follow a strict protocol as originally planned. The house sensor phase was first interrupted and then abandoned due to technical problems. In earlier studies, support was often given by the research team throughout [Starkhammar and Nygård 2008] which may not represent a realistic user experience as this study has shown. While the results from the study phases therefore cannot be directly compared, the range of insights helped to find overarching themes rather than critiquing the individual devices and foregrounding technical issues.
The method of reflection was adapted as the study progressed. For the first and second phase I took notes whenever notable events happened. Notes were completely exploratory and no criteria were set at the beginning for what would constitute a noteworthy event. For phase 3 I recorded reflections digitally whenever outstanding events happened, which was mostly once a day in the beginning, but even less often as the study progressed to avoid repetition.

6.2.5. Analysis
For the analysis I was drew from the thematic analysis approach outlined by Braun and Clarke [2006], and also took guidance from Joffe [2012]. Preliminary analysis of data was conducted after each stage and in depth analysis when data collection had ended. The analysis was done in four steps:

Firstly, I transcribed the data and read through it a couple of times to re-familiarize myself with all the reflections and took initial notes. Secondly, I inductively and iteratively applied codes to the written data to identify meaningful and coherent patterns. Thirdly, I developed themes by grouping codes, which led to the three themes discussed below. Lastly, the full analysis was written up. Progress was discussed between myself and the research team throughout the whole process.

6.3. Results
6.3.1. Adherence
The study was purposefully open ended and few criteria for reflection or evaluation were set at the beginning. Nonetheless, as adherence is a familiar measure to rate an intervention in dementia technologies, I added this to the analysis. For the reminder study, this was straight-forward, as I set three types of adherence from my observations: Full adherence, when I responded immediately, i.e. within few minutes after the reminder was received, delayed adherence, when I responded at a later time and no adherence, in cases when I took no action. Overall adherence to the reminders was low. Of the 51 reminders received, 20 were not responded to at all, 17 were responded to with a delay and only 14 were responded to at the correct time.
As Table 2 shows, this was partly related to the type of reminder. Three main issues were found that impacted adherence: social pressure, wrong time or place, and lack of understanding. While distributed throughout, each of these could be seen predominantly with one of the three types of reminders, therefore they will be presented in relation to each type.

Social pressure was the first issue identified. Most of the reminders in the ‘Contacts’ category were delayed because the time the reminder was received did not feel ‘natural’ to contact those mentioned. The reminders referred to my partner, close friends and family, for all of whom ways of communicating had been established before the study started. When the reminders suggested breaks in these ‘routines’ e.g. calling my parents at 8 o’clock in the morning due to a technical glitch or getting in touch with a friend who had not responded to an earlier contact, the perceived social breach was higher than the anxiety of not responding to the reminder. The reminders could not enable a breach of learned and accepted habits.

The second issue identified was the time and place when the reminder was received. During the time of data collection two trips took part which could be considered as ‘non-routine events’ [O’Kane et al. 2014]. One overnight coach trip to a workshop could be considered a work event, while a long weekend with friends and family to which I flew was considered a private event. During travel times, both for the larger trips and regular ones, such as travel to work, the phone was in my bag, therefore I often missed reminders that came in during these times:” On the tube I see that I missed another reminder: Writing an email to my friend.” (Reflections Reminder, Day 17). Another problem, more common to the larger trips, was that unusual surroundings (e.g. being in a friend’s house with everyone asleep when a breakfast reminder came (Reflections Reminder, Day 20)) or social pressure made it hard to respond to the reminders:

<table>
<thead>
<tr>
<th>Type of reminder</th>
<th>Reminders</th>
<th>Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>no action</td>
<td>delay</td>
</tr>
<tr>
<td>Chores</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>Contacts</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Eat/Drink/Pill</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>51</strong></td>
<td><strong>20</strong></td>
</tr>
</tbody>
</table>

Table 2: Overview of reminder by type
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“The reminders are uncomfortable in social situations, not only because of the ‘pling’ but also because they often force me to step out of the conversation, do something that may not be acceptable, fully understandable by others out of the context or just plainly impossible at the time.” (Reflections Reminder, Day 22)

Receiving reminders that were not timed well led to annoyance, such as reminders to drink water between coffees before I had any coffee or a reminder to have breakfast before I had woken up completely. The reminders also did not give any indication about urgency or the timeframe in which events were supposed to take place, therefore reminders that could not be completed due to external circumstances turned into a source of worry:

“On the tube I heard my phone vibrate in my bag and quickly checked. It was a reminder to drink some water between coffees which made me … worried because I had not [sic] water with me. I drank something as quickly as I could when I arrived at the office and only released the reminder after that” (Reflections Reminder, Day 17).

A lack of understanding what the reminders were meant to achieve was another issue that hindered adherence. While most reminders were straightforward (e.g. take your pill), others caused confusion and I was not able to respond to them easily or quickly (e.g. when asked to prepare for a journey to the airport a couple of hours later). As none of the reminders was set by myself and I was unsure about the aims of the reminder, some were considered confusing and I struggled with interpreting what they entailed, I felt like not “being in the full picture” (Reflections Reminder, Day 15). This lack of understanding was a constant source of annoyance, not only aimed at the reminder, but also at my partner. Even though it was acknowledged in the reflections that he “set it up to do me a favour” (Reflections Reminder, Day 13), I found it “hard not to feel grumpy” with him and to blame him for this reminder that upset me. The notion of ‘feeling grumpy’ and the irritation shows that the devices had an impact on my quality of life and led to conflict with my partner.

While adhering to the reminder was easy to classify, the process was more complicated with the other two types of devices. For the house sensor no criteria could be set as the device needed no input from my side to function. For the GPS tracker I analysed how well I maintained the device, i.e. whether I carried it with me charged, so that it could fulfil its function. I generally wore the GPS tracker and it only ran out of battery once and was forgotten for lunchtime outings three times.
While it might have looked on the outside as if I was happy to interact with the device, this was not really the case. One day I felt particular strongly about wearing the device and the feeling of being controlled as I had broken with routines and considered whether that might have improved my visibility (Reflections GPS tracker, Day 25). But, even on this day, I did not let go of the GPS tracker, but instead tried to stick to it:

Nonetheless I comply. I comply as well as I can. I carry the device with me. I even charge it. I do take care. I comply so that negative feelings [...] cannot be seen. I do not want anyone to know how I feel about the device at the moment. (Reflections GPS tracker, Day 25)

This was true for most of the study where I carried the device on most instances, regardless of my feelings to it.

How users can give informed consent has recently attracted attention within the technology community, for example when discussing the ethics of mobile apps [Rooksby et al. 2016] or the use of social networks by people with dementia [Batchelor et al. 2012]. Compliance was not really an issue with the home sensor, as this worked completely without any active input from me. This approach might become more normal as smart technologies develop and become more seamlessly integrated. But the understanding that adherence does not necessarily indicate full acceptance of devices might have an impact on their design.

In the coming section 6.3.2 Quality of Life I reflect further on the impact the devices had on my quality of life before describing in more depth the conflicts that arose with my partner throughout the periods of use in section 6.3.3 Conflict. Even though instances could be observed in the reminder study I draw my examples from the use of the other two devices as the themes played out more clearly.

### 6.3.2. Quality of Life

For this theme I collated insights that were mainly based in observations about the everyday, felt experience of the device: problems with maintaining and wearing the device as well as considerations about the way the device was perceived by others.

During all phases of the study I felt out of control as the devices sent notifications to my partner, but gave very little feedback to me directly. The GPS tracker for example indicated its status – connection with the satellite and battery level –
through a set of blinking LEDs on the side, which had to be decoded: “It all happens invisible inside [the device], except for the blinking lights whose functions I have mostly forgotten again” (Reflections GPS tracker, Day 6). The devices were not only complicated to use, but also had technical faults that stopped them from working as described in the procedure section. The study with the house sensor had to be interrupted. My partner and I reset the device after the notifications stopped earlier, but the device started ringing his phone without break instead of sending the notifications it was programmed to. Neither the computer interface nor the device itself indicated what caused this. This constant struggle with the technology led me to doubt myself as I constantly had to refer back to my partner who had more control over and information about the devices. It also hindered me in maintaining the device, such as charging its battery. Because I was not in charge of the devices, I felt constantly out of control.

Both devices were set up collaboratively between my partner and myself. For me this was really important as a means to accept the devices, as it helped me to understand what they would do. The devices did not support this process, but addressed a caregiver or next of kin alone. I struggled to accept this, as potentially being out of the loop led me to question myself. In addition, I became suspicious of my partner’s behaviour as it was not transparent to me. Whether he had accessed the data and whether he might change the settings in the case of a conflict in future added to the feeling of insecurity. The house sensor was experienced as less intrusive than expected and enabled me to focus on the experience of being monitored: “I still detect the reason for it being there and making me feel insecure but the data itself is not as intrusive as expected” (Reflections House Sensor, Day 23).

While the type of data collected and the location of the sensor had less of an impact on me than originally expected, it led to reflections on the impact of monitoring itself. As control is externalized, it can reduce the feeling of autonomy within the person monitored (see e.g. [Niemeijer et al. 2010]).

Monitoring in addition led to behaviour being ‘normalized’ as the technology depends on patterns, which did not impact much on my behaviour, but did on the way I thought about myself:

“I slept quite long today and I am not sure if the device did not register any information in time or whether my partner got a notification today. It is a first indication of how I
started to think about my behaviour in terms of normal and not normal again”
(Reflections House Sensor, Day 4).

Monitoring devices divide behaviour into that which is normal and that which is not. If behaviour is supposed to be adapted to what is normal these devices execute power over the person using them and “normalize” their behaviour [Kenner 2002:255]. Vulnerable populations, such as people with dementia or children might be particular affected by this when the technologies are not only used to monitor, but also to manage them. While smart technologies promise to become more granular, personalized and able to adapt more closely to the user, they still carry an expectation of normal behaviour in them and act upon what is considered deviant [Franco et al. 2008]. This can impact the quality of life of the person monitored as it seems to undermine their autonomy.

The house sensor offered a level of customization, e.g. to change the text of the notifications. This had a strong effect on my level of self-esteem, compared to the GPS tracker which gave out only very generic messages. The house sensor manual made it clear that the device was meant to be used in this context and used personal language that felt much more acceptable than the GPS tracker, for which caregiving was only one of the use cases and for which the language was factual throughout. This can be seen in Figure 9, which shows a screenshot of the notification sent out when I left the geo-fencing area. This made me feel “objectified” (Reflections GPS tracker, Day 2). As a result I never considered the device to be a connection to my partner and the call function of the GPS tracker was never used, even though I had the device with me all the time. While it might support care from a practical point of view, it did not support the feeling of ‘being cared for’ by the user. How this could be facilitated might be particular relevant to HCI researchers.

Both monitoring devices were made to be unobtrusive. Nonetheless, they felt stigmatizing to me as they seemed to stand out. The blinking lights and the SOS button on top of the GPS tracker in particular made me question how other people would experience them. I repeatedly noted down concern that other people might
stare at the device, when it was worn openly (e.g. Reflections GPS tracker, Day 21) or concerns that it might attract unwanted attention, e.g. by setting off the theft protection at shops or libraries when the device was worn hidden (Reflections GPS tracker, Day 10). These concerns show less of a danger of stigmatization from the outside, but my lack of acceptance. Unobtrusive appearance is not only individual; it might also not be enough to relieve concerns when the wearer of the device feels uncomfortable about wearing it.

While I was the only user of the devices, other people were affected by them as well. My partner and I decided not to use the listen-in function of the GPS tracker as we considered it unethical. We tested the function during the setup and were amazed by how clearly the device transferred all conversations around it. As a result, I was concerned about becoming a “danger” to others (Reflections GPS tracker, Day 2). During the house sensor study, I had a friend staying over and felt a strong urge to explain the device to her, which felt “awkward” (Reflections House sensor, Day 32). The house sensor was also installed in my bedroom against the recommendation of the manual to avoid data collection from flatmates. Making decisions and explanations were uncomfortable, but I felt it had to be done in this case, so as to not collect data from anyone without consent. None of the devices gave any advice or reflection on these important moral decisions.

To overcome the perceived loss of control, I tried to develop strategies to make the technologies my own. In the GPS tracker study, I experimented with wearing the device, e.g. by wearing it close to the body or further away in a backpack, or wearing it visible or hidden, depending on the circumstances and on her mood. In addition, I tried to joke with my partner when I felt uncomfortable about a situation. None of these strategies worked particularly well as they were not supported by the technologies themselves, which led me to doubt myself even more.

I have shown how the device in multiple ways – some related to privacy, others less so – impacted on my everyday life, mostly in a negative way. In the next section 6.3.3 Conflict I expand on the relationship with my partner and why the device use became problematic during the study.

6.3.3. Conflict
For this theme I collated observations about observations that went beyond the irritations that were described in the last section 6.3.2 Quality of Life. Throughout
the study I did not only feel out of control, but also felt annoyed regularly – both
towards my partner and the devices. Technical problems and lack of clarity were
the main reasons for conflict that led to feelings of guilt by both partners.

The devices were demanding of my partner and me, in terms of technical knowledge
(e.g. activating the SIM card), dexterity (e.g. small screws or climbing on the bed to
install the sensor) and ethically (e.g. making decisions about listening in). The setup
for each of the devices was complicated and although it was considered ‘fun’
(Reflections GPS tracker and house sensor, Day 1) by both of us, the mood was
nonetheless tense. The setup of the GPS tracker took about 1:30 h as we both tried
to understand the limited descriptions in the manual. The house sensor setup took
even longer, mostly because the SIM card could not be activated. Both devices
offered a wide range of potential functions with little guidance on how they could
be used and how they might be beneficial for the care context.

Both devices promise peace of mind for their use, but frequent malfunctions during
the study show that the technologies are not yet reliable. The house sensor was
abandoned in the end due to technical problems and it is expected that the other
devices might have been abandoned earlier if the use had not been limited to one
month from the start. I was also annoyed that the devices did not offer me any
benefits directly. The GPS tracker in particular was considered a burden as it had
no positive impact on my everyday life: “It just does not do anything.” (Reflections GPS
tracker, Day 14). This made little inconveniences such as the weight of the device
when it was worn around the neck even more annoying.

Conflict further arose from a feeling of guilt. When the devices did not work, I had
to turn to my partner to ask for help, e.g. when the house sensor stopped working.
As he was busy and did not necessarily have time to engage with the devices
immediately, this took up time for negotiating and led to guilt about bothering him:
“He is very busy now, which makes me feel guilty to bother him with this …” (Reflections
House sensor, Day 32).

Additionally, conflicts arose when expectations were broken. At two points my
partner checked my location. I previously expected that he would do that only in a
case of emergency. My partner had before tried to contact me via instant messenger
and phone and had failed, but it was not a situation I considered to be an emergency.
“He said he could not reach me on IM [the instant messenger we were using], so he checked where I was. Even though I was obviously aware of this possibility – and prepared to take it – I feel a strong reaction. Nearly physical, like a bit in the stomach.”

(Reflections GPS tracker, Day 28)

While rules were set in the beginning, each partner interpreted these individually and we had to negotiate these further. To some extent this raises questions about informed consent for the use of monitoring equipment. During use it should be carefully monitored whether the agreements are meaningful to both parties and whether they are still agreed on as the experience of being monitored can have an impact on the acceptance.

6.4. Discussion

For this study I used three monitoring technologies for dementia care in a self-study over one month each to explore how these devices affect the lived, everyday experience. To simulate the experience of non-mutual tracking tools, my partner took on the role of a data monitor. In this role, he was involved with setting up the technologies, but also received push notifications about my behaviour as well as gaining insights he could not have received otherwise. The results have shown that even though adherence to the devices varied, none were particularly liked. For all devices the lack of control was of higher importance than the decrease in personal privacy.

The results of this study have to a large extent influenced the development of the design fictions that are shared throughout the thesis. In contrast to the literature that mostly debates abstract, high level concerns about these technologies, the study provided intimate and situated insights. In the following sections I discuss the relationship between the results and the existing literature, focussing on two points: first, I discuss how the insights of the study shift the framing of these technologies, which indicates novel solutions are needed. I further outline how the insights underline the usefulness of design fiction in this area. Second, I discuss the insight that the lack of control over the device was problematic as a contribution to monitoring technologies in dementia care.
6.4.1. **Beyond Privacy: Everyday Experience**

Monitoring tools rely on constant monitoring and therefore impact on the privacy of those using the devices. With users such as children, people in the later stages of dementia or those with learning disabilities, this poses questions about consent to monitoring and whether the benefits of using such a technology outweigh potential infringements. It has been argued that these technologies can lead to greater autonomy, e.g. when they delay the move into a care home, when they enable people to leave home on their own, or when they prevent people being locked indoors (e.g. [Wigg 2010]). As these considerations did not apply in this study, it enabled me to focus on the experience of the devices, which differed from expectations about their use. I had planned to use devices increasingly intrusively, by handing over my unlocked phone to my partner first, with a GPS tracker next and finally a sensor in the heart of my home. The study revealed that the GPS tracker was actually experienced as more intrusive as the level of information that could be read from the data was higher than with the house sensor. I was aware before the study that the device was able to monitor data. However, being confronted with the fact nonetheless impacted me deeply. This poses questions about consent and at what stage it should be given. While questions of consent to monitoring have been debated, little consideration has been given to the question of how technology could affect or guide the process.

As tracking devices rely on data collection, the question of how privacy can be maintained and negotiated is of high importance if the devices are to be accepted and adopted. Increasingly, technical solutions to this question are developed such as encryption [Solanas et al. 2013]. Other researchers have suggested that alternative measures of behaviour (rather than video), such as sound [Chen et al. 2005], electricity consumption [Franco et al. 2008] or infra-red sensors [Nakano et al. 2002] might be more acceptable to users. While all these solutions could help to increase acceptance, this study suggests that the type of data collected is not the key issue. Control over the data might be more important. Focus group studies about the acceptance of smart home technology have already outlined this point [Milne et al. 2014; Wild et al. 2008]. This study confirms that this is not only a theoretical consideration, but that it could have an impact on the wellbeing of the users. While I accepted the type of data collected by the house sensor, I nonetheless opposed its use as it made me feel weak and out of control. Gaining more control over the data
would have been an important step towards acceptance, but another important factor would be usefulness for the person monitored. Rogers and Marsden [2013] argue that technology should not only be used to support people, but also to empower them. Current technologies that aim to support care often lack this ambition and rely on a caregiver to give support, rather than providing support for the people in need of care themselves. This study has highlighted how this lack of empowerment can have a strong impact on a healthy person. It is likely that it might be even stronger for someone who is vulnerable and in need of care. Developers and designers need to look beyond the technical possibilities, to also consider how interfaces can be designed to enable shared support and decision making. I expect that the HCI community will have a lot to offer to address current shortcomings and design innovative interfaces and means of communication.

The study has underlined that design fiction could be a useful method to apply in this field. Design fiction has a strong focus on data, security and values as I discussed in 3.6.3 Complexities & the Long-Term. With this self-study I have shown that the situation in which these artefacts are employed is comparably complex to any of the previous example. Design fiction could be seen as a means to provide alternative views of these problems and reframe them. As the study has underlined this is urgently needed in this field in which the debate focusses heavily on the potential for privacy intrusion, rather than the everyday problems that this study has shown. Using design fiction could be a means to make these everyday problems tangible and therefore debatable. This in turn could might lead to a shift in perspective of the whole problem area. Design fiction could be an alternative to studies such as this. The study was complicated to execute, both methodically, but also emotionally. Design fiction could be a means to communicate the insights in a manner that enables other researchers to draw from, without having to undertake a self-study themselves. Within this thesis I follow up this question.

6.4.2. “It just does not do anything”: Care & Burden

Monitoring devices such as the ones used in this study promise peace of mind for caregivers, without putting undue stress on those monitored. The results of this study show that the tested technologies failed to match either of these goals. They created additional burdens, both in the workload they created, but also emotionally. Deciding which devices to get, setting them up and maintaining them all took time
and required a great deal of both technical understanding and conviction. This study shows that the process is stressful and, in the case of the home sensor, was unsuccessful, resulting in the abandonment of the device. When evaluating the usability of these devices, little consideration has gone into the question of how people chose and set up healthcare devices. Tolmie et al [2007] suggest the term “digital housekeeping” to summarize the complex activities that go into shared decision making, setting up and maintaining domestic technologies and a comparable understanding is needed for monitoring technologies. This study suggests that this might be a relevant area for research into the acceptance of these devices. Starkhammar & Nygard [2008] identified that some caregivers do not adjust the settings to their own needs, but expect that the researchers ‘know best’ when technologies are set up by a research group. I did not have this advantage, but set all the functions ourselves, which was an emotionally draining process. It was not only a lot of information to take in, but also a lot of uncomfortable decisions to be made: How large should the geo-fencing area be? Should the listen-in function be enabled? While the house sensor manual made suggestions, the GPS tracker addressed only the technical aspects, which made it harder and had a negative impact on my quality of life. There is a need for a humane setup process to lead users through these issues and scaffold the challenging discussions they necessitate.

Research suggests that caregivers can experience an additional burden when monitoring technologies are introduced, such as the “Big Brother effect” (see e.g. [Casas et al. 2006:779]) where people feel an increased responsibility to monitor because they have the tools to do so. The effect on the person monitored is less understood, even though it can have an impact on the use of the devices. In a recent study, Berridge [2015] analysed how people used a monitoring home care package and found that they appropriated the technologies, e.g. by pressing the emergency button when they wanted to chat or avoiding pressing the button so as to not worry their relatives. This self-study shows that monitoring can also put a burden on the people being monitored. While the house sensor did not cause any work – when it was working correctly – the GPS tracker needed constant maintenance: charging and wearing. This was little effort, but it caused a lot of worry, especially as it was unclear how my partner would react to notifications, whether it annoyed him, caused him work or worries. Therefore, the device caused emotional burden as well as work.
While my partner could to some extent appropriate the devices and the notifications he received, the devices always looked the same to me, which made it hard to accept them. The study shows that these devices might not be appropriate for people who want to keep an active lifestyle and keep control over their life.

### 6.5. Conclusion

This study has given insights into the lived experience of monitoring technologies as I used a reminder app, a GPS tracker and a house monitor together with my partner in a self-study. The results were useful for the development of design fictions in two regards: First they sensitized myself to the problems that arise from these technologies and allowed me to experience their mundane use. The results indicate that the erosion of privacy by these technologies had less impact than was expected as personal trust encountered this effect. Rules were made up collaboratively throughout, which indicates that it is not a simple question of whether these technologies are to be used, but rather how they can be used and how the complex discussions can be facilitated. Second, it shows that the aim to keep devices simple as not to overwhelm the person living with dementia can have a detrimental effect on quality of life and might hinder early and responsible adoption.

Second the study enabled me to reflect in more depth how design fiction might be useful in the context of sensitive topics. The debate about monitoring technologies in dementia care is set on the grand themes autonomy versus privacy. My study in turn has shown that in everyday use the matter is not only more fluid than the literature suggests, but problems occur beyond these abstract concepts. This last two studies therefore have inspired me to use design fiction as a means to enable more nuanced discussion about these technologies. But as Study 1, presented in Chapter 2 Understanding Critical Design, has shown, it is not clear how to use design fiction and how to judge the merits and qualities of design fictions. In the remainder of these thesis I therefore use the Constructive Design Research
framework [Koskinen et al. 2011] to describe the merits and limitations of design fiction in more depth.
In the first part of the thesis, Refine, I narrowed down the focus of this project from critical design generally towards design fiction. I further outlined two areas in which the literature is lacking: first, a lack of clarity on how to use design fictions and how to evaluate their quality. Second a lack of reflection on how design fictions are made.

In the second part, Prepare, I responded to the second limitation by outlining which work inspired and informed design fictions. I described the context of sensitive settings and more specifically monitoring technologies in dementia care. I linked this to design fiction by proposing how design fiction might be useful in this area. I further addressed the gap in understanding what types of information and insights design fictions can be based on, by undertaking three research activities: first a literature review that outlined ethical concerns about monitoring technologies, second an expert study that brought previously unheard opinions to the discourse and led to more nuanced insights and third a self-study that added an emotional connection and a rich layer of everyday experiences. Through this preparatory work
I developed a range of design fiction artefacts that I further evaluate in the upcoming part to answer the overall research question: **What can we learn about technology use in sensitive settings through research through design fiction?**

As I have shown in the literature review in Chapter 3 Understanding Design Fiction, the answer is not as straight-forward as it may seem as design fiction is used in a variety of ways that currently sit alongside each other. Therefore, criteria to judge the quality of a design fiction are not clear: “Indeed, given the increasing amount of design fiction published at HCI venues, it seems absurd that we have little idea of how to judge a good design fiction paper from a bad one. However, setting out to come up with a comprehensive framework for judging the quality of contribution also seems absurdly optimistic and reductionist.” [Lindley and Coulton 2016a:595]. This quote hints at an ongoing struggle of design research to balance the need for structure without being too restrictive: “A challenge for HCI, and for design research in general, is how to share and discuss ideas, practices, patterns, synergies and salient features without needing to codify it” [Swan and Boehner 2013:24]. Nonetheless, attempts have been made to develop frameworks that classify the results of design research. Most prominently in HCI sits the Constructive Design Research framework [Koskinen et al. 2011], that aims to classify design projects based on the epistemology that underlies them.

The framework has been developed to address ambiguities in research-through design. As I have shown in the literature review in section 3.3.1 Research through Design, many authors link design fiction to the concept of research-through design. Nonetheless, whether the framework can be extended to design fiction and how useful it will be to establish criteria and judge the quality of design fictions has to be seen. In the remainder of the thesis I introduce the three parts of the framework in more depth and further reflect how they might be used to classify design fictions by reflecting on the use of a range of design fictions on technologies on dementia care.

The framework provides three categories into which design research can fall: showroom, lab and field. While showroom is inspired by critical art movements, lab and field draw from more empirical epistemologies. Showroom favours ambiguity and presents artefacts as research outcomes. Lab research in design is classified by practical experimentation and quantitative measures. The field approach understands use as contextualised, situated and draws on rich understandings of
everyday experiences. The approaches sit alongside each other and differ in their aims, methods and quality criteria. Each of these offers different takes on what it might mean for design fiction to “elicit reflections” [Wong et al. 2017a:1] or “stimulate conversations” [Lindley et al. 2015:82]. In the coming chapters I explore how design fiction might fit into each strand of design research, what its contribution might be and how its quality might be judged.

In Chapter 7 In the Showroom, I summarize all the design fictions that were developed around this project. The artefacts themselves are presented in the additional material and can be read throughout the thesis or as a complimentary part to this chapter. I further outline how artefacts are considered contributions in themselves in this approach. To do so, I present two research activities: First, I present summaries of the artefacts and provide additional information on how they relate to the research undertaken so far in the first part of the thesis. By explaining how I used them, I outline problems when aiming to evaluate their quality and impact. Second, I describe two ways of communicating the insights I gained from writing the design fictions to a wider audience as a means to make them debatable. I chose an annotated portfolio as well as more explicit implications for design and describe how these are related.

In Chapter 8 In the Lab, I outline how design research leads to insights in the lab setting. I further expand on these insights to explore how design fictions can be used in this paradigm. To do so, I explored how participants responded to design fictions as a means to learn how the audience relates to them. As I outlined in Chapter 2 Understanding Critical Design, the role of the audience in regards to critical design is often neglected. But, both critical design and design fiction have been introduced as means to stimulate debate (see e.g. [Lawson et al. 2015; Fuchsberger et al. 2017; Dunne and Raby 2013]). In this chapter I describe what types of discussion design fiction can lead to beyond the reflection of the maker themselves. I present the results of a study in which I shared both my design fiction and future scenarios that were not design fiction with groups of students to learn which types of discussions it would elicit and whether there were any differences between the two (see 8.2 The Use of Homes for Life in the Lab). The study answered the research question: **What types of insights can be gained by using design fiction in the lab?** The results show that both types of videos elicited critical debate, but that the design fiction triggered more arguments and anecdotes
that linked to personal experience. It further foregrounded debates about the way technologies could be and should be applied to care rather than the technologies themselves.

In Chapter 9 Evaluation of Homes for Life with Professionals, I expand on these results by turning to participants who identify more strongly as designers and developers, rather than students. It has been argued that critical design and design fiction is often addressed at designers themselves as a means to reflect on their practice. In the study presented in this chapter I explore what types of insights they might contribute, but also what types of benefits they gain themselves. The study answered the research question: **How do participants with professional experience respond to a design fiction?** The results support the results from the previous study. In addition, means of presenting the design fiction and gathering data differed between study 4 and 5, and in this chapter I also present first insights into the importance of considering the type of data collection.

The third study using the lab paradigm, presented in Chapter 10 Evaluation of HawkEye with HCI Experts was done in preparation for Chapter 11 In the Field. We gave experts in HCI research the opportunity to experience a tangible design fiction probe and interviewed them to learn how they evaluated the experience. The study answered the research question: **What benefits do experts in HCI research perceive in a design fiction probe?** The results show that participants enjoyed the experience and felt immersed throughout, even though the experience was challenging for some of them. It further showed that the tool enabled participants to argue from a personal, rather than professional point of view in an empathic manner. This indicates that design fiction probes can be a useful tool to not only elicit rich data, but also overcome othering.

The lab studies overall reveal that the design fiction elicited emotional and personalised discussions about monitoring in dementia care as well as wider societal discussions about care giving and responsibilities. Nonetheless, all of these were derived in artificial environments, away from the home where care normally takes place. In Chapter 11 In the Field I outline how field studies are employed in design research. Moving away from the lab setting of the previous studies I explore how participants respond to design fictions that are embedded into their everyday life and whether this has an effect on the way they perceive the design fiction.
In 11.2 The Deployment of HawkEye in the Field I describe participants responses to a three-week deployment of a design fiction probe in their home to learn about which types of insights can be generated this way. The study answered the research question: **What is the lived experience of a design fiction probe?** The results show again that most participants argued from an empathic and individual standpoint. As the artefact was deployed over a three-week period, the results also give rich insights into the sense-making processes of the participants. The results further show that the different point of view participants experienced compared to 8.2 The Use of Homes for Life in the Lab and Chapter 9 Evaluation of Homes for Life with Professionals led to a reframing of the debate about monitoring tools. This indicates that design fiction has a strong impact how topics are perceived by the participants.
Chapter 7. In the Showroom

In this chapter, I:

- Describe the showroom approach to design research
- Establish the artefacts that were derived from the research as contributions
- Outline problems when using design fiction artefacts in an academic setting
- Suggest means of communicating the insights gained through design fiction writing to the design community

7.1. Understanding the Showroom Approach

Design has long been described as a “third culture” [Cross 1982:221], contrasted with science and the humanities. Design methods and more specifically design research methods have tried to distinguish design research from these, especially since design research “borrows heavily” [Koskinen et al. 2008:46] from other epistemologies. This has opened up the field to the question what counts as a contribution to design research and how ‘rigour’ or ‘quality’ might be judged (see also [Boehner et al. 2007; Bardzell et al. 2015]). The Constructive Design Research framework [Koskinen et al. 2011] distinguishes three strands of research through design: research in the showroom, in the lab and in the field. While both lab and field approaches draw on empirical epistemologies, showroom has a different background. Its name refers to the mode of presentation of the resulting artefacts, which are often presented in galleries or shops, outside of the academic literature. This decision is a deliberate choice, as practitioners of this paradigm align their practice more closely with art than science.

Practitioners of this approach often push back against empirical approaches more closely associated with ‘science’: “Showroom relies on debate rather than statistics, like Lab, or precedents and replication, like Field” [Koskinen et al. 2011:94]. The importance of debate and ambiguity is based in radical art movements of the 1960s and 70s, especially radical Italian Design Groups. It therefore shares strong links with critical or speculative design and related approaches (see e.g. [Malpass 2013]). Koskinen et
al. [2011] place critical and speculative approaches firmly within this category and emphasise the relationship between art and design, but do not mention design fiction specifically. As I have already shown, e.g. in the results of the survey with critical designers (see Chapter 2 Understanding Critical Design), this link between critical design and the art world is not viewed unanimously as positive, but it is a useful means to highlight some of the distinctions between this approach and others. I focus here on two aspects: the role of the artefact and the resulting questions of how to evaluate design fictions and how artefacts are distributed.

The showroom approach is distinct from empirical research methods, as the artefact in itself is considered the contribution to knowledge. Koskinen et al. [2008:53] state that “ultimately it is the designed object that is at the center of attention”. Nonetheless, the important part is not the object as a design object, but the knowledge that it represents. Bardzell and Bardzell [2013:3298] argue that in critical design “its [the artefacts] primary intended outcome is knowledge, not a design product”. The artefact itself is not analysed in the empirical sense, but more often referred to as being “read” (e.g. [Koskinen et al. 2008; Bardzell et al. 2014]), highlighting its fluid and ambiguous nature.

According to this definition, the artefacts that have been presented in this thesis, do not need further evaluation to demonstrate their value. Even more so, it is debatable whether evaluation is actually acceptable and which criteria might be suitable. Koskinen et al. [2011:89] claim that “it is possible to encounter outright hostility towards many scientific practices”, as practitioners working within the showroom approach aim to push back against the move in HCI to apply scientific methods, rigour and evaluation to design work (see e.g. [Pierce 2014]).

An artefact is in its nature ambiguous and open to interpretation. This understanding of a contribution at times is at odds with HCI’s empirical and pragmatic background. The ambiguity that comes through the use of artefacts, has already been debated in HCI, with the introduction of cultural probes [Gaver et al. 1999]. While the original cultural probes were considered tools in their own rights, through their transformation into informational probes [Crabtree et al. 2003] they were drawn into a more empirical framework as the rigour of the original probes had been debated (see e.g. [Mattelmäki 2005] for an overview about the use of probes). Design fiction sits at a similar crossing as it is used in a variety of ways. In
the coming sections I describe the artefacts derived from the research already presented and discuss how they sit within the narrative of this thesis. I further describe less ambiguous means of communicating insights derived from design work: the annotated portfolio and implications for design.

As these descriptions show, design fiction can be a useful tool for self-reflection. But, as the name ‘showroom’ suggests, many of the artefacts are made for publication, exhibition and distribution. Therefore, it is unclear not only who the audience is, but also who the gatekeepers are. Showroom research is traditionally presented in spaces more closely related to the art world or the commercial world, such as “shop windows, exhibitions and galleries” [Koskinen et al. 2011:89] than the academic world of publications and conferences. Within this thesis, I already referred to some artefacts that could be classified as design fiction outside of the academic world, such as the work of design studio Superflux or “incidental design fiction” [Lindley et al. 2015] such as the British TV series Black Mirror. But increasingly the academic world turns into a showroom for this type of design research, through the development of fictional or imaginary abstracts or research papers (e.g. [Lindley and Coulton 2015a; Fuchsberger et al. 2017; Fields 2016]). While initially limited to more exploratory outlets of HCI, such as the alt.chi or video showcase tracks of the CHI conference, examples are now presented as full papers in multiple venues (e.g. [Wong et al. 2018; Luu et al. 2018; Noortman et al. 2019]). This blurring of designerly showroom tactics and academic rigour, makes this distinction less clear in practice as I show when describing the artefacts presented in this thesis.

7.2. The Artefacts

As I outlined in Chapter 4 Understanding Technologies for Dementia Care, design fictions might be a useful means to further research into the use of monitoring technologies in dementia care. In chapters 5 and 6, I reported a series of research activities that informed and inspired artefacts in this domain after it became clear that little is known what speculative artefacts can be grounded in. In this section I present the artefacts that are spread throughout the thesis. I further present a new design fiction, the title story for this thesis: Homes for Life. Each section contains a summary of the design fiction, an explanation of how it relates to the literature, how it contributes to the narrative of the thesis, and reflections on what makes the
artefact a design fiction rather than e.g. a scenario and considerations about its evaluation.

7.2.1. The Wearable GPS Tracker

This design fiction can be considered as a prologue to the thesis, to be read before the introduction. It is told from the point of view of a now retired engineer who developed a GPS tracker she now has to live with. As such, she is forced to step into the shoes of her former research participants, or those she only considered as users.

![Figure 10: Picture taken during self-study, own photography, 2016](image)

The design fiction was inspired by the distanced way with which monitoring technologies are described in the academic literature. As I outlined in 4.5 Problems with Technology Design for Dementia Care, their use and evaluation is rarely situated. Instead an argument for the need of such technologies is made. It further builds on some of struggles I lived through in the study presented in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies. While my partner did not make any claims on my behaviour, I was strongly aware that he could and started to self-censor my behaviour. Small instances like a drink in the pub in the evening became a notable event through the use of the tracker (see Figure 10).
I placed this design fiction at the beginning of the thesis to ‘set the scene’ and hint at the understanding in which this thesis is written. The design fiction establishes that I problematize technologies as well as presenting the turn to the future of this method. It further indicates that I consider technologies to be situated and that they might lead to conflict as well as promising solutions.

As I outlined in section 3.4 Design: Fiction & Narrative, what distinguishes design fiction from other types of stories, such as scenarios is not clear cut. Narrative and world-building have been established as criteria, but their application in practice is complicated. Even though no time is specified, the setting in which tracking technologies are not only voluntarily used, but actually employed on a large scale through insurance companies, implies a near-future setting. This on its own is not a sufficient distinction. More suitable is the framing of the future world as world building, because it provides information about the world in which the technologies are set. In contrast to scenarios, the artefacts are not only presented in use, but information about their acquisition is provided as well. This also provides the narrative that frames the story. Its places the beginning of the story at the point in which the GPS trackers were invented and its (open) end to the point of conflict that resulted from the changes that have taken place in the meantime. While the plot can be considered minimal, it can nonetheless be traced.

At this point, the question of whether it is a design fiction, whether it is a ‘good’ design fiction or whether it does what it sets out to do are with the reader of this thesis. No outside evaluation has taken place. Even more so, it remains open whether this question is actually applicable to design fiction. Like other design methods, design fiction in this paradigm sits outside the scientific evaluation measures. In the coming sections, I present alternative measures of evaluation and discuss their merit in regards to design fiction.

### 7.2.2. RocCo – the Robot Companion

This design fiction can be read as an interlude, between the introduction and the first part of the thesis. It is told from the perspective of an elderly woman who – without family to take care of her – is forced to employ a care robot. While the robot proves to be useful in many regards, it prevents her from leaving the house to protect her from harm, which causes her distress.
RocCo is an alternative solution to the stand-alone technologies presented above in 4.3 Technologies for Dementia Care. Care robots have been left out of the literature review, even though this is an area that attracts a lot of interest (see e.g. Bossen et al. [2015]). Like the Wearable GPS Tracker this design fiction presents a lived experience of someone directly affected by technologies. But, going beyond that, it makes the problem of technology becoming controlling more tangible. The technology has a direct – and striking – impact on the protagonist’s life. This artefact therefore builds on the first one. Within the narrative of this thesis it provides a shift from stand-alone devices towards more integrated connected devices.

The technologies presented here could be considered more inventive than those in the first design fiction as they not only provide a background to a technology that does currently exist, but invent a whole new application. While care robots are currently in development, the tasks they are supposed to do are not yet defined. RocCo stimulates discussion whether they could or should take on the role technologies currently fulfil and through this ‘defamiliarization’ questions the current technologies. The design fiction could also be considered more provocative as the pressure exerted by the technology is more tangible than in the first design fiction. The same argument that it is a design fiction that has been made for the first design fiction – applicability of narrative and a “story world” [Lindley 2015a] – could be made in this case. Nonetheless, from the current theory of design fiction it is unclear whether that makes it a ‘better’ design fiction or if design fiction artefacts can be compared directly. If so, it also remains unclear whether there are general aspects to design fiction or if each should be compared to its own individual goal. These goals are not always communicated (see e.g. the alt.chi submission [Kirman et al. 2013] in which the story is presented without any commentary). As I established at the beginning of this chapter, this is true to this paradigm as the artefact stands on its own and has its own merit. The artefact is the outcome. While outside validation might not be required, conclusions about its merits can be drawn from responses to it.

From all the design fictions presented here, RocCo is most easily placed in the showroom approach. It was evaluated by peers and was chosen to be presented at a curated literary salon. During the evening it led to critical discussions about the future of care technologies with interested audience members. In the short term it
has stimulated discussion. Long term changes are not only complicated to evaluate; the question also remains of whether any type of empirical proof or evidence would be suitable as a measure of its quality or merit.

### 7.2.3. DEO Ex Machina: a New Framework for Automated Care Provision

This story can be read as an interlude, between the first and second part of this thesis. Written as the abstract to a fictional research paper, this story establishes that elderly people hesitate to adopt virtual agents and suggests that these should be designed to overwrite the decision of their user, should it go beyond their best interests.

The story addresses the same topic as RocCo as it questions the autonomy of elderly people to make their own decisions. It extends the idea of communicating with the technologies to fully fledged virtual agents that have not only been widely employed, but their use has already widely studied. This design fiction therefore could be considered more futuristic, even though the time frame remains undefined.

Within this thesis it builds on the element of autonomy and in addition presents a novel technology. It further gives an example of an imaginary abstract that has been discussed before in 3.3 Design Fiction in Relation to Other Research Methods. While the format alone does not make it a design fiction, it is relevant as the format has been prescribed through the context for which it has been developed. It has been written for an academic context, which in this instance gives outside validation or evaluation of its merit. This abstract has been submitted and accepted to a workshop about the Futures of Wisdom of Computing at NordiCHi 2018, which indicates that it has been recognised as a design fiction by peers. It further suggests that it could be considered a ‘good’ design fiction as it has been accepted without any comments or revisions. It has already stimulated discussions about future technologies during the workshop.

### 7.2.4. Homes for Life

The story can be read as an interlude to this chapter. It forms the title story of this thesis. The story presented below contains two parts, indicated by different font types: The first and last part presented in bold sets the story in the future as a TV broadcast, looking back into our time. The first paragraph sets the scene, while the
last paragraph invites participation as it announces that they will now gather responses. The first line, set in italics, can be considered as stage directions. The part within, presented in regular font, contains an interview with an unspecified interviewee, of whom we only learn that they bought a smart home as an alternative for a care home for her mother and other family situations, such as that they are married to a man called Peter and have a son. The interviewer has no voice within the discussion as questions are only implied in the responses of the interviewee. The technology is never shown in the design fiction and in no way visibly represented, but only referred to through people’s responses to it.

Homes for Life extends existing technologies and provides a fictive account of what it might be like living with these technologies. Most of the features suggested in this house are based on technologies currently in development or available (see 4.3 Technologies for Dementia Care). Some have been expanded, such as the medication in the drinking water to make the story more provocative and speculative. Not as provocation for provocations sake, but as a means to make concerns around autonomy open and debatable. As I outlined in section 3.5 Design Fiction & Future, Past and Present in the literature review, both scenarios and design fictions are often situated in a near-future, but the range of potential time frames is wide. When to set the story for me was connected to plausibility and how far I wanted to deviate from what is available now. Grounding the story within a contemporary account has been a deliberate move to address criticism of design fiction. Gonzatto et al. [2013:1] observe that future speculations are always grounded in “desires, that bear no accountability in the present”. It has therefore been decided against an account in a far future, rendering the technology unrecognizable or too far advanced to relate to. The technology presented in the design fiction aims to be relatable, with little, though imaginable technical progress. This also encounters a criticism of Walsh [2007] that a scenario can hinder a debate when the content is too far removed from the experience of the audience. Further considerations that played into the making of this story and how it relates to the literature can be found in Schulte, Marshall and Cox [2016].

Comparable to the first story presented in this thesis, the Wearable GPS tracker, Homes for Life mostly expands on existing technologies. Comparable to RocCo it provides a novel shape of the technologies and comparable to both it discusses these in more depth, going beyond its use. It gives the concerns and evaluations
more space, which makes it appear more like a story and less than a snippet or a vignette. While some design fictions are presented mainly through artefacts, they must contain an element of narrative or a representation of a story-world to qualify as design fiction as I outlined above. It is debated to what extent a design fiction contains a narrative and to what extent it must present a world-building element. I suggest that the narrative creates the world in which the artefacts exist. While the plot of the story can be considered to be independent of the world in which the story takes place, it is often through the description of the plot that the use of the artefact is motivated. Following from this, the narrative in itself should not be measured by literary standards, i.e. how entertaining, insightful, etc. the story is, but to the extent to which it motivates the interactions and motivations of the characters. The plot of Homes for Life could be summarized in one sentence, e.g. ‘Woman buys smart home for her mother as alternative to a care home in which the mother lives until her death’, but the details with which the story is narrated make the artefact and establish its place in this world. This understanding of narrative goes beyond that suggested by Blythe [2017] who draws on literary theory to reflect on narrative and its means to develop stronger design fictions, especially as a means to distinguish them from scenarios. As I have shown here, a range of contrasting opinions exist on what makes a design fiction. Further questions arise when external validation of the design fiction is sought.

Even though Homes for Life has been published, its evaluation is not as clear as for example RocCo or DEO. The paper in which it was published did not only contain the story on its own, but also additional content that framed the story. Homes for Life has been part of a panel presentation on design fictions in academia at NordiCHI 2016. But it is unsure whether this has been due to the merits of the design fiction or the surrounding reflections and framings of the paper. Another open question is whether the peer review process is comparable to a curated or juried selection. It is at the current state unclear whether reviewers are familiar with design fiction and which criteria they apply to evaluate its merits (see e.g. [Lindley and Coulton 2016a]). It is therefore unclear whether the publication can be considered an indication of the quality of the design fiction.

Nonetheless, Homes for Life is now part of academic discourse. Its publication and presentation at the conference led to discussions about the use of technologies, which imply its merits. Traces of its impact can for example be shown through
citations, where it has been used to discuss design fiction as a method [Lyckvi et al. 2018], other speculative design methods around dementia care [De Haas et al. 2018] or elderly home care [de Podestá Gaspar et al. 2018]. Its publication even inspired a collaboration with a MA student, who visited UCL to work on a collaborative study, which is described in section 7.2.4.2 HawkEye: a Tangible Probe.

In contrast to the other stories presented here, this story has been used for empirical evaluation, both in the lab (Chapter 8 In the Lab) and in the field (Chapter 11 In the Field). It was therefore necessary to provide alternative means of presentation of the original narrative. I present the resulting artefacts here and describe how their relationship changed.

### 7.2.4.1. Homes for Life: the Video

![Figure 11: Homes for Life video starting screen on online platform, 2018, own screenshot](image)

The story presented above was published in an academic paper for the design fiction panel at NordiCHI’16 [Schulte et al. 2016], therefore a written account was an adequate representation. When planning out the studies in which the fiction was to be used (see 8.2 The Use of Homes for Life in the Lab and Chapter 9 Evaluation of Homes for Life with Professionals) questions of how to share the story started to arise. Two considerations played a part in this: first, I evaluated the practicality of asking participants to read a design fiction in advance of a focus group, and to test how to deal with participants who had not done so, in pilot studies within the
department. Even though in this instance all participants came prepared, they reported that they either skimmed through the story shortly before the focus group, which had led them to miss important themes - or they reported this task was onerous. I considered it therefore questionable how participants who had no personal connection to me would feel about this task. Second, I was concerned about managing expectations when asking participants to discuss a story. As it is not a common activity for many people, I wondered whether it might open specific expectations about literary critique, rather than a discussion about the technologies and their implications. First attempts to recruit participants with this set-up confirmed these expectations and I therefore resorted to a way of delivering the story in a way that I expected participants to be more familiar with: a video. The video has been put online on YouTube [Schulte 2018].

While this breaks with the expectation of design fiction presented above, the tangible representation of design fictions is not uncommon. Not only “do designed artefacts tell stories, even by themselves” [Bleeker 2009:6], they have often been chosen deliberately as means to tell stories as I showed in section 3.3 Design Fiction in Relation to Other Research Methods. An example of the variability of design fiction is the paper on their work on empathy and technology, based on the movie ‘Blade Runner’, in which Sturdee et al. [2016] present a prototype and a related programming language as well as a video and a comic as the outcomes of their work. Design fiction presented in a video is common as a search on video publishing platforms, such as vimeo or youtube shows. Videos have been used in research studies [Heibeck et al. 2014], but rarely has this specific medium been discussed. One of the few exceptions is Briggs et al. [2012] who reported on their study of video used to generate a discussion about artefacts beyond the aesthetics and practicalities of a
technology and conclude that the video is useful in this regard, even though not all participants felt able to discuss the technologies without seeing them. In the making of the video I followed a similar strategy and left the technologies themselves entirely to the imagination of the viewer, following not only this strategy, but also the observation by Blythe et al. [2016:1] that “representation is crucial to how we imagine future technologies”. The video is deliberately different from the technology-driven scenarios or “glossy and white-walled worlds that are the norm in the corporate ‘vapour fiction’” [Coulton et al. 2016:4] of big companies.

I decided to develop the video myself to keep control over the process. It was important to me that the key points I wanted participants to discuss came through in the ambiguous way I intended it to be. To represent the protagonist of the story, a call for an actress was made via an email newsletter for artists. Due to the lack of props or shift in scene, the focus of the story is solely on the protagonist. I therefore tried to work together with someone who had enough acting experience to draw the viewer in. The actress read the story prior to filming and clarified main points in discussion with me. She improvised the contents of the story in her own words to create a natural feel to the story, which is presented as an interview.

I edited the video material after filming with two aims: first to enhance the quality of the video and audio where needed and second to cut down the video to a usable length. The sound quality was improved and filters were applied to make the colour of the video more coherent. Parts of the video were then cut and combined using blends. Two hours of original material were edited down to about 13 minutes to capture the main points of the original story but allow for the time constraints of the study. In the process two changes to the story were made: first the initial framing of the story that sets the interview within a future TV presentation was cut. Therefore the video was not introduced and no explanation was given to its purpose which led participants to question whether it was real or not (see 8.2 The Use of Homes for Life in the Lab). I do not consider this a negative effect. Critical design is often presented through tangible prototypes, which can be functional or non-functional and can be used to disrupt everyday routines [Dunne 2005]. Their appearance should be convincing, leading the viewer to question whether these are real products or serious suggestions for future products [DiSalvo 2014; Dunne and Raby 2013]. Second, some details had to be cut and the order of some instances were re-arranged to ensure that the video felt coherent. This process highlighted
what was important to me in the video as there were items I felt uncomfortable to cut. These were the two ‘taboo’ or sensitive issues that I brought into the story: the intruder in the bedroom and the death of the resident. Asking ‘What if?’ during the writing process was useful to foreground issues beyond the use of smart homes, e.g. acquisition or maintenance in the writing process. Some of these elements were dropped in the video to streamline the story. I tried to balance my wish to present a nuanced picture of the technology with the level of detail presented to viewers. As videos are inherently linear and it would not be possible for participants to go back as they would be when reading at their own leisure, the story is harder to follow. This was useful to consider when making the video.

Even though changes were made to the structure, I consider them the same narrative and for the purpose of this thesis the same design fiction. While it might be fruitful to research how participants respond to different kinds of design fiction artefacts, I consider it to be outside the scope of this thesis. All lab studies were undertaken with the video, which left no room for comparison between the written account and the video. The video was a useful tool to elicit discussion as I show below. But it is still removed from the lived experience of care-giving, home life and everyday life. To encounter some of these limitations, I worked collaboratively with an MA student from the TU Eindhoven to develop a tangible probe from the design fiction that could be shared with participants in field studies (see Chapter 11 The Deployment of HawkEye in the Field). Here I have shown how the video developed from the original story and where the discrepancies lie. I describe in the coming section how it had been developed into a tangible probe.

7.2.4.2. HawkEye: a Tangible Probe

HawkEye is further removed from the original story than the video, but the artefacts are nonetheless related. The artefact has been developed by Renee Noortman, a visiting MA student from the TU Eindhoven. She took inspiration from the original story and imagined an artefact that could control a Home for Life. But taking the idea further, we developed the HawkEye company that added another layer of complexity to the narrative. The artefact itself consisted of four items: a control panel, an information booklet and a patient file, plus an additional welcome letter.
The letter (full text in appendix V) was of particular importance as it conceptualised the artefact and ‘crafted’ the narrative. Within the letter the ‘story world’ was established as the reader learned how the artefact came to be, what it is and how they came into its possession. It suggested that the participant was chosen to take care of an elderly person who lived in a smart home that could be controlled remotely through the control panel. The letter was therefore important to the study as it provided the user with instructions of how to interact with the device. It was further essential to the design fiction as it made the story work tangible and provided a lot of the narrative of the artefact. Without it, the artefact could be considered to be more speculative as Tanenbaum [2014] suggested and might fall more into the realm of technology probes.

The control panel had five modules that group specific functionalities of the house: medication, nutrition, location, identification and communication (see [Noortman et al. 2019] for a full description of the modules and the motivation behind these groupings). In addition to these modules that enabled the user to take care of the settings in the house, it provided the reader with daily information on Annie, the fictional resident of the HawkEye home, through printed receipts (see Figure 14 for an example). The receipts arrived daily at the same time and included up to three things, depending on the settings of the modules: first, a short summary of Annie’s behaviour in the paragraph at the top of the receipt. Second, this would at times result in recommendations to turn a module up to support Annie. Third, the receipt
further provided detailed information on Annie’s behaviour, e.g. the amount of medication taken, calorie intake or time spent outside. This last data was only revealed once the modules were set to a certain level. In general, the higher the module was set, the more detailed information users got. Annie’s mood and behaviour improved when the settings were raised, otherwise the situation became subtly worse for Annie. The HawkEye house covered all the functionalities described in Homes for Life, including the more provocative ones, such as medication in the drinking water.

The information booklet explained how the smart home operated and how the settings on the control panel influenced the person living in the house (see also Figure 15). The patient file was less important for the narrative but used primarily for data collection (compare 11.2 The Deployment of HawkEye in the Field).
HawkEye provides a different experience not only because it takes the conflicts around monitoring technologies out of the family context and places them in the commercial sector, but also because it shifts the perspective with which participants experience the story. Both readers of the story and the viewers of the video are passive consumers of the artefacts. HawkEye, instead, places the participant in the shoes of the caregivers and gives opportunities to influence the story that unfolds. In encountering HawkEye, the viewer experiences ethical conflicts first-hand. HawkEye not only presents the viewer with the opportunity to alter the physical surroundings of the person living in the house, e.g. when making signage in the house or increase the level of surveillance when altering the settings in the control panel, the system also provides initiative to do so, by suggesting changes. As such it does not only offer another level of complexity, but also adds interactivity. The HawkEye experience unfolds over time, when the probe is employed in a participants’ home over a couple of weeks.

7.2.5. Homes for Death
In the narrative of this thesis this story follows this chapter and could be read as a prologue to Chapter 12 Discussion & Conclusion. It is written from the point of view of a woman, who uses her voice-controlled agent to plan and support her assisted suicide after a dementia diagnosis.

The story has been written last, shortly before the completion of this thesis. It responds to the research undertaken in two ways: first it picks up a suggestion of a participant in Chapter 9 Evaluation of Homes for Life with Professionals, who mentioned that end of life care was not considered in the Homes for Life story. This story is my first attempt to broach the topic and imagine how smart home technology could play a role in such a setting. But second, the tone of the story is different from the others as the main character stays in control over the technology throughout. Even though she was not fully convinced at the beginning and did not chose the technology on her own, she has learned to use the technology and appropriated it. This shift was driven by the results of employing Homes for Life where the wish to stay in control came out strongly throughout, which confirmed my impressions from Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies. Homes for Death therefore is a manifestation of this approach to
open it up for discussion. It further precedes the future work section, 12.5 Future Work, as an outlook of what the future might hold.

Homes for Death clearly follows a plot line in which decisions build up to a climax. The narrative element of design fiction therefore is fulfilled. But from all the stories presented here it might be the most closed up, giving only hints of the world surrounding the story. Currently it is not agreed on whether this makes it a design fiction or whether it remains something else.

Like the Wearable GPS Tracker this story has been written for and as part of this thesis and has not yet been shared otherwise. The evaluation or judgement lies with the reader of this thesis. I have shown in the other sections in this chapter that the task is not a simple one as not even the questions that could be asked are clearly laid out. Neither is the type of response that would be adequate. Generalisability or other types of scientific evaluation measures do not apply as they would for empirical work. Publication or curation might be one way of judging the quality of this contribution, but as I have shown in this chapter, this is not as clear-cut as it might be with other types of research outcomes.

But the stories are outcomes of the research undertaken and they are part of the narrative of this thesis. They are contributions in themselves. They had an impact on me and have helped me to reflect on technology for dementia care and distil the results into the stories presented here. While they are not generalizable, nor should be, I derived insights that I consider to be important for others who wish to work on technologies for dementia care. In the next section 7.3 Intermediate-Level Knowledge, I apply design methods that have been devised to communicate the insights from design work in a structured manner: an annotated portfolio and implications for design. I discuss how they apply to design fiction.

7.3. Intermediate-Level Knowledge
As I have shown in the introduction to this chapter, in the showroom approach designed artefacts are contributions in their own rights that do not need further evaluation. As such researchers operating in this area have often pushed back against attempts to examine and evaluate critical design of this stance in an empirical fashion. Nonetheless, attempts have been made to generate other types of knowledge from the artefacts, such as “annotated portfolio” [Gaver and Bowers 2012]. An annotated portfolio “entails a collection of designs, representing them in an appropriate
medium, and combining the design re-presentations with brief textual annotations” [Löwgren 2013:30]. This approach and other types of “intermediate-level knowledge” [Löwgren 2013] are not yet theories of design research, but instead represent a level of presentation of design work that highlights outstanding aspects about the artefacts. Here I present two types of contributions: first, an annotated portfolio and second a more elaborate description of the concept derived through the reflection process as implications for design.

7.3.1. Annotated Portfolio

On page 150 I present an annotated portfolio. It contains two elements: a background that visually represents the stories and four high-level abstractions. Following the description of the approach given by Gaver and Bowers [2012] I annotated my own portfolio, which therefore reflects my own view of what is outstanding about the work. I chose aspects that I “would like to see extended in the future” [Gaver and Bowers 2012:42], which were then abstracted to develop larger “conceptual themes” that might be “generalizable to other designs” [Gaver et al. 2003:40]. I present the four conceptual themes, or abstractions, as short, snappy discussion points, that I expect to be inspirational to other designers. The annotated portfolio aims to communicate aspects of the story that were important to me as the maker in a way that is deliberately ambiguous and abstract to facilitate reflection and discussion.

As with many design tasks few specific guidelines are available. Gaver and Bowers [2012] instead specifically highlight that annotated portfolios can take many shapes. Their annotated portfolio contains visual representations of a range of design projects as well as annotations that were derived from reflection. I chose a comparable method, but had to find a way to represent the stories. With written material rather than prototypes, sketches or other types of visual renderings, the question of what constitutes an “appropriate medium of presentation” (see above from [Löwgren 2013]) has yet to be answered. I chose an artful and deliberately ambiguous representation of the stories. The text of the stories is layered with some representations of the annotations where they apply. This has been done to leave the artefact deliberately ambiguous and stress its difference from empirical evaluation. The references are not to be considered as quotes or to make the process transparent and defensible, but only as a means for high-level abstraction.
I worked on annotating the portfolio while analysing the results from the empirical studies. I took great care to keep the two strands of inquiry apart by choosing different strategies. For the evaluation presented here, I worked with the original text, i.e. the stories I wrote and stayed close to their text, words and meanings. For the evaluation of the studies I analysed participants’ responses, i.e. transcripts of group discussions and interviews, so the basis was entirely different, but again I stayed close to participants’ expressions to ensure that I gathered their responses rather than reflecting on my artefacts. In addition, the process for this type of evaluation was much more personal. Figure 16 shows an example of the annotation and reflection process that led to high-level abstractions of conceptual themes. While the process might look comparable to thematic analysis, as it included iterative reading, annotations and the collapsing of ideas into higher level themes, the process was more personal and reflective. In contrast to the writing process, this was not done as a process of reflection-in-action but in hindsight. Therefore, these insights do not necessarily reflect what I aimed to achieve at the moment of writing, but might have only been highlighted through the combination of the artefacts and the way they influenced and built on each other. Following the list of different contribution design artefacts can develop [Bowers 2012] I focussed on the question “Why are we doing this?” building on the relationship between reflection on values and critical design (see e.g. [Tanenbaum et al. 2012b; Bardzell and Bardzell 2013]).
All texts that are presented in 7.2 The Artefacts were used as a basis for this reflection. I consider this work to be a portfolio as all these artefacts were derived from the same research. This collection of work nonetheless does not represent a canon of work, as it is not a selection that has been validated by others, but is instead a collection that is based mainly on the time of creation as they fall within the time frame of my PhD project. Another distinction has to be made to the more humanities-based ‘reading’ of artefacts or the systematic analysis of a canon of work, as done e.g. by [Ferri et al. 2014]. While individual expressions have been highlighted, see e.g. highlights in Figure 16 this is not a literary critique of my work. Instead it is a means of finding comparable and contrasting features from it. Annotated portfolios have been used for designed objects in a variety of ways [Gaver and Bowers 2012; Hauser et al. 2018; Löwgren 2013]. An example of fictional artefacts presented in this way can be found in Wong et al. [2017b]. This goes beyond the pure description of the artefacts, but instead can highlight novel – or even desired – suggestions for future design work or research in the area [Gaver and Bowers 2012]. Comparably I understand the portfolio as a tool for communication that is distinct from the contribution of the artefacts themselves. The portfolio summarizes the stories to some extent, but also provides inspirational ‘discussion points’ through the four high level abstractions.

In the next section 7.3.2 Implications for Design I built on the high-level annotations I derived from the process and explain their meaning to me in more depth. To do so, I turn to implications for design as a format.
Figure 17: Annotated portfolio of design fictions presented in this thesis, 2018, own illustration
7.3.2. Implications for Design
In the last section 7.3.1 Annotated Portfolio I have shown that design fictions can be used for self-reflection by the maker and have further presented these reflections in a way that can be inspirational to other designers: an annotated portfolio. As this artefact is deliberately ambiguous and leaves a large part of the sense-making process to the viewer, I turn here to a more elaborate means of communicating my insights: implications for design. In HCI the “Implications for Design” section in academic papers or other writing, such as a PhD thesis is a more familiar way to represent design insights. Their predominance has been criticised by Dourish [2006] as the richness of many, especially ethnographic, research projects cannot be easily translated into actionable points. In addition, they are not the only useful outcome of the research. Nonetheless, the reflection points in my annotations could easily be translated into such recommendations, both for design fictions and artefacts for care. While the annotated portfolio only holds inspirational discussion points through the four high-level abstractions, here I expand on them and explain what I intended to express through them.

7.3.2.1. Gentle Provocation
Compared to many famous critical design projects (see for example Chapter 2 Understanding Critical Design), none of the artefacts in this portfolio, are provocative on first glance. They share few of the transgressions that are outlined in Ferri et al. [2014] for example. Nonetheless, as I outlined above, the Homes for Life story above touches on sensitive issues, such as intimacy and death. The other stories offer comparably ‘provocative’ elements, such as the idea that a woman might be locked in her house to keep her safe or that a woman might sneak out to the pub from time to time. This might be considered too mundane to be considered critical design – and might well be. But it still encompasses elements of transgression, as current scenarios of elderly people often provide a very sterile picture of their daily activities that many technological solutions are built on. Considering that my assumed audience for these stories is not necessarily accustomed with critical design and might not be well-versed in ‘reading’ design artefacts, I considered the subtle transgressions a suitable move to provide talking points or as a means to “build discursive spaces” [Lindley and Potts 2014:1082]. The gentle provocation included into these stories presents an adequate way to do so.
7.3.2.2. Power Unfolding
Be it over time (as in the HawkEye project), or through the robot (as in the story about RocCo), all of these artefacts contain an element of power that is not obvious on the first glance, but ‘unfolds’ as the story progresses. I consider that a suitable means to enable readers of the story to reflect on where they draw the line and which steps are going too far. In using the HawkEye design fiction probe, users have to literally make the decision how far they are prepared to go. As one of the aims of critical design is to “present alternative products, systems or worlds” [Auger 2013:11] I used the design fictions to offer alternative solutions within the same frame of mind.

This might be a useful tool for a design fiction when used in research, but also for reflection when developing designs for dementia care. Dementia is a progressive illness, which leads to a decrease in abilities and therefore might lead to increasing need for support, which could be enabled through technologies. Boundaries for these have to be established though on a societal level in relation to what is technically possible. It leads to the question of the responsibility of the designer, when building the tools and values built into them, but also of Everyday Design [Wakkary and Maestri 2008]. None of the artefacts provide answers to these questions, but instead make the problem itself tangible and debatable.

7.3.2.3. Nobody is Normal
Especially the Homes for Life story and the Prologue describe how people’s expectations of their loved ones were broken as behaviours were revealed through the technology. As I outlined above, the provocations were only subtle. But they question what normal behaviour is. This is linked in the understanding that many, especially smart or automated technologies, have an in-built understanding of what normal behaviour is and respond to behaviour that is beyond the norm. The approach in itself is not questionable. Instead, the stories problematize assumptions on which these technologies are built. Currently, the technologies in development indicate that elderly people, and especially those with dementia, are expected to live a very sterile, sheltered life, in which digressions are not considered. Design fictions, especially in the way they are presented here are a useful tool to explore the issues in a sensitive manner and approach the subject gently.
In addition, the question remains whether designers and developers can anticipate all behaviours, or whether the devices should provide opportunities for users to adjust settings and suggest measures that they are interested in. This poses the question how interfaces could scaffold the process and offer suggestions without overwhelming users.

### 7.3.2.4. Family & Beyond

Technologies do not exist in a vacuum. All the artefacts presented in the design fictions share that they make visible who is involved in the care process and how differing expectations can lead to conflict. Family, insurance companies and health professionals are involved in the decision making process of what technologies are used and how they are used. This, as I outlined above can lead to the execution of power over a relative or about complex ethical questions about power structures. This reflection ponders on the insight that the power is not exerted through the technology itself, but rather through the way it is used. In this selection, this is further highlighted through the wide range of technologies used, e.g. GPS trackers, robots and smart homes, that all led to unexpected consequences over the time of their use. Questions of whether these tensions could or should be addressed somewhere in the technology are generalizable are seen throughout the whole body of work.

### 7.4. Conclusion

In this chapter I described the showroom approach to design research. I further outlined ambiguities of how this approach fits within HCI: questions of how the merits of an artefact can be judged and who should be the judge remain open. Following these considerations, I used the artefacts presented in the thesis as a means to analyse these frictions in more depth. I further used established means of design research to build on the artefacts and communicate the insights derived from them. The artefacts presented within the thesis provide a means to communicate research results in a way that goes beyond what has been done in design for dementia care so far. The results show that design fictions can be a useful means to build on and communicate research insights by placing technologies in sensitive settings and present them in a situated setting as I have shown with a range of artefacts.
This chapter has two contributions: first it establishes the artefacts developed in this PhD project as outcomes of the research. Second, by using them as exemplars, it shows that outside evaluation is problematic as these artefacts sit between the scientific and humanistic paradigms. Within this chapter I further suggest means of assessing the impact of design fiction, e.g. its merit to communicate in a specific way or to inspire new projects and collaborations.

While the artefacts can be contributions in themselves, their ability to elicit responses promises to be useful for research as well. The Constructive Design Research framework also suggests more empirical approaches to design research in which the artefact is not the outcome of the research, but rather a tool through which research is undertaken. As the role of the artefact changes, so does the type of evaluation. Design fiction does not require outside evaluation when used in the showroom approach. But in a study used with participants it is used comparably to a questionnaire, which should open it up to scrutiny. What can be learned by showing design fiction to others differs strongly from what we can learn through the development of the artefacts themselves. In the next chapters I present the lab and field approach to design research and through the use of the artefacts presented in this chapter show what types of insights can be gained through the use of design fiction with participants.
Chapter 8. In the Lab

In this chapter, I:

- Describe the lab approach to design research
- Establish design fictions as a tool for empirical research to elicit participants’ responses
- Outline participants fears and wishes about smart home technology, especially their concerns about technologies replacing human caregivers
- Clarify which types of responses can be expected:
  - In relation to other types of future scenarios
  - as a means to foreground values and participant’s personal opinions

8.1. Understanding the Lab Approach

I have shown in the last chapter, Chapter 7 In the Showroom, how the design fictions I developed can be understood as a contribution in its own rights. Nonetheless, through the literature review in section 3.1 Mapping the Use and Evaluation of Design Fiction in HCI and the survey presented in Chapter 2 Understanding Critical Design I raised the question whether design fiction can be—and even if it could be—held accountable to its promise of stimulating discussion.

To address this question, I turned to a second strand of the Constructive Design Research framework [Koskinen et al. 2011]: in the lab research. HCI has a strong tradition of undertaking empirical research studies in controlled settings, following from its roots in psychological research. Design research often separates itself from this type of research as I have shown in the last chapter, Chapter 7 In the Showroom, even though it offers different advantages. Koskinen et al. [2011] outline that it is suitable for some types of questions surrounding design. They illustrate this by using the example of Joep Frens’ experimental approach to building and testing prototypes of “rich interaction cameras” to reflect on the strengths and limitations of design methods compared to other research methods. In this example prototypes are tested iteratively to learn how they are perceived by potential users.

For the coming series of studies, I draw on this approach by sharing design fiction
artefacts with participants and gauge their reactions to learn how the artefacts are understood and perceived. I do so as a response to the claim that design fictions can be used to stimulate discussions (see e.g. Chapter 2 Understanding Critical Design) or even a means to elicit data (see e.g. [Stals et al. 2014; Dunne and Raby 2013]). In Chapter 2 Understanding Critical Design I outlined that these claims are interpreted differently by practitioners who use this approach. They are further rarely measured or tested. While that might not be a requirement for design fiction artefacts to be justified as contributions as I outlined in Chapter 7 In the Showroom, the understanding of how people respond to design fictions might be useful for two reasons. First as a general response to the claim that design fictions can stimulate discussions. Second as a means to learn more about how design fiction can be used as a method. In contrast to earlier studies in which artefacts, especially videos were shared via the internet and online comments were evaluated, I chose a more controlled setting that is closer to the lab study approach. Nonetheless, in contrast to the study presented by Koskinen et al. as an example, the criteria which are to be evaluated have not yet been established, due to the exploratory nature of this study. I therefore deviate from the lab approach by not taking quantitative measures, but instead turn to a more qualitative approach that promises to be useful to establish criteria by adding to the understanding how participants respond to a design fiction.

The importance of this approach is further underlined through other design theorists. In his description of design-oriented research, Fallman [2007] introduces the term “research prototype”, which is not the outcome of the research project, but a means to generate different types of knowledge. As I have shown in the section 3.1 Mapping the Use and Evaluation of Design Fiction in HCI of the literature review design fiction has been used in this way in HCI in a variety of ways. Design fiction generates “rich contextualised” [Stals et al. 2014:1] data, but little is yet known of how participants make sense of design fiction and how this influences their discussion of design fiction artefacts. In this chapter I turn to the lab approach as I deploy my design fiction in a controlled setting as a means for data collection, but with the overall question what type of data it elicits.
8.2. The Use of Homes for Life in the Lab

8.2.1. Introduction
Design fiction has been used for a variety of purposes and some have included its use with participants. Wong et al. [2018] describe their plan to share their design fictions with practitioners, while Fuchsberger et al. [2017] and Lawson et al. [2015] did so to gather participants’ responses to potential future technologies. Nonetheless, these approaches have not yet explicitly been classified as ‘lab’ research. Within this two-part study I do so explicitly with the aim to not only elicit participants’ responses about smart home technologies for people living with dementia, but more so to put design fiction under scrutiny and explore in more depth how participants respond to it and what types of discourse it can elicit. The study is guided by the research question: How do participants respond to design fiction? Instead of asking participants directly about their response, which I considered to give too limited responses, I instead used methods to gather a range of responses that could then be contrasted and juxtaposed [Dourish 2014]. I therefore worked with student groups, which gave me the opportunity to access a large number of participants. I also worked with two groups of students, some with a more technology-centric background as MSc students of Interaction Design and some more human-centric coming from a BSc programme of Psychology with a module on Interaction Design. In addition, I chose a range of videos in addition to my design fiction video presented above that I classify as techno-positive future scenarios rather than design fictions. The results indicate that all videos worked well and enabled discussions among student groups, but also shed light on the specific types of responses the design fiction elicited: nuanced and personal. Participants who watched the design fiction were prompted to be more thoughtful about the way the technology impacted on social relationships. The study results further indicate that it enabled participants to draw on their personal experiences, which can be a useful tool for research and design, but also leads to open questions about research with design fiction.

8.2.2. Method

8.2.2.1. Design
In this exploratory, qualitative two-part study I used videos to elicit participants’ responses. I prompted participants through open-ended questions to discuss the
videos in groups and from those discussions gathered insights into the types of discussion the videos generated.

8.2.2.2. Participants
Two groups of participants were chosen to take part in this study: part 1 included 52 MSc students from an HCI course and part 2 included 41 3rd year BSc Psychology students who undertook an optional HCI module. By working with two groups of participants with varying backgrounds, though similar interests, I was able to identify differences in responses. Participants were not reimbursed for their participation as the studies were part of their scheduled sessions.

8.2.2.3. Materials
Participants watched the videos on their own devices as they were available within the groups. Three videos were used in this study:

<table>
<thead>
<tr>
<th>Videos</th>
<th>Participants</th>
<th>Summary</th>
<th>Duration in min.</th>
</tr>
</thead>
<tbody>
<tr>
<td>DF</td>
<td>design fiction</td>
<td>part 1 &amp; 2 – all students Groups 1 – 4 and 10 - 12</td>
<td>Design fiction interview with daughter reflecting on the process of buying and maintaining a smart home as an alternative to a care home for her elderly mother.</td>
</tr>
<tr>
<td>FS1</td>
<td>future scenario</td>
<td>part 1 – MSc students Groups 5 - 9</td>
<td>Animated video in which smart home technology is presented</td>
</tr>
<tr>
<td>FS2</td>
<td>future scenario</td>
<td>part 2 – 3rd year students Groups 13 - 15</td>
<td>Three scenarios using actors focussing on how smart technology could be used to enhance well-being and health care.</td>
</tr>
</tbody>
</table>

Table 3: Types of videos and participants’ groups

The first video was my design fiction (presented above in the section 7.2.4.1 Homes for Life: the Video) which is referred to as DF in the following results section. It was used both with the MSc and the BSc students and was always presented to half of the student groups.

The other two videos used were made in a commercial context and presented future scenarios rather than design fictions. They are referred to in this section as FS1 and FS2.
FS1 was shown to half of the groups in part 1. This video has been made by Jung Smart Housing, promoting their range of smart home technologies, ranging from internal systems such as lighting solutions to outdoor solutions, such as intruder alerts [SMARTHOME DESIGN 2012]. It shows a wide range of technologies in action in an animated video. The video was chosen because it also discussed smart homes, but in a contrasting style to the design fiction – completely animated and without human actors – and as it had a different message. It presented smart home technology as a solution to everyday problems without engaging critically with it.

For part 2 I chose a different video to contrast with the design fiction as the results of the first study indicated that the tone of FS1 had a strong impact on the participants’ discussion. As many of the discussions following this video were on security, which might have been impacted by the technologies introduced, I changed to one that had a stronger focus on health care technologies. FS2 was “Technology Meets Health Care”, a visionary video by Peak Productions [Peak Productions 2009]. It presents three scenarios of users interacting with technology: 1) a woman who uses a fitness tracker that links data with her doctor, social contacts and her fitness trainer, 2) a man living with diabetes, who uses technology to manage his illness, whose data is further shared both with the family and the doctor and 3) an elderly woman who uses a smart pill dispenser and is connected to her son through both monitoring tools in her house and a video screen on her bedside.

8.2.2.4. Procedure

Part 1 took part during the MSc students’ induction on the first day of their course in HCI. The study followed an introduction to HCI and a short outline of the year ahead. Part 2 took part in the last session of the HCI module with the overall topic ‘internet of things’ (IoT). The study followed an introduction to the aims and history of the concept of IoT by the module leader. At the beginning of each study I introduced myself as a researcher with a research interest in the future potential of smart homes for health care and particularly for people living with dementia. Participants were then instructed that they would watch a video, discuss its contents and audio record their conversations. Students were given the questions: “What is
“the video about?” and “How does it make you feel?” to guide their discussion. Students were instructed that they could refuse to take part in the data collection, but that they should engage in the activity nonetheless as an icebreaker activity.

In part 1 participants were put together randomly in 10 groups of 5 to 6 members. Half of the groups were asked to watch the DF, and half to watch the FS1 video. One participant did not give consent to be recorded so this group was excluded from data collection. All other groups were given audio recorders and asked to record their discussion after watching the video. Due to technical problems with accessing the internet and the video for some but not all groups, the time for discussion ran between 7:02 and 15:01 minutes. One group did not switch on the audio-recorder correctly but recorded a summary of their discussion that lasted 03:09 minutes after their discussion. In part 2, 7 student groups of 3 to 5 members each –were assigned a video randomly and 4 of the groups were asked to watch the DF video and 3 were asked to watch the FS2 video. Groups knew each other from previous course work All groups were given audio recorders and asked to record their discussion after watching the video. As the videos differed in lengths, students were advised to discuss the video for 10 minutes. Some groups did not talk for the whole time and recordings varied between 3:22 and 10:26 minutes. One audio recording was discarded as the audio quality was too low for accurate transcription. After the data collection ended, audio recorders were gathered and students were debriefed with a short discussion about the two types of video, and critical design as a method. I transcribed the audio recordings including non-verbal utterances, such as pauses and laughter and stop words, such as “ahm”.

8.2.2.5. Analysis
The analysis took part in two stages, first analysing the data from part 1 in total and second building on this analysis with the data from the second study. All transcripts formed part of the analysis. Comparable to a thematic analysis [Joffe 2012; Braun and Clarke 2006] I first familiarised myself with the transcripts by reading through them and annotating them iteratively. The number of iterations varied but the process was stopped when no new ideas were brought to the forefront. I did not directly contrast the videos, but used the rich data to find patterns through juxtaposition across multiple observations of particular discussions [Dourish 2014]. Extending on the thematic approach, I deliberately looked out for traces of
discourse that influenced how participants considered the technologies presented or the people within the videos (compare e.g. [Jupp 2006]) which was done using a critical discourse analysis approach (compare e.g. [Paltridge 2013]). This was done to learn whether discourse had an impact on the discussion or whether participants would refer only to the videos. I was both interested in academic discourse, i.e. the way technology design for care is framed in academic papers or popular discourse, e.g. the way smart technology is presented in advertising or popular movies. Additionally, I was particularly interested to learn whether participants picked up on the issues I raised in the DF video and I therefore looked out for traces of what participants foregrounded and which aspects they did not consider worth mentioning or commenting on.

8.2.3. Results
The analysis is based on 14 audio transcripts of group discussions of varying lengths: 7 that discussed the DF, 4 that discussed the FS1 video, and 3 that discussed the FS2 video. The quotes given below give an indication of the video watched, the group number, followed by a participant’s number within the group, e.g. (DF 1, P1). The discussions touched on many issues related to smart home technology and care that cannot all be discussed here. I focus here on the discussions about values surrounding care and technology that differ strongly from the current discourse around the topic (see section 4.4 Problems with Technology Use) and therefore show how the use of design fiction probes leads to rich and novel data.

8.2.3.1. Values
Participants engaged critically with the videos and discussed openly what they did not like about the technology or about potential issues it might cause. But the analysis has also shown that the DF video in particular worked well as a means to learn more about the participants’ values. Instead of focusing on the style of the video, participants who watched the DF video voiced their beliefs about health care, technology and family values. Most groups shared specific perspectives on family life, even more specifically around the mother-daughter relationship. Only one group raised the point that conflicts in the family could actually impact on the quality of care: “And obviously it is even worse if you don’t have a good relationship with your parents to begin with” (DF 4, P5). All other participants assumed a strong and positive bond between mother and daughter: “like even mother and daughter that should be a really
close relationship” (DF 1, P1). As a result, people expected that next of kin should take care personally: “Yeah, she is actually not checking up on her herself, and I mean she should” (DF 2, P4). Technology as a response was seen negatively because it “does start to show in that people start distancing from each other” (DF 1, P1). Convenience of the technology was then brushed off: “fair enough she was obviously working but you can take time for your mother” (DF 2, P4). Care was considered a duty and technology a disrupting factor in the family relationship.

As a result, participants questioned the approach of using technology for care. Some participants expressed their view strongly that technology was not suited for care situations and that personal contact would be preferable: “… And I felt like [pause] maybe a social worker would have been better like some[pause] like a carer [pause] that could have been better, like” (DF 1, P4). Most participants argued about the responsibility of taking care of their parents and suggested that technology was not a suitable replacement for human interaction:

P3: “her mom needed someone to be there”
P2: “not a house, a person” (FS2 11)

Participants were also expressive about the fact that technology was not a suitable solution in itself, but that it should rather be a tool: “… this rush towards a technological solution whereas in this situation I think technology should facilitate interactions with other humans” (DF 2, P3). In contrast to the FS1 video in which participants discussed technology as a potential solution to a specific problem, the DF brought a different view to the foreground: technology as a tool that is used in – or hinders - interaction with the users.

One common critique by participants was directed towards the backdrop for the technology: the house itself. As only one type was presented, participants speculated how limiting this technology would be as it only fitted with one style of home: “… and it doesn’t seem like [pause] those technologies would blend well with structures of other houses” (FS1 7, P3). The style of house chosen stood out to participants: “Yeah, it showed that one type of house which is an ultra-modern [pause] like I have never really been in a home that looked like that” (FS1 6, P1). This setup was also far removed from the life situation of many participants who asked how this technology would fit for example with “one-bedroom flats” (FS1 6, P2). This mismatch let them to question the usefulness of such devices: “I was thinking like imagine a smart apartment it would really make a [pause]
wouldn’t make much sense” (FS1 7, P4). Showing the place where the technologies would be implemented also led participants to think about problems that could arise from this, e.g. “One thing I realised was, when technology changes like the next one you want comes out, you have to rip everything out of your walls” (FS1 8, P3), a point not mentioned by participants who watched the DF. This setting of empty, disconnected spaces to introduce technology is a common motif in technology visions since Weiser’s [51] presentation of the invisible computer, which profoundly influenced the field of ubiquitous computing (compare e.g. [Dourish and Bell 2014]). Choosing this type of representation led participants to one practical critique of the technology, but not to wider personal or societal consequences.

Control, autonomy and power played a large role in the participants’ discussions about all videos, but differences can be observed between participants’ understanding of the structures of control. Participants who watched the FS1 video were mainly concerned about two things: losing control as the technology malfunctions or losing control when hackers intrude into the system. Participants in group 5 (FS1) crafted a dystopia in which doors are locked and communication lines are severed due to a power cut, “the house heats up to 200 degrees” (P5), while “the shades will not lift up” (P2). As a result, participants were concerned with taking back control, e.g. by asking “how to turn it off, like can you simply turn it off if you don’t want to have it anymore?” (FS1 5, P5). They also felt that the makers of the video had used control as a means to make the technology more appealing, by explaining how “they are always saying that yeah, with pressing the button you can see this stuff” (FS1 8, P4). The psychology students in contrast trusted technology less and wondered if it could be relied on at all: “And in the beginning she was saying she was getting false alarms but then I also thought What if I don’t get an alarm? you know” (FS2 13, P2). Participants wondered what effect that might have not only on the person monitored, but also on those employing the technology: “if she’s my mom, I would be worried if she I can rely on this system to … work properly everyday” (FS2 15, P1). Both sets of participants had varying expectations of what technology can do, but they both framed the technology as autonomous. Only one group of the MSc students touched on the wider control structures, i.e. those who might have access lawfully: “And all the people who can access it, like the people who built it, people who are selling it to you have so much control over your life” (FS1 8, P2). The psychology students for example explored the wider societal implications e.g. by stating that “it is really hard to set the boundaries [for data collection by
insurance companies via the fitness trackers]” (FS2 13, P2). In addition to the technology itself, the family was also seen as holding control – and maybe exerting it in a negative way. The FS2 video presents a man living with diabetes uses the technology to manage his illness. Both his doctor and his daughter nudge him to exercise, even though he is already going for a walk. Participants commented the scene by stating:

P1: “Yeah, I don’t know the kid calling the dad and being like ‘Don’t forget to walk’ and the doctor being like ‘Don’t forget to walk’”
P2: “Yeah”
P1: “And it’s like ‘Ok, I am gonna walk’”

[laughter] (FS2 13)

Participants felt strongly about the power expressed by the family members in this case and in the DF. Instead of considering hackers or the maker of the smart home – even though both were referenced in the DF video – some participants raised the issue of the daughter’s control over her mother’s life:

P1: “so the daughter can monitor her mother every time, yeah and”
P4: “Yeah, it’s almost like the technology became too controlling. Over her life. Too controlling” (DF 2).

Nonetheless, participants did not necessarily empathise strongly with the mother. They still voiced very general remarks, such as “yeah and generally older people they do like to do some stuff themselves [pause] because ahm, so you don’t feel that old …” (DF 2, P4) or making suggestions that did not increase the mother’s control “I think there should be like a switch that you can turn the switch to only like share shadows” (DF 2, P1). The setup of the movie in which the mother herself was not seen and did not have an active part might have had an influence on this. Participants therefore were able to critique the daughter’s behaviour and views, but the video was not fully able to change participant’s perspectives.

Participants drew on their own experiences to make sense of the videos which indicates that the background of viewers of DF matters. Nonetheless, they mainly shared strong values about technology and care and the power that was exerted through the technology in all videos. The DF was successful as a means to elicit rich data from participants. In the next section 8.2.3.2 Types of Discourse I describe
in more depth the types of discourse it elicited and the way the videos shaped discourse.

### 8.2.3.2. Types of Discourse

Overall, all participants watched all videos critically in the sense that they discussed them openly and felt free to voice criticism. Here I describe the way the videos influenced the style of the discussion. Participants who watched the FS1 video (Groups 5 – 9) in particular focused a lot on the style of the video rather than its content. Participants questioned who the audience for the video might be and considered it either “boring” (FS1 8, P4) or like “reading out a catalogue” (FS1 6, P5) because it lacked the kind of narrative that the other videos provided. The effect was generally not as strong in the discussions about the FS2 video, which was based more strongly on a narrative. Here, only one group focused on the aspect that the video seemed old and stopped the discussion after 3:22 minutes. The style of the video also seemed to have an impact on the type of discussion it elicited.

Participants who watched the FS videos overall did so more jokingly. Analysis of the transcripts showed that elements of laughter noted in the transcripts made up between 1 and 2 percent of each group for groups 5 to 9, but only about 0.5 % for groups 1 to 4. The second part of the study shows a similar picture, but one DF group shows high occurrences of laughter and one FS video group very low occurrences. Considering that the DF has a scene very close to the end in which the daughter discusses the impact her mother’s death had on her, that is not surprising, but it leads us to the impression that the character and story chosen was successful in generating serious and meaningful discussion between many, but not all participants.

Some participants seemed to distance themselves from the DF by linking it to popular fictions. Participants linked the video to other media they had seen. Participants both referenced very technology critical fiction, such as “Black Mirror, one of those kind of movies that focusses on technologies that can go wrong” (FS1 8, P2) or “Smart Home”, a Disney Channel movie in which “the house turned against them [the residents]” (DF 4, P2) and positive examples, such as the “Jetsons” (DF 4, P4). Participants drew on varying backgrounds to make sense of their video and it can be expected that they had different views on the technology because of that. Others
seemed to have experienced the DF as more real as they drew on their real life rather than fictional experiences.

Even though the FS2 video based the technologies it presented in scenarios in which users interacted with them, the focus was always on the technologies. In the DF the technologies were more in the background as they were never shown and only became real through the responses of the actors in the story. The results show that the participants who watched the design fiction were more open to discuss personal experiences of their family, both positive and negative, while participants who watched the FS1 video only mentioned relatives in passing, e.g. “[programmable remote controls] had like a screen and I remember my mom having one and it was just like ‘How do we use the TV?’ like” (FS1 8, P2). This also happened in part 2: “If you put my grandmother in a house where everything operates by her voice, she is probably going to freak out” (DF 10, P3). While other types of technology and outside media references were a common theme to make sense of the FS videos, the DF elicited more examples from participant relatives or people they know: “For example my grandpa … he was looking after my grandma, he was like a lot more active … but then after my grandma got a helper, he got a lot more … he did not do as much” (DF 3, P2).

Participants who watched the DF overall ‘opened up’ more than with the other video, for example when bringing in examples of family conflict: “I have a sister but we are [pause] she does not speak to me anymore, so” (DF 4, P1). This is an indication that participants who saw this video were more personally involved and more willing to make references between what they saw and their own lives. Participants were furthermore more open to discuss how personal preferences could impact how family members decide to live, e.g. as grandparents who live actively, with support from the neighbours and a cleaner who would “cook for them, sometimes take them to hospital”, while a cousin of the grandfather “would rather stay in a nursing home, because he felt like if he had a heart attack or something [pause] there is a doctor” (DF 4, P5). As a result, discussions were less abstract than those presented in earlier studies and responses were more nuanced.

The patterns in the conversations suggested that in the discussions between the MSc students, there was little willingness to engage in open conflict. In many cases, participants did not follow up on their arguments, but accepted new trains of thought. In most cases, new opinions were accepted and the new topic was taken
on, e.g. when P4 (DF 2) argued that “maybe a social worker would have been better like some … like a carer ….” P1 adds “Yeah, like a robot … a robot that follow [sic] her every day”. P4 does not follow up on the thought of human caregiving instead of technology, but instead agrees that “Yeah, even a robot would be better”. The discussion here strays from the original point that human caregiving would be preferable to technological solutions. An explanation might be that the MSc students had just met and knew they had to spend another year working together and therefore felt stronger social constraints than the psychology students who had been working together for more than two years when the study took place and were more prepared to take a stance when they felt strongly about the topic they had raised. They discussed whether children had a responsibility to care for their parents or whether this social contract had been replaced:

P1: “Yes, I know but you are not going to move in with your parents in the same house.”

P3: “You would, you would. Forgive me but you would” (DF 11)

In contrast to the preceding exchange, P3 does not take back or adjust their opinion as expressed. The experience of the participants seemed to have an impact on the type of discourse they engaged in and to what extent they felt prepared to argue their position.

While the level of discussion varied, the results show little indication that any of the videos were successful in changing participants’ opinions about the technologies presented. In all but one case, participants seemed to have ended the discussion with the same sentiment that they started it with. In one group discussion about the FS2 video participants changed from a positive stance to an emphasis on the negatives: In the discussion from group 15, that shift can be traced to one exchange about the FS2 video:

P3: “Yes, there is a lot of potential, definitely. More convenient, more supportive, more secure …”

P2: “Jaa “

P3: “Then on the other hand it might mean less privacy”

P4: “Yeah, if your family members are constantly checking up on you it might be a bit invasive”.
While this exchange suggests that participants considered two potential outcomes of the same technologies, other groups mainly followed one line of argument throughout.

Design fiction has been presented as a means to stimulate debate and change discourse. These study results give an initial insight into the types of debates that can be generated. Participants’ background and experience seems to have made a strong impact on the way they perceived, assessed and discussed the videos.

**8.2.4. Discussion**

In the series of studies presented here, I shared videos with participants that were either commercial future scenarios or a design fiction I developed. Resulting group discussions between the participants were analysed. Through comparison of the responses to the two types of videos and by involving two types of participant groups, I explored how participants responded to design fiction.

The results show that all videos stimulated discussion between the participants, but differences could be observed. All videos also elicited critical discussion, but the focus shifted observably when the video contained a narrative. The design fiction video also elicited the most personal accounts and personal examples. The level and style of discussion also differed by group, indicating that participants were partners in the sense-making process. The following discussion addresses this point, after I discuss to which extent claims about design fiction were fulfilled in this study.

**8.2.4.1. Critiquing Design Fiction**

In this study I shared a design fiction with participants with the aim of learning more about the types of discussion it elicits. In contrast to the previous showroom approach, the artefacts were not considered as “end products but should rather be seen as tools for communicating and collaborating with different actors” [Pargman et al. 2017:781]. Even though approaches have been made to classify design fiction or develop taxonomies (e.g. [Knutz et al. 2014; Blythe and Encinas 2016; Hales 2013]), fewer studies look at individual design fictions and their ability to elicit discussion. Lindley and Coulton [2016b:2] state that “bold claims” have been made about design fiction and its impact, which “are impossible to meaningfully verify”. In Chapter 2 Understanding Critical Design I highlighted that it is unclear at the moment what the ‘bold claims’ are specifically, e.g. what individual aims practitioners of design fiction have. Here
I discuss potential areas of evaluation and also discuss whether design fictions should be put under scrutiny in the first place.

Design methods are often withdrawn from scrutiny, as they are inherently individual and subjective. Terms crucial to the rigour of scientific experiments, such as generalizability or replicability are not necessarily applicable to design methods as even provided with the same materials to work with, two people are unlikely to come up with the same design. Comparably, factors can hardly be controlled for as our understanding of creativity is still in its infancy. Discussions around design fiction to some degree build on these legacies of other design methods as researchers describe the term as “elusive” [Hales 2013:1]. While I agree that design research will not benefit from step-by-step guides of how to make design fictions as they vary widely in medium, audience and aim, I suggest that the aim of making and distributing design fiction needs further explicit discussion in the literature. The lack of clarity surrounding design fiction comes partly from the two-fold use of the term. Ferri et al. [2014] suggest the development of a shared language for critical design which could be extended to design fiction. While some of the classifications of critical design extent to design fiction, design fiction has benefits beyond its use in critical design. This study has shown that participants didn’t necessarily adopt a ‘Critical’ stance towards the technologies I presented in the Homes for Life design fiction, but instead all videos were discussed with a ‘critical’ stance. This in turn led to a nuanced and personal discussion which added to what is already known on the topic of care for dementia.

8.2.4.2. Criticality lies in the Eye of the Beholder

In the first part of this thesis I presented not only a literature review on the use of design fiction in HCI, but also the results of a survey with people who undertake critical design projects, in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies. I presented a range of views on where criticality lies: in the intention of the designer, in the artefacts itself, or in the discussion it generates. The role of the audience of critical design is given little attention. Indeed, it is often not even mentioned. The results of this study add a fourth perspective: criticality is produced in collaboration between the designer, the artefact and the viewer. Participants not only took critical views on the future scenarios, which I did not consider to be inherently critical, but also drew on their own examples of what they
wanted to discuss in response to the videos and how they framed them. Nonetheless, the results indicate that their level of criticality differed, from arguments about the style of the video and the house in the first future scenario to arguments about people’s responsibility to take care of their parents as a response to the design fiction. When comparing individual groups who watched the same videos, the results also show that the type of examples and the level of conflict they were willing to engage in varied. The design fiction deliberately did not focus on one aspect of the technology, but instead contained a range of issues, both positive and negative. Participants raised and discussed those related to their own experience, which indicates that they experienced the video in different ways and took control over it. I deliberately kept the design fiction neither utopian nor dystopian as a means to enable participants to position themselves in regards to the technology and the behaviour of the stakeholders. Even though responses were mostly negative, the responses were nuanced and indicate personal preferences in regards to the type of data collection and who might have access to data varied depending on personal preferences, which builds on the results of Chapter 5 Dementia & Privacy – A Survey with Privacy Experts and Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies.

Even though design fiction is often deliberately “ambiguous” [Blythe and Encinas 2016] or “poetic” [Markussen and Knutz 2013; Morrison et al. 2013] the process of how participants make sense has been given little attention so far. As design fiction has so far rarely been used in lab settings, little is known about the way of how to guide and scaffold the process of viewing or sharing the design fiction. In this study I kept the process deliberately open with limited questions and guidance on what to discuss and consider. Apart from one group who discussed the video only cursorily before moving on, little encouragement was needed. Nonetheless it is unclear what participants gained from taking part in the activity. This has implications for the engagement of participants. But even more importantly, this could influence who could be involved in the discussion of design fictions.

### 8.2.4.3. Strengths & Limitations

Even though other videos were involved, this was done only at the example of one design fiction, which could be considered to be a limitation of this study, leaving me unable to generalise the results to other design fictions in a quantitative, direct
manner. Nonetheless, generalisation is a common means to trace back commonalities and discrepancies in design fictions and provide a classification (see e.g. [Blythe and Encinas 2016; Knutz et al. 2014]). As a range of design fictions would have led to novel questions about generalisability in the lab paradigm as described by Koskinen et al. [2011], I turned to juxtaposition as a means to elicit patterns of comparison. I contrasted design fiction with future scenarios to learn more about narrative and criticality, two items highlighted to be of importance to design fiction. Combining two analysis approaches has enabled me to compare and contrast rich data and look not only for themes, but also for traces of what they were influenced by. This has led to insights that may not be generalizable to design fiction in general, but to factors inherent to design fiction. As little is known about the way design fictions are perceived, these insights can inform further research with and about design fiction.

The results of this study also played an important part in charting out the terrain of design fiction research and establish which type of question should be asked. As design fiction is currently hardly evaluated, even when it is used in the lab, we have yet to establish the criteria by which to judge its quality. Even though claims have been made why design fiction might be useful to HCI research, the terms are still open for debate, as e.g. the survey results presented in Chapter 2 Understanding Critical Design show. The results of this study goes towards a shared vocabulary of what design fiction could or should achieve, as they provide insights into the sense-making process behind the experience.

8.2.5. Conclusion

I presented the results of a two-part study using a design fiction to not only understand participants’ views on smart home technology for elderly care, but also to understand how design fiction is understood by its viewers and which types of discussion it can elicit. This was done to add to the understanding of how design fiction can be used in HCI research in an empirical way, as the rigour of the method is not well understood. I have shown that the way design fiction is perceived and discussed depends highly on the personal experience of the viewer. By using a range of videos on the study, not all of which I would consider to be design fictions, I have been able to outline and discuss a variety of meanings of what critical engagement might mean and how it might be influenced by the type of video. By
taking the design fiction out of the showroom and into the lab, I have been able to put it under scrutiny and explore some of the claims often made about design fiction. While the students I engaged in this study had varying experiences of HCI design and research, they acted outside the tensions of professional design and the market. In the next section I present a series of studies undertaken with professional designers to learn whether their understanding of the design process had an impact on the way they perceived the design fiction.
Chapter 9. Evaluation of Homes for Life with Professionals

In this chapter, I:

- Explore how designers and developers discuss design fictions
- Explore the impact the type of data collection has on the discussion of the design fiction
- Discuss the role of the participants in the sense-making process and potential benefits they might gain through this approach to research

9.1. Introduction

As I outlined in Chapter 2 Understanding Critical Design the understanding of who is considered to be the audience of design fiction varies. Whether it is the designer who makes the design fiction themselves or viewers of the design fiction, depends on the project and the intention of the designer. In research studies, the viewer can be understood as a separate other. The results presented in section 8.2 The Use of Homes for Life in the Lab indicated that the experience of the viewer plays a role in the sense-making process. To examine this further I undertook a second two-part study. As in the first study I engaged those who might be responsible for the development of future technologies, BSc and MSc students, in this series of studies I focus on those who already have experience with the design and development process. This enabled me not only to extend on the two part study presented in 8.2 The Use of Homes for Life in the Lab, but also to learn whether design experience had an impact on the way participants perceived and discussed the video and the technologies presented. I hypothesised that an understanding of the constraints of the design process as well as the need to generate monetary gain through the design work might have an impact. The study was led by the research question: **How do participants with professional experience respond to a design fiction?** The results indicate that the background of the participants mattered. Those with an interest in smart home technology were not convinced by the design fiction and discarded it. Those who already had taken a critical stance on the technologies presented engaged with it. In addition, designers engaged more constructively with the technology than the students did. I further provide insights on the way the data was collected, e.g. type of discussion, verbal vs. written feedback impacted on the type of data gathered that can give useful insights into design fiction research.
9.2. Method

9.2.1. Design
In the two-part study presented in this chapter I used a design fiction (DF) video to elicit participants’ responses (see section 7.2.4.1 Homes for Life: the Video for further information about the artefact). The focus was only on one type of video, but I still used juxtaposition to make sense of the data. First, two types of participants were engaged: in part 1 one group of developers with an interest in smart technologies was approached; in part 2 a group of designers with a critical view on technologies. Second, the type of data collection varied. In part 1 data was collected on worksheets participants filled in individually, while part 2 was set up as a focus group in which the video was discussed between all participants.

9.2.2. Participants
Two groups of participants were chosen to take part in this study: part 1 included 5 attendants of the London IoT meetup group. The meetup group attracts a wide range of professionals and enthusiasts with an interest in IoT devices. Visitors to the event were recruited through self-selection when they talked with me at one of their events. Part 2 included 7 participants who worked in a co-working space in London. The co-working space was chosen as their organisers arrange a wide variety of events to explore the interplay between society and technology. Participants were recruited through the internal channels of the co-working space and agreed to take part in a lunch time discussion. Lunch was provided and participants received a 15 GBP voucher for their collaboration.

9.2.3. Materials
In part 1 participants watched the DF video on a laptop I provided in pairs, using headphones. I also provided a worksheet for participants to fill in (see Appendix III).

Participants in part 2 of the study watched the DF video in a conference room in the co-working space, equipped with a projector. The discussion was audio recorded.

9.2.4. Procedure
For part 1 I introduced myself as a researcher during three consecutive monthly meetups of the IoT group in London to generate interest in the study. During the
last event attended, I set up my laptop with the video in the demo session after the
scheduled talks were finished. If visitors expressed an interest to take part in the
study after talking to me, I provided them with an information sheet and answered
all the questions they might have. If participants agreed to take part I gave them
headphones and started the video, which they watched in groups of two or three. I
gave out the sheet with the questions before participants watched the video, but all
decided to fill it out after the video ended.

For part 2 I approached a co-working space which regularly organises talks and
events on topics in technology, science and society. On the date, we all watched the
video together. After the video ended, I guided the discussion with the questions
tested during the pilot study (see Appendix IV) and audio-recorded the
conversation. After about 45 minutes of discussion I ended the recording and had
lunch together with the participants and a debriefing conversation.

9.2.5. Analysis
Both the worksheets filled in by participants in part 1 and transcripts of the audio
recording of the focus group in part 2 formed that basis for the analysis. The
process was comparable to the one described in section 8.2 The Use of Homes for
Life in the Lab, combining aspects from both thematic analysis and critical
discourse analysis in which the data was transcribed, coded iteratively and
inductively and grouped together into higher level themes, while looking out for
references to other discourses in the data.

9.3. Results
The results are based on 5 worksheets filled in, completely or partly, by participants
at the IoT meetup and about 45 minutes of audio transcription of the focus group
discussion. Quotes from the worksheets are referenced with the abbreviation WS,
while participants in the focus group are referenced as P. The results are divided
into the same two categories as the study presented in section 8.2 The Use of
Homes for Life in the Lab to enable comparison.

9.3.1. Values
In contrast to the results described in 8.2 The Use of Homes for Life in the Lab
questions were less open-ended but more specific on the worksheets and in the
focus group. The topics were not enforced and I did not deliberately steer the
discussion, but let the participants take it where they wanted to. This was done to
learn what participants themselves considered important to discuss and what they
considered useful to take away from the session.

Even though the structure of the discussion in the focus group was different to the
student discussions as a result to this, two similarities can be observed: Participants
brought comparable values about family life and technology to the fore. One main
point which related to the students was that they considered the technology to “take
care of a lot of the human interaction” (P2) or that it even might have “stopped those
conversations” (P3). Comparable to the students, participants in the focus group
argued that it was a “conversation about human vs. technology” (P4). One participant broke
it down to the question of whether the technology is “supposed to bring the family
together and [inaudible] when there is no alternative and when it is supposed to replace the family?”
(P4). While the negative impact of the technology on communication was expressed
repeatedly by participants, this argument also attracted some criticism, as one
participant warned that “there is also a danger of us romanticizing her [the protagonist of the
video] relationship with her mother” (P3) or arguing that “not every conversation I have with
my mother is easy and sometimes you don’t get on you know as the lady said in the video ‘Oh you
know what it’s like sometimes you do not get along” (P1). In contrast to the discussions the
students led, the participants of the focus groups were more aware of potential
conflict in families. The way in which the technology influenced the relationship
within the family was discussed with more nuance than within the student groups.
Nonetheless, an overall expectation seemed to be that conversations about care
should take place among family members, which was intertwined with the
discussion about what technology should measure and what constitutes quality of
life.

One participant asked “where was the conversation about the psychological well-being of the
person?” (P4). They summarized the conflict as “I thought there is something about the
smart home vs a caring home and what you want is a caring home, not necessarily a smart home”
(P4). Participants further commented on the fact that the technology measured that
there was “a man in [the mother's] bed” (P3), but “you don’t have her feelings about that”
(P5). As a result, they suggested affective computing to “check if she was like shocked
or something” (P3). Another participant suggested that it was “more like they are being
monitored rather than cared for” (P2). This critique also entailed questions of trust, as
the technology was considered to be “a bit extreme” (P4), raising concerns about the
dangers of “hackers” (P2), whether technology “can really be trusted to care for someone” (ibid.) and that it could be considered “quite intrusive” (ibid.). Comparable to the students’ perception, smart technology was inherently considered cold and uncaring by the focus group participants. As a solution participants suggested a wide range of measures including biomedical measures: “did she sleep? Was her heart rate up? … Was her … how is her digestion? Like we know none of that” (P4), or even behavioural measures: “Equally, what was she reading? Watching? What was she listening to?” (P1). These last measures were suggested to “get a balance of how perhaps entertained they may be or seeking interest” (P1) or even more applied to “Check that they are not depressed?” (P3). This approach was rejected by some participants who argued that this was not a suitable aim for technology, as technology was not considered a means in itself, but rather a tool which “allows you [laughter] to have the time to then go and interact” (P4).

While participants seemed to agree that the technology as presented in the video was flawed, their opinions of what was acceptable varied widely.

Another point of conversation was whether the notifications to the daughter should have been framed differently, e.g. by suggesting that the notification should not be about the man in the bedroom, but that “your mother had been visited with [sic] a certain gentleman” (P4). Alternative suggestions were about using technology to “augment empathy” (P4) and highlighting that the mother “hasn’t had an interaction with another human she might be lonely” (P4). Instead of notifying the daughter of the mother’s death, the app could have intervened more sensitively, e.g. by suggesting that “your mom has about a month to go you might want to start preparing and start spending time with her” (P4). Overall, participants did not argue against data collection through the technology in the house or even against sharing information about the mother, but rather thought of more empathetic or holistic ways in which care could have been given. Fewer suggestions included that the technology should be used to enable interaction or benefit the person in the house more, e.g. by enabling social contacts as “especially when there is [sic] multiple houses it would be very easy to connect them” (P5) and for example suggest: “Oh there is a coffee morning go and see your friends sort of thing” (P3). Another suggestion was “to ab help the memory” (P7) and “even integrate exercises for them to do or daily tasks to help strengthen memory faculty or also physical grip as well on things that could be integrated as well like mind gym in the house” (P3). Participants made a wide range of suggestions to fit the technologies into their expectations of how they should behave. Most of these were extensions from what was presented in the video, which
to a large extent supported the caregiver in their tasks. Others did take a more holistic view to support the person living in the house as well.

Participants who filled in the worksheet did not suggest as many alternatives, but rather stayed more to the point of the story as it was presented to them. The question whether they would like to move into the house – or change anything for that to happen – elicited the most suggestions of what should be different. One participant suggested that the role of the house should be different, i.e. they expected it to be “my assistant or at least mentor” (WS4) as they felt that the technology in its current state was too controlling. This ties in with another suggestion that the person living in the house “should have possibility voluntarily select functions/functionalities for the smart house and be able to switch them off at any time” (WS1). Another participant reflected that the notification of the mother’s death, that left a strong impression with them as they outlined in the worksheet, should have been done differently and they suggested “someone more neutral” (WS3) should be informed, who would in turn pass sad news on. This extends the results from many of the student’s opinions that some roles are not suited for technology and should be done via human caregivers. While the topics they raised are comparable, it is noticeable that participants using the worksheets felt less inclined to suggest alternatives, but rather critiqued what was presented.

Participants in the focus group ‘opened’ up in a comparable way to the student groups in that they brought in personal examples to underline their points. One participant argued how useful they would have found the technology when their parents were caught in an emergency situation: “I would have loved a smart situation like this where I could see that they are fine because we were texting the whole time ähm which is fine” (P4). As outlined above, participants did not only raise positive points, but also drew on their own experience to describe the negative aspects of relationships and potential conflicts: “I remember speaking to my grandmother and watching my father interact with her when she was in the latter stages of Parkinson [sic] and he asked ‘How are you?’ and she was like ‘What do you care?’ and she would turn around…” (P1). While participants seemed to bring in a more professional perspective as I outline in the next section 9.3.2 Types of Discourse, the story still resonated with them on a personal level. Participants who filled in the worksheets at the workshop did not show the same openness.
9.3.2. Types of Discourse

Compared to the students’ discussions, participants in the focus group had a different style of discussion. In the student discussions, most contributions were short and others interrupted regularly. Nonetheless, often one group member took the lead in the conversation. With the professionals, individuals often spoke longer without being interrupted and therefore made more elaborate arguments than the students did. Many comments participants made were assertive in their generality, e.g. when stating that “One should not die alone completely like that” (P4) or when arguing that “perhaps … the dictatorial approach to smart technologies is just … it is just never welcomed” (P1). Overall, participants were more expressive in their critique than the student participants had been.

Comparable to the students, the participants of the focus group often agreed with each other’s arguments, e.g. through utterances, such as “mhm” or “yeah”. Conflict was still rare, apart from one situation in which one participant critiqued the arguments that had been brought up so far. They questioned the suggestion by one participant to measure the mother’s activities (see above) by asking: “Why do you need to know that though?” (P6). P1 as a result tried to explain his suggestion, but P4 interrupted by arguing that this could be done on a personal level as I described in the previous section. P6 furthermore was the only participant to question the realness of the video, by calling it an “almost utopian or semi-utopian if potentially dystopian scenario”. They further questioned “everyone” who critiqued the model, by arguing that “this is a big statement, I am assuming you wouldn’t take in your mother to look after her for example” (P6), thereby questioning how applicable statements made earlier by the other participants were. While P1’s responses indicate that although they agreed with P6, they disregarded their arguments: “Yes, I agree with you, but I am referencing the video and what we ingested …” (P1). The worksheets show a similar picture. Participants who filled in the worksheets were asked explicitly whether “the story has changed the way you think about smart homes? In what way?” One participant did not fill it in, one rejected the question by stating that it “was not [their] idea of a smart home” (WS5) and two participants argued that it hadn’t (WS1 + 2), in one case because they were “still a bit sceptical about technology controlling your life & your devices” (WS 2), indicating that they had been critical of technology before the survey. The remaining participant had not considered “a more ‘human-less’ care home before where an old woman spends much time alone with technology” (WS4). In the follow-up question they argued that they
might discuss the question with others “How modern tech can improve lives of my parents while they are getting older” (WS4). When asked in the focus group whether the video changed their opinions, the discussion started off with the statement “I don’t think it is smart” (P1) followed by examples of technology that do not match their expectations. This was followed by a discussion about the shortcomings of the current approach to develop technologies that do not directly solve empirical needs. They conclude that the story and the resulting discussion “just further exacerbates or … gives weight behind my personal opinion on them” (P1). This is followed by the exclamation: “Spoken for all of us I think” (P5), without any direct contradiction. Apart from the one explicit remark, the DF does not seem to have much impact on participants’ opinion of technology, but rather confirmed their opinion or has been disregarded.

Even though the focus group discussion had been planned to be more structured as more specific questions were asked, participants overall were less engaged with the questions. No question was answered directly and participants instead viewed them more as a means to discuss their initial thoughts and concerns. One participant used the phrase: “but none of us are answering Britta’s question” (P4) and stated that they would like to move into the house “because it sounds like a nanny [laughter]” (ibid.), before moving the discussion away to reflect on electricity and practical questions related to it. Participants used the questions in a different way than the students did, as can be observed well in regards to the opening question of each study. Comparable to the student groups who were asked to discuss the question: “What was the video about?”, in the focus group I asked participants to “start with … a summary of what you thought the video was about.” I further asked about “the main message you took away from it?”. Responses differed widely between the students and the focus group participants. Nearly all student groups responded with a one question summary of the story. Focus group participants instead started with a discussion of the topic close to their heart, in this case a critique of the lack of empathy in the technology as presented. Going around the room, participants then expressed their initial thoughts about the video, with topics ranging from a systemic view on how individual living was critical to the question of how the technology hindered communication. While the writing process for the DF had to a large extent already helped to find previously unconsidered aspects about smart home technology
[Schulte et al. 2016], I extended on this by asking participants what they considered missing from the debate so far.

Both the responses from the focus group participants and those from visitors at the IoT meetup about the video varied widely. The first comment was an extension on the designer critique already mentioned as developers “don’t take time to talk to neither scientists or [sic] designers” (P4). P2 and P3 discussed the lack of “end of life care” (P2) or “existing palliative care” (P3) in the planning of the application. P7 argued that the daughter might experience guilt for not having engaged with her mother, but instead left it to technology. They therefore concluded that technology “shouldn’t be smart” (P7). These three topics were raised quickly one after another without direct links. Participants appeared eager to get these noted. Most of these comments though were related to earlier discussions, none completely new. In the worksheets, the question was worded slightly differently, asking participants more directly about their impression, by asking about “the first thing [they] noticed’. Responses here varied as well, ranging from comments about style: “The video was very quiet” (WS 5) to reflections about the “plot’, which was “very realistic (WS 4) to “the stand-out moment of the story” (WS 3). Participants of both studies added limitations of the video or story, but few of these offered novel ideas or suggestions.

I struggled to recruit participants for this study. Calls via social networks and via the personal networks of the researchers to attend a focus group received little interest from the IoT community or those interested in smart homes. The few who showed interest mainly wanted to help out a research project and were discouraged by the fact that it was to take place at a certain time and around the university. Participants did not see value in it for themselves to have a critical discussion about the technology they worked with on a daily basis. Reducing the effort by either going to the meetup or arranging a focus group where people already are at work, led to success with the places in which the studies took part, even though more were approached. The results indicate that the discussion was mostly interesting for participants who already had an interest in the impact of new technologies. The setup of the study did not work well to attract or engage participants who had a more applied view on smart technology.
9.4. **Discussion**

In the results section, I presented the results of both a focus group discussion between professional designers and the responses of visitors of an IoT meetup, collected on worksheets. The results extend those from the studies presented in the previous chapter. They underline the active role of participants in the sense-making process as well as underlining how personal participants’ responses were. But they also hint at the impact the type of data collection had on the results. The discussion is structured into three main parts: First I discuss how this study builds on the understanding of the participants’ role, second I discuss in more depth how the lab methods influenced what can be learned through the use of design fiction and third I pose the question of how watching a design fiction might benefit the participants.

9.4.1. **Professional Tensions**

In this two-part study, I deliberately chose different groups of participants to those involved in 8.2 The Use of Homes for Life in the Lab to learn more about the impact of personal circumstances on the way design fiction is perceived. While I used the same design fiction as a means to contrast the results, I deliberately analysed the impact beyond the university. Even though that could have been achieved by addressing the other groups – such as the general public or people who are currently in health care professions, as well as people who might be affected by dementia - I built on the insights of the first studies to learn how design fiction might affect the professional discourse of designers and technologists. To do so, I recruited participants who had an interest in or personal experience with building smart technologies. As I outlined in the introduction, the expectation was that people who had more extensive experience with working within the market and the tensions that arise within design projects might have a different view on the technologies than those held by the students.

Even though the topics discussed were similar and many exclamations were as personal as the students, discrepancies can be found in the way participants discussed the technologies. In the focus group participants not only discussed the impact the technologies might have, but also questioned how the technologies would be developed. Participants did not focus on the technical realisations, but instead questioned the design process, e.g. when discussing how one would go about ‘packaging’ the modules or quantifying the services. Participants picked up
on this even though the makers — like the technologies themselves — remained mainly invisible in the video. A short section of the video introduced the maker of the technology himself, when the protagonist explains that she went to an information event and learned that the maker developed the project from his PhD thesis. The results therefore further underline that design fiction enables the foregrounding of values that has often been attributed to critical design [Markussen 2013; Bardzell and Bardzell 2013; Tanenbaum et al. 2012b]. One of the reasons that participants felt open to critique the technology and the participants might have been the self-reflective tone chosen for the main character. In the discussion, participants quoted her as a starting point to share individual and personal experiences.

Participants here not only imagined themselves in the shoes of people using or living in the house, but additionally also tried to emphasise with the designers and their motivations. This confirms that different groups will draw on different experiences and therefore the use of design fiction will elicit a wide range of discussions. In the survey with critical designers, presented in Chapter 2 Understanding Critical Design I reflected on the various positions between the critical design and the design world as a whole. While some participants argued that critical design should be self-reflective or be a means to critique design methods themselves, others looked beyond the design world. This study suggests that design fiction can be a useful tool to encourage discussion about design processes, even if the designers were not engaged in the making process themselves. Nonetheless, participants discussed the designers who developed the Homes for Life as others, so the question remains to what extent the discussion might impact their own work.

Even though the focus of this study was on the use of design fiction for research, this study indicates that it has benefits when used in a design workshop setting, which extend the findings from e.g. [Lyckvi et al. 2018; Tsekleves and Darby 2016]. Unprompted, participants started to discuss how the design could be reframed, shifted and improved on. Most design fictions present a future that is not entirely desirable, thereby enabling participants to reflect on their own expectations. In the next section I discuss the impact the type of data collection had beyond the video itself.
9.4.2. Scaffolding the Process

Taking a hybrid approach combining thematic analysis and discourse analysis has enabled me to go beyond the similar themes that were discussed in all the studies, to learn more about the ways in which participants approached the artefact and the task connected to it. Overall, the two studies in which the design fiction was used, introduced three types of data collection: short group discussions between participants themselves, a focus group in which the researcher was present and a series of worksheets filled in individually. Here I reflect on the impact of time, on the role of the researcher as well as on the relationship between participants in relation to their responses.

During the focus group I was actively involved in asking questions. During the student discussions I was available, but did not interact after giving initial instructions, which was comparable to the way the data collection took place in the worksheet session. The results show little indication that my physical involvement had an inhibiting effect on the participants. In all instances participants voiced their concerns about the video and the technologies presented in it. Nonetheless, participants in the focus group expressed themselves differently in relation to the earlier studies with students and the participants who filled in worksheets. The type of question asked had a strong impact on the participants’ responses, but the discrepancies in the way participants addressed these questions might also indicate that they approached them differently. Students were presented with a task, to discuss and summarize a video, and did so accordingly. Participants in the focus group approached the topics in a more open way and as a means to reflect on their opinions and express themselves.

The change in setting might have had some impact on this as it was made clear to the participants that the whole focus group was to take up about one hour, while student participants only had about ten minutes. As a result, the arguments were more nuanced than many of the students’ arguments. Participants who filled in the worksheets in contrast gave shorter responses. A reason behind this might be that responses were given in writing, which led to less elaborate responses due to the effort of writing. In addition, it might also have resulted in a more ‘formal’ evaluation of the task at hand. The results suggest that the type of response to the design fiction also plays a role in how it is perceived. So far all other responses were in the type of a group discussion, while this was the first written – and individual –
response. This difference in response might be interesting to follow up in future studies. The framing of what is to happen in the session might also have an impact on the way participants received the study and to what extent they benefit from it, which I discuss in the next section.

9.4.3. Benefit to the Participants
In the first study presented in this thesis, in which I undertook a survey with practitioners of critical design (see Chapter 2 Understanding Critical Design), few participants explicitly mentioned who their intended audience was or who they considered to be the audience for critical design in general. Even though this might be due to the fact that audiences vary too widely depending on the project undertaken, it stands out as many definitions of both critical design and design fiction imply that it is directed at someone. In a lab setting, a specific set of participants is clearly addressed, but the role participants play in the design process is less clear.

Even though the level varies, design fiction is inherently “provocative” [Bleeker 2009], “challenging” [Lindley et al. 2015] or otherwise disruptive. This poses the question of how it will be perceived by those who work within the market and who do necessarily have the intention or resources to disrupt their practice (cf. [McVeigh-Schultz et al. 2018:819]). This in turn puts a degree of responsibility on the researcher to support the participants in the process. In this study I outlined in the information sheet that the discussion was likely to touch on issues such as death and illness and gave participants the opportunity to withdraw if they felt uncomfortable with that. No participant in any of the studies chose that offer and nobody showed signs of lasting distress in any of the studies. Instead, uncomfortable topics were discussed, often with a smile and in a joking manner, but with a certain seriousness nonetheless. The design fiction presented in the video created an atmosphere in which it was possible to discuss conflict. The results suggest that the tone of the video, in which the protagonist spoke very naturally and showed emotions herself might have had an impact on this. Participants at times referred back to her statements to underline their point as a means to justify their own statements. Design fiction is distinctive in its use of narrative, rather than visual or tangible representation. While repeatedly used in collaboration with artefacts to underline the message, it is up to the designer how graphic they want to be. I
therefore argue that design fiction offers outstanding opportunities to broach subjects in a manner that is responsible towards participants. Design fictions not only contain a prototype, but also a world in which the prototype works, which has been suggested to ‘situate’ the technology in the sense suggested by Suchman (see [Coulton and Lindley 2016]). Most participants told me that they had enjoyed the session after taking part in the focus group after the data collection ended. But it remains open what they gained from taking part. While this has not been followed up in this study, I suggest this as a fruitful area for future research.

One important factor might also be the question of how the session and the technologies within it are presented to the audience. Participants were hard to recruit for this study, as it was only relevant to those who were already critical of technology and wanted to share their views. While some participants were generally interested in discussing the future of smart homes, their interest dropped when they realised that there was no ‘actual’ technology involved in the study. One participant who filled in the worksheet argued that there was no technology involved, indicating that their expectations were not met. In the current literature, examples have been presented of how design fictions could be made relatable to an audience of developers, e.g. through job adverts [Fuchsberger et al. 2017] or media such as github comments [Wong et al. 2018]. This approach might be more suitable to make the technologies and the issues surrounding them ‘visible’ to an audience, but the question remains of how to design the session in a way that suits the participants and benefits them.

9.5. Conclusion
In this chapter I presented the results of a two-part study with professional designers who watched the design fiction video I developed (see section 7.2.4.1 Homes for Life: the Video) and discussed its impact either in a focus group or on worksheets. Going beyond the content of what was raised by the participants I discussed how the participants related to the designers of the technologies in the video and the reflection on their own work. In addition, I clarified the impact the type of data collection had on the type of discussion and in the last step posed a question previously overlooked in research with design fiction, of how the participant can gain benefits from the process. These insights built on those presented in the previous section and extend what is known about research using
design fiction in a lab setting. Both of these studies were undertaken with videos, which present a relatively familiar type of engagement for participants. In the next chapter, I present a pilot study in which experts in HCI research engaged with a novel type of artefact: a tangible design fiction probe.
Chapter 10. Evaluation of HawkEye with HCI Experts

In this chapter, I:

- Introduce the HawkEye artefact as a tool for data collection
- Outline how the artefact was experienced and evaluated by HCI experts

10.1. Introduction

In this study I expand on the results from the last two studies to learn from experts in HCI research how they would evaluate the approach of using design fiction artefacts as probes. Within this study the HawkEye design fiction probe was used (see section 7.2.4.2 HawkEye: a Tangible Probe) and shown to experts in HCI research. The main question was: **How do HCI experts evaluate the suitability of this method for HCI research?** Dyads of HCI experts simulated the deployment of the probe in a session of about one hour during which we recorded their conversations and followed up with an interview. The study not only gives insights into the understanding of the possibilities HCI researchers perceive about design fiction probes, but also influenced the field deployment described in Chapter 11 in *The Deployment of HawkEye in the Field*. The results show that participants brought a similar personal stance towards the study, but that the focus of the discussions shifted in comparison to the Homes for Life probe.

10.2. Method

10.2.1. Design

The study consisted of two parts: a deployment phase in which pairs of HCI experts simulated the deployment of the prototype and a follow-up interview.

10.2.2. Participants

For this study we recruited three pairs of participants within our department through internal messaging tools. Participants all had experience in HCI research and were recruited independently of their understanding and experience with dementia. Participants were not reimbursed for their participation.
10.2.3. Materials
Participants were given the whole HawkEye design fiction probe as described in section 7.2.4.2 HawkEye: a Tangible Probe, i.e. participants were given the box that contained the welcome letter, control panel, information brochure and patient file. Both participants received an information brochure, the rest of the artefacts were shared.

10.2.4. Procedure
The expert sessions lasted about 1.5 hours each, during which both Renee Noortman and I were present at all times. With the participants’ consent, the sessions were fully video and audio recorded. The sessions were divided into two parts: use sessions and interviews. The use sessions started when participants were given the box that contained the materials of the design fiction probes, which they unpacked in their own time. After the control panel was plugged in by the participants, it gave out a report in the shape of a printed receipt. Instead of receiving a receipt each day, the participants received a receipt every 3 minutes. This allowed for discussions in between the receipts, and gave them the possibility to change the modules accordingly. Each pair of participants went through 10 to 14 days’ worth of receipts.

After using the design fiction probe for a total of 60 minutes, participants were interviewed by Renee Noortman in pairs about their experience with HawkEye and the design research implications of using design fiction probes as a research tool, using a semi-structured protocol. The interviews varied in length between 24 and 42 minutes. The expert interviews and use sessions were transcribed verbatim for analysis by Renee Noortman.

10.2.5. Analysis
All transcripts were analysed first by Renee Noortman with support from me and both of our supervisors as part of her course requirements. This has been published in [Noortman et al. 2019]. After her analysis finished, I undertook a further independent analysis which differed in two main ways: first, I deliberately contrasted the results with those from the lab studies presented in section 8.2 The Use of Homes for Life in the Lab and Chapter 9 Evaluation of Homes for Life with Professionals, which were not available to Renee Noortman at the time. Second, I extended the analysis method to combine thematic analysis with discourse analysis.
as already described in section 8.2 The Use of Homes for Life in the Lab. This combination has enabled me to go beyond the themes that were discussed by the participants to also learn more about the way they perceived the probe and made sense of the process.

10.3. Results
The results are based on two types of responses: first the transcripts of the use sessions in which the experts used the artefacts themselves to familiarise themselves with the design fiction probe and the method, and second the transcripts of the following interviews in which they were asked – in their role as experts in HCI research – to evaluate the artefacts. This distinction is relevant, because the results from the use session show that participants were immersed in the experience and were engaged emotionally as well. In this analysis I focus on the expert interview and draw on the use sessions mainly at key points where the results underline or contradict what has been said in the interview. The results are structured into two parts: In the first part I give an overview over the sessions and categorize the participants’ interactions. In the second part I describe the role of the artefact to foreground participants’ values and how the experts evaluated the artefact as a tool for research based on their activities.

10.3.1. The Sessions
Three sessions were set up, each with two experts. Here I describe both the similarities and the discrepancies between the sessions. Even though both Renee Noortman and myself were in the room to observe the session, we tried to reduce the number of interactions with the participants. Due to problems with the probe we intervened a couple of times: during the second session the print-out of day 1 was corrupted, which was resolved by re-starting the control panel, while the third session had to be interrupted to resolve a technical fault with the control panel. Other interventions were to clarify with E3 that they should not interact with the researchers:

E3: “One question, are we supposed to ask you questions or just read?”
RN: “No, just discuss with each other. Pretend like we’re not here.”

When asked whether HawkEye was a real company in session two, Renee Noortman gave an evasive answer: “That’s up to you”. While we tried to refrain from
giving instructions of how to approach the probe, Renee Noortman intervened when participants had problems handling the materials, such as how to insert the receipts into the resident file. The strongest intervention was in the second session in which participants engaged in an extensive discussion about their role before even turning on the prototype and were prompted by Renee Noortman to do so after a while: “If you feel like you sort of have an idea of how it works I think it might be a good time to also plug it in, you will still have time to discuss”. Even though the set-up was originally the same, the sessions had different dynamics and moods, depending on the expertise and values of the experts. Here I focus on two themes: first, what participants talked about and second how they responded to the systems suggestions, that were printed onto the receipts that came out of the control panel.

10.3.1.1. Session 1: The Optimists

The two experts who took part in the first session were the most positive about the interaction and engaged with the device in the most playful manner: “What’s it saying? It’s so funny! ‘Annie skipped one her pills today but she has been eating well.’ One of her pills, okay” (E1). E1 and E2 discussed Annie’s care and not only worked with each other, but also with the device to make sense of the data and care for Annie:

E1: “[…] So the system says that we should raise the level of this module, do you think we should do it?”
E1: “Well, yeah I would probably do it”.
E2: “Why?”
E1: “I don’t know; it makes sense to just do it.”
E2: “Okay, cool. So you think that we should do what the system says?”
E1: “For now, well, I’m really thinking of the doctor. So the doctor calls- Well they advise- HawkEye advises. Yeah I would, I mean, just for now.”

While they were questioning how the data was summarized and speculated about the workings of the system, overall they were positive about the system and appear to have trusted it:

E1: “…which made her happy’. How do they know? That she was so happy?”
E2: “Maybe the system is capable of analysing your mood, because it’s a SMART phone. I guess”.

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Even though they relied highly on the data the system suggested, they took their role seriously and discussed what might be best for Annie:

E2: “And do you think that the way we adjust the system it also affects her everyday living and her wellbeing?”

E1: “Yeah, possibly. Because, if we were for example to change, let’s say the location module to 3, then she might get all these signs and signposting and all the- which she might find helpful, she might not find helpful so then you are affecting wellbeing somehow”.

E1 argued during the session that they felt “very responsible” and E2 commented on something that had happened to Annie by blaming themselves: “Oh, now it’s our fault, right? Now it’s our fault”. These quotes hint at the level of engagement and responsibility that participants developed. Overall, the participants tried to work collaboratively with the system. When data was missing or inconsistent, they challenged it, but found responses that satisfied them.

10.3.1.2. Session 2: The Engineers

The two experts in the second session had expertise with smart home technology and sensors and had different expectations about the type of data they would receive. The reports on the printed receipts included a short paragraph about Annie’s life and – if modules were activated – specified information about her life, e.g. the number of hours and minutes she spent outside. But this data was not recognized or framed as sensor data by the participants who wondered about the lack of data: “Yeah, I’m curious- we could get more information, like sensor data from the house. Maybe they are keeping it because of privacy issues?” (E3). Nonetheless, they were also critical of receiving data and the personal insights into Annie’s life: “Well I mean, this entire thing about who called Annie is beyond any privacy issues already” (E4).

In addition, they questioned their involvement in the process from the outset and saw themselves as mere extensions of the technology. E4 in particular emphasised their reliance on the data they received:

E4:” I agree, but the other way around it’s- why do I need to make that decision? Why can’t the system just make the decision itself?”

E3: “But I think it’s maybe- I think it’s also a question of how one feels comfortable letting the decision up to the system because based on the sensor data you can leave the system do it automatically but sometimes even-“
Chapter 10 Evaluation of HawkEye with HCI Experts

E4: “But for the patient it feels as automatic as- either through the AI or through me because I’m not going and say "well, today I’m going to force feed you", no I’m just going to turn up one of those knobs here.”

E3: “But I can, as a caregiver, I can have a say to whether the system will actually need to- will be doing the force feeding. So, for example I was saying, so if we leave this decision to the system doing it automatically, the system might go to the level four to force the feeding, but if I can make a decision based on the information that I have, then I might in some case I might not really- don’t like the concept of force feeding module, so I might not choose the option 4. And then maybe I would go and visit her and check with her how she is doing actually and then consult the caregiver who is taking care of her and then take the decision to actually.”

E4: “But that doesn’t seem like what this programme is about. I don’t know. Why can I not just ring them up? Why can I not just ring them up?”

While E3 originally tried to argue against this, they refrained from doing so for the remainder of the session, but took on a more active role and initiate changes to the modules:

E3: “Okay ‘It has been very quiet at the house today and nothing alarming has happened’. Okay.”

E4: “So I assume if she would be dead we probably would know, right?”

E3: “I was think that visitor 0 and callers 0, was there a communication module that we can increase?”

E4: “Oh yeah she can- she can call random people. Well it’s already set to 2, so.”

E3: “But we can change.”

E4: “Oh, wait, through smart telephone. Oh, but wouldn’t it say that we would be alerted if she feels lonely. If you want to we can increase it, that means you get someone sent over.”

E3: “Yes, let’s see what happens because it has been very quiet, so.”

In comparison to the first session, the collaboration between both the experts and with the system was less harmonious as the experts struggled to find their role in relation to the artefact.

10.3.1.3. Session 3: The Cautious

The experts in this session were very aware that they intruded into Annie’s – the fictional character’s – privacy. They did not feel confident about receiving
information and turned down the modules whenever possible. Already on the first day – when the modules were set to a maximum of 2 out of 4 – E5 asked: “No, it all seems fine. ... So, can you reduce the fact that she is doing okay and reduce the module information?”. As a response to their level of discomfort they used very negative language:

E5: “[...] I don't like the idea of changing the surveillance scale.”
E6: “The what?”
E5: “The level of information that we get out.”

As a result, they struggled with their role in the system. While they took their role as “humans in the loop” (E5) seriously, they also questioned whether their decisions were in Annie’s best interest:

E5: “We wanted to have visitors.”
E6: “[Laughing] Yeah, she doesn’t want it.”
E5: “But we're in control of the big brother house”

Consistently, their mistrust of the system shone through. When data was missing or inconsistent therefore, they were more negative about it:

E5: “So what do we have at three now? Location? And nutrition? Three doesn't help.”
E6: “Yeah I mean, assume this means that the system takes over. We're not gonna tell you anything.”

While these participants also questioned their role, their experience with the artefact was nonetheless different, because they struggled with their role more personally than conceptually.

10.3.1.4. Session overview
Overall, with little information given, it was up to the participants to learn how the system worked. What was expected from them was kept vague in the letter they received and participants had to a large degree define their role as they went along. To do so, they had three means of information: first, the receipts that gave daily information about Annie’s life and on some days included suggestions to raise the module level, second the welcome letter and information brochure and third each other. As the control panel started printing the moment it was plugged in, most groups had to ‘catch up’ with the information they received through the receipts
and turn to the brochure to make sense of it, as illustrated by this excerpt from the beginning of the first use session:

E2: “[Pointing to medication module in brochure] So these are the modules, Annie’s currently on level [checking receipt] level 1. She has no trouble with taking medication, which is true. [Reaching for second receipt] Let’s check out what it says. ‘The doctor called Annie today but she seemed very confused, based on this incident we would advise to set the identification module to level 2’, yeah, [flicks to identification page and starts reading the different levels]”

All groups kept on reading throughout to extent what they had read or to confirm with each other whether they understood it correctly:

E3: “‘Annie has been stumbling around the house recently, we think that turning the location module to 3 would help her find everything better’”.

E4: “Hm. What is location module again? I think that turns on the signs in the house. I think we can do that.”

E3: “Wayfinding symbols on the door, remind which room.”

But not only the materials, also the other expert in the room was a source for information. Information was sometimes asked for, when one party had missed information:

E1: “[...] So location is on two.”

E2: “Which means?”

E1: “That we are able to keep track of the amount spent outside”.

But understanding was mostly established collaboratively when information was missing or lacking:

E5: “So, basically we have to do 21 days of this.”

E6: “Yeah. So the different settings give you more information and don’t increase interventions. Is that right?”

E5: “I think for medication it did something, right? No, it says based on the data on the receipt you can make changes to the environment. [reading from brochure] It says “Turning the knobs on the control panel you can set levels for five modules, a higher level means more assistance for the resident in that specific area.”

E6: “Yeah, that’s what I thought but in the explanation it says- oh, but we can and add more information and more assistance.”
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E5: “Yes.”

While participants recognized the booklet was important to their process of understanding how the system worked, the collaborative nature was not as obvious: “Yeah, so I feel like I have to go back to the booklet so many times, just to- I depend so much on it. ‘Occasionally forgets to take one or two pills‘ 0 time spent outside, 0, 0. What would you do? Would you- no, I don’t know (E1)”. While few decisions were made by one of the two experts without confirming – e.g. “Well at least she had a good day. Let’s just not make any changes then” (E4), most decisions were agreed on through collaboration and deliberation:

E5: “Set medication level to 2’ What will happen if we set it to 2?”
E6: “You’ll notified about whether the resident took medication. We set up a daily audio reminder at the time the medication should be taken.”
E5: “They set a reminder”.
E6: “Yeah”.
E5: “Shall we then?”
E6: “Yes, sure”

In some instances, information was just not available or perceived as lacking by the participants. In many cases, this triggered participants to improvise and speculate about Annie’s life. Sometimes this was playful, for example as the experts of both the first and second session used the stapler that was available to put the receipts into the resident file as a prop to mimic a phone with which to call Annie:

E2: “Yeah. [Holding stapler for E1 like a telephone] Would you like to call her?” or
E4: “Maybe we should call her and ask, if she wants to have more entertainment. [Picking up stapler] Is this a telephone? Hello?”

Other examples shared a darker undertone, e.g. when E5 and E6 started to question whether Annie had started to play the system:

E5: “She went out for a walk and got back safely, well done! ‘Medication taken: yes’”.
E6: “Calorie intake nothing?”
E5: “[Laughing] what? The nutrition is still at 2, right? But calorie intake zero. She did not use a thing, from the fridge.”
E6: “Maybe she slept or something? Maybe she went out?”
Most improvisation though were done with the aim to make sense of the sparse data and as a means to get more information even though it was clearly not available as Annie could not be contacted:

E2: “Why are you frustrated when you get visitors? Is she cooking and something went wrong?”
E1: “She’s also spending- she spent one hour outside.”
E2: “Maybe she got some groceries.”
E1: “For the visitors?”
E2: “Yeah, exactly. Maybe she’s going to make chili sauce and she forgot to buy beans or something.”

Even though it was a playful way to engage with the lack of data – and potentially deal with tensions that arose from the task as the example from E5 and E6 shows – it was a serious means to ‘take care of Annie’.

While the sessions varied widely in the predominant mood and in the attitude participants developed towards the HawkEye system, participants developed comparable strategies to deal with the ambiguity of the data they received. Even those who were critical were often emotionally involved, as little exclamations show, e.g. “aww” (E1). While the data presented here was derived from the transcripts of the use session, I focus on the following interviews in the next section 10.3.2 HawkEye – the Artefact, in which participants were more clearly addressed as experts.

10.3.2. HawkEye – the Artefact

In contrast to Homes for Life, HawkEye is tangible, which was acknowledged and commented on by participants. Participants enjoyed the “visual appearance of the booklet” and “the design of the box” (E2). But this in turn was not only seen as a means
in itself, but also had practical implications. Participants argued that this “worked really well for me”, especially as a means to “mak[e] it more realistic” (E3). Nonetheless, in the interview participants described that the device also broke their suspension of disbelief as they contrasted it with ‘real life’ devices: “If you take a look at the box, obviously there is not a product like that and if someone would design a product for supporting the controlling of a smart home, it wouldn’t be a box I think and it wouldn’t provide receipts like that. And if you start reading about smart homes then you realise that it’s not the main functionalities are not feasible at the moment” (E2). E4 describes the “futuresque” feeling the artefact evoked, which also points towards their discomfort with it: “It doesn’t feel like it’s now. Like, I get an anonymous letter from HawkEye Technologies, asking me to take care of Annie, and the system even knows that I like her cookies. That seems like - that’s odd a bit of like, how do they know that I like her cookies?” Nonetheless, they “could imagine myself being in that situation in, I don’t know, 20 years from now” (E4) which poses an interesting view on what plausibility and realism constitute in regards to design fiction.

According to E1, the probe also worked very well to draw participants in: “it was there for us and from the very beginning we were engaging with it”, which “really enhances the whole experience”. The language used on the receipts also played a role in engaging participants: “Somehow connected, even though we have not made any phone calls, we didn’t know anything that was going on we still felt connected. It was also the use of the language, ‘Oh she’s feeling very happy’, ‘You should do this’, ‘You are strongly advised’, it felt very personal” (E1). In addition, the appearance of the design fiction prove seems to have been considered non-threatening, making it easy to approach, as this quote by E4 indicates: “It’s very cute and here, the entire home overview looks really nice and playful and you just fiddle about with some knobs and buttons”. The carefully crafted appearance of the artefact made it – and with it the topic of the study - approachable to some participants: “it’s an important thing, it’s not something that you do for fun, ..., there is a serious nature” (E1). While the device appeared non-threatening, participants nonetheless had negative experiences with it, which they put down to some extent on the design fiction probes themselves.

Participants not only commented on the control panel, but also the artefacts that surrounded it. E4 critiqued the wording that they considered “a bit of priming us to be negatively”, or “like choice of words here in the starting seems very priming of I immediately am hesitant to agree to everything they say. So, maybe that was on purpose, maybe it was not but it was not-“. E6 goes even beyond this and argued that they felt influenced by the way
the system suggested changes: “especially with the advice that they were giving, or saying like
“We noticed this so we strongly advise you to crank it up to three, so that’s what we did. But I
don’t really know that I would have taken that decision otherwise but I thought, well if the machine
is saying it I might as well. So it’s also like we were giving up a little bit of control.”

Comparable to Homes for Life, the experience the experts had with HawkEye, developed and changed over time, as information was given intermittently: either in the interview as the protagonist reflected on buying and maintaining the house or through the daily receipts experts received and their consequent reading-up of the information. E5 commented on the fact that it “is just unfolding in front of you”, which in turn “effectively questions what are the things around trust…”. But as outlined above, the experts not only commented from a professional stance, but also described their personal experience: “And another thing that I thought as I was doing it, that I think is really good is- even though it was a very short time between each report, I was kind of anticipating, I was curious- ‘Would it be better? Would it not?’ after we adjusted” (E3).

10.3.2.1. Personal Role & Values
While the three sessions differed as I described above, one element they all shared was that the participants had to make sense not only of what the artefact did, but also how to respond to it. In short, they had to become caregivers and lay out the rules of what that would entail. This was not always easy as E2 pointed out: “So, there was some tension regarding what you can do and what you can’t do in order to make use of the tool.” E3 and E4 identify different reasons behind this lack of comfort. E3 gives a personal response and reflects on their contrasting emotions toward the task:

“So for me I think I was thinking about my experience as a caregiver, so I don’t have an experience with being a caregiver and at first, at the start, I was thinking that I’m like-feeling that I’m invading her privacy, so I was a bit cautious about kinda changing the level. But at the same time I also feel a bit more pressure, like responsibility that I need to take action to make sure that she’s okay so that was something that I wasn’t sure about the role or responsibility, to what extent I am having the responsibility.”

E4 in contrast puts more emphasis on the lack of information, thereby challenging the system more directly: “We made sort of decisions based, I think, on half of the information we could have.” E5 also commented on the lack of information, but brings in the question of trust:
“So there was a mismatch in the information anyway but more information sometimes makes you feel like you're more comforted, you think they have a basis for this information, they worked it out, but if you look back at when she was frustrated, it probably doesn't have a basis.”

Even though participants had been struggling with the lack of information in the use session, E5 identified one of the advantages of design fiction as the “level of ambiguity that you would feel”. This was recognised as a useful strategy of design fiction after the activity took place. This ambiguity further meant that participants had to do a lot of emotional and collaborative work to interpret their role and define their role as caregivers.

Participants had already discussed in the sessions that they wanted to contact Annie herself to learn more about her emotions, wishes and needs. In the interviews, E3 built on that and questioned the remote nature of care and their relationship with the ‘professional caregivers’ that were already there: “…I was kinda thinking that those kind of people who are taking care of Annie now will make better decisions than me, I think.”

This was mainly due to the lack of information and the inability to talk with Annie herself about her needs and wishes. As a result, participants questioned the summaries and recommendations given by the device:

E4: “I think we tried a bit to emphasise with Annie, but I think we were quite guided by those little ‘Annie had a great day’ things.”

E3: “And ‘she’s frustrated’”

E4: “Yes, ‘she’s frustrated’, and of course then we tried to empathise with her but it’s on a very abstract level because whether she had a great day, it’s the AI’s decision so we don’t really know if she had a great day because we don’t have the information and we didn’t talk to her”

While there were discussions about behavioural and environmental information, participants mostly questioned the ability of the device to gauge and communicate Annie’s emotions: “Yeah, especially when they were talking about her emotions, and they said she was frustrated because she had visitors or she was happy because she had visitors. I was like, how do you know these things?” (E6). All these doubts and queries led participants to question the artefact and their part in the collaboration. Even though it was perceived as problematic E4 summarizes that they “think we were able to sort of play our...
role”, which indicates that participants felt challenged, but not alienated by the experience. The experts were personally and emotionally involved and often referred to issues they encountered in the sense-making process of the experience. On first glance this contrasted with the earlier compliments they paid to the experience that I referred to in the first section of the results 10.3.1 The Sessions. But closer analysis shows that this ambivalent experience, did not take away from the overall engagement as shown e.g. in this opening quote by E1:

“I really enjoyed it as in, the pilot now, I really, really enjoyed it. It was very interactive, I don’t remember how often it was set to remind me of stuff but it was very interactive, like I was super-engaged at every single point. There was something- not only something to think about but also something to do which became frustrating at one point. I was always doubting- not always - but sometimes I was doubting myself whether I’m doing the right thing or whether I’m not doing the right thing. But overall, I quite enjoyed it.”

This duality could be observed in all pairs, even though the level of agreement differed. E6 for example starts off by arguing that “it was good, especially at the beginning” but went on to describe how their experience changed due to the lack of information to which E5 responds that they “also felt a bit uncomfortable”. Even though participants disagreed on how the experience made them feel, their first evaluation throughout was emotional and personal.

Comparable to the responses to Homes for Life, participants did not take a detached, objective stance towards the experience, but immersed themselves freely, which led to rich insights about their values and expectations surrounding the use of the technologies. Nonetheless, the study setup enabled them to take a step back from the experience and reflect on it critically.

10.3.2.2. Design Fiction as a Method

Even though participants were chosen as experts in HCI research, none had personal experience of planning and executing a design fiction project. This showed to some extent in their responses, e.g. when participants were keen to point out that “I don’t have much expertise with design probes and just giving things to people … so I guess I have research experience, but not so much in the design probe – and especially not in design fiction” (E6). The experts were also quick to point out that they “don’t have any” experience in dementia research (E3) or to specify that their research topic is “while not dementia,
there are parallels” (E5). As a result, participants were unsure how to define or discuss the method and for example clarified terms: “is it called a probe?” (E1). Nonetheless, participants were interested in the method and its relationship to other methods. E2 stated that “it would be quite interesting to compare the findings of those studies [applied methods like interviews, observations and focus groups] with the types of findings that you would get out of this intervention”. Participants saw differences between this type of research and other methods.

While we missed the opportunity to ask participants how they would define design fiction, some of their beliefs shine through their answers. E2 for example emphasised that E1 had “worked as a designer” and “designed business products”. As a result, they argued that it made a difference whether one “applies human centered design in order to incrementally improve products and if you think about this”. Design fiction was considered more ‘revolutionary’ than commercial UX work. Even though it was not openly articulated what design fiction was, it was often contrasted with other methods, e.g. as a “more realistic way than saying, just in a focus group or interview. Exploring a hypothetical situation that you can’t explore [in] interviews” (E4). E6 wondered whether “realistic is the right word”, but instead proposed that it “makes you immerse more in the scenario. I could quite imagine this being real and happening to a real person so that was the advantages”. The method enabled speculation and immersion, as participants reflected themselves: “I mean, it’s quite personal, but I’ve never been a caregiver before and I think just having participated in this really short session, I think it just inspires you to think about these important decisions that we’re going to take at some point in life I guess” (E2). Participants further had strong views about the context in which this method could be deployed. Participants not only considered “research through design and critical design” to be “valuable and worth to explore future scenarios and to probe how people think about important and pressing issues” (E2), but also argued that the method enabled one to “explore more extremes than in other methods” (E4). Even though they had not used it themselves, participants had strong impressions about what design fiction entails. Even though they saw positive motivations for using it, they also proposed changes.

In their role as experts, the participants also felt confident to critique the method and make suggestions of what could be improved. These suggestions were mainly focussed on the use of design fiction probes as a research method, rather than the artefact itself. The experts thought about ways in which the experience could be made more engaging or immersive. These included small adjustments, such as
providing a photo of Annie (E2), or changing the scenario to “Your grandmother, Annie” (E4), as they thought “a bit of the scenario that it was very detached from who Annie is as a person, and how to best respond to it without actually the communication about it”. But participants also considered more impactful changes, such as a personalised timing of when the next receipt is provided: “I think just one thing on the technical side which might be difficult to influence is the frequency of how often they came out, so in the beginning, after we still could read all the rest of the brochure but after day 8 or day 7 I was done with reading so we were just waiting the two minutes for it to come out. But on the other hand, if we would have had a really lively discussion for two minutes then it would have been to quick” (E4). Beyond the session itself, participants also considered how the method could be applied in the field and which problems that might bring with it.

When considering the deployment in the field, participants were thinking about data collection in “long-term engagement”, because “at some point it would be quite tedious, like after 3, 4, or one months or 3 months” (E2). Already in this short session, E6 commented that they “didn’t really know what else to write down. I kept making notes but I don’t know how informative it was what we wrote down.” Practical considerations that apply to other studies, such as diary studies about engagement and participants burden seem to apply to design fiction probes as well and might have to be carefully balanced. But burden was not only interpreted as timely cost, but also as emotional burden. Those participants who felt more uncomfortable about the method warned that the probe might have an impact on participants who were in a similar situation as the scenario suggested: “But if I was dealing with that situation in my life, I would be quite ‘I don’t know what I’m doing’” (E5). This was built on the professional experience that “with using probes in general, […] people find it difficult to keep a distance” (E5). Participants drew on their experience of comparable HCI research methods to suggest changes to the protocol.

Overall, participants stressed that they felt engaged with the study. Even thought they were personally involved, they were able to critically engage with the study and make suggestions of how the artefact and the method could be improved, drawing on their experience as HCI researchers.

10.4. Discussion

In this study we shared the HawkEye design fiction probe with participants who were consulted as experts in HCI research to discuss the method. The session was
two-fold to give participants the opportunity to experience the process, before answering questions about the method, as: “People cannot readily answer questions about their interest in something of which they have neither direct nor indirect experience” [Schön 2017:224]. The results underline the variability in responses and preferences that could be observed in earlier studies (compare both the study with privacy experts presented in Chapter 5 Dementia & Privacy – A Survey with Privacy Experts and the other studies presented in relation to the lab paradigm), but also show differences through the type of interactions. The coming discussion is divided into two parts, in which I first discuss how participants defined their role and how that relates to the design fiction before, second, discussing the differences between watching the video and the interactivity of the HawkEye probe in more depth.

10.4.1. Becoming a Caregiver

Even though it is built on the same story, HawkEye differs from Homes for Life. Participants’ experience shifted from a passive viewer to an active participant. Participants in The Use of Homes for Life in the Lab and Evaluation of Homes for Life with Professionals could observe the conflicts as they unfolded and felt engaged and empowered afterwards to take a stand towards them. When interacting with HawkEye, participants were not afforded this distance, but instead had to make decisions themselves. As such, they had to become caregivers, which touches on points that I could not previously observe. Homes for Life already placed the activities of buying and maintaining a smart home into context, but it only described some of the challenges of taking on and maintaining the role as a caregiver.

To some extent, this brought the experience ‘closer to home’ for the participants, who could experience, rather than observe. This goes towards one proposition by Elden et al. [2017:1] to go “beyond stimulating discourse about speculation, towards developing means to act amidst it”. Providing means to do this enables participants to explore a role in a safe environment and take on a new identity for a while. Critical design often comes from an emancipatory point of view (see e.g. [Bardzell and Bardzell 2015; Tanenbaum et al. 2012b; Light 2011]) which might not have been satisfied through this study. But the results show that it enabled participants to take a role they were not familiar with and reflect on the way the technologies involved shaped their experience.
As participants experienced and told us, the HawkEye design fiction probe shaped their experience and ‘forced’ them into a particular role, or enforced a particular way in which they could act. This underlines the point made by Dahl and Holbo [2012:572] that assistive technologies “to varying degrees, … also define care”. The design fiction as a probe emphasised the socio-technical nature of care and made the effect tangible for participants. The question remains of how design fiction could be used in the design process, e.g. of care giving technologies.

10.4.2. Attitudes towards Data

Like Homes for Life, the HawkEye probe brought many of the participants’ values about caregiving to the forefront. In addition to Homes for Life, HawkEye foregrounded some of the participants’ responses towards data. The receipts participants’ received were partly individualised as they depended on the module settings participants chose, but overall, they were in the same style and contained similar information. As I have shown in the beginning of the results section, participants’ responses differed in the way they interpreted and felt about the data they received. Participants not only mistrusted the data to varying degrees, but also had different views on what ‘sensor data’ might look like. In Evaluation of Homes for Life with Professionals, I describe a similar situation in which one participant rejected the notion that the video contained technology, as this was only hinted at in the interaction between the protagonist and the house. This puts emphasis on the importance of considering the user group when developing artefacts and drawing on their understanding and expectations.

While Homes for Life put the experience of buying and maintaining a smart home into perspective, it remained vague about the interactions with the technologies themselves. This had the advantage that participants could imagine the technologies based on their understanding of smart homes. HawkEye in contrast did provide rather detailed descriptions about functionalities and interactions. While this led to discussions about the appearance of the artefact, it was still vague enough for participants to foreground their values. Compared to the studies using the Homes for Life probe, the focus of the discussion shifted as a result. In both studies with Homes for Life the discussions focussed to a large degree on the question of whether technology can replace the human factor in care, which played less of a role in the study presented in this chapter. While participants wondered about the
human factor and whether caregivers who had access to Annie might not be better suited, the discussion was even more fine-grained than those triggered by Homes for Life.

### 10.4.3. Bias, Reality & Plausibility

With HawkEye I observed a similar duality as in the Homes for Life studies, as participants were invited to comment as experts, but did so from a deeply personal perspective and by drawing on their personal experiences. This is not a criticism of the method, but rather points towards the strengths of the approach. In contrast to previous studies that address the problem from a decontextualized theoretical point of view, e.g. the framing of monitoring as surveillance (see also section 4.4.3 Caregiver Conflicts), the artefacts used in this and previous chapters, encourage a more nuanced debate around the development of technologies that might fit into a range of situations.

While participants voiced concerns that the tool might bias them, or push them in a certain direction, the difference in opinion indicates that this was not necessarily the case. While not neutral, the device was open and ambiguous enough for participants to project their own fears and wishes onto it and emphasise issues they were interested in. Grand and Wiedmer [2010:10] have placed design fiction in relation to scientific knowledge by arguing that research through design does not look at the world as it is, but as it could be and emphasise that design fiction enables to explore a “plurality of possible futures”. This study indicates that ambiguity built into the artefact can be a resource not only for design as Gaver [2003] suggests, but also an important tool for research. While the design fiction probe provided a series of topics for participants to talk about, it foregrounded individual values, wishes and concerns that participants held about the technology.

This was further supported by the speculative and fictional nature of the probe. Especially in the interviews, participants put the probe into perspective, e.g. when discussing how far into the future it projected. Instead of debating whether it was real or not, they accepted the way the artefact worked as a premise, after defining their own paradigms. This adds to the importance of keeping the narrative and experience open to enable participants to suspend disbelief and find their own workarounds and justifications for the experience they are having.
10.4.4. Handling Care

As outlined in the last section, participants were more active in this study than in the ones described in the previous chapters. This not only refers to their sense-making process, but also the active handling of artefacts. In the Homes for Life studies, the sessions were clearly divided into the first part of video watching and the second part, the discussion. With HawkEye, both events were intertwined as information only became available over time and participants ‘caught up’ with what they needed to know as the story unfolded. Through the timing of the session, participants received new information every three minutes, which structured both their quest for information, but also their discussion. As I already outlined in section 9.4.2 Scaffolding the Process, the way the artefact is presented and data is collected has an impact on the type of discussions it triggers, which presents itself as an interesting area for research. Nonetheless, I would not argue that one led to more useful results than others, as they all triggered a rich, personal and nuanced discussion.

Participants referred to the impact the constant engagement through the new receipts had on them. While the timing might have been at times counter-productive, it also increased engagement as it led to curiosity and therefore an element of tension in the participants. While the activity of handling the artefacts was to some extent considered mundane by the participants, they showed few signs of a lack of engagement during the activity.

HawkEye leaves out a wide range of experiences that caregiving entails, especially physical ones. Even though it hints at some aspects, e.g. force feeding that might be enabled when the nutrition module was set to 4, participants were still removed from the actual activity itself. While this is inherent to the physical distance and remoteness of the scenario, HawkEye could be considered more sanitized than the original Homes for Life scenario, which emphasised aspects such as intimacy, family conflict or death in the scenario. The intangible nature of the story made it easy to raise such topics and for participants to engage with them. At this point we can only speculate that the increased engagement with the tangible artefact might have made these issues harder for participants to engage with, but this poses a challenging new area for research.
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10.5. Conclusion

Using HawkEye enabled a comparably rich and nuanced discussion to using Homes for Life, which foregrounded participants’ values, hopes and fears about caregiving. Participants who were actively engaged as experts and brought in to evaluate the experience, were still drawn in by the probe and discussed the topic in an engaged and personal manner. The ambiguity of the artefact nonetheless left room for critical analysis. While both design fiction probes share many similarities, this study reveals that the focus shifted through the direct experience, which poses questions about how design fiction probes can be used to control topics.

In the last three chapters, I presented a series of studies that share similarities with the lab approach to design research. All three were undertaken in a controlled setting, in the sense that all participants were in the same environment as compared to for example a video shared over the internet. Even though few quantitative measures were taken, especially the two studies with the Homes for Life video were done with comparison and juxtaposition as a means to contrast and compare and thereby qualify and classify the results. These measures – and therefore deviations from the lab approach as described by Koskinen et al. [2011] – were a necessary response to my research question and the exploratory nature of the research. In contrast to e.g. Joep Frens’ experiments with the rich interactions camera, the studies here were needed to establish and explore the criteria which were to measure. The studies therefore go a large means towards understanding how participants respond to design fictions and therefore towards the understanding how they can be used in lab research in general. The results indicate that responses might be more strongly based in the individual experience of the audience, but also that they might be a successful means to foreground values through emotional responses. Future studies might be needed to establish whether responses to design fiction could be measured in more traditional settings.

Even though participants showed individual responses to the artefacts, they encountered it in an artificial setting, which might have limited their ability to imagine themselves in the situation. In the next chapter I describe the use and evaluation of HawkEye in the field, i.e. in a three-week deployment in participants’ houses.
Chapter 11. In the Field

In this chapter, I:

- Describe the field approach to design research
- Differentiate between written and tangible design fictions
- Present design fictions as a tool not only to elicit, but also to shape discourse

11.1. Understanding the Field Approach

As I have shown in the last chapters, design fiction can be a useful tool to elicit discussion as data in the lab. By doing so, I further placed design fiction under scrutiny and traced back how participants responded to it. While these studies have already revealed new perspectives on technologies for dementia care, these insights have been gathered in a lab setting, away from the home and other places where the technologies might be used. The design fiction videos of ‘Homes for Life’ provide descriptions of everyday events and context of use that were derived through a range of different studies, such as probes with experts and a self-study. The videos were used to elicit empathic discussions that went beyond the workings of the technologies themselves. Nonetheless, participants only encountered the design fiction in artificial settings, not their everyday experience. Whether everyday factors would have an impact on the way the artefact is understood still have to be explored.

Koskinen et al. [2011] included a third strand in their Constructive Design Research framework that addressed the question of how the impact of design in society can be traced and analysed: through research in the field. In the lab research deliberately reduces the natural context to focus on one specific aspect, while research in the field – a term borrowed from social science research – deliberately gives up control by observing their study object in a less controlled, but more natural environment. Adapted from ethnographic fieldwork, field research in design is concerned with the everyday, mundane experiences. While both showroom and field aim to take designs out of the lab, showroom aims for the elated spaces of the gallery or design book, in which the focus can be on the artefact, while field aims for the mundane
and the everyday experience [Koskinen et al. 2008]. Design fiction artefacts, such as videos by the design studio Superflux [Superflux 2015] are often presented in the ‘wild’ i.e. they are available to everyone over popular platforms on the internet. However, this is not done in the empirical framework of both lab and field research, in which the designed object is mainly a tool to gather data, as responses are rarely collated and analyzed. Comparable artefacts, such as the “material speculations” from Wakkary et al. [2015] are comparably closer to showroom research than the empirical approach of lab and field. Nonetheless, situated use, i.e. the deployment of an artefact, is often at the heart of this type of research. Increasingly, design fiction goes beyond presenting narratives in various media, such as stories or videos, towards a more situated, immersive [McVeigh-Schultz et al. 2018; Skirpan et al. 2018] or even embodied [Rozendaal et al. 2016] experience as I outlined in section 3.6.2 Embodied, Immersive Futures of the literature review. Many of these take part in staged encounters, such as events and exhibitions. While this may be suitable for many of the interactions presented above, care is a personal and intimate experience that is often placed in the home. “Speculative enactments” as defined by Elsden et al. [2017] for example enable participants to experience future technologies, but these are spectacles, outside of the mundane, everyday experience.

For design fictions, this poses a challenge as these are often concerned with technologies that do not yet exist. Many types of probes have been developed to elicit diverse types of responses as I outlined in section 3.7.2 Data Collection of the literature review. Many of the prototypes are deliberately poetic and ambiguous (see e.g. the drift table described in [Gaver et al. 2004b]), few have included a world-building element or a narrative, that explained their presence in participant’s live. Design fiction offers the ability to create a story-world around themselves as well as providing a narrative, which as I have outlined in Chapter 8 In the Lab supports participants to discuss them as they were real. In the following study I explore whether this effect can be taken out of the lab and allow for an even deeper immersion in the field.

To learn how participants make sense of design fiction that they encounter more situated in their everyday life, myself and Renee Noortman developed a design fiction artefact that could be employed in participant’s homes. In this chapter I describe their responses in a three-week deployment study.
11.2. The Deployment of HawkEye in the Field

11.2.1. Introduction

In the last chapters I presented a range of studies in which I shared design fiction artefacts with participants in controlled environments. This showed how the participants would make sense out of the artefact and which types of insights can be gathered through this. While the results have shown that the artefacts were useful to elicit rich data, that was grounded in participants’ experience and values, the study still shares the limitations of lab studies, that data collection took part removed from participants’ everyday life. Building on the concept of design research in the field as outlined above, I here present a follow-up study in which design fictions presented through physical artefacts were deployed in participants’ homes. In addition to giving insights into the situated nature of experiencing potential future technologies, this poses questions about the medium and materiality of design fiction.

11.2.2. Method

11.2.2.1. Design

During this study a design fiction probe was employed in eight participants’ homes for three weeks each, followed by interviews with participants individually.

11.2.2.2. Participants

<table>
<thead>
<tr>
<th>P#</th>
<th>Country</th>
<th>Experience with Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>UK</td>
<td>Design/research work around dementia</td>
</tr>
<tr>
<td>P2</td>
<td>UK</td>
<td>HCI researcher with personal experience of caring for someone with dementia</td>
</tr>
<tr>
<td>P3</td>
<td>UK</td>
<td>Design/research work around dementia</td>
</tr>
<tr>
<td>P4</td>
<td>UK</td>
<td>Design/research work around dementia</td>
</tr>
<tr>
<td>P5</td>
<td>NL</td>
<td>Personal experience of caring for someone with dementia and volunteer in dementia initiatives</td>
</tr>
<tr>
<td>P6</td>
<td>NL</td>
<td>Design/research work around dementia</td>
</tr>
<tr>
<td>P7</td>
<td>NL</td>
<td>Professional experience of caring for someone with dementia</td>
</tr>
<tr>
<td>P8</td>
<td>NL</td>
<td>Design/research work around dementia and personal experience of caring for someone with dementia</td>
</tr>
</tbody>
</table>

Table 4: Participants demographics and experience

Participants were recruited through my and Renee Noortman’s social networks, both online and offline. Participants were selected to have some knowledge about
dementia, either personally, through caregiving experience or professionally through caregiving or research on dementia.

While nine participants originally agreed to take part in the study, one participant dropped out directly after receiving the probe as they considered participation to be potentially too distressing due to personal experiences with dementia.

11.2.2.3. Materials
For this study, Renee Noortman crafted the HawkEye tangible probe, which builds on the Homes for Life story presented in 7.2 The Artefacts. The probe contained a tangible control panel for a smart home that enables the participants to control the home of ‘Annie’, a fictional character who lives with dementia. The probe package also contained a welcome letter that introduced the fictional company that produced the package and crafted the narrative of why the participant was in charge of Annie. It furthermore contained an information booklet for the participant that explained the control panel and how it influenced the house as well as a participant file, which could be used by the participants for notetaking (see section 7.2.4.2 HawkEye: a Tangible Probe for a full description of the probe).

11.2.2.4. Procedure
Participants were fully briefed about the study in an information sheet first, and were told that the story presented to them in the study was fictional. A couple of days later, they received a parcel with the HawkEye materials via mail. Instructions about the artefact were provided in the parcel. Participants had a number to contact Renee Noortman in case of technical difficulties, which only one participant used. After three weeks Renee Noortman contacted the participants and scheduled an interview. The interviews were conducted by Renee Noortman and transcribed after. Renee Noortman did an initial analysis for her coursework, which has been published in [Noortman et al. 2019].

11.2.2.5. Analysis
Data collection took part in in English for participants in the UK and in Dutch for participants who took part in the Netherlands. The Dutch responses were translated into English for my analysis. Due to this discrepancy I refrained from the mixed thematic and discourse driven approach I outlined in the last chapters. Instead I used a thematic approach only, inspired by Braun and Clarke [2006], for which I
iteratively coded the transcripts I received from Renee Noortman in an exploratory way. In a first round I read through the material, i.e. the interview transcripts, the transcripts of the diaries and the transcripts on an unboxing video one participants provided, and took notes on outstanding passages. It was during this phase that I decided not to build on the coding scheme developed for the preceding studies as the results were too different in content and style. Instead I developed a new coding scheme during a first round of analysis, which was then refined during memo writing. Through writing and mind-maps the initial codes were grouped into themes which were then written up for analysis. Discussions between members of the research group throughout were used to resolve issues and decide on codes and themes.

Analysis was not only done after the data collection ended in both countries, but also after the results of study 4 and 5 were done. The results were compared to learn how the results of this field research differ from and expand on the results of the lab study.

11.2.3. Results
In contrast to the study presented in Chapter 9 Evaluation of HawkEye with HCI Experts, I was not able to follow participants’ interaction with the design fiction probe in real time in this study, but instead learned about their experience in follow-up interviews after the deployment ended. The entries participants wrote during the study in the resident file helped me to learn more about their decision-making throughout. The results section is structured into three parts; first I present the views participants revealed about technology in caregiving by tracing back the impact the artefact had on their decision-making, before second, describing the role of the artefact in the study. Third, I reflect on the situated nature of the research and how that influenced the sense-making process over time. Quotes that have been translated from the original Dutch are highlighted by a * after the participant number, e.g. P6*.

11.2.3.1. Material Care
HawkEye is a fictional company that comes to life through a series of artefacts. In this section I trace back the way in which the artefact shaped participants’ experience. This is done especially in contrast to the other ways in which the Homes for Life narrative was presented to participants in the earlier studies presented in
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this thesis (see Chapter 8 In the Lab). Participants were engaged with the artefact throughout and I outline how that is linked to the level of detail in the narrative we provided them with. While the probe itself consisted of a range of materials (control panel, welcome letter, information brochure, resident file, see 7.2.4.2 HawkEye: a Tangible Probe for more detail), the fiction included two main elements: the company, called HawkEye, and Annie, the fictional character who participants cared for. The role of the artefacts from the view of the designers was to bring these two elements to life for the participants, i.e. to develop artefacts that could plausibly represent these two entities. Here I focus on the elements of craft and detail and their importance to achieve this task.

11.2.3.1.1. Appearance & Engagement

The way the artefacts were crafted led participants to engage throughout the whole duration of the deployment. Many participants commented on the appearance of the artefact and how it influenced their perception of the study as a whole. Participants frequently referred to the artefact as “nice” (P1, P3, P6*). More specifically, they commented on the appearance of the “little booklet” (P1) or the way in which the parcel was packaged (P7) as something they wanted to highlight. In addition to complementing the design, e.g. as “really fantastic” (P1) or as something they “love” (P3), one participant commented on the craft of the artefact and stated that it “felt like it’s really well put together” (P3). Without prompting, P1 made an ‘unboxing video’ when they received the parcel and recorded their first responses to each item. They complimented the appearance throughout and their summary highlighted that the appearance of the artefact had a positive effect on the perception of the study: “Okay, all right… So far my impressions that … yeah, I am very interested actually … you really … It’s really exciting, its … just the entire thing is so bizarre I find it [leaf through the materials] I don’t know I find it exciting, I am really excited to actually read through the volunteer information brochure and get my first receipt” (P1). The appearance triggered participants’ interest to engage with the study. But the professional appearance that was projected through the artefact also had another impact on the perception of the study: plausibility.

Participants described the way the probe was designed as professional, which had a strong impact on the way they perceived HawkEye and Annie. Many participants described the appearance of the box that contained the physical artefacts of the
design fiction as “professional” (P2, P4) or “official” (P7*). When unpacking the device P1 contrasted the device with other study prototypes and concluded: “So far everything that has been made it feels very professional erm, like almost industry it does not feel like a research programme”. Details beyond the artefacts themselves, such as giving an address where the company was based (P1) or providing an email address (P1, P2) added to the impression that it was real and led participants to feel “immersed” (P1). One participant even “almost felt tempted to go on Wikipedia and search” (P2), indicating that they were questioning whether the artefacts were fictional. Another participant reflected that it was the “personal style” (P5*) in which the information was given made the design fiction feel plausible to them, even though they were aware that details, such as that there are “that many hundred houses” from the company were all made up. The style of the artefacts had an impact on the way participants perceived them.

Some participants started to reflect on the values they projected to the company through the materials that were provided, e.g. when analysing the logo’s impact. P2 explained that they “liked how the logo looks like an eye but almost like a flower, so it’s quite friendly and not like ‘yes, I’m spying on you, I’m monitoring you’ but in a nice way rather than in a creepy way”. While few participants went beyond describing the artefacts in neutral terms, their appearance had an impact and communicated company values. In this instance the artefact was read and interpreted like any non-fictional design object. In contrast to a technology probe that is more deliberately ambivalent, participants found it useful that a rich description filled the narrative of the design fiction. It enabled them to immerse themselves in the study.

11.2.3.1.2. Future & Fiction

This level of detail not only had an impact on the way participants experienced the design fiction, but also affected the way they perceived Annie. In their description, P1 linked elements that make up the company with those that describe Annie: “everything felt so realistic and so kind of, it felt very branded, like to actually have the company and even the little bits of information about Annie and the visitors that came, it did feel quite real, to me anyway”. P4 expands on this and explains that “the box itself is professional looking” which “helps with the immersiveness”, because it means: “the person that you’re dealing with feels like a real person as well so that was really good, yeah”. The level of detail that could be given to the whole design fiction through the tangible artefact that participants
received at home had an impact on the level to which they could emphasise with the fictional character.

Participants to some extent used the fact that Annie was made up as a means to distance themselves from Annie and their own decisions: “It felt quite uncomfortable in a way, that I could just influence her life by just changing a dial from 3 to 4. Yeah, it was quite a-obviously if it was like a real scenario you wouldn’t-you’d feel to uncomfortable doing it” (P1). P7* instead felt less uncomfortable “because Annie is fictive”, which made them think: “What I do is not real”. The references participants chose to make sense of their experience and describe it, also show that participants were not fully engaged, but distanced themselves to some extent. One participant described it as a “Black Mirror [Dark TV series in which fictional future scenarios are explored] type of situation” (P1) which not only places it into the realm of fiction, but also an experience that is consumed rather than interacted with. Other participants felt even more removed: “So you can’t really feel removed from it so you don’t really feel like there’s too much of a human aspect there. It’s almost more like a bit of a game sort of thing or something you’re just sort of monitoring” (P3). Another participant specifies the type of game and describes it as “some sort of Tamagotchi” (P6*) even though qualifying it with the addendum: “but then real”. But even though they were aware of the discrepancy between fact and fiction, most participants still sympathised with Annie and wanted to “try and help a lot with that so I wanted to change obviously her emotional state despite she is a fictional character. So yeah, I would say that I started to kind of empathise towards Annie” (P1). Even though one participant thought that they “should set them [the modules] to 4 because I am just curious what report I get back” (P8*), they refrained from doing so and even felt “guilty” even though it was all fictional. Only P4 on the last day “turned everything up to 4, because I wanted all the information. Which I know is, like, it’s more to do with feedback on how they were the previous day so just for the last day I wanted to see what happened so it was all on 4 but yeah”.

While the participant seemed to have had a strong interest in the data and the wish to get a full picture, they waited until the last possible opportunity to ‘break the rules’ and use the tool without consideration for Annie. While the study could not give ‘real’ insights into a care situation, results to a large extent reflect participants’ views and values, as if it were real.

Overall, the suspension of disbelief was strong in this study. Participants were briefed that the artefacts were fictional and were left with no doubt that neither Annie, nor HawkEye as a company existed. Nonetheless, the artefacts conjured up
such strong images, that most participants acted as if they were real. But participants also took the opportunity to reflect on how plausible or ‘real’ they considered the study to be. Participants for example described elements that were “obviously not true” (P6*), e.g. they considered the suggestion that a smart bracelet could examine blood without someone noticing unbelievable. Some of these elements, such as the aspect that food consumption could be measured and controlled were considered “not altogether realistic, but as a whole I find them very interesting” (P5*) or that the “smart cooking interfaces … offered many possibilities” (P6*). Overall, participants expressed many expectations or fears about technology when reflecting on what was plausible or possible.

Some participants qualified their responses how they related to the scenario by stating that not all technologies were plausible now, but some might be in future. P3 considered the technology to “be beyond what we have at the moment”, but speculated that “maybe in like 10 years that could be, sort of, a reality, I guess”. Other participants did not consider the time frame, but evaluated specific technologies. P4 for example mentioned the items they considered plausible: “I think it was quite, like, futuristic so yes, certain measurements around the house you could believe like the weight measurement and monitoring certain bio markers and that kind of thing. I think there were some things, I liked a few and thought 'oh, that's a good idea' and maybe even having a visual aid for the communication and that kind of thing. Yes, so I think some things probably, like the technology- I don't know actually, I don't know how easy it is to test, like, bio markers and like, fat percentages on the person without it being more invasive. So in general I believe most of this stuff will be something you could do- something you could implement in a smart home, yeah”. They went on to say that “I don't see why not – why you wouldn't have one of these smart homes in the future I think that would be believable”. This participant had a positive attitude to the future of technology and “hope[s] it’s something like this”. Others were more likely to mention what they considered unrealistic, especially the medication in the water was highlighted. P7* asked themselves, whether “can this [happen] in future?”. They reflected that this “was against the law”. They also questioned whether it was “realistic” that “everywhere cameras hang”, especially in the house of a “granny”, who does not know herself, “where she lives, where the bedroom is and how she is” (P7*). As these examples show participants not only questioned whether these technologies could exist, but also whether they should exist.
Even though participants considered the artefact to be well-made and commented that they liked the appearance, some had problems with the printer. Six out of the eight participants experienced problems with the printer or the receipts not coming out of the machine properly. Problems went from small inconveniences when there “was an actual technical glitch in the sense that the paper got stuck” (P2) to moments in which the printer had shifted during transport, e.g. “turned upside down” (P1) or “twisted around so it was facing the wrong way” (P2) which meant that participants took the machine apart to fix the problems. While for these participants the technical problems did not have had an impact on the enjoyment of the control panel, others started to question the functionality of the machine. One participant considered the artefact to be “nice” (P6*), but wondered “why is it a printer?” and further suggested that the information could be sent for example via text message. Their response was based not only on the experience that the printer caused troubles, but also that this would limit their workload to take part in the study as they would have to take fewer notes. P5 saw a similar discrepancy between the simple appearance of the control panel and the advanced technology of the whole system and suggested that the system might have a screen instead. While the physicality of the object and the aesthetic appearance of the material drew participants in and supported their engagement over the three weeks of the deployment, participants nonetheless were interested in more common technologies, especially if they would provide more convenience. The artefact was not perfect as these quotes suggest and the experience not without conflict. Nonetheless, the suspension of disbelief was strong enough for participants to stay in the fiction – even though it led to critical engagement with all aspects of the technology. Participants not only questioned what Annie had in her house, but also what they were provided with.

11.2.3.1.3. Tangible Probes & Practicalities

Through the tangible object of the control panel, the experience of caring for Annie was situated in participants’ homes. Participants noticed that the panel was a “stationary object” and therefore experienced a connection with Annie: “because your house and their house are sort of tied together” (P3). This ‘bond’ was strengthened for some participants through the routine that developed as receipts arrived every day at the same time. It led participants to develop a routine or bind it to specific events: “you know; it was kind of on my mind. I mean, obviously not all the time but I’d be thinking ‘Oh when I get home I need to, obviously, see how Annie’s doing and it was kind of- her day almost fit
with my day in a way” (P1). The control panel was set to print out the daily receipt every day at the same time, which was set at the moment when participants plugged it in the first time. Participants saw this as a sign that it worked: “Technically it went well, I mean every day at a fixed time” (P5*). The empathy participants felt towards the fictional character was not only built up through the information given about Annie, but also through the regular interaction that happened throughout the duration of the study.

Because of that, most participants experienced the device as problematic or “kind of hard to use” (P3) when going away, because they would miss the reports. Participants found different ways to deal with the situation. One participant took the control panel with them on holiday, which even led them to think about Annie as a member of the group and declare that “we are actually with 11 people on holiday” (P6*). Another participant declared that they adjusted the settings to ensure that Annie had all the support possible while they were not around: “and then in the two occasions I left it was me wanting to ensure that she had more support than what she currently had. So the first time I put everything to three and the second time I put everything to four” (P2).

Participants chose different levels of action to deal with the fact that the device – and therefore the care - was bound to the house.

In addition to these events, the long-term deployment gave insights into participants’ behaviour beyond the everyday use. Practical aspects had to be organised, such as the distribution of the tangible probe. One participant gave the example of how the parcel stood with the neighbours for a week, because they were not around for them to pick it up (P7*). P6* “took it with her a lot” and took an “extra bag for Annie”, wishing the control panel was smaller and thought that “No, you need to be very careful with Annie” when packing it into their car. Instead of exploring the interactions with the design fiction probe in a controlled lab setting, this led participants to reflect on their responsibilities towards Annie in “non-routine events” ([O’Kane et al. 2014], see also Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies).

The situated nature of the artefact meant that it was easily visible to others who shared a space with the participants, e.g. for the short term when they visited (P7*), went away on holiday with P6* and Annie, but also in the long-term e.g. as P2 shared the home with a partner. The physical nature of the control panel led to
conversations about the study. These conversations did not seem to have been in the abstract, but emotionally led, inviting participants to reflect on their relationship. P7* for example refers to an instance in which a friend asked “What is this?” about the control panel to which they responded: “Yes, I care for Annie” and further explained that “she is a granny and I care for her”. Comparably, P2 explains that their partner did not feel “ownership or responsibility” and did not approach the control panel or the receipts on their own, but instead pointed P2 to it, when “I’d come back from work and he was home all day and he said ‘Oh, check Annie’s report, it came out! Oh, what have you done! Is she going to be okay? Did she die?’” (P2). Even in these instances, the study was not discussed in the abstract, but the fiction of Annie was upheld. The materiality of the artefacts meant that participants engaged actively with the control panel as a visual reminder of their tasks and to varying degrees tried to fit the probe into their changing everyday lives.

In this section I drew on the interviews, entries to the resident file and the unboxing video to describe the impact the artefact had on the way participants engaged with the study. I have shown that the level of detail and the professional appearance of the probe was not only a useful tool to trigger participant engagement at the beginning, but also had a strong impact on the suspension of disbelief that led to engagement throughout the whole deployment. The professional appearance of the artefact enabled participants to not think about the study, but to engage with the fiction as if it were real. By doing so it highlighted values and views participants held when aspects broke down for them. In the next section I move beyond the physical artefact and towards the data that participants received to bring Annie to life.

11.2.3.2. Mediated Care
In this design fiction participants cared for Annie, a character they never physically met or interacted with directly. Interaction was done solely through the control panel that gave participants’ a daily report on Annie’s behaviour, mood and environment and also gave participants the ability to change settings in the house and impact on Annie’s life. In this section I describe how this influenced participants’ experience of care. I focus on the way participants dealt with missing or ambiguous data to shape their roles as caregivers and how it led them to reflect on the technologies at hand.
11.2.3.2.1. Mediation & Immersion

Many participants stayed in the fiction and referred to ‘Annie’ and ‘her’ throughout the study, instead of talking more generally about e.g. data. Many participants substituted the data they received through the system with life and emphasized with Annie: “When she was 0 minutes outside, then I thought ‘oh poor Annie, head out and get yourself some sunlight’” (P7*). Only one participant considered their experience with Annie to be limited, which was due to the means of communication: “I wouldn’t say immerse myself in the scenario because as I was saying before, the only interaction I would have with Annie and her house would just be the little summary sort of thing that I would get and- so it’s kind of- it doesn’t really immerse yourself in it and the rest of it is kind of updates and current intake of medication and that sort of thing so, I mean, that could be anybody really” (P3).

Participants frequently noted the wish to contact Annie to learn more. Participants felt at times that they needed more information than the system could give them. P2 for example asked: “I don’t know what to do, can I call her? I don’t know what to change to make her happy”. P6* wanted to call to “see how it actually is with someone”. The wish to contact Annie here could be considered a strategy to deal with the ambiguity of the information the system provided.

Participants considered some of the data they received about Annie lacking or contradictory. One of the strategies to deal with this perceived lack was to ‘fill in the gaps’ with their own imagination. This was done in small instances e.g. when noting down that “Stephen”, “a relative” (P5*) stopped by, when the system only mentioned a caller or in the larger picture “imagining Annie in her home or in her room” (P4). This enabled them to “make decisions with an emotional kind of feeling” (P4). But it also let participants imagine how the technology might actually hinder Annie, e.g. when asking whether the person who was not allowed into the house was “an old friend, whom Annie does not recognize anymore but who was also looking for contact” (P6*).

The ambiguity of the data gave participants the space to interpret the information the design fiction gave them in their own way. As such they became active creators themselves.

While participants were mainly forgiving about hardware failures, such as the printer not working, they were more thoughtful about the data they received and what happened when the system failed. Some of these instances were classified as technical glitches by participants, who nonetheless questioned whether it was
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intentional: “There were some glitches with the device which I wonder if they were intentionally designed into the interaction or it is was just a tech issue” (P2). The question whether it was “purposely done or something in the software” (P1) led participants to “treat it like I couldn’t trust the system” (P1). Some participants reflected on the fact of how much they relied on the information from the house or control panel. As data was missing at some instances, P2 started to reflect on the experience: “And it made me realise how dependent I was on HawkEye to make this work”. P8* in addition was hesitant to set the modules to the highest level 4, because “then you have no say over it”. Participants themselves felt at times out of control of the situation, which was likely due to the data they received.

11.2.3.2.2. Control & Quantification

Two main reasons were behind the contradictions participants perceived: the type of information given and the physical make-up of the control panel. The information on the receipt was two-fold: first, it contained a short paragraph about Annie’s day, before second showing a list of values for each module that was set beyond a specific level (2 or 3 depending on the module). Participants perceived contradictions between the two: “there were lots of times when I started thinking like ‘is the system trying to contradict what the paragraphs are saying?’ So sometimes it’d say the module needs to be like level 3, but it really didn’t need to be influenced because I knew she was taking sort of like her medication” (P1). Mostly related to the way they were created, the dials caused some of the instances in which participants perceived contradictions. The dials at times registered a different stage than was visible from the outside. Therefore, the system logged a different setting and made unsuitable recommendations. Participants e.g. received the advice to set the identification to 2, “but it stood on 2 and then I have increased it to 3” (P5*). This participant commented on the lack of feedback from the dial that did not “klik” (P5*) when a new level was reached, which left them guessing whether they had actually changed the setting. While these events were perceived as contradictions by participants they seemed to have made less of an impact than the complete lack of data as it led to less speculation of how it was caused.

But participants also questioned the system when it was working correctly, especially the impact the quantification had on Annie’s life – and on their role as caregivers. One of the aspects participants needed to make sense of when they
received the design fiction probe were the different modules and the range of levels to which it could be set. One participant considered it “really helpful” to have Annie’s behaviour broken down into different levels, but immediately qualified that “obviously communication doesn’t break into, like, four sections in a way. It would probably a bit further than that” (P1). One participant criticised that there were only four steps, rather than e.g. “1 out of 10” (P8*) which they considered not fine-grained enough, because they considered steps too intense. They discussed at another point in the interview that they would have preferred to be able to set it to “2.5”. Another participant wondered how specific aspects, especially emotions could be quantified: “it’s like how do you define her emotional state, like saying like she’s 39% happy today” (P1). They go on to ask: “What does that even mean, is that good, is that bad?” The understanding was not intuitive, but had to be learned and made sense of. In addition to questioning the specifics with which Annie’s life was represented, participants also discussed whether this was the right type of intervention and care in the first place and whether it enabled them to take the right steps.

P8* placed the quantification into the wider societal perspective and warned of the danger that people might worry too much about “statistics” without considering the “context and situation of this specific individual” in care. Participants thought about the role of technology in relation to human care-giving, the “human personal touch” (P1). Many participants had the impression that their communication was ‘filtered’ through the technology as a gatekeeper and in some instances this made participants realise the importance of the “human contact” (P7*). While they could see “that the care company might be easier inclined to replace a human with a machine”, they concluded that the technology should not be used “as a replacement of the human, but more as support” (P7*). P2 argued that a solution could be to “force you to either talk to the caretaker or the doctor or the neighbour or the person themself, or a combination of them, to make sure that you can’t change them unless there is a constant monitoring”. Participants easily imagined the technology not as a stand-alone solution, but as a means within a socio-technical system.
11.2.3.2.3. Role & Meaning of Care

When considering their role, participants made different distinctions of what was important to them as a caregiver, as shown for example though their responses to the suggestions on the receipts. To prompt participants, the receipts would on some days contain suggestions to raise the level of a module. Reducing the level was never suggested. Overall, 13 suggestions were given, two or three for each module. Figure 18 shows the settings as suggested on the receipts.

Many participants commented on the suggestions and indicated that they influenced them: “and then I’ve been gradually increasing them as the machine’s been telling me to do so” (P3). In some instances, participants considered their caregiving task “clear”, because they were given suggestions which they followed (P5*). This participant also explained that they followed the suggestions throughout when they found them “logical”, which was “most of the time” (P5*). P1 argues that they would take the suggestions “always into account”. But, all the settings entered by each participant differed from Figure 18, which shows that their decisions were more personal than these responses suggest. When prompted in the interviews whether participants perceived differences between the modules, two types of ‘care’ emerged: those who took care of the body and health of Annie and those that cared for her wellbeing.
and quality of life. Each of these was linked to different modules and was impacted by different parts of the fiction.

### 11.2.3.2.3.1. Bodily Health

Participants who cared for Annie’s (bodily) health found it easiest to adjust the medication and nutrition module. But as Figure 19 and Figure 20 show, this meant individual strategies, which in turn hinted at values behind their decision making. Figure 19 shows that P5 agreed to all the suggestions as the graph exactly follows the suggestions presented through the coloured area. P1 in contrast stays beyond the suggested values until day 14 at which they even exceed the suggestions. P2 stays within the suggested area for the first couple of days, but from day 10 onwards stays above the suggested module setting.

![Figure 19: Selected participants' changes to the medication module over the 21 days of deployment](image)

![Figure 20: Selected participants' changes to the nutrition module over the 21 days of deployment](image)

Food and medication were often grouped together in participants’ reflections, e.g.: “I think the medication and the nutrition ones- I never thought of this during the study but the medication in particular and maybe the nutrition ones, are ones where I thought things could really go wrong” (P2). These were important to some participants who stated that: “I obviously wanted her to eat and I obviously wanted her to take the medication” (P2). P8* also reflected that medication was relatively easy to change as it the decision was simple and closely related: “Annie does not take her pills, then I raise this up”. Participants
thought about “the food and medication ones” as “they seemed a lot more sort of necessary”, and as a result “when I was told to up those I wasn't really arguing that too much” (P3). P4 in contrast acknowledges that they might be problematic: “I could see how maybe turning the medication one, that might be a bit- because you’re taking it out of their control a little bit more”, but states that “for me it's wasn't such a tough decision to change that one”. P1 offered a different view, as they considered their impact on Annie: “Something like medication that had so much influence, I felt less comfortable changing that, compared to something where it was just knowing just a bit more information about who was seeing her and sort of just knowing a bit more about her actual emotional state, while something that would physically change Annie’s state” (P1). P6* also was concerned about technologies that could be activated through these modules, such as the force feeding or the smart bracelet that would test blood.

When reflecting on their role as caregivers, many participants mentioned that the device was – or could be – convenient. Nonetheless, this was not considered equally good or bad, but rather a “double-edged sword, really” (P3). While participants considered it “handy” (P7*) that care could be done from the distance, they also warned that this might encourage a more remote relationship as “they can do it all from home” (P7*), which would give them “flexibility” (P2). While they considered the technology useful to take care of everyday tasks, they did not consider it to be a “solution to quality of life” (P8*). In addition, this participant also reflected that “things get complicated quickly” (P8*) when thinking about the ethical problems, leading caregivers to ask questions, such as “Should I know that?” and “Do I need to know?”. Especially “practical things” (P8*) could be taken care off, for example: “Has she taken her pills” (P8*) or “it’s easier to help people who have a fall or medication not working” (P3). While participants acknowledged the advantage to “have one less thing to worry about” (P3), they also warned of unexpected consequences. While participants saw opportunities and dangers in caring for Annie’s bodily health, they also worried about her well-being.
11.2.3.2.3.2. Wellbeing

The communication module (see Figure 21) was considered to have the most impact on Annie’s wellbeing. The high value participants placed on communication in general might have been a factor in this, which could be seen by their wish to get in touch with Annie without the mediation: “But I found myself at moments really, especially at the beginning, really caring for- so my care, my elderly person is called Annie, and really caring about her and thinking ‘Oh, she’s lonely, I’ll give her a call, oh no wait, I can’t’” (P2). While the lack of contact did not necessarily break down the belief, it led participants to contrast it with “real life” in which they hoped, they “would live a little closer to Annie to be able to be there more often” (P5*). The lack of ability to contact Annie led to frustration in participants (P2, P8), who in return, considered the experience as “cold” or “remote and distant” (P3). Even though participants accepted that they had “a lot of responsibilities there”, they also felt like they “don’t really have any interaction with this person, because it is so remote” (P3). The participant went on to explain that “some sort of connection” could be achieved through the functionalities of the communication module that provides: “the other stuff in the actual scenario where you have more support kind of like the AI stuff and the phone you were getting sort of thing, that was kind of good stuff” (P3). Many participants contrasted the mediated care with human care and following the efficiency of the system with the well-being of the patient.

While P8* was concerned about the future of care “if there are not enough people”, they cared about the personal touch, such as “what is important in care is that you are occasionally hugged”, which included “a sort of humanity”. As a result, they concluded that technology might be useful in care, but more as a means to support caregivers than the people in need of care themselves. They suggested that the technology might be “mega helpful” to caregivers, by providing accurate information that the person with dementia might not be able to, especially “when they [caregivers] are not
trained” (P4). P7*, who was employed in care themselves, expands on this and explains means employed in the care to make people feel “at home as much as possible”, which made them “a bit sceptical about care robots” (P7): “love and attention”, such as addressing people with their first name, as well as “hugs”, “kisses” and “jokes”. They also classified technology as a “tool” (P7*). Another participant argued for a reframing of the problem, by not saying: “This is care and we make that technological” but rather “We enable people to live independently at home with technology and if that still doesn’t work we have care” (P6*). The responses show that participants saw benefits from the use of the technology, but aimed to get away from a techno-deterministic paradigm and towards an individual evaluation.

Participants qualified their responses about the usefulness of the system by emphasising the importance of human interaction: “Yeah, I wouldn’t want it to be in place of people going to visit and - like an AI being in place of human interaction” (P4). But these concerns are qualified by “it’s better than no interaction at all” (P4) and the consideration that “I know that any family that’s got like an elderly person with dementia that it’s really really tough and time consuming, so anything that can help in this way” (P4). The design fiction not only enabled participants to consider whether they accepted the technology, but even more so, enabled them to reflect under which circumstances it might be acceptable, or even preferable. The criticism went beyond the system as such, but included views on the wider societal impact. Reflecting on the communication module has been a useful trigger for reflection on the values behind care for participants. But not all saw the distinction between this module and the others as clear-cut.
Figure 22: Selected participants’ changes to the identification module over the 21 days of deployment

Figure 23: Selected participants’ changes to the location module over the 21 days of deployment

The identification and location module were based by Renee Noortman on the many technologies that aim to cater for the safety of people living with dementia (compare section 4.3 Technologies for Dementia Care). But this was not as clear for participants who grouped the remaining modules in varying ways. Figure 22 and Figure 23 show that the two remaining modules share a similar variability than all the others.

P3 and P8* considered “communication and identification” to be one category, while P1 reflected on “communication and location”. Some participants considered these to have less impact than the first two, because: “it was kind of just you receive more information about the resident’s life and she can stay that way” (P1) which made them feel “quite comfortable” about changing them. For some participants, they seemed to lend themselves more to experimentation, as P8* stated that “and most of all identification and communication have I played around with the most”, while P1 used it as an additional means for information: “So I’d look at the like, calorie intake and stuff but there were times when the system didn’t suggest it and I thought maybe knowing a bit more about her identification would help me understand what was going on” (P1). Others had reasons to avoid them, either because “they [communication and identification] seemed to be the more intrusive ones” or because “I found it a bit vague myself” (P7*). P7* developed the strategy to go by the systems’ suggestions for these modules, while P3 considered on a case-to-case
basis: “so I was like should I or shouldn’t I, that sort of thing, because they seemed to be the more intrusive ones”. P6* was concerned about people being locked out by the system, which they understood to potentially be detrimental to Annie’s wellbeing: “And also with identification, if some people are locked out, then I thought ‘Ok, I consider that to go too far’” (P6*). While nutrition and medication were seen as more essential, these modules seemed to appeal more to participants’ empathy with Annie: “I have raised the communication to 4 yesterday, because she was lonely” (P7*). While both participants’ responses and values towards these modules seem to be highly individual, the responses reveal that participants felt unclear how to interpret their role beyond the physical care for Annie.

Location for most participants seemed to have made less of an impact than the other modules as it was only rarely mentioned. P2 considered its negative consequences when reflecting on its evaluation of Annie’s abilities: “Like, if location were to tell me whenever she left the premises of the house. It’s almost like - or if the house was trying to not let her go out because they don’t trust her sense of direction” (P2). P6* in contrast had a much more nuanced view on the module, particularly as “I have heard about this myself”. As a result, they set location up to 4, because it meant that “at nights the doors are locked”. While the two participants got close to the same information about the modules, they interpreted in different ways based on their understanding and therefore adjusted the modules in a variety of ways.

In this section I presented how participants experienced care as it was mediated through the system. Participants reflected both on their individual role, but were also inspired to think about the wider implications of this type of technology. Nonetheless, participants did so in an empathic and personal manner. The daily receipts and suggestions not only enabled participants to define their role, but also to reflect on the type of intervention, the role technology took within this and how they felt about such technologies.

11.2.3.3. Situated Care
In this study participants were asked to take the role of a remote caregiver for someone they barely knew. Participants were provided with the tools to do so and information about their role. Beyond this information, there was no description of the role and participants had to interpret the role and make decisions on their own. I have shown in the last study, in section Chapter 10 Evaluation of HawkEye with
HCI Experts that participants interpreted their role differently, based on their own values and expectation. In this section I describe in more depth how participants developed that role. I base the results to a large extent on the notes participants left in the resident file as these give insights into their reasoning and questions during the deployment.

Participants were interviewed at the end of the deployment, but most also filled in the resident file, which gave insights into their decision-making throughout, as well as emphasising what was important to participants. Also, within the resident files could we observe the individual journey participants took. While the resident files included prompts of what to write, e.g.: “What are your thoughts on the resident’s wellbeing?” or “Did you make any changes to the modules? Why?”, participants were not further instructed of how to use the file. The notes show that most participants seemed to have been engaged with the task throughout the study. Most participants took down notes throughout the process, either in the resident file we provided for them or the receipts themselves. P8* was the only one from whom no notes were recorded. They offered no reason for this lack of engagement in the interview. P7* started with everyday notes, but stopped more or less after the first week. P4 in contrast only started on day 6, but then continued throughout the duration of the deployment. The diary entries underline the active role participants had in making sense of the data and shed light on participants’ struggles to do so.

11.2.3.3.1. Getting to Know Annie

When they received the tangible probe, participants fell into two groups of how they interacted with the material: those who prepared themselves e.g. by reading the available material and those who experimented. In addition, participants developed a range of strategies to learn and make decisions.

A first group read through the information (P1, P5), e.g. before installing the control panel (P7), or when changing the settings on the control panel (P6). Some participants highlighted that this was not a one-off event, but that it happened over time: “Gradually you get to know what information you get and it builds up a bit” (P6*). They particularly highlighted that the visual style (P3) or details such as the floor plan (P6) were useful to not only learn about the functionality of the house, but also to “got you thinking a little bit more before you turned the dials up, I think, which is good” (P3). The detail stimulated participants to “get a picture” (P6*) of the house, rather than
factual information and might in turn have influenced their immersion in the fiction and engagement with Annie.

A second group turned to experimentation to learn about the tangible probe, e.g. P4 explained that: “I was like, enthusiastic at the start, so I turned some of the modules up without kind of realising what I was doing, so later I then read that you would actually turn them up when you need to turn them up”. Beyond this initial exploration, participants turned up the module without being prompted as a means to help Annie out. P8 for example outlined that they noticed that “she [Annie] for example was unhappy and had not been outside” they decided to “set location one up”, because “maybe that might help”. Even though they emphasised that they wanted to help Annie, participants were open to explore and experiment with the tangible probe and to ‘learn on the job’.

This learning process did not take part in a lab or other controlled environment, but was situated in their everyday life and influenced by other events. Participants used the resident file to reflect on their behaviour and place their own life in relation to Annie’s. As a result, they provided additional context to their decision making. While most participants used the field titled “Did anything remarkable happen today?” to note down items from the text paragraph on Annie’s receipts, such as “Annie is having trouble navigating” (P3), one participant described elements that happened in their life, such as “Came back home” or recorded their thoughts towards the control panel: “I noticed the receipt printed and instantly engaged with it but also thought the box was recording me. I know it isn’t” (P2). This implies that participants not only reflected on Annie, but also on their behaviour, role and responsibilities. Some participants’ resident files mirrored the situated nature of the study as participants gave insights into their life – normally when it influenced their decision making. Participants for example described whether they were available, e.g. by stating that “I went to work. Long day” (P2) or “Was unavailable for the day to change” (P1). In addition to insights into their travel plans: e.g. “Bank holiday. Lots of catch up” (P2), or practicalities of the study: “A bit strange that I have to glue in this report … I expected more with such a high-tech application” (P5*), participants noted down when they had an emotional reaction that did not inspire any action: “Concerned about stumbling” (P3). Participants further took notes when adjusting the module, which fell into two categories: factual or explained. Factual entries only mentioned that a module had been changed, but not why: “Location > 4” (P3). Some added to the information by explaining why they had been changed. Participants noted down that the change had been “suggested to
me” (P1) or that they acted “on advice” (P6*). But they also explained some individual decisions, such as: “All modules > 4. Get more information on Annie’s welfare, help with her confusion” (P4). The resident file therefore gives an insight into participants’ rationalisations and decisions: “She is lonely but I don’t want to confuse her w/ increased communication” (P4). It shows that participants were not making abstract decisions, but instead aimed to act in Annie’s best interest.

Not all participants got their information solely from the study materials, but one participant also turned towards other people. P6* was active in engaging others in Annie’s care, e.g. by engaging them as experts, i.e. “friends, people who I think know something of this” or by asking for their opinion e.g. “Should we do this or is it too much?”. While they emphasise that these interactions were not planned, but occurred by happenstance, it shows an underlying need to learn more. Many participants were furthermore interested in the workings of the machine and caught up with questions about its workings after the official part of the interview had ended. These ranged from straightforward enquiries about its workings: “I have questions about how HawkEye works from a technical point of view” (P2) to more precise questions to the workings behind the artefact: “Now, is this all controlled by a computer, but there could as well be people who type it all into the receipts” (P7*). While participants’ expertise about the technology and what it could do varied, they shared a common interest about the workings of the design fiction. They were engaged throughout the study and waited until the moment when the interview ‘officially’ ended to satisfy their curiosity on how the fiction was actually upheld. Participants used a variety of ways to learn about Annie and develop strategies to engage with the task at hand. Nonetheless, they did so carefully and cautiously, in a manner that enabled them to stay in the fiction.

### 11.2.3.3.2. Personal Background

Participants drew on prior experience to make sense of the design fiction. Some of the participants had background knowledge about dementia. P4 explained that the way Annie behaved met their experience of what dementia is like: “I think she was—first of all she was believable I think with everything that was mentioned and the feedback she was believable that she was a real person. I think also seeing someone with dementia as well, you kind of—yes you can see a lot of similar characteristics in their behaviours and what they’re doing. So kind of both because of the information you’re given here and because of real life, yeah”. Two
participants argued that monitoring technologies do not meet the needs of people living with dementia well, because “sometimes technology just tries to push it a little bit too far in terms of not actually treating that person as a real person really” (P1), but also because people with dementia need “structure and order” as well as “love and attention” which would not be provided by technology (P7*). In contrast, one participant argued that their experience with dementia had taught them that “sometimes you have to make tough decisions” therefore for them it “wasn’t that hard to decide to turn up a module” (P4). P3 instead argued that “wandering”, a symptom of dementia, might not have to “be a bad thing” and therefore that the intervention through the technology might not be needed.

Beyond dementia, participants drew on their own experience to make sense of the data the design fiction provided. One participant argued that the experience quickly became “personal”, as they “get older [themselves] of course” (P5*). Participants further related through personal experience with dementia and therefore asked themselves when making decisions: “What should I do, if it were my mother or so” (P8*). Experiences were further influenced by other examples of relatives. P2’s mental model of the technology was influenced by their mother’s care for her grandmother: “So, my grandmother passed away in 2010 but she- the last few years she lived in a house that was within a- she lived in the US and there was this kind of village where every elderly had their own house but then they had a common house where they would go for meals and they'd have nurses and doctors on site available if they needed anything and I think there was a special internal phone that they could use to call someone or help or assistance and so I was imagining, like what if my mother had something like HawkEye monitor my grandmother”. These insights show that participants’ experiences were influenced by their knowledge and previous contacts not only with dementia, but also other people.

Two participants already had experience with the narrative through the Homes for Life story, either through reading the paper in which the story was presented or by taking part in a pilot study. They were able to reflect on some of the differences between being presented with a written scenario and the interactive HawkEye one. P8* perceived the experience in a different way, as on the one side “you have the interview story that you can relate to” but that “it is different to do it yourself”. P2 argued that the shift in perspective changed how they thought about the control panel and its wider implications: “When she read the story to me I was like ‘Oh no’, I was identifying with my grandmother and thinking about what happened with my parents and how one of my parents
would be really happy, my mom, and my dad would hate that kind of monitoring system. And I think it made me think—maybe Britta’s experiment, Britta’s study made me think more about my personal—how this would relate to my personal life and experience, whereas this made me more think in general of caring technologies for people who don’t have a lot of agency left in them, in a way. That sounds horrible. But, it made me immerse me into the experience of the video and thinking right, okay, so this is probably what that woman in the video is feeling like when she was taking care of her mother”. This quote shows a strong discrepancy between the two artefacts presented in this thesis and their responses. It indicates that this was not only due to the shift in artefact, but also due to the changed role of the participant. Building on their experiences with technology, participants had different ideas about the workings of the technology. Participants had different levels of experience with technology and therefore their expectations about the technology and its future opportunities varied. While it inspired one participant to think about “ideas of how, like, artificial intelligence might come into play in terms of, like, dementia” (P1), other participants thought about the technology in a more embodied way, such as “robots that give elderly people also a bit of company” (P5*). While this term might have been introduced by the researcher to explain the technology of the probe, as a “care robot” (P7*), participants had filled up the term with their own expectations and values. P7* declared that “you cannot let a robot wash someone”, but argued that “robot dogs” could be beneficial. The difference lies in the expectation of what care is and that the robot dogs or other companions constitute “some sort of entertainment, not really care” (P7). Their understanding of how the technology worked and how it would fit into the everyday led to reflections on the nature of care.

11.2.3.3.3. Understanding & Interpreting
Based in these differences in strategies and prior understanding, participants interpreted the data in different ways as can be seen in the way they described the process in the resident file. Many notes participants took are short snippets that appear factual at first. Nonetheless, they show what was important to participants, as they did often not take down the full information of the receipt, but highlighted one or two aspects: e.g. “Satisfied, but little sleep” (P6*). Others added to the information, by tracing back changes or straits. Some participants traced Annie’s development over a couple of days and for example noted that “Her walk was only 24m. Almost 1 hour less than Monday” (P1). Not only did participants’ notes differ as
to what was important to them, the entries suggest that they evaluated events differently. Participants received slightly different data as their module settings differed, but some entries can be traced back to the same event and show that they interpreted the data differently: “- Nutrition better. - Struggle on the phone though” (P1), “Upset at salesman after a call” (P3) or “a crazy caller” (P6*). Throughout the data participants’ active role can be observed through the way they interpreted and talked about the data they received. But participants also used the resident file more strategically as a means for communication and reflection.

The majority of notes show that participants were not just passively accepting the data, but instead questioned and interpreted it. When prompted: “What are your thoughts on the resident’s wellbeing?” many participants for example qualified their response by arguing how Annie ‘seemed’, rather than how she was. P1 for example argued that “Annie seems healthy. Went out for over an hour and found her way home” or P3 claimed that “No eating seems worrying”. These go beyond the factual statements about Annie’s behaviour, but instead contain participants’ interpretations about Annie’s state, e.g. when her state was appraised as “Very good” (P4) or “Reasonable” (P5). While these statements might have been influenced by the text of the receipts, they are an interpretation by the participants.

Reflections were triggered when the system did not work for participants, either through technical faults or when messages did not make sense to participants. Many of the entries show elements of sense-making when participants noted down their thoughts on items that appeared missing or did not physically work, such as the problems with the printer. Participants chose different strategies. P3 only noted down one instance that appeared problematic to them, when the system “stopped printing”. P4 did not seem to have evaluated the break downs, e.g. when information was lacking on the receipts as outstanding events as they did not felt compelled to make a note of them. The other participants more regularly noted down items that went wrong and either complained: “Not all info printed, therefore little context” (P6*) or “Too bad I can’t see the data!” (P2). Others described that the faults had an impact on their decision making: “Identification stands on 3. Advice is not right. System-fault? Module therefore NOT changed [emphasis in original]” (P5*). P4 and P6* did not seem to have evaluated the break downs, e.g. when information was lacking on the receipts as outstanding events as they did not feel compelled to make a note of them.
Even though participants questioned the system at points, the engagement with the story itself, did not break overall. Even when data was missing, participants speculated about facts unknown to them and thereby filled the story with life: “Maybe she is bored, it was a quiet day” (P6*). Participants further actively questioned the interpretations by the system, such as “Thinking Annie’s lonely? Maybe she enjoys some alone time” (P1). Participants further looked for their impact on Annie’s behaviour: “Seems Annie’s life is better since having more influence on communication” (P1). In addition, participants questioned themselves and their decisions: “Comm, not set well to 4, now leave it as is” (P6*). These insights indicate that the data was ambiguous enough for participants to fill in the gaps and interpret them. This in turn enabled participants to be critical of the technology.

Apart from P7*, all participants at some point used the resident file to note down instances for later considerations: “- needs her medication. Keep alert on this. Might get worse” (P1). Some of these were followed up later, e.g. P4 noted down on day 18: “I think it would be good to have more details on Annie’s well-being – I may increase all modules”, which they actually only followed up on day 20. Due to the time frame of the project, participants were able to not only make ad-hoc decisions, but also to observe and explore. The resident file supported the process by enabling participants to reflect on their behaviour. In some instances, participants used the file actively to pose questions they had, as a conversation partner. P2 for example asked: “Something is wrong? What can I do?”. P6* noted down that “maybe identification becomes an issue later?”. The entries into the diary show that participants aimed to make decisions in Annie’s best interest, but did not always feel well equipped to do so.

As time progressed therefore, participants’ experiences towards the study shifted. The emotion towards the suggestions also shifted over time. P1 felt their interest vanish: “I noticed that from the beginning I was more invested emotionally and after a while I kind of let the machine dictate what I needed to do and I lost that interest over time”. In contrast, P4 felt more emotionally involved as the project progressed: “It was definitely interesting, like the more it went through the more- first of all it was just this kind of like-interesting like okay, you can sort of see the effects and changes but then the more it was going on the more emotional it became because you had like feedback from the patient and actually you really wanted to change things for the better and as I was changing the modules more and more, and I was like "oh no, maybe they’re not doing very well" or something”. The advice given by
the system clearly had an impact on participants’ decision making, but their role in the process was nonetheless individual.

Decisions were partly situated, e.g.: “both times when I left, I put all the numbers up because I thought if something was happened, I want to make sure that there’s already extra support there because I am not here to adjust it” (P2). In other cases, participants reflected that they lacked information to act without the system’s suggestions: “Maybe sometimes a bit difficult to know if, so, for instance, if her calorie intake on that day was around 50%, then I’d even bump it up but if it was only on one or two I would have less information about her so it was always, sometimes a bit difficult to know when to bump it up if the actual system didn’t suggest it” (P1). Participants made individual decisions that were based in their background and understanding of the data. In addition, their decisions were based on their feelings towards Annie and the way in which they evaluated the modules.

The results presented in this section give rich and detailed insights into the experience participants had with the HawkEye probe. The results not only underline the insights from deploying the Homes for Life video about the variety in preferences, but even more show how participants interacted with the probe and which types of insights it generates. The results show that the detail provided in the story engaged participants in an empathic way, which not only elicited rich data, but also enabled participants to engage with the artefact with the understanding that it was not real, but nonetheless behave as if. This in turn led to insights into the quantification of health data, which was highly influenced by the interactivity of the design fiction probe that led participants to experience conflict in a safe environment. In addition, the results show that the deployment in participants’ homes led to increased and continued engagement that foregrounded many of the beliefs, understandings and values that participants held. In the following discussion I place the results not only into relation to insights about the technologies deployed, but also to related methods of data collection.

### 11.2.4. Discussion

For this study we deployed HawkEye in the field, i.e. in participant’s home environments. Results were generated through an analysis of the entries in the resident files, the logs of the control panels and follow up interviews, as well as the transcript of an unboxing video that one participant volunteered After a three-week deployment participants were interviewed about the experience. Control panel logs
and filled in diaries – the resident files – formed the basis for analysis. The results both underline the previous results that participants’ responses and opinions vary widely as well as the insight that participants are active partners of the sense-making process. But they further point towards differences between watching a design fiction and the long-term deployment presented here. This discussion is divided into three parts: first the relationship to other, non-speculative studies about dementia care, second the impact of the physical artefact and third the shift in perspective of the participants.

11.2.4.1. Wellbeing vs. Safety

The study results show that most participants built a strong relationship with Annie, the fictional character of the story. Participants frequently argued that they wanted to get in touch with her, imagined her life and cared about her well-being. They frequently explained their aim to do what was good for her, even though they did not share the same views on how to do it. The results indicate that participants saw a division between caring for the body and caring for her well-being beyond physical health, e.g. social life and happiness. Both of these approaches were inspired by the technologies provided, which in turn were inspired by products currently in development (see 4.3 Technologies for Dementia Care). But participants’ responses do not entirely reflect the current technology landscape. Many of the technologies in the house were not only engaged to support the resident, but also to keep Annie safe. As I outlined in section 4.5 Problems with Technology Design for Dementia Care, the previous engagement with caregivers has led to a strong focus on technologies developed to keep people living with dementia safe. This in turn has sparked an intense discussion about ethical concerns regarding these technologies. Even though some instances show that participants were concerned with Annie’s safety and for example raised the location module, so that she could not go out at night, it did not appear to be a main concern for most of them. This might be due to the lack of knowledge and dementia symptoms and therefore a lack of the understanding of what people with dementia might need.

Participants had varying levels of knowledge of caregiving which might have influenced their approach towards caregiving and their understanding of the dangers of dementia symptoms, but the results still show little explicit consideration of safety concerns from any of the participants. As participants were strongly
Chapter 11 In the Field

engaged throughout the study, it does not appear likely that they did not care about Annie’s safety. But participants with experience of dementia acknowledged that the system presented a convincing image of Annie. Therefore, the reason might lie in the way the focus was set in the materials.

HawkEye as a design fiction probe worked as a means to shift discourse from one commonly addressed problem to alternative ones. This might be useful to situations in which one position predominates, but other views or aspects of the problem might need exploration as well. Walsh [2007] for example describes the use of thought experiments in medicine. In this field they are used to move beyond common arguments and into a more nuanced discussion about sensitive issues such as abortion. When deployed over time, such as the HawkEye design fiction probe, this could be achieved not only by ‘making strange’, i.e. reframing the problem, but rather through a shift in perspective in which the major concern occurs less frequently.

Even though participants referred less to the safety and privacy of Annie, they nonetheless cared strongly about her autonomy. As with the other studies (see Chapter 8 In the Lab), the artefacts foregrounded participants’ values about care. The results show a comparable level of nuance in the responses. With its increasing level of interference in Annie’s life, the HawkEye control panel was a useful tool to gather insights into participants’ reasoning of what was acceptable to them. Both the interactivity of the device and the deployment over time proved useful to enable a rich reflection and discussion not in general terms, but on a case-by-case basis. Participants were enabled to individually and personally decide what they felt comfortable with, which stands in contrast to the Homes for Life study results (see section 8.2 The Use of Homes for Life in the Lab and Chapter 9 Evaluation of Homes for Life with Professionals). When watching a video together and discussing it, most participants felt open to share their views and opinions, but a consensus was generally sought. While this gave rich data and insights into the arguments and values underlying these decisions, it can be argued that the private contemplation led to an even more fine-grained understanding of the values surrounding the matter at hand. It poses questions about the type of data collection and how a discussion might be structured.
11.2.4.2. Fiction as Prop

In its written form design fiction is non-material. If artefacts are developed, they mainly serve as a vehicle to convey the fiction. This lack of emphasis on the material artefact distinguishes design fiction from other types of design, such as “industrial design” [Lindley 2015a:4]. As the results show, the material nature of the artefact had an impact on the way participants encountered the fiction. Here I discuss in more depth what role the artefact had in participants’ life.

Design fiction artefacts used as probes share similarities with technology probes. Like technology probes, they enable the collection of data ‘in-situ’, based on the understanding that the technology will not be neutral, but instead change participants’ behaviours and strategies [Hutchinson et al. 2003]. Hutchinson’s [2003:2] view that “on the technology side” the probe needs to “work in its intended setting” is debatable after this study. While a lot of effort has been put into the design and build of the probe to send a reliable product to participants, issues occurred. Some were more or less easily resolved by participants themselves, such as problems with the print-out. While this might be dependent on the user group – ours was mainly highly tech-literate – this could be understood as sense-making by the participants.

While it might be unsuitable in many instances to put unduly stress on participants, they should be understood as active users who might have an interest in trouble-shooting. The study results suggest that overcoming problems such as these can increase connection and engagement as we have seen little indication that it was a hindrance. Other issues, such as the lack of data, have proven useful to enable reflection on the participants’ side. This indicates that there is a space between the technology probes as understood by Hutchinson, and cultural probes, such as the Drift Table by Gaver et al. [2004b], which behave within commonly understood boundaries, but break with expectations and therefore pose questions about trust and reliability. Design fiction probes, with their often critical stance towards technology, suggest a useful way to bridge this gap.

HawkEye also shows similarities also with “breaching experiments” as described by Crabtree [2004]. Their evaluation of probing is similar to ours as the artefacts intervene in everyday life, even though they do not necessarily ‘disrupt’ as described by the original descriptions of breaching experiments (ibid.). In contrast to many critical design artefacts, HawkEye is hardly provocative, but it enabled deep and personal reflection by the participants, which in turn led to rich insights for the
researchers. The ‘critique’ or provocation of many of the critical design artefacts is replaced by ongoing and constant engagement. The differences in the way these artefacts are encountered here are relevant: critical design aims to provoke a response or reflection in a gallery space, a comparably short encounter, while a probe is responded to in many short intervals. This needs to be acknowledged, not only in the design of the design fiction probe, but also in its evaluation and distinction from more provocative artefacts.

The role of the artefact therefore went beyond what was often described as “intermediary” or “boundary” objects (see [Eckert and Boujut 2003] for an overview), e.g. when used in workshops or comparable. I consider the role of the artefact to be more that of an “endowed prop” [Howard et al. 2002]. As such it can be used by the participants to enact or play out the narrative, but also has the role of structuring and shaping the interaction, as “Without props, acting-out too easily becomes science fiction” [Howard et al. 2002:9]. In this study, participants responded to the artefact as if it were real, discussed what they found realistic and therefore how they interacted with the device. This was mainly due to the ambiguity in the design fiction probe. Gaver [2003] describes three different types of ambiguity: that of information, of context and of relationship. HawkEye gives a lot of information of the context, i.e. explains why the artefact has come to participants and what its background is. Nonetheless, through the technical glitches and quantified data, the information was not clear and participants found their own strategy to deal with the ambiguity of information. But even more so, participants had to discuss and explore their relationship with the artefact.

11.2.4.3. Reading vs. Interpreting

Building on humanist theory, Bardzell et al. [2014] describe a way to read critical artefacts. This suggests that signs and signifiers of the material artefact are read like words on a page. Participants’ responses to some degree show that they did this and for example analysed the logo of the company. But overall, the results show that participants were active in making up the story, filling in details and reasoning about the intention of the designer. While this includes the reading of the materials, it also contains strong elements of interpretation and sense-making. The results to some extent also show that participants used the artefact in different ways, i.e. to the extent with which they let Annie into their lives but also to the extent with which
they used it for self-reflection. Even more than the lab studies (see section 8.2 The Use of Homes for Life in the Lab and Chapter 9 Evaluation of Homes for Life with Professionals), this study shows that participants are active in the analysis, reading and interpretation of the artefact.

This stands in contrast to the opinion about critical design that was presented for example in Chapter 2 Understanding Critical Design, in which participants argued that criticality lies within the artefact itself or even in the intention of the designer. Both the intention of the designer and the relationship to cultural norms needs to be taken into account, but this study puts emphasis on the interactive nature of the design fiction probes. While most participants were critical of the proposed technology and felt empowered to argue against the parts they did not like, they also highlighted items they felt comfortable about or even wished for.

While it is clear that design fiction probes influence participants’ perception of topics and to some extent shape them, they are still ambiguous and interpretable. I therefore suggest a shift in language from the reading of critical artefacts to the interpretation of design fiction probes to acknowledge the active role of participants.

### 11.2.4.4. Roles

Participants took on the role of caring for Annie by making sense of the tasks at hand and their experience. To some extent, this act was collaborative, as participants responded to Annie’s behaviour and vice-versa. Nonetheless, the collaboration was at no point actively acknowledged, defined or discussed, as it was always mediated through the company HawkEye and their tools. Therefore, goals were open enough to be interpreted by participants themselves as I outlined in the results section. Here I discuss how this relates to real caregiving experiences.

Increasingly, technological solutions aim to address the collaborative and to some extent interdisciplinary nature of care. While solutions particular to dementia care exist (see e.g. [Huldtgren and Endter 2014; Mahmud et al. 2010; McGee-Lennon et al. 2011]), this field is still underrepresented as people living with dementia are often seen as unable to have a voice in their care. As a result, caregivers have to make a lot of decisions themselves, which adds to the burden of caregiving. Results of this nature, shown for example by Gibson et al. [2015] and Casas [2006] could also be observed in this study. While we missed the opportunity to develop an alternative
technology that overcomes current limitations, we seem to have been able to build a reflective tool that presents a suitable mirror to existing technologies to enable participants to reflect on many – even though not all – aspects of caregiving.

HawkEye does not touch on physical and bodily aspects of caregiving, through the remote set up. While this opens up the work to the criticism that we avoided the discourse about a complex and complicated matter of caregiving, it has been done in the understanding that a wide range of technologies are currently developed to enable remote caregiving (see e.g. [Hamada et al. 2009; Yasuda et al. 2009]). By pretending that there is no physical contact for three weeks, we have taken the approach to extremes, as the remote control is normally a supplement to local care, e.g. overnight [McCullagh et al. 2009] or while caregivers are working (see e.g. examples reported in [Gibson et al. 2015]).

Neither of the participants commented on the impact the technology might have had on Annie’s perception of home, even though has been observed that the introduction of care facilities might distort the perception of home [Dyck et al. 2005]. Few participants questioned whether it was preferable for Annie to stay at home like this. This indicates that participants lacked motivation to explore some aspects of Annie’s life and perception. But they nonetheless had an active image of Annie. Some of the aspects they reflected on or imagined hinted at Annie’s independence to either do things they could not observe or that she even did to remove herself from observation. This mirrors insights by Berridge [2015], who found similar patterns of behaviour by residents of an existing, though less sophisticated, assisted living facility in the US. Concluding from this, other aspects could have been made available or highlighted to participants, but overall they developed a round and immersive picture of Annie.

In addition to being remote, the data was highly quantified, which led to a range of reflections from the participants. To understand how participants made sense of the quantified data, the concept of “caring-through-data” as developed by Kaziunas et al. [2017] proves useful. It emphasises that “both care and data can mean many different things depending on the particulars of family, social contexts, life stages, etc” (ibid. 2269), which we also observed from this study. The authors further take a critical stance towards ‘technosolutionism’ of data which they argue might stand in contrast to care.
While it has been acknowledged that datafication in health is increasing, Ruckenstein and Schull [2017:262] argue that we need to learn how this practice “takes shape” through “rigorous accounts of the actual reality”. As participants in the study presented here in many aspects behaved as if the data – and the people involved – were real, it indicates that speculative methods might be a useful complement to insights into actual practices. While they might not be useful on a large, societal scale where such a make-believe might be too complex to uphold, it offers strong promises to be useful in the personal and intimate sphere e.g. of the home. The “Speculative Enactments” described by Elsdon et al. [2017] were set in comparably intimate settings, such as dating and weddings, while wider societal consequences are explored e.g. through written fiction, such as [Ylipulli et al. 2016]. Probing design fictions might be particular useful to explore and enact the personal, sensitive and intimate. The point of view viewers of design fiction hold might have an impact on this.

11.2.4.5. Point of View
The study presented here differs from those in the last chapters in two accounts: first the artefact, but second also the deployment during which participants played an active part in the story. This poses questions about the impact of the viewpoint on the understanding of the story and its narrative.

While participants took part in the story and shaped it, it was still pre-scripted. But, design fiction employed as a probe is not fixed. Indeed, Renee Noortman placed a lot of effort into make the story interactive and subjective to the individual’s experience. Elements were still connected as in a story or plot, e.g.: Participants changed the modules, therefore Annie’s behaviour changed (see also [Blythe 2017]). The story further lacked a deliberate turning point, but instead hinted at problems and conflicts and left it up to participants which of those they recognised as such. Another distinction further used is whether a fiction has a beginning, a middle and an end. In Homes for Life, the beginning lies at the decision making and acquisition of the house, the turning point is the death of the mother and the end point is the (open) question of what to do next with the house. In HawkEye the beginning is strongly emphasised when participants receive the probe, but it lacks a clear end. From this point of view, it could be argued whether HawkEye is a design fiction probe or rather something else, such as a technology probe. My position is that
even though it lacks a strong ending, the other elements of narrative are given – and this lack could easily be addressed in a future deployment.

Another view on design fiction is that it contains elements of world-building [Coulton et al. 2017]. This is clearly given through the elaborate backstory that explains how and why participants were chosen and how they end up with the tangible probe. While traditionally these elements are seen as contrasting, we followed Luu et al.’s [2018] assessment, that a combination of the two approaches can lead to a strong and compelling design fiction. While the active role of the participants does not seem to interact with the definition of design fiction, the question of viewpoint remains.

Annie, the fictional character of the HawkEye probe is more visible than the unnamed mother of the protagonist of the Homes for Life story. She was given a name, cute illustrations were included to bring her to life for the participants and the control panel gave out daily reports about her life. Nonetheless, the story was still not told from her point of view, but instead again from the point of view of the caregiver. This might have caused some of the limitations described in this discussion. Nonetheless, we observed differences in the way participants understood the design fiction probe and how that influenced their evaluation. P2, who was aware of both studies, probably offers the most reflective insights, when arguing that the Homes for Life story made her reflect more on the personal experience, while HawkEye led her to consider the societal perspective and impact of such technologies. This might have been due to the foregrounding of other parties, such as the company. Other participants, such as P8* who reflected on the role of e.g. health providers in this context, took a comparable societal stance. Homes for Life appears to have been more framed and understood as a case study, while HawkEye was more successful in projecting a world in which the artefacts were used commonly. The shift in perspective from viewer to active participants does not seem to have hindered this reframe. Even though reflections were personal, they were not limited to the personal experience. The situated nature of the study that for some participants involved bystanders and other interested parties might have had a similar effect.
11.3. Conclusion

In this chapter I described the field approach to design research. Following this theoretical discussion, I presented one study in which an artefact was deployed in the field, i.e. in participants’ homes over three weeks. The results underline the results from the lab studies that show that participants are active partners in the sense-making process and that results therefore are highly individual. In comparison to the results from the previous lab studies, the results show that participants’ engagement developed over time and that the shift in perspective led participants to pick up different topics. The results have shown that the professional appearance of the artefact played a large role in enabling participants to build up an emotional connection with the fictional character they cared for in the narrative of the fiction. This in turn ‘forced’ them to suspend disbelief and interact with the artefact as if it were real. Through this act of mediated care, the results have not only revealed further values of people’s fears and wishes towards smart home care, but also worked towards an understanding of the strengths and weaknesses of employing design fiction in the field.

This chapter concludes the second part of the thesis in which I presented and categorized design fiction artefacts that take part in sensitive settings. The Constructive Design Research framework by Koskinen et al. formed the basis for this evaluation. All the artefacts were derived from research presented in the first part of the thesis. In the coming chapter I summarize what has been learned both for technology use in sensitive settings as well as for design fiction.

Interlude: Homes for Death

Appendix IX
Chapter 12. Discussion & Conclusion

In this chapter, I:

- Summarize the types of insights gained through making and using design fiction artefacts
- Discuss the insights gained through using design fiction to engage with sensitive settings
- Discuss the insights gained about design fiction and place them in relation to research in HCI and in relation to research-through design
- Reflect on my role in the design process and about the role of the maker of design fictions more generally
- Present directions for future work derived from the research
- Conclude the thesis

This discussion chapter is divided into five parts: first I describe what types of insights I gained and how they relate. Second, I discuss what these results mean to the understanding of the use of design fiction in sensitive settings. Third I discuss what can be learned about design fiction through these insights. Fourth, I clarify my position within the different paradigms I touched upon in this thesis. Fifth, I describe the opportunities for future work that arose from this PhD work and conclude the thesis.

12.1. Types of Insights Gained

12.1.1. Making Design Fictions
As I outlined in Chapter 3 Understanding Design Fiction, design fictions differ strongly in the medium they are presented in, the people who are involved in their making and the way they are used. In the last chapters I outlined how design fictions can be used in design research and which types of insights can be gained through the variety of uses. In Chapter 7 In the Showroom I further outlined how the design fictions can be a contribution in themselves. But in addition, I included a range of research activities in the second part of the thesis that were useful to inspire and inform the design fictions I presented. One further contribution of this thesis
therefore lies in the reflections and insights of how each of these activities contributed to the design fictions.

Overall, the making of design fictions is rarely illustrated, let alone reflected on, in publications on the topic. One exception is collaborative writing which is often the focus point of the publication (e.g. [Nägele et al. 2018; Edwards et al. 2016; Tsekleves and Darby 2016]). It has therefore been mainly unclear what resources makers draw on to develop their fictions. This project adds to the understanding that the literature review was useful to highlight big ethical issues, the study with experts has helped to add nuance and the self-study has partly reframed the problem area and introduced an emotional layer by giving insights into the everyday of living with technologies under examination. This contribution is a useful extension as it adds a level of accountability of what design fiction aims to achieve. Wong et al. [2018] argue that benefits can be gained from placing design fictions in an everyday, mundane world. Whether this is the direction makers aim to go for or whether they aim to address larger, complex, theoretical aspects, these insights give directions of which types of research activity can be a useful basis for the speculation. Together with the reflection in Chapter 7 In the Showroom these reflections illustrate the step further of how one goes about developing such fictions. Even though it might not be suitable for all types of design fiction, the research establishes self-study or own experience as a useful basis for speculation.

12.1.2. Using Design Fictions

The empirical studies in this thesis were undertaken to learn which types of insights can be gained through design fiction. The artefacts were presented as insights in themselves, but were also the basis for further insights. Here I summarize the results throughout all research activities and discuss their relationship.

As I have shown in section 3.6 Topics & Strategies in the literature review, design fictions are not supposed to be provocative for provocations sake, but instead as a means to trigger reflection and elicit discussion. In Chapter 4 Understanding Technologies for Dementia Care I outlined why design fiction might be a useful area of research into monitoring technologies for dementia care. Through sharing design artefacts with participants, I have been able to elicit their views about monitoring technologies in dementia care. Taking all studies in the second part, from chapter 7 to 11 into account, these can be summarized as follows:
Chapter 12 Discussion & Conclusion

In most studies the discussion went beyond whether technologies should be used at all, but moved towards asking which tasks might be appropriate for technologies to address and how these technologies relate to human labour. The topic was predominant in the lab studies presented in Chapter 8 In the Lab. While many participants held a strong mistrust towards the technologies, others were more open towards the opportunities they offer.

While current monitoring technologies offer few means of individualization as I observed in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies, people's opinion of what is acceptable differs widely. This insight came through strongly in the study with the privacy experts (see Chapter 5 Dementia & Privacy – A Survey with Privacy Experts), but also showed in the discussions that derived from the design fiction. Indications for these are the conflict that arose in response to the design fiction video in one group (Chapter 8 In the Lab) or the variety in the settings participants chose during the HawkEye deployment (Chapter 11 In the Field).

The topic of dementia care appears to have been novel to many participants. This not only confirms earlier insights that technology is brought in too late as it is not considered before (see section 4.4 Problems with Technology Use) but also indicates that design fiction is a useful tool to elicit discussion.

The studies also showed that participants need time to make sense of the artefacts and the technologies and that their attitudes might change and shift over time. That not only showed in the self-study presented in Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies, but also over the long-term deployment of HawkEye as shared in 11.2 The Deployment of HawkEye in the Field.

These empirical studies contribute to the overall research question by showing what type of insight about technology use in sensitive settings can be gained when using design fictions with participants. In addition, in Chapter 7 In the Showroom I frame the design work as an additional contribution. The four high-level abstractions and the following “Implications for Design” I derived through the reflection process of annotating the portfolio of design fictions add to this contribution:

- family & beyond
- nobody is normal
Even though the empirical insights and design contributions are presented here as distinct contributions, they are nonetheless intertwined. Participants discussed technology on the level of “family & beyond”, taking the larger picture of technology use into account. The differences of personal needs and wishes links with the point that “nobody is normal”. While rarely discussed by the participants, I observed that values changed over time, which is related to the “power unfolding”. Going beyond the topic, but analysing the way participants responded, the design fictions only were “gentle provocations” to them. The distinct nature, but interconnectedness poses the question what the relationship between these two types of insights is.

While they are related, participants did not discuss these points explicitly and not all of the discussion points were raised by the participants. If the empirical studies were a means to understand whether the design fictions are read ‘in the right way’ by the participants, i.e. the way I intended, the approach could be considered as failed. Instead I frame them both here as insights in their own rights that can exist independently from each other. This is supported by the difference in outcomes and results: those of the empirical studies are descriptive and those of the design work are ambivalent and inspirational.

In the section 3.2 History & Definitions I presented the following working definition of design fiction:

**Design fiction uses design methods to discuss technologies and their societal consequences within a world in which these technologies can plausibly exist with the aim to elicit debate of such technologies from the audience of the design fiction.**

Building on the work presented in this thesis, I extend it to the following:

**Design fiction enables (self) reflection by designers to foreground their values, the values presented through the technologies and the potential societal consequences by placing the technologies within a world in which these technologies can plausibly exist.**
Design fiction probes use artefacts to elicit responses and (re)shape discussions around technologies that do not yet exist by presenting them in contextualized or situated settings with the aim of eliciting empathic and personalized reflections about plausible technologies.

Whether these terms in themselves are adapted and useful to the wider community, only time will tell, but their contribution lies in their ability to stimulate debate and demystify the concept of design fiction.

12.2. Insights Gained into Technology Use in Sensitive Settings

In this section I discuss how the results of this thesis led to insights about technology use in sensitive settings. This section is divided into two parts: first, I discuss how the results build on the extensive research in the area of monitoring technologies for dementia care. Second, I discuss how these insights that deal with monitoring technologies in dementia care can be generalized to the wider field of sensitive settings.

12.2.1. Relation to Previous Literature

In addition to the exploratory studies, the design fictions were informed through an extensive literature review presented in Chapter 4 Understanding Technologies for Dementia Care. Here I discuss how the research activities undertaken in the second part of this thesis (Chapters 7 to 11) this thesis build on these insights and expand what is known about monitoring technologies in dementia care. In section 4.5 Problems with Technology Design for Dementia Care I named problems surrounding the development of monitoring technologies in dementia care currently: first, the application of the medical model of dementia that addresses the illness as an independent problem as well as defining symptoms as deviations from the norm. Second, the problems with recruiting users that lead to a lack of situated insights. Here, I describe how the work with design fictions responds to these problems.

Both the design fictions and the empirical studies problematize the medical view and therefore respond to the first problem. As I stated with the discussion point that “nobody is normal” and as participants emphasized through their wide range of preferences, the concept of normality and regularity does not fit well with everyday
The results show that participants drew on their own experiences as well as personal examples. Throughout all studies undertaken with the design research artefacts, most participants responded in an empathic manner. While pragmatic voices have been raised, most participants argued from a personal point of view. While the claim that design fiction or scenarios have the ability to do so, has been made before [Kumagai and Wear 2014; Wright et al. 2014], the studies presented here provide evidence for this. Linking them back to the four stages of action I presented in section Chapter 2 Understanding Critical Design - challenge, critique, call to action and change - it can be more specifically said that:

- The design fictions challenged some participants to address issues they had not considered before
- The design fictions invited critical engagement. While future scenarios were critiqued as well, the design fictions enabled critical discussions about the social context rather than the technologies presented or the style of the video
- Few results indicate that participants took action or changed their view after watching the videos. Even more so, it was complicated to recruit participants who were not interested in engaging critically with technologies.

The design fictions themselves address this second problem by providing situated accounts. Design fictions can combine the ethical concerns around these technologies with a lived account of using them, while still highlighting the motivations and benefits.

Nonetheless, the design fictions do not represent ‘everyday life’ in themselves, as they are made up. Dunne and Raby [2013] distinguish four types of futures: possible, plausible, probable and preferable, which have been taken up extensively. What is unclear though, is how one gets to these futures and who gets to decide which one is which. Criteria to evaluate and judge the merits of fictional accounts still have to be established. In my project I drew extensively on existing technologies and found alternative shapes and forms for individual items that already exist. In addition to what might be possible in the technical realm, I further drew from papers that started to problematize emerging technologies, such as [Jakobi et al. 2017; Tolmie et al. 2007] to base my concerns in everyday experiences. Nonetheless, speculation enables to extent these considerations to technologies that do not yet
exist. My views were not always shared by my participants, which leads to the question of how the results can be generalized.

### 12.2.2. Generalisation

In all studies, participants discussed monitoring technologies in dementia. This presents a specific use case. Here I discuss the extent to which the results can be generalized to other sensitive settings. First, I focus on the uniqueness of dementia as a use case. Even though dementia has distinctive symptoms, it shares concerns and problems with other long-term illnesses. Monitoring of symptoms for example has received a lot of attention in the care of diabetes, another long-term condition [Kaziunavas et al. 2017] or multiple-sclerosis, an illness in which symptoms can fluctuate [Ayobi 2018]. Dementia can affect people of all ages, but it is often seen as a problem of old age and some participants focused more on the age of the mother in the Homes for Life video, than the illness itself. Therefore, not all observations were specific to dementia as a use case, but in itself generalizations, inaccurate as they might be. Second, when deriving the insights, especially the Implications for Design, presented in section 7.3.2 I added a further level of abstraction that adds to the generalizability of the results.

In addition, I discuss whether the work provides enough basis to generalise from. Even though I presented a range of artefacts in this thesis and explained how they relate, the empirical work is derived from fewer artefacts. Therefore, the question remains to what extent the insights can be generalised to other design fictions as well. Barab and Squire [2004:3] ask: “How do we understand the conceptuality of research claims generated in situ and use them to inform broader practice?” In the context of this PhD project the question could be understood as: how can reflection based on one artefact inform the design and evaluation of design fictions more generally? Gaver [2012:945f] argues that “convergence [towards design theory] may not be the only or best model for progress”. Lindley [2015a:2] expresses a similar view on design fiction more specifically and suggests that: “… the accumulation of design fiction ambiguities cannot be usefully addressed through working towards convergence, or through standardisation as facilitated by generalisable theory”. The work was undertaken in this vein, not as a means to provide guidelines for design fiction research but to add to its clarity. This was done firstly by observing participant interactions to establish whether claims made about design fiction hold, secondly by problematizing its use within HCI and design...
research and thirdly by providing terms and suggestions to overcome some of the current limitations. I expand on this in the next section where I focus on the insights gained into design fiction.

12.3. Insights into Design Fiction

The insights presented above are useful to designers and developers interested in developing technologies for dementia care. In this section I address those who are interested in working with design fiction as a method. The term design fiction is currently open and ambiguous and can describe both a wide range of artefacts as well as a range of use cases. As Lindley et al. [2017b:273] describe, “there is no specific formula describing how to use design fiction to probe the significance of a technology’s future adoption”. This in itself is not problematic, as design itself is inherently hard to define and should not be formulated so as not to stifle the creativity of the field. Nonetheless, it is problematic to the point in which design fiction is a “mystified concept”, that is: “a concept that is both regarded by a community of users as ‘obvious’, while carrying significantly divergent meanings, which makes the concepts difficult to reason coherently about” ([Wennberg et al. 2018:4], see also [Minnich 2010]). Design fiction in HCI fits this concept as definitions are rarely given, even though authors have different frames of reference. In this thesis I applied the Constructive Design Research framework [Koskinen et al. 2011] to describe more clearly similarities and discrepancies between the different applications of design fictions. I outline what can be learned about design fiction from eliciting and discussing these insights. Within this section I first discuss the ‘realness’ of design fictions and the resulting questions of accountability of the results. Second, I outline what the problems with classifying the results indicates for research in HCI. Third, I discuss the framework used to classify the studies and the results and what the results mean for research through design.

12.3.1. Make believe

Design fiction has been introduced as a means to ‘suspend disbelief’ (see e.g. [Lindley 2015a]). To some extent it follows a strong tradition in HCI to build on make-believe [Turner et al. 2014] to enable for example the evaluation of prototypes, i.e. of things that do not yet exist. Design fiction can fulfill a similar aim and can be used as a prototyping technique (compare e.g. [Blythe 2014; Lindley and Coulton 2016b]) with the additional value that the technologies under review are
embedded in a wider story-world. But, design fiction has been called into question: for example, Gonzatto [2013] challenged the accountability of future scenarios in the present. A contrasting view is offered by Brodersen et al. [2008] who emphasise the advantages of ‘setting the scene’ and enabling participants to step out of everyday concerns. The question of how participants respond when they encounter fictional artefacts is currently explored and this work adds to the understanding.

The series of studies presented in chapters 8 to 11 give insights into participants’ responses and suggest two means that aid the suspension of disbelief. When using the Homes for Life video in the studies described in Chapter 8 In the Lab, participants were given little introduction to the video, but instead were left to wonder whether it was real or not. Dunne and Raby [2013:40] argue that the viewer of speculative design should “experience a dilemma” and asks: “It is serious or not? Is it real or not?” The fact that some participants raised the question in the discussion shows that the video balanced the tension successfully. Nonetheless, the ambiguity also enabled some participants to reject the fiction and claim it as ‘unrealistic’. This could be considered a limitation of the design fiction. Instead it leads to relevant insights into participants’ perception of technologies. Many of the technologies perceived as unrealistic were rejected by the participants because they were not considered desirable. As this was individual and based on personal needs, fears and wishes, it shows that the distinction between what is real and plausible is also individual. The interesting questions are situated at the edges and design fiction can benefit from learning what users consider to be unrealistic. Vines et al. [2012] use a similar technique of providing obviously questionable examples of technologies to invite critique and ideas that are more acceptable by the users. Design fiction when used in the probing manner I developed can be used in a similar way. Additionally, the way the technologies were embedded into a narrative that hinted at the world in which the technologies would be deployed enabled critique that went beyond the artefacts themselves. In the next paragraph I discuss in more depth how this can be achieved.

The individuality participants’ showed when engaging with the HawkEye probe also hints at a strategy employed through design fiction: empathy. While the instructions of the prototype were deliberately ambiguous to enable participants to make sense of the artefact, they were informed before the beginning of the deployment that the artefact was fictional. Nonetheless, as I showed in the discussion of this particular
study, participants felt connected to the (fictional) character and therefore treated the device for most parts of the study as if it were real. Empathy as a strategy therefore builds on ambiguity as a strategy or others outlined in the literature. Helms and Fernaeus [2018] for example points toward humour as a strategy to suspend disbelief. Empathy or personal connection might be an additional way to deal with sensitive topics, such as care, illness and death, where humour could be considered too provocative. The empirical work undertaken for this PhD project has therefore helped to identify novel strategies for design fiction. Empathy as a strategy is not novel to HCI as it has e.g. been employed by Mattelmäki and Battarby [2002] or Lindsay et a. [2012]. Design fiction enables empathic research beyond the possibilities of what is technically currently possible and therefore extends these approaches.

Throughout the thesis I discussed participants’ responses in terms borrowed from identity theories and theatre, e.g. when discussing the role participants took on (8.2 The Use of Homes for Life in the Lab) or when discussing the HawkEye probe in relation to props (11.2 The Deployment of HawkEye in the Field). Other researchers have used similar framing, as e.g. the term “speculative enactments” by Elsden et al. [2017] shows. Overall, the use of performance to address sensitive settings has risen, e.g. [Boger et al. 2010; Coughlan et al. 2014]. Here I discuss to which extent design fiction relates to this method or whether it constitutes something new.

By using design fiction to elicit responses and analysing these responses, I have shown that the design fictions I developed consistently elicited nuanced and personal discussions by a wide range of user groups. The artefacts not only broke with the techno-optimism of many future scenarios by presenting a more nuanced view that was picked up by the participants, but also served as a means to reflect and discuss views and values. Design fiction goes beyond tools for discussion though, but instead more actively enables role-playing and role taking. As I have shown when comparing the results from the field study with those from the lab studies in 11.2 The Deployment of HawkEye in the Field the design fiction artefacts I developed were interpreted differently by participants and brought a range of opinions, values and topics they cared about to the forefront. Set in sensitive settings as in this project, design fiction probes sit between informational probes
and technology probes, but the term leaves enough openness for practitioners to
design and develop their own artefacts and research strategies.

Design fiction therefore appears to go beyond the mere spectacle, but instead could
be seen as a performance in which participants have an active role. Speculative
design has been called a spectacle as discussion points are presented as “dramatic
events” [DiSalvo 2012:115]. As I outlined above, the Homes for Life video might fall
into this category, as participants observe the events unfolding in the video like a
spectacle. Narrative and aesthetics are used to draw them in and keep them engaged.
The issues are enacted on this stage, but participants have no means to interact with
it, only respond. But as DiSalvo [2012] outlines, it is unclear to what extent this can
stimulate change and lead to tangible outcomes.

As I discussed earlier, participants did not indicate that they were likely to take
action based on the design fiction. This leads to another problem with the
evaluation of design fiction, as it is unclear, which criteria would be adequate to use
to ‘measure’ change. The problem is not new to HCI, as it has been for example
observed in the field of behavior change (see e.g. [Free et al. 2013; Klasnja et al.
2011]). This should therefore not be seen as an issue for design fiction research, but
rather poses questions about HCI more generally. For research-through design it
poses the question whether these quantified measures are applicable and how we as
a field frame outcomes [Boehner et al. 2007; Pierce 2014].

Design fiction sits within a turn to the cultural, that has been called for as a means
to deal with the complexities that come through pervasiveness of modern
technologies (e.g. [Heidt et al. 2014]). But, as Benford et al. [2015] outline, this
brings new responsibilities with it. In the next section I therefore discuss what the
implications of this research project add to the understanding of how design fiction
sits within HCI and what is accepted or understood as a contribution to HCI.

### 12.3.2. Implications for HCI

Even though cultural and critical wok has increased in HCI in recent years, its
paradigm is often not yet well understood. As a result, many attempts have been
made to explain how and why the approach should not be subjected to the rigour
of empirical work (see e.g. [Gaver et al. 2004a]). Participants in the survey presented
in Chapter 2 Understanding Critical Design shared similar views. My decision to
use the artefacts in lab and field could be understood as a contradiction of these
claims. Instead, showroom research has its benefits, as it leads to specific kinds of insights that might be impossible to generate with other means. The work further clarifies what these kinds of contributions are. The results are threefold: first, the artefacts that can be used by the maker for reflection but also for communication. Therefore, second, the artefacts and reflections can be useful to other designers and developers to reflect both on the context and the method itself. In addition, and third, the artefacts can be useful as a means to elicit discussion.

Critical design has presented itself as a means to reject existing narratives, for example through “transgression”, i.e. the application of a concept to a novel context as a means to make strange or provoke. Critical design is revolutionary rather than incremental. Design fiction often presents itself in a different light, which might make out some of its appeal for HCI. Technologies are often projected into a near-future rather than transgressing, such as the Data Economy by Luu et al. [2018] or the Homes for Life narrative itself. Nonetheless, the revolution of design fiction lies somewhere else: in the critical stance on technology itself. As I outlined in Chapter 2 Understanding Critical Design, I suggest a new reference for design fiction: critical design instead of Critical Design. Design fiction is a suitable way to encourage role taking and exploration, but in many instances does so through only gentle provocation. As such, design fiction could be considered to stand between Critical Design and the traditional, affirmative research-through design. This work goes towards the establishment of design fiction as a method in its own rights that brings a critical stance to research-through design. As technologies invade our everyday life and are likely to touch on sensitive topics, methods are needed that support and facilitate rich and situated discussions. Design fiction promises to be a tool to enable this sort of discussions in a variety of contexts. In the next section I expand on these insights by debating how design fiction sits not only within HCI, but also within research-through design.

12.3.3. Implications for Research through Design
Design fiction has been used in lab settings to elicit participant data (see e.g. Lawson et al. [2015]). But this has traditionally avoided either classification as showroom, lab or field. Only recently (see Wong et al. [2017a]) has the term lab research been applied to design fiction. In this section I look further into reasons behind this lack of engagement with existing frameworks.
Design fiction is often placed within the toolbox of Critical Design (see also Chapter 2 Understanding Critical Design). But the insights generated from this work also go beyond the clarity gained about the showroom approach. First, I present a clear motivation for using design fiction not only, but also in the lab and the field. In addition to providing insights into specific problem areas, some of which may be complicated to research otherwise, this enables insights into the way design fiction is understood by participants. Participants numbers were often small, but most were deeply engaged and contributed rich data which enabled me to explore their views and opinions in depth. While it is neither a requirement nor the only valid way to generate design insights (see e.g. [Fallman 2007; Pierce 2014]), it is done increasingly as I outlined in Chapter 7 In the Showroom. The empirical work presented in chapters 8 to 11, was therefore also analysed to understand how insights generated through design fiction differ from those generated e.g. from the exploratory studies presented in the first part of the thesis. I not only coined the term ‘design fiction probe’ (see section 12.1 Types of Insights Gained), but also draw on their understanding in HCI to place design fictions within the field.

Thoring et al. [2013] argue that probes need to be understood better, both from the point of view of the participants and from the researchers. The series of studies presented in this thesis has been done in a similar vain. Studies have mainly been exploratory with open ended research questions and qualitative research methods as neither the problems, nor potential methods to address them are common within HCI research. The empirical nature of the work opens up a comparable discussion as it has been led about probes. It has been suggested that cultural probes lost playfulness and subjectivity when they were developed into informational probes and were “rationalise[d]” [Gaver et al. 2004a:7]. As I have shown above, authors have placed them next to each other in the meantime (see [Mattelmäki 2005] for an overview). Different probes are by now used for their distinct properties. Design fiction is at a comparable turning point as different uses appear to contradict each other. As a result, authors might refrain from placing their work explicitly in one or the other framework as a means to avoid criticism from the other side, with the result, that the term appears to mean different things to different people. Within this thesis I aim to resolve some of the conflicts, by suggesting that each approach leads to distinct insights that are relevant to different target groups and in differing

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settings. This adds to the understanding where design fictions are placed within research-through design.

At the time of planning out the studies, the constructive research framework was chosen to classify the research activities and insights. Its appeal lies in the aim to bring together the many different uses and motivations of design research and making their differences explicit; a problem I was faced with in regards to design fiction as well. A further advantage of this model is that it places the varying positions next to each other without ranking or judgement. As the series of studies presented within this thesis has shown, design methods are rarely applied in a distinct and rigorous manner as the Constructive Design Research framework [Koskinen et al. 2011] suggests. The framework contains little information on how to identify specific properties of an artefact within each paradigm. The clearest example showed itself in the use of HawkEye. This artefact that could easily have been imagined at a design show – and has even been exhibited as part of a degree show – in the showroom approach. Instead it has been used in the field which poses the question which qualities classify it for either. This insight confirms the understanding that design work cannot easily be classified without losing its creative edge. Nonetheless, working with the framework has proven useful as it brought these points to the forefront and made them debatable. In hindsight, the division by Fallman [2007] appears to be more useful through its focus on the function of the object. If design fiction is to be used in a probing way, the decision of whether it is in a lab or field does not play much into the question of how the results are to be evaluated.

While I tried to follow the framework as suggested by Koskinen et a. [2011], the process deviated at times from the ideal structures. This shows the strongest maybe when comparing the way lab studies are described in the Constructive Design Research framework (ibid.) and how they were executed as described in Chapter 8 In the Lab. While a range of studies were executed that built on each other, the design itself was not iterated. The study design was improved consequently but the artefact used stayed the same throughout. Koskinen et al. [2011] instead describe the iterative development of the Rich Interactions Camera. Design fiction has yet to build up a culture of consistent reporting and the development process has mainly been neglected (compare e.g. Sturdee et al. [2016]). The focus has mainly been on the finished artefact. But even though iteration was limited, reflection took
place, partly during the making process as I describe in [Schulte et al. 2016], but also after, as I describe in Chapter 7 In the Showroom. In the coming section I describe my role as well the responsibilities that derive from developing design fictions in more depths.

### 12.4. Reflective Design

Reflection is a large part of research-through design, as e.g. Sengers et al. [2005] suggest when introducing the term reflective design. I already laid out some insights gained from reflection in the section on the showroom approach where I describe the motivation and background of the artefacts (see section 7.2 The Artefacts) as well as important issues that were foregrounded through the development of the artefacts (see section 7.3 Intermediate-Level Knowledge). I expand on this by first addressing the responsibilities of the maker of design fiction and resulting questions about potential bias in this work. I second explain how I position myself in regards to the work before third explaining the understanding my role in more depth.

#### 12.4.1. Bias & Responsibility

By not only presenting the artefact, but also framing its use and the way it is presented “designers who create fictions” are left with “a substantial amount of power and responsibility” [Lyckvi et al. 2018:18]. Design fiction is used as a means to stimulate and frame discussion. As I have shown in the comparison of the discussions that arose from Homes for Life as compared to HawkEye, these aims succeed to some extent. This opens up design fiction to the question of bias, especially when used with participants. But, participants’ responses varied widely. Participants were active partners in the sense-making process. While not common, misunderstandings occurred and some aspects I considered important were not touched upon by the participants or the other way around. Bardzell et al. [2015:2095] already outline that three factors are involved in making sense of the artefact and interpreting its aesthetics: “the work, the spectator and the (cultural) context.” The studies presented in chapters 8 and 9 paint a similar picture. Participants actively drew on their past and experiences to fill in perceived gaps in the design fictions and make sense of perceived discrepancies. Ambiguity of the artefact can be a useful factor as argued for example by Gaver, Beaver and Benford [2003]. I took great care to develop and use artefacts that are neutral in the sense that they enable participants to take a stance towards them and do not feel compelled to accept them as true or false.
Neutrality is expressed through ambiguity which leaves control over the narrative to a large degree in the hands of the participants.

Design fiction has been chosen in this project as a means to go beyond measured, abstract and detached responses, but instead to elicit personal responses as a means to overcome the limited technologies that were mainly inspired by the medical model of dementia. This contradicts the measured and objective nature of scientific research. To some extent design fiction sits within a larger design research, which acknowledges that “design changes the context within which it is working” [Lindley 2015a:2]. Neither generalisability nor subjectivity are inherently part of design research (see e.g. [Fallman and Stolterman 2010]). Rigour – if that is even the right word (see for example [Bowers 2012] for a critical discussion)– is constituted through other means, often highly specific to the design project itself (see e.g. [Fallman and Stolterman 2010]). Within this project this was done for example by developing intermediate-level knowledge from the artefacts as a means to communicate them in a less ambiguous manner. In addition, I used the work presented here as a means to start to problematize what rigour might mean in a field as contradictory as design fiction. Design fiction links to design research more generally, but also borrows from other research methods, such as those that employ theatrical means.

In addition, the use of make believe to suspend disbelief in the viewer is a means to enable users to observe and discuss the objects as if they were real. Depending on the shape and form the artefacts take this can border on deception as Coulton et al. [2016] outline. With the power of making up worlds therefore comes the responsibility to engage with the participants in a fair and transparent manner. At the beginning of the studies presented in chapters 8 to 9 participants were left in doubt whether the technologies presented were made up, but in the debriefing sessions I ensured that everyone was aware that they were made up. For the studies using HawkEye we tried to find a balance between priming the participants and keeping up the notion that the artefact might be real by sending an information sheet in advance that stated clearly that the device was fictional, but letting time pass before the prototype was send out.

Another responsibility I foresaw was the question of distress when raising sensitive issues, such as illness or death. Following the concept of ‘Gentle Provocation’ few
participants showed signs of distress. An exception was the one participant in the HawkEye deployment study who felt too involved to be able to take part in the study (see Chapter 11 In the Field). Measures to ensure that the participant was cared for were taken and even more had been prepared for all other studies in this project. This might include debriefing protocols that leave no doubt in participants which parts of the design fiction were real, but also to address some of the stresses that might occur when participants are forced to reflect on potential negative futures. While design fiction can be playful, fun and engaging, this does not relieve the maker and researcher from considering the potential harms and benefits to the participants. In the coming section I expand on this by outlining my position and motivation behind the work.

12.4.2. My Position

If design fiction has the ability to shape and frame discourse, this also poses questions about the position of its maker. While not inherently part of Critical Design, many design fictions take a critical stance and can be placed within the realm of activist or political design. Reflecting on my own stance here, I included my own fears and concerns about monitoring technologies and their future outcomes in the design fictions. They cannot be understood as neutral, but instead come from a certain techno-critical perspective. But I used design as a means to pin point the areas that I was concerned about, which in turn has led to reflections on how to potentially improve them. It is further a perspective that is critical of the predominant medical model of illness and the way ageing is framed in many technological solutions. My position could be understood as Critical, or Foucauldian (see for example [Bardzell and Bardzell 2015]) with the aim to question inherent biases and the related aim to change designers’ and developers’ positions to enable the development of technologies that are more empowering. But this is only true to some degree.

Even though this thesis draws on Critical and Foucauldian perspectives, it does not give a voice to an important group: people living with dementia, those could be considered to be directly affected by the technologies discussed here. This decision has not been taken lightly as I understood the danger to further marginalise this group. Hendriks et al. [2013] stress the importance of including people with dementia into research. Design fiction has been used directly with marginalised
groups [Nägele et al. 2018] and even with people living with dementia [Tsekleves and Darby 2016]. Participatory methods in this area are advanced by these authors among others. But instead of following this trend, I decided to test technologies myself (see Chapter 6 Mundane Tracking – A Self-Study of Monitoring Technologies) and evaluate the design fictions with students 8.2 The Use of Homes for Life in the Lab and design practitioners Chapter 9 Evaluation of Homes for Life with Professionals. We further included people who had second-hand experience of working with dementia or through personal contacts in study 11.2 The Deployment of HawkEye in the Field. But also here we refrained from addressing people living with dementia directly. The motivation to do so is two-fold: self-reflection and the expected target group. The self-study and to a lesser degree the design work had the important part to sensitise myself to certain aspects of the technologies and provide an in-depth experience. Working with people living with dementia would have given me a better insight into their situation, but it is to be expected that I would have remained more distanced from that experience and get less finely grained insights.

But the target group of this work had an even larger impact on this decision. As I outlined above, the artefacts presented in this thesis are not applied solutions to today’s problems. Instead, their focus is much more on the future. Practical outcomes might more likely only be available to future generations. The studies therefore aimed at people who do not have dementia. Instead it gave everyone a possibility to reflect on and discuss considerations as if. But for different technologies to be available in the future, the insights derived from the design fictions need to be communicated to and discussed by designers and developers. Their understanding of the method therefore has been foregrounded in this thesis. While it would have been an exciting undertaking to gather the responses by people living with comparable technologies today, this was out of the scope of this PhD project.

While my stance might not be neutral, it had to be agnostic for wide parts of the project as I deliberately moved between contrasting frameworks to evaluate the design fiction and follow up its impact. This approach has not been chosen in a serendipitous manner. Neither has it been done in the spirit of a mixed-method approach, as a means to combine methods to explore a topic in depth through triangulation. Instead, methods have been chosen from a critical point of view, as a
Chapter 12 Discussion & Conclusion

means to evaluate each paradigm and the contribution it makes. It has been driven by the interdisciplinary nature of design research. Cross [1982] famously defined the “designerly way of knowing” as a means to contrast design from both art and science, even though it borrows from both. My design training has therefore helped me to maintain an outsider perspective when navigating the requirements from each paradigm and keep close to the literature I reviewed to guide my work.

12.4.3. Writing & Designing

Design fiction poses questions about the artefact and the role of the maker as it is not bound to a specific medium. It is therefore not clear what the outcome of a specific project might be or how it is to be evaluated. Design in many disciplines focusses heavily on the production of an object, i.e. a material and tangible artefact. As I have shown in section 3.8.1 Using Design Fictions

Without an explicit understanding of what design fiction is and how it could or should be used, how can we evaluate the rigour or value of this promising method? What framework or theory should we use to classify, test and judge the quality of design fiction? As Lindley and Coulton [2016a] point out, this leads to the bigger question of what the nature of contemporary HCI research is, what types of insights it could or should generate and which topics it should address. Instead, in HCI a “current, intense discourse on forms and values of design fiction” prevails [Fuchsberger et al. 2017:581]. Creative methods, such as design fiction, have been said to “not sit well” [Blythe 2014:1] within HCI research and the question of understanding why and where it fits in or where its limitations lie will not only be relevant to the rigour of design fiction itself, but to HCI research more generally. Within this thesis I expand on the suggestion that design fiction can be used within a research-through design framework and more specifically how it can be used within the three categories of the Constructive Design Research framework [Koskinen et al. 2011]. Drawing on the framework I describe how one specific design fiction can be used within the showroom (Chapter 7 In the Showroom), lab (Chapter 8 In the Lab) and field (Chapter 11 In the Field) approaches and present study results and discussions on the different types of insights it can generate. Before I do so, I describe in more depth the problems of making design fiction artefacts.

Making Design Fictions design fiction can take the shape of material artefacts, such as research papers [Fields 2016; Lindley and Coulton 2015a], catalogues [Brown et
al. 2016] or counterfunctional cameras [Pierce and Paulos 2014], it can also appear in the written form. Design has an implicit focus on materiality and aesthetics. These do not necessarily apply here as design fiction does not have to appear as material or particularly visual. Even though the Homes for Life video was made on a small budget and deliberately lacks the shine and glamour of industrial future scenarios, participants were drawn in and responded to it. The appearance of the video was not a quality by which the video should have been judged – and the responses show that participants rarely did so.

Instead, they were drawn in by the story told by the fictional character. It might appear useful therefore to turn to the literary world to judge a design fiction. Especially science fiction appears related as both mainly turn to the future as the main means of defamilirization. Again, this evaluation is not straightforward as the narrative can be expressed through objects. Instead, I suggest “narrative aesthetics” as deployed by Dunne [2005]. Design fiction is caught in a duality between the material design world and the literary world. This duality poses questions about the role – and skill – of the maker. As outlined in section 3.2 History & Definitions of the literature review, the practice of design fiction has as a starting point both been attributed to Bruce Sterling, who identifies as an author and Julian Bleeker, who is a designer, who did “a small bit of writing” [Bleeker 2009:4] Nonetheless, many suggest that it is neither the skill of the designer, nor that of the writer, but the combination of both that makes the design fiction compelling. Bleeker [2009:7] himself argues that design fiction is “a kind of authoring practice that recombines the traditions of writing and story telling with the material crafting of objects”. Knutz and Markussen [2013:234] expand on this and “argue for the need of turning towards design practice itself and make further explorations into how tools and technique of the designer may integrate with those of the author in the construction of design fiction”. As I showed in my reflections in section 7.2.1 The Wearable GPS Tracker, the designed object and the world or narrative they inhabit should not be divided but form a unity. To express this duality, I use the term maker throughout when describing my role in creating the artefacts. Even though design fictions borrow both from the material language of designs and the poetics of fiction, they should be evaluated by their skill of combining the two to bring an artefact to life.

As I outlined in this discussion, the work presented in this thesis has helped to ground some of the claims made about design fiction, but it has also opened up
further questions. Within the coming section, I describe salient areas for further research that emerged from this work, focussing both on future questions for the development of technologies for dementia care as well as the use of design fiction.

### 12.5. Future Work

Throughout the thesis, I reference short design fictions that were developed from the debates surrounding technologies for dementia care, which can be found in the accompanying material. They were inspired in the beginning by the academic literature and existing technologies and appear rather bleak. The more recent ones instead, are inspired by the discussions held by participants and reflection by myself. Homes for Death is such an example and while it might be considered the bleakest of the design fictions as it deals with assisted suicide, but it is also the most hopeful. Within the design fiction the point of reference has shifted from the outside views of those who have technologies thrust upon them, to someone who is in control and uses the technology to support their wishes. This development shows the power of design fiction not only to critique, but also to prototype and develop. While the work has answered many questions, it has also opened up new areas of research, both into technologies for dementia and for design fiction as a method. In the coming two sections I first present open questions about the context in which the design fictions have been made, which have been opened up through the development and deployment of the artefacts. Second I present potential future questions about design fiction that could strengthen the method.

#### 12.5.1. The Use of Technologies in Sensitive Settings

One major strand of research that winds throughout the thesis is the question of how technologies in dementia care can be made collaborative and mutual. My initial studies showed that the paternalistic approach of current technologies is problematic for users who are still capable of making decisions of their own and – beyond questions of dignity and autonomy – hinder the uptake of technologies. But the remaining studies have shown that this approach poses new problems for caregivers as well. Especially 11.2 The Deployment of HawkEye in the Field has shown that the technologies can add to the emotional pressure of users, who might be forced to make decisions on behalf of someone they do not know much. Instead of disregarding the use of technology in the sector, this poses the question of how technologies can be improved. Keeping technologies simple to make them easily
usable by people living with dementia is an often declared goal (see for example [Orpwood et al. 2007; Skillen et al. 2012]). As the dementia care setting is complex, concerns are raised that these simple solutions may not be adequate [Rosenberg and Nygård 2012]. One of the questions that surround the adoption of technology is at which stage of dementia the technologies can and should be introduced. Stigma or lack of perceived need might reduce engagement in the early stages of dementia, while in the later stages symptoms might be too advanced for successful implementation (see [Nijhof et al. 2013; Perry and Beyer 2012]). In addition, caregivers may be hesitant to introduce a new device before an actual problem has arisen [Starkhammar and Nygård 2008]. Technology is often seen as a means to compensate for the lost needs of someone with dementia, rather than a supportive aid [Rosenberg et al. 2012].

One open question therefore is how technologies can adapt to changing circumstances. Even if technologies are introduced at an early stage, e.g. shortly after or even before a dementia diagnosis, symptoms will worsen and decision making might be impacted at some point, thereby rendering the technology impossible to use. The question has started to emerge, e.g. in regards to driving [Brown and Ott 2004] or social media use [Batchelor et al. 2012]. How these processes are currently handled and how technologies can address this in a sensitive manner poses a relevant area for research.

Another remaining question is about the role participants hold. So far, the work presented here has placed participants in the role of caregivers, not yet the receivers of care. De Haas et al. [2018] for example probes questions around assistive suicide and dementia with speculative artefacts that invite the viewer to consider their relation to these artefacts, but not yet push the viewer to make the decision for themselves. Could design fiction be a way to stimulate meaningful conversations about potential future wishes of people living with dementia? The Privacy Living Will presented in Chapter 5 Dementia & Privacy – A Survey with Privacy Experts was a first probe to go into this direction. Even though it revealed the level of variety in participants’ opinions, it remained abstract. Some participants described in section 11.2 The Deployment of HawkEye in the Field tried to put themselves in Annie’s position, but overall this position has been neglected in design fiction research.
Another issue that links both context and method is the question of to which extent design fiction can be pushed to discuss sensitive topics. Even though Homes for Life hints at sensitive issues, intimacy and death in particular, they were not the main focus. The Homes for Death design fiction referenced prior to this chapter is built on suggestions from participants in Chapter 9 Evaluation of Homes for Life with Professionals who noticed the lack of palliative care as a missed opportunity in the Homes for Life design fiction. In the Homes for Death design fiction I broached the topic in a sensitive, not provocative manner. Nonetheless, it remains to be tested how participants will respond to this – or comparable - probes.

12.5.2. Design Fiction
Critical design is often linked to art and the boundaries are blurred, not only through the fact that artefacts are often publicly exhibited (see also Chapter 2 Understanding Critical Design for a critique of Dunne and Raby’s work). A similar question – if not the same – could be posed for design fiction and its relationship to science-fiction and literature in general. While reflections have started to emerge on this (see e.g. [Blythe 2017]), I extent the question, based on the results from the survey presented in Study 1: What is the relationship between design fiction and design more generally? If some design is critical, what is the design that is not? Does it “confirm the status quo” and what does that mean in practice? If some design is speculative, what is the different to that, which does not go beyond the prototyping phase (see e.g. Coulton and Lindley’s reflections on vapourware [Coulton and Lindley 2016]). At which point does design stop to be speculative and becomes status quo? This thesis provides answers on this when reflecting on what makes the presented work design fiction rather than scenarios and by discussing to which extent it is critical. Future studies in this area could help strengthen the understanding of what the defining features of design fiction and related methods are.

In this thesis I reflected on the different media I chose to represent the design fiction and my motivations to do so in section 7.2 The Artefacts. I further included a wide range of examples that chose different representations of design fictions. While this is useful to foster creative engagement, it makes it hard to differentiate design fiction from other speculative methods and might lead to the criticism that ‘anything goes’: a lack of rigour behind the method. As the series of studies has
further shown that it has an impact on participants’ perception and communication how they encounter the design fiction, this might pose an interesting new area for design fiction research. Following the question whether the medium and the message (free after McLuhan) could be separated, following the same design fiction through several iterations might help strengthen the definitions of the different speculative methods. While this thesis work has taken first steps into this direction, future work is needed.

Especially after trying to recruit participants for the Evaluation of Homes for Life with Professionals I pose the question of to which extent design fiction can be beneficial to participants. While most participants who did take part in the studies presented in chapters 8 to 11 enjoyed the experience and many found it useful for personal reflection, it attracted participants who are already critical. When trying to engage participants who are technology-optimistic, the use of critical methods, such as design fiction might imply a criticism of their way of working. As in my understanding design fiction is a means to encounter problems before they actually occur more related to prototyping (see also Lindley and Potts [2014]). The question therefore remains who should be involved into research with design fiction, how the design fiction can be made suitable for this target group and how can potential benefits be communicated successfully.

12.6. Conclusion

In this thesis I shared designed objects, reflected on them and used them in empirical studies to answer the research question: **What can we learn about technology use in sensitive settings through research through design fiction?** As a result, I provided three types of contributions: a design contribution, through the development of artefacts, a contextual contribution, through insights into people’s expectations of technologies for dementia care and a methodological contribution into the use of design fiction. Lindley [2015a] argues that “Regardless of what position you adopt, we can assume that it is possible to produce knowledge by practicing design fiction.” The work presented here not only confirms this assumption, but also works towards understanding what type of knowledge can be produced, depending on the way it is used. While open questions remain, the work has helped to demystify design fiction, reveal some of the tensions within HCI regarding its use and offer a novel vocabulary to relieve some of these tensions. The work presented here is relevant
not only for those who are interested in developing technologies for people living with dementia or breaching other sensitive topics, such as health care but also for those who are looking at novel methods to do so. Designers and developers can benefit from the insights presented here to support their design (fiction) work through personal and empathic debates and discussions as well as reflection. In addition, the artefacts presented are suitable for a wide range of audiences and can be used to stimulate further discussions.
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PURPURA, S., SCHWANDA, V., WILLIAMS, K., STUBLER, W., AND SENGERS, P. 2011. Fit4life:


SMARTHOME DESIGN. 2012. What is a Smart Home? Video Example of Smart Home Technology in Action... https://www.youtube.com/watch?v=i73nLTXPIM&feature=youtu.be.


Stray Star Ltd. GPS Trackers for Dementia • Personal GPS Trackers. *Personal GPS Trackers*. https://www.personalgpstrackers.co.uk/.


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“I really did not think it would come to this. I mean I knew it was possible that I might get dementia, but, well, it is not really something you want to think about. So, it was not something I considered when I worked in this team to improve the first generation of GPS trackers. We thought we would be doing something for people whose dementia has gone so far that they do not really know what is going on. People whose relatives would decide what is best for them. The relatives could use the tracker to find them when their loved one with dementia got lost. We focused on the usability, while others in the team made sure that the accuracy was getting better and better. We packed the device in a nice case that could be worn as a pendant or key fob, or clipped into a wristband which made it look like a watch. The interface was really cleverly made, so that even people who had little experience with technology could set it up and use it quickly. First tests showed that participants were fine using it.

I did not think that it would go this far. That everyone would be made to wear one of these directly after the diagnosis. Insurance companies did a lot of lobbying on this and well, it can be quite useful in many cases so not many people complained. Now I have to wear one or otherwise my insurance company will not pay out any costs should I have an accident. I hate this. I got into a big fight with my son yesterday when he saw that I had been to the pub twice this week. No matter arguing that I only had a pint or two and made my way home. No, he worries about me being lonely and becoming an alcoholic. I wish he'd just leave me alone; I mean I am a grown woman. I am by far not as confused as he makes out. I only had the diagnosis half a year ago and do everything I can to delay the symptoms. Not that we wouldn’t argue if I didn’t have the tracker, but it has made things tenser between us, I have to say. I am thinking about not wearing it. It could get me into trouble, but let’s be honest that is quite unlikely.”
Appendix II: Interlude – RocCo, the Robot Companion

She just gave up. It was just not worth the fight. She could only win a couple of … what, months? One month? A couple of weeks? So why fuss about it? It had all started out so calm, but escalated quickly.

When the notifications came that the house sensors had identified changes in her behaviour which indicated that she should see a doctor, she had not been too surprised. It had happened to her grandmother, her mother after that … and her uncle who no one in the family mentioned anymore. She went to the doctor, got the diagnosis she expected and went home to make arrangements. One was buying a new upgrade package for the house. In the beginning nothing much changed. It may have gone even more smoothly than she expected. The reminders and easy-access updates helped her out and overall she went along just fine. Things started to take a bit longer or got abandoned half way through, but as she was on her own that was not much of a problem.

Until the day RocCo came. RocCo was the ‘robot companion’. The newest gadget issued by the health service to every patient who had no partner and no children to be cared by. She had tried to argue that she had all the support she needed from her smart home; that she was happy living on her own; always had lived on her own; that she really did not want any companions. But there was no way out. Her plan to hide that ugly thing with its big eyes in the broom closet were smothered as she was told she now had to contact the GP through the robot. When a RocCo had been issued, all reports had to go through it, no excuses.

RocCo was delivered, followed her around the house, dutifully learned and sent out the regular reports. Sometimes RoCo and the smart house had different ideas of what she was supposed to do next, which confused her, but overall they got along just fine. RocCo did not get under her feet too much. She actually enjoyed having him read her stories and fall asleep to the deep and calm voice she had chosen for him.

Until the day RocCo started to lock the door. He had noticed that her gait had become more irregular and deemed it too high a risk for her to go out. It started on rainy days. It extended to evenings and night times. RocCo kept her safe. Inside the house. She pleaded, insisted, shouted at him to let her go out. When she needed to go shopping and did not want to have stuff delivered this time. When she would miss the movie. When her friend was waiting in the café. But RocCo insisted. In his deep voice and calm manner, he offered her a cup of tea, a game of cards, a snack?

She did by far not feel as vulnerable as he tried to make her, but she did not get through. RocCo was built to deal with ‘aggressive patients’ and that was what he
did brilliantly. She missed going out and running little errands. She lost nearly all contact with the people she loved because she could not bring herself to tell them that she was trapped in her own house. Because she was ill. Maybe worse than she realised. Sometimes she forgot the outside. RoeCo gave her new exercises to keep her fit. But sometimes the urge to go out – just for a little while – was just too big. The she pleaded, insisted and shouted. But to no avail.

In the end she just gave up. It did not seem worth the fight to go outside, to go for a walk, to feel the sun on her skin. In a couple of months, maybe weeks, the illness would get too strong a hold on her anyway. She would not be able to go outside. She did not even try.

In his office, the doctor received RoeCos regular reports. He noted that she needed a while to come to terms with the diagnosis, but now she was a calm and responsive patient. He was very happy with her progress.
Appendix III: Survey Materials for Critical Designers

Exported from Qualtrics Survey Tool

Start of Block: Default Question Block

Who are we? My name is Britta Schulte and I am a PhD student at the UCL Interaction Centre. My project is about the impact of Critical Design (CD) on the discourse surrounding technologies for people living with dementia. I undertake this study in collaboration with my supervisors Paul Marshall and Anna Cox.

What is this study about? In this online questionnaire I will ask you questions about CD: your definition, expectations and the values you attribute to it. I want to learn what participants consider critical design and how they use it. I am particularly interested in the question whether these differ from the existing theoretic literature on the topic. In addition I am interested to learn what measures designers use to evaluate the quality of critical design projects. To analyse this exploratory data, I aim to combine thematic analysis and discourse analysis to develop a new classification and potentially an evaluation matrix.

☐ Yes, I wish to proceed with the study (1)
☐ No, I do not wish to proceed with the study (2)

Is participation required? No, it is entirely up to you to take part or not. Choosing not to take part will not disadvantage you in any way, now or in the future. Before you decide, please read the information on this and the following pages carefully and discuss it with others if you wish, or ask us if you have any questions. If you agree to take part, please continue with the survey; however, you can still withdraw until 01/08/2018 without giving a reason and without penalty. To do so you will have to quote this code: ${e://Field/Withdraw_ID}. Please do take a note of this code now.

☐ Yes, I understand how I can withdraw now or later and wish to proceed in this study 1)
☐ No, I do not wish to proceed with the study 2)
**What are the eligibility criteria?** You are eligible to take part if you are over 18 years of age and work in design, technology development or academia and have a strong interest in CD.

- Yes, I confirm that I meet the requirements and wish to proceed with the study (1)
- No, I do not match the criteria or wish to withdraw (2)

---

**Are there any risks?** We do not foresee any risks when taking part in this study.

**What are the benefits?** There are no financial benefits associated with this study. We nonetheless hope that you might find the study useful as a means for reflection.

- Yes, I understand that there are no risks or financial benefits associated with the study and wish to proceed (1)
- No, I do not wish to proceed with the study (2)

---

**What about confidentiality?** We will not gather any personal data for this study, all answers will be recorded anonymously.

**How will the data be stored and used?** All data will be collected and stored in accordance with the EU GDPR 2018. Your responses will be stored in a secure facility within the UK, it will be used for research, publication, and teaching purposes only. The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL’s Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk. Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be performance in a task of public interest. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

**How will the results be disseminated?** The results will be disseminated through academic venues such as conferences and journals and will be used in BS's PhD thesis.

- Yes, I consent to the data collected in this study to be stored and disseminated in this way and wish to proceed with this study (1)
- No, I do not wish to proceed with the study (2)
You can find an information sheet that summarizes all the points here. Please read through it carefully and get in touch should any questions remain before proceeding.

Name | Britta Schulte | Paul Marshall | Anna Cox
--- | --- | --- | ---
Work Address | UCL Interaction Centre 2nd floor Gower Street 66 – 72 University College London WC1E 6BT | UCL Interaction Centre 2nd floor Gower Street 66 – 72 University College London WC1E 6BT | UCL Interaction Centre 2nd floor Gower Street 66 – 72 University College London WC1E 6BT
Contact Details | britta.schulte.15@ucl.ac.uk | paul.marshall@ucl.ac.uk | anna.cox@ucl.ac.uk

Otherwise please indicate your consent and start the study!

- Yes, I confirm that I have read and understood the Information Sheet for the above study. I have had the opportunity to consider the information and what will be expected of me. I also that the opportunity to ask questions which have been answered to my satisfaction. (1)
- No, I do not wish to proceed with the study (2)

Q31 Please describe the sector you work in.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
_____________________________________________________________
Q30 Which of these fields are you working in?

- Commercial (1)
- Research (2)
- Education (3)
- Other (4)

Skip To: Q33 If Which of these fields are you working in? = Other
Skip To: Q26 If Which of these fields are you working in? != Other

Q33 Please describe your field of work.

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Page Break

Q26 Which area has your education or training been in?

- Design (1)
- Arts & Humanities (2)
- Social Sciences (3)
- Engineering (4)
- Other (5)

Skip To: Q29 If Which area has your education or training been in? = Other
Skip To: Q13 If Which area has your education or training been in? != Other

Page Break

Q29 Please give more information about the training or education you received.
Q13 Have you undertaken one or more CD projects yourself?

- Yes (1)
- No (2)

Display This Question:
If Have you undertaken one or more CD projects yourself? = Yes

Q14 Please tell us a bit more about the projects you have undertaken, e.g. what topic they addressed, how you used CD or for how long you have been working in this area.

Display This Question:
If Have you undertaken one or more CD projects yourself? = No

Q15 What is your interest in CD?
Q1 How would you define CD?

Q2 Please describe an example of what you consider CD either from your own or other's people work.

Q3 What stands out to you about the project you chose?
Q4 Do you consider the example you have chosen a good piece of work? If so why?
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Q12 What makes this project critical in your opinion? How does it relate to more traditional design?
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Q5 Can you describe a bad example of CD? What does it lack?
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
Q16 Are you aware of the work of Dunne & Raby who coined the term 'Critical Design'?  
   ○ Yes (1)  
   ○ No (2) 

Display This Question:  
If Are you aware of the work of Dunne & Raby who coined the term 'Critical Design'? = Yes

Q17 How would you say your understanding of CD relates to this definition?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Display This Question:  
If Are you aware of the work of Dunne & Raby who coined the term 'Critical Design'? = No

Q18 You can familiarize yourself with their work [here](opens in a new window). How would you say your understanding of CD relates to this definition?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Page Break

Q19

If you wish to withdraw your response for any reason, please contact me at britta.schulte.15@ucl.ac.uk and quote your identification number: ${e://Field/Withdraw_ID}. I will remove your data as soon as possible and not regard it for the analysis. You do not have to
give any reason for wanting to withdraw. If you have any other questions, throughs or comments, please do not hesitate to contact me via the email quoted above or leave a comment here:

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

End of Block: Default Question Block
Appendix IV: Probe Materials for Privacy Experts

Tell me what you think about

Dementia & Privacy

Study by Britta F. Schulte
as part of my PhD in Interaction Design

In these packs you will find collages showing practices in dementia care in a stylized way, which have been developed from academic literature around the topic of technology use in dementia care. Please use the pens and materials provided to express your feelings towards these practices, highlight benefits and to point out possible ethical and technical issues. Each page has questions on them for you to start with, but I am interested in all your thoughts and reactions around the scenarios: emotional, sociological or technical. You can write or draw and use all sheets and materials provided.

By returning the filled-in pack:
- You agree to take part in this study voluntarily and are aware that you can withdraw without penalty at all times.
- You confirm that you understand what the aim of the study is, who undertakes it and what is asked from you. Should you have any questions regarding this study or wish to discuss any issues related to it do not hesitate to get in touch with any of the researchers:

Britta Schulte
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2nd floor
Gower Street 66 – 72
University College London
WC1E 6BT
britta.schulte.15@ucl.ac.uk

Paul Marshall
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paul.marshall@ucl.ac.uk

Anna Cox
UCL Interaction Centre
2nd floor
Gower Street 66 – 72
University College London
WC1E 6BT
anna.cox@ucl.ac.uk

You should keep this sheet with you for further reference. Further information about the research project and reflections about this study can be found on my blog under www.dementiahacks.wordpress.com.
- You understand that your data, such as texts or drawings on the sheets is used to inform my future PhD research and may be shared in my PhD thesis or may be presented in other academic publications and/or conferences, workshops or teaching. All data will be fully anonymized and it will not be possible to identify you in any way. The data provided will be stored anonymously until the end of the project, when it will be deleted.

The study has been approved by the UCL Interaction Centre Research Department’s Ethics Chair [Project ID 8139/001]
Camera surveillance in dementia care homes

To enable the nurses to respond quickly to falls or attend to confused residents, the care home in which Laura lives has set up cameras in the living room and hallways.
GPS trackers

This is Peter. He has dementia. Because his wife worries he might get lost if he does not remember the way home, he wears a GPS tracker. When he is not home by a specified time, she checks where he is and goes out to search for him.

What do you think about this technology? Who benefits? Are there any issues?
Jane has not left the bedroom since 10 h.

Janes house has been fitted with motion sensors. When she deviates from her normal pattern her family is alerted by text.

What do you think about this technology? Who benefits? Are there any issues?

Your response:
RFID tags used in dementia care homes

In the new care home Doris wears a wrist monitor. It opens some doors for her, but not the front door. Her friend George can go out, but staff will be notified if he goes further away from the care home than 500 m.

Your response:
Camera surveillance at home

John's father was diagnosed with dementia five years ago. When leaving for the office John worries about leaving his father on his own in their shared flat. So he has set up a webcam there so that he can check if his father is alright from his desk.

What do you think about this technology?

Who benefits? Are there any issues?

Your response:
And how about you? What would you like to use if you had been diagnosed with dementia? Dementia is an umbrella term for degenerative brain disorders that affect memory, communication, personality and mood. As the illness progresses people may not be able to voice their preferences or make decisions about their future. Have a think how you would like to be treated and tell the ones next to you, so that they are able to act in your best interest.

1. Monitoring
In the later stages of dementia people may lose balance and may be prone to falls. These can lead to serious injuries and long stays in hospital during which dementia symptoms typically worsen.

To detect that I have fallen, I allow

☐ my partner ☐ family members ☐ paid carers ☐ care home staff
☐ other: ___________________________ ☐ none of the above

To monitor me using

☐ video ☐ audio ☐ other environmental sensors such as pressure sensors
☐ other: ___________________________ ☐ none of the above

These can be installed in

☐ my bedroom ☐ the bathroom ☐ public places such as a living room
☐ other: ___________________________ ☐ none of the above

2. Tracking
People living with dementia may have problems with orientation even in formerly known surroundings and are therefore considered in danger of getting lost when leaving the house. People with dementia have been known to be unable to reach help soon enough and suffer severe bodily harm or even die as a result of this.

To enable search parties to find me more easily I agree to wear a tracking device and allow

☐ my partner ☐ family members ☐ paid carers ☐ care home staff
☐ other: ___________________________ ☐ none of the above

To track my movements.

These should be

☐ followed in real time ☐ stored for a limited time only
☐ accessed only when certain incidents occur:

______________________________
3. Tagging
Tagging technologies that open or lock doors automatically or alarm carers when the person with dementia leaves the house or a predefined area are in use in some care homes. They have been put in place to replace other physical restrictions and are set into place to allow wider movement but keep the person with dementia within a safe space.

I allow

☐ my partner ☐ family members ☐ paid carers ☐ care home staff

☐ other: _________________________ ☐ none of the above

☐ to notify the above when I leave a specified area ☐ to set boundaries in which I can move
Thanks for taking part!

If you would like to be informed about the progress of the project or would be available for follow-up interviews, please leave your email address below:

Deutsch: http://www.wegweiser-demenz.de

English: https://www.alzheimers.org.uk

Image credits:

All images have been selected and edited without endorsement by the producers of the images. The scenarios presented within this pack are based on real scenarios, but are in no way connected to the producers of the images.

Surveillance in care homes:
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"Renaissance Care Center Living Room" licensed by Cantex Senior Communities, available at flickr.com

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Motion monitor:
"Blueprint for 4 Timber Dwellings, Adam Street 1909" licensed by Dunedin City Council Archives, available at flickr.com

Tagging:
"Open door" designed by Freepik, available at freepik.com
"Closed door" designed by Freepik, available at freepik.com
Background image licensed by OpenStreetMap, available at openstreetmap.com
"Tracker on wrist" own photography

Surveillance at home:
"New office" licensed by Dave Linbury, available at flickr.com
"Hugely Happy Webcam Face" licensed by Karl Gookey, available on flickr.com
"Grandpa @ Breakfast Table 1977" licensed by Anthony Catalano, available at flickr.com
Appendix V: Interlude – DEO Ex Machina: a new Framework for Virtual Agents in Automated Elderly Care Provision

Recent years have seen an increase of technologies that build on interaction between virtual agents and humans (VHI). While the adoption has been successful in many areas such as production and education, other areas - specifically elderly care - show a lack of engagement. Age seems to be a defining factor as users are not used to the technology and do not benefit from its full potential. Recent updates of the virtual agents (VA) technology specifically for the sector, aesthetic adaptions or new interfaces did not seem to have made a significant change in the area.

In this paper we present an analysis of interaction logs gathered in a care home equipped with VAs throughout. Contrary to common beliefs the interaction does not break down on the side of the VA, but on the human side as people reject, misinterpret or ignore the well-intentioned suggestions of the VA. Following these insights, we present a new framework to support interactions: DEO. We propose the three steps: DISPENSE and log how the human responds, EDUCATE the human of the insights he is lacking to make the necessary changes and OVERWRITE his decisions, should he repeatedly decide not to follow them. We give detailed instructions on how to best implement each step based on our results. We argue that these steps will lead to increased adherence to the suggestions by VAs even by the elderly population, thereby making the technology accessible to a wider audience.
Appendix VI: Worksheets for IoT meetup participants

Homes for Life - a critical design fiction to explore the use of smart homes for home care

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8139/003

<table>
<thead>
<tr>
<th>Name</th>
<th>Britta Schulte</th>
<th>Paul Marshall</th>
<th>Anna Cox</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work Address</td>
<td>UCL Interaction Centre 2nd floor&lt;br&gt;Gower Street 66 – 72&lt;br&gt;University College London&lt;br&gt;WC1E 6BT</td>
<td>UCL Interaction Centre 2nd floor&lt;br&gt;Gower Street 66 – 72&lt;br&gt;University College London&lt;br&gt;WC1E 6BT</td>
<td>UCL Interaction Centre 2nd floor&lt;br&gt;Gower Street 66 – 72&lt;br&gt;University College London&lt;br&gt;WC1E 6BT</td>
</tr>
<tr>
<td>Contact Details</td>
<td><a href="mailto:britta.schulte.15@ucl.ac.uk">britta.schulte.15@ucl.ac.uk</a></td>
<td><a href="mailto:paul.marshall@ucl.ac.uk">paul.marshall@ucl.ac.uk</a></td>
<td><a href="mailto:anna.cox@ucl.ac.uk">anna.cox@ucl.ac.uk</a></td>
</tr>
</tbody>
</table>

What is this study about? We are interested to learn the views of developers and designers on potential uses of smart homes in health care.

What are you asking of me? You will first read this consent form and ask any questions you might have about this study. If you are comfortable taking part in the study, you will sign this consent form. You will be shown a video about smart homes and will be asked to fill in a form with questions about the video.

Is participation required? No; it is entirely up to you to take part or not. Choosing not to take part will not disadvantage you in any way, now or in the future. Before you decide, please read the following information carefully and discuss it with others if you wish, or ask us if you have any questions. If you agree to take part, you will sign a consent form; however, you can still withdraw at any time without giving a reason and without penalty.

What are the eligibility criteria? You are eligible to take part if you are over 18 years of age and work in the development or design of smart technologies/IoT devices or have a strong interest in the topic.

Are there any risks? The video touches on topics that might cause slight inconvenience: illness and death. If you feel uncomfortable at any time, you can withdraw from the study or refuse to answer without penalty of any kind.

Will I be recorded? What about confidentiality? You will not be recorded. We will use notes made by the researcher and your notes on the worksheet for analysis. We will further ask demographic data. We will not ask your name, email or any other identifiable data and will ensure that quotes will be used anonymously by using identifier e.g. participant 1 at a technology meetup in London.
How will my data be stored and used? All data will be collected and stored in accordance with the Data Protection Act 1998. Your data will be anonymised and stored in a secure facility; it will be used for research, publication, and teaching purposes only.

How will the results be disseminated? The results will be disseminated through academic venues, such as conferences and journals and will be used in my PhD thesis.
Participant's Statement

I ................................................................. agree that I have:
- read the information sheet and/or the project has been explained to me orally;
- had the opportunity to ask questions and discuss the study; and
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.

... and I understand that:
- I am free to withdraw from the study without penalty if I so wish;
- I consent to the processing of my personal information for the purposes of this study only;
- the information I have submitted will be published as a report. Confidentiality and anonymity will be maintained, and it will not be possible to identify me from any publications;
- such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed:                                         Date:

What was the first thing you noticed about the story and why did it stand out to you?

What did you think about the technology presented in the video?
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
<td>What do you think about the people in the video?</td>
<td></td>
</tr>
<tr>
<td>Would you move into the house? What – if anything - would you like to change before you did?</td>
<td></td>
</tr>
<tr>
<td>Do you think the story has changed the way you think about smart homes? In what way?</td>
<td></td>
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<tr>
<th>Which points – if any – do you think you might discuss with others in future?</th>
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<table>
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<tr>
<th>Thank you! Please tell us something about yourself:</th>
<th>My occupation is</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am ..........years old.</td>
<td>I am male / female / prefer not to say.</td>
</tr>
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Appendix VII: Focus Group Protocol for Design Practitioners

Homes for Life - a critical design fiction to explore the use of smart homes for home care

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8139/003

<table>
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<td><a href="mailto:paul.marshall@ucl.ac.uk">paul.marshall@ucl.ac.uk</a></td>
<td><a href="mailto:anna.cox@ucl.ac.uk">anna.cox@ucl.ac.uk</a></td>
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What is this study about? We are interested to learn the views of developers and designers on potential uses of smart homes in health care.

What are you asking of me? You will first read this consent form and ask any questions you might have about this study. If you are comfortable taking part in the study, you will sign this consent form. You will be shown a video about smart homes in use and will be asked question to be discussed in the group.

Is participation required? No; it is entirely up to you to take part or not. Choosing not to take part will not disadvantage you in any way, now or in the future. Before you decide, please read the following information carefully and discuss it with others if you wish, or ask us if you have any questions. If you agree to take part, you will sign a consent form; however, you can still withdraw at any time without giving a reason and without penalty.

What are the eligibility criteria? You are eligible to take part if you are over 18 years of age and work in the development or design of smart technologies/IoT devices or have a strong interest in the topic.

Are there any risks? The video touches on topics that might cause slight inconvenience: illness and death. If you feel uncomfortable at any time, you can withdraw from the study or refuse to answer without penalty of any kind.

Will I be recorded? What about confidentiality? The focus group will be audio-recorded. These will be transcribed to support the analysis of the data. Quotes might be used anonymously for publication, but the audio data will only be shared within the research team.
How will my data be stored and used? All data will be collected and stored in accordance with the Data Protection Act 1998. Your data will be anonymised and stored in a secure facility; it will be used for research, publication, and teaching purposes only.

How will the results be disseminated? The results will be disseminated through academic venues, such as conferences and journals and will be used in Britta Schulte's PhD thesis.

Will I be compensated? You will receive a £15 voucher if you participate in the focus group.
Participant's Statement

I …………………………………………………………………………………………….. agree that I have:

- read the information sheet and/or the project has been explained to me orally;
- had the opportunity to ask questions and discuss the study; and
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.

… and I understand that:

- I am free to withdraw from the study without penalty if I so wish;
- I consent to the processing of my personal information for the purposes of this study only;
- the information I have submitted will be published as a report. Confidentiality and anonymity will be maintained, and it will not be possible to identify me from any publications;
- such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed:  
Date:  
Contact email:  

Questions:

How would you summarize the video?

What did you think about the technology presented in the video?

What do you think about the people in the video?

Would you move into the house? What – if anything - would you like to change before you did?

Do you think the story has changed the way you think about smart homes? In what way?
Appendix VIII: HawkEye Welcome Letter

HawkEye
healthcare technologies

HawkEye Headquarters
Gower Street
London WC1E 6EA
+44 (0) 7517280301
hawkeye-technologies@outlook.com

To new volunteers in the HawkEye programme

April 2018

Welcome to the HawkEye programme

Dear reader, dear volunteer,

Thank you for participating in the HawkEye dementia care programme and joining us on the path to better and more personalised dementia healthcare. As more and more people are living with dementia, there is an increasing shortage of medical personnel to attend to each individual with dementia. Having some extra eyes within the community greatly helps us to personalise care and allows people with dementia to stay independent and live at home for a longer time. We have designed software to analyse the well-being of individuals with dementia and to be able to personalise their care package completely. In line with the recent Artificial Intelligence and ethical standards report by the European Commission, we believe that a human factor should always be kept in the loop. Therefore, we would like to ask you to help this software system to make humane decisions for one of our people with dementia. Don’t worry, we also do regular check-ups on all residents and are alarmed in case of an emergency, but you are our eyes for when we are not looking.

You have been selected to care for Annie, a lively 82-year-old woman who lives on her own. Her husband passed away last year and as they never had any children, much of her support system has fallen away. A detailed analysis of Annie’s social network brought us to you, as we understand she used to be a close family friend; our systems indicate you used to go on holidays together and that she would always bake you the greatest cookies. Annie was recently diagnosed with Alzheimer’s disease and was moved into a smart home that can care for her. The home takes care of her basic needs and notifies us - and you - of alarming situations. Living in this house means that Annie can stay independent for as long as possible and the house is flexible to adapt to her changing needs. We have all basic things such as grocery shopping covered for her and the house is very safe.
Each day, you will receive a report on Annie’s wellbeing. Several kinds of data will be displayed for you, depending on which modules you have activated. Based on the report you can decide to increase the level of the different modules that are installed in Annie’s house. Higher levels will generally give you more information on what is going on in Annie’s life and thus allow you to make more informed decisions. You can change the level of a module at any moment. An explanation of the different modules and technologies in the house, as well as the instructions for installation can be found in the information booklet in this welcome package.

You will have a trial period of 21 days with Annie, after which we will have an evaluation for the continuation of your participation in the HawkEye programme. Please keep track of the experience in the resident file, such that we can use your notes as the base for our evaluation.

Thank you for signing up for the HawkEye programme on behalf of Annie and the entire HawkEye community!

Kind regards,

ETHAN WYATT
CEO HawkEye Healthcare Technologies
Appendix IX: Interlude – Homes for Death

“Dasha, I am scared.”

“I understand Clare. Would you like me to call someone? A chat with your daughter has helped you in the past to relax.”

“No. No. No. She really is the last person I want to talk to right now. She will be upset I know. This is not something I want to burden her with.” Clare wondered what this conversation would be like. Darling, do you think I’ll go to heaven? Are you scared of death? Clare shook her head to wipe the thought away.

“That is really nice of you Clare. Is there anyone else you would like me to get you in touch with?”

“Thank you Dasha, but I think it is down to the two of us.” Clare could not help but snigger. Here she lay, in her dark bedroom, talking out loud to the furniture – and the furniture replied. Dasha was an integrated smart home solution, discreet, adaptable, always on. When her daughter had urged Clare to get the monitors – “Because everyone has them now, you will be surprised how much easier everything becomes” - Clare had been hesitant. It was true that a lot of her friends had been started to use these and most were quite happy. Clare did not really feel like she needed any of it though. But her daughter had taken care of it and had helped her out and had the smart home packet installed. It had only been two days of builders taking over her house, but she had to admit that now you could not see any of the tech if you not tried to find it. But the boxes were there, they measured where she was, what she did, said and ate. And plenty of other things, but Clare had stopped caring what it all was.

It was useful. Not really necessary, Clare had thought, but it was fun and it reminded her of stuff so she did not forget her keys anymore and it made cooking so much easier with the spoken recipes and she loved that she could now listen to the radio and it just followed her around the house.

So, when her daughter had suggested the care package as well, Claire thought it was even more unnecessary, but went along with it because it was so important to her daughter. It was not as if it was much effort now that the main installation had been done. Just a couple of clicks and a credit card payment. Well, monthly payments. The care package took care of her medication and had a lot of emergency functions, so whenever something would happen to her, her daughter would be the first to know. Clare had secretly switched some of them off after her daughter had stood on her doorstep a couple of times, scared and panicky, because the system had gotten it completely wrong. Oh, the incident when she forgot the sausages on the oven and had to convince her daughter that the house was really not burning down. They would always end up having a coffee together and laughing about that, but it hurt Clare that her daughter thought her incapable of dealing with problems on her own. It was well-meant, but Clare could not help thinking that is had been the other way round not too long ago. Clare worrying over her daughter, who made it quite clear that she was old enough to make her own mistakes, thank you very much. Clare did not feel she could go through this all over again. She had found the manual
online and learned how to over-write the functions she did not like. It was hers and Dasha’s little secret. It was stupid, but afterwards Clare felt closer to this machine. The machine that did the things SHE wanted. It became her toy as much as it was her daughter’s. Or maybe even more hers.

Some of the things it did in the background though, keeping them a secret from Clare as well. The diagnosis system had been measuring her sleep, gait and behaviour for about a year until it urged Clare to go and see a doctor.

The diagnosis of Alzheimer’s was not that much of a surprise to Clare, she had seen it in her family and a couple of friends and she was rather relieved that it had taken until she was 92 for it to come through. She told her daughter who was much more upset than she was at this point and then went along and bought some more specific care packages. Advice, brain games, counselling – and the one she was about to deal with now. There had been a couple of times, especially in the evenings, when she got scared and confused and it was so good to have the tech talk her down, advice what she could do, rather than putting any of this strain on her family. Talking to Dasha was quite natural to her by now, but sometimes, in moments like these, it struck her how weird it all was. The two of them had found their rhythm, Clare knowing that it was not necessary to talk as much as she did, knowing that Dasha did not know what she was actually saying, but it felt ok after she had gotten used to it.

She thought about what she wanted to do next. She had no problem to admit that she was scared. It was a big step she was about to take. Final. Much planning had gone into it, but Clare did not feel ready yet. “Dasha, can we go through the list one more time? I want to make sure that I have put my house in order” Clare sniggered at her pun. Dasha really did not get jokes, but Clare was sure she would have enjoyed the pun as well if she could.

“Sure Clare, just to confirm, is this the ‘end of life’ list you refer to? It is the one you accessed last.”

“Yes, Dasha, that one. I want to make sure that I have put the essential information in there.”

“I’ll have a look for you. I have the points: testament, funeral and last words in there. We will need to add the last point you have snoozed, which is the declaration. You will have to do it before you can proceed.”

“Ok, Dasha, I will do that soon. Can you make sure that the last word settings are all in order?”

“Clare, the last words folder contains a video to your daughter, which we recorded together on the 20th of March at 11:23 pm. It contains a message about your relationship and why you took the steps you did. I will make her aware of this message when she comes into the house the first time after you left and play it on the big screen in the living room if she wishes to see it. If she denies, I will remind her at occasions after that, about once a week when I see her. Another option will be for her to email the video to herself. Would you like to see the video?”
“No, god, no, you know how much I hate it when you play things back to me. I just wanted to be sure that it is there and that she will get it. She will be so upset when she finds out and I want to be sure that she gets the video at least. I don’t want her to blame herself. I don’t want her to worry that I suffered.”

“Would you like me to record your last moment for her? Should we add that to the video?”

“No, thank you, you have offered that before, but the answer is still no. I think it would be wrong to have that. Macabre. Can you not ask me again?”

“Yes, Clare, I will save your options as final.”

Clare lay in the dark of her bedroom and tried not to think of the last moment. She wondered if it would be better if someone was around. Someone to hold her hand, hold her, someone who would care – but she could not imagine who that might be. She had the conversations after some of her friends had passed on, at funerals, descriptions of rooms full of people, last goodbyes. It sounded great, but she was not sure if that was what she wanted. She was scared that it might be weird, ugly. Scared that she would harm her daughter. She so badly wanted to spare her any pain. Even though her daughter had learned to make her own mistakes, Clare could not help feeling responsible. The two of them had been making their way on their own for so long … She did not have friends so close that she wanted them here and her ex-husband really was the last person she wanted to see as the last person on earth.

Having Dasha around was a nice alternative, something, someone she could confess to, someone to calm her down. She was not that far gone, she knew it was all fake, but to some extent that just made it better. Easier. She took a deep breath and said: “Ok, Dasha, I am ready, what do I need to do for the declaration?”

“To ensure that I can help you with what you want to do, to ensure that I do not take any measures that would keep you alive, to ensure that no emergency contacts will be notified even though the data suggests that they should, I need you to confirm that you are aware of the consequences of your actions, that you are of sound mind and that you are undertaking this on your free will. This takes the shape of a declaration that you speak out and I will record. It will be made available to anyone who might have an interest in the matter e.g. close family, my production company or law agencies, especially the police or any insuring companies that you relate to. Otherwise I will keep the data secure under the data protection laws. I also need you to tell me when you would like me to tell others of your passing, and in which order as the normal emergency procedure will be interrupted.”

Clare took another deep breath. There she was. It was getting serious. She could stop it anytime or go ahead with it. But she had come a long way from her first tentative thoughts and steps. “Dasha, low lights in the bedroom, please”. In the low glim of the lights Clare sat up and let her feet dangle off the bed. She checked the two medications she had gotten from the chemist a month ago. Still ok. She had been putting it off. Found enough good days to enjoy. Brought her house in order. But recently there had been many days when she was confused. She got scared she might not be able to do it. Already a couple of doors had closed where she could
have done it because of the dementia. Doctors would not help her because she might be confused and not herself anymore. Same with this place in Switzerland. Dementia was a reason why people started to question herself, her identity, her mind. Ironically, dementia was also the reason why she wanted to take this step in the first place. But Dasha had no ethical concerns, no concept of suitability or acceptability beyond what Clare told her. Nothing to hold her back.

The medication was there. The setting up of Dasha was nearly there. Clare wore comfortable clothes she liked and her mother’s pearls. The pearls had been in her family for generations. At least that’s what she was told – and what she had told her daughter. The pearls had become part of a larger circle. They felt like a part of her, after she had taken care of them for so long, but she was happy, she was ready, to pass them on. After a second of hesitation she took them off and neatly arranged them on the bedside table. She did not want her daughter to have to go and take them off a dead body as she had done so many years ago. Times had been different then. And her mother really old-fashioned. But Clare was not. She was ready to take the plunge and do what she felt had to be done.

“Dasha, what is the example text of the declaration?”

“I, Clare Chuong, confirm that I am aware that the action I am about to take will end my life. I am currently of sound mind and I do so without any external pressure. You are free to alter parts of the message, but I need you to confirm that you are of sound mind, do this at your free will and know what is going to happen.”

“I understand. Dasha, start recording my declaration: I, Clare Chuong, know that the medication I am about to take will end my life. I wish to take it out of my free will. I do so because I am still of sound mind, but as the illness progresses I will be unable to do so. I still have great times, I am happy and I have people I love, but I feel strongly about my autonomy and wish to end my life now, while I still feel this way.” Clare took a deep breath and thought about what she had said: “Dasha, would that do?”

“Yes Clare, that declaration is sufficient. The normal emergency procedures have now been disengaged. Would you like me to set up new procedures?”

“Yes Dasha. I want to do it exactly as we discussed earlier. Once you are satisfied that I am dead, please call 999 and inform them off my suicide. They will arrange the next steps. Please unlock the door for any medical staff or the police who might come to arrange matters. Please provide them with my daughter’s contact detail as the next of kin and ensure that they notify her at some point. Refrain from sending out notifications yourself. Once she is in the house, please give her full system access, so that she can control the house in my place. Please confirm.”

“Clare, I understood that you would like me to contact the emergency services after your vital sign readings have stopped. I will make arrangements for the emergency personnel to enter and give them access to your daughter’s contact detail, but will refrain from sending out notifications myself. She will be given access to the data and controls once she is physically in the house.”

“Excellent. Please engage the new emergency procedures.”
“New procedures up and running”.

“Ok then, sounds like all is ready.” Not sure if I am ready Clare thought to herself. She had never come so far. She had spent the last month setting it up though and planning it even longer. She had had long conversations with Dasha’s counselling service. She had spent long hours with the end of life programme to think about her will and all that should go in it. Talking to a machine made it so much easier than talking to anyone else. She had tried to talk to her GP about hospices and other ways how they might be able to help her, but she could never shake off the feeling that she made that poor woman incredible uncomfortable. She had had a chat with a friend of hers who was a Vicar to get a second opinion but as she had expected he only tried to talk her out of it.

Dasha never judged. The advice she offered was based in sheer numbers, not religious values or morals. It made it easy to ask outrageous questions like “Dasha, should I end my life?” She had laughed at some of the first approaches with which Dasha had tried to make sense of her question and some conversations had been plain ridiculous as the machine tried to solve existential questions the same way she normally tried to answer the question what best to cook with the contents of the fridge. To Dasha there was no difference in the question. Dasha had offered her to look up rituals on Wikipedia, had pointed her towards Government statistics and had asked if Clare wanted to call her daughter – Dasha’s go-to solution if she did not know what to do. It had taken a couple of discussions for Clare to narrow down what she was interested in and explain it in a way Dasha could help her out. Clare wanted info on so many things to make her decision. She wanted to know what would happen with her. Which Dasha could not tell her, because dementia had such an individual pathway, nobody could foresee if she would develop symptoms and when. Dasha could make some estimations based on her past behaviour, gait pattern and some of the stories Clare could remember about her mother. But then there were the drugs that might help out or not. And there was Clare herself. She wanted to be in control. That was her main concern. She did not care if she was happy, if she was cared for. She had seen people living with dementia live happily for years, in their own world sometimes, sometimes good, sometimes bad. But she did not want that for herself. She wanted to be able to say “Stop” and a point where she now thought it was ok. Weirdly enough, she really did not care if she would be happy then. She had discussed that with Dasha, whether the decision should be bound to a value: XX number of days in which she could not remember something, her happiness level being constantly below value XX when she started to sleep all day or not at all. It had taken a lot of discussion to help her figure all this out and Dasha’s patience had been a joy and a burden at the same time.

Convincing Dasha had taught Clare what was important to her and why she wanted to go ahead. She felt safe to ask the question as often as she needed to until is changed into “Dasha, how can I end my life?” She had found the package online that dealt with the complex questions around medical and legal advice and had used it extensively to make sure that the procedure would not get anyone in trouble, that her testament was set up that her daughter would get the best of the little she had and that professionals would find her and she would not lie in her house for days on end. Everything was ready. She was ready. “Dasha, please play the ‘last day’
playlist. Oooh, go down five levels, yeah, that sounds about right. Nobody could go to sleep in this racket.” She smiled to herself again at this little pun. She read one last time through the instructions on the medicine. Let the pearls glide through her fingers one more time. “Dasha, can we alter the emergency procedure please?”

“Sure Clare, what would you like to change?”

“When you do not detect vital signs anymore, please shut off all the lights in the house and do not start a new song. Only then do I want you to go ahead with the procedures as discussed. Please repeat for me.”

“Clare, you would like me to shut off all the lights and finish the music once I do not detect vital signs anymore. I will make arrangements for the emergency personnel to enter and give them access to your daughter’s contact details, but I will refrain from sending out notifications myself. She will be given access to the data and controls once she is physically in the house.”

“Thanks Dasha, please go ahead.”

“New procedures up and running.”

“Thank you Dasha.” Clare slid from the bed. She read through the instructions one last time, yes this time it would really be the last time, she assured herself and went to the kitchen to carefully measure the right amount of water for the medicine. She felt as ready as she would ever be. She had put her house in order. Did the best she could to make this easy for her and for her daughter. She hummed along to her favourite song all the time as it followed her through the house. Kitchen, bedroom, bathroom. Not happy maybe, but determined. Back in the bedroom, she took the last preparations. She took the medicine and lay down on the bed. One by one the lights around her shut down and the last song ended in silence.