

Surveillance technology, dementia and the media: Responses from people living with dementia and family carers

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Declaration

I, Yvette Cornelia Maria Linda Vermeer confirm that the work presented in this thesis is my own and hereby declare that this work has not been submitted for any other degree at this university or any other institution and that, except where reference is made to the work of other authors, the material presented is original. Some portions of the thesis chapters have been published as follows:

Parts of chapter 2 in

- Vermeer, Y., Higgs, P., Charlesworth, G. (2019c). What do we require from surveillance technology? A review of the needs of people with dementia and informal caregivers. *Journal of Rehabilitation and Assistive Engineering*. (6): 1-12. DOI: 10.1177/2055668319869517

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Surveillance technology and dementia: empowerment of people living with dementia and family carers

VERMEER, Yvette

Abstract

Globally technology has become a popular response to the challenges of ageing populations. Dementia presents a particular problem for family carers and policy makers for which surveillance technologies (STs) such as monitoring devices are posited as solutions. ST products are marketed online focusing on their capacity to empower people with dementia; however, these products are developed without considering (potential) user input. The literature about dementia and surveillance was reviewed as was the nature of the ST market. The involvement of users in setting the parameters and utilities of such products was investigated through qualitative research. This interdisciplinary research undertook a tripartite approach studying: production (what is on the market); audience reception (what do users need); and media content (what media techniques are used to attract attention) in the United Kingdom, Sweden and the Netherlands. The key finding across studies was that there was little recognition that people with dementia have different needs from those of carers. A “wanderer” discourse gave minimum representation to people with dementia interacting with technology stressing instead the dangers of wandering from carers’ perspectives. This dichotomy was reflected in the different interpretations that each group made of advertisements. Carers focused on wanting small trackers for covert use. People with dementia conversely thought ST was not for them as it stigmatised them. People with dementia are not passive. They have individual needs for independence and these can conflict with those of carers. These findings are relevant to technology designers and advertisers by highlighting their assumptions about this gap in the (civil rights) movement market.

Impact statement

The aim of this thesis was to understand how surveillance technology products are marketed and how this impacts the experiences and needs on people with dementia and family carers. This thesis is positioned on two contradictory ideas: 1) that technology can be a solution for an ageing population and 2) that people with dementia can be empowered while valuing the needs from carers. Therefore, this interdisciplinary qualitative study examined the surveillance market, user needs and how such products are marketed in the United Kingdom, Sweden and the Netherlands. The literature review and the market examination of 242 websites explores user needs for surveillance technology such as GPS trackers intended for dementia-care. The findings show that a niche market targets carers to sell their passive tracking products with promises of increasing the safety of people with dementia, pets and possessions. This market and research do not acknowledge individual differences and disregard carers and people with dementia within the discussion, design and dissemination of surveillance technology. Therefore, a public involvement group of carers and people with dementia has helped shape this study and for the first time separate (online) discussions were used to develop a framework of user needs towards surveillance and advertisements.

Furthermore, a lose-lose situation occurs in the surveillance market as marketers are not getting their commercial messages across, carers struggle to find products that meet their needs and people with dementia felt stigmatised by the advertisements. The generated knowledge gives attention to how advertisements sell not very useful technology, shape people's perception and contribute to lack of understanding about dementia. Recognising these issues will inform society and result in a step helping develop dementia-friendly products and advertisements. Accordingly, the framework of user needs aimed at healthcare professionals and designers can be used to improve products. This knowledge also impacts how surveillance is seen by policymakers as a 'solution' to ageing populations. The view that technology saves costs in healthcare has, for some time, enjoyed widespread and uncritical acceptance at the heart of policymaking.

If media and technology sectors become more responsive to the new market, which includes people with dementia, they will be empowered to engage with policymakers, ensuring that future policy will encourage designers and policymakers to celebrate individuality and set the agenda. However, user and public involvement are not boxes to be ticked off an agenda and should not be used in a tokenistic fashion. Instead, the focus should be on diversity and inclusion of human beings with

their own needs, experiences and rights. Similarly, if citizens accept the challenge to critically review the market, then they will be able to make informed decisions on how to ensure that technology can empower people. This will then enable citizens to become actively involved and influence what this market offers. In conclusion, before one develops a product for empowerment, think about what empowerment actually means in the context it is going to be used. Failing to do this can result in underdeveloped markets, frustrated users and technological irrelevance.

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Abbreviations

AT	Assistive Technologies
AAL	Ambient Assisted Living
ALT	Assisted Living Technology
GPS	Global Positioning Systems
ICT	Information and Communication Technology

INDUCT	Interdisciplinary Network for Dementia Using Current Technology
NL	The Netherlands
PPI	Public and Patient Involvement
QOL	Quality of Life
SHT	Smart Home Technology
STs	Surveillance Technologies
SWE	Sweden
UK	The United Kingdom
USA	The United States

Chapter 1: Introduction

1.1 Introduction

There is an ageing population and dementia has become a public health priority (Alzheimer's Disease International, 2019; World Health Organization, 2017). The estimated number of people with dementia is expected to grow to 152 million by 2050 and there is no cure or a treatment which can prevent the disorder from worsening (Alzheimer's Disease International, 2019). There is a high rate of failure in drug development and the growing number of older people and set prevalence of dementia itself has led to the necessity to find other strategies (Alzheimer's Disease International, 2018). Research and public health media have turned from focusing on medicine as a solution to prevention and social intervention strategies at the present moment (Prince, 2017). One intervention strategy in Europe is the significant investment in technological products as part of a cost-efficient healthcare delivery approach in order that people with dementia are enabled to remain independent in their own homes (ageing in place) for longer (European Commission, 2015; Scholz, 2016). Indeed, technology has become popular due to a recognition that populations are ageing globally; that the number of carers is decreasing; that the costs of healthcare are increasing; and that people want to age in place (Neven, 2010). In particular, surveillance technologies (STs), such as Global Positioning Systems and tracking devices have been promoted as a resilience tool to increase the safety and independence of people with dementia (McCabe and Innes, 2013). There are various STs available online to locate people for safety reasons. To illustrate, GPS which can be incorporated, into the coat of a person with dementia, identifies the location and signals that position of a person from the device to a carer (Gibson, et al, 2016). These technologies monitor movements and may offer a cost-effective way to support people with dementia to live independently, delay institutionalisation and to provide freedom with security by tracking them so that family carers can intervene if necessary (Brittain et al., 2010; Department of Health and Social Care, 2019; Niemeijer, 2015). In this thesis, descriptions of family carers and people living with dementia who might use ST or have needs towards such products, might be termed interchangeably with (potential) users, but nuances depend on the context.

1.2 Research Background

To understand the role of ST in dementia it is necessary to look at the idea of the emergence of what has been described as a 'surveillance society' (Lyon, 1994). Studies outside the field of

gerontology tend to think of surveillance as a constant feature of modern society. For example, Gary Marx (2002), describes a generalised focus on discovering personal information through surveillance as a feature of contemporary society. In this view the collection of data and the surveillance of people becomes deeply enmeshed in a myriad of social practices (Marx, 2002). Similarly, Foucault's (1977) well known discussion of the idea of the 'Panopticon' in his work on prisons and its role in the construction of what he termed the 'docile body' (Caluya, 2010) is another example of the role that surveillance is projected to have in wider society. In 1957, the first globally orbiting satellites were tracked by surveillance on the ground (Meyer, 2016). In the 1960s, electronic tagging and tracking of individuals was introduced as an alternative to custodial sentences (Gable, 2009). Since that time the potential of surveillance has increased exponentially as technology has become more sophisticated and individuals have come to be more scrutinised in their everyday actions. Technology developed in one field rapidly extends to others. This has been as true in the field of social care as in other more obvious areas such as computer technology. Social care became an area ripe for technological intervention as the latter decades of the twentieth century saw an increase in the needs of an older population and a shift in the responsibility of providing care to the informal sector of family, friends, and neighbours (Gray, Normand and Whelan, 1988). This was accompanied by a discourse that the care provided by families was "good" whereas dependence on the state was "bad" (Barnes & Walker, 1996).

From the 1980s onwards, two events occurred in the field of dementia research and technology. First, much academic research was conducted to see how these technological developments could be extended into the field of dementia care; however, there was a dearth of take-up from designers and administrators (Day et al., 2000). Second, an impetus for developing the perfect ST also emerged leading to an ongoing perception that these products would meet a yet untapped market need which would both be profitable and cost effective (Algase et al., 1996; Kenner, 2008). Later in the 1990s, technology was seen as a way of providing a variety of solutions for the welfare state in the United Kingdom (UK) (Henman and Adler, 2003; Hudson, 2003). The National Health Service and Community Care Act, (1990) promised a 'mixed economy of welfare', focusing on market forces for the delivery of technological services (Phillipson, 1998). A justification for this policy was the assumption that older individuals should to be cared for in their own homes for as long as possible (National Institute for Health Research, 2018). However, reforms in UK care and social services also led to a narrow market-orientated approach based on consumerism and to a lesser degree "user involvement" or "user empowerment" (Barnes and Walker, 1996).

Technology users generally had the option to choose between competing providers and reject products which do not meet their needs (Means and Smith, 1994). User empowerment, however, is often confused with consumerism but there are important differences (Barnes and Walker, 1996). In a supermarket analogy it is consumerism which ensures that users have a wide choice in products to purchase and have some safeguards regarding safety and quality. In such circumstances a user who can choose between products in a supermarket becomes a consumer. However, consumerism does not really consult consumers about what types of products they want to have in the supermarket, nor does it involve consumers in the management of that supermarket. Therefore, in such a (super)market analogy the consumers remain powerless (Barnes and Walker, 1996). This makes it distinct from user empowerment which can have important consequences. In particular it can mean that the technology develops in particular directions. Research on the family or friends (hereafter “carers”) who provide unpaid care to support a person with dementia found that they favoured tracking people with dementia as a way of benefitting from technology (Welsh et al., 2003). This not only started an ethical debate on the morality of surveillance (Welsh et al., 2003) but also brought to the surface the question of who actually were the users and who was being empowered.

These tensions between consumers and users can be seen in relation to design. In the late 1990s, specially adapted technological designs became standard features of mainstream products (Cook and Hussey, 2002). This transformation of adaptation into mainstream technology designs became widespread and contributed to a larger trend that is based on universal design (Cook and Hussey, 2002; Newell, 2011). This led designers to base their ideas on previously perceived needs generated by a market which resulted in designs that are reflections of what has been previously created (Hyysalo, 2006; Strickfaden and Heylighen, 2009). For example, while cassette tapes were initially created to support talking books for the blind they became mainstream when used by the general public, yet later these tapes were specially repurposed for the blind (Cook and Hussey, 2002). This can also be seen with the “Wristcare” design for dementia care (Hyysalo, 2006). The designers had years of experience with developing safety phones and later adapted these phones by adding monitoring features. The Wristcare was designed in the light of the growing ageing population and was anticipated to have considerable potential for an ageing market. The monitoring safety phone market was also anticipated to open up a new market among younger consumers (Hyysalo, 2006).

Consequently, in the last few years the market for ST has expanded as the number of unpaid carers increased (Kenner, 2008) but without any real development of what users needed or indeed who

they were. Other commentators, however, have argued that the surveillance market was in reality underdeveloped and is now just starting to use technologies to improve services for older adults (Sixsmith, 2006). Nonetheless, one major development was that in the UK it became common to monitor people with dementia (Gibson et al., 2016), so that by 2010 there were 1.7 million telecare users in a market valued at £106 million (Deloitte, 2012; Goodwin, 2010). Such devices are provided by local authorities, then private companies, followed by local and national technology resources (Gibson et al., 2016). This market is supported by the public sector with a small subsector selling directly to the public (Gibson et al., 2016). Policy makers continue to ‘mainstream’ ST within health-care given that there is a belief that it might alleviate the challenges of providing care without resort to institutional care and all of its costs (Gibson et al., 2016). Again, what is common in this process is that the development of ST has not addressed user involvement or indeed empowerment. However, it is not that there is not a perspective from the users: it is just not heard or considered.

The user voice

Some might argue that there is an expanding focus on the voice of users, which are both the carer and person with dementia, in debating public and professional beliefs (International, 2017; Swaffer, 2015). However, technology, which is often designed and sold with an ideal user in mind, is enshrouded by popular discourses that accentuate the equity of technologies (Joyce & Mamo, 2006). Marketing messages highlight youthful able-bodies who can use the “one size fits all” technology through an anti ageing discourse (Joyce & Mamo, 2006). Whilst the older woman is not the intended user, the ideal user presented through marketing is often inscribed in the technology design (Joyce & Mamo, 2006). Furthermore, there is an increasing concern of how people with dementia can act in empowered ways but also how they accept, negotiate and resist technology and its discourses, and how their social positions within hierarchies of power variously shape these actions (Brittain et al., 2010; Joyce & Mamo, 2006).

However, with this increasing concern about empowering people through technology, interpretations of power and empowerment are rather different ” (Schneider, Eiband, Ullrich & Butz, 2018). Rather, people living with dementia have traditionally lacked power and voice (Brooks, Gridley, & Savitch, 2016; INVOLVE, 2012; Ocloo & Matthews, 2016). More recently, there is this idea that public involvement in research may lead to empowerment as it enables people to influence change and development in issues which concern them most (INVOLVE, 2012).

Involvement of research advisors

In particular, there is an urgency to involve carers and people with dementia in patient and public involvement (PPI) (Brooks et al., 2016). PPI is research being carried out “with” or “by” members of the public (INVOLVE, 2012). For example, members of the public can offer advice or comment on research materials as they have personal knowledge and experience of the research topic and might provide a more general perspective (Ocloo & Matthews, 2016). However, PPI is often criticised as an exclusive and tokenistic practice involving a narrow group of experienced members (NIHR, 2015). In addition, researchers have been concerned about the consequences of PPI members displaying eagerness to be involved for payment rather than relevance to the field of study (NIHR, 2015). Therefore, INVOLVE, (2012) created briefing notes for researchers involving the public and NIHR, (2015) recommended to continuously improve the development of PPI by beginning with diversity and inclusion (INVOLVE, 2012; NIHR, 2015). Despite these criticisms, PPI can improve the quality and relevance of research and lead to the empowerment of those members involved (Brooks et al., 2016).

This indicates a need for understanding which products are marketed, with what ideals are in mind to which social actors, if technologies are taken up and how people make sense of this in their lives (Joyce & Mamo, 2006). Indeed, little is known about the perspectives and needs from family carers and people with dementia towards ST (Carmody, Traynor & Marchetti, 2015) and even less is known about the impacts of using these technologies (Woolrych, Sixsmith, Mortenson, Robinovitch & Feldman, 2013). Accordingly, the European Interdisciplinary Network for Dementia Using Current Technology (INDUCT) aims to advance dementia research by acquiring a deeper understanding of the nature of dementia and needs in relation to the use of technology (Klinkenberg, de Oliveira, Verhey, Orrell & de Vugt, 2018). The INDUCT project involved PPI members, who in turn, gave advice on how to engage and involve people with dementia for this thesis (INDUCT, 2016). The support from the European Working Group of People with Dementia has been valuable in the design of this research.

1.3 Aim of the study

This research is based on the assumption that a closer investigation of the perspectives from (potential) users towards ST, and what sort of impacts these products can have on them, might

shed new light on technology design and development, and perhaps also on ageing. Several scholars have insisted on examining the perspectives from (potential) users and the impacts ST can have on them. Nevertheless, they have not really questioned the meaning of the media messages that are sent, which (as we shall see) are not entirely consistent with the consumption or the design details of surveillance products. Following this line of enquiry, this study proposes to use media analysis to examine STs and the perspectives of users towards these products as they are constituted by marketing messages. No previous study has explored how ST and accompanying media messages may influence potential users, and in turn, how users can become empowered through having their views recorded. **The specific aim of this study is to gain an understanding of the perspectives and needs of people living with dementia and family caregivers towards surveillance technology and the media surrounding it.**

1.4 Research statement

Therefore, the thesis statement became:

‘To understand how surveillance technologies in the field of dementia are marketed and how this impacts the experiences and needs from family carers and people with dementia’.

In order to answer this research statement and contribute to the research aim, it is necessary to understand ST and how these products are marketed in the field of dementia. This understanding benefits consumers for they can hereby be informed regarding ST available on the market and evaluate these products. Furthermore, this product and market knowledge highlights the influences, which these products may have on people living with dementia and carers. Knowledge about products already on the market can inspire and improve novel designs aimed at healthcare professionals and designers. The focus on how ST are marketed contributes to making recommendations for future designs.

Another necessity is to understand how people living with dementia and carers’ experiences and needs are impacted by ST and its media messages. This impact knowledge gives attention to issues of power and inequality, along with inquiry into the design of ST. Therefore, a broad social gerontechnology perspective highlights what is necessary to empower individuals and unstated assumptions are recognised and provides an unique view for perceiving and understanding ST. This view is a step towards developing new media and dementia-friendly designs that empower.

1.5 Research questions

1.5.1 What is the current practice of ST and how are such products marketed in the field of dementia care? (*what is on the market*)

1.5.2 What are the views and needs from family carers and people with dementia towards ST? (*what do users need*)

1.5.3 What media techniques and ideals do messages contain that market ST to users? (*what media techniques are used to attract attention*)

1.6 Media literacy view

Hereby the answers to the research questions seek to contribute to the understanding of ST in dementia care by a marketing perspective breaking it down into three sites of answering what is on the market (the site of production), what do users need (the site of audience reception) and what media techniques are used to attract the attention of these users (the site of media content). Accounts of exploring the sites of production, audience reception and media content were often coined the approach of 'media literacy' (Lewis & Jhally, 1998; Kellner & Share, 2007; Rose, 2007; Thoman & Jolls, 2005). Media literacy aims to educate citizens so that they can contribute to public discourse and make informed choices (Thoman & Jolls, 2005). Strengthening individuals' critical media skills and to actively use it for democratic engagement, empowerment and resistance is another aim of media literacy (Kleebpung, 2010). Another way to enable public involvement whereby people have their voices heard and the opportunity to influence policy and research by helping others is to involve the "subjects" as research advisors (INVOLVE, 2012). The focal points in this thesis being carers and people who live with dementia are often not heard and usually excluded from research (Brooks, Gridley, & Savitch, 2016). Accordingly, supporting citizenship and transparency lead to empowerment it also enhances research quality and relevance (INVOLVE, 2012). Therefore, a decision was made to create a patient and public information group in the United Kingdom. Carers and people living with dementia were invited to become advisors to shape the study throughout different stages of the research cycle.

1.7 Thesis structure

The present thesis is a component of INDUCT uses an overarching media literacy approach divided into eight chapters (table 1). The eight chapters focus on three major sites in order to better understand what is on the market (the site of production), what do users need (the site of audience reception) and what media techniques are used to attract the attention of these users (the site of media content). In particular, chapter 1 provides a general background to STs for dementia-care and reports the aim of the study. In chapter 2 the literature about surveillance and dementia is reviewed to provide an overview of the views and needs from (potential) users. After this introduction to a theoretical framework that acknowledges the literature about user needs, the production site that follows, chapter 3 explores the current practice of surveillance and describes the nature of the surveillance market and how such products are marketed in the field of dementia-care. Table 1 shows that chapter 3 reports on study I. A new site is addressed in chapters 4 and 5 which concentrate on audience reception and addresses user needs towards STs and advertisements. Table 1 shows that chapters 4 and 5 includes study II (patient and public information group), study III (online discussions) and study IV (focus groups). Due to the length of the three studies, chapter 4 describes only the methods used to involve users, whereas chapter 5 reports the results from the collected views and perspectives from the carers and people with dementia who have helped and/or participated in this study. Chapter 5 reports the results by describing conflicting user needs and how participants conceived and experienced the media and surveillance products. The third site of media content in chapter 6 explores the signs and media techniques used in the surveillance advertisements in order to attract the attention from users. Table 1 shows that chapter 6 discusses the final study V media content. The discussion chapter 7 relates the results from these studies to six ageing and technology propositions (Peine and Neven, 2018) and contributes to this ageing and technology framework by focusing on dementia. This framework enabled the description of the main findings, the contributions made to current knowledge, implications, recommendations for future research and ends with a concluding thought. Finally, chapter 8 addresses the main conclusion by briefly reflecting on the research questions.

Table 1: Overview of the media literacy thesis

Aim		To understand how STs are marketed and how this impacts potential users				
Site	Production	Audience reception			Media content	
Contributes to research question	1. What is on the market	2. What do users need			3. What media techniques are used to attract the attention	
Chapter	3	4 & 5			6	
Study	I Production	II Public and Patient Information	III Focus group discussion	IV Online discussion	V Media content	
Sample	242 ST products	1 Person living with dementia 6 carers	5 People living with dementia Separately 4 carers	7 People living with dementia 38 carers	6 ST advertisement campaigns	
Sampling technique	Purposive sampling Inclusion criteria	Purposive sampling & snowballing Inclusion criteria			Purposive sampling Inclusion criteria	
Procedure	Literature review Questionnaire 382 products surveyed online with search words in Excel	Developed in London, United Kingdom according to INVOLVE (2012) guidelines	Held at Alzheimer Netherlands Voice-recorded +90 minutes Watched commercial Discussion	Discussion placed on online dementia forum	Advertisements from ST providers Online (websites, social media, reports) & visual based (YouTube)	
Analysis	Environmental scan October '16 to '17 quantitative qualitative Translated to English		Qualitative content analysis. Transcribed & made anonymous through adding codes. Translated from Dutch to English.		Qualitative content analysis Dutch advertisement was translated to English	
Data validation	Quotations added Reviewers PH, GC, LN	Research advisors could comment on paper	All participants were given the opportunity to comment on identified themes Reviewers PH, GC, JM		Reviewers SG and SW	

Chapter 2: literature review

This chapter reviews the literature about surveillance products for dementia care which provides an overview of the current knowledge about what users need and require in ST design whilst highlighting gaps in literature.

2.1 Introduction

Dementia is recognized as a major global health problem with an aging population and the demand for care is increasing (Gridley, Brooks, Birks, Baxter, & Parker, 2016). In 2015, 46.8 million people were estimated to be living with dementia, and estimated costs were \$818 billion in the United States (Alzheimer's Disease International, 2015; Anders Wimo et al., 2017). In Europe, dementia was identified as a societal challenge and the necessity for research on technology-related care was highlighted (European Commission, 2015; European Parliament, 2011). In the literature, the focus is on supporting older adults to live independently at home and to delay institutionalisation (Brittain et al., 2010) with families using technologies such as surveillance products to diminish risks (Kenner, 2008). 'Wandering' away from home is considered a major risk in dementia due to the potential adverse consequences such as injury and even death (Rasquin, Willems, de Vlieger, Geers, & Soede, 2007). STs, product devices that monitor movements with the intention of cost-effectively supporting health and independence (Woolrych et al., 2013), are preferable to sedation or incarceration as a strategy for protecting the person with dementia from harm. ST has particular relevance for unpaid carers as products are perceived to increase safety by monitoring a person with dementia such that the carer can intervene if necessary (Niemeijer, 2015).

A challenge of reviewing ST is the inconsistent terminology. Surveillance has been classified as: an Assistive Technology (AT) (Robinson et al., 2007); Assisted Living Technology (ALT) (Niemeijer, 2015); Ambient Assisted Living (AAL) (Sixsmith, 2013); Information and Communication Technology (ICT) (Kenner, 2008), or Smart Home Technology (SHT) (Rialle, Ollivet, Guigui, & Hervé, 2009). A second challenge is the range of products that could be considered relevant to surveillance, including: video and audio monitoring products, environmental sensors that alerts (formal) carers, tagging systems with wearable transmitters, and Global Positioning System (GPS) tracking systems (Te Boekhorst et al., 2013). For the purpose of this review, we use the definition of ST as comprising "monitoring systems that can allow for 24-

hour supervision by carers”, with specific technologies including, but not limited to: monitoring products, personal and social alarms, telecare, electric tagging and tracking, and GPS (Kenner, 2008; Niemeijer, 2015; Robinson et al., 2007). A third challenge is the rapid advance of technology and the proliferation of products, with the potential consequence of studies becoming quickly out of date. Design features such as shape, size, buttons and so on have a powerful influence on whether and how technologies are used (Greenhalgh et al., 2013). Technological products to support those who wander have been available since the 1980s (Algase et al., 1996), however, many ST products available for purchase online continue to be non-preventative devices which track but do not send alerts (Vermeer, Higgs, & Charlesworth, 2019a). For example, even in April 2018 only half of the “top 10 lifesaving location devices for dementia” include GPS (Sauer, 2018).

Previous research has mainly focused on needs related to the broader category of AT (Topo, 2009), through focus groups, interviews, questionnaires, and ethnographic studies (Rialle et al., 2009). Such studies are challenging to synthesise due to different data collection instruments, inconsistencies, or criteria used (Stajduhar et al., 2010). Robinson and colleagues (2007) conducted focus groups in which they describe both the perspectives from people with dementia and carers towards technology. Results showed that carers had a great interest for the use of trackers. Yet people with dementia had concerns over carer surveillance (i.e. big brother is watching) (Robinson et al., 2007). Later McCabe & Innes, (2013) examined the perspectives from older adults, carers and people with dementia through focus groups. All participants thought that a discreet GPS product would be useful and outweighed ethical and privacy concerns. McCabe & Innes, (2013) found differences between focus groups and stresses the importance of developing technologies that can be adapted for individual users. Indeed, a review of unmet needs from carers and people with dementia showed that “ICT” should be personalized to fit the needs and capacities of those involved (Lauriks, Reinersmann, & Roest, 2007). For products to be successful, the needs from those who might use them have to be included (McCabe & Innes, 2013). However, few studies have explored the needs of carers and people with dementia, and failed to address implications for ST development (Carmody et al., 2015; McCabe & Innes, 2013; Wan, Müller, Randall, & Wulf, 2016).

There is a knowledge gap of needs listed in such a manner that it can be used by designers for product development. Therefore, this review is based on the assumption that a closer investigation of carers and people with dementia ST needs, might shed new light on technology design and development. Following this line of enquiry, this study aims to outline the different needs of carers and people with dementia towards STs, within a scoping context. In particular, the study examines

(1) the nature of use of STs by carers and people with dementia, (2) and ST design needs among carers and people with dementia.

2.2 Method

An iterative scoping literature review was employed (Arksey & O’Malley, 2005), to map out the state of published knowledge concerning the needs of carers and people with dementia towards various ST. The scoping review consisted (1) a literature search (2) selection of eligible literature through application of pre-defined eligibility criteria (3) data synthesis through thematic analysis.

Table 2: Search terms

Search word	Synonyms
Surveillance Technology	Surveillance technologies, devices, products, assistive, GPS, tracking, tagging, tracker, track, monitor, locate, locator, AT, ALT, AAL, ICT, SHT, environmental sensors, transmitter
Dementia	Alzheimer, Alzheimer’s, person with dementia, people with dementia
Carer	Informal carer, carer, family carer, family carer
AND ...OR	Safety, independence, empowerment, risk, danger, alert, peace of mind, consent, informed consent, wander, lost,

Search selection and strategy

An initial scoping literature search was carried out in December 2016 using terms for surveillance technology, dementia, caregiving, and their synonyms (table 2). The following databases were searched, with a start date of December 2006: LexisNexis, PubMed, Scopus, EMBASE, MEDLINE, Cumulative Index to Nursing, Allied Health Literature, PsycINFO, Web of Science, and the AT database (ABLEDATA, 2016). In addition, Google Scholar and Google were used to identify ‘grey literature’, and google alerts were set. Abstracts and websites with at least two of the search words were selected for further analysis by the main researcher and saved into Mendeley. When a potentially relevant study was identified, the dataset was screened for duplicates using the Mendeley search function. If a duplicate was found, the new literature would not be entered. However, there was a possibility that duplicate material was entered in alternative formats (e.g. conference abstract and published article). Therefore, data were re-searched and cleaned to remove duplicates set after the exclusion criteria (table 3). Then a snowball effect enabled retrieval of other publications based on the reference lists from the literature initially

found. Exclusion mainly occurred when studies did not address individuals with dementia and or family carers or when the described technological product could not be used in a home setting. Other reasons for exclusion were products being non-technical devices that did not track or alert.

Table 3: Eligibility criteria

	Studies were included if it contained:	Exclusion criteria were:
ST	<ul style="list-style-type: none"> any published account of ST technological products that tracks and/or alert 	<ul style="list-style-type: none"> 'non-technical' products e.g. keychains, bracelets technological products that do not track and/or /alert
Participants and setting	<ul style="list-style-type: none"> product can be used by a person with dementia or a carer product could be used in care homes, institutions, and/or at home participants living with dementia 	
Studies	<ul style="list-style-type: none"> any empirical account relevant for carer and people with dementia needs published since 2006, or if it was recently cited, or a foundational piece written in English 	<ul style="list-style-type: none"> any theoretical account relevant for carer and people with dementia needs policy and instruction reports about any care setting

Following the initial search, the search terms were validated through discussions with fifteen researchers from INDUCT at the winter school in Germany (January, 2017). Additional keywords were recommended. These keywords are shown in table 2 by the Boolean operators AND/OR. To further facilitate the search, Boolean operators between each of the keywords has been applied. The search strategy was repeated in January 2017 using the re-defined search terms. The searches initially resulted in 135 publications and websites. The search was updates by adding studies found by google alerts only in January 2018. After the exclusion criteria in January 2018, an “AT” report was circulated to the main researcher, which led to the identification of four additional studies. Twenty-eight studies were included in the final review.

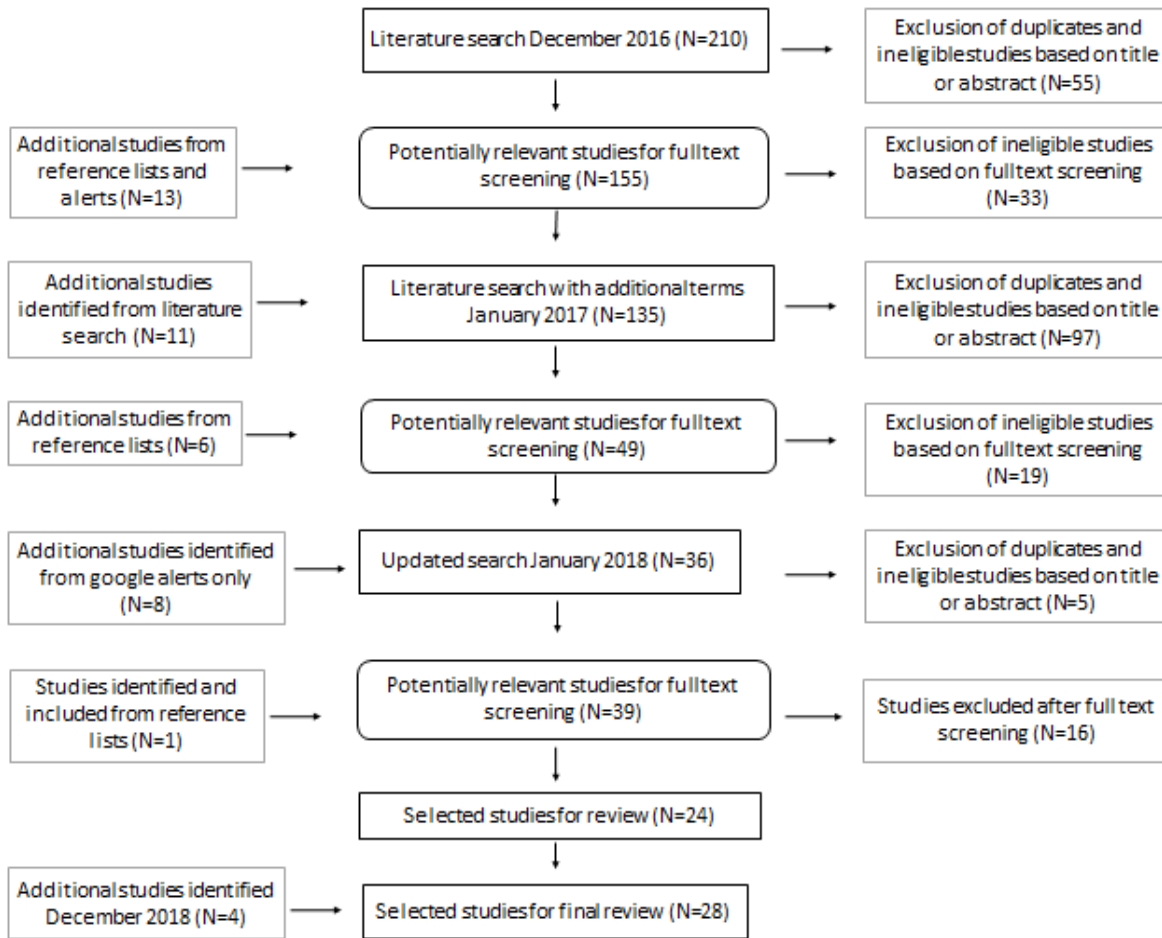


Figure 1: Flow diagram showing selection of studies

Synthesis strategy

All eligible studies were read in detail and field notes were placed in the data set by the main researcher (YV) of this thesis. Data on requirement specification in relation to users' needs was extracted (Figure 1). A categorisation of features was developed (table 4) through an iterative process of applying the categorisation to each successive study, adding and collapsing feature descriptions and the constituent items. Features and items were tabulated for each study, and described narratively. Feature and item categorisation were discussed with the two other researchers (PH and GC) active in the field of technology and dementia research and further refined.

2.3 Results

Of the 28 included studies, the majority are from the UK (N=10) and the United States (USA) (N=7) with a minority in the Netherlands (NL) (N=3), Canada (N=3) and Germany (N=2). Individual studies collected data in Sweden (SWE), Ireland, Scotland, France, Norway, Spain and Israel. Sample sizes range from single cases to 208 carer dyads. Most studies are qualitative, using interview or focus group methodologies with four studies reporting results from questionnaires.

The majority of the studies reported on carers' perspectives and what they think people with dementia need. One study described this as "my, your and our needs for safety" (Olsson, Engström, Skovdahl, & Lampic, 2012, p. 109). Nine studies did not include people with dementia in their sample (Altus, Mathews, Xaverius, Engelman, & Nolan, 2000; Czarnuch & Mihailidis, 2011; Dawe, 2006; Kinney, Kart, Murdoch, & Ziemba, 2003; Landau, Auslander, Werner, Shoval, & Heinik, 2010; McShane et al., 1998; Niemeijer, 2015; Olsson et al., 2012; White & Montgomery, 2014). Other studies reported on people with dementia through observations, or vaguely identified participants as "users" (Melillo & Futrell, 1998; Miskelly, 2004; Rahimi & Vaughn-Cooke, 2007; Wigg, 2010; Williams & Ware, 2014). Thirteen studies described the perspectives from both carers and people with dementia (Clyne et al., 2014; Faucounau et al., 2009; Juzwishin, Lui, & Raadik-Ruptash, 2015; Liu, Miguel Cruz, Ruptash, Barnard, & Juzwishin, 2017; Mahoney, 2010; McCabe & Innes, 2013; Mulvenna et al., 2017; Øderud et al., 2015; Rasquin et al., 2007; Robinson et al., 2007; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009; Tetley et al., 2017; Wan et al., 2016). However, several of these studies did not include more than one or two persons living with dementia (Clyne et al., 2014; Faucounau et al., 2009; Mulvenna et al., 2017; Rasquin et al., 2007; Wan et al., 2016), even though the needs of the person with dementia may differ from carers' needs (McCabe & Innes, 2013; Robinson et al., 2007). One study stated, "If possible, both the person with dementia and the informal carer were interviewed separately, elsewhere they were interviewed together" (Øderud et al., 2015). However, only one study expressly involved people with dementia *separately* from carers during the ST development process to prevent the voice of people with dementia being overruled by the dominant voices of carers (Meiland et al., 2014). Results from included studies are synthesised under six categories (table 4; effect, product characteristics, user-friendliness, user-context, privacy, design details) each of which encompassed a number of subcategories. Table 5 illustrates the spread of issues covered within each study.

Table 4: Themes of features and items

Features	Description	Items
Effect	Description of the intended effect of the product on or for the user	safety, independence, confidence, peace of mind, free time
Product Characteristics	Characteristics of the product	price, size and weight, SOS-button, one technology
User-friendliness	Centres on the product and how well it is designed for the user	Simple to use, but useful, capacity, routine
User-context	Contextual, situational differences relevant to the person using the technology	acceptance, navigation, locate accurately, notifications, performance, communication
Privacy	Issues relevant to the ethical debate surrounding the data gathered by ST and who is being is being monitored	privacy data, adjustable settings, safety and risk zones, autonomy, legal and liability
Design details	Product design characteristics that can be added or deleted to a product to protect, change, or enhance durability	battery, simplicity, visibility & aesthetics, reinforcements

Table 5: Thematic results of user perspectives on STs

Design-details		Privacy		User-context			User-friendly		Product			Effect			Feature													
Reinforcements	Visibility & aesthetics	Simplicity	Battery	Legal & liability	Safety riskzones	Privacy data	Communication	Reliable	Notifications	Locate accurately	Navigation	Acceptance	Routine	Capacity	Simple to use but usefu	One technology	SOS button	Size	Weight	Price	Free time	Peace of mind	Confidence	Independence	Safety	Item	Study	
																											Rasquin et al 10	
																												Niemeijer 12
																												Robinson et al 13
																												McCabe & Innes 23
																												Wan et al 26
																												Olsson 29
																												McShane et al 30
																												Altus et al 31
																												Kinney et al 32
																												Dawe 33
																												Landau et al 34
																												Czarnuch & Mihailidis 35
																												White & Montgomery 36
																												Miskelly 37
																												Rahimi et al 38
																												Wigg 39
																												Williams & Ware 40
																												Melillo & Futrell 41
																												Faucounau et al 42
																												Clyne et al 43
																												Juzwishin et al 44
																												Liu et al 45
																												Mahoney 46
																												Robinson et al 47
																												Tetley et al 48
																												Mulvenna et al 49
																												Øderud et al 50
																												Meiland et al 51

Effect

Sixteen of the 28 studies considered the effect or impact of surveillance technologies on the carer or person with dementia, for example increased confidence and peace of mind. ST was seen as increasing autonomy and independence for people with dementia, and reducing carer burden (Øderud et al., 2015; Wan et al., 2016). However, benefits were often associated with risks or drawbacks. For example, one study described how people with dementia used ST and could walk around freely, but carers want to know their location constantly, or even prevent them from walking again thus restricting autonomy (Niemeijer, 2015). People with dementia commonly expressed the need to be able to walk outside independently (Liu et al., 2017; McCabe & Innes, 2013; Robinson et al., 2009, 2007; Wigg, 2010) but were aware of limitations, for example that monitoring restricts their freedom and that there are risks associated with carrying a product that could get stolen (McCabe & Innes, 2013; Robinson et al., 2007). In addition, carers pointed out that they often lack time and need ST that gives them more free time, or diminishes the time required to do a certain activity (Williams & Ware, 2014). Unfortunately, using ST might actually be time-consuming, especially when false alarms happen (Niemeijer, 2015). Carers expressed the view that ST use would result in greater confidence and peace of mind if they could rapidly locate a lost person (Liu et al., 2017; Robinson et al., 2007). However, it is of concern that carers may be falsely reassured by the technology. To quote Landau and colleagues “The major benefit [to carers] seemed to be their perception that tracking would control wandering and prevent their relative from getting lost or harmed *in any way* (emphasis added)” (Landau et al., 2010, p. 413).

Product characteristics

Price

Both carers and people with dementia associated ST with a “high cost” (Mulvenna et al., 2017). When carers identified problems for using ST, costs was one of them; yet they were willing to pay for it (Altus et al., 2000; Melillo & Futrell, 1998). Given the international spread, studies took place within different funding contexts. In Sweden, for example, the municipality would not pay for ST (Olsson et al., 2012). However, in one study the majority of participants thought the government should pay for ST (Juzwishin et al., 2015). It is a challenge for carers and people with dementia to decide what the best cost option is for ST in their situation (Tetley et al., 2017). The amount that consumers are willing to pay for ST remains unclear as numbers differ per product and there are

other options to consider (e.g. purchase, rent, lease) (Juzwishin et al., 2015; Tetley et al., 2017). In one Canadian example published in 2015, one carer was willing to pay around one hundred dollars, another thought seventeen dollars per year was acceptable for an emergency phone whereas a third found a fee of fifteen dollars a month was reasonable for multiple smart technologies that monitor (Juzwishin et al., 2015).

Size and weight

Early studies reported that carers thought the ST receiver was too large for easy use (McShane et al., 1998) with carers and people with dementia concerned that products would be left at home due to their size and weight (Robinson et al., 2009). Recent studies found that carers want something similar sized to a wristband or a watch (McCabe & Innes, 2013; Wan et al., 2016). Some carers prefer smaller products to enable covert use ST on people with dementia (Clyne et al., 2014; White & Montgomery, 2014) however, this raises the ethical debate on covert surveillance as the smaller the product, the larger the involuntary compliance by people with dementia, as it is difficult to know if ST is being used on them (Niemeijer, 2015).

SOS-Button

People with dementia described how they need help in case there is an emergency (McCabe & Innes, 2013; Meiland et al., 2014). Hence, a considerable amount of literature is about pendant alarms, emergency buttons or sometimes referred to as products with SOS-buttons. However, in one study a person with dementia worried the SOS-button may be pressed in error triggering a false alarm (Robinson et al., 2007). People with dementia do not want to have too many buttons involved due to the new learning required and the risk of accidental activation (Tetley et al., 2017). A carer explained that the person with dementia did not understand such buttons and sometimes activated it by mistake (Tetley et al., 2017). Accordingly, carers have expressed concerns about receiving too many alerts (Mahoney, 2010), and that false alerts should be minimized (Faucounau et al., 2009; Liu et al., 2017; Tetley et al., 2017). Consequently, both need a large-enough recognisable SOS-button to press in an emergency (Liu et al., 2017). There was a lack of consensus over ideal design with carers in one study advised that designs should incorporate only a single SOS-button with a protective case (Rahimi & Vaughn-Cooke, 2007) whereas carers in another study wanted three buttons, and the person with dementia one (Rasquin et al., 2007).

One technology

Carers were concerned of having to use too many components also termed “technologies” (Mahoney, 2010; Tetley et al., 2017). For example, when there is a charger attached to a watch it could be easily detached and become lost or forgotten to bring along (Tetley et al., 2017). Another example is where the carer had a mobile phone to track; but, the person with dementia forgot to carry the tracker (Faucounau et al., 2009).

User-friendly

Simple to use but useful

The use of ST by carers and people with dementia has been studied by several authors (McCabe & Innes, 2013). Carers and people with dementia need a product that is simple but useful (Juzwishin et al., 2015; Liu et al., 2017; Rasquin et al., 2007; Tetley et al., 2017). People with dementia stress the importance of a ‘simple to use’ ST (McCabe & Innes, 2013; Meiland et al., 2014; Robinson et al., 2009). Carers argued that a product should be intuitively simple to use, require little skill, with manuals or technical support provided in order to learn how to use it (Czarnuch & Mihailidis, 2011; Mahoney, 2010). By contrast, other carers thought that a manual would be too difficult to understand (Olsson et al., 2012). ST is perceived as useful when carers and people with dementia encourage each other, have low anxiety and a high level of acceptance for using such products (Juzwishin et al., 2015). In terms of social context, carers and people with dementia would use ST for the others’ peace of mind or safety (Liu et al., 2017). Within such context, their mutual perceived usefulness of, and intention to use ST is positively influenced (Liu et al., 2017).

Capacity

There seems to be an ambiguous relationship between technology that is simple to use and user’s capacity. Especially ST should be flexible in use as the disease progresses (Robinson et al., 2009, 2007). Each individual has different skills, sensory abilities and experiences with, and attitude towards technology, and consequently carers need ST to be adaptable to individual needs (Czarnuch & Mihailidis, 2011; Olsson et al., 2012). Furthermore, carers thought gender, age and the stage of the disease would influence ST usage (Olsson et al., 2012). Nevertheless, carers often described that the person with dementia would not be able to understand using ST (Olsson et al.,

2012; Rasquin et al., 2007). If ST is too complex and does not fit individual capacity, it is less likely to be routinely used in daily life by people with dementia (Robinson et al., 2009).

Routine

Carers and people with dementia need ST to fit within their routines, and be easily integrated into day to day tasks (Robinson et al., 2009, 2007; Wan et al., 2016). People with dementia routinely use ST more if it fits within activities such as walking and washing (Robinson et al., 2009, 2007; Wan et al., 2016). However, if a person with dementia has to use ST but never has used it before, it will eventually be disposed (Robinson et al., 2009).

User-context

Acceptance

Some carers expressed concern about the attitude from a person with dementia towards a passive alarm, yet thought the person would accept it (Olsson et al., 2012). Therefore, carers need ST to be a familiar product as they feared that otherwise the person would not accept the product (Wan et al., 2016). Seeing that people with dementia who have unknown products attached to them would sometimes remove them (McShane et al., 1998). Another important consideration for acceptance is performance expectancy and whether carers and people with dementia perceive ST as useful (Liu et al., 2017). A study found that people with dementia were encouraged to use ST by their carer for reasons of peace of mind and decreasing carer burden (Juzwishin et al., 2015). Also, people with dementia stated they carried the ST, not because they need it, but in case the carer wanted to locate them for safety reasons (Øderud et al., 2015).

Navigation

Some carers and people with dementia expressed the need for indoor navigation and prefer the functionality of having outdoor navigation with movement sensors (Meiland et al., 2014; Wan et al., 2016). For example, one person with dementia described wanting a large navigation screen similar to TomTom (McCabe & Innes, 2013). Navigation is needed as people with dementia want keywords to support them to go back or guide them home (Meiland et al., 2014; Robinson et al., 2009, 2007; Wan et al., 2016).

Locate accurately

A predominant theme for carers is the need to locate accurately. Carers need accessible ST that locates those who wander quickly and accurately (Altus et al., 2000; Melillo & Futrell, 1998; Miskelly, 2004; Tetley et al., 2017; Wan et al., 2016). For example, carers considered locating someone within 10 meters as inaccurate (Rasquin et al., 2007). Accuracy can be achieved by showing the exact street in a rural area (Tetley et al., 2017), or a common travelling route, or a history of routes which can identify and predict the person with dementia's location (Rahimi & Vaughn-Cooke, 2007; Wan et al., 2016). Furthermore, ST should; monitor health and safety status; provide actual reporting life (i.e. the amount real time location is updated); be accessible and quick, back up data; connect to an app or support platform; support cooperative monitoring (i.e. system that supports access, communication and coordination between professionals) (Altus et al., 2000; Melillo & Futrell, 1998; Miskelly, 2004; Wan et al., 2016). Some carers want actual reporting life to be accessible without the internet (Faucounau et al., 2009). Internet was often ruled out because participants described they did not know how to use it (McCabe & Innes, 2013).

Notifications

More modern designs incorporate “geo-fencing”, where a safety area is set up using GPS so that when the person with dementia leaves this area, the carer receives a notification (Niemeijer, 2015). In this case, carers expressed they need the option to choose between displaying or concealing the real-time location of the person, and be able to set the tracker so that it automatically or manually provides updates (e.g. tracking or polling mode) (Wan et al., 2016). This option is important as carers experienced that continuous display of location and receiving notifications drained the battery (Faucounau et al., 2009). Some carers expressed they need to receive a loud alarm in case of an emergency (Rahimi & Vaughn-Cooke, 2007). In contrast, people with dementia expressed concern that receiving notification noises from ST in public would be embarrassing (Robinson et al., 2007).

Reliable

Notably carers expressed they did not trust ST and the notifications they received, and thought the ideal product should be reliable for them and the person with dementia (Liu et al., 2017; Niemeijer, 2015; Wan et al., 2016). A carer explained that one provider sold a ST with technical problems and consequently the person with dementia could not be found (Olsson et al., 2012). Reliability also entailed that ST would have a system that works, functioning is guaranteed and is 99.9 percent

reliable (Niemeijer, 2015). In addition, carers need waterproof and shock-resistant ST (Rahimi & Vaughn-Cooke, 2007). Similarly, carers expressed their need for ST that loads with speed and a minimum of technical problems (Czarnuch & Mihailidis, 2011; Kinney et al., 2003; Wan et al., 2016).

Communication

Studies have revealed that carers and people with dementia expressed the need to be able to communicate through ST (Liu et al., 2017; Robinson et al., 2009, 2007). One study tested GPS and a Global Communication System products with carers and people with dementia (Robinson et al., 2009). Results showed that both want a two-way communication. Interestingly, one person with dementia expressed the desire to talk quietly to the technology (Robinson et al., 2009). However, another study found that a person with dementia was unable to use the buttons in order to communicate (Tetley et al., 2017).

Privacy

Privacy Data

Much ethical debate from professionals is about the need for a product that does not invade privacy (McCabe & Innes, 2013). This debate, however, lacks the perspectives and experiences of carers and people with dementia. People with dementia subject to ST are the ones who may have to sacrifice autonomy or privacy for safety (Niemeijer, 2015). In theory, ST should be able to increase safety and maintain autonomy or privacy simultaneously (Wan et al., 2016). In practice, however, people that wear ST could feel embarrassed and uncomfortable as the carer would know their exact location (Niemeijer, 2015). One argument is that carers should be respectful and diligent about this by not filming toileting behaviour or making pictures (Kinney et al., 2003; Niemeijer, 2015). Yet, compared to formal carers, those who care for person with dementia, cohabiting or otherwise, are more likely to accept filming in the home (Clyne et al. 2014). Indeed, some carers were excited about placing cameras in the home and receiving images from ST when the family member with dementia would wander (Kinney et al., 2003), whilst spouses found it important to involve the person dementia in the decision making of using ST (Olsson et al., 2012). Furthermore, placing a camera in the home may lead to other concerns, for example other family members being able to log onto the website and receive the data (Olsson et al., 2012).

Safety zones

With privacy there are other concerns about who has access to ST data, especially with design considerations such as; reporting life, backup of data, or if the product is connected to a monitoring app or support platform (i.e. third party that has access such as an alarm centre) (Niemeijer, 2015; Wan et al., 2016). In one study, participants expressed the view that immediate family members should be the first to respond, whilst others argued this should be done by an alarm centre (McCabe & Innes, 2013). Furthermore, ST with geo-fencing collects data about a person's location (Wan et al., 2016). Therefore, ST should have a fine-grained adjustability of privacy and safety settings, which provides the user to suit the technology to their needs (Niemeijer, 2015; Wan et al., 2016). For example, one study provided the option for users to involve an alarm centre (Rahimi & Vaughn-Cooke, 2007).

Legal and Liability

Some studies pose the question if using ST would result in legal or liability issues (Niemeijer, 2015). One conclusion is that unobtrusive ST should not undermine; individual autonomy, control, dignity, or, privacy (Niemeijer, 2015). In one study, carers preferred technologies that were autonomous and unobtrusive (Czarnuch & Mihailidis, 2011). Although this might be true, other carers would sometimes disguise, or hide the small ST without consent inside the pocket of the person with dementia (McCabe & Innes, 2013; Niemeijer, 2015; White & Montgomery, 2014). Therefore, one study posed the question of who is authorised to know the location of the person with dementia (Rasquin et al., 2007).

Design details

Battery

Carers and people with dementia require ST with long battery-life including display of remaining duration and receive notifications when the battery is running low (Altus et al., 2000; McCabe & Innes, 2013; Wan et al., 2016), for example, a lithium ion battery (Rahimi & Vaughn-Cooke, 2007). Carers experienced difficulties when a product shut down at times of need. They want a long battery life to avoid constant charging or change of battery. Furthermore, some thought a charger should be anchored to the product to prevent detachment (Tetley et al., 2017).

Simplicity

A predominant theme found for people with dementia was the need of simplicity. One study with the focus on “AT” adoption by carers and young adults with cognitive disabilities including dementia, reported the need for designers to consider the multiple individuals and stages involved in the technology adoption process (Dawe, 2006). Simplicity should be embedded in the design, configuration, documentation, maintenance, upgrade or replacement (Dawe, 2006). Another designed ST with options for “starters” and “experts” (Wan et al., 2016). The starter sees a design with reduced settings to “start” using the product easily and intuitively with basic tailorability, and the expert sees all settings which can be tailored to their needs. The switch between these options should be easily accessible (Wan et al., 2016). This study concluded that a design should have a small screen, and a configuration process with few buttons and manageable functions (Dawe, 2006; Wan et al., 2016). Somewhat different from a study were carers needed a large screen with a reduced menu style, so that one does not get lost within the product (Rahimi & Vaughn-Cooke, 2007). Another study found that people with dementia, liked the iPod Nano as it was simple and the external design was aesthetically pleasing (Robinson et al., 2009).

Visibility and aesthetics

In one study, some participants would feel embarrassed by using ST, whilst others were more open about it (McCabe & Innes, 2013). Studies found that ST should be attractive because people with dementia who found a certain product ugly would not wear it (Faucounau et al., 2009; Robinson et al., 2009). Carers did not like ugly products either as they were then looking for the removed product (Faucounau et al., 2009). People with dementia need a small familiar looking ST so that it is discrete and less stigmatizing ST (McCabe & Innes, 2013; Robinson et al., 2009). Feelings of stigmatization occur when the person with dementia visibly wears ST; for example, electronic bracelets on the body (Niemeijer, 2015). In an earlier study, two persons with dementia expressed they would want to carry an identity card as they were used to it (Robinson et al., 2007). For the same reason, in a later study, participants expressed they would prefer pendant alarms (McCabe & Innes, 2013). Colour might also be important, as for example, one man was strongly against pink (McCabe & Innes, 2013).

Reinforcements

Carers want reinforcements that are flexible in use and can be added to or remove from a product (Robinson et al., 2009; Wan et al., 2016). For example, ST should have an expandable strap that

could be taken on and off, because when the illness progresses the person with dementia might forget to wear ST (Robinson et al., 2009, 2007; Tetley et al., 2017). Much literature describes how ST should be fixed to the person with dementia (Rasquin et al., 2007). However, in another study participants had no clear answer to whether or not ST should be flexible or fixed to the body (McCabe & Innes, 2013).

2.4 Discussion

This study sought to bring together the needs from carers and those living with dementia as identified in literature about ST. The research conducted in this area remains predominantly qualitative, with the majority reporting on the needs from carers. However, the voice of the person with dementia is gaining presence in more recent studies, and differences in perspective are being revealed. Problems arise when the voices of people with dementia are excluded (Dahl & Holbø, 2012) as people with dementia want to influence products, services and policies that affect their lives (Deep, 2013).

Many of the identified studies reported the effect of safety, independence, and peace of mind. Safety is often highlighted by describing “wandering behaviour” where a person with dementia walks aimlessly or attempts to leave the house (Hope & Fairburn, 1990). This fear of a person with dementia getting lost might lead to people becoming scared of wandering (Alzheimer Europe., 2013; Brittain, Degnen, Gibson, Dickinson, & Robinson, 2017). However, ‘walking out of the house’ may not be ‘aimless wandering’ (Alzheimer Europe., 2013), but healthy and meaningful exercise or activity (Brittain et al., 2017). There appears to be an ongoing conflict between carers and people with dementia perspectives of ‘wandering’ and the need for ST to increase safety and independence (Robinson et al., 2009, 2007). Furthermore, the large debate about privacy is mostly from the perspectives of professionals (McCabe & Innes, 2013). Other literature does suggest that carers need fine-grained privacy settings (Phillips & Zhao, 1993b). However, privacy settings are not a consideration in a recent list of top ten location devices for dementia (Sauer, 2018).

Findings suggest that safety is relevant in multiple features, and often depends on the user-context and user-friendliness. Carers were concerned if the person with dementia would accept and know how to use ST. Taking an example from the “top ten” list, PocketFinder features a user-friendly app and a long battery life which would fit with the needs identified in this review. However, SOS-buttons are redundant when they are unreliable and/or the person cannot use it. Consequently, four

out of the top ten ST for dementia (including the PocketFinder) may rely on irrelevant features perhaps because usefulness to the person with dementia is not fully considered by designers.

The findings also suggest that higher levels of acceptance can be accomplished by ensuring that ST are experienced as “useful”, that is when the functionality of the product can do what is needed and the users are able to access that functionality (Nielsen, 1994). This study also highlighted that the perception of usefulness can be influenced by the social context in which ST would be used. However, current findings about how well people with dementia can use ST mainly stems from carer perspectives. Few studies report that people with dementia need navigation that provides them with directions and the ability to communicate. The feature of navigation, for example people with dementia using ST to navigate their walking route, was not mentioned in the top ten ST for dementia.

The largest amount of information on needs expressed by people with dementia concerned the feature ‘user-friendly’. People with dementia need ST to be simple to use and useful. This coexisted with another predominant theme found for people with dementia, namely, the need for simplicity of design details. Simplicity might also contribute to an increased perception of ST as useful, which, as mentioned above, will likely lead to people with dementia accepting and using ST. Overall, the reoccurring coexistence of needs often stems from two pertinent needs of safety and simplicity. This might explain why carers customize technology by adapting or combining new products or parts with technologies already in the home or affordable outside (Longo, 2009). For example, one carer attached a child-lock to the door alarm was because they were afraid that the person with dementia would continue to leave the house at night (Olsson et al., 2012). In other words, the door alarm did not meet the needs of safety and simplicity. However when carers do this ‘tinkering’ to adapt products to their changing needs, it might again result in a mismatch amidst applicability and capacity (Greenhalgh et al., 2013).

Limitations

The review presented here used a transparent and rigorous scoping process to identify relevant literature that was not limited to any specific evaluative design or to peer-reviewed papers. The keywords for searching the databases were developed and refined over the years of searching, but some key studies were only identified through personal contacts, indicating the challenges of searching for this topic. The source literature is limited by small sample sizes, and the predominant

focus on carers. The benefits of this inclusive nature of a scoping review (Whittemore & Knafl, 2005) highlights the importance of covering practical, ethical, design and usefulness findings from various interdisciplinary studies. This method has enabled the production of a roadmap for further investigation of needs towards technology design that stresses the importance of including the voices from people with dementia.

Implications

Designers face a challenge when considering conflicting needs translated into ST design. However, from a Human-Computer-Interaction view it is not only designers who need to acknowledge user needs in ST. More attention needs to be paid to the practices of users, industry and academia partners and in the ways in which they interact which can benefit the evolution of a design solutions (Wan et al., 2016). Nonetheless, improved designs will not be found and not used if older versions such as the “top 10 life saving devices” are the first ST consumers find when searching online.

A recent systematic review of AT for memory support in dementia conducted searches in databases such as the HCI Bibliography and Human-Computer Interaction Resources (Van der Roest, Wenborn, Pastink, Dröes, & Orrell, 2017). Future searches should include broader databases and keywords such as ‘wayfinding’ and ‘safer walking technologies’. Furthermore, whilst ST is preferred over strategies such as locking doors and medication, relying on “not so useful” technology means that technology will continue to fail as a solution for dementia care. As many have previously argued, technology should not be a substitute for care. One implication is the continuation of conflicting needs between carers and people with dementia, and that currently provided technology may not be considered useful. The findings also lead us to believe that current research practices will continue to produce the same results if we do not consider individuality. Future research should concentrate on individuality and conflicting needs in different countries. In addition, there is a need to further investigate the technologies available on the market and compare them with the ones found in the literature. Although there is a need for small sized ST, this does not necessarily mean designers should develop products which can be covertly used. Rather, it shows the continuous ethical debate and stigmatisation that could occur when people with dementia wear ST.

2.5 Conclusions

The needs of people with dementia must be considered when designing surveillance products. Previous studies have mostly focused on carers, and do not go into-depth into ST product requirements. Further work is required to establish effective support to technology development, intervention projects, services and dementia care. Therefore, further research should cross analyse these results by separately examining both the needs of carers, and people with dementia.

Chapter 3: Production

The literature review in chapter 2 made clear that not much information is known about what sort of STs are available on the online market and who the companies are behind these products. Therefore, chapter 3 discusses study I “production” which is the first site of the Media literacy approach.

3.1 Introduction

The preceding chapter described the tensions surrounding ST and prompts the necessity to examine what is available on the market. Therefore, a better understanding of the ST market and what sort of impacts these technologies might have on potential users is necessary.

In Europe, the use of technology has been identified as a potential solution to help lighten the care burden, and to support caregiving (Berridge, Furseth, Cuthbertson, & Demello, 2014; Bharucha et al., 2009; Cahill, Macijauskiene, Nygård, Faulkner, & Hagen, 2007; Kenner, 2008; Kubitschke et al., 2010; Pollack, 2005; Topo, 2009). In common with many other nations, the UK, Sweden and the Netherlands all have ageing populations. Projections show that life expectancy for 65-year olds is similar in each of these countries (UK 17.9; NL 18.2; SWE 19.8), and the proportion of older adults who live alone is also similar (UK 32%; NL 32.2%; SWE 39%) (Eurostat, 2015; Office for National Statistics, 2017). As these societies age, the number of vulnerable people requiring long-term care also increases (Berridge et al., 2014; Niemeijer, 2015).

In the UK, the government ageing agenda has an eye to cost (Duijnste, 1992; Goins, Kategile, & Dudley, 2002; Kodner, 2003; Walker, 2008). The UK National Health Service and Community Care Act (1990) highlighted the need to incorporate market forces in the delivery of services that facilitate ageing in place as opposed to more institutionalised care settings (Alzheimer’s Society, 2011; Department of Health., 2009; Department of Health Social Services and Public Safety, 2011; Health Department of Health, 2006; Phillipson, 1998; The Scottish Government., 2010). Despite the differences in health care systems, the Netherlands and Sweden also have national health and social policies that promote the move from institutional care to ‘ageing in place’ (Kümpers, 2005; A Wimo, Winblad, & Grafstrom, 1999). The capacity to leverage technology for increased well-being is measured by the ‘Networked Readiness Index’, which is similar to those in the UK, SWE and NL (Dutta, Geiger, & Lanvin, 2015).

Marketers have begun to recognize the importance of ST as a market and, accordingly, there has been an increase in numbers of such technological products being sold, particularly through online platforms (Rialle et al., 2008; Robinson, et al., 2009; Wan, et al., 2016). The knowledge base on how ST products for dementia are marketed is very limited, with little beyond the work of Kenner (2008) who describes an ‘aging enterprise’ which constitutes technologies as part of a privatized consumer healthcare trend (p.262); a trend which might not be influenced by older adults, but rather by other external pressures. These pressures include discourses that influence our understanding about diseases, as well as those affected by them, and which are often framed and negotiated through media messages (Clarke, 2006; Collin & Hughes, 2011; Lyons, 2000; Seale, 2003; Williamson & Skinner, 2011). Clarke (2006) described the importance of recognizing the relations between media, disease representations, and the interests of powerful organisations who play on underlying fears to market products that offer a solution (Fuller, 1998). Clarke, (2006) called for a ‘dementia media analysis’ (Miller et al., 2012; Kleebung 2010) to identify and assess what cultural stereotypes and values underlie the media messages that describe and portray people with dementia.

Aim

The aims of this study are to (1) investigate the online market for surveillance products for people with dementia in three comparable, ageing countries (UK, SWE, and NL), and to describe the marketers’ characteristics; and (2) to respond to the call for dementia media analysis by exploring the marketing messages in online advertisements for surveillance technologies for people with dementia.

3.2 Method

To identify surveillance products used in dementia care, and explore media messaging used by marketers, environmental scan methodology was used, adapted from a procedure of Choo and colleagues (Choo & Auster, 1993; Choo, 1999, 2001). Environmental scanning is an information viewing, seeking and organizational learning strategy (Aguilar, 1967; Choo & Auster, 1993; Choo, 2001) through which companies get to ‘know’ the market in which they are situated and are able to effectively respond (Choo & Auster 1993; Choo 1993) Originating in a company context, health care researchers have started using environmental scans (Graham, Evitts, & Thomas-MacLean, 2008); however, there is not, as yet, a standardised approach to environmental scanning (Choo &

Auster, 1993; Choo, 1999, 2001). A common approach is to seek answers to a set of pre-defined questions regarding the product of interest (Graham et al., 2008). To provide information on the ST market for people with dementia and their carers, the environmental scan detailed in this paper entailed (1) an online product search (2) selection of eligible products through application of pre-defined eligibility criteria (3) extraction of product data and marketing messages through answering a set of questions for each eligible product (4) data synthesis through both qualitative and quantitative means.

Search strategy

An internet search for surveillance products was carried out using the Google search engine. Search terms and their synonyms are shown in English in table [2](#). Each search term was translated into Dutch and Swedish for product searches in NL and SWE respectively (translated search teams available on request).

Eligibility criteria

The product web-descriptions identified in the online search were assessed for eligibility using pre-defined eligibility criteria.

The inclusion criteria were:

- technological device that tracks and/or alerts;
- marketing makes reference to dementia, Alzheimer's or similar
- product can be used by a person with dementia or a carer;
- marketing website based in the Netherlands, United Kingdom or Sweden;
- marketing of the product targets care homes, institutions, people with dementia or carers.

Exclusion criteria were:

- 'non-technical' products
- manufacturer not involved in retail
- traders between the manufacturer and marketing website
- website designers
- webpages marketing second-hand, previously used, or previously owned goods

Four researchers PH, GC (English), YV (Dutch) and LG (Swedish) were involved in developing the search criteria and screening the websites for information. Every website with at least two of the keywords was selected for further analysis. The researchers placed field notes in the data set, and provided descriptions of what was portrayed on websites. When a product was entered, the

reviewer would screen for duplicates by the excel search function in the data set. If a duplicate was found, the new product would not be entered. However, there was a possibility that similar products were displayed by alternative websites under different circumstances. Therefore, the reviewer screened again the data set to remove repetition and irrelevant products (for example, non-technological products sold on Amazon). This removal was carried out twice after the exclusion criteria. Duplicates of products were included only if they were provided by alternative websites using different marketing techniques.

Data extraction

A draft data extraction tool was devised, based on domains relevant to characteristics of products and marketers, and the anticipated information needs of potential users. The draft tool was validated through discussion with researchers from INDUCT and piloted by the main researcher (YV) after which additional subcategories (market share and growth) were added. The final data extraction tool covered 9 domains, extracting information on: identification; marketer characteristics; product functional availability; target market, sales; safety; privacy and portrayals (table 6). The extracted data were entered into an excel spreadsheet, in formats suitable for the nature of the data. Data types included nominal, categorical, numerical and qualitative formats (table 6). Qualitative data included quotations from websites. Data were collected over a period of one year, between October 2016 and October 2017 with data regarding product prices gathered on the same day in August 2017.

When websites did not provide information about the marketer that provided the product (e.g. size of marketer, country origin, number of employees), additional public-domain information was gathered online, for example from LinkedIn. Classification of the size of the marketing organisation was based on the number of employees within that organisation, with ‘cottage industry’ defined as “a small-scale informally organized industry run from home” (Investopedia LLC, 2017) and operationalised as “online web shop indicative of; its location being a private house, a private phone number communicated, or listed with one employee usually described as the owner”. Small scale companies were defined as having a maximum of 10 employees; small-medium between 10 and 50, medium-large between 50 and 200; large more than 200 employees.

Table 6: Data extraction items and data types

	Domain	Item	Data type
1	Identifiers	Product name Company / organisation name	Nominal Nominal
2	Marketer characteristics	Organisation size Market share / growth	Categorical (cottage industry, small, small medium, medium, large) Numerical
3	Product function	Main function Additional information	Categorical (track, alarm, track & alarm) Qualitative
4	Availability	Availability in Sweden, UK, Netherlands? Country of product origin Availability online / in store	Categorical (Yes/No) Categorical (Sweden, UK, Netherlands, Other) Categorical (online, in store, both, other)
5	Target market	Target purchasers Target end users	Categorical (consumer, care home, company, other) Categorical (person with dementia, carer, unclear)
6	Sales	Price ⁺ Additional information	Numerical Qualitative
7	Safety	Safety messaging Additional explanation	Categorical (User activated alert, User alerted, Alerts carer, Alerts both, other) Qualitative
8	Privacy	Access to data Additional explanation	Categorical (user only, carer only, user & carer, 3 rd party, other) Qualitative
9	Portrayals	Presence of portrayals Keywords	Categorical (Yes/No) Nominal

⁺ If the origin of a product was unclear, it was classified according to the country in which it could be purchased.

⁺ ⁺ Purchase price excluded monthly fees or shipping costs.

Data analysis

Price conversions were made into pounds and the Excel ‘AVERAGE’ function was used for calculating the mean purchase prices. The ‘COUNTIF’ function was used to summarise the frequency of specific words in nominal data (e.g. ‘safety’). For categorical items the SUM function was used.

3.3 Results

In total, 382 products were identified online. After the application of the eligibility criteria and removal of duplicates, 242 products remained. Reasons for exclusion included: being ‘non-technical’ products e.g. identification bracelets without tracking facility; networking facility without detection monitors (e.g. for temperature, light or fire¹). In descending order of frequency, the identified products originated from: the UK, Australia, USA, SWE and NL.

Price

The purchase price of ST displayed ranges from £0 to £654 in the three countries, with similar products priced differently by different providers. Thirteen products were under £10. The headline price displayed often included extras (i.e. shipping costs, monthly fees). However, the mean price is unknown because many websites displayed neither prices, nor included extras.

Marketers

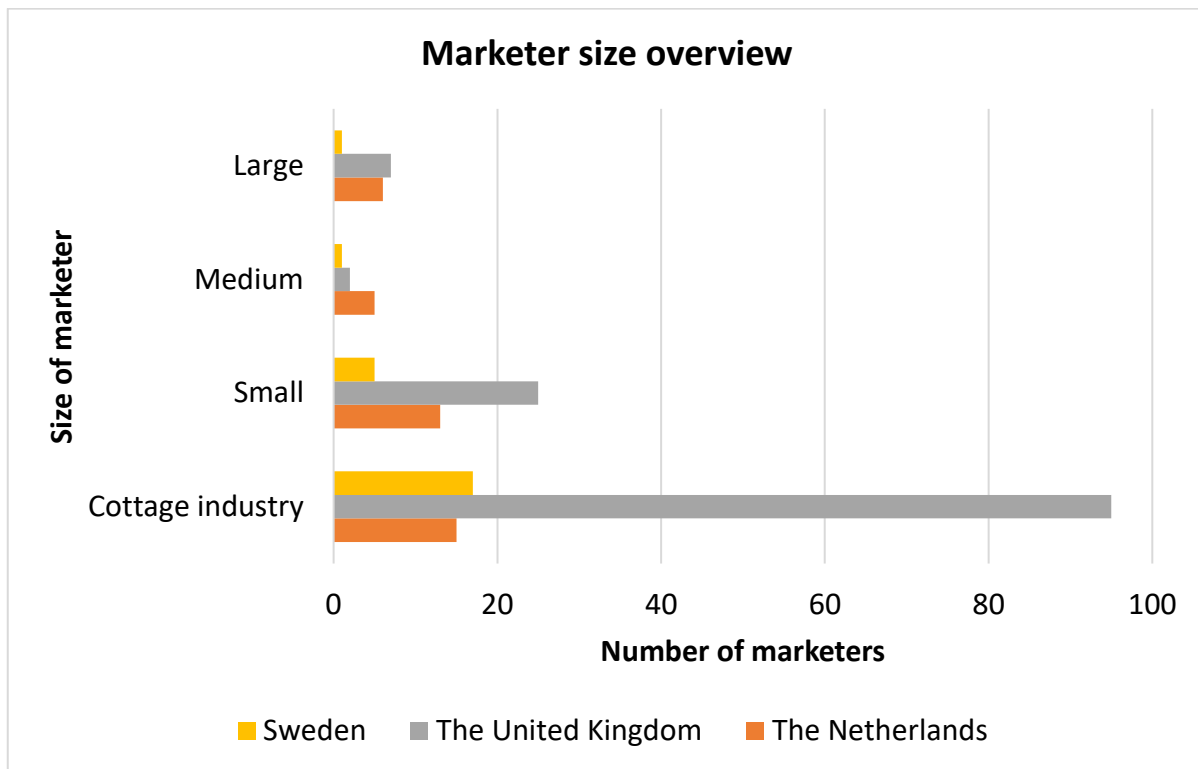


Figure 2: What is known about the size of the marketer?

[Figure 2](#) displays the response to the question “*what is the size of the marketer*”. The ‘cottage industry’ category was the largest single category in all three countries, marketing through single-handed online web shops or companies with up to ten employees. Whereas the majority of ST marketers in the UK and Sweden were cottage industries, there was a different pattern in the Netherlands where there was more balance across size of company. Many marketers in the dataset made unsubstantiated claims to be the market leader.

Safety

In scanning the web-descriptions for “*what is mainly communicated about what the product does for safety*”, two main types of products were elicited; products that ‘detect’ and those that ‘alert’. The latter required that the person with dementia should push an alert button in case of emergency, or that somehow the carer was made aware of an emergency, although there was generally scant

detail on how, when, where or to whom alerts would be raised. Most of the detectors did not send notifications. However, some products both detected and alerted, for example a tracker watch that could notify the carer with information about the recipients’ location and health status.

“The can act as both a locator for keys and bags or a tracking device for a loved one, to help keep them safe if they wander” Location tracker – cottage industry 1.

Location finding may require the carer to access real-time monitoring on a computer or phone (Kenner, 2008; Mulvenna et al., 2017).

“Ideal for monitoring: pets (e.g. dogs / cats / horses etc...), children / teenagers of all ages & abilities, vulnerable adults or frail elderly who may misuse the SOS & on / off buttons e.g. autism, Alzheimer’s / dementia sufferers” SOS button - cottage industry 2.

A minority of products were described as ‘preventing risk’; however, little or no explanation was provided on the mechanism for this.

Marketing by keywords and portrayals

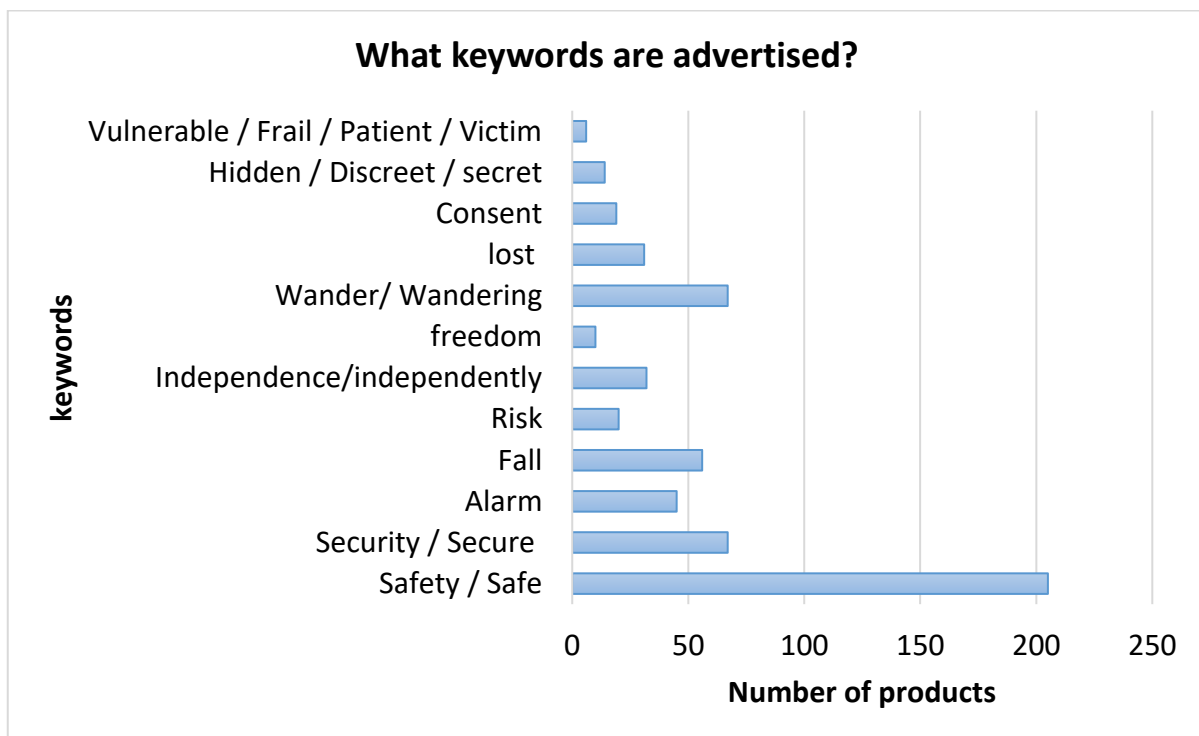


Figure 3: The keywords advertised on providers’ web-descriptions

[Figure 3](#) illustrates the key descriptors used on websites. The greatest emphasis was on safety and security. The target problems were wandering, being lost, and falls. There were differences in the diversity of keywords used in each of the three countries. In Sweden, keywords were descriptive of ‘spy’ and ‘camera’. In the Netherlands ‘sensor’ was a common keyword. In the UK words such as ‘ethics’ and ‘consent’ were used, which remarkably were not used in Sweden and the Netherlands. However, the word ‘consent’ was not used in relation to having have approval to use ST on a person with dementia. Instead, words such as ‘hidden’, ‘discreet’ and ‘secret’ were used, indicating covert surveillance. Keywords were often accompanied by striking visuals of people with dementia, pets, children, and possessions, either kept safe through ST use, or portrayals of being lost and harmed through non-use of ST. No major between-country differences were identified in visual portrayals.

Marketing target

There were no examples of marketing messages being targeted at people living with dementia. Instead, messages were aimed at families and carers, researchers or organisations involved in social care provision:

“... provides an ideal way for families and carers to keep track of the people they love. Ideal for children....and seniors who value their independence. It’s all about having peace of mind when you’re not there with them” location tracker – cottage industry 3.

“Our customers include: dementia & Alzheimer's patients, stroke patients, local councils, care homes, schools, rehabilitation centers, dementia research groups, universities, cautious parents, travelers / employers” location tracker, cottage industry 4.

Privacy

Most products identified through the environmental scan required data-sharing. The majority reported that carers would receive data, such as the location of the person with dementia. However, the second largest group involved data-sharing with third parties (e.g. online cloud storage, alarm centre).

“GPS personal alarm and its 24/7 response service lets you to carry on with your life knowing that there is help available at the press of a button” location tracker with SOS button – Cottage industry 5

Few ST reported that they provided the person with dementia with the data of their location or gave them instructions to guide them home although this is an expressed need of people with dementia (Robinson et al., 2009).

3.4 Discussion

This study represents the first media analysis of online marketing of surveillance products for use with people with dementia. The key finding about marketers was that they were predominantly ‘cottage industries’, especially in the UK. In all three countries, the products being marketed were generally unsophisticated, able to either detect *or* alert, rather than both. Product descriptions emphasised safety and security, referencing risk situations such as wandering, falling or being lost, even where the product had no function that would prevent such risk. Advertising was targeted at carers or service providers, and not people with dementia. People with dementia were commonly portrayed as a ‘problem to be managed’, and consideration of ethical issues (such as freedom to choose, consent and covert surveillance), whilst varying by country, was largely absent.

Niche market?

Huge investments have been made in the research and development of telehealth and telecare (Department of Health, 2008; Woolrych et al., 2013), including the Whole System Demonstrator randomised controlled trial (Steventon et al., 2013) and NHS testbeds such as ‘Technology Integrated Health Management for dementia’ (Galea, Hough, & Khan, 2017). Yet, counterintuitively, the majority of marketers identified in the environmental scan were ‘cottage industries’ suggesting a ‘niche market’. This finding may be due to data collection being by *product* rather than by *market-share*. The UK has a large home-care social alarms market, and is a significant adopter of telecare (Gibson et al., 2016; Goodwin, 2010; Frost & Sullivan, 2010; Taylor, 2012). People who meet the eligibility standards for social care can access pendant alarms commissioned by local authorities (Berridge et al., 2014). In Sweden, municipalities pay for alarm installation, and users contribute to this monthly service. There is a mix of public and private sector provision, with private manufacturers financing much of the research and development into advanced telecare (Berridge et al., 2014). In the Netherlands, the social security system, municipalities, well-being organisations, and other home-care organisations provide alarms but

payments are not standardised but vary according to who is using the technology, and for what purpose (Kubitschke et al., 2010).

Not 'fit for purpose'?

The number of websites claiming to be 'market leader' suggests that a certain amount of creative licence was employed in advertising, and it was clear that many products had been 're-purposed' for the dementia market having originally been designed for a different use.

People living with dementia have expressed the need for technologies to have a simple user interface that can be tailored to individual needs and skills, that allows people with dementia to engage in everyday activity and allows carers to have a break knowing that they will receive an alert if risk situations arise (Dixon, 2016), such as personalised notifications when the person with dementia leaves an area of safety (Phillips & Zhao 1993; Schulz et al. 2012; Schulz 2012). However, the majority of identified products could either detect *or* alert, *or* required real-time monitoring.

Carers have concerns over false alarms (Dixon, 2016; Niemeijer 2015; Hall et al. 2017), privacy (Dixon, 2016), and data-sharing with other parties (Robinson et al. 2007; Fisk 2015; Niemeijer 2015) yet most products involved third parties such as call-centres. Product descriptions included only limited information on functionality, and focused instead on risks such as falling, wandering and getting lost. Whilst promotion of ST products emphasises independence and safety (Kenner, 2008), this outcome has not necessarily been established through research (Futrell & Melillo, 2002; Hughes, 2008a, 2008b; Marr, 1989; MWCS, 2005; Moffat, 2008; Nelson et al., 2004; Niemeijer, 2015; Plastow, 2006; Robinson et al., 2007; Sävenstedt, et al., 2006; Welsh, et al., 2003). Alerts from ST devices can signal when a fall happens, but do not avert the fall. The question posed by Niemeijer and colleagues (2015, p.124) therefore remains unanswered "... does ST actually offer more security?".

In Europe there is an expectation that businesses to not misrepresent their products when advertising to consumers (Collins, 2005; Van Boom, 2015). The 'Unfair Commercial Practices' directive underpins the national advertising authorities in the UK, the Netherlands and Sweden (Advertising Standards Authority Ltd, 2018; Netherlands Enterprise Agency, 2018; Reklamombudsmannen, 2017). Consumers in the three countries can submit complaints about misleading advertisements, and companies are penalized where complaints are upheld. However, problematic practices are not always addressed (Van Boom, 2015) and in a media-rich online

environment consumers may not be aware of being misled (Mitra, Raymond, & Hopkins, 2008; Van Boom, 2015).

Portrayals of dementia

The portrayal of people with dementia as a ‘problem to be managed’ has been highlighted in previous research (Rozanova, Miller, & Wetle, 2016). Placing people with dementia in the same class as wallets, keys, young children, dogs and/or prisoners is reminiscent of the ‘objectification’ described in healthcare prior to the person-centred care movement, and is concordant with ‘abjection’; a defining feature of the social imaginary of the fourth age (Higgs & Gilleard, 2014). Marketers may have simply adapted existing advertising materials when dementia care was identified as a potential new market, assuming a lack of autonomy and decision-making capacity in line with the ‘empty shell’ portrayal of dementia (Alzheimer Europe, 2013).

No marketing was directed at the person with dementia themselves even though people in early stages of dementia may choose to engage with surveillance, for example actively seeking out devices such as ST bracelets (Niemeijer 2015), safe in the knowledge that they can be monitored by a ‘supportive other’. In these circumstances, ST can indeed help to maintain independence (Essén, 2008) and freedom (Dorrestijn & Verbeek, 2013), reflecting Foucault's (2000) notion of freedom incorporating an individual's conscious choice to use technology.

There was between-country discrepancy in use of terms such as ‘ethics’ and ‘consent’, but none of the marketers considered personal choice of the person with dementia. Little information was provided on the acceptability of surveillance devices from the perspective of people with dementia. Whilst most products are solely designed for, and used by, carers (Demers et al., 2009; Topo, 2009), this should not mean that the perspective of the person with dementia should be ignored. Some people may not like having an unfamiliar device attached to them (McShane et al., 1998; Wan et al., 2016) and may take off items such as pendants or bracelets. As Niemeijer and colleagues (2015) observed, when an ST bracelet is taken off, it no longer does its job. This may explain the emphasis on ‘hidden’ devices for covert monitoring. Media representations of dementia can influence interactions with people with dementia and make a difference to the utilisation of health care resources (Kessler & Schwender, 2012). Bodies now exist that review and counteract media messages. For example, the Glasgow Media Group (GMG) reviewed various claims used in the media (e.g. issues of war, representations of AIDS, communications of risk), and how this impacts negatively on certain groups (e.g. refugees, disabled people) (Briant, Watson, & Philo, 2011; Eldridge, 2000). Whilst members of the GMG have worked, and continue to work, to

publicise their critiques (Eldridge, 2000), unhelpful media coverage of dementia keeps on growing (Kessler & Schwender, 2012).

Implications for stakeholders

There are important implications from this study for a range of stakeholders including manufacturers, marketers, the media, and researchers, in addition to all those living with dementia. Families, and people living with dementia themselves, should consider the power of media messaging which may present out-of-date and inappropriate technology as ‘tried and tested’ or ‘market leading’, or may emphasise safety-enhancement or risk reduction for products that provide only ‘after the event’ alerts. Organisations that support people with dementia and their families could play a role in highlighting some of the decisions that need to be made, such as whether a product has the appropriate combination of detection and alerting functions to suit an individual’s particular circumstances. In addition, support organisations could also highlight ethical considerations of surveillance, for example whether a person with dementia themselves is choosing to use technology, or whether carers are making choices in circumstances that do not yet require ‘best interests’ decision-making (for an illustration of carer fears over safety leading to autonomy restriction see Graneheim et al. 2001). Manufacturers and marketers should pay closer attention to the potential market of people in the early stages of dementia who can express their own needs and preferences. Furthermore, marketers and the media should be made aware of the potential for stigma-exacerbation from media messages that objectify people with dementia.

3.5 Conclusion

This study draws attention to an emerging issue of ST for people with dementia. The marketing of ST does not take into consideration the needs of people with dementia themselves. Marketing of ST raises issues of rights, autonomy, dignity, privacy and consent but all too often the marketers’ messages run counter to the maintenance of dignity in later life.

Chapter 4: Methods audience reception

The preceding chapter reviewed the ST market, which contrary to the perception of future dependence on technology, sells mostly passive trackers. The marketing messages target carers and stress the need to increase the safety of people with dementia, however, such messages are not entirely consistent with what these ST products can do. Meanwhile, the needs from people with dementia are not taken into consideration and therefore this chapter describes the second site of the media literacy approach; audience reception. The chapter describes the three studies used to examine user needs and to understand first-person perspectives.

4.1 Introduction

The ageing population together with visuals of dementia have gained publicity and mass media is a prominent source that presents audiences with information about dementia (Kessler & Schwender, 2012). Part of the media are advertisements with visuals and texts which are effective tools to grab consumer attention (Pieters & Wedel, 2004). In order for people to be aware that technological products exist and believe that they work (Greenhalgh et al., 2013), companies use advertising to shape consumer perceptions so that they can differentiate the company's brand from those of its competitors (Aaker, 1996). Advertising is successful when consumers are aware, recognise and purchase a product from the brand (Aaker, 1996; Jones and Slater, 2013). Furthermore, advertising enables promoting products, yet it can also be a way of disseminating certain representations of intended audiences, or in other words, stereotypes (Vulpe, 2017). Stereotypes become problematic when people select such cultural resources and then interpret living situations; for example, what it is like to live with dementia (Vulpe, 2017). Similarly, brands are built on symbolic visuals which are designed to convey the values of a company (Salzer-Mörling & Strannegård, 2004). Studies have reported that our understandings about dementia, as well as those affected by them, are formed through media discourses (Clarke, 2006; Collin & Hughes, 2011; Williamson and Skinner, 2011).

However, dementia itself does not discriminate against gender, race or class (Medina, 2014), rather it leads to a cognitive decline for many older adults (Sixsmith, 2013). Dementia is often perceived as part of the normal ageing process and ageing is associated with negative descriptions that relate to disease and disability (Sixsmith, 2013). Much gerontology attention has stressed that dementia and ageing are socially constructed (Medina, 2014; Thornton, 2002). For example, Gilleard & Higgs', (2000) use of “cultural turn” led to a focus on the third age and researching discourses of

ageing in cultural texts. More recently, there have been studies describing the magnitude of culture producing meaning and contextualising how dementia is portrayed within discursive frames (Medina, 2014). For example, people with dementia are often represented in a negative, and less often, positive light (Van Gorp & Vercruyssen, 2012). However, both representations may negatively impact a person's health and personhood as the person disappears behind the diagnosis (Loos & Ivan, 2018; Minichiello, Browne, & Kendig, 2000; Van Gorp & Vercruyssen, 2012; Van Gorp, Vercruyssen, & Van Den Bulck, 2012). Therefore, researchers have reported the necessity for examining media and audience responses (Loos & Ivan, 2018; Minichiello et al., 2000; Van Gorp & Vercruyssen, 2012; Van Gorp et al., 2012). In particular, van Gorp et al., (2012), studied Belgian advertisements and reported that participants (none who lived with dementia) preferred those advertisements drawing on fear of death and degeneration because they were easier to understand, more credible and attention-grabbing (Van Gorp et al., 2012). Dobos, Orthia, & Lamberts, (2015) in another study based upon subscribers to an Alzheimer newsletter found that visual images which evoked emotions were preferred by subscribers over scientific visuals. In relation to discourses of dementia and technology, websites use keywords such as "safety", "independence", "wandering", "lost" and "fall" and signal people with dementia, as lost and/or wandering and kept safe through surveillance. There is much terminology debate about negative connotations and ethical implications for the word 'surveillance', yet it does describe the offered for sale monitoring products originally used for tracking dogs, children or prisoners (for discussion see chapter 3 Vermeer, Charlesworth & Higgs 2019b). These websites were directed to carers and do not include the voices from people with dementia (Vermeer, Higgs and Charlesworth, 2019a) and this is becoming the source of some tension given the images of dementia that are being transmitted. In particular, it is problematic when money-making organisations are behind discourses; yet, none have the real person at the centre of their interest (Medina, 2014).

Part of understanding the impact of discourses involves analysing how older adults may recognise and give meaning to ageism (Minichiello et al., 2000). For example, older adults were opposed to using a robot because discourses signified user-representations as old, frail and lonely and they imagined themselves as the opposite (e.g. helpful and active). In particular, one older adult stated "*If you were, say, old and growing demented, than I could imagine this being a good thing, but for me?*" (Neven, 2010, p. 341). If a greater acceptance of technology is desired, it is important to appreciate older adults understanding and potential opposition to technology (Neven, 2010). Opposing the use of a certain product or message might be the result of a certain meaning attached to what the product or message represents. According to Hall, (1980) audiences decode messages

in accordance with a dominant and preferred hegemonic position, negotiation position or an oppositional position. The dominant position is where audiences accept the message as common sense whilst with the negotiated position audiences relatively agree but also challenge it. Finally, the oppositional position occurs when audiences reject the message (Hall, 1980).

Involvement of potential users

To prevent opposition, technology developers should consider that people have their own sense of personhood and individual preferences which operate within a social context (Brankaert, 2016; Wallace et al., 2013). In particular, understanding how carers and people with dementia perceive and use technology both inside and away from the home will help developers, marketers and care practitioners respectively to produce, market and provide appropriate products. For example, the DEEP (2013) network of people living with dementia published various guides on how researchers and developers need to involve people with dementia to collect their views, especially considering that they might not have a wish for ST (Greenhalgh et al., 2013; Neven, 2010). Furthermore, Nygård, (2006) reported the importance of giving people with dementia a sense of control during research and that including carers in the same discussion might alter data collection. Similarly, another study recommended to recognise the needs from people with dementia separate from carers (See chapter 2, Vermeer, Higgs, Charlesworth 2019c). Meanwhile there is an urgency to involve carers and people living with dementia in patient and public involvement (PPI) (Involve, 2012).

Online views

With this in mind, the voice of the person with dementia is increasingly heard online, using platforms such as blogs, Facebook and Twitter (Kenigsberg, et al., 2017; Craig and Strivens, 2016; Talbot et al., 2020). In particular, online forums allow individuals to (anonymously) have asynchronous conversation, express their needs and join the discussions at their own convenience (De Simoni, Shanks, Balasooriya-Smeekens, & Mant, 2016). As a wide range of tracking devices are available online in 'direct to consumer' outlets (Rialle et al., 2008; Robinson et al., 2009; Vermeer et al., 2019a; Wan et al., 2016), online discussion forums are likely to be an ideal setting from which to gather consumer views of products and to observe 'consumer to consumer' discussion on which products best meet their needs. Indeed, it has been argued that the internet is an appropriate and rich way to understand public health issues and individual user needs (Keeling

et al., 2013; Jamison et al., 2018; Newman et al., 2019). People can voluntarily decide to post in the threads that they are interested in, resulting in insights that may go beyond the reach of interviews (Jamison et al., 2018). In particular, online communities engage, discuss and inform their purchasing activities and give more open insights into consumers' needs, wants and choices compared to traditional research methods because of anonymity (Taylor and Bogdan, 1984; Childress and Asamen, 1998; Kozinets, 2002, Xun and Reynolds, 2010). Consumers use forums as a tool where they gather information before making a purchase (Adjei et al., 2010) and information created within forums can have a greater influence on consumer's decision-making than 'offline' word-of-mouth (Steffes and Burgee, 2009). Service providers can use online consumer input to inform service improvements (Keeling et al., 2013) and the analysis of respondent involvement within a forum can serve as crucial input for marketing research (Kozinets, 2002). Accordingly, online forums are seen as "goldmines of information" (Childress and Asamen, 1998; Xun and Reynolds, 2010). A popular method for studying naturally-occurring engagement with online forums has been the use of 'netnography' (Kozinets, 2002). Indeed, a recent review 'netnographic studies' of customer behaviour online identified 321 studies published in marketing journals in the two decades between 1997 and 2017 (Heinonen and Medberg 2018). There has been recent interest in applying netnography to online activities of people with dementia (Conger et al., 2019; Thomas, 2017), However, there are, as yet, no published studies of engagement of people with dementia with online discussion of ST.

In sum, it is important to examine how media can construct what meaning the imagery of ST carries and how the 'problem of dementia' is understood by audiences. Furthermore, researchers have explored technology user-needs but there are no known studies that have evaluated how ST advertisements impact audiences. Whilst, 'offline' research exists on user-needs for ST, online research is only just beginning and gathering the views of people with dementia and carers could provide new insights. This study wishes to contribute to research in this area by contrasting the differing needs identified by carers and people with dementia as regards technology design as well as the exploration of their responses to ST advertisements.

4.2 Methods

The aim of this qualitative research was to investigate the views of carers and *separately* people with dementia about ST designs and advertisements. These different points of view can shed light on understanding responses to advertisements and user needs that can facilitate the development

of improved ST in the future. Following the first study of production, the next three studies were conducted: (II) PPI, (III) online discussions and (IV) focus group discussions (Table 8).

4.2.1 Patient and Public Involvement

Choice went out to create another PPI group in the UK. It was hereby hoped to include more views from people with dementia and carers about ST and empowerment. The research advisors could give advice and contribute to the shape of this thesis. The group was developed through adhering to the guidelines from INVOLVE (2012), NIHR (2015) and a role description was distributed on the NIHR join dementia research website. The role description asked for members of the public with personal experience of living with dementia, who wanted to influence policy and research and were interested in sharing their thoughts on ST and empowerment (see appendix A). In addition, the role description described what was expected from the PPI members as research advisors and the amount of expenses, which were covered for taking part in a half-day meeting.

Eligibility criteria

Table 7 describes the inclusion criteria for the research advisors. Three people living with dementia and seven carers registered to take part, however, on the day itself two people living with dementia cancelled. Therefore, the PPI group included seven research advisors who cared for someone living with dementia and one advisor living with dementia. The pseudo names for the male cares are Pete and Leo, the person living with dementia is Jacky and for the female carers Annet, Femke, Maud and Manon. The meeting took place in London in March 2018. During this meeting, the main researcher (YV) of this thesis facilitated the discussion, one researcher active in the field of stigma and dementia research (JB) had a supportive role and another researcher (GC) participated. The discussion included ‘what is ST’, ‘can ST be empowering’ and ‘how would you categorise ST’. The full presentation can be found in appendix B. Hereby, the PPI group discussed ST and illustrates the existence of many tensions that are subsumed under the label of ST.

Table 7: Inclusion criteria for research advisors

Inclusion criteria for research advisors	
The individual should have direct experience with dementia of being either:	
-	A person living with early set/ moderate dementia
-	A [former] family carer supporting a loved one with dementia
-	Live at home
-	Have some knowledge of ST, or use ST

Second, this study undertook a qualitative analysis of comments to the Alzheimer Nederland forum to investigate needs for ST. A forum is examined which comprises discussion threads dedicated to ST. Second, focus group discussions were conducted in the Netherlands as they are known to decrease the pressure to respond, increase quality of interaction and shared experiences might trigger memory (Bamford & Bruce, 2000). These methods are guided by employing the theoretical frameworks of Hall (1980) and Vermeer, Charlesworth and Higgs (2019c) and therefore subjected to qualitative content analysis because a series of analytical constructs investigated through theory-driven coding from previous research was employed (Downe-Wamboldt, 1992). Attention was also paid to examine other themes that might provide alternative conclusions to those suggested by literature.

Table 8: The methods and individuals involved for audience reception

Method	PPI	Online discussion	Focus groups	
Group Role	Research advisor	Respondent	1 Participant	2 Participant
Characteristics individuals main discussion	1 person living with dementia 7 carers	9 People living with dementia 42 carers (see table 12)	5 People living with early/moderate dementia 4 men, 1 woman 2 participants live with young-onset dementia Aged between 40 and 85	4 women carers (1 spouse, 2 daughters and 1 friend supporting one or two people living with dementia) Aged between 40 and 70
Group facilitators	Main researcher (YV)	Main researcher (YV) Forum moderator	Main researcher (YV) Advocate for people with dementia Notetaker	Main researcher (YV) Advocate for carers Notetaker
Supportive roles	(GC, JB)		Volunteer 4 Female spouse-carers	
Date data collection	March 2018	June – September 2018	June 2018	September 2018
Presented advertisement films	N/A	N/A	“SafetyOldCard” “Carebelt”	“The Family” “Carebelt”
Presented advertisement figures	N/A	N/A	Older adults and children smiling with pets Older adults fallen down and/or lost	

4.2.2 Online discussions

This naturalistic, netnographic study involved gathering qualitative comments from the Alzheimer Nederland online forum, in particular from discussion threads dedicated to ST for carers and people

living with dementia at home. Descriptive data about the forum was also gathered from the archived history of activities. Alzheimer Nederland provide a Dutch-language online forum dedicated to providing information on dementia. The forum is a source through which carers and people with dementia can search and/or offer information and support. The page “dealing with dementia at home” was started by the forum moderator in 2014 and, according to the Google Analytic “Page views” measure (Pakkala et al., 2012), had over 45,000 views from April to August 2018. Within this page there were two threads on ST: (1) “Surveillance technologies to follow someone with dementia” started by the forum moderator in January 2014 (viewed 34636 times by 3rd September 2018) and (2) “Surveillance and wandering technologies to prevent people getting lost” also started by the forum moderator, this time in July 2015 (viewed 99223 times by September 2018). Alzheimer Nederland noticed that, besides a growth in popularity of the existing threads, they received additional enquiries about ST. In collaboration with the main researcher, an additional thread “How do you find the best surveillance technologies?” was posted in April 2018. By September 2018 it had viewing figures of 2516.

Participants

In order to post on the forum, members were required to register, accept the disclosure page (see appendix [E](#)) and indicate their role (i.e. researcher, student, carer, or person living with dementia). Members that responded to posts (henceforth termed “respondents”) were identified by usernames and role descriptions linked to each of the selected posts. Other characteristics (e.g. gender, year of birth) were not retrieved as not every respondent chose to display this to the public.

Eligibility criteria

Eligible respondents and their comments were included if they met the following criteria: (1) identified themselves other than a researcher, student, or forum moderator (2) wrote diligently and understandably in Dutch. As such, comments from forum moderators, students and researchers were excluded.

4.2.3 Focus groups

Focus group discussions are a well-established research method for involving people with dementia to elicit their views on technology because they are known to decrease the pressure to respond, increase quality of interaction and shared experiences which might trigger memory, and enables to examine similarities and differences between participant responses (Bamford and Bruce, 2000; National Audit Office, 2007; Innes, Kelly and Dincarslan, 2011). Therefore, focus groups were conducted in an all-inclusive way following the guidelines from Deep (2013) and Brooks and Gridley, (2016) with two diverse samples in order to investigate differences and similarities between the needs and responses to ST designs and advertisements.

Sample

Table 9 reports that in order to take part in discussion, the participants needed to be able to communicate their perspective in Dutch, have some knowledge of ST, live at home and not present any behaviour that might prohibit watching or hearing the advertisements. Furthermore, the individual should have direct experience with dementia of being either a carer or living with early set/moderate dementia according to the Mini Mental State Examination (MMSE) baseline (Folstein, Robins and Helzer, 1983). Furthermore, groups were designed not to be larger than six individuals to stimulate a more accessible interaction and to comply with communication and cognitive impairment (Gridley, et al., 2016).

Table 9: Inclusion criteria participants

Inclusion criteria for focus group participants
- Have some knowledge of ST, or use ST
- Live at home
- Be competent to provide written informed consent
- Be able to speak Dutch
- Be able to attend, listen and watch short films
The individual should have direct experience with dementia of being either:
- A person living with early set/moderate dementia (MMSE)
- A family carer supporting a loved one with dementia

Recruitment

The recruitment stages involved: 1) the dissemination of invitations and information booklets about the focus groups in the already existing emailing list and database (including MMSE

information) from Alzheimer Nederland by the main researcher (YV), 2) Alzheimer Nederland approached new contacts and existing groups they already work with, 3) if people were interested in taking part, they could contact the main researcher and Alzheimer Nederland, who in turn, answered questions and send the consent forms to people so that they could already read these and ask questions before the discussions took place, 4) Alzheimer Nederland and the main researcher screened the potential participants for meeting the sample criteria by telephone or e-mail before any consent or discussion took place. Hereby, purposeful sampling was used to include participants that met the criteria, the conditions of the Mental Capacity Act (Department of Health., 2005) and were competent to give informed consent. To facilitate participants groups were held locally at convenient times in two different cities in the Netherlands. However, before the discussions took place, two carers excused themselves and two other focus groups were cancelled when participants dropped out last minute with reasons of heavy care duty or experiencing distressing behaviours.

Informed consent

Participants were provided with information sheets prior to the focus groups taking place. The information sheets described the project, what would be expected of participants and their right to withdraw without penalty. The group facilitators present during the discussions were the main researcher, and two members of Alzheimer Nederland. They all provided additional support during the discussions and have previous experience of organising focus groups with people with dementia and carers. The main researcher guided the discussion and one member of Alzheimer Nederland took notes. Furthermore, Alzheimer Nederland employs advocates who are specialised in collaborating with and within the best interest of people with dementia and carers. Therefore, the advocate for people with dementia was present during group 1 and the advocate for carers was present during group 2. The advocate assessed mental capacity the day of the focus group and before the discussion took place by having a conversation with the participant about their understanding of the purpose of the study, the nature of their involvement and the use that will be made of their data. Everybody present were asked to read the sheets, which the researcher talked them through. The researcher explained the purpose of the study, what the discussion entailed, that there were no associated risks to participating and what was proposed to do with data (i.e. storage, anonymity, confidentiality and analysis). Written consent was obtained from all participants' and the present supportive carers before the discussions took place. Participants were also asked if they would like to continue to take part in the discussion after the coffee break and watching the films.

Emotional distress

Although it was not anticipated that participation in this study would lead to significant emotional distress, the group facilitators made some prearrangements to prevent this from happening. This entailed briefings that participants are in control during the discussions, that they can request for recording to pause at any time, are not obliged to answer questions if they do not want to and can withdraw consent at any time without giving a reason. Another example is that family, friends and professional carers were invited to be present to offer support so that they could be called upon at any time during both the discussions. In the event that someone did become upset, the researcher would ask if they would like to take a break and remind them of the support available and the right to withdraw.

Table 8 shows that Alzheimer Nederland arranged that before the main discussion took place with group one, the supportive carers were given the opportunity to share their experiences with the volunteer in another room. The volunteer and carers helped with the consent process; however, they did not participate in the main discussion (Gridley et al., 2016). They could return any minute and if required they could provide support during the discussion. Participants from group 2 did not wish to bring additional support to the discussions.

Table 10: Focus group pseudo names

Focus group	1 People living with dementia	2 Carers
Pseudo names	Martijn Tom Tim Stephan Kristel	Kim Anouk Linda Carlijn

Procedure main discussion

A cultural probe the Spotter (2018) was used for facilitating communication, ensuring participants felt in control and to develop a deeper understanding of their needs (Wherton et al., 2012). The “Spotter” is a GPS-tracker with a SOS-button that can be connected to an online account where someone can see the location of the person wearing the device. Furthermore, it is a brand that advertises to spot smiling older adults (with or without dementia), dogs, cats and possessions. The full procedure for selecting the two ST advertisement films shown to participants (table 8) can be found elsewhere (see chapter 7). Initially the idea was to show both groups the same ST advertisements which entailed: two films (SWE and NL) and printed visuals (e.g. one from UK,

SWE and NL). In particular, the English narrated film “The family” includes negative representations and the Dutch spoken “Carebelt” film includes positive representations (e.g. Mr. van Dijk uses ST to find his way back home) to examine if participants would respond differently to such representations. In particular, “The Family” (Wittra, 2016) shows a narrator who helps a family to monitor their dog, baby and grandma who is lost in the woods. This brand markets ST as an intelligent solution technology, which provides indoor and outdoor positioning through tags and sensor data. Further, the slow-paced “Carebelt” film shows a man walking outside who panics when he is lost but uses the ST to find his way back home (Zorgriem ZHO, 2016). The “Carebelt” is a GPS device with a SOS-button connected to an online account for tracking the location of the person wearing it. Towards the end of the discussion, participants were asked to watch and respond to ST advertisements which were visuals of positive representations (e.g. happy older adults, children and pets) and negative representations (e.g. older adults fallen down and/or lost). The positive representations were from the Dutch brands “Carebelt” and “Spotter” and the negative representations from the English “Trackyour” and “Stray Star”. However, the Dutch spoken film “SafetyOldCard” (2016) was shown to participants from focus group one when they mentioned not wanting to watch the English spoken film because of having difficulties with the language. The bankcard sized “SafetyOldCard” is for around the neck and includes the option to call and has four buttons, GPS and a SOS-button. The slow paced film shows negative representations of older adults who appear to have fallen down or are lost. The film includes the text; “do you have a father or mother who lives alone, or do you live alone, afraid to not be able to reach the phone, or does your loved one wander because of dementia? This is the solution because it is easy to use, low purchase price and cheap in use”.

A topic guide inspired by Nygård's, (2006) and Deep, (2013) was used to structure the discussions and to ensure explicit and few reflective questions (table [11](#)). Each discussion lasted approximately 90 minutes and were digitally recorded. After the main discussion, the carers from group one were asked to return to the room and in both groups the additional question for the carers was how they searched for ST. Followed by providing a summary of the main discussion and asking all participants if they had anything to add.

The people living with dementia in group one have participated in research and collaborated with Alzheimer Nederland before. Therefore, they knew each other before taking part, which encouraged an open discussion between participants. The carers in group two did not know each other. However, after the introduction round and sharing their experiences they could relate to each other. All participants were considered potential users of ST and able to contribute to the discussion

although some required more encouragement and support from the researcher. In both groups, some participants came across as more vocal than others were. The researcher encouraged and addressed questions using first names and clear eye contact to encourage people to speak if they came across as silent. In addition, the researcher gave each participant enough time to think before answering any questions. All participants expressed they valued taking part in research because they wanted to contribute to society. Participants were encouraged to contact the researcher or Alzheimer Nederland if they had any questions or additional comments.

Table 11: Focus group procedures

Focus group part	Procedure and questions
Introduction	Explain the project, introduction round and writing consent forms
Main discussion	<ul style="list-style-type: none"> - Ask those with supportive roles to leave the room - Present the “Spotter”
Present advertisement films	After each advertisement <ul style="list-style-type: none"> - What is your first reaction? - What do you think about surveillance technology for dementia? - Would it make you / your loved one feel safe? - Do you think these technologies could be improved/ more adapted? - Can your carer know your whereabouts? / Does your loved one want to be tracked? - Would using surveillance technology make you feel more empowered?
Break	
Present advertisement figures	After each figure <ul style="list-style-type: none"> - What is your first reaction? - How should people with dementia be represented in the media?
End of main discussion	<ul style="list-style-type: none"> - Ask supportive roles to return - Provide summary of main discussion - Ask the carers: How did you search for surveillance technology products? - Has anybody anything to add?

Ethics audience reception

The UCL Research Ethics Committee (10989/001) gave ethical approval for this study. In addition, Alzheimer Nederland gave permission to use the data for research purposes before data were collected (appendix [C](#)). This was consulted with the external Law of Medical-Scientific Research committee (Wet van Medisch-wetenschappelijk Onderzoek met mensen) and deemed unnecessary

for a formal procedure due to the non-medical nature of the research and the precautions taken (Centrale Commissie Mensgebonden Onderzoek, 2001). In adherence with the Dutch law regarding protection of personal data (Wet Bescherming Persoonsgegevens), precautions were taken to protect the identity of participants by anonymization of names and places, translating the comments into English and using descriptive quotes throughout the text (Jamison et al., 2018). With regards to the online discussions, the website's disclosure page provided information about this study by referring to the information booklet (appendices [D](#), [E](#), [F](#)). Respondents were made aware that by clicking "agree" and posting on the forum, their responses were available to the public. By clicking on "agree" respondents consented that their comments could be used anonymously. If respondents had any questions, they could contact the researchers using the email addresses or telephone numbers provided in the information sheet. Furthermore, focus participants were provided with information sheets prior to the focus group taking place (appendix [F](#)). The information sheets described the project, what would be expected of participants and their right to withdraw any time without penalty and that taking part is voluntary. Participants were asked to read the sheets, which the main researcher (YV) talked them through. The main researcher explained the purpose of the study, what the discussion entailed, that there were no associated risks to participating and what was proposed to do with data (i.e. storage, anonymity, confidentiality and analysis). Written consent was obtained from all participants' and their carers (appendix [G](#))

4.3 Data analysis

Data were collected over a four month period in the summer of 2018 (table [9](#)). The main researcher extracted thread comments posted between 20th January 2014 to 7th July 2018 and copied this into Word. All discussions were read through in Dutch, transcribed, translated into English and made anonymous through adding codes by the main researcher in the Netherlands. All synopses and the brandnames "Carebelt" and "SafetyOldCard" have been adapted and translated from their original Dutch versions into English. Then the data was scanned, read through, re-read in detail, and field notes were placed in the data set. Followed by a modified content analysis (Downe-Wamboldt, 1992) that involved both inductive and abductive inference in a process of either organising the data according to the framework of features initially developed in chapter 2 or assigning new themes on the basis of surprising or unexpected incidents of data (Kelle, 1997). Then the main researcher categorized the data by themes manually and then imported it into Nvivo V.12. NVivo was used to aid analysis by facilitating double coding and retrieval of participant quotes. Data analysis for Nvivo was broken down into four major steps: 1) Explore transcripts, 2) Explore broad

themes, 3) Review a theme node, and 4) Code on. Prior to the use of Nvivo 12, all data transcripts were read for initial impressions and then read to identify key words and phrases that would be used with Nvivo to detect trends. Therefore, the first step of exploring the transcripts consisted out of detecting trends, counting frequently mentioned words and deleting stop words. The second step included running multiple keyword and word frequency searches. For example, “wandering” based on the search words from table 2. Step 3 included reviewing theme nodes which are a collection of references about a specific theme, case, or relationships. Nodes have allowed to select a sentence from a participant and place it into a node which were based on the features and items from table 4 to search for emerging patterns and ideas about ST. However, a quatioation could include multiple nodes. For example, “I like to have a small sized ST that has an SOS button and phone option” would be coded as the nodes Product characteristics, size, SOS-button and node User-Context, communication. Therefore, the fourth step was opening the nodes in Nvivo and exploring the references gathered and “coding on” by discussing the nodes with multiple researchers. Four researchers (YV), (PH), (GC) and (JM) discussed the nodes of features and items initially validated by the literature review (see chapter 2) and how they related to the participants discussions. This discussion included looking at multiple triangulation as some words or descriptions have different meanings depending on context. For example, “wandering” and “walking” could be to describe the activity of walking about or different activites one being scary and becoming lost, and the other good for your health. This was followed by examining the quantity of the nodes and how often a key word or phrase appeared in the transcripts. For example, “wandering” was referenced verbatim 104 different times in the discussion transcripts by 11 different participants.

For the online discussion, respondent characteristics were classified according to Kozinet’s (2002) typology of “tourists” (which this study defined as respondents who placed fewer than three posts on the overall forum), “minglers” (remained on the forum for 6-12 months, showed strong social associations but minimum consideration for the consumption activity, which this study defined as those who posted between three and 50 messages), “devotees” (focused on the consumption activity without interested in the social aspect and this study added that they should have placed over 50 posts on the overall forum) and “insiders” (long-standing respondents with interested in the social aspect of the forum as well as the consumption activity and who also posted over 50 posts on the overall forum. The Google Analytic “Page views” measure was used to generate data on page views (Pakkala et al., 2012).

Furthermore, the transcripts were reread and discussed by two native dutch researchers (YV and JM) and two native english researchers (PH and GC) to ensure familiarity and the list of categories

adapted to ensure all themes were identified. The themes were examined, as well as compared and contrasted to explore participants' needs towards ST. Furthermore, risk of interpretation bias was minimized by ensuring that the paraphrasing of quotes reflected as closely as possible the original comments. Queries arising from this process were resolved through discussions between the main researcher (YV) and three researchers active in the field of technology and dementia research (PH, GC, JM).

In relation to the focus groups, the additional analysis focused on the participants responses to the shown ST advertisements, and the way they positioned themselves according to Hall's (1980) communication model of "accept", "negotiate" or "oppose". Their responses were examined and how they contested the dominant discourse that was driving each image, and the ways in which their responses articulated and intersected with positive or negative representations of people with dementia. Focus group participants were given the opportunity to comment on the themes, as a means of validating and extending the data. Their comments were incorporated into the data before a final analysis was undertaken and quotes are provided to illustrate themes from the data analysis.

Chapter 5: Audience reception results

Following the first site of production, this chapter describes the results from site number two from the media literacy approach: audience reception.

5.1 Introduction

This site reports the results from the following three studies (II) PPI, (III) online discussions and (IV) focus groups. These methods have allowed contrasting the needs from carers with those from people with dementia about ST designs and advertisements.

5.1.1 Results: PPI

What is ST?

The PPI advisors spoke very passionately about surveillance. In particular, about the term surveillance and how it reminded them of police, prisoners, spies and the military. They emphasized that they feared this negative term might even put people off who want to use surveillance. The fear of how surveillance is used, as well as the tension surrounding its ethical implications was discussed. For example, people may not be aware of Facebook and CCTV monitoring them, with or without their consent. Annet asked “am I actually in control or do third parties have access to my data? Femke commented with “surveillance is propensity for abuse”. Therefore, the group agreed that regulations should be introduced in relation to ST and the monitoring of people. One major reason given for this was by Pete disliking “big brother watching and collecting personal data”. In spite of not liking the term, advisors felt they were all participating in surveillance in daily life without necessarily recognising it. Although there was a tendency to regard surveillance in a negative light, the group also discussed what benefits technology might bring about.

Jacky thought that her latest Apple watch which was connected to an iPhone was helpful giving her a feeling of safety. The group discussed how the iPhone is not designed to keep an eye on people but can be used to do so with apps. Illustrating personalisation, customisation and bricolage of everyday devices for everyday purposes. In her situation, Jacky reported that, everything was co-jointly discussed and decided upon with her partner. The group agreed that consent and joint-decision making is something that would enable people to accept the use of technology more. Furthermore, technology was seen as a helpful tool to support the giving of care. However, the

carers described their concerns with the improvement of technologies. One major reason that improved camera's in the home might be used as an excuse to reduce human interaction. For example, Maud mentioned concerns about "helpers only walk into the home when they spot the problem on camera". This led to the discussion of seeing ST not as a substitute of care. They agreed that technology usage should improve the QOL of people with dementia and support carers and not only have the purpose to reduce costs for the government. This led to talking about the tension of [not] increasing safety. The group questioned if technology prevents wandering and if carers then only react when a person has already fallen, which is not useful. Rather technology should enable people to do things they would not be able to do without it. However, some stressed again that the help from formal and family carers is essential. Consequently, they wondered if a passive tracker would be helpful at all.

Can ST be empowering?

The advisors expressed different opinions on the issue of empowerment. Manon expressed the view that empowerment through the use of technology is the capacity to be able to do the things they would not be able to do without it. Others described empowerment as anything that creates, promotes or enhances autonomy, QOL, skills and the power to do what one wants. For example, Jacky reported "my [tracking app on the] iPhone gives me power to walk outside and my husband has the power to know that I am okay". Jacky described how this power made her feel empowered. However, the carers felt that surveillance can quickly take away someone's power. The example of placing cameras in the home was described as taking away someone's power. Annet asked "what happens when someone else has power over you". The discussion focused on the ethical implications of collecting personal data, which was considered disempowering. Descriptions were given of people in the later stages of dementia who had someone acting in their interest. Another example, giving another illustration of 'bricolage' Leo gave a description of using a home burglar alarm to provide an alert should his older relative with dementia open the front door. Carers having the power to make decisions on behalf of the person with dementia. However, no consensus was reached on how society could ensure that this "power" is safely used. The group agreed that disempowerment is when someone else has power over you. Power should not be abused when making decisions on behalf of others and it was a priority that individual needs should be met.

How would you categorise ST?

Initially, the PPI group did not reach consensus when discussing what different categories there are of ST. Surveillance was sometimes termed as a “technology” or “concept”. When the group questioned whether technology would fit their and other’s individual needs, they decided upon the category of needs. For example, ST should be adaptable when dementia progresses to fit the needs of the persons using it. Manon described ST was initially easy to use. However, the person they supported started having troubles with the off button when the disease of dementia progressed. The carers explained how they used existing technologies to support caregiving and other activities in daily life. Besides the earlier described iPhone, the advisors also mentioned products such as ‘Amazon Echo’ and ‘Fitbit’ which they used for surveillance. These products were discussed as “high-tech” and were perceived as a technology rather than just being forms of surveillance. Reasons given were that these high-tech products supported them to perform a task, or make certain tasks easier or safer. For example, the Amazon Echo played music whilst a timer was set for the stove.

Another topic was that of the effect of using ST. The group questioned what the purpose of ST should be and described that it should enable people to find their way home, or enable someone to find them. Again, the tension between increasing safety and independence emerged from this discussion. This category was discussed conjointly in terms of the reliability of the product; for example, batteries going low in times of need was an important issue. Given this point, the group agreed that ST is not just “Technology” as people are also involved in the practice of surveillance. For example, neighbours and carers checking in on a person living with dementia. In this case, advisors said it was important to leave the “technology” out of “surveillance technology”. The importance of the role of carers was emphasized again and it was agreed that technology is just a support tool. Technology is considered to be an expensive tool for some and the focus should be on investing in healthcare instead.

5.1.2 Discussion: PPI

This PPI study (II) examined theoretical attempts to define and describe ST which resulted in three tensions. ST might (not) 1) increase safety, 2) be a substitute for care, 3) have ethical implications. These theoretical attempts were followed with an exploration of the concept of “Surveillance Technology” and what it means to people living with dementia and carers. The PPI group had an

immersive understanding of ST which brought out some of the tensions implicit in the technology; ones that are rarely alluded to in the literature.

The PPI's intertwined discussion concurs with literature about the three tensions surrounding ST. The group discussed that ST can promote a false sense of safety by its passive use similar to Schulz *et al.* (2015). Furthermore, the PPI group questioned whether ST prevents wandering and falls corresponding with Niemeijer (2015). The group also discussed safety and how consent and joint-decision making is essential similar to previous studies (McCabe and Innes 2013; Robinson *et al.* 2007). In addition, the group discussed the ethical implications of ST collecting data and how this can be disempowering. The PPI expressed how "Big Brother" (e.g. Facebook, CCTV) collects their data and hereby had power over them by dishonoring their privacy and autonomy. This contrasts with Judd's (1997) argument to support people with dementia and to stress individual empowerment.

In line with the literature, the group describes that ST may not reduce costs, improve QOL and alleviate carers (Cartwright *et al.* 2013; Duff and Dolphin 2007; McHugh *et al.* 2012). Rather, ST is just a supplement and instead they believed that more investment is needed in healthcare. Other similarities with the literature found that users associated ST with prisons (McCabe and Innes 2013; Robinson *et al.* 2007) and that all of society is involved of data collection and categorization of people (Marx 2002). This might explain why the group termed surveillance as technology yet, sometimes stressed the importance of 'surveillance' as a separate concept. When discussing this, there should be an awareness that definitions are often bound by those making them. There are differences from those in the industry and those actually using it. This may mean that the unproblematic adoption of such technologies may well be disempowering as well as being unresponsive to the needs of the users.

Leave the "technology" out of "surveillance technology"

It therefore might be helpful to distinguish between "Technology" and "Surveillance". Technology is something that responds to a need as shown by the advisor's use of existing "High-tech" products for various purposes. These technologies might then be placed within AT as they allowed individuals to perform tasks with ease and safety. Surveillance, on the other hand has a more specific purpose. A previous study found that simple low-tech trackers were sold to track not only people with dementia, but also dogs and prisoners (Vermeer *et al.*, 2019a) Companies are looking for a market and surveillance is what the market offers for dementia (Hyysalo 2006). If the

supermarket analogy is used again it becomes noticeable that the ideology continues to be that dependence on the state is bad – and that families purchasing “surveillance products” is good (Barnes and Walker 1996). However, literature and the PPI group described how low-tech products might not meet individual needs which creates tension.

Within this user empowerment, which is confused with consumerism, consumers remain powerless, when surveillance is done to people anyway – or others can take away our power quickly. That is, the PPI group emphasized that surveillance is done to persons without asking and operates outside users. Hereby the question shifts from “is surveillance part of AT?” to “is it part of a market ideology”? As regards AT’s terminology (WHO 2004), the anxieties people have about what surveillance means, as well as how does it serve the purpose of supporting people, seems to suggest that it is the opposite from AT. When people see ‘Surveillance’ as not increasing safety or reducing costs it is viewed as unhelpful. This negative assessment has more to do with ‘big brother’ than with technology itself. For ST to be empowering in the field of dementia care: the intentions that can emerge from the term ST need to be addressed. The difference between ST and AT is that surveillance is done to people whilst high-technology as part of AT, aims to supports people in their daily activities. Therefore, surveillance should be differentiated from AT and its positioning should be re-oriented to keep up with the rapidly changing nature of what is possible with technology and how this meets the needs of its users.

5.1.3 Results: online discussions

This paragraph reports on the results from the online discussions (study IV). In total, 120 eligible comments from a total of 45 distinct respondents (38 carers and 7 people with dementia), posted over the 3 ‘surveillance technology’ threads within the online forum. The most popular thread concerned ‘technologies to prevent people getting lost’ which attracted 28 respondents. Threads on ‘ST for following’ and ‘finding the best ST’ attracted 15 and 8 respondents respectively. An additional five comments were excluded as they were not from respondents identifying either as people with dementia or family carers. The majority of respondents were carers (42/51). In terms of Kozinet’s classifications, the prevailing respondent category was ‘tourist’ (table 12). In addition, there were both carers and people with dementia who met the criteria of ‘insiders’, that is respondents who were not only very active on the overall forum but also sharing their experiences of ST. No respondents met the criteria for ‘mingler’ or ‘devotee’ and there were a small number of respondents who posted between 2 and 50 messages in the overall forum, but did not continue to follow the ST thread.

Table 12: Number of respondents on the Alzheimer Nederland forum discussing ST.

Number of respondents within each thread		Thread		
		ST for prevention	ST for following	Finding the best ST
Carers		24	12	6
	‘Insiders’	2	3	2
	‘Tourists’	15	6	3
	Other	7	3	1
People with dementia		4	3	2
	‘Insiders’	1	1	1
	‘Tourists’	3	1	1
	Other	-	1	-

*Three carers and one person with dementia (both ‘insiders’) posted comments in more than one thread.

Looking at the content of posts, the most frequent words mentioned were: 1) watch (as in a timepiece worn on wrist), 2) GPS, 3) technology device, 4) “Spotter”, 5) app, 6) phone, 7) “Drugstore” and 8) track. The “Spotter” is a brand that sells devices which includes a GPS tracker and a SOS-button. It can be connected to an online account where the carer can track the location of the person wearing the device, from their tablet, or mobile phone. “Drugstore” (“Kruidvat in Dutch”) is a well-known retailer that sold the Spotter in-store and predominantly online.

Key topics discussed on the forum were (1) *providers* of devices and services (72 mentions across 3 threads) (2) surveillance technology *products* (55 mentions across 3 threads) (3) *questions* about user experience (13 mentions across 3 threads) and (4) comments on people with dementia wandering, going missing or getting lost (13 mentions across 2 threads). Respondents discussed providers by recounting their experience with informing and purchasing certain ST. This was often followed by comments about the level of (mis)trust regarding providers. Respondents did not trust websites perceived as “messy” and or where it was difficult to contact the provider.

“I know the site of the “Carebelt” but it is messy and doesn’t make me trust their service and support” (carer)

Strikingly, many respondents did not know where to buy ST, or what is available on the (online) market. A few carers even mentioned that there is a low supply on the market.

“it’s kind a weird that the industry doesn’t respond to the increasing number of people having dementia” (carer)

Only one respondent mentioned purchasing ST in a physical store.

“Great products, a bit commercialised. In the beginning of my dementia, we made several purchases at various care stores. Purchases advised by healthcare professionals or if we thought that a product might actually help. Looking back, it costed us more money than that it actually benefitted us.” (Person with dementia)

The main products under discussion were “Spotter” (see above) and “Carebelt” (another frequently mentioned brand who also market a device similar to “Spotter”). The first comments on the forum described the “Spotter” and “Carebelt”, and these continued to be the most discussed ST across the forum. In addition, many respondents gave general descriptions of a “watch” and few mentioned brand names. Respondents tended to ask others about their experiences or recommendations rather than describing their own, but there were examples of respondents recommending brands, or trying to dissuade others from making purchases. Table [13](#) illustrates the coverage of the online discussions on features and items identified in the review of 28 offline qualitative studies (see chapter [2](#)).

Table 13: Content of posts about products on the online threads about surveillance technology, organised within Vermeer, Higgs and Charlesworth (2019c) framework.

Features	Items	Threads	Mentions
Effect		3	15
	Safety	1	1
	Independence	1	1
	Confidence	1	1
	Peace of mind	3	12
	Free time	0	0
Product Characteristics		3	37
	Price	3	15
	Size and weight	3	5
	SOS-button	3	11
	One technology	1	2
	*Clock	2	4
User-friendliness		3	57
	Simple to use	3	7
	Useful	2	9
	Capacity	2	14
	Routine	3	21
User-context		3	65
	Acceptance	2	2
	Navigation	1	3
	Locate accurately	3	23
	Notifications	3	10
	Reliable	3	10
	Communication	2	17
Privacy		2	12
	Privacy data	1	2
	Safety and risk zones	1	3
	*Autonomy	2	2
	Legal and liability	1	3
Design details		1	2
		3	34
	Battery	3	16
	Simplicity	3	8
	Visibility	0	0
	Aesthetics	2	3
	Reinforcements	2	6

*Additional items not included in the Vermeer *et al.*, (2019c) framework.

Effect

The most commonly mentioned effect of using ST products was “peace of mind”.

“ST is not only to prevent him getting lost ... for everyone’s peace of mind”
(carer)

“If I feel like she is wandering off for a long time, I can directly locate her position” (carer 2)

“It [ST] gives you a feeling of safety, because he has been lost for two days and a night and that experience was no good for anyone” (carer 3)

However, the contention that ST products increase safety was disputed. For example, the following exchange took place in the thread *“wandering technologies to prevent people getting lost”*:

“This morning I saw a sign that stated ‘ST prevents wandering with dementia’. This statement hit me... Even though my mom didn’t wander because my dad did all he could to take care of her, ST of course does not prevent wandering. That statement isn’t right and that’s also what I think of the title of this thread” (carer)

“Ofcourse you’re right! ST cannot “prevent” wandering. I can imagine that you found that text misleading and offending. ST “can” help give the family of a person-with-early-dementia peace of mind, or to locate someone who is lost. Actually ST has an “expiry date”. There are risks attached.” (carer 2)

Product characteristics

The most often mentioned item within product characteristics was price. Carers paid or were willing to pay between 50 and 70 euro for STs. Some mentioned how they disliked paying a monthly fee. Others even warned of additional costs that may occur when ordering from abroad or online. Only one person with dementia mentioned costs.

The second most commonly mentioned aspect of product characteristics concerned SOS buttons which carers described as beneficial. However, some commented that it should be large enough to press.

“the SOS-button from “Spotter” is larger so that’s easier” (carer)

The size of product received a small number of mentions, with carers describing a preference for a small sized product, often with descriptions indicative of covert use.

“It’s about 5 to 4 cm, we put it in her wallet...she doesn’t know that” (carer)

A theme emerged when both carers and people with dementia described that tracking watches should have a familiar display time with a clock face, or dial.

*“The good thing is that it’s a watch and hopefully my mother in law carries it
(always) with her”* (Spotter – carer 1)

*“After a lot of fuss, he uses it. He had trouble saying goodbye to his familiar
watch”* (Spotter – carer 2)

User-friendly

All items within ‘user-friendly’ were frequently mentioned, and this was especially apparent in the comments of people with dementia. Both carers and people with dementia liked products that require little skill.

*“the most important thing as someone with dementia is that you don’t get all these
undertakings and you lose a looooooot of things, especially your phone, or watch.
My advice is keep it as easy and simple as possible”* (Spotter - person with
dementia)

If a product was difficult to use, carers thought that guiding instructions should be provided.

“It didn’t come with a guideline.... but I liked that I could use it intuitively”
(Spotter - carer)

*“Important: for its followers (including my elderly mother) it should be easy to
use”* (carer)

In contrast, people with dementia stressed that what might be considered simple by some could be difficult for others. Consequently, many people with dementia and some carers expressed that STs are just not designed for dementia.

*“Most products are not conceptualized by people with dementia. But they do get
their insights from professional carers. However I had to work with it or learn
how to use it. My spouse did understand it and was able to explain it. But me as
someone with dementia has difficulties with operating or understanding the
product. With some doubts we bought it anyway”* (person living with dementia)

“The product is just not designed for people with dementia” (Spotter- carer)

References were also made about the stage of the disease. Some carers described how they were no longer able to use ST due to the person with dementia being “too far gone”. Some carers recommended that ST should be adaptable for advancing impairment. Others thought that a solution would be to teach people with early-stage dementia to use ST. Yet others thought teaching “new” things would be impossible. One person with dementia commented:

“There are many products you won’t be able to use due to the progression (Not one salesperson pointed this out btw). Then quickly there will be irritation, spouse being impatient and this following pressure makes me just even more insecure and angry. They’re like hello this costed us a lot of money and you said you wanted this as well” (person living with dementia)

Respondents need a product that fits within the daily routines of those involved. Emphasis was on how products should be easily integrated into day-to-day tasks.

“I wear it around my neck or under my sweater, every night when going to bed I charge it” (Spotter - person living with dementia)

“My dad is used to taking off his watch every night (put it in the charger) and wear it in the morning which has been a habit for years [...]. Spotter is something new. New things which are often difficult to learn for older adults (not trying to be mean) that is why I choose this solution. Everybody has their own choice” (Spotter - carer)

User-context

In the three threads, a pre-dominant theme for carers was user-context. They discussed how the person with dementia would use ST. However, most discussed how the person with dementia would not have the capacity to use ST. There were no descriptions of needing ST that provides navigation and gives directions to the person with dementia. Instead, carers stressed the need to locate someone accurately. Some carers explained they want to locate someone by seeing their historical route taken. When carers reviewed ST negatively it was often because the product could not locate someone in or outside of buildings.

“If my dad’s inside we get to see this whole bunch of streets... the last time he went inside somewhere we had to call the police” (Watch - carer)

Carers would recommend how their product would notify them if something happened. They also wrote their need for a reliable product that loads with speed and has minimum technical problems.

“For others who are still looking, I came across a nice watch [...] It has a SOS-button and via the app on your mobile you can log in and: 1. Determine and follow the location 2. See the route travelled 3. Set a "geofence" and if the person leaves this you will receive a notification 4. You can call the watch” (Watch - carer)

Few carers mentioned that they wanted the person with dementia to accept the product, which according to them would happen by using familiar products (e.g. watches or bracelets). Carers also described how there could be some resistance by the person with dementia. Further, carers and people with dementia liked being able to communicate with each other through ST.

“Being able to communicate from a distance is perfect” (Spotter - person living with dementia)

Privacy

There was less discussion about privacy. Carers described how other family members would have access to the ST “to see where mom is to help out”. Few carers raised questions about who would have access to the data generated by ST. However, these questions remained unanswered. Only a couple raised legal and liability issues surrounding ST and that the privacy of a person with dementia should be respected.

Design details

On occasion there was discussion about design-details. When this occurred, respondents would mainly discuss the (charging of) battery. In particular, carers would outline how they would run out of battery quickly. A minority even mentioned the number of days they would want the battery to last and how much they were willing to pay for a battery-life of over a year. A few carers’ stressed they want to see how much percentage of the battery is left and to receive a notification when it is almost empty. Scarcely any contributors discussed the simplicity or visibility of ST

designs. Only one carer mentioned that a product should be waterproof and three others commented on aesthetics. Occasionally respondents expressed their liking for reinforcements that are flexible in use and can be added to a product. Options to attach ST to a person with dementia were considered useful. Furthermore, if the product has a hole for such reinforcements it can meet this need better.

5.1.4 Discussion: online discussions

This is the first study to our knowledge that retrieved insights from an online forum where carers and people with dementia shared their experience of, and questions about, wearable surveillance technology (ST) products designed for use outside of the home. Respondents were predominantly carers, but the independent and authentic voice of people with dementia was also present. The findings reinforce and extend existing knowledge on the differing needs and preferences of people with dementia and family carers. Whereas people with dementia focused mainly on user-friendliness of products, carers prioritised location accuracy for their peace of mind.

The four key topics raised by respondents in the ST discussion threads were: providers, products, questions about user experience, and stories of wandering or being lost. Forum discussion demonstrated brand awareness, possibly boosted by one of the providers running an advertising for one of the products during the course of these discussions, but also an erroneous belief that there was a lack of availability of ST products. The posts on products covered all six features of an existing framework previously generated (see chapter 2: Vermeer et al., 2019c). Online discussion forums can serve as peer support given their accessibility for carers and people with dementia who feel isolated or lonely (McKeckie *et al.*, 2014; Craig and Strivens, 2016). However, the type of information being shared on the forum was focused on raising questions before purchase or making recommendations about different STs.

Consumer to consumer contributions to the forum provided data on a greater range of product features and items than any one of the 28 studies in the Vermeer and colleagues (2019c) review indicating the value of gathering data from online forums. The replication of findings from earlier 'offline' studies suggests that online forums as a source of consumer views are a feasible alternative to qualitative interviews or focus groups, as previously concluded in comparisons of online forum versus offline interview data-collection (Jamison *et al.*, 2018). There were, however, differences in emphasis when comparing findings from this online study with previous literature.

As might be expected, the consumer to consumer communication in the online forum had greater focus on providers and brands than could be reported in academic research. A second contrast was the difference in positioning in the role of ST in maintaining the safety of the person with dementia. The theme of safety was reported in 13 of 28 studies in Vermeer and colleagues review (2019c) with a number of studies accepting the marketing position that ST increases safety. However, neither safety nor independence were strongly represented in the online threads. Indeed, one carer disputed the contention that ST reduces risk. Within the forum threads, ST was primarily recommended for carers' peace of mind. Thirdly, design details, which have been major themes in previous ST research (McCabe and Innes 2013; Rahimi *et al.* 2007; Robinson *et al.*, 2009) were hardly discussed. An exception to this was consideration of the battery as this was seen as vital to the reliability of the device and thus peace of mind.

Implications for designers and researchers

Two assumptions were apparent in the online data. First, carers are the main user and ST should be designed for them and second, people with dementia are unable to use ST. Potential conflicts between the interests and expectations of carers and persons with dementia have been noted previously. For example, Boman, Nygård and Rosenberg (2014) pointed out that 'significant others' often have worries about the person with dementia and therefore wish to use technology to monitor from afar. However, the implicit assumption that technologies that help carers will also be beneficial for the person with dementia does not necessarily hold true. Technological solutions can challenge the self-determination and sense of freedom of the person with dementia (Boman *et al.*, 2014). This is, however, a point of individual difference as some people with dementia find renewed freedom and independence in travel with the reassurance of knowing that they can, if needed, be located through an application on their smartwatch (see chapter 3: Vermeer *et al.*, 2019b).

"New innovations" need to be critically reflected in order to produce meaningful user-centred technology which improves daily-life enabling arrangements and effectively support caregiving (Puig de la Bellacase, 2012; Lopez, 2015). The findings suggest that this can be achieved when ST is person-centred and adaptable. The development of ST may have to be limited in order to make it useful for individuals in the different stages of dementia (McCabe and Innes, 2013; Meiland *et al.*, 2012). However, the focus of development could also be on empowering people in regard to their personal strengths and abilities, rather than focussing solely on deficits (Huber *et al.*, 2011).

Future studies should be carried out in other countries and cultures so that comparisons can be drawn, and further involvement from people living with dementia is needed. Given the speed of development of technology, frequent updates are required, and online forums provide rapid access to consumer views.

Implications for practice

Practitioners in dementia services should be aware of the availability of products online and the limitations of the product descriptions and specifications. Organisations that support people with dementia may wish to review the information that they have available to signpost service users to ST. They should be aware of whether their organisation is in a position to endorse products freely or within a restricted range of locally commissioned devices. Any suggestions provided should take into account individual needs and preferences, bearing in mind that people with dementia commonly express a preference for technology that is simple to use, within one's capacity and compatible with existing daily routines (Robinson *et al.*, 2007; Malinowsky *et al.*, 2010; Nygård *et al.*, 2012; Lopez, 2015; Wallcook *et al.*, 2019). Manufacturers and marketers information does not necessarily provide the information that service users/ consumers need to make a decision on which device would best suit their needs at the time of purchase or in a future, considering that a person with dementia's navigational abilities might decline at a different rate to their physical mobility. Practitioners may wish to signpost to device-lending services or retail outlets where devices can be handled prior to purchasing. Practitioners should also consider ethical and legal issues such as potential deprivation of liberty especially as such discussions were notable by their absence in the online forum.

5.1.5 Conclusion: online discussion

Recognizing the ST needs of carers and people with dementia is important when developing technologies. In particular, ST developers and health professionals should incorporate both the needs from carers and people with dementia when designing and prescribing technologies. People with dementia and carers use online forums as a source of information for their purchasing decisions. Gathering data from online forums enriches findings from 'offline' methodologies. Forum posts reveal a lack of trust in providers and marketers due to poor provision of information. Furthermore, the results suggest that the features verified in chapter 2 (Vermeer *et al.*, 2019c), could be considered as input for ST design. However, more in-depth research should focus on what users specifically need from the perspective of privacy, effects and design details. When designing

or prescribing technologies, ST developers and health or social care professionals should take into account the potentially differing needs from people with dementia and carers, and their changing needs over time.

5.1.6 Results: focus groups

This paragraph reports the results from the focus groups (study III). Similar to the online discussions, it appears that the advertising of the “Spotter” successfully impacted people as the majority of the participants knew the product when it was presented to them and carers often recommended the brand. After watching the advertisement film: “SafetyOldCard” and “Carebelt” for the group of people living with dementia and “The family” and “Carebelt” for the carers, the majority of the participants reacted by saying “*I don’t understand it*”. The majority of participants described not understanding the functionality of the product or recognising the brand and thought the films were too fast. People living with dementia perceived the “SafetyOldCard” and the carers saw the “The family” as incomprehensible and stated it lacked meaning. The carers questioned if someone with dementia can use the “Carebelt”, yet some participants living with dementia thought it was a good device to help those who become lost.

Themes

Whilst participants did not recognise the brands from the films “SafetyOldCard”, “The family”, and “Carebelt” they did recognise the issues surrounding wandering. Both groups described situations where participants themselves, or a person they cared for were lost, missing or wandering. Similar to findings from Brittain et al., (2017), the carers used terms such as demented and wandering when describing dangerous situations where the person they supported was lost and hurt. For example, some carers discussed a Whatsapp-group and how neighbours, police and ST should track and keep people with dementia inside.

Anouk: Our neighbourhood made a WhatsApp-group. The moment that [name] will wander ...our friends and neighbours could let us know. For example if someone went to visit her for social contact.

Suddenly we got a message that she was walking with her garbage can in her pyjamas and it was not even the day that the garbage would be picked up. So you do it because you have nothing better available.

Carlijn: Yes! That’s the same thing with a neighbourhood-watch who keep criminals out, they can now keep people with dementia in.

Anouk: to keep your demented neighbours inside.

The most striking result to emerge from the discussion comparison was that people with dementia also reinforced this division between walking and wandering. In the following example, the term walking was used for descriptions of being lost as something which can happen to anyone.

Martijn: Well I can figure that one out when I'm walking, but the moment I'm on my bicycle it goes a lot faster and suddenly I'm in the wrong street and then I think 'where the hell am I'.

Alzheimer Nederland: what is then the solution?

Martijn: I just ask people where do I need to go? But when you are in a street and no one is there, then I'm in trouble

Wandering was used to describe how they made grave mistakes or how other people with more advanced dementia had become lost because of the progressing disease. The fear of wandering was expressed by people with dementia themselves.

Tom: Well with me, it is going downhill. Unless it is something that did not happen to you, you don't think about the idea [using ST] but as soon as it starts to gnaw at you... faster and faster... you need to do something
Martijn: yes then you need to do something. Not like is it [ST] something? No but if you don't have it, don't want it, then you are suddenly standing like a wanderer in the middle of nowhere.
Tom: yes that malfunction [points at forehead] becomes worse

Effect

In contrast to previous studies, the carers hardly mentioned that ST should and could increase the independence and confidence of a person with dementia (Brankaert, 2016; McCabe & Innes, 2013; Robinson et al., 2007). Instead, the carers hoped ST would give them more peace of mind and free time because of their worries and care burden, whereas people with dementia stressed that ST needs to increase their independence because they want to be able to participate in society. However, some felt they were losing their freedom either way. They discussed how ST can give you a feeling of safety but not increase it if the device is distractive when crossing a busy street.

Tim: why should we use these supportive tools?

Martijn: well that you can participate in society

Group: yes

Martijn: then we will be independent and that's what it is about right?

Stephan: but you also get dependant...or that product is from someone else, you just lose your freedom.

Kristel: yes but either case you lose your freedom

Martijn: yes

Both groups discussed that society should become dementia-friendly through informing citizens to help a person with dementia who is lost. In particular, the carers described needing help because they felt uncomfortable or inadequate when it comes to caring for a person with dementia. For the participants the films lacked meaning and they did not recognise the role of the product. However, participants recognised the fear of wandering and discussed the challenges of their interpretation of (in)dependence.

Kim: as a family carer you are on your own. There are websites such as Alzheimer Nederland but everybody has individual needs. It's a load of information. I would make a distinction between the type of dementia and say if they have these symptoms, this would help.

Carlijn: I think it would be smart if Alzheimer Nederland encourages communities on their website to share more information more easily so that we can help each other.

Anouk: Everybody in the Netherlands should be dementia-friendly

Linda: the search for every carer of someone with dementia is difficult. I don't feel comfortable visiting an Alzheimer Café they have so much experience.

Plus young people should become involved with this as well.

Carlijn: Yes my husband loves to go to the supermarket where the employees are so friendly and patient. I got the feeling they received a bit of dementia-friendly training. Everybody and every company should do that.

Kim: if we were just all a little bit more patient

Marketers

Statements about uncomfortableness and inadequacy also occurred when the carers discussed how they had little trust in stores that sell an overwhelming number of expensive products. Similar to Greenhalgh et al., (2013) and the online discussions, participants repeated questions of “do certain ST like that exist” and did not seem to be aware of what is on the market. Particularly, one carer looked on the Alzheimer forum where respondents recommended the Spotter one carer watched a television show about tracking children with this product and another one came across its advertisements. The majority agreed that they are too busy to visit stores and therefore search for products online. When carers found a product online, they needed to be able to call and ask questions about ST in order to trust the provider.

Carlijn: busy family carers like us don't know that whole care world and when you go to a care-store then you think oh my god what is this? You'll be blinded by everything. That's why you search online.

Participants thought the films were confusing and did not provide information about the ST. Especially, the carers described how they and other carers do not know where to buy ST and need more tailored information.

Product Characteristics

Mainly the carers described needs towards price and size and thought that STs are expensive and worried about the costs, which they and other carers, have to pay for from their own pockets. Accordingly, some carers stressed that the government should pay for ST. The majority of the carers had bought their Spotter for 70 euros and a few paid an extra 3 to 4 euro a month for subscription costs. The carers agreed this was a good price. Furthermore, the predominant theme was that ST should be small-sized. People with dementia occasionally mentioned that ST should be small so that it does not draw attention. The carers discussed in-depth the need for a key-change or chip-size ST which enables covert use.

Furthermore, the carers had conflicting views about the SOS-button. Some carers found the SOS-button irrelevant because they only need a tracker function or they thought that people with dementia are unable to press such buttons. One carer found the SOS-button useful for citizens to press when they find the person with dementia.

Linda: I also have the Spotter. Never used it because my dad did not want it. I also tried other products but I bought it because if people find him they then can push that SOS-button so that I can help.

Whilst, people with dementia did not explicitly mention the SOS-button, the majority of them and some carers highlighted the need for just one technology.

Stephan: I don't like that. I don't want another extra device for my route. Then I would prefer something that's combined.
Group: yes

User-friendly

Participants responded to the films by describing how ST is not user-friendly because they did not understand the product's functionality. A large part of the discussion was about how people with dementia need to be able to use ST. Similar to chapter 2, participants described how ST should be simple to use, useful and therefore fit someone's capacity and routine (Robinson, 2007). In particular, people with dementia described having difficulties when using smartphones and that those products are not designed for them whilst carers stressed how their loved ones did not have the capacity to use ST.

Stephan: I have difficulties using my phone. I have a special Nokia for older people with Alzheimer's but I don't remember it or it is too complicated. I cannot keep up. It is too much.

Martijn: Yes, they have to keep it simple because I'm not so capable of using that.

User-context

Similar to the online discussions, the greatest conversation was about user-context. However, the discussion was about if people with dementia would accept using ST. Evidently, people with dementia expressed how ST should match their situation and user needs (e.g. provide navigation to guide me home) and carers described meeting their own needs (e.g. locate the person with dementia accurately, receive notifications and great performance). Both groups agreed that a familiar device such as a phone or watch might lead to greater acceptance of ST.

Furthermore, people with dementia expressed their liking for a "home button" that would guide them to their own homes, which was also reported by Brankaert (2016). In particular, two participants described how a map with their location should have an arrow that gives signals to turn left or right. However, no consensus on how people with dementia want to be navigated by ST was reached.

Kristel: with a map you can see where you are walking.

Martijn: that seems convenient because then you know immediately if you're walking the wrong way

Kristel: I think it has its disadvantage because then you see on which street you're standing and then I think hell I know that. Then you'd need to know the right route to follow.

Martijn: you have to choose to go home yes

Stephan: there's an app for that right?

I want it simple so when I say I don't know where I'm and I want to go home, well it gives me the direction to go home

Martijn: that would be convenient

Tim: those apps exist right?

Martijn: in general no, but as long as it is not clear in your head like I need to go there and there then I don't know, and then you can have all these maps with arrows and go left, right, but then you skip a step and everything goes wrong.

Similar to the online discussions, the carers described that ST should be introduced in the early stages of dementia so that people can learn to use it and accept it. However, people with dementia stated it should be used for later stages. Five participants with dementia expressed they would like to try ST, however, their views about acceptance sometimes included descriptions of not thinking it is relevant to them. In particular, when referring to the films many stated “*but not for me*” or “*I don't need it right now*”.

Stephan: I believe that I don't need it right now but in the future I might, so then I'll look on the machine how I can go back to my home. But for now I don't need it.

All carers stressed the importance of acceptance for reasons that otherwise their loved one would resist the use of ST. They described how the person with dementia would eventually accept care because otherwise they would lose their independence. Some carers discussed their loved one's resistance to ST by pretending nothing is wrong or “*not needing it ...yet*”.

Kim: I use the Spotter and in the beginning, it was problematic because my husband did not think he needed it.

Anouk: we are about to get to that phase where she needs to accept care in order to remain at home. She is often lost and does not want us to know that because of course nothing is going on.

Linda: how do you care for someone who resists care? My husband was suddenly gone and I had to call the police. He was standing at my daughters' house at 3 AM and probably cycled for hundreds of kilometres.

Kim: my husband also pretends nothing is going on. More like 'I'm not ill and everybody forgets something at some point'.

Carlijn: my mother also resisted care and we explained it to her and I think she understood us. We explained that if we are not able to take care of you we must bring you to a care home, so she said I want to stay at home.

Participants expressed different views regarding communication. People with dementia agreed they need to be able to have a two-way communication with ST. However, some participants expressed they are unable to phone someone because of the disease progression. No consensus was reached whether this two-way communication would entail calling the carer or strangers.

Some participants explained they did not trust alarm-centres to give them directions. Different from the online discussion, the majority of the carers did not need to communicate through ST.

Design details

Similar to the online discussions, people with dementia would on occasion mention the fear of running out of battery whereas the carers stressed for a long battery life but expressed difficulties with charging batteries because it did not fit within their routine. Furthermore, the majority of participants need a simple to use device, however, no consensus was reached on what simplicity in a design would entail. The carers hardly mentioned aesthetics while people with dementia thought that ST should look “cool”. They thought that otherwise ST becomes visible and stigmatising, different from some carers who need a grey ST for reasons of covert use.

Tom: if people see you wearing ST they think you're not doing well

The majority of participants did not express their liking for reinforcements that are flexible in use and can be added to a product. Although carers in a previous study reported the need for, for example, expandable straps that could be taken on and off so that the person with dementia would not forget to wear ST (Vermeer, Higgs and Charlesworth, 2019c), the carers described how reinforcements such as plastic straps can break or become lost. Nonetheless, the carers gave descriptions of bricolage and how they temper and add reinforcements such as key-chains so that the product would work better (Gibson et al., 2018; Greenhalgh et al., 2013).

Privacy

The major differences occurred with views on privacy and who is allowed to receive data from the ST. People with dementia described they would agree to being monitored if the device could guide them home and if it would give their carer peace of mind. Those opposed mentioned how friends already meddled enough in their lives and that there is no need (yet).

Yvette: would you like it that someone knows your location?

Stephan: in the past I did not like it ha ha

Researcher: and now?

Stephan: sometimes you don't need it

Martijn: I agree

Stephan: on the other hand, well at least you are getting somewhere

Kristel: you know that sort of thing is already going on with me [tracking]. I know that everybody is doing their best for me but please sometimes just leave me alone because I'm going nuts. Then someone calls and the other is like hey

*I don't have time can you keep an eye on her and then I think like euhh?
Alzheimer Nederland: does it feel like your friends are doing that behind your back?*

Kristel: I know they have good intentions but I'm going crazy about it. Then I think guys please stop. Please stay away I'm not a moron yet.

People with dementia expressed that it should be a joint-decision to use ST and that such products need to enhance their autonomy and independence.

Reactions printed advertisements

The discussion about privacy shifted after seeing the printed advertisement. Carers affirm that the prints equate people with dementia with dogs but they did not consider it to be offensive. Rather they discussed how product features, especially the small size for covert-use, are more important than the advertisement itself. Similar to McCabe & Innes, (2013), the carers reported that tracking a person's location outweighs respecting their autonomy and independence. One carer did not use ST without consent; however, the majority of carers discussed how they see no other option.

Anouk: what can you do if people don't consent? It's an ethical discussion and for a clear conscience you need to think of what I can and can't do.

We try to help her according to her wishes but she refuses care and you try in other ways so that she will eventually accept it. I was happy with her phone that had the option "follow my iPhone". It worked just fine and she wasn't aware. She was gone for a while on her bike and didn't respond to WhatsApp and we were worried and looked at her location. We noticed she was going in circles in 34 [Celsius] degrees heat and had cycled for 12 kilometres. That's why we called like 'hey you are not at home and we wanted to ask you something'. She said yes I'm on my way to day-care. Which wasn't open. We asked her, pretending we did not know, 'What are you doing then'? We had to and then we said we will pick you up she said no that's not necessary. Well we went to get her anyway. She sat there completely exhausted from the heat and all she wanted to do was to get into the car.

Anouk: that's just it when do you cross a line? Our family asks please help us to remain independent for as long as possible. You do everything to help them. But I think if I'd ask them to share their whereabouts, they would say no. But it does help to remain independent!

Anouk: we didn't ask for permission! In case they say no. So we are not going to ask that question. We didn't let other people who care for her know we can follow her to keep her integrity in case they would accidentally say that half of the world can follow her. We don't want her to get a big brother feeling.

The carers questioned who is liable if something dangerous happens, what is legal and how to respect the wishes from the person with dementia.

Linda: we requested that we should make the final decision

Carlijn: we did too

Linda: when my dad could understand things a little, we made him make his will and then it's not such a grey area. Then it's easier to say okay we will take over because he gave us permission to care for him. That was good.

Anouk: I agree we also asked to be the one's making the final decision. We explained to her if she won't be able to talk later on, we're the one that know her, and we can make the decisions for you. I want to make sure that I can make the last days of your life pleasant. She agreed. But later when she's in front of a judge she probably says NO! [raised their tone of voice]

Kim: Yes! you never know what they want.

People with dementia were suddenly opposed to being tracked after seeing the printed advertisements and some started to raise their voices. They described how these representations are inapplicable or disgusting because they do not see themselves as dogs or fallen down. The member of Alzheimer Nederland, who had a pre-existing relationship with the group, had to intervene and ask one participant to stop interrupting others when they spoke and stop raising his voice. The participants were reminded that they could always take a break and step outside the room or if they needed further support.

Stephan: I think it's disgusting

Martijn: yes these images are extreme ... something going terribly wrong

Stephan: doesn't make me happy

Person with dementia5: no

Martijn: why do you have to come up with worst-case scenario visuals?

Stephan: yes

Kristel: as if that's the average person with dementia

Martijn: I think it's just to attract the attention

They felt the advertisements only showed worst-case scenarios to attract attention. Upon answering whether ST would make them feel empowered, the discussion was about disempowerment. One person with dementia expressed this is because of the lack of understanding and that there are more stages before people become the stereotype of ‘wanderer’. The group agreed upon the lack of understanding and felt objectified and stigmatised by society and need help from people accepting them as they are.

Kristel: Acceptance is also that someone can get lost. So if you're lost then you're just lost. You can make a big deal out of it and think that I'm crazy or you can think let's help that person. It's that simple.

Martijn: yes

Kristel: but when you're diagnosed then they think of you as crazy right? This is something I need to re-address.

People with dementia agreed that negative advertisements do not contribute to a better understanding of dementia and some thought positive representations would improve the situation. Others described how they actively inform people what it is like to live with dementia and its reality.

Yvette: How do you want to be represented?

Martijn: that's tricky

Kristel: I think just as it is. I will not deny that I have difficulties remembering, more than average but that doesn't make me crazy. I can walk and still do loads of things.

Tim: yes

Kristel: I even give workshops

Martijn: yes but that almost implies that the moment when you get a device, you are going from half crazy to full crazy right?

When discussion continued about the printed advertisements, it seemed to deepen the fear of wandering and negative impacts of living with dementia. That is, a person with dementia mentioned wanting to end things before getting to the stage of wanderer. Others agreed and further discussed how they have thought of or planned euthanasia which is an option in the Netherlands (van Wijngaarden & Alma, 2019).

Kristel: they all have something to say about you or think of you as a care object

Martijn and Tom: yes

Tim: is there a cure for dementia?

Martijn: No

Tim: WHAT'S THE POINT THEN!

Martijn: well we are here to discuss tools, which can support us. It's about how people can do things independently and that depends on how far along you are in your disease

Kristel: yes and if you want to die you have to do a lot of things to get there

Martijn and Tom: yes

Kristel: I will do euthanasia if I become a wandering moron

The researcher intervened and asked the group how they were feeling and if they would like to stop the discussion early. However, the participants were eager to continue and asked enthusiastically questions about what ST are on the market and described their ideas for a great product. At the end of the main discussion, the carers from group 1 were asked to return to the room and they sat next to the participants with dementia. The carers return seemed to impact the group dynamics. That is, the carers enthusiastically described how happy they were with ST for their spouse. Consequently, the individuals with dementia, whom which moments before were against ST, abruptly capitulated. At the end of the discussion, it became clear that two persons with dementia were actually wearing a “Spotter” and a “Carebelt”.

5.1.7 Discussion focus groups

The present study was designed to shed light on understanding views of carers and people with dementia about ST designs and advertisements to support the development of improved products and media messages. The results report that participants need simple to use ST, which fits their routine in order to be useful. In addition, the carers thought the government should pay for ST and even though these results are similar to the previous studies reported in chapter 2 (Innes McCabe 2013 Robinson 2007), the separate discussions have allowed us to find discrepancies. For example, participants did not express a need for a “SOS” button, but people with dementia did want a “home” button to guide them back.

Furthermore, carers’ use of “Bricolage” and people with dementia’s descriptions of how devices are not designed for them continues to show a mismatch in ST designs and support (Gibson et al., 2018; Greenhalgh et al., 2013). In contrast to previous studies, people with dementia did not report a clear wish for ST (McCabe & Innes, 2013; Robinson et al., 2007). Perceptions on (in)dependence differed as some participants with dementia thought it would make them dependant on supportive tools, yet expressing the need to use ST for navigation. This contrasts the views from carers who do not need navigation but a simple tracking function because the person with dementia does not have the capacity to use it. The theme privacy showed that the need for a small ST had different underlying motives for people with dementia (e.g. non-stigmatising) and carers (e.g. covert-use).

No consensus was reached on the ethical debate of tracking and carers in particular struggled with gaining consent but seeing no other option than to covertly use ST for safety.

That people recognised, recalled and even recommended the “Spotter” implies that the brand successfully distinguished and marketed their product in the Netherlands. For example, the carers mentioned how they came across information about the product and other participants recalled the brand, which can be explained by the intense advertising of the “Spotter” in stores and online. However, most advertisements came across as confusing and product functionalities were not understood. Less successful were the not recalled brand-named “Carebelt” and the “Household”, which were only advertised online. This implies that the intense advertising of the “Spotter” diminutive brand name with its easy message to “spot” the lost person, dog or possession does have an impact on people and might even shape their perception of dementia and wandering.

In relation to perceptions of wandering, this study contributes to Brittain et al., (2017) conceptual shift of how carers discuss walking (good) and wandering (bad) by adding the views from people with dementia. Indeed, the carers discussed the dangers of wandering but people with dementia also shifted from positive descriptions of getting lost (“can happen to anyone”) to negative descriptions of wandering (“those who are far worse in their disease”). This counter-intuitive result of people with dementia shifting between resisting and wanting to try ST with descriptions of “but not for me” could be the result of perceptions of wandering or not having their carers present during the discussion.

However, that people with dementia did not have a wish for ST or fully considered themselves at the stage of wandering could also be explained by previous research (Greenhalgh et al., 2013; Minichiello et al., 2000; Neven, 2010). The latter was termed by Minichiello, Browne, & Kendig, (2000) as older adults “arriving at stage”. When the participants created an image of people “far off” in their disease they actively dissociate themselves from that group (Minichiello et al., 2000; Neven, 2010). For example, Greenhalgh et al., (2013) found this dissociation and how participants explained not wanting to need technology because then they would belong in a hospital or were closer to death.

Furthermore, the participants living with dementia did not perceive themselves as tracked dogs and some give workshops to inform people about the disease. This is similar to Neven (2010), who found that participants did not relate to advertisements selling technology for lonely old people. These participants also wanted to contribute to society and hereby created another image of themselves as successful people who are active advocates, helpful, and sometimes seemingly

untouched by the negative consequences of ageing (Neven, 2010). This study corroborates with the idea of how older adults (unconsciously) confirmed with “successful ageing” stereotypes because they actively negotiated new images of ageing for themselves and those ageing even more, while accommodating stigmatisation (Calasanti & King, 2005; Minichiello et al., 2000; Neven, 2010).

In addition, this study found that the prints deepened the fears of wandering. However, this does not fully explain the striking descriptions from people with dementia about wanting to die before getting to the stage of “wanderer”. Perhaps the cultural shift between wandering and safety, the media impact of images that injure (Lester & Ross, 2003), how participants contributed to their own perception of dementia and the ideological pressure from Dutch society could all impact this decision to end one’s own life (van Wijngaarden and Alma, 2019). This turns the question of how ST can be accepted by people with dementia to how can we accept people living with dementia.

5.1.8 Conclusion: focus groups

This study argues that part of the tension that surrounds ST is that the need to move beyond the idea that consuming ST will empower people with dementia and their carers. Instead of consumerism the focus should be on empowerment. That it has been missing from the debate, other than in the form of framing aspirations, is an indictment of the shift away from the users and towards something that has a more unconcerned set of priorities. In conclusion, it is important for gerontologists to become clearer about the implicit assumptions and unstated tensions that exist in the field of ST if only to ensure that such technologies do not lead to the persistence of exclusionary practices in the care of people with dementia.

Furthermore, this work shows that carers and people with dementia can provide valuable insights about their needs and ST. The PPI advisors provided focal points and have hereby contributed and helped shape this thesis. Their input regarding ST privacy, effect, and design details, affirmed some of the themes found in chapter [2](#) the literature review.

Findings of this study are important for designers of ST and other technological products dealing with the challenges of dementia. It highlights the importance of user-friendly and non-stigmatising designs, individual needs for independence and personhood. Recognising and taking into account different views of people with dementia and carers, specifically their understanding and rejection of wandering stereotypes could help prevent resistance to ST. However, ST as a standalone is not

sufficient to support dementia care. Innes and McCabe (2013) have argued that the Nuffield Institute of Bioethics framework provides significant components to be considered when using technology for people with dementia. This study would like to extend this notion with regards to component four: promoting the interest of both people with dementia and their carers. This can be achieved through co-joint decision making with the recognition of individual needs as well as the involvement of people with dementia as co-creators at different stages of research, design and development. In particular, recognising individual views and concerns about privacy and usefulness of a device. In addition to component five: regarding solidarity and recognising citizenship, this study found that current ST often does not suffice but rather stigmatises and that carers and people with dementia are in need of more support from society than is presently offered. Solidarity is recommended because it entails society's duty and responsibility to act to destigmatise dementia and support those challenged by the condition. For example, the government could pay for ST instead of focussing on cost-efficient healthcare. Citizens can help those who are lost and caseworkers or community nurses could be assigned. The latter can advise carers on grey areas of "privacy" by relating to similar experiences. Finally, more attention needs to be paid to the issues of ageing and ageism within studies of science and technology (Joyce & Mamo, 2006) and stigmatising advertisements need to be stopped.

People with dementia and carers recall intensively marketed ST and recognise the issues surrounding wandering. However, the content of the advertisements does not resonate with them; they do not understand the products, and needs are not being met. In particular, the advertisements seem to affect people with dementia as representations of wandering results in them contemplating feared futures and negative projections of old age. This is ultimately a lose - lose situation for audiences who are negatively impacted by the messages and ST marketers are not getting their commercial messages across.

5.1.9 Strength and limitations

Much of the previous research, on ST has involved spouse carers (Vermeer et al., 2019c) and the strength of this study is that the voice of the person with dementia is included, as are the voices of carers. Qualitative studies on forums are strong and trustworthy when accompanied a structured framework informed by previous literature (Jamison et al., 2018) as was the case here. In this research, the framework of features and items from Vermeer and colleagues review was used when considering the content of online postings about ST. However, applying the framework in this way also revealed its limitations. As with any structure for categorising information, challenges arise

when cross-category coding is required, such as the carer who commented on their ‘cost-benefit’ analysis of price and function.

“It cost us 130 Euro but we did it as the battery life was 30 days”

Whilst more research is needed on the framework from Vermeer and colleagues (2019c), this study shows re-occurring features and items. For example, when people with dementia described the item of navigation which might lead to greater acceptance of ST. It might be interesting to use the classic technology acceptance model from Davis, (1989) to examine if the perception of usefulness and thus acceptance is indeed influenced by the social context in which ST would be used (Vermeer, Higgs and Charlesworth, 2019b).

A challenge for the interpretation of data from online forums is the potential for an ‘echo chamber’ effect where the prevailing views from early in a thread are not merely repeated but amplified by later contributors. In the way that the ‘loudest voices’ might influence focus groups, early contributors to online discussion may unduly influence those joining in at a later point (Steffes and Burgee 2009; Newman et al., 2019). Online platforms also have the potential to transmit and perpetuate unhelpful stereotypes (Newman et al., 2019).

Using the Kozinet (2002) typology of respondent engagement with the forum, ‘tourists’ and ‘insiders’ were identified, but not ‘minglers’ or ‘devotees’. With its focus on the consumer experience on purchasing and using ST, the potential ‘emotional support’ element of peer support may have been missed in the analysis. However, it was noted that respondents to this forum took on the role of “consumers” rather than peer supporters and did not react directly to other’s personal experiences with ‘wandering’ behaviour. A minority of respondents fell outside the Kozinets typology (designated ‘other’). There is much debate in current research about ways to term or classify respondents. For example, Pongsakornrunsilp (2010) draws distinctions according to the level of engagement and intensity of resources invested by respondent (e.g. time, experience, knowledge).

Other limitations include: data extraction from only two focus groups and one forum; the purposively full selected sample, terminology such as terms “wandering” and “technology” were selected by the moderator prior to the involvement of the researchers; the self-selecting nature of the sample, and the potential ambiguity of some comments when the ‘tone of voice’ cannot be heard. Some of the 5 comments deleted from the dataset were excluded to the impression that the comment was sarcastic rather than genuine. Nevertheless, anonymity also carries a strength as respondents may feel safer, more comfortable, and more willing to share their views.

Furthermore, conducting focus groups come with unexpected challenges. After focus group one, the group facilitators and the volunteer felt they needed to reflect on the moments when the participants started to raise their voices, interrupted and talked of euthanasia in the context of wandering. Even though preventive measures for emotional distress were taken, there is no script, framework or after care program on how to deal with situations like this. This also raised an important ethical issue of where to draw the line that people can express their views, which in this case meant for people with dementia discussing euthanasia, or when to stop the discussion to prevent emotional distress (for participants as well as group facilitators). A strength was having the advocate present as she could make a better judgment on what action to take compared to the main researcher who did not know the participants beforehand.

Chapter 6: Media content

The preceding chapter reported user needs and audience responses to ST designs and advertisements. Audience responses were sometimes in conflict, in particular the understanding and rejection of wandering stereotypes. More attention needs to be paid to issues of ageism within technology studies as we have seen that advertisements seem to affect audiences in a certain way.

6.1 Introduction

Studies have highlighted the necessity to examine the representations of people with dementia in technology advertisements and how this impacts audiences (Clarke 2006; Peel 2013; Vermeer, Higgs, and Charlesworth 2019a). Numerous media messages have picked up on the global challenge of dementia. An article in the Sun posted: “*Dementia patients being given NHS slippers fitted with GPS tracker so they can be found if they wander off*” (The Sun, 2018). Picturing an older adult in a wheelchair whose hand is held by a smiling younger looking female. The text describes how it gives families peace of mind that patients are tracked to reduce risk which costs less compared to people occupying NHS beds. Professor Young stated: “*Through this competition, we are seeking the latest, greatest ideas and technical solutions to help address the modern challenges facing our health and care services*” (The Sun, 2018). Indeed, technology has become popular due to claims of; populations are ageing globally, the number of carers is decreasing, the costs of healthcare are increasing and people want to remain independently in their own homes (Neven, 2010). In general, politicians, policymakers and developers are concerned about wandering and popular discourse often shows individuals with dementia wandered off and found dead (Carr et al., 2010; Petonito, Muschert, & Bhatta, 2010).

Media discourses are important to investigate because they shape society’s perception about dementia (Fuller, 1998; Medina, 2014). Studies focusing on dementia discourse have examined stock images (Harvey & Brookes, 2018), films (Medina, 2014; Zeilig, 2014), magazine and newspaper articles (Clarke, 2006; Kessler & Schwender, 2012; Peel, 2013). Studies reported how advertisements mainly represent sick older women with dementia who need their dutiful female carer (Clarke, 2006; Harvey & Brookes, 2018). Media critics have suggested that people with dementia are often portrayed using negative and sometimes positive stereotypes (Van Gorp & Vercruyse, 2012). Table [14](#) captures the negative representations of “demented” sufferers who look withdrawn, are losing their identity and humanity, invaded by the disease, a terrible destiny that awaits or call for constant care and burdens the family (Braun & Clarke, 2006; Harvey &

Brookes, 2018; Van Gorp & Vercruyssen, 2012). Whilst it is unknown how and if people with dementia are represented using technology, older adults are often represented as not understanding technology (Joyce, Loe, & Diamond-Brown, 2015). Positive representations include those smiling and actively living well by taking a walk to prevent dementia, have “faith in science” to find the cure or make the most of the present (“carpe diem”) (Harvey & Brookes, 2018; Peel, 2013; Sweeting & Gilhooly, 1997; Van Gorp & Vercruyssen, 2012). However, both representations may negatively impact a person’s health and personhood as it does not construct reality or the challenges people face and consequently the person disappears behind the diagnosis (Kessler & Schwender, 2012; Minichiello et al., 2000; Van Gorp & Vercruyssen, 2012).

Table 14: Negative and positive representations

Negative representations	Positive representations
<ul style="list-style-type: none"> • “Demented Sufferers” • Look withdrawn call for constant care • Invaded by disease • Terrible destiny awaits <ul style="list-style-type: none"> ▪ Not understanding technology 	<ul style="list-style-type: none"> • Smiling • Actively living well • Taking a walk to prevent dementia • Faith in science • Carpe diem

Compiled by the main researcher (YV), summarised from Braun & Clarke, 2006; Harvey & Brookes, 2018; Joyce et al., 2015; Peel, 2013; Sweeting & Gilhooly, 1997; Van Gorp & Vercruyssen, 2012.

When advertisements reinforce the misunderstanding of dementia, it can prevent social change and negatively affect technology development for people with dementia (Joyce & Mamo, 2006; Peel, 2013; Vulpe, 2017). For example, if user representations are based on stereotypes it can emerge in the work of designers and become inscribed in technology design (Akrich, 1992; Joyce & Mamo, 2006; Latour, 1992; Neven, 2010). In addition, little attention has been paid to the organisations behind media messages and the part they have in forming user representations (Akrich, 1992; Latour, 1992; Clarke, 2006; Joyce and Mamo, 2006; Neven, 2010; Peel, 2013; Vermeer, Higgs and Charlesworth, 2019a). Joyce and Mamo (2006) suggest that technology is developed with a much younger audience in mind and that older adults (particularly older women) are not the intended user. A recent study described how carers are the intended ST user and not people with dementia (Brankaert, 2016).

Media literacy

How audiences perceive and negotiate representations can be uncovered through media literacy (Kellner & Share, 2007). Media literacy aims to uncover signs of ideology and power and the organisations that drive the media industry (Kellner & Share, 2007). Accordingly, a tripartite

approach to media literacy incorporates production, semiotic textual analysis and audience reception (Lewis & Jhally, 1998; Rose, 2007; Thoman & Jolls, 2003). Production explores the organisations behind the advertisements of products and what sort of messages are circulated and to which social actors (Thoman & Jolls, 2003). This might be problematic when money-making organisations are behind discourses; yet, none have the real person at the centre of their interest (Medina, 2014). The production exploration is reported in chapter [4](#).

Another part of media literacy is to recognise what signs and meanings are used in advertisements through a semiotic textual approach (Kellner & Share, 2007; Lewis & Jhally, 1998; Machin, 2004). Saussure (2011) introduced semiotics as the relationship between language and meaning through the signifier and signified. Acknowledging the relationship between signifier (e.g. literal meaning) and signified (e.g. the mental concept it represents) enables uncovering the meaning the sign represents (Saussure, 2011). However, audiences might interpret these meanings differently or in a way that retains “the institutional political/ideological order imprinted on them” (S. Hall, 1980, p. 134). How audience respond and the examination of semiotics by exploring the social construction of how media is produced, enables uncovering the social and power relations present in discourses (S. Hall, 1980). However, examining the personal experiences of people with dementia is a neglected area in discourse studies (Harvey & Brookes, 2018; Loos & Ivan, 2018). Therefore, the cultural contexts in which advertisements are produced might offer insights about the relationships between technology, dementia discourse and the interests of organisations (Clarke, 2006; Fuller, 1998; Joyce & Mamo, 2006). Although some research has been carried out on dementia discourses, no study has been found which examined technology advertisements with questions of production, textual semiotics and audience reception. This study looks at the interplay between ST messages and audiences, whilst it is aware of the wider discussion available on media messages connected to dementia and ageism. Its primary purpose is to present the study and reflect on what it means for this discourse and market.

6.2 Method

The objective is to consider the ways advertisements represent dementia in technology advertisement and how carers and people with dementia respond to such messages. The advertisements were subjected to qualitative content analysis as analytical constructs investigated through theory-driven coding from previous research was employed (Downe-Wamboldt, 1992).

Attention was paid to look for other themes that might provide alternative findings to those suggested by literature. The main researcher (YV) carried out the search for advertisements using the Google search engine in January 2018. Search terms from table 2, were used and the word “advertisements” was added with equivalent translated synonyms (e.g. commercial, flyer, communication, endorsement, poster, video, film). The websites were ranked according to Google’s “most relevant results”, “last updated up to a year ago” and screened for information. Websites with at least two of the keywords were selected for further analysis to ascertain that the study includes discourses that are most common and likely found by audiences. Websites were then searched based on the presence of (1) older adults as main and/or secondary actors with reference to dementia, (2) products that are technological and track and (3) a combination of factors (e.g. grey hair, wrinkles, walking aids) and (4) stem from the UK, SWE or NL. The findings from the content analysis were triangulated by consultations with researchers and focus group participants (see chapter 4 and 5) to enhance credibility (Lincoln & Guba, 1985). Table 8 shows that two independent researchers (SW and SG) were consulted and asked to respond to the analysis results. One reason herefore was that these two researchers were active in the area of dementia and technology research in Sweden and the United Kingdom as well as part of the same network INDUCT. Then participants were asked to respond to visuals of happy older adults, children and pets (number 4 and 5 in table 15) followed by older adults fallen down and/or lost (number 6 in table 14).

Analytical approach

The method was guided by employing the theoretical frameworks of Hall (1980) and Saussure (2011) which offered a critical discourse approach to semiotic analysis while incorporating production and the responses from participants. For production, the main researcher (YV) explored the websites and examined the organisation’s size and country origin. Where possible, public information about the organisation’s financial status was sought. Then the sample was read, reviewed and audio from the films was transcribed and translated. The semiotic analysis was extended by exploring the represented actors, signifiers and narrative summaries were made to determine the dominant discourse (Hall, 1980; Saussure, 2011). For the purposes of the analysis, dichotomous categories have been created, however, in practice such binary distinctions are unusual and contextualised. To provide a cleared basis for understanding the tensions that exist, these distinctions have been drawn out in table 3. These results were discussed by the main researcher (YV) and two researchers (SW and SG) in order to reach consensus about the dominant

themes. The two researchers were involved within this study as they were part of the same interdisciplinary network focused on researching technology and dementia (INDUCT), native English speakers and conducting their research in Sweden. To further validate these interpretations, the main researcher (YV) discussed these results with the two researchers (SW and SG), adjustments were made accordingly and compared with the participants' responses. The participants were sent these results and asked to comment. In June 2019 the main researcher (YV) reviewed the sample's organisation size and financial status to account for any occurring changes.

6.3 Results

Table 15: dichotomous categories within the advertisements

Number	Country	Discourse	Representations	Signifier and signified
1	NL	Film SafetyOldCard ¹	Older woman Older male	Lost/Wandering Withdrawn and call for constant care Fallen Terrible destiny awaits
2	SWE	Film The family	Family-members Older women Children, pets, possessions	Lost/Wandering Withdrawn
3	NL	Film Carebelt	Older male Younger alarm centre employee	Lost/Wandering Withdrawn and call for constant care Using technology
		Visuals Carebelt	Younger carer and older women	Withdrawn and call for constant care Terrible destiny awaits
4	UK	Visuals Trackyour	Younger carer Older women Children, pets, possessions	Lost/Wandering Withdrawn and call for care Fallen Smiling Actively living well
5	NL	Visuals Spotter	Younger carer Older women Children, pets, possessions	Smiling Actively living well
6	UK	Visuals Stray Star	Younger carer Older women Older male Children, pets, possessions	Lost/Wandering Withdrawn and call for constant care Fallen Terrible destiny awaits Smiling Actively living well

Table 15 presents an overview of the dichotomous categories present in the sample. Some

¹ SafetyOldCard is the literal English translation of the Dutch "VeiligOudKaart".

advertisements include positive representations of (predominantly) women with dementia who are depicted smiling, actively living well and kept safe through using ST. However, the majority of the advertisements include negative representations of (predominantly) women with dementia. They are signalled as lost, wandering, withdrawn and calling for constant care because they should be kept safe through using ST. As seen in chapter 4, these technologies simultaneously target tracking pets and possessions through visuals and texts which seem to be directed at carers. Accordingly, categories of gender signal how younger carers are responsible for taking care of the older women. Furthermore, privacy or autonomy concerns and who receives the data from the ST (e.g. tech companies, alarm centres, other family members) is not addressed. Rather, text often describe small ST to covert-track someone's location. While one advertisement describes a person with dementia using technology, the majority seem to visually "place" the ST on people with dementia, or the technology is not shown at all. Hereby, the dominant theme shows a "wanderer" discourse which stresses keeping the person with dementia safe through ST without acknowledging them as human technology users. What signs are used to communicate this theme to audiences is described in the following section.

SafetyOldCard

The Dutch organisation behind the film SafetyOldCard was no longer active in June 2019. Nonetheless, their YouTube channel continued to circulate the film. *The text describes: "Do you have a parent who lives alone, or do you live alone, afraid not being able to reach the phone or does your loved one wander because of dementia? This is the solution because it is easy to use, four buttons, SOS-button, low purchase price and cheap".* The channel describes the product as small and easily worn around the neck. The film shows the product which looks like a bank card. Later visuals are shown of Caucasian older adults who look withdrawn out of a window, have fallen or may be lost. The text seems to be addressing carers and those who are in need of care but the visuals indicate that the latter are not the intended target audience. Rather, the visuals in combination with keywords such as "wandering" and "afraid" makes a discourse of a terrible destiny that awaits if technology is not used.

The family

Wittra, based in Sweden and founded in 2013, circulated the film on YouTube. According to LinkedIn, this small-sized organisation shows an increase in the number of employees and

products on sale from 2017 to 2019, whilst other publicly available information shows a decrease in profits (UC Allabolag AB, 2019). The first scene shows a blonde male actor who directly gazes into the camera whilst sitting between two withdrawn brown-haired actors. The brown-haired actors seem to be in their thirties. The blonde male actor says, *'These guys decided they needed a little help organizing things and who can blame them'*. While the two actors remain parallel to that of the viewer, the blonde actor speaks to the audience *'the important things in life are the things that we care about. They move around making them even harder to keep track on...well that's where I come in'*. The use of "we" and "I" are connotations for allowing the audience into the world where families need support tracking moving things. Moving things such as *"DOGS impossible to understand even harder to keep track of. I'm Tagged and it's my job to keep this family safe and sound"*. The blonde actor's diminutive name signifies him as being the ST. Later Tagged is sitting and leaning over a grey haired actress, who in turn, seems to be unaware of his presence. He says *"let me show you grandma in her favourite chair but sometimes she can get a little [whistle sound] bit lost if you know what I mean"*. The signified meaning when Tagged makes a hand gesture with a whistling sound indicates grandma as a bit crazy who needs to be looked after. These signs represent that the technology will keep grandma safe.

The next scene signifies a white furry dog with Tagged saying *"I'm on it"*. Seconds later, we see the male family member looking on his mobile phone and finding the dog. Later the female family member places a baby in a crib. The signified meaning forms her as a mother-figure. Tagged watches over and says: *"Relax I'm on it. Think of me as the guy who's always there watching every move sitting next to your sleeping baby --- errr not in a weird way"*. The mother opens the app on her phone, walks away and when the baby cries Tagged says *"a little help!"*. The mother returns looks at the app and bends over the crib. The combination of signifier and signified present the meaning that mom is supported in her caring role whilst the baby is monitored by using the technology.

Another next scene shows grandma walking and looking distanced in the woods. Tagged says *"oh grandma... so you get the point, right. If you put me on it you'll know what's happening and where it's happening... safe and sound"*. The signs that grandma tends to get lost and is vulnerable might be a search for sympathy and empathy from carers who can relate to having one's care recipient lost. The final scene quickly shows the product, icons and the text; *"pets, baby watch, bag safety, elder, bike safety, car alarm, smoke detector, key camera"*. It suggests the safeguarding of certain categories. Noteworthy is that the first person pronouns are recurrent, with "I" conveying an

individual identity whilst “you” refers to the viewer. The language focusses on the individual without acknowledging the company, which implies a customer-oriented attitude.

Carebelt

This film was circulated on Youtube and broadcasted multiple times on Dutch television. It was also placed on the brand’s website, which is part of the mother company MobileTrack based in the Netherlands. It is unclear when MobileTrack established the Carebelt however, press releases date back to 2008 (MobileTrack, 2008). The Zorgriem was considered a ‘cottage industry’ in 2017, but the number of employees listed on LinkedIn had increased in 2019, making it a small-sized company. The brand’s diminutive name signifies that the ST is to be worn on a belt. The first scene states “*find the person immediately*”. Signifiers in the next scene show a grey-haired man behind his window who seems withdrawn and gazes outside. Then a male narrator voice starts with; *This is Mr van Dijk, 62 years old. In the past year, he increasingly had problems with memory loss.* The actor starts walking in his house and the viewer sees a portrait of a woman. The narrator says: *He lives together with his wife Truus in a village.* Whilst the actor grabs his keys, another device is shown which looks like a mobile phone with a few large buttons. When he presses a button, the device is activated. As we see the actor leaving the house the narrator says: *He carries his mobile GPS-alarm system that monitors your location. Relaxed as he is walking now... this has not always been the case. He cannot orientate and that is why he gets lost.*

Suddenly, the actor’s facial expression shows uncertainty and the switching between the scenes increases and the music becomes intense. The narrator continues: *That caused a lot of tension and he became insecure.* When the narrator says “tension” the camera angle goes from left to right. It is as if the audience sees through the eyes of the actor experiencing tension. The actor looks from left to right and the narrator says: *luckily, he now has his mobile GPS-alarm system with him.* When the actor presses the “SOS” button and tries to phone, the narrator says; *it gives him confidence, especially when he suddenly doesn’t know which direction to take.* A woman in her late thirties answers the phone and in the system, she sees his location.

*Mr van Dijk: I’m not sure where I am. Can you give me directions to go back?
Alarm-centre responder: Do you see a street sign behind you?*

The responder gives walking directions and when the actor starts walking, the narrator says:

Thanks to modern technology, he can go outside independently and if he is lost, there will always be a friendly employee that will guide him home safely.

The final scene shows the actor together with the text: *“Thanks to my mobile alarm system I’ll never get lost again”* and ends with *“quality of life”*. The narrator describes how surveillance can help families in various ways in order to make an emotional connection with consumers. An emotional connection such as fear of becoming lost and the need for surveillance. Whilst the film did not portray that the product should be worn on a belt, the website includes visuals of the ST attached to a belt. The website also includes a visual of an older woman who grabs her coat and looks scared whilst in the background a group of young males with dark hoodies on, are pointing at her. Although the text described *“monitor your loved one”*, the woman is signalled to be in danger.

TrackYour

The organisation TrackYour was established in 2012 in the UK. According to LinkedIn and Companies House public beta service (2019), the organisation matured from a cottage industry in 2017 (e.g. one employee no physical office) into a small company in 2019 (two shareholders and a registered office) whilst the annual summary shows a loss in income. The website includes texts such as *“wandering”*, *“peace of mind”*, *“retaining their independence”* and *“FREE”*. In bullet points, the website describes product features and how small and conceivable the ST is. Whilst the diminutive brand name signals tracking, the logo of the band signified visual stereotypes through icons of a child, an older adult with a walking stick and a dog. In a circle, a female in her twenties is smiling and leaning on the shoulder of an older woman in her seventies. The younger female caresses the shoulder of the older woman indicating that the former is a family member and/or carer. The older woman (e.g. white hair, wrinkles) is smiling and the product is shown with a SOS-button. Furthermore, four boxes show a girl, an older woman, a dog and a businessman standing next to a car with suitcases. The website states *“people, pets & possessions”*, which is accompanied by typical stock photos found on many websites selling ST (Harvey and Brookes, 2018; Vermeer, Higgs and Charlesworth, 2019a). Another webpage contains an emotional narrated story through words such as *“being separated from your loved one”* and *“out and about is everyone’s worst nightmare”*. This indicates that the text is targeted at family members. Similar stock images are shown, such as happy children, older women smiling and a younger female. Another page includes an older woman who lies on the floor and looks distressed whilst pressing the SOS-button. It

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appears she has fallen and is in danger and the text described how the technology helps them.

Spotter

The organisation behind the diminutive brand name Spotter is based in the Netherlands and established in 2015. According to LinkedIn, the organisation grew from a small-medium company (e.g. max 50 employees) in 2017 into a medium company (e.g. 50 to 200 employees) in 2019. However, other public information shows how the subsidiary organisation only has nine employees and is part of a mother company owned by one person, whom in turn, is not obliged to share financial statements to the public (Kompass, 2019; KVK, 2019). The website describes how their small product is the GPS tracker for dementia indicative of presenting it as the solution. The visuals represent female carers in their thirties and older women in their seventies who are smiling and actively living well with keywords as signifiers. The website shows a generic stock-photo of an older woman and signified categories of tracking children, pets and possessions which are kept safe by using the product.

Stray Star

Stray Star LTD based in the UK shows a decrease from 2017 to 2018 in capital and reserves (Companies House public beta service 2019). LinkedIn lists zero employees, which is the responsibility and choice of the company to present this information to the public. The website includes keywords together with representations of younger carers in their twenties and thirties, older women in their seventies and the categories of track children, pets and possessions. The webpage dementia trackers states, “*essential for peace of mind*” and signifies actors as lost, wandering, looking withdrawn, or fallen down beneath a stairwell. Hence, a terrible destiny awaits if surveillance is not used. These visuals are stock photos, which can be found on numerous websites. The elderly tracker and fall webpages, show an older man walking with a walking stick but also older couples holding each other and smiling. The text describes how fall detectors will not reduce the risk of falling, whereas, the dementia webpage describe the ST as “*the best dementia trackers on the market – a simple great solution, offering reassurance and convenience in being able to find your loved one quickly*”.

Audience responses

Table 16: Audience responses to the advertisements

Discourse	Audience response
Films	Participants do not understand it <ul style="list-style-type: none">• Negotiation
Visuals	<ul style="list-style-type: none">• Negotiation (carers)• Opposition (people with dementia)

Table 16 describes how participants responded to the films and later the visuals. The initial reaction was that the participants did not understand the films. The carers did not receive the meaning that Tagged is the technology. As a result, the carers started negotiating and questioning what the product is supposed to look like and what it does with regards to functionality.

Kim: I don't understand how the products look like
Anouk: yes something with a phone but how does it work?
Linda: that was a camera that you can hang around the house
Carlijn: but also in the forest?
Linda: Grandma is carrying that one. Right?
[Carers about The family]

The carers described how the film did not make any sense and led discussion back to what they are looking for in a small tracker for safety reasons. In particular, the carers explained that they type their need for a small covert ST into Google. Furthermore, people with dementia described how frustrated it made them feel to watch the films, which according to them were too fast in pace and provided little information on what the product does. They agreed that especially the film SafetyOldCard was difficult to follow and to understand.

Yvette: does anyone know what's it about?
Martijn: too fast, too much text
Tom: no clue
Tim: at some point I saw that telephone
[People living with dementia about SafetyOldCard]

Participants did receive the message that the lost actor used the Carebelt and found his way back home. Despite the diminutive brand name, the carers asked whether the Carebelt should be worn on a belt and did not understand product functionalities. They negotiated the film by describing how a person with dementia is unable to remember to carry such a product or call the alarm-centre.

Kim: so it isn't a belt?

Carlijn: but if it's a belt he needs to wear it
[Carers about Carebelt]

People living with dementia continued to negotiate the film by discussing technologies they can use and which they cannot. Even though one person with dementia was content with the Carebelt, the others negotiated the usefulness of the technology by asking questions about how it would work in their situation.

Tom: YES amazing
Martijn: but what's that supposed to be?
Tom: a belt for on your pants
Martijn: oooh
[People living with dementia about Carebelt]

Some participants with dementia could relate to the experience of walking outside and forgetting how to walk back home. However, they did not understand how the product works and others thought it was all contradictory. Similar to the online discussion, the issue was raised that producers do not make useful technologies for people with dementia.

Tom: then he remembered again [when the actors calls the alarm centre] but during the film I thought this is terribly contradictory. I have it [dementia] and I succeeded to walk with the help of my smart phone. But even that I don't have anymore. But with this film its all contradictory... that you call and the alarm centre gives you directions
Martijn: there is someone who is asking questions like oh you're there... that's where you need to cross the corner. I think that's pretty smart but what's the use of a smart phone? Then I need to know how to get that thing started.
[People living with dementia about Carebelt]

Martijn: I don't agree with having solutions for problems that aren't smart things. Everyone should be able to use it. I think this all is very complicated.
[People living with dementia about SafetyOldCard]

Printed advertisements

The participants had different views about the visuals from the printed advertisements. The carers negotiated the visuals, for example, by expressing their liking for the diversity of representations used, whereas other carers found the categories of tracking dogs and people with dementia “a bit too much”. Although participants picked up on the use of positive and negative representations in

the advertisements, the carers described how such visuals do not influence them to buy the product. They explained that their focus is on what the product does and moved the conversation about their daily struggles with caregiving.

Anouk: that film shows more diversity. Not just old people with walking sticks. I did this dementia-friendly e-learning and they use good images instead of just really old people. They use representations of an active grandma that is picking up her grandchildren from school

[The family]

Yvette: is it that you think oh this commercial is showing a lost person with dementia and therefore I want to buy this product?

Carers: no!

Anouk: no I just type in Google 'GPS tracker small unnoticeable' and search for that [feature].

These responses were different from the participants living with dementia who became frustrated when seeing the visuals and being compared to pets.

Martijn: I don't want to be compared to a dog.

This frustration became more apparent when they discussed the negative representations and started interrupting each other or raising their voice.

Kristel: what happens here is that they show the worst-case scenario but there are so many things happening before. I don't recognise myself in it.

Martijn: I think if you want to make something clear then this isn't the right image.

Kristel: but I don't think there's an image for that. There's no label you can tape on your forehead because everyone is so different.

When the researcher asked how people with dementia would like to be portrayed in the media there was no consensus. Some participants with dementia thought positive representations would be better compared to negative representations. However, others described they just want to see the reality of what it is like to live with dementia.

Alzheimer Nederland advocate: you just said you will lose your freedom and that it makes you happy if they show you something that will increase your independence?

Kristel: yes

Alzheimer Nederland advocate: that's something you would prefer over negative?

Kristel: well yes but I also understand there is a lack of understanding and people do not have any experience with dementia, so I get that this can happen, but you're more than just your disease. It's just a tricky disability... I can live well with it by the way

6.4 Discussion

This study set out with the objective of considering the ways advertisements represent dementia in technology advertisements and how carers and people with dementia respond. It does so through a qualitative tripartite approach, however it does not provide unquestionable results about the organisations behind these websites. Some organisations seem to grow with regards to the numbers of employees, but a decrease in capital. However, a normal part of growing in business is to expand in employee size as human capital is a valuable resource which costs capital (Chung-Jen Chen & Jing-Wen Huang, 2009).

The examination of representations provides grounds for the charge of rampant, if largely unintended, stereotyping. The advertisements wish to speak to the ideal user through typical stock-photos of younger female carers and text descriptions targeted at them. Minimum representations were given of people with dementia interacting with technology whilst their viewpoints and those of different ethnic cultural groups were omitted. These findings support the idea that the voices from people with dementia are excluded while low-cost stock photos show female carers and focus on the dangers of dementia (Clarke, 2006; Harvey & Brookes, 2018). This corroborates the idea that ST are designed for (younger) female carers and that people with dementia (particularly older women) are not the intended user (Brankaert, 2016; Joyce & Mamo, 2006). This might be explained by the large debate about how advertisers neglect older consumers, both in the market they target and the actors they depict in advertisements (Corlett 1998). Advertisers recommend including female actors in their thirties to target women consumers in their forties (Financial Times, 2014). The idea is that consumers in their forties (those who are more likely to have parents with dementia) feel cognitively younger than their chronological age and would relate more to younger actors which influences purchase decisions (Barak, 1987; Schiffman & Sherman, 1991; Stephens, 1991). The effectiveness of this influence, however, has been challenged in research (Greco, Swayne, & Johnson, 1997; Mazis, Ringold, Perry, & Denman, 1992).

An important consequence of this study is that there is not one unitary way of understanding or

interpreting the advertisements for dementia. Rather, participants did not understand the advertisements or the displayed technology and some became frustrated for not understanding these meanings. This is similar to Dobos, Orthia and Lamberts, (2015) who reported that the ambiguity in visual imagery is not a surprise. Even though there was no consistent response from the audience, the participants noticed the use of positive and negative representations. The carers negotiated how the advertisements did not influence their purchase decision because they look for product functionalities, in contrast to participants living with dementia who negotiated the films and thought ST are not so useful products for people with dementia. They opposed the visuals with agitation and thought it was offensive and stigmatising. That people with dementia were more noticeably impacted compared to carers is not surprising given that the negative representations try to represent them and their disease.

The dissemination of negative representations is not the only concern, rather it shows a lack of reflexivity from marketers who do not realise that people with dementia are not objects. Similar to previous findings, a “wandering discourse” where people with dementia are placed in the same category as pets and possessions in need of covert tracking will not change technology development (Vermeer, Higgs, and Charlesworth 2019a). Rather, the current display of people with dementia as non-human technology users enhances stigma which might negatively affect personhood and prevent empowerment. Accordingly, the intended consumers, who are the carers expressed their need for a conceivable ST. They also liked the diversity of representations in the advertisements used even though similar Caucasian actors were shown. This insinuates that audiences (unconsciously) accept certain meanings that might contain ideologies and indicate complex power relations. These messages corroborate with Hall's (1980) concern of media power and how it propagates certain social values to create dominant ideologies, which will ultimately influence audiences to construct this as the truth.

Therefore, this study is not directed at website providers alone but also those who design technology and media that represent people with dementia. Similar to recommendations from Harvey and Brookes (2018), it is important for researchers, media developers and policymakers to be conscious of the power within dementia discourses that shape public understandings and perceptions. This leads inexorably to questioning if non-stigmatising representations are fathomable or culturally possible. Hence, more research is necessary on representations of dementia that offer some hope and allay support for people with dementia and carers.

However, the approach and small sample must be interpreted with caution as the findings might

not be transferable to other advertisements or representations. Even though it was not the intention to study a large sample, one finding shows how carers use search words such as small and conceivable tracker and it is through the use of these keywords that organisation's draw visitors to their websites and consequently see these advertisements (Patruti-Baltes, 2016). It becomes problematic when 89 percent of consumers turn to Google and type in search words, whilst Search Engine Optimization techniques then position the providers website to be the first on display according to such keywords (Fleishman and Hillard, 2012; Patruti-Baltes, 2016). Furthermore, the results about providers should be taken cautiously as they are often not obliged to publicize such information to the public. An intended issue that was not addressed in this study was whether Dutch participants would respond differently towards advertisements originating from another country. Therefore, it would be useful to investigate a larger sample of organisations that disseminate discourses about dementia and ST and to understand their reasoning behind the decisions of these discourses and whether or not they are successful financially. In addition, a future study investigating the differences in participants' background (e.g. culture, gender) would be interesting.

6.5 Conclusion

This study found a “wanderer” discourse evident in much of the advertisements which signals to covertly use simple trackers on people with dementia. The advertisements sketch stories of how families are in need of surveillance through making an emotional connection with female carers. This emotional connection is established through exacerbating fear by signs of possessions, children, pets and the person with dementia not being safe, whereby text signifies a problem in terms of concern and distress combined with visuals which signify a conceivable location monitor as the ideal solution. However, carers and people with dementia did not understand the advertisements and the displayed technology. Instead, people with dementia felt stigmatised. It is not just that negative representations are disseminated, but the lack of reflexivity from designers and marketers when they see people with dementia as objects. This study believes that by solely relying on stereotypes targeted at carers with misunderstood conceivable technology hinders resilience for people with dementia and implies the continuous stigmatisation that occurs when they are disregarded as human technology users.

Chapter 7: Discussion

The number of people living with dementia is increasing and it is unsure how costs of care provision can be met. One strategy in Europe are the major investments in technological products as part of a cost-efficient healthcare delivery for people living with dementia to age in place and remain independent. This thesis is about the nature of one of the strategies being advocated in particularly by advertisements to advance dementia care: surveillance technology. There continues this widespread idea that carers who can use ST to track people living with dementia, both have the same needs and experiences when it comes to ST use and design details requirements. Whilst, few studies have questioned the design details of ST, no study has explored the ST advertisements that are sent which portray people living with dementia and carers and how these (potential) users respond separately to such discourses.

Therefore, this research extends our knowledge of the nature of the market for commercially available STs as well as how such STs are marketed and how this marketing impacts on the experiences and needs of carers and people with dementia. The present study makes several noteworthy contributions to the typology and the split of the user voice. First, this interdisciplinary thesis used a media literacy approach and a broad social gerontechnology perspective to give further nuance to the research. This is the first media literacy tripartite approach that examined the perspectives from people living with dementia separately from carers towards STs and how such products are constituted by marketing messages. Second, it is the first study to include users for examining their requirements for ST design as well as their responses to ST advertisements. Third was the involvement of people living with dementia and carers not only as participants but as research advisors as well. Hereby this thesis addresses important topics by advocating to focus on diversity and inclusion of human being with their own needs, experiences, and rights.

Taken together, the various perspectives and examination of ST advertisements suggest that the media might reinforce the misunderstanding of dementia which can prevent social change and negatively affect technology development. This is because one of the most important results was the lose-lose situation where marketers are not getting their commercial messages across and sell not so helpful products. Another important result was that users felt stigmatised by ST advertisements and do not receive useful products or help. Hereby this thesis gives attention to how advertisements sell not so useful technology, shape people's perception and contribute to lack of understanding about dementia. These implications are not only addressed to ST providers, but also to the designers, who now have a framework for improved ST products which meet the needs

from users (Appendices I and J). In addition, the thesis and in particular the framework gives users more information about what is available on the market. The thesis argues for policymakers to critique the idea that technology is a ‘solution to wandering’. Instead of seeing people with dementia as ST objects it is essential to consider such individuals as part of a new market. However, this thesis also argues that users of products should not be used in a tokenistic fashion just to tick of boxes. Instead, let us all think before a product is developed for ‘empowerment’ by asking: what is empowerment and how is it going to be used? Otherwise ageing populations will continue to have underdeveloped markets, frustrated users and technological irrelevance.

As a result, it was discovered that the context in which this research sits is the idea that technology represents a solution for an ageing population, however, it also sits within a social policy discourse regarding dementia which has empowerment at its core. The starting point of empowerment is the awareness to ask who one is designing for and to then acknowledge these user needs within the product design (Thomas & Milligan, 2015). Social policy discourse advocates that people with dementia should be enabled to make empowered choices; in addition, the choices that carers make should also be valued. It is not surprising that these different contexts often clash and that the research reflects this reality. The research found different assumptions and ideas which led to tensions and contradictions between different groups. Not only were there differences between groups regarding design and function of STs, but there were also similar differences in the way that media messages were understood by different groups.

Given that research covered a number of different themes in relating to the relationship between ageing and technology, it was decided to relate the research to an important intervention concerning the topic made by Peine and Neven (2018) published in the *Gerontologist* in order to facilitate the study and development of the use of technology by older adults. Six ageing and technology propositions from Peine and Neven (2018) help frame the contradictions and tensions found in the research and help to shed light on the implications of this study (table 17). Whilst the focus is on ageing, this study wishes to extend the outlined propositions, as dementia is often perceived as an age-associated problem (Alzheimer’s Disease International, 2019).

Table 17: The Co-constitution of Ageing and Technology: Six Propositions made by Peine and Neven, (2019)

	Proposition
1	<p><i>“By replacing an interventionist logic with a co-constitution perspective, the ways in which certain images of ageing are foregrounded in design can be challenged, along with the constraining and enabling effects of such technologies on the everyday lives of older people”</i> (Peine and Neven, p. 18, 2019)</p>
2	<p><i>“Further advancing dialogues of concepts, theories, and methodologies from Science and Technology Studies and social gerontology is [sic] pertinent to theorizing about ageing–technology relations.”</i> (Peine and Neven, p. 18, 2019)</p>
3	<p><i>“Instead of focusing on the possible impact of new technologies on ageing, studying the use of existing technologies by older people is empirically and theoretically illuminating and offers opportunities for attuning the design of innovations with existing technologies, skill sets, and technological literacy.”</i> (Peine and Neven, p. 18, 2019)</p>
4	<p><i>“Instead of focusing on acceptance or impact as qualities that can be defined a priori, studies in ageing and technology need to explore how they are created in interaction”</i> (Peine and Neven, p. 18, 2019)</p>
5	<p><i>“Studies in ageing and technology would benefit from extending their scope beyond the traditional sites of gerontological inquiry and embrace technology projects and innovation discourses as significant sites for the constitution of ageing, too”</i> (Peine and Neven, p. 18, 2019)</p>
6	<p><i>“Engaging co-constitution studies with the work of policy makers, designers, engineers and other practitioners will, hopefully, help create innovation policy and design that overcomes simplistic and often ageist ideas about older people and their relations with technology that have prevailed in gerontechnology practice and policy so far</i> (Peine, van Cooten, & Neven, 2017).” (Peine and Neven, p. 19, 2019)</p>

7.1 By replacing an interventionist logic with a co-constitution perspective, the ways in which certain images of ageing are foregrounded in design can be challenged, along with the constraining and enabling effects of such technologies on the everyday lives of older people (Peine and Neven, p. 18, 2019).

This thesis is about the nature of one of the strategies used in dementia care: surveillance technology and agrees that ageing and dementia images are inscribed in designs. It also agrees that

the disempowering effects of such technologies on people with dementia should be challenged. The collected studies attempt to understand how STs are marketed and how this impacts the experiences and needs on carers and people with dementia. They also demonstrate the presence of two contradictory ideas or discourses. First, the idea that technology is a solution for an ageing population. Second, the idea that people with dementia can make empowered choices and that one should value these choices as well as the ones that carers make. However, this research found assumptions and tensions within these different groups and contradictions between these ideas and tensions, as illustrated in the introduction (pages [11-17](#)) within the literature review (pages [20](#) to [39](#)) and from the discussion with the PPI (page [67](#)). The debate continues about user needs and the best strategies for designing STs, which indicate a lack of understanding of what is available on the market and how policies and marketing messages are projecting these two ideas (page [113](#)). Utilising a media literacy approach showed how pervasive the assumption of seeing technology as a solution for dementia care was while also pointing out the limitations of both the market and marketed products in three ageing countries as well as the limited engagement with users (pages [39](#) and [51](#)). This co-constituted approach demonstrated the tensions and contradictions occurring within the ST market and social policy.

Previous studies have reported that there is a lack of co-production as user needs are disregarded, rather designers incorporate their own perspective of what ageing and dementia are into technology designs (Hyysalo, 2006; Joyce & Mamo, 2006; Suijkerbuijk et al., 2019; Wan et al., 2016). For example, Hyysalo (2006) examined a business which provided a new safety alarm (“Wrist-care”) for older adults. The main inventor estimated that if a certain feature could be incorporated it would replace their existing devices and open up a new market. This product was not aimed at the medical market for commercial reasons as well as the necessity for the product to be thoroughly clinically tested (Hyysalo, 2006). The wrist-care was inspired by their previous experience of developing safety phones and drawing on other practices (Hyysalo, 2006). However, the business efforts and the product were eventually partially successful but mostly unsuccessful in meeting user needs (Hyysalo, 2006).

In the context of dementia, ST stakeholders have not focused on how people use it, what they think about it or how such technologies impact them. Instead, the motivation behind the ST websites are concerned with the proposition of “let’s sell something”. In particular, as found in chapter [3](#) the market does not really exist in any kind of sophisticated fashion as it does not generally test its products. Instead, a product is “just” presented as a solution for wandering. This was also seen in chapter [6](#) regarding media content where projections that the technology is there to increase safety

and meet the “need” of the wandering person were deemed to be central. This perception of need responded more to a cultural perception of the problem of ‘wandering’ rather than meeting specific challenges of dementia. The messages used to market ST seem to come from this background of expediency, leading to the risk of making the condition more stigmatised and therefore does not facilitate any idea of meeting needs or helping the situation of people with dementia and their carers move forward. In fact, it could be argued that it potentially actually deepens the stigma surrounding dementia by not providing a technology which relates to the people who are using it and perpetuate images of what dementia supposedly is. The provision of ST as a solution to wandering then shifts into a market sales loop focused on a form of consumerism where safety can be bought. This may imply that the ageing-technology argument of saving costs becomes a strategy to market products as a substitute for care.

However, the shift from care to consumerism, contradicts a generalised aim of social policy, which is to acknowledge a need and to provide a solution in the hope of a better outcomes and individual choice. In particular, failing to ensuring that business and research agendas are consistent with the needs and legitimate expectations from citizens with disabilities (“nothing about us, without us”) (Charlton, 2000) creates even more tensions (page [67](#)). However, increased user-involvement is not necessarily the answer if the real intention behind it disappears. In particular, when corporate accounts assimilate social-movements for ideological profit-making reasons (Ganchoff, 2004; Joyce & Mamo, 2006; Paulsen, 1993), they are not really addressing the issue. Instead, the issue around carers and people with dementia is much imbedded in social policy than it is in commercial concerns.

Throughout this study, the findings report on a lack of awareness that the needs of one group are not necessarily the same as to the other. Carers or people with dementia themselves, have very little role within the planning of the ST market. Chapter [2](#) the literature review found that few studies draw on carer involvement, only cursorily describing design features for STs and disregard people with dementia as technology users. Therefore, the findings from this study stress the lack of awareness that for dementia, the efforts from researchers, designers and businesses have not even grasped the bottom-line of this kind. Whilst Peine and Neven (2019) refer to the work of e-bikes, it should be noted that this is a slightly more different and sophisticated market. Rather, there should be a realisation that not all parts of ageing are equally valued.

Altogether this research has shown that technology and dementia are not perceived as co-constituted, rather the design and use of STs derive from other fields. In fact, surveillance and its origin from prisons were used by small sized companies as a marketing opportunity to sell

products. People should be aware that co-constitution can be a desirable factor; however, it will have no real debt if the problem is taken over and presented in the media in a stigmatising matter.

7.2 Further advancing dialogues of concepts, theories, and methodologies from science and technology studies and social gerontology is [are] pertinent to theorizing about ageing–technology relations (Peine and Neven, p. 18, 2019).

This thesis advanced ageing–technology dialogues by addressing these studies. Joyce and Mamo’s (2006) call for researching advertisements was fruitful as the exploration of the ST market (chapter 3) and media analysis (chapter 6) has dominated discussion about the “wandering discourse” impact on its users (chapter 6). However, as this thesis has demonstrated, it is also important to acknowledge marketing and media literacy perspectives and human-computer interaction resources (chapter 2), which can illuminate the gaps that even exist taking the first proposition into consideration. One limitation was that whilst this thesis was written, the field of human-computer interaction and design produced an increasing amount of literature on user-experiences and developing technology for and with people with dementia (Suijkerbuijk et al., 2019). This limitation, however, brings forth how important it is to bring together different disciplines in order to expand ageing-technology dialogues and knowledge.

7.3 Instead of focusing on the possible impact of new technologies on ageing, studying the use of existing technologies by older people is empirically and theoretically illuminating and offers opportunities for attuning the design of innovations with existing technologies, skill sets, and technological literacy (Peine and Neven, p. 18, 2019).

This study has been doing this and the findings from chapters 5 and 6 report on the use of bricolage. These chapters about the involvement of PPI members and potential users found that they used some form of ‘bricolage’ in order to make the existing technology work successfully. Successful technology use characterised by the concept of bricolage provides a useful tool to understand how users engage with technologies when managing care (Gibson et al., 2018). What this thesis adds to current knowledge is that people with dementia also use bricolage. This implies a tension that users apply bricolage because their needs are not met by current technologies, which requires further examinations. It might be useful to approach pre-existing arrangements with an occupational therapy perspective.

This is evidenced in chapter [3](#), which reports on the ST market, showing that providers are providing pre-existing technology. However, they are selling pre-existing technology to be used on people with dementia, pets and possessions. Chapter [6](#) media content broadened the ageing-technology knowledge through the examination of signs used in ST advertisements. The findings report a “wanderer” discourse, which does not represent people with dementia interacting with pre-existing technology. Rather, the themes of the dangers of wandering and the importance of independence and safety were targeted at younger female carers. This highlighted that it is not just that people with dementia are placed in stigmatising categories, but the lack of reflexivity from designers and marketers when they see people with dementia as objects. The message that carers should use pre-existing conceivable trackers hinders resilience as people with dementia were disregarded as human technology users.

7.4 Instead of focusing on acceptance or impact as qualities that can be defined a priori, studies in ageing and technology need to explore how they are created in interaction (Peine and Neven, p. 18, 2019).

This study supports this proposition as chapters [2](#) (literature review), [5](#) (audience reception) found that many of the carers accept the technology but hide the device for the person with dementia. This is not to criticise carers given that they lack support and are influenced by the motivation to keep the person safe. Nonetheless, they imagine that someone with dementia cannot make sense of the world and therefore covertly use ST. As a result, the person with dementia is unconsciously using ST. Therefore, it is important to acknowledge that there are different positions to take when it comes to carers or people with dementia interacting with technology. However, it is important to recognise that there is a general desire of both providers and users for technology to be useful and therefore be accepted (pages [30](#) and 31).

7.5 Studies in ageing and technology would benefit from extending their scope beyond the traditional sites of gerontological inquiry and embrace technology projects and innovation discourses as significant sites for the constitution of ageing, too (Peine and Neven, p. 18, 2019)

By embracing an interdisciplinary perspective, this thesis fruitfully explores discourses of technology and its users through an overarching media literacy approach. For example, chapter [3](#) focused on the ST market and found that the three countries use a universal language to project the idea that ST is a solution to wandering. The more-in-depth media analysis in chapter [6](#) highlighted the finding that such advertisements mainly seem to target women through positive and negative representations of younger looking female carers and the older woman with dementia. In chapter [6](#), the same positive advertisements of smiling carers, smiling people with dementia, pets and possessions were shown to people with dementia and carers. Later, negative representations of people with dementia falling down and being lost were shown. This enabled the contrasting of user views about ST and self-representations. The findings show that people with dementia and carers did not know what was available on the market; they did not recognise brands or understood the advertisements; neither did they understand the displayed technology. This seemed to indicate that the advertisements were unsuccessful. However, when applying the results from chapter [6](#) we see that a wandering discourse with semiotic signifiers is embedded within these advertisements. This is because the message of ST is promoted as a solution for wandering through the discourse being embedded with signs of “small tracker” and “increase safety”, which seemingly creates a need for the product. For example, the carers thought they disregarded the advertisements, yet continued to describe and search for a small concealable product for covert use to manage wandering. Furthermore, the participants living with dementia also described wandering in a negative fashion. Both positive and negative representations of wandering and dementia have a baleful impact and deepen the stigma of technology use for its represented users. In particular, the participants living with dementia felt stigmatised as they did not want to be compared to dogs. In the group discussion they physically concealed that they were wearing ST and discussed that they were not accepted by society.

In a recent report on attitude towards dementia, journalist Pippa Kelly states, “*Stigma stems from fear. Fear breeds silence, which in turn perpetuates ignorance and misunderstanding*”. (Alzheimer’s Disease International, p. 14, 2019). When the media portrays dementia as the most feared illness, stigma occurs which may negatively impact research and technology development (Joyce & Mamo, 2006), policy development and general knowledge of the disease (Alzheimer’s

Disease International, 2019). This creates barriers for people seeking help and induces discrimination, loss of rights and isolation (Alzheimer's Disease International, 2019). Therefore, it is likely that stigma influenced the participants living with dementia views of 'wanting to end it all' before becoming a "wanderer".

Whilst this study found no golden rule for dementia discourse, it is clear that comparing people with dementia with dogs is not helpful. Therefore, as this thesis has shown, it is essential to further examine discourses from different countries and evaluate its impacts on users from varying backgrounds. In particular, feminist work has suggested the need to examine the gender roles displayed in such discourses. Important starting points to improve current discourse practices are the reports from Alzheimer's Disease International (2019), Alzheimer Europe (2013) and Deep, (2014).

7.6 Engaging co-constitution studies with the work of policy makers, designers, engineers and other practitioners will, hopefully, help create innovation policy and design that overcomes simplistic and often ageist ideas about older people and their relations with technology that have prevailed in gerontechnology practice and policy so far (Peine et al., 2017, Peine and Neven, p. 19, 2019)

This study agrees with proposition 6 as the media research shows that the ST niche market targets carers with ageist messages. The ageist tensions and contradictions that arose did not occur because of an obvious failure by designers or businesses. Rather, a mismatch often occurs with researchers, designers and businesses who all have their own constraints (Brankaert, 2016; Hyysalo, 2006; Wan et al., 2016), constraints in terms of different expectations, resources, time available and the quickly evolving technology market (Brankaert, 2016; Hyysalo, 2006; Wan et al., 2016). Accordingly, businesses left little room for the design and research phase and disregarded user needs because implementing such design features would cost more and they wanted to quickly bring the product to market (Brankaert, 2016; Hyysalo, 2006; Wan et al., 2016). Another factor that also needs to be considered in this discussion is the changing nature of dementia. As the early diagnosis and awareness of dementia has increased, dementia self-advocacy has opened up a new market which is different from the previous assumptions that it was carers who constituted the users and consumers of such devices. Regarding the market as static is as much a failure in this area as it is in technology generally.

This general problem in the industry requires further examination. Therefore, the findings are also directed to those who design media, who in turn, also have not been completely successful with

selling their products. This lose-lose situation implies that the stakeholders involved in this niche sector will continue to struggle (Hyysalo, 2006; Wan et al., 2016) and inevitably new businesses will take on the same idea again because nothing changes.

Furthermore, the generated co-constituted knowledge from this thesis is important as it directs attention to issues of power and inequality in the surveillance market and dementia discourses that shape public understandings and perceptions. Recognising these issues will inform society and result in a step towards developing dementia-friendly products and advertisements. Accordingly, the user needs listed in this thesis aimed at healthcare professionals and designers can be used to shift from “low-technology” to “high-technology” and contribute to the more widely technology market (pages 67-71). This knowledge also impacts how STs are seen by policymakers as a ‘solution’ to ageing populations and dementia. The view that technology ensures a cost-efficient solution for healthcare has, for some time, enjoyed widespread and uncritical acceptance at the heart of policy making. If media and technology sectors become more responsive to the new market, which includes people with dementia, they will be empowered to engage with policymakers, ensuring that future policy will encourage designers and policymakers to celebrate this ethos and set the agenda. At the same time, if citizen-consumers accept the challenge to critically review the ST market and media messages, then they will be able to make informed decisions on how to ensure that technology can empower people with dementia and support carers. This will then enable citizen-consumers to become actively involved and influence the demand and supply aspect of the market.

Empowering and supporting citizens through providing space for influence and having their voice heard, however, does not seem to be incorporated in the final proposition from Peine and Neven, (2019). Similarly, the research field and ST market seems to have a set of empowering aspirations about citizenship, however, it does not consider actively involving their individually different users in the debate, design and dissemination of technology. Consequently, the tension of unmet needs will then never be resolved.

This was one of the reasons why PPI members have helped shape this thesis. Involving carers and especially people with dementia is rare in technology and discourse studies and therefore one of the major contributions was their active involvement in this study. The discussions and the advice from the PPI members provided the opportunity to explore how they conceived and experienced the media and STs. Therefore, proposition 6 is somewhat naive to PPI. Furthermore, user-involvement and PPI are not boxes to be ticked off any agenda. If research and designers implement co-constituted user-involvement, it should not be used in a tokenistic way. Instead,

user-involvement includes human beings with their own needs, experiences and rights and the focus should be on diversity and inclusion by adhering to the Nuffield Institute of Bioethics framework and PPI guidelines (Innes and McCabe, 2013; INVOLVE, 2012; NIHR, 2015). In sum, what this framework and this thesis have shown is that there are many different perspectives to consider and various views of looking at the issues surrounding technology and its users. More importantly, what this thesis argues is the importance of asking the initial question: where do needs for, and ideas about, technology and ageing come from?

In conclusion, this study has developed the argument that before one develops a market product for empowerment, think about what empowerment actually means in the context it is going to be used. Failing to do this can result in underdeveloped markets, frustrated users and technological irrelevance.

Chapter 8: Conclusion

This thesis aimed to contribute to the understanding of how STs are marketed and how this impacts the experiences and needs on carers and people with dementia. The first chapter reveals two pertinent ideas 1) STs form a solution for an ageing population and 2) while valuing the needs from carers, people with dementia can be empowered. However, these ideas often contradict because of the occurrence of certain tensions and unstated assumptions. The value of this research is that it provides a new critical angle on these occurrences in technology and dementia care through a media literacy approach and a broad social gerontechnology perspective. In particular, this dissertation examined three main research questions:

8.1 What is the current practice of ST and how are such products marketed in the field of dementia care?

- The ST market shows a lack of co-production by not considering or including its users
- The ST market provides mostly passive detect or track products
- Ageing and dementia images are inscribed in ST designs by the marketing of increasing the safety of the wanderer

The results of chapters [1](#) and [2](#) revealed the assumption that the needs of people with dementia are often perceived to be similar to those of carers whilst both user groups are disregarded within the discussion, design and dissemination of ST. Rather, as chapters [3](#) and [5](#) revealed the idea of consuming ST for the empowerment of its users, actually focusses on consumerism which leads to the persistence of exclusionary practices in the care of people with dementia. The evidence from chapter [3](#) provides new insights with respect to the ST market and how small providers target carers to sell their passive tracking products with promises of increasing the safety of people with dementia, pets and possessions. These findings have gone some way towards enhancing our understanding of how STs are marketed as it was shown that advertisements focus on the dangers of wandering and disregard people with dementia as technology users.

8.2 What are the views and needs from carers and people with dementia towards ST?

- Carers views and needs might differ from people with dementia towards ST
- Negative views towards surveillance

The theoretical framework developed in chapter [2](#) provides a new understanding of user views and needs towards ST designs. This study has demonstrated that involving carers and people with dementia as research advisors and participants in online discussion and focus group that needs of these separate groups regarding ST differ. In particular, the findings that emerge from chapter [5](#) show that people with dementia need ST for the purposes of navigation whilst carers may only want to locate the person. Furthermore, people with dementia shift between wanting to try ST to avoiding it in the sense that it was “not for me” whilst carers looked for a small-sized ST for covert use. Furthermore, more negative than positive views towards ST were described by the research advisors as surveillance reminded them of the tracking of prisoners and pets. More importantly, some individuals with dementia talked of planning euthanasia before becoming a “wanderer” in the focus groups. Therefore, appendices [I](#) and [J](#) include reports, which describe these findings aimed at carers, people living with dementia, health professionals, technology providers and designers. In appendix [J](#) the framework of user needs is translated into a design protocol which can be used by technology designers and providers.

8.3 What media techniques and ideals do messages contain that market ST to users?

- A wandering discourse fearfully urges carers to track people with dementia and pets
- Both positive and negative representations rely on stereotypes
- ST is presented as the ideal solution for the (female) carer to manage wandering

This is the first study reporting the advantages connected with using a media analysis approach to the wandering discourse message which was the same whether it was being used to track pets or people with dementia with a focus on risk (see chapters [5](#) and [6](#)). Chapter [6](#) contributes additional evidence to the ‘lose-lose’ situation which occurs because marketers are not getting their commercial messages across, carers struggle to find products that meet their needs and people with dementia felt stigmatised by the advertisements. The reliance on stereotypes targeted at carers with misunderstood ideas of ST hinders potential support and implies the continuous stigmatisation of excluding people with dementia.

8.4 Recommendations

This research highlighted many questions in need of further investigation. Several practical applications give attention to how advertisements sell not very useful technology, shape people's perception and contribute to lack of understanding about dementia. There is, therefore, a definite need for bringing together different disciplines to recognising these issues in order to inform society so that dementia-friendly products and advertisements can be developed. Although this study includes a small sample of users, if the debate is to be moved forward, a better understanding of user needs might be developed by exploring:

- The re-occurring mismatch between designers, businesses and users
- The presented user needs framework with regards to privacy and usefulness of ST
- A separate examination of user needs from carers and people with dementia
- A greater focus on media analysis

Another important practical application is that the framework of user needs aimed at healthcare professionals, businesses and designers can be used to improve products. The approach outlined in this study should be replicated in order to further examine the mismatch between designers, businesses and users. The framework presented in this thesis will serve as a base for future studies and could improve the understanding of users concerns about privacy and usefulness of ST. This could be done by further examining the needs from carers and people with dementia, *separately*, in order to promote their specific interests. Furthermore, appendix I is a report that informs people about what is available on the market and describes tips on how to look for ST online. However, more research is required to better understand how users perceive dementia stereotypes which could help prevent resistance to ST. Furthermore, this thesis assists in our understanding of how surveillance products are seen by policymakers as a 'solution' to the challenges posed by dementia and ageing populations. For some time, the view that technology saves costs in healthcare has enjoyed widespread and uncritical acceptance at the heart of policymaking. It is therefore recommended that marketers and designers should consider the following:

- Focus on empowering users by including them in the design and dissemination of technology in order to provide products tailored to user needs

- Focus on ways to market technology in a truthful non-stigmatising way by considering users' rights, autonomy, dignity, privacy and consent
- A co-constituted approach focussed on the tensions and contradictions occurring within the ST market and social policy
- Think about how technology is going to be used in its context before it is developed and marketed

Media and technology sectors can become more responsive to the new market by including and empowering people with dementia in order to engage with policymakers so that future policy encourages designers and policymakers to set a fruitful agenda and celebrate user centred individuality. However, user-involvement or PPI should not be used in a lucrative or tokenistic fashion. Instead, the inclusion and diversity of individuals with their own needs, experiences and rights should be promoted. Similarly, citizens who critically review the media and the ST market should be able to make informed decisions on how to ensure that technology can empower people with dementia and support carers. Informed decisions enable citizens to engage in and influence the ST market. In conclusion, this study argues that before one develops a market product for empowerment it is important to think about what empowerment actually means in the context it is going to be used. Failing to do this can result in underdeveloped markets, frustrated users and technological irrelevance.

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Being a research advisor: role description

Getting involved in research at UCL

Are you a person living with dementia?

Are you family or a friend of someone living with
dementia?

Would you be interested in sharing your thoughts on
research projects?

Do you want to influence policy and research?

For further details please contact
Yvette Vermeer (Y.vermeer@ucl.ac.uk)
Jem Bhatt (Jemini.bhatt.15@ucl.ac.uk)

1- Role Description

Advisors in Public Research are wanted for the UCL-**S**tudy **U**ser **R**eview **P**anel (**SURP**).

At University College London we are starting a new group for family and friends of, and people living with dementia. Who would like to be meaningfully involved in research. This sheet contains information for people who would like to be research advisors.

2- What we are looking for and how will you be involved?

Research Advisors will have experience and knowledge of dementia and be able to

- Have an interest in talking about research
- Influence the future of dementia research at UCL
- Attend meetings at 1-19 Torrington Place, London, WC1E 7HB roughly 3-4 times a year
- Contribute to research projects by giving feedback over the phone, online or through the post
- Have time to attend meetings (preferably face to face or via telephone)

Aims of the Service User Review Panel (SURP)

We are inviting people living with dementia and supporters/carers to act as research advisors. We are finding new ways for people living with dementia and family and friends of to actively take part in research and to ensure that UCL's research benefits people affected by dementia.

As a member of **UCL-SURP** you will be involved in influencing research as it happens in the field of dementia at UCL. **UCL-SURP** is based at the Research Department of Clinical, Educational and Health Psychology at UCL, London.

What will you be helping us with?

We have various research projects. Below are some examples of involvement:

- Highlight any issues that people living with dementia may identify in research – wording and language used in consent forms or recruitment flyers
- Offer advice on methods for conducting research with people living with dementia – help inform interview questions for researchers as part of their protocol
- Share ideas or comment on any findings, and make suggestions about communicating the research

3- What happens if you get involved?

You would work in partnership with other family and friends of, and people living with dementia, academics and researchers. You do not need any previous experience, just a willingness to attend meetings and to give your perspective as someone with experience of dementia.

We will discuss beforehand when the meetings will take place and make sure you are informed of all the details through your preferred form of contact (email, telephone, post). The length of a group meeting may vary. Some meetings may be a couple of hours and others may be

longer. However, it is always your choice whether or not you wish to attend. Yvette Vermeer and Jem Bhatt (UCL) will arrange meetings on behalf of the research project.

The position is voluntary, but training and support will be provided, and all travel and out-of-pocket expenses will be reimbursed. Research advisors will also be reimbursed for their time, please see the “payment for your role” section.

You should live in London or have easy access to this area (nearest Tube: Warren Street, Goodge Street, Euston Square).

If you are interested in finding out more, please contact Yvette Vermeer via email y.vermeer@ucl.ac.uk or call 077 09 77 6290 or post address:

Yvette Vermeer
Maple House,
Wing A 6th Floor
149 Tottenham Court
Rd London
W1T 7NF

4- Matters for consideration by research advisors: Important matters when in the role of research advisor

Conflicts of interest: Much research is commercially sensitive. Therefore, as an advisor, you will be required to disclose any involvement you may have with other organisations, government bodies or corporate / commercial interests if these could result in a conflict of interest with the work of UCL-SURP. For example, if you are already involved as an advisor or participant in other research projects.

Confidentiality: As an advisor of UCL-SURP you are asked not to share confidential information you may have received as a result of your position. If you are concerned about any aspect of the research this should be discussed with the project group or their contact person for complaints.

Support:

Advisors are able to access support and advice from Jem Bhatt (UCL-SURP Organiser) via email, telephone or in person. They may also email Dr Georgina Charlesworth (UCL-SURP Lead, g.charlesworth@ucl.ac.uk) or Jem Bhatt (UCL-SURP Organiser, jemini.bhatt.15@ucl.ac.uk) When needed the team will provide advisors with appropriate documents such as literature, glossaries of terminology, and we will support involvement by asking for regular feedback.

Payment for your role:

Reimbursements are in accordance with the INVOLVE (2012) guidelines. Advisors on this project will be reimbursed for their time this includes travel expenses and out-of-pocket expenses. Refreshments will be provided where appropriate.

The below table outlines payment values:

Activity	Price Per Person
Travel Costs per day	Reimbursed
Tea/Coffee (half day) Or Lunch (full day)	Provided
Half day involvement (3-4 hours with breaks included)	£75
Full Day involvement (with breaks and lunch)	£150

Further Information:

<http://www.ucl.ac.uk/pals/research/cehp>

B: Powerpoint presentation UCL Research Advisory Group



UCL RESEARCH ADVISORY GROUP

Yvette Vermeer
Jem Bhatt
Georgina Charlesworth



The role of Research Advisors

What public involvement it is...

Research being carried out **'with'** or
'by' members of the public

What public involvement is **NOT**...

Research activity that is done
'to', **'about'** or **'for'** members
of the public

UCL Research Advisory Group

We want to find new ways to for people with lived experience of dementia to actively take part in research because you are the experts

Does everyone have a copy of the role description?

Examples of research advisor involvement are...

involvement in identifying research priorities

undertaking interviews with research participants

commenting and developing patient information leaflets or other research materials

Our Joint Agreement

Empowerment and Surveillance



Yvette Vermeer
Y.vermeer@ucl.ac.uk
Division of Psychiatry



Content

What is surveillance technology for you?

What is the research about?

What do you think?

Question

- **What is surveillance technology for you?**

Question

- **What is empowerment for you?**

What is surveillance technology

In this research we consider the following:

It can be a range of technological devices:

GPS on your mobile phone, video monitoring, to walking around with sensors in your shoes

It can locate the person who is wearing or carrying around the technology, and sometimes alert friends or family in a case of emergency



What is NOT surveillance technology

In this research we consider the following:

Non-technological devices such as

Bracelets

Technologies that do **NOT** locate or send alerts

For example mobile phones without GPS or WIFI

Playing games on iPad without GPS or WIFI

Radio without GPS or WIFI



Introduction

It is important to study media representations of dementia & technology

To understand **HOW**

- Surveillance products are marketed
- This impacts people with dementia & family/friends
- People with dementia & family/friends are empowered

8 October 2019

Advice needed on

What do you **need** in surveillance technology?



What do you see in advertisements portraying people with dementia and technology?



The results from the discussions

8 October 2019

What categories would you make?



Thank you



Twitter @yvette_vermeer



Wordpress vermeerresearchingdementia

8 October 2019

The research presented in this report/paper/deliverable was carried out as part of the Marie Curie Innovative Training Network (ITN) action, H2020-MSCA-ITN-2015, under grant agreement number 676265



INDUCT: www.dementiainduct.eu

ESR 1: www.dementiainduct.eu/project/esr1/

C: Consent form for Alzheimer Nederland online discussion

Alzheimer Netherlands - Online Forum www.dementie.nl

I understand that my organization's support and participation in this project will involve:

- Assisting Ms Yvette Vermeer to conduct focus groups and research on the online forum
- Allowing Ms Yvette Vermeer to arrange focus groups and to develop a new post on our forum Which entails asking questions and reacting to other posts as an '*Alzheimer Netherlands expert*'.
- Providing Ms Yvette Vermeer with an Alzheimer Netherlands e-mail address for research communication purposes.

Voluntary

I understand that Dementie.nl forum participation in this study is entirely voluntary and that we can withdraw at any time without giving a reason. Further, I understand that participants can voluntarily attend the focus groups being held and voluntarily react to the online discussion on the forum www.dementie.nl from Alzheimer's Netherlands, and withdraw at any time without giving a reason.

Confidentiality, anonymity and storage

I understand that the identity of all participants must be treated confidentially by Ms Yvette Vermeer and our organization and that all information will be stored anonymously and securely. Contact details of potential and actual participants will be held by Alzheimer's Netherlands offices separately from any research data in a manner commensurate with Data Protection Policy in the Netherlands (the '*Wet Bescherming persoonsgegevens*' legislation).

Further, each individual will be assigned a code. The master list of names and codes will be kept securely in a locked drawer in a locked office at Alzheimer's Netherlands during the data collection phase, and will be destroyed once the data verification phase is complete. No identifiable data will be transferred or stored outside this premises. All information appearing in the final thesis will be anonymous.

Transcribing of data

I understand that the completed questionnaires, written statements and voice recordings will be brought together in the Netherlands. This data will be typed out and translated into English by the (Dutch and English speaking) researcher Ms Yvette Vermeer. The researcher will carry out all transcriptions, and remove information by which participants might be identified, and data will be stored securely (see above). Names of participants, affiliated organisations and the regions in which participants are situated will be changed through adding codes.

I understand that completed transcripts will be sent to participants as a 'double check' for highlighting identifiable information for removal (e.g. a participant tells a personal experience which could be identifiable to others). Participants will be shown quotations selected for inclusion in the final report, which can be removed if requested. Only the researcher Ms Yvette Vermeer will have access to this information.

I understand that I am free to discuss any questions or comments I might have with Ms Yvette Vermeer, Paul Higgs, or Georgina Charlesworth.

I also understand that at the end of the study I can request additional information and feedback about the purpose of the study.

I, _____(NAME) consent to Ms Yvette Vermeer proceeding with this study with the supervision of Paul Higgs and Georgina Charlesworth.
NAME

SIGNATURE

DATE

The current research study is not of a medical scientific nature (Niet-WMO plichtig onderzoek), and therefore it is not subject to the Dutch WMO legislation (Wet medisch-wetenschappelijk onderzoek met mensen). This research study should adhere to Dutch law regarding protection of personal data

(Wet bescherming persoonsgegevens). Therefore, we seek to obtain your permission to use your organisation's support to conduct focus groups and online discussions in a confidential manner for above-mentioned purposes.

This means that personal details will be handled according to the Data Protection Act 1998 and the 'Wet Bescherming persoonsgegevens' legislation. Ms Yvette Vermeer will not share details with anyone. She will listen to the recorded discussion and write down what participants said in a transcript. Anything that participants say during discussion that might identify you will be removed. Yvette will then look in the discussion transcript for themes. If you are willing and interested, Yvette will re-contact participants to ask what you think about the themes she finds. She will also offer you a copy of the final report. Individuals, places and organisations will not be identified in any research reports, unless they chose to be.

D: Information for participants placed on Alzheimer Netherlands forum

Post: *What do you think about commercials that include surveillance technologies for people with dementia and caregivers?*

This forum post is made in order to discuss surveillance technologies such as trackers, video monitors and GPS for research purposes. We want to find out what your opinion and experiences are with using or buying surveillance technologies.

What is surveillance technology?

Surveillance technology can be a range of technological devices. For example, GPS on your mobile phone, video monitoring in your house, to walking around with sensors in your shoes. The surveillance technology can locate the person who is wearing or carrying around the technology, and sometimes alert someone in a case of emergency. This study does not research technologies that do **not** locate or send alerts. For example a NOKIA phone without internet or GPS. We are **not** going to research non-technological products such as ID-tags or bracelets.

What is the research about?

In this study we are having discussions with people living with dementia and family caregivers, who have some knowledge of surveillance technology such as GPS. We want to find out what your opinion and experiences are with using or buying surveillance technologies. We hope that what we learn will increase the opportunities for individuals with dementia and family caregivers (who want to) become empowered.

Voluntary Participation

This discussion is voluntary. You do not have to take part, you do not need to answer to this post or react in a matter that makes you uncomfortable and no choice you make will effect you personally. You can withdraw from this research at any time without giving a reason.

What will happen with what I say?

The written comments might be used for research. Therefore, the comments will be translated into English. Transcripts of your comments will not identify you. We will change the names of commentators. Records will be stored securely on password encrypted University College London server for a maximum of five years, and is only used by the researcher for the intended purposes. The transcripts will be destroyed after completion of the research project.

Questions

If I have any additional questions about the evaluation, I may e-mail y.vermeer@alzheimer-nederland.nl

Yes, I would like to take part in this forum discussion.

No, I would not like to participate in this forum discussion.

By clicking ' Yes' , you agree that you have read this information, had time to think about taking part in this discussion, have asked questions if you wanted to, know this is voluntary, agree to take part and that written comments might be recorded.

Extra Information about the research:

The research project is being run by researchers at University College London.

Project title: Needs for Surveillance Technology and caring designs: *Helping to empower people living with dementia and support family carers*

Risks

There are no known risks for those who take part in this study.

Privacy

Your name will not be associated with what you write nor will it be used in any report that is published. We will not share what you say with anybody in any forum in a manner that, in our best judgement, can be linked to you. If you have any questions please contact Yvette Vermeer (Dutch speaking) or Prof Paul Higgs (English speaking)

Contact details

<u>Research Investigator</u>	<u>Principal Researcher</u>	<u>Work Address</u>
Yvette Vermeer University College London London WC1E 6BT y.vermeer@alzheimer- nederland.nl +447709 776290 (UK) +316 10311745 (NL) This study has been approved by the UCL Research Ethics Committee (Project ID Number): 10989/001-	Prof Paul Higgs University College London London WC1E 6BT +44 20 7679 9466	Division of Psychiatry Maple House 149 Tottenham Court Road London W1T 7NF

The current research study is not of a medical scientific nature (Niet-WMO plichtig onderzoek), and therefore it is not subject to the Dutch WMO legislation (Wet medisch-wetenschappelijk onderzoek met mensen). This research study should adhere to Dutch law regarding protection of personal data (Wet bescherming persoonsgegevens). Therefore, we seek to obtain your permission to use written statements during online discussions in a confidential manner for above-mentioned purposes.

Your personal details will be handled according to the Data Protection Act 1998. This means that Yvette will not share your details with anyone. She will read the forum discussion and write down what you have commented. Anything that you say write that might identify you will be removed. Yvette will then look in the discussion transcript for themes. If you are willing and interested, Yvette will re-contact you to ask what you think about the themes she finds. She will also offer you a copy of the final report. Individuals will not be identified in any research reports, unless they chose to be.

E: Disclosure form Alzheimer Netherlands forum

The disclosure page included on the Alzheimer Netherlands Website.

Forum Alzheimer Nederland - Registratie

Bedankt dat u wilt deelnemen aan het forum van Alzheimer Nederland. Op dit forum hanteren we enkele beleefheidsregels. Door het registreren op "Forum Alzheimer Nederland", gaat u akkoord met onderstaande voorwaarden.

1. Een forumaccount is voor persoonlijk gebruik; het plaatsen van oproepen door organisaties wordt niet toegestaan;
2. Het is niet toegestaan berichten met een commerciële strekking te plaatsen;
3. Ga respectvol om met de andere forumgebruikers. Laat ze in hun waarde en wees niet onnodig kwetsend of storend tegenover anderen. Ga niet in op kwetsende of storende berichten van anderen, maar rapporteer ze aan de forum moderator (forum@alzheimer-nederland.nl);
4. Om misbruik door derden te voorkomen wordt het afgeraden persoonlijke (contact) gegevens van uzelf op het forum te posten. Het is verboden persoonlijke (contact) gegevens van anderen op het forum te plaatsen. Hou er rekening mee dat het forum van Alzheimer Nederland volledig openbaar is en dat iedereen uw berichten kan lezen. Bovendien wordt de inhoud van dit forum door zoekmachines als Google geïndexeerd.
5. U gaat ermee akkoord dat beheerder(s) en vrijwilliger(s) het recht hebben om onderwerpen te verwijderen te wijzigen te verplaatsen of te sluiten wanneer zij dit nodig achten.
6. Als gebruiker gaat u ermee akkoord dat de informatie die u bij ons invoert wordt opgeslagen in een database. Hoewel deze informatie niet aan een derde partij zal worden verstrekt zonder uw toestemming, kunnen beheerder(s) of phpBB niet verantwoordelijk worden gehouden voor een hackpoging die ertoe kan leiden dat de gegevens vrijkomen.

Alzheimer Nederland draagt geen enkele verantwoordelijkheid voor de door bezoekers ingebrachte inhoud op het forum en onderschrijft niet altijd de inhoud van de berichten. Alzheimer Nederland accepteert daarom op geen enkele wijze verantwoordelijkheid en/of aansprakelijkheid voor de teksten op dit forum.

Dit forum draait op phpBB. phpBB is een bulletinboard oplossing dat is uitgebracht onder de "General Public License" (hierna "GPL") en kan gedownload worden via www.phpBB.com en via de Nederlandstalige website www.phpBBservice.nl.

Ik accepteer deze voorwaarden Ik ga niet akkoord met deze voorwaarden

[Privacy](#) | [Cookies](#)
Een phpBB forum

F: Information booklet focus group discussion

Please note that these materials were translated into Dutch.

Empowerment and surveillance

- ▶ Taking part in research



We are doing research about surveillance technology - Can you help?

- ▶ **Our invitation to you**

We would like to invite you to take part in a focus group discussion about surveillance technologies such as GPS. The discussion will be with other people living with dementia, and family or friends of someone living with dementia.

This is part of a larger research study that will run till October 2019.

- ▶ **This leaflet**

This leaflet contains information about the research. Please read it all before agreeing to take part

- ▶ **More information**

If you have any questions please contact Yvette Vermeer via y.vermeer@Alzheimer-Nederland.nl or call +31610311745

What is surveillance technology

Surveillance technology can be a range of technological devices.

We refer to technology which are automated, digital, or run by electricity or a battery.

For example: GPS on your mobile phone, video monitoring, to walking around with sensors in your shoes.

The surveillance technology can locate the person who is wearing or carrying around the technology, and sometimes alert a friend/family member or carer in a case of emergency



What is NOT surveillance technology

Non-technological devices such as

- Bracelets

Technologies that do NOT locate or send alerts

For example mobile phones without GPS or WIFI

Playing games on iPad without GPS or WIFI

Radio without GPS or WIFI



Details of Study

- ▶ In this study we are having discussions with family or friends of, and people living with dementia. It is important that they have some knowledge of surveillance technology such as GPS.
- ▶ We want to find out what your opinion and experiences are with using or buying surveillance technologies.
- ▶ We hope that what we learn will increase the opportunities for family and friends who support people with dementia and individuals living with dementia who want to become empowered.

The research is being conducted by the division of Psychiatry, University College London, in partnership with INDUCT and Alzheimer Netherlands.

5

Getting involved

We want to hear what you and other people in your group think about surveillance technologies

- ▶ A group discussion will take place on

Date	
Time	
Venue	

Please note - you do not have to take part:

It is entirely up to you whether you take part in this study. Please discuss with Yvette any questions or concerns you have. If you agree to take part, we will then ask you to sign a consent form

Tape recording: we will tape record the discussion so that we can remember exactly what everybody said.

The recording will be kept safe and confidential. *If you do not want to be tape recorded you will not be able to take part.*

What will we do?

- ▶ We want to have a discussion about surveillance technologies and the media. During this discussion we might ask you what you think about surveillance and what you (dis) like about these products. We will also watch and listen to advertisements that include these products.
- ▶ The discussion will last for up to 90 minutes including a coffee break

We will arrange the discussion at a local Alzheimer Cafe.

The discussion will be recorded on a digital voice-recorder.

The research is being conducted by the division of Psychiatry, University College London, in partnership with INDUCT and Alzheimer Netherlands.

▶ Changing your mind about taking part

You can change your mind about taking part at any time before or during the discussion. You do not have to give a reason.

If you change your mind once the discussion has started we will still keep a record of the things you said up till that point.

▶ Confidentiality

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you said in a safe place.

If you tell us that you or someone else is being hurt, we might have to tell someone, but we would try to talk to you first.

► **Support to take part**

If you would like someone, like a friend, support worker or family member, to be with you during the discussion, that's fine - please discuss this with Yvette. If you need help to hear or speak, or any other support to take part, please let us know.

If you need help to travel to the discussion or home again we could help with this, please let us know.

► **Risks**

There are no known risks for those who take part in this study. In the unlikely event that someone becomes upset during the focus group, Yvette will deal with this in a sensitive way. You can also choose to bring a friend or family member.

► **Thank you**

If you take part in the focus group, we will give you a gift of 10 euro to say thank you

► **Deciding whether to take part**

Remember, you do not have to take part in the focus group.

When deciding whether or not to take part, it might help to talk to someone at home, or a friend.

► **If you do not want to take part**

You can withdraw from the study at any time without giving a reason.

Also, you can still come to your group as usual - there will be other things for you to do

► **Privacy**

Your name will not be associated with what you say nor will it be used in any report that is published. We will not share what you say with anybody in any forum in a manner that, in our best judgement, can be linked to you.

► **What happens after the focus group?**

The tape recording of the discussion will be typed out and analysed by researchers.

Once this is done, Yvette will present what they have learnt and ask you what you think. The project is due to be completed in October 2019, after which we will send a short summary of all the research findings to your group.

The research is being conducted by University College London in partnership with INDUCT and Alzheimer Netherlands.

It has been approved by the ethics committee project number 10989/001

Further information

If you would like further information about the focus group, please contact Yvette Vermeer: 0610311745 or y.vermeer@Alzheimer-Nederland.nl

G: Consent form focus group discussion participants

This is the English translated version of the consent forms for the focus group participants. Please note that dementia-friendly booklets were created and translated into Dutch for the Dutch participants living with dementia.

Contact details		
<u>Research Investigator</u>	<u>Principal Researcher</u>	<u>Work Address</u>
Yvette Vermeer University College London London WC1E 6BT y.vermeer@alzheimernederland.nl +447709 776290 (UK) +316 10311745 (NL)	Prof Paul Higgs University College London London WC1E 6BT +44 20 7679 9466	Division of Psychiatry Maple House 149 Tottenham Court Road London W1T 7NF
This study has been approved by the UCL Research Ethics Committee (Project ID Number): 10989/001		

Project title: Needs for Surveillance Technology and caring designs: *Helping to empower people living with dementia and support family carers*

Voice and written comments recorded during [Focus Group number] on the [DATE].

Adult Participation in a focus group discussion

What is the research about?

In this study we are having discussions with [Group people living with dementia OR family caregivers] who have some knowledge of surveillance technology such as GPS. We want to find out what your opinion and experiences are with using or buying surveillance technologies. We hope that what we learn will increase the opportunities for individuals with dementia and family caregivers (who want to) become empowered.

Why have I been asked to take part?

You are familiar with, or have bought one of these products. More importantly, you probably have an interest in or an opinion about surveillance products. We want to know these thoughts and opinions.

What will we do?

First we will watch a commercial about a surveillance product. Then discussion starts and later we will look at some printed advertisements portraying people with dementia. It will last for 90 minutes including a coffee break. Yvette will ask you what you think about surveillance products and what you (dis)like about these products.

Voluntary Participation

This discussion is voluntary. You do not have to take part, you may leave at any time, you do not need to answer any questions that make you uncomfortable and no choice you make will effect you personally.

Risks

There are no known risks for those who take part in this study.

Benefits

Coffee and tea, hopefully an interesting conversation and, to say thank you, we will give participants a small token of appreciation.

Privacy

Your name will not be associated with what you say nor will it be used in any report that is published. We will not share what you say with anybody in any forum in a manner that, in our best judgement, can be linked to you. The other individuals in the group will be asked keep what we talk about private, but this cannot be assured.

What will happen with what I say?

The discussion will be recorded to ensure accuracy. Transcripts of the recording will not identify speakers. Records will be stored securely on password encrypted University College London server for a maximum of five years, and is only used by the researcher for the intended purposes. The transcripts and recordings will be destroyed after completion of the research project.

Recording Permission

I have been told that the discussion will my voice and written statements will be recorded and I consent.

Questions

If I have any additional questions about the evaluation, I may e-mail Ms Yvette Vermeer

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

Please complete this form after you have read the Information and/or listened to

an explanation about the research. You will be given a copy of this Consent Form to keep and refer to at any time.

I agree that:

Please tick the boxes and sign at the end	Yes	No
I have read the information documents provided		
I have had time to think about taking part in the research		
I have asked questions if I wanted to		
I know I do not have to take part in this research if I do not want to		
I agree to take part in a group discussion about surveillance products		
I know I can change my mind before or during this discussion and can withdraw at any time without giving a reason		
I understand that my participation will be voice recorded. I consent to use of this material as part of the project.		
I agree that you can type record the discussion		
I agree that you can keep my contact details and a record that I took part in this research for five years after the project ends		

Please write your name below and check yes or no. If you want to take part sign your name at the bottom.

NAME

Yes, I would like to take part in the focus group.

No, I would not like to participate in the focus group.

SIGNATURE

DATE

The current research study is not of a medical scientific nature (Niet-WMO plichtig onderzoek), and therefore it is not subject to the Dutch WMO legislation (Wet medisch-wetenschappelijk onderzoek met mensen). This research study should adhere to Dutch law regarding protection of personal data (Wet bescherming persoonsgegevens). Therefore, we seek to obtain your permission to use voice-recorder and written statements during focus groups in a confidential manner for above-mentioned purposes.

Your personal details will be handled according to the Data Protection Act 1998. This means that Yvette will not share your details with anyone. She will listen to the recorded discussion and write down what you both said in a transcript. Anything that you say during discussion that might identify you will be removed. Yvette will then look in the discussion transcript for themes. If you are willing and interested, Yvette will re-contact you to ask what you think about the themes she finds. She will also offer you a copy of the final report. Individuals will not be identified in any research reports, unless they chose to be.

Investigator's Statement

Iconfirm that I have carefully explained the aims of the study to the participant and outlined any foreseeable risks or benefits (where applicable).

H: The advertisements

Due to copyright issues it is not possible to include screenshots from the films and printed advertisements in this thesis. The translated and analysed materials used for this thesis can be send upon request.

However, the film SafetyOldCard, which was shown to the participants living with dementia, is available from <https://www.youtube.com/watch?v=U8ZkZslTrbE>

The film, the family, which was shown to the family carers, is available from <https://www.youtube.com/watch?v=FO9f2zXADv4>

The film, the Carebelt, which was shown to all participants, is available from <https://www.youtube.com/watch?v=8PTkJz5n1RQ>

The printed advertisements, used for the focus groups as well as the media content analysis, are available from <http://www.trackyour.co.uk/>, <http://www.spottergps.uk/>, <https://www.spottergps.com/> and <https://www.personalgps trackers.co.uk/products/gps-dementia-tracker>.

I: Issue 01 Surveillance technologies for dementia care

English version distributed on the CHAIN Network https://www.chain-network.org.uk/subgroup_resources.html#Tec.



In this issue

Findings from three countries **P.1**

Safety and price **P.2**

Privacy and users **P.3**

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Dementia has become a major global concern

Technology can be used to help older adults to remain living in their own home. Especially, surveillance technology might provide support for carers and people living with dementia. These technologies are promoted as products that keep people with dementia independent and safe.

Surveillance Technology (ST) can be a general description of monitoring systems where a carer can supervise a person with dementia 24/7. For example, a tracking device that the person with dementia carries around. This tracker is often connected to the mobile phone from the carer. Hereby, the carer can see the location of the person. There are many different ST products available online.

However, websites often provide unclear information about what the product does. Carers thought that such websites look like they are made for specialist. Further, these products often do not meet user needs. Therefore, we looked at over 300 websites that sell ST. We read through the information about the product's functionality, country origin, intended user, price, and the keywords and portrayals used on the product websites.

Findings

The majority of products come from the United Kingdom. In the United Kingdom and Sweden, the companies behind the websites appeared to be webshops made by one employee. In the Netherlands there was a more balanced mixture of small, medium and large companies. In all three countries the website messaging focussed on the need to manage safety concerns, with less focus on privacy or consent.

Safety and independence

There are no hard facts that ST keeps people with dementia independent and safe.



Price

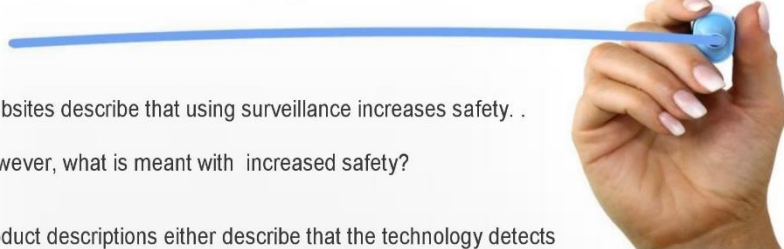
The purchase price ranges from £0 to £654 in the three countries.

Similar products are priced differently by different providers.

Only 13 products were under £10. The headline price displayed often included extras (i.e. shipping costs, monthly fees).

However, the mean price is unknown because many websites do not display price, or additional costs.

SAFETY



Websites describe that using surveillance increases safety. .

However, what is meant with increased safety?

Product descriptions either describe that the technology detects the person “wandering”, or that carers are alarmed with no further explanation.

We found two types of products being sold online:

1. **Detect.** A passive technology that monitors and detects the recipients' location.

Location finding may require the carer accessing a mobile phone or computer.

The recipient cannot push an alarm button or communicate in any other way.

For this reason, the carer has to constantly monitor the person's location.

“The ... can act as both a locator for keys and bags or a tracking device for a loved one, to help keep them safe if they wander”

Location tracker – webshop

2. **Alert.** A technology with an alarm button, but without a Global Positioning System (GPS).

A person can push the alarm button in case of an emergency. Somehow the carer is then made aware of this emergency, and can intervene accordingly.

Some website claim that their products both detect and alert. For example, a watch with GPS and an alarm button. It would then notify the carer with information about the recipients' location, and the alarm button can be used when necessary.

“Ideal for monitoring: pets (e.g. dogs / cats / horses etc...), children / teenagers of all ages & abilities, vulnerable adults or frail elderly who may misuse the SOS & on / off buttons e.g. autism, Alzheimer's / dementia sufferers” SOS button – webshop

A minority of products were described as ‘preventing risk’; however without an explanation.



Privacy: Who receives the data?

When you have a technology that monitors it collects data. Most products identified online share this data. The majority of websites mention that carers would receive data, such as the location of the person with dementia. The second largest group of products found share data with third parties. Third parties include online clouds or alarm centres. Online clouds often backup data that involves sending it to a public network or off-site server. Alarm centres may gather information about the recipient location and when an alarm button was pressed

Country differences

In the United Kingdom, product descriptions use words such as ethics and consent. In Sweden and the Netherlands, descriptions explained how surveillance can be disguised and covertly used. Majority of Dutch websites clearly state that no data will be send to third parties. Instead most data is send to the carer. Products from Sweden are often trackers that film or detect a person's location. It is unclear what happens with this data.

Who can use surveillance according to websites?

Messages were aimed at carers, researchers or organisations involved in social care provision. Websites would explain how they can benefit and keep a person with dementia independent and safe.

However, few websites would describe if people with dementia can use the product, and how they would benefit from it.

Notably, the majority of websites sell products that can be used for older adults, wanderers, children, pets, and possessions.



Tip 1: searching online for surveillance technology

1. Be careful with certain search words

Webshops use search words to attract consumers. For example, search words such as; Alzheimer, dementia, wandering, safety, and independence. Whilst this may be important to you, ask yourself can a technology do these functions? Our advice is to search for features you want a technology to have. It can be helpful to discuss this with a care professional. Every situation and individual is different. Use the features you want as search words. For example, try "nagivation" and "geo-fencing". Once you find a website check if it has a contact form. It is important that you can contact them with questions.



Top 10 words used on websites

1. Safe
2. Wandering
3. Security
4. Fall
5. Alarm
6. Lost
7. Independence
8. Consent
9. Secret
10. Vulnerable



“The same use of visuals.. over and over ...again”

Advertisements on websites

• Similarities countries

The websites use an universal language with a focus on safety and security. The problems described are loved one's that are wandering, become lost, or have life threatening falls. The same visuals are used to portray people who are lost or fallen. Further, many websites use visuals that portray a younger carer and an older adult. Other visuals are often stereotypes of people with dementia, pets, children, and possessions. Stereotypes suggest that if you buy the product you will keep them safe. Otherwise a person or becomes lost or harmed.

• Differences countries

In Sweden websites described their products more as camera's than can spy. In the Netherlands the products were described as sensors. In the United Kingdom products were mentioned as monitors with short descriptions of ethics and consent. •

Tip 2: searching online for surveillance technology

2. Read the manufacturer guideline and ask questions

When there is limited information available you can also search online for the manufacturer. Usually these companies provide guidelines. Another tip is to visit an electronic store. It might be helpful to ask employees who sell GPS and navigation systems some questions about the product. Finally, check if the webaddress is trustworthy. You can look at the date underneath the page to see when it was last updated. When the website doesn't show HTTPS:// you can always type the website in a search engine. See if there are reviews available from others.

Contact



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WWW.DEMENTIAINDUCT.EU

J: Issue 02: Surveillance protocol

English version distributed on the CHAIN network.

Issue

02

October 2019

Surveillance technologies for dementia care



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Surveillance protocol:

A summary of what people living with dementia and family carers need in surveillance technologies. *By Yvette Vermeer*

Surveillance technologies (STs) can be a range of electronic/technological devices that are part of today's society, including assistive technology of this kind. These technologies monitor movements and may provide freedom with security by tracking people with dementia so that family or friends can intervene if necessary. The previous issue reported the research findings about how STs are marketed to users. This issue presents a protocol for design details of STs by addressing user needs



This protocol is based on Vermeer, Y (2020). Surveillance technology and dementia: empowerment of people living with dementia and family carers. Doctoral dissertation, London, University College London.

The problem with surveillance

There are many STs commercially available, however its popularity does not guarantee uptake from people with dementia and carers. The term carers is used in its broadest sense to refer to all family or friends who support someone living with dementia. Furthermore, when people have concerns about the devices (e.g. invasiveness, conditions of surveillance, stigma and the effects on one's dignity), it will lead to a low uptake. People with dementia will not use technology if it does not fit their needs or capacities and their needs might differ from those of carers. In sum, designs that do not address user needs are more likely to be abandoned. Therefore, this protocol was developed through involving users and lists the needs from people with dementia and carers in STs.

What can the protocol contribute to research and practice?

This protocol was created with the intention of providing a tool that could rapidly assist designers and providers of surveillance technology. It can be used as a checklist to see if user needs are met, to compare products and inspire novel designs. Offering a method for testing user needs enables researchers to identify areas for intervention so that it becomes an evidence-based method that has been validated for a variety of populations and countries.

Who needs what?

Each section describes if it is a need expressed by carers, people living with dementia or both.

"A product should meet my individual needs"
(Person with dementia – focus group)

"I need the product to do what I want"
(Carer– focus group)

Features and items

This protocol is based on a study which involved people with dementia and carers through various methods (Vermeer, 2020). Data regarding user needs have been gathered by a review of the literature, online discussions, focus groups and a patient and public information group.

Features	Description	Items
Effect	Description of the intended effect of the product on or for the user	safety, independence, confidence, peace of mind, free time
Product Characteristics	Characteristics of the product	price, size and weight, SOS-button, HOME-button, one technology
User-friendliness	Centres on the product and how well it is designed for the user	Simple to use, but useful, capacity, routine
User-context	Contextual, situational differences relevant to the person using the technology	acceptance, navigation, locate accurately, notifications, performance, communication
Privacy	Issues relevant to the ethical debate surrounding the data gathered by ST and who is being is being monitored	privacy data, adjustable settings, safety and risk zones, autonomy, legal and liability
Design details	Product design characteristics that can be added or deleted to a product to protect, change, or enhance durability	battery, simplicity, visibility & aesthetics,

2

Features and items based on the research article from Vermeer, Higgs and Charlesworth (2019)

User needs explained: **Effect**

Using a product should have the following effect:

- Increase safety
- Increase confidence
- Provide peace of mind
- Increase free time or diminish the time required to do a certain activity

It might seem obvious that the use of ST should keep a person safe. However, it is of concern that carers may be falsely reassured by the technology. For example, a passive location tracker will not prevent falls or someone getting lost. People with dementia discussed how ST can give you a feeling of safety but not increase it if the device is distracting when crossing a busy street.



Carers described how ST use could result in greater confidence and peace of mind if they could rapidly locate a lost person. People living with dementia described the need for ST to increase their independence because they want to be able to participate in society.

Price

- Carers were willing to pay **between €50 and €70,-** *

However, this depends on the product features such as battery life. Carers were willing to pay more if the product has a long battery life.

The study also found that products sold online had an average direct purchase price of £ 102.88, - and prices ranged from £1067, 99**, - , to free apps*. However, other literature suggests that 20 percent of carers are not willing to pay anything (Barrett, 2008; Cook & Polgar, 2014).

*Results from the Dutch online discussions **Prices were converted in to £ (January 2018)

False safety

“ST is not only to prevent him getting lost...for everyone’s peace of mind” (Carer - online discussion).

“It does give you a feeling of safety, because he went missing...and that experience was not fun for anyone” (De Zorgriem - carer - online discussion).

“It does give you a feeling of safety, because he went missing...and that experience was not fun for anyone” (Carer - online discussion).

“Yes it takes a lot of energy and effort but this product is the only way for me that he can stay in his own home” (Carer - online discussion).

Extra costs

“We didn’t like that we had to buy call-credit for a couple of months while we would probably only call like twice a month” (Carer - online discussion)

“I am looking for a GPS that doesn’t come with extra costs” (Carer - online discussion)

“it costs € 70,-...and plm € 4,00/mnd prepaid...a fine product” (De Spotter - carer - online discussion)

Size & buttons

"The most important thing is the SOS button"
(Wherecom watch - carer - online discussion)

"the SOS button from 'De spotter' is larger so that's easier" (De Spotter - carer - online discussion)

Product characteristics: what matters?

A minimum size & weight

❑ Size of a wristband and/or watch

Carers think people with dementia are more likely to accept a product with that size. However, some carers also indicated a need for products which are less than 5 cm in order to hide the ST in the clothes or possessions from the person with dementia.

Analogue clock

❑ Display time with a clock face

Carers need a watch with a display time that has a clock face or dial. They prefer not to see a black screen, dots and AM/PM display. The carers thought this would otherwise confuse the person with dementia.

SOS-button or HOME-button?

There were many conflicting views about what sort of buttons to incorporate. Some carers expressed that the person with dementia was not able to use buttons. However, people with dementia stated they need a home-button to guide them back home. Therefore, it is advisable to have both options available in order for users to choose which button they can use. These buttons should be:

- ❑ Recognisable and large-enough to press
- ❑ SOS alarm is accurate with minimum false alarms



User friendly: for both users

Simple to use and useful

- ❑ Simple to use and require little skill
- ❑ Provide guiding instructions

A product is simple to use when it requires little skill, can be used self-efficient and intuitively by users. Otherwise there should be sufficient training available or guidance instructions.



Simple

"It didn't come with a guideline.... but I liked that I could use it intuitively" (De Spotter - carer- online discussion)

"The most important thing is that you don't understand many actions. My advice is to keep it as easy and simple as possible"
(De Spotter - person¹ with dementia - online discussion)

User-friendly

"I cannot keep up with a smartphone" (Person with dementia - focus group).

"I don't use it anymore because he really can't leave go out by himself anymore" (De Zorgriem - carer - online discussion).

"The product is just not designed for people with dementia. It's sort a key change, which that person obviously should bring along" (De Spotter- carer - online discussion).



User-context

I forgot my mobile a couple of times ... But the most important thing as a person with dementia is that you don't get all these buttons to press,. My advice keep it as easy and simple as possible (Person living with dementia - online discussion)

"Setting up safe zones is only possible via the app and not the website.. Tip: don't set the zones too closely, otherwise you'll get flooded with e-mails" (De spotter - carer - online discussion)

Can the person use it?

The feature of user-friendly emphasizes individuality and that products should not be designed solely for the carer. Carers and people with dementia stressed that products should fit their:

- Individual needs and capacity
- Routine and of those involved



User-context

User-friendliness can be achieved when the context of the user is considered. The following items were described as important:

Acceptance

- When a product is familiar users will accept it better**

Both users stated that they need ST to be a familiar product. This entails a product that they already use in their daily life (e.g. watch). People with dementia, who were not used to using smart phones, stated they had difficulties with using a regular mobile phone.

Locate accurately with notifications

- The location of the person in and outside of buildings should be provided in the metric system depending on the country**
- Geo fence option with safety zones**

Notifications should be real-time and adjustable to personal needs so that users are not overflowed. For example, silent and vibrating option when person leaves the pre-set safety area.

Performance

- Reliable and loads with speed**
- Minimum technical problems**

Carers need products which are durable and lasting longer than two years. A product should have speed when loading content and history of routes taken by the person with dementia.

Communication

- Ability to phone.**

Both users need a product with which they can phone each other. Preferably with pre-set phone numbers and names and quick dial.

Consent?

"Ask the client and their first-contact-person for permission"

(carer - online discussion)

What is legal?

"I read a lot about these gps systems. Well I'm curious what about laws and regulations, when do organisations use this. Privacy? Responsibility?"

(carer - online discussion)

Privacy and consent

Adjustable settings

- Product that does not invade privacy**
- Fine-grained adjustability of privacy and safety settings**

When the product provides the user with tailored setting that can be adjusted by the user to suit the technology to individual cases. A product should be unobtrusive and not undermine individual autonomy

Safety and risk zones

- Geo-fencing with safety and risk zones**

This includes the option to choose what information will be shared and with who (e.g. carers, alarm centres)

Legal and Liability

- Product should be unobtrusive**
- Not undermine legal or liability issues**

Design details: what makes it simple?

Battery life

- Long battery life**

Recommended is a battery life of a month to avoid constant charging or change of battery. Both carers and people with dementia want to see how many percentage of the battery is left and receive a notification when it is almost empty.



Simplicity and aesthetics

- Screens and buttons should be simple**
- Waterproof and not visible**

A design should have small screens, few manageable functions, not too many buttons and include keywords that guide the person with dementia on their way (see home button). Both users also reported the need for product designs to be waterproof and not noticeable and/or visible when being worn.

If a product is noticeable it might become stigmatising.

Battery life over 30 days

"I don't want to charge it every day - I forget"
(Person with dementia-focus group)

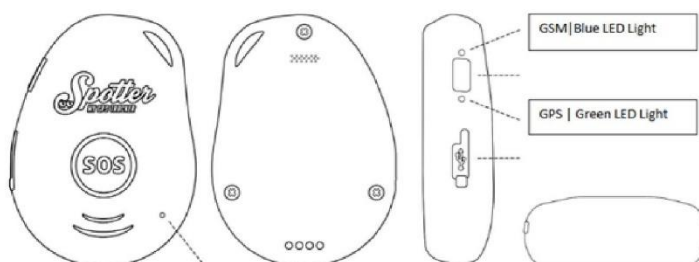
"it costed € 130 but we did it as battery life was 30 days" (Concox GPS Vehicle tracker G 103A - carer - online discussion)

Other considerations for carers

The provider

Trustworthy

Users deemed a provider trustworthy when a website provides clear information about who they are and what services and support they provide. In particular, carers stated they need to be able to contact the provider or manufacturer if there is something wrong with the product.



De Spotter image from information booklet <https://www.spottergps.com/>

Locate and monitor

Some carers described they need products that monitors the health and safety status from the person with dementia from a distance. This includes the items of:

- Actual reporting life
- Quick accessibility of data and automatic back up



Some carers stated they need to be able to monitor the recipients location status through 'reporting life' which is frequently updated and locates the person quickly. This data should be saved automatically and can be accessed anytime. Carers also reported the need for a product that provides information about the care recipient's condition and whether the person is safe. Furthermore, the product should have the option to be connected through either a monitoring app or a support platform.

- Connected to app or support platform
- Cooperative monitoring with professionals
- Human-centred support



The support platform (e.g. alarm centre) can have access to the product in order to monitor the person with dementia. However, this alarm centre should be trustworthy with regards to data sharing and be decided upon by both users. All support should be human-centred and enable cooperative monitoring. This includes systems that supports access, communication and coordination between health-care professionals such as occupational therapists, doctors and nurses. .

Providers

*"In the beginning it worked really well but since ..2015 it doesn't work anymore. It seems it very difficult to get in touch with Track and Trace by phone (*left a voicemail and email). I'm curious what other people's experiences are with this web shop" (GPS in sole-carer – online discussion)*

Monitoring

"it's impossible to set up safety zones and because of this we have to constantly watch the app" (Premium gps-watch – carer – online discussion)

"5 days standby - charge with a magnetic plate - touchscreen -SOS button - set-up emergency number - tracking with smartphone - waterproof - I'll order one" (Track Watch - carer)

It has a SOS button, and by the app on your own mobile you can log in and

1. determine and follow the location

2. See the route travelled

3. You can also set a "geofence" and if the person leaves this you will receive a notification

4. You can call the watch." (T58 Watch - carer - online discussion)

Guide me home

“I want it simple so when I say I don't know where I am and I want to go home, it will give me directions to go home” (Person with dementia - focus group).

“I want a big arrow on a map that guides me home like TomTom (Person with dementia - focus group).

if the product has a voice-over that gives directions then it should be familiar and recognizable (person with dementia –focus group).

Covert use

“It shouldn't be behind my back. I'm not a moron” (Person with dementia - focus group).

Important for people living with dementia

Navigation

- Outdoor navigation
- Voice-recognition and home-button

People living with dementia expressed they wanted navigation for outside. They know their way inside the house and need something that guides them home when they press the HOME-button.

- Google Maps navigation OR TomTom arrow

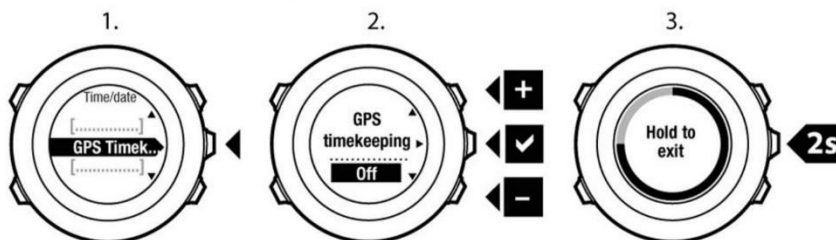
People with dementia stated their liking for brands such as Google Maps and TomTom. Advised is having options so that users can choose navigation settings similar to Google Maps* or TomTom. There should be a HOME-button and voice-recognition that when the person says 'guide me home' the product will automatically provide directions home. The information provided should be concrete and not too fast. Repetition of the directions may be required. The address should be installed before use as people with dementia mentioned they might forget their own address.

** Please see the latest features of Google Maps AR navigation*



One technology

People living with dementia reported the need for an all in one technology. There should not be too many technologies involved. They already have a mobile and do not want to carry another device with them. Preferably the device or app can be incorporated in their familiar watch or mobile phone.



SUUNTO Ambit 2 R - picture from information booklet - GPS timekeeping

All in one product

“I don't want two technologies” (Person with dementia - focus group)

“I do not want an extra technology to know my way..then I'd prefer something combined” (Person with dementia - focus group).

Important for people living with dementia

Communication

❑ Call a real person who will give them directions

People with dementia stated the need to be able to phone and communicate with a person through the technology. They do not want to talk to a “robot”. If directions are provided by a person it should be simple directions such as “turn left” and “cross the street”. The focus should be on the direction they want to go and not the location where they are now

User-friendly

❑ Adaptable for advancing impairment

People with dementia stressed that what might be considered simple by some could be difficult for others. It is important to also consider the person’s stage of the disease (mild or moderate) and it is recommended to have options available regarding the interface. For example, option a includes the items “phone”, “home-button” and “navigation” whilst option b only includes the “home-button”.

Few actions

“But the most important thing is that you don’t understand many actions, and you often have to look for something, certainly your mobile, or your watch advice is to keep it as easy and simple as possible”
(De Spotter - person with dementia - online discussion)

Visibility and stigma

“if people see you wearing that [surveillance]..they go like “He isn’t doing well you know””
(Person with dementia - focus group)

Person-centred design

“Most products are not conceptualized for people without dementia. Rather they do get their insights from family and professional caregivers. However, from my point of view, I had to work with it or learn how to use it. My spouse did understand it and was able to explain it. But me... as someone with dementia.. has difficulties with operating or understanding the product. With some doubts we bought it anyway.” (Person with dementia- online discussion)

This protocol is based on Vermeer, Y (2020). *Surveillance technology and dementia: empowerment of people living with dementia and family carers*. PhD Thesis, London, University College London.

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