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**Challenges and possibilities in telecare: Realist
evaluation of a Norwegian telecare project**

A PhD thesis by publication

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Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. This thesis is entirely my own work.

Mari S. Berge

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Abstract

This thesis reports from a telecare evaluation in a Norwegian municipality (2012-2016). The project was established to provide domestic results from a hitherto new field in the country to underpin future policy.

This evaluation includes pre- and post-implementation data collection, which has been scarce in telecare. The methodological approach was realist evaluation that seeks to explore how telecare works, for whom, why and in which circumstances – or why it does not work. The research aimed to explore the hypothesis elicited from national policy documents: *‘If telecare is used, then people are enabled to remain safe in their own home for longer’*. Various methods were used to gather data from multiple stakeholders as they have different knowledge about how the implementation developed. The methods in this evaluation included literature reviews, observations, and sequential interviews with users and relatives in addition to sequential focus groups with frontline staff.

Realist evaluation was particularly suitable in demonstrating how and why telecare is useful to some users but not to others. Telecare had to match users’ abilities and needs for them to benefit from it. Telecare operates in a dynamic context, and therefore requires adjustment according to the user’s current situation, taking into account changes as they occur. This appears to have been often underestimated. Telecare holds a different position from other devices and technologies in people’s everyday life, which also needs to be acknowledged. Correct assessment is significant for users to obtain the intended effect from telecare.

When telecare is correctly adjusted to users, it increases safety, which is essential for enabling older people to remain living at home. Several challenges in establishing telecare projects are identified and alternative ways to understand multi-disciplinary partnerships are suggested. By using realist evaluation the findings are nuanced and point to elements that are significant for achieving the intended outcomes.

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Chapter 1 Introduction

This contextualising paper draws together four papers submitted in this PhD by publication. Together the papers and this document contribute to drawing a coherent picture of challenges, possibilities and gains from implementing telecare in community care services in a Norwegian municipality. I use the concept telecare in this study, as defined by Department of Health (UK) (2011, p. 4):

Personal and environmental sensors in the home that enable people to remain safe and independent in their own home for longer. 24 hour monitoring ensures that, should an event occur, the information is acted upon immediately and the most appropriate response put in train.

The expected outcome of telecare implementations is thus increased safety of individuals, enabling them to remain at home. That is also the expected outcome in the governmental documents underpinning this telecare study (Helse- og omsorgsdepartementet, 2011a, 2013). Enabling people to remain at home is a major goal as future demographics require novel thinking; however, there are side effects, which this PhD project demonstrates.

Life expectancy is increasing worldwide while birth rates are decreasing (United Nations, 2013). The simultaneous decrease in birth and fertility rates are an amplifying factor and life expectancy at birth is globally projected to rise from 69 in 2005-2010 to 82 in 2095-2100 (United Nations, 2013). As a result, the shrinking working age population during the next 50 years is expected by Eurostat European Commission (2012) to lead to an increase in social expenditure related to an ageing population. This demographic development additionally includes other significant socio-economic implications. Amongst these is projected considerably more very old people who are estimated to need a greater level of support, while there will be fewer family carers to provide informal unpaid support (Kubitschke, Cullen, & Müller, 2010). Together these factors are widely assumed to affect the ability worldwide to provide health care services, and thus innovative solutions are sought (Kubitschke et al., 2010; United Nations, 2004).

Norway is among the countries that face challenges in future health and care due to the demographic forecasts in age distribution. The recent Norwegian White Paper (Helse- og omsorgsdepartementet, 2013) and its preceding Green Paper (Helse- og omsorgsdepartementet, 2011a) emphasize the need to mitigate these challenges in future policy planning.

The projected demographic change has been a strong driving force for governments to use telecare (Kubitschke et al., 2010) to improve allocation of increasingly limited resources resulting from a growing proportion of older people (European Commission, 2012; Helse- og omsorgsdepartementet, 2013; WHO, 2011). Governments all over Europe have embraced telecare and appear to regard it as an acceptable approach in dealing with the forecast challenges to the health and care systems (Kubitschke et al., 2010). Equally, the Norwegian government is seeking to improve the provision of health and care services by the means of telecare (Helse- og omsorgsdepartementet, 2013). Consequently, telecare evaluations will be important guidance to governments in planning future health and care policy. Unfortunately however, telecare evaluations have shown substantially different results to date (Bowes & McColgan, 2006, 2013; Cartwright, Wade, & Shaw, 2011; Steventon et al., 2013).

The Norwegian policy documents referred to above might be understood as relying on what may be called a traditional view of ageing (Denton & Spencer, 2002). The traditional view of ageing focuses on chronological age and definitions of age-specific topics commonly relate to this view. A different view of ageing is encouraged by Sanderson and Scherbov (2008) who critique the above demographic forecasts based in chronological age. They argue the need to rethink how age is regarded, building on the initial work by Denton and Spencer (2002). They propose measuring and assessing age and ageing by focusing on *remaining life expectancy*, which is years left to live. Sanderson and Scherbov (2008)

advocate that many age specific characteristics will change and have changed: thus a 60-year-old person in 1900 had much lower life expectancy than today, and was then considered quite old. Now 80-year-olds get knee replacements, which were hardly considered some decades ago. The view of age and ageing influences how policy is planned (Hirshbein, 2001). When referring to age-specific changes entirely related to chronological age, a misleading picture of the whole ageing population emerges which, according to Sanderson and Scherbov (2015), biases how future populations are regarded and planned for.

Initially I understood the policy documents to build on a traditional view of ageing. However, in their expectations of using telecare they appear to intend to build on resources held by individuals. This view matches the view of ageing as remaining life expectancy because the changes in health and society that are influencing the ageing population are taken into account. The main difference between the traditional and the prospective ways of regarding age is that the latter recognize that the 'old age threshold' changes over time as life expectancy changes (Sanderson & Scherbov, 2015). Older people will have better health, higher levels of education and better incomes which are resources that might support them in their expectation to remain and age at home, often referred to as 'ageing in place' (European Commission, 2012). Telecare might support their expectations to remain at home by improving safety. I have outlined that telecare might support governmental aims to improve resource allocation and indicated how it might also support individuals in ageing in place. If successful, this would deliver the aims and aspirations of Norwegian health and care policy.

Norwegian health and care policy has aimed to provide care provision in an enabling way during recent decades, shifting from institutional towards home-based care. This shift has been particularly emphasised during the last decade through initiatives aiming to support individuals to remain living at home (Helse- og omsorgsdepartementet, 2006, 2009, 2011a, 2013). This policy covers all ages,

however the demographic perspectives have led to a major emphasis on the ageing population. There has been particular interest concerning benefits from using technology like telecare in health and care services; however, domestic initiatives have been scarce. Therefore, the author and colleagues at Bergen University College established this telecare study in cooperation with the telecare company, Tunstall, and the municipality of Lindås, as I have described in the first publication (paper 1) from this study (Berge, 2016a). Our mutual aim was to provide evaluation results about domestic experiences achieved by implementing telecare as part of the community care service in a medium Norwegian municipality. These results will in turn inform national policy concerning telecare. The governmental approach might be regarded as compatible with the prospective view on ageing as suggested by Sanderson and Scherbov (2015).

Lindås is an average municipality in Norway with approximately 15,000 inhabitants. The municipality is a typical representative for many municipalities in Norway. Its geography covers 475km² and has a coastal location with mountains and fjords criss-crossing the land, causing long distances for road travellers. The inhabitants are scattered; the majority inhabit one larger and a few smaller villages. The community care services work from four locations that cover five districts; two district teams being located in the same building. These districts are adjacent and they merge during weekends and holidays to improve utilization of the resources. The municipality had not used telecare before it was introduced in the project reported here. The telecare devices that are used in this project are described in detail in paper 4 (Berge, 2017) and include home units, smoke detectors, bed occupancy sensors, movement sensors, fall sensors, door sensors, flood sensors, social alarm pendants and pull cords (Table 11, page 75 and Table 12, page 76).

Telecare is a complex social implementation and there are many explanations as to why the uptake has been slow despite several governments' enthusiasm for its

potential influence on future health and social care (Chrysanthaki, Hendy, & Barlow, 2013; Kerbler, 2013; Sanders et al., 2012; Sorell & Draper, 2012). Through experiences from this project and literature, I have illuminated in a published paper how challenges might occur in telecare partnerships and discussed how they might work to facilitate or hamper telecare uptake (Berge, 2016a).

I start here by addressing gaps in current evaluations that occur due to the weaknesses of sensitivity in methodology before demonstrating how new insight emerges from applying realist evaluation. The realist approach requires opening the black box. Realist evaluation provides outcomes that are more usable than are those from previous evaluations. This insight can enable policymakers and practitioners to understand what is causing the differences, why they appear and how to improve the possibilities for making telecare work (Tilley, 2000).

Throughout this contextualising document and the papers that constitute the thesis, I consciously prefer certain terms to others. I use telecare as defined above but recognise that readers need to be aware of the various terms that describe technology in health and care. A number of authors comment on the inconsistency in the terminology in this area (Cartwright et al., 2011; Doughty et al., 2007; Oh, Rizo, Enkin, & Jadad, 2005). The Scandinavian use of the concept 'welfare technology' is particularly challenging, as the concept is vaguely compatible with how academic literature refers to technology in health, care and social services. The concept 'welfare technologies' as described in Norwegian health and care policy documents (Helse- og omsorgsdepartementet, 2011a) includes domestic technologies like coffee machines and robotic vacuum cleaners. It also includes the wide range of assistive technologies like wheelchairs and spectacles; communication technologies like mobile phones and video conferencing systems. The concept includes administrative technologies like computers and software for patient records in addition to technologies for telecare and telehealth. As a result, ambiguity and inconsistency characterize the concepts currently describing

technology in health and care services in Norway. The inconsistency in terms does however occur worldwide in clinical settings as well as in academia (Oh et al., 2005). Researchers and clinicians argue it to be necessary to develop international consistency in terminology to improve future work and research in the area (Martin, Kelly, Kernohan, McCreight, & Nugent, 2008), but this has not so far been achieved. Due to the inconsistency, I have focused on the technologies that occur in the studies discussed, rather than on how they are labelled.

The empirical work reported here was designed to unravel how telecare worked in the various settings. Accepting that telecare proves beneficial to some people in some situations, the questions that needed answering would be to sort out to whom, when and why and explore *what* it is with telecare that works. To illuminate how the telecare programme worked I sought to achieve knowledge from multiple participating stakeholders with various experiences. It is the combination of underlying mechanisms and contexts that generates the outcome patterns that help answer the question ‘why does telecare work (or not work) here?’ The research aim is to understand how telecare actually works to enable people to remain at home. In order to understand that, I asked the following questions, exploring the experiences from users, relatives and staff to uncover their experiences with telecare. Within these questions that have guided the research are embedded the realist tenet of what it is that works for whom in what respect and why (Pawson & Tilley, 1997), even if the questions themselves might only display the tenet partially (Westhorp, 2014).

- How do users experience the influence of telecare in their everyday lives?
- How do relatives experience the influence of telecare in their everyday lives?
- How do staff in community care experience the influence of telecare in their working situations?

According to realist evaluation, the different layers of context influence each other and it is expected that individual contexts might influence the infrastructural context, which leads to understanding effect on society.

Chapter 1 Introduction

- What is the effect of telecare on society?

My background is in nursing, my clinical experience is from being a health visitor, and thus I am trained to look for health-promoting activities. I hold a specific interest in combining technology with health and care to gain improvements that might support the enabling of people in everyday life. My master's thesis concerned telemedicine in the deep-sea fishing fleet. Deep-sea fishermen do not have access to trained health personnel at sea, and are exposed to dangerous situations that too often cause severe accidents. I discussed how telemedicine might enhance safety in emergencies on board vessels operating far from shore, improving the situation for the injured, the captain and the crew on board.

My interest in using technology in health and care increased even more when at Bergen University College we started developing a new postgraduate educational course, cooperating with the engineering department. Paper 1 (Berge, 2016a) explains how this telecare project originated from our work with this new course intended for health care personnel.

This document is organised as follows: Chapter 2 presents my published papers in context. I consider it to be useful for the reader to know the contents of the papers while reading the thesis and therefore I introduce them early on. I will refer to them as the thesis progresses to facilitate understanding how the different pieces fit in with the whole story. The papers give an in-depth discussion of the subjects they address. I tie them together in this chapter with short narratives to explain their contribution to the overall study. Chapter 3 gives an overview of the literature that I have used to elicit the programme theories that have guided the steps in the realist evaluation. In addition, as all the papers are stand-alone publications, they contain literature reviews particularly aimed at the specific topics discussed in the paper. In Chapter 4, I describe and discuss the research design that involves sequential focus groups and interviews using the realist

Chapter 1 Introduction

evaluation approach. Paper 3 (in review) and paper 4 (Berge, 2017) both contain in-depth discussions of methodology. The findings are presented in all publications and Chapter 5 elaborates the findings from the staff perspectives, as this is initially introduced in paper 4. Finally, the implications are discussed in Chapter 6 and conclusions drawn in Chapter 7.

Chapter 2 Papers in Context

The publications from my research are, in a way, evidence of my journey in this study. They document how I have discovered and learned from the many facets emerging in researching telecare. They summarise outcomes from my exploration of the various layers of contexts and the numerous interacting stakeholders that constitute telecare. By choosing some perspectives, I have inevitably considered others in less depth. The perspectives I have pursued have emerged from the particular challenges and possibilities encountered in my particular study. They represent issues I have needed to understand before moving on. The issues appeared significant due to circumstances, stakeholders and actions that took place. I suggest that the papers provide improved coherence to this contextualising document when read in the order that I recommend; however, feel free to read according to your preferences. I present each publication and the abstracts appear in boxes, which also indicate where to read the publication.

Looking back on my research, I can see how it is characterised by discovering several gaps to which I was not able to find adequate answers in the existing literature. In exploring these gaps and using new approaches to understand them, I am now able to understand their important role in telecare. I will argue that these gaps occur due to telecare involving new but ignored aspects that significantly influence its uptake and thus must be considered in all telecare planning and at all levels of uptake. Telecare entails multiple innovations and changes, in providing telecare in health and social services and in including telecare as part of everyday life. In trying to mould telecare into existing ways of cooperation, service provision and daily life, the need for new approaches and knowledge becomes evident. My research has explored new approaches that may improve telecare understanding and in turn develop its acceptance and thus uptake.

Paper 1 Challenges and possibilities in telecare partnerships

Berge, M. S. (2016). How do we understand partnership working: Experiences from a telecare project. *Social Policy & Administration*. doi:10.1111/spol.12273

Telecare appears to be an area of multiple contradictions, shortcomings and ambiguities that were, each in different ways, hampering its uptake. When approaching telecare from a research perspective the question of slow uptake revealed itself to be a core challenge quite early on. Telecare requires new ways of cooperating and several researchers have demonstrated this to be a challenge that has caused slow uptake (Chrysanthaki et al., 2013; Greenhalgh, Procter, Wherton, Sugarhood, & Shaw, 2012; Milligan, Roberts, & Mort, 2011; Sugarhood, Wherton, Procter, Hinder, & Greenhalgh, 2013). However no one has scrutinised the complex social interactions and discussed their influence in partnership functioning. In my first publication from this study (Berge, 2016a), I attempted to understand what characterised telecare partnerships and what were their shortcomings. I used empirical data from establishing the partnership and built my understanding by alternating between theoretical and empirical data to explore this telecare partnership in particular and similar partnerships in general. Telecare partnerships are characterised by depending on disparate partners holding and contributing complementary resources, knowledge and skills that affect all involved in pursuing a mutual goal. These required dissimilarities cause challenges due to the holding of disparate cultures (Barth, 1966, 2007; Schein, 2010). Ideally the partners should relate to a mutual culture in progress but the culture in which they originate is highly influential and might prevail, if not compatible with the shared culture (Riggs, Block, Warr, & Gibbs, 2013). The originating culture holds values that direct partners' actions and choices and thus rational choices might be perceived opportunistic when the benefits to the partnership of a particular action are not evident to other partners (Greenhalgh et al., 2012; Parkhe, 1998). In this way, trust is threatened and challenges cooperation (Ansell & Gash, 2007; Mohr & Spekman, 1994). Understanding what hampers telecare partnerships may

influence future partnership cooperation. There is a growing interest concerning telecare and several governments regard it as an approach to improve future health and care provision (Department of Health (UK), 2011; Martin et al., 2008; Willems, Spreeuwenberg, van der Heide, & de Witte, 2012). Understanding the challenges in telecare partnerships is an important key to improving uptake.

Paper 1

Berge, M. S. (2016a). How do we understand partnership working: Experiences from a telecare project. *Social Policy & Administration*. doi:10.1111/spol.12273

Abstract

Implementing telecare requires experience and knowledge from different disciplines and sectors; business, technology and care. The uptake of telecare has been slow, which is assumed to be caused by difficulties in cooperation within telecare partnerships. This paper presents a new approach to improve understanding of telecare partnerships. The approach builds on theories of trust and partnership working and is informed by rational choice theory.

Within this paper the approach is applied to recent experiences from a telecare project in Norway, to demonstrate how different ways of interpreting the complex social interactions in telecare partnerships yield new insight and understanding. Examples from the Norwegian project illustrate how different understandings of actions and choices affected trust and caused either improved or deteriorated cooperation in the partnership. The partners that were able to develop trust through a common evaluation of the problems, cooperated better. However, when partners lacked or had insufficient knowledge, either of each other or of the situation, this led to disparate understandings that threatened trust and affected further cooperation. The new approach presented here is helpful in analyzing and understanding the actions of different partners within a telecare partnership and identifying why things worked well or went wrong. The approach may have wider relevance for other partnerships.

This paper is published in *Social Policy & Administration*, which is a well-regarded journal with a good impact factor. Publishing in this journal provided an

opportunity to reach a wider audience than the specialist telecare audience. The strength of this paper is that it takes a novel perspective in understanding cooperation in telecare partnership. The understanding that arose from this paper laid the ground for choosing the realist approach in further researching telecare. At this stage, the perspective was not fully developed and the development that followed the paper is done in the thesis. The perspective that I took, continues to be novel as recent literature has not addressed similar issues.

Paper 2 Challenges in understanding telecare acceptance

Berge, M. S. (2016). Telecare acceptance as sticky entrapment: A realist review. *Gerontechnology*, 15(2), 98-108. doi:10.4017/gt.2016.15.2.023.00

After having experienced the challenges of establishing the telecare partnership, I next immersed myself in another possible reason for slow uptake: understanding what influences older people's acceptance of telecare (Bouwhuis, Meesters, & Sponselee, 2012; K. Chen & Chan, 2011; Peek et al., 2014; Van Hoof, Kort, Rutten, & Duijnste, 2011). My question developed while trying to understand telecare acceptance by reviewing the literature presenting common approaches to understanding telecare acceptance. I realised there were numerous shortcomings in the presented approaches as several authors have highlighted. Despite some authors trying to modify existing models there were, in my opinion, significant areas still lacking. To be able to assess existing models in relation to telecare I needed to document their shortcomings in telecare acceptance. Thereafter I had to identify the areas that needed attention and recognise how to improve usable assessment models.

I have used realist evaluation in my research and aimed to apply the principles from realism throughout. Context plays a vital role in realism, and acknowledging context is vital in my further pursuit of telecare acceptance, and thus supports my decision not to use standard literature review approaches that omitted context. Context is considered vital by several authors that do not use a realist approach (K. Chen & Chan, 2011; Koivisto, Anttila, Ikonen, & Reiman-Möttönen, 2010; Tsai, 2014). I used a realist review that highlighted the influence of mechanisms and used iterative searches to explore various models used in assessing telecare acceptance. I identified shortcomings in existing models and aspects that needed special focus when assessing telecare acceptance with older people. The main model currently used is Technology Acceptance Model (TAM) and to some extent, also Health Technology Assessment (HTA): both have several shortcomings (Bouwhuis et al., 2012; K. Chen & Chan, 2011; Koivisto et al., 2010; Tsai, 2014). The purpose of developing these models was to assess technology acceptance in working settings (Davis, 1989; WHO, 2015) and not telecare at home, thus shortcomings should be expected. In my literature review, I identified several aspects that need attention in telecare acceptance including complexity, context, interactions between technology and user, and anxieties about using technology. Several other authors also argue for the importance of addressing these aspects in assessing telecare acceptance (Bouwhuis et al., 2012; K. Chen & Chan, 2011; Koivisto et al., 2010; Peek et al., 2014; Tsai, 2014).

My next step then was to investigate possible approaches that addressed these issues. Telecare includes several social aspects that call for a sociological perspective to be taken (Martin et al., 2008). Actor-Network Theory (ANT) has been tried with some success (Ballantyne, 2015) and I perceived it to supersede previously assessed models. However, I considered it to have some key limitations compared with entanglement theory (Hodder, 2011, 2014). By applying entanglement theory to three different cases drawn from literature (Bouwhuis et al., 2012; Bowes, Dawson, & McCabe, 2014; Breivik, 2014; Steele, Lo, Secombe, &

Wong, 2009), I demonstrate how important areas emerge and suggest how to improve their understanding.

I chose the journal *Gerontechnology* because it had previously published papers debating the challenge of assessing telecare acceptance, thus my paper contributes to this debate. The strength of this paper is in how it identifies shortcomings in existing models and demonstrates how to capture these limitations using a novel approach, with examples from the literature. Repeating the search, using Web of Science and Scopus years 2015-2017, resulted in no new relevant papers except mine within this particular focus. There are a few papers discussing *related* topics, however emphasizing staff perspective, focusing on telehealth or taking a different approach than the one I raise about telecare acceptance. I take a novel

In this paper, I am opening up a new avenue, which will remain exploratory and tentative until being validated by others. Other researchers have regarded this approach interesting and cited the paper (Peek et al., 2017; Stokke, 2017).

Paper 2

Berge, M. S. (2016b). Telecare acceptance as sticky entrapment: A realist review. *Gerontechnology*, 15(2), 98-108. doi:10.4017/gt.2016.15.2.023.00

Abstract

Introduction: Telecare is important in future governmental health and social plans. Telecare acceptance is one of the factors that appears to be vital for uptake and thus important to understand. Different *technology* acceptance models have been applied but judged to be insufficient in assessing *telecare* acceptance with older people. The purpose of this paper is to review and evaluate why the existing technology acceptance models fall short when applied to telecare and propose an improved approach for assessing telecare acceptance.

Methods: This is a realist review with iterative searches. Four search engines covering approximately 50 databases in health, social science and technology were used in each of the three stepwise searches. The searches started wide, funnelling down to pursue the interesting results that emerged. According to the realist approach, particular focus has been on context, and transparency is applied by explicitly documenting the reasons for decisions to enable readers to make their own judgments.

Results and Discussion: This literature review provides evidence for the shortcomings of the existing *technology* acceptance models when used for assessing *telecare* acceptance. By applying entanglement theory on issues where *technology* assessment models have been shown to be inadequate, new perspectives emerge. These perspectives are significant for users' acceptance of *telecare*, but are not highlighted when using *technology* acceptance models. These perspectives include dealing with imagined situations, fear of not handling technology, the significance of contexts, and users' adjustments of technology to better suit their needs. The identification of these dependences and dependencies appear to be essential for assessing telecare acceptance, and were not previously captured by *technology* acceptance models.

Paper 3 (*in review*) Possibilities in using a realist approach

In review in *Evaluation: 'Opening the 'black box' in telecare: using Realist Evaluation methodology'*

Telecare implementation is a complex social intervention (Martin et al., 2008) and thus has been suggested to be challenging to evaluate (Richards & Hallberg, 2015). I have already demonstrated that telecare includes numerous perspectives, and that results from previous telecare evaluations vary substantially (Cartwright et al., 2011) (Chrysanthaki et al., 2013; Steventon et al., 2013). This intrigued and inspired me because I realised that the perspective of the evaluation would be significant. I tried to adjust various evaluations from health care interventions to capture the variety in telecare (P. Craig et al., 2008; Øvretveit, 1998), however without sufficient success. Being a complex social intervention, telecare included

numerous interacting stakeholders working in different contexts causing the situation to appear chaotic and ambiguous. When I came across realist evaluation, I remember getting the 'yes-feeling'. The tenet 'What works for whom in what circumstances – or not' (Pawson & Tilley, 1997), promised an approach that looked at several perspectives, anticipating outcomes with various degrees of success. This appeared to be a solution to my searches for methodology as negative outcomes from an implementation would add valuable knowledge for further refinement of a telecare service, and thus I explored the realist approach. I soon realised that the overall idea of realism was attractive, but that it was hard to get to grips with the methodology. This appeared, however, to be how many newcomers to the methodology experienced it, as I soon learned from on-line interest groups that I joined, from workshops and conferences that I attended, and from discussions with fellow students. Socialising myself in 'the realist society' was immensely useful, as discussing ideas and understanding was helpful to improve my understanding. Compared to other evaluation methodologies, this was a new methodology and one previously never applied to telecare. Using realist evaluation includes accepting that partial knowledge and uncertainty is inevitable as there is no decisive data, according to Pawson (2013) who emphasises that partial knowledge is important as it adds to the body of knowledge.

In my third manuscript, I describe how I used the structured approach in realism (Pawson, 2013) to untangle the complexity in the telecare implementation study. The structured approach enabled visualising numerous interacting stakeholders in different contexts in a lucid way. Telecare may give various outcomes and the paper aims to demonstrate how realism is a powerful way to illuminate the reasons for the various outcomes. Realist evaluation enables highlighting interactions between different layers of contexts, from the individual and interpersonal to the institutional and infrastructural contexts. In this paper, I demonstrate how stakeholders reason differently about telecare due to differences in context and how this influences their expectations of the outcome. Reading this paper enhances understanding of the many facets in telecare, how

realism illuminates this diversity and the coherences in which they interact. It also explains why controlled evaluation designs such as RCTs cannot identify significant coherences that need to be identified in telecare.

Several articles concerning realist evaluation has been published by *Evaluation*. This journal publishes refereed papers and focuses particularly on approaches that serve to bridge theory and practice. Several papers in *Evaluation* are part of my knowledge base in realism (Manzano-Santaella, 2011; Manzano, 2016; Marchal, van Belle, van Olmen, Hoérée, & Kegels, 2012; Pawson & Manzano-Santaella, 2012). I aimed to contribute to the discussion by introducing a new and important area, telecare. This paper, currently still in review, would be improved with a clearer demonstration of how the demi-regularities emerge from the clustering of the CMOs from all the participants to better illustrate the programme theories. An illustration similar to the ones used in paper 4 will provide additional improvement to this issue.

Evaluation publishes articles concerning evaluation in various disciplines. They have hitherto not published articles referring to realist evaluation of telecare; however, a recent article discusses an approach with resemblances to the views I advocate in paper 3 and also in paper 2 (Gomersall et al., 2017).

Paper 3

In review in *Evaluation*: 'Opening the 'black box' in telecare: using Realist Evaluation methodology'

Abstract

Telecare is a proposed solution in health and care services to meet future demographic challenges, and so evaluations are important in informing future policy. Results from published evaluations in telecare vary substantially and are thus far of little help to policy makers. There is a need to open the 'black box' of these evaluations in a way that approaches such as randomised controlled trials cannot do. Realist evaluation offers an alternative approach. This paper

illuminates the importance of understanding *how* and *why* telecare causes change and *who* the various stakeholders are, by using findings from a realist evaluation in Norway. The structured approach offered in realist evaluation helps to visualise the numerous interacting elements in this complex social intervention. The paper demonstrates how contexts influence stakeholders' reasoning about possible gains from telecare and sheds light on the complexity of successful telecare implementation.

Paper 4 A realist evaluation of telecare for vulnerable people

Berge, M. S. (2017). Telecare - where, when, why and for whom does it work? A realist evaluation of a Norwegian project. *Journal of Rehabilitation and Assistive Technologies Engineering*, 4(0), 1-10. doi: 10.1177/2055668317693737

This paper is my third accepted publication, which was written to succeed the above paper as it reports outcomes from putting realist evaluation into action in evaluating telecare. The paper refers to outcomes from telecare implementations and provides evidence from post-implementation research on telecare acceptance by home-dwelling older people. According to Peek et al. (2014) this area has been scarcely researched and thus they call for evaluation of cases where older people have experienced the technology in question. Experiences from Denmark indicated that older people liked technology better when it was not abstract to them (KMD Analyse, 2011a).

I used sequential interviews in this realist evaluation to illuminate people's expectations of using telecare (before having it), their early experiences and those after using it for almost one year. The outcomes are highly dependent on the contexts and on individual reasoning about how they might benefit from telecare. I argue that these results are not achievable by methodologies that are more rigid. Previous evaluations are typically based on interviews with older people and /or

relatives where they are given explanations of the technology and how it is *supposed* to work (Mehrabian et al., 2015; Steele et al., 2009). Mehrabian et al. (2015) included persons with Alzheimer's Disease and people with mild dementia in their study, and explained the devices before interviewing them. This calls for people to imagine how they would use and benefit from technology. My approach reveals how people change their minds in different ways: some were anxious about using telecare, but experienced it to be beneficial, while others expected it to provide benefits whilst did not accept the interference it brought. These aspects cannot be researched unless the participants have experienced telecare. Many users were satisfied and felt safer due to telecare that worked well. However, the cases that provided the most information were those that experienced some sort of mismatch from the expected outcome. This links with the social approach to technology (Callon & Latour, 1981; Hodder, 2012; Latour, 1992, 2005; Law, 1992) which argues that human and things shape each other independently in the process, as I discuss in paper 2.

One outcome that this paper highlights is the differences between users and their relatives. The users perceive more to be at stake than do their relatives, and thus endure more side effects from telecare than their relatives do. This paper refers to differences in expectations of and experiences from using telecare and to a diversity of outcomes. I have showed how this understanding is achieved by using realist evaluation.

This journal was chosen because it was a special issue that fitted well with my work and the timing was good. I have discussed the significance of cooperation between various disciplines in telecare in paper 1 (Berge, 2016a). Submitting in this special issue gave the opportunity to reach a wider and new audience as the readership of this journal usually includes engineers. Being able to present findings from the human perspective regarding how and why telecare works is important knowledge for all working with telecare. The strength of this paper is that it compares data

from pre- and post-implementation of telecare, shows how attitudes change over time and highlights what influences these changes, that is, the role of contexts. Literature questions the usefulness of RCTs and asks for alternative evaluations of telecare. More details in displaying the CMO configuration would have increased the transparency; however, the word limitation in this issue was not optimal when reporting a realist evaluation of telecare.

Technology in health and care is a broad field, with a variety of stakeholders. In this broad perspective realist approaches are now used more frequently, like in telehealth, focusing on self-management for diseases (Vassilev et al., 2015). In assistive technology a realist review is undertaken in assessing how technology support physical and cognitive abilities (Vichitvanichphong, Talaei-Khoei, Kerr, & Ghapanchi, 2014). In telecare as defined in my study, focusing on how telecare enable people to remain safe and independent in their own home for longer, it still has not been used.

Paper 4

Berge, M. S. (2017). Telecare - where, when, why and for whom does it work? A realist evaluation of a Norwegian project. *Journal of Rehabilitation and Assistive Technologies Engineering*, 4(0), 1-10. doi: 10.1177/2055668317693737

Abstract

Introduction: Evaluations of telecare demonstrate disparate results, which are of little help for understanding what the users need from further policy and development. This study aims to provide a more nuanced approach to telecare evaluations.

Methods: Realist evaluation is used to scrutinize what it is about telecare that works for whom, why, how and in which circumstances. Sequential interviews were conducted with telecare users and relatives at pre- and post-implementation stages.

Result: Some users experienced the intended effects from telecare, such as increased feeling of safety, whereas others did not. Various contextual elements

influenced how people reasoned about the resources provided by telecare and affected the individual outcomes.

Discussion: The desire to remain in one's own home appeared to be a major driving force in accepting telecare. Users had surprisingly high tolerance to side effects of telecare, which might indicate that much was at stake. Some users disapproved of having telecare due to contextual reasons; however, readjustments proved successful for some.

Conclusion: This study illuminates how and why telecare works differently in different situations, and thus leads to different outcomes. When telecare is correctly adjusted to match the user's needs, abilities and contexts it enables them to feel safe and remain in their own homes.

The papers that I have presented form a sequence, and thus they are presented in a particular order. The papers refer in depth to various parts of the study and I link them to the appropriate parts in where they provide comprehensive information to the text in the thesis. To make it easier to distinguish which paper discusses different aspects, I additionally refer to the paper's number when referring to them.

Chapter 3 Eliciting the programme theories

This study follows the principles of realist evaluation in which literature reviews are part of the process of eliciting, refining and eventually testing programme theories (Pawson & Tilley, 1997). The purpose of programme theories is to identify and explain how the programme is expected to work (Pawson, 2013) and they guide the evaluator's search for evidence to allow for refining and testing of the programme theories. Realism starts by elucidating the underlying assumptions that the programme intends to achieve by using existing research (Pawson, 2006a). Following the principles of realist evaluation (Pawson & Tilley, 1997) I started by searching for the reasons why the Norwegian government promotes telecare implementation; the hypothesis. The hypothesis is often implicit but needs to be explicitly formulated to demonstrate which change(s) telecare expects to cause (Pawson, 2013). Arising from the hypothesis there might be several programme theories, as I have explained, in paper 3 that is submitted for publication and in paper 4 (Berge, 2017). The review of literature is an iterative process interchanging with empirical data to elicit and refine the programme theories until testing them, following Wallace (1971) '*permanently rotating wheel of science*' as referred in Pawson (2013 pages 87-88) (Figure 1).

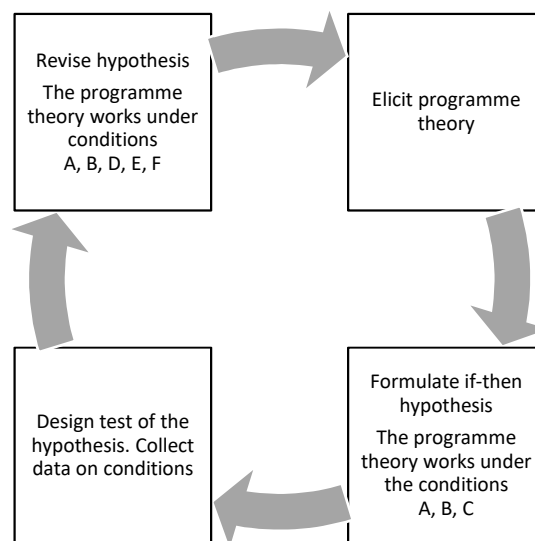


Figure 1 The wheel of science

Pawson (2013) emphasises that all knowledge is partial, but important in adding to the body of knowledge. Reviewing literature aims to explain and according to Pawson (2006a) the basic logic in realism is to provide a comprehensive explanation of the subjects, circumstances, and respects in which a programme theory works and in which it fails. Realism uses the concept of context (C), mechanisms (M) and outcomes (O), constituting the CMO configuration (CMOc) in this process (Pawson & Tilley, 1997). Pawson (2006a) recommends searching literature to find elements that provide explanations for what influenced the outcomes and thus he discards systematic reviews, as I have discussed in my review in paper 2 (Berge, 2016b). Pawson (2006a) encourages looking for ‘nuggets of evidence’ and argues that when focusing on programme theories there is evidence to be drawn from various parts of several studies. There might for example be outcomes from one study, context from another, participant information from the third and so on that all yield valuable knowledge in illuminating CMOc, even if the full study might be of less use (Pawson, 2013). My searches aimed to find pieces of evidence that together make up a whole to elicit elements that make up programme theories as is further discussed in paper 3 (in review). The programme theories are refined, refuted and then tested, which in this study happens empirically.

Eliciting the hypothesis

The policy documents from which this study originates (Helse- og omsorgsdepartementet, 2011a; Teknologirådet, 2009) build on recommendations in research (Bowes & McColgan, 2006, 2009), policy documents from Scotland (Joint Improvement Team, 2008a, 2008b) and reports from Denmark (KMD Analyse, 2011a, 2011b) that suggest that telecare can improve older people’s abilities to remain living in their own homes. I used the Norwegian policy documents as a starting point for strengthening the body of evidence and for exploring reasons to implement telecare in Norway. I drew the following hypothesis from the Norwegian policy documents: *‘If telecare is used, then people are enabled to remain safe in their*

own home for longer'. In exploring the policy documents, I found two main ideas that underpinned the hypothesis. One idea is to improve allocation of limited resources that follow from demographical changes (United Nations, 2013). The other is that remaining safely at home supports independent living and quality of life (Bowes & McColgan, 2006, 2009; Joint Improvement Team, 2008a, 2008b). These ideas guided my initial searches aiming to elicit programme theories.

The initial searches

To improve understanding of the various contexts I searched for literature that could illuminate the influence from contexts on using telecare. I looked closer at the suggested outcomes from using telecare, which included demographics, quality of life, and the impact of living at home vs. moving. Telecare sits across different disciplines and therefore I used search engines that included databases from sociology, health, care and technology. I used the search engines Web of Knowledge (later branded Web of Science), Scopus and ASSIA as they contain relevant peer-reviewed literature of cross-disciplinary topics. The hits in ASSIA coincided with Scopus, which usually had more hits, therefore I continued only with Scopus and Web of Knowledge. I used EndNote to find and remove duplicates. The initial searches used the following terms: telecare, 'home care', technolo*, 'quality of life', implement*, evaluat*, carer, relative*, 'living at home', 'demographic change', surveillance. Subsequently I combined the terms. This study did not include children and thus I limited the searches by using NOT child* OR paediatric*. I used alerts to include new publications.

I conducted the initial searches between January 2013 and February 2014, and limited them to peer-reviewed articles in English. Telecare is new, its use in services is progressing, and therefore I concentrated on recent publications, thus limiting the searches to 2008 and later. I scrutinised the literature references in the included

papers, and pursued relevant publications by using Google Scholar or Web of Knowledge to gain the original literature cited, and consequently included publications even prior to 2008 when relevant. Looking for evidence in one field sometimes yielded 'nuggets of wisdom' that directed me to finding knowledge in new settings, and thus my literature search in addition followed a snowballing approach in finding CMOC. The principle areas identified to elucidate the hypothesis and the programme theories that followed are presented below and include demographics, qualities of home, quality of life and various effects from telecare.

Demographic prospects

As I discussed in the introduction, demographic changes are expected to bring about socio-economic implications. Like the global situation, the Norwegian population is ageing. This ageing population is characterized by being healthier, better educated, having better income than previously, and they prefer to remain independent in own home (Helse- og omsorgsdepartementet, 2013). People in Norway live longer than previously with their diseases (Daatland, Veenstra, Kjellvik, Otnes, & Aksøy, 2012). Research indicates that in the near future older people in Norway will be highly conscious of their rights and more eager to demand what they perceive they need to be able to continue living independently (Slagsvold & Solem, 2005). These changes in Norway are similar to those expected in other western countries (Bishop, 2009; Bowling & Dieppe, 2005; Kassner et al., 2008).

Despite the prospects of a healthier, older population, ageing includes increased risk in developing diseases. Dementia is a major risk and challenge to individuals and to society (Beydoun, Beydoun, & Wang, 2008; Cooper et al., 2012; Ferri et al., 2006; Hendrie, 1998). The worldwide prevalence of dementia will double every 20 years and is expected to reach 81.1 million by 2040 (Ferri et al., 2006). Dementia is a complex condition with many factors influencing the risk for developing it: amongst the known factors are age, ethnicity, gender, genetic factors, lifestyle,

environmental and social factors (Chen et al., 2009, Beydoun et al., 2008). This study does not focus on any age-related disease but expects dementia to be amongst the influencing factors due to its prevalence.

These prospects highly influence future health and care policy. Chan, Campo, Estève, and Fourniols (2009) suggest that the increasing costs in delivering health care services to an ageing population will bring about change, and the delivery of services will change from institutional services to home care services. Homecare services will also need to be carried out in new and innovative ways (Kubitschke et al., 2010; United Nations, 2013). These are all prospects that influenced the Norwegian government in planning for future health and care services in which they consider using telecare (Helse- og omsorgsdepartementet, 2013). Telecare appears to be a potential solution to future health care services from an economic perspective (Milligan et al., 2011).

Qualities of home

Governmental policy emphasises home as an arena to replace institutions, and thus, I searched for possible qualities the home might hold in particular for older people. A main reason to support people to remain living in their own homes is that this is where people in general want to live (Bergland & Slettebø, 2014; Haak, Fänge, Iwarsson, & Dahlin Ivanoff, 2007; Sixsmith et al., 2014). Living at home holds positive effects *per se* on peoples' everyday life (Mahler et al., 2014; Parks, 2015; Sixsmith et al., 2014). Older people perceived that remaining at home enabled them to maintain control, stay active and independent and participate in social life (Sixsmith et al., 2014). G. Craig (2004) found similar findings 10 years before when he demonstrated physical independence to be important and highly valued by older people. G. Craig (2004) found physical independence to be connected to autonomy and to the ability to choose and suggested these aspects to be closely connected, overlapping and interrelating. Feeling independent influences social participation,

which, according to G. Craig's study, was easier to maintain for older people when they remained in their community. Staying in familiar surroundings enabled socially engagement that in turn influenced positively on maintaining identity. Older people referred to being dependent on 'the charity of others' - a demeaning situation that threatened their dignity (G. Craig, 2004). Home is essential in supporting independence and social contact with family and neighbours when people age (Mahler et al., 2014), and it is significant to people's identity by supporting their cognitive capacity as home enables continuing habits and routines that supports memories and sense of self (Parks, 2015). Home also represents identity and continuity in containing memories and history (Young, 1997) which is important for older people's feeling of independence and autonomy (Haak et al., 2007). In addition, peoples' self-perception appears to have a strong bodily dimension that is influenced by objects in their environment (Nagel & Remmers, 2012). The recent researches confirm results from previous studies where older people considered it important to remain living at home because they perceived home to be an integrated part of themselves (Borglin, Edberg, & Rahm Hallberg, 2005; Kassner et al., 2008). Borglin et al. (2005) suggest that the older people in their study continued being active due to remaining at home, as it enabled them to maintain familiar routines.

This is also the finding from the earlier study by Urciuoli, Dello Buono, Padoani, and De Leo (1998) where older home-dwelling people were compared to older people in nursing homes. Those living in their homes continued their level of activity while those admitted into nursing homes reduced theirs. When moving in to nursing homes, the older people adjusted to the routines decided by others, which might be understood as their acceptance of losing autonomy (Urciuoli et al., 1998). This is similar to results from a later study that researched which changes occurred when older people became nursing home patients (Kofod, 2008).

There are thus multiple studies emphasising several positive outcomes for older people from remaining in their own familiar settings. From older people's perspective, research today suggests they want to be able to remain in their own home, stay in control, make decisions, be able to choose and maintain their social life whilst feeling safe.

Perspectives on quality of life in old age

The above studies emphasise the importance of remaining at home, causing outcomes that influence quality of life. Quality of life, especially in older age, might be conceptualised and understood in disparate ways, and the older persons' view can differ substantially from how literature describes it. The World Health Organisation (WHO) defines quality of life to be (Kuyken et al., 1995:1405):

(...) individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

This definition emphasises the person's perceived feeling of quality of life, and avoids standardised measures. The WHO's definition does not depend on absence of disease or disease related disability; furthermore it allows for health and age to influence a person's perceived quality of life. Perceived health is suggested to correlate to successful ageing, however without being an independent factor (Moraes, 2005) and it does also play a significant role in quality of life studies among older people (Borglin et al., 2005; Sarvimäki & Stenbock-Hult, 2000). Health status is often mentioned in connection to being able to cope with everyday challenges and having autonomy (Moraes, 2005; Sarvimäki & Stenbock-Hult, 2000).

The health prospects of the future older generations referred to above might cohere with 'successful ageing' (Rowe & Kahn, 1987, 1997). The highly cited works of Rowe and Kahn define 'successful ageing' as including three main components: low probability of disease and disease-related disability, high cognitive and physical

functional capacity and active engagement in life. The combination of these components and their interrelations are suggested to be essential for a person's successful ageing (Rowe & Kahn, 1987, 1997). Others argue it is difficult to define the concept of 'successful ageing' although there does seem to be widespread agreement that the concept needs to include the three original components presented by Rowe and Kahn (Depp, Vahia, & Jeste, 2010). Different terms conceptualise what appear to be the same subject; quality of life (Borglin et al., 2005; Farquhar, 1995; Sarvimäki & Stenbock-Hult, 2000), psychological well-being (Ryff, 1989), well-being (Sarvimäki & Stenbock-Hult, 2000) and successful ageing (Rowe & Kahn, 1987, 1997). Some authors combine these concepts (Moraes, 2005). The authors belong to different disciplines; nursing (Borglin, Farquhar, Sarvimäki and Stenbock-Hult), psychology (Ryff and Kahn), and medicine (Rowe and Moraes). It could be suggested that different disciplines use different terms to describe the same concept.

Bergland and Slettebø (2014) use the concept 'health capital' in their study of how women aged 90 and older experience and cope with the challenges of everyday life. Their findings suggest that older women's health capital includes positive expectation, reflection and adaptation, function and active contribution, relations and home. These resources were significant in experiencing their daily life as comprehensive, manageable and meaningful. Earlier qualitative studies suggest that older people perceive having quality of life when they feel independent in performing activities of daily life (ADL), when they feel autonomous, and when they are able to maintain relationships with relatives and friends, thus staying socially active (Borglin et al., 2005; Farquhar, 1995). Farquhar (1995) found that the elders she interviewed also included things that were not positive when they described their quality of life, as many thought of themselves as being happy and well even when they were ill or disabled. Older people considered themselves to have aged successfully even where the medically-based classifications would not (Bowling & Dieppe, 2005). Bowling and Dieppe conclude that the criteria for successful ageing are unrealistic for most people and suggest the criteria to represent an ideal.

Another perspective in discussing classifications of quality of life is pointed to by Bearon (1996) who suggests using the indicators of subjective well-being when describing successful ageing. She argues that since the term describes ageing in a continuously changing context, it is likely that older people of today (NB, written 20 years ago) will be in a different situation and thus not similar to older people of tomorrow. This matches how Sanderson and Scherbov (2008) argue the need to rethink how age is regarded, building on the initial work by Denton and Spencer (2002). They propose to consider *remaining life expectancy*, which is years left to live, rather than measuring and assessing age and ageing. Sanderson and Scherbov (2008) advocate that many age-specific characteristics will change and have already changed: a 60-year-old person in 1900 had much lower life expectancy than today, and was thus considered already quite old.

The debate about ageing often appears to ignore modifying factors such as diet, exercise, personal habits and psychosocial factors that influence ageing. Amongst the important psychosocial factors are being autonomous and able to choose, as life feels more predictable to people that are in control themselves (Rowe & Kahn, 1987). When referring to age-specific changes entirely related to chronological age, a misleading picture of the entire ageing population emerges which, according to Sanderson and Scherbov (2015), biases how future populations are regarded and planned for. Yet another pitfall is the widespread tendency to treat older people as a homogeneous group when differences between individuals ought to be emphasised (Farquhar, 1995; Rowe & Kahn, 1987). Treating people as a homogeneous group tends to mask differences (Farquhar, 1995).

As shown, there are different names and measures for what I suggest can be understood as describing quality of life. Because quality of life is multifactorial, measurements are challenging. There are both subjective and objective indicators

and Farquhar (1995) suggests that research participants tend to use their own descriptions and definitions of quality of life.

With regard to quality of life for persons with dementia, there is, according to Cooper et al. (2012), no consensus about any definition. Measuring quality of life for people with dementia is difficult and even if the methods can be sensitive to change, they may still not be sensitive enough to detect the minor changes that are meaningful to a person with dementia (Cooper et al., 2012). Maintaining the ability to execute ADL appears to influence quality of life, as does the ability to learn and to be supported which can have a positive impact, whilst on the other hand being deprived of control causes helplessness (Rowe & Kahn, 1987). Evans, Fear, Means, and Vellelly (2007) found in their study that people with dementia and their relatives valued independence highly. They regarded it as important to be able to make their own decisions without having to rely on others to perceive quality of life.

To conclude, demographic changes will require novel thinking and better use of resources, and using telecare may support better resource allocation due to more people remaining safely at home. Evidence shows that remaining at home is important for older people for them to continue being physically, mentally and socially active. The outcome of remaining in familiar surroundings influences positively how older people perceive themselves to be living a meaningful life using their own resources. In addition, improved utilisation of these resources is significant for society for the benefit of all.

Effects from telecare

Telecare is technology that includes social aspects. I have thoroughly discussed how telecare acceptance needs to be assessed differently from technology acceptance

in paper 2 (Berge, 2016b). Still, people might refer to their experiences of using technology and to prospects of using telecare when reasoning about possible benefits from telecare. To improve understanding of how older people reasoned about telecare, I explored research that discussed their attitudes towards technology, and paid special attention to contextual influences on their reasoning, as context is essential to how the mechanisms work and influence the outcome (Pawson, 2013).

Attitudes towards telecare

Research indicates preconceptions about older people lacking acceptance of technology (Karlsson, 2013; Kerbler, 2013). Some studies used scenarios to explain how telecare works, upon which people gave their opinion (Kerbler, 2013; Steele et al., 2009). Their response consequently depended upon their imagination and how they understood the explanation given, associated to earlier experiences and prior understanding. Karlsson (2013) warns against generalising negative attitudes towards one specific technology to technology in general. When people understand the advantages and disadvantages, they tend to have a more nuanced understanding (Boise et al., 2013). People in general need to experience technology being useful and purposive to have a positive attitude towards it (Karlsson, 2013; Kerbler, 2013). It appears that age *per se* is not a barrier for older people to use technology, however knowledge appears to be essential for acceptance (Cartwright et al., 2011; Kerbler, 2013). Learning to use new devices does not necessarily correlate with age; it is also dependent on mental and physical capacity, social habits and roles (Karlsson, 2013; Lunde, 2012).

Studies demonstrate that older people stop using telecare if they do not perceive it to be beneficial (Peek et al., 2014; Steele et al., 2009). Their acceptance of technology is, however, also influenced by attitudes from people in their surroundings (Karlsson, 2013). This emphasises the importance of the context when

planning for implementing telecare. Karlsson (2013) suggests there is a balance between the perceived usefulness and the effort associated with accessing these benefits that influences the adoption process. Older people use and relate to technology regularly on a daily basis. Some demonstrate being innovative in taking advantage of benefits held by certain technologies, for example in using microwave ovens to avoid forgetting to turn off the stove (Nygård, 2008).

This indicates that older people need to understand how telecare might work for them in their situation and therefore need to experience it before making a decision. Previous experiences from using technology and responses from people in their surroundings influence how older people perceive and relate to telecare. Age *per se* is seldom a reason for people to reject telecare but perceived benefit is a major reason to accept it. These are circumstances that need to be taken into account in exploring the programme theories (Pawson & Tilley, 1997).

Possible benefits from telecare

I have outlined several advantages of remaining at home for older people. However, studies show that they prioritise safety over independence, and risk to safety is the major reason for older people to move into an institutional setting (Fonad, Wahlin, Heikkila, & Emami, 2006). Fear of falling is a key safety issue for older people (Scheffer, Schuurmans, van Dijk, van der Hooft, & de Rooij, 2008). Their precautions when feeling unsafe include decreased activity that can cause severe negative side effects that in turn increase risks (Fletcher & Hirdes, 2004) and cause reduced quality of life (Friedman, Munoz, West, Rubin, & Fried, 2002).

There are multiple studies suggesting that telecare supports independent living and quality of life as it improves safety and thus enables older people to remain living at home (Bowes, 2007; Bowes & McColgan, 2009; Chan et al., 2009; Kubitschke et al.,

2010; Sorell & Draper, 2012). Remaining at home increases their ability to continue living independent physical, cognitive and socially active lives in familiar surroundings (Mahler et al., 2014; Parks, 2015; Sixsmith et al., 2014). Bowes and McColgan (2013) found that people felt independent when they were able to choose, and they perceived being in control having telecare. The users perceived being safer and more in control with telecare than with help from others. They found their day to be more predictable when they did not have to wait for a carer to arrive. A timely question is whether telecare enhances independence or if dependence is shifted from dependence on a carer to dependence on technology. People preferred telecare to being dependent on 'other people's charity' in enhancing independence. It therefore appears that older people prefer dependency on telecare to dependency on 'other people's charity' (Milligan et al., 2011). Relatives also appreciated using telecare to support independence, without necessarily regarding it as *the* solution for all needs to enable ageing in place at home. It was, however, considered to be more acceptable as a means to enhance the ability to remain independent and safe and less acceptable as a means to gather and analyse remote data (Milligan et al., 2011).

Telecare is put forward as a solution to support people to remain at home and to prevent negative side effects from feeling at risk (Cartwright et al., 2011). Some studies also refer to positive outcomes for persons with dementia and their carers (Bowes, 2007; Bowes & McColgan, 2009; Dutton, 2009).

Possible negative effects from telecare

However, telecare might cause negative influences in people's lives. I have discussed how people perceive telecare differently in paper 2 (Berge, 2016b), emphasising the need to assess telecare according to the user's needs and requirements. I discuss in depth how assessing telecare acceptance is different from assessing technology acceptance as it serves a different purpose. To avoid negative

effects from telecare, it needs to be individually adjusted (Chan et al., 2009) and accepted by users (Peek et al., 2014).

Yet another aspect concerns the role held by health care staff in telecare. Implementation needs to be supported by educated health care staff (Willems et al., 2012) an issue which I thoroughly discuss in chapter five. These areas are in need of more research (Peek et al., 2014) as are the gaps in knowledge concerning depersonalisation of care and possible lack of social contact that are raised as issues by several researchers (Chan et al., 2009; Milligan et al., 2011; Mort, Roberts, Pols, Domenech, & Moser, 2015; Sorell & Draper, 2012). I discuss these aspects further in chapter five. There are several questions related to telecare causing surveillance (Essén, 2008; Nagel & Remmers, 2012; Sorell & Draper, 2012). In my study, before trying telecare some users were concerned about being under surveillance, however after experiencing telecare for about five weeks, they argued it was not an issue (Berge, 2017). The same concern applied to staff, who changed their opinion accordingly. There are also some concerns related to telecare influencing financial priorities due to telecare potentially offering less expensive services (Chan et al., 2009; Milligan et al., 2011; Sorell & Draper, 2012; Willems et al., 2012). I discuss how users' acceptance links to and influences financial policy and allocation of resources in health and care in paper 3 (in review).

In my study, the use of realist evaluation allows a wider understanding of how probable negative effects develop and thus how to mitigate them. I therefore discuss negative effects in the context in which they are relevant.

Surveillance, privacy and isolation

Surveillance and lack of privacy are concerns often mentioned in relation to telecare (Boise et al., 2013; Demiris, Hensel, Skubic, & Rantz, 2008; Essén, 2008; Sorell &

Draper, 2012). Some studies find that users are concerned about being monitored (Sorell & Draper, 2012) while others report that people are surprised that the question is raised (Essén, 2008) and other studies demonstrate how older people balance safety with privacy when considering whether they are under surveillance (Demiris et al., 2008). Essén (2008) found that the majority of users in her study perceived electronic care surveillance solutions to be less intrusive than the alternatives, especially when it meant moving to institutional care. However, the context is significant for whether people perceive technology to cause surveillance, as this might be both enabling and restraining (Demiris et al., 2008; Essén, 2008). People appreciated being able to maintain independence which they often regarded to be more important than concerns about privacy (Boise et al., 2013). Remaining at home includes experiencing some aspects of privacy that are lost when moving into institutions, namely being unable to withdraw or find a personal, private space, and to have to witness other patients' problems. Essén (2008) refers to this aspect of privacy as having freedom from observing and reacting to others. This aspect is also emphasised by Sorell and Draper (2012) who suggest that the side-effects of the alternatives are frequently ignored. They argue that routinely institutional care is likely to be more intrusive than telecare.

There are discussions about whether telecare makes people more isolated (Chan et al., 2009; Milligan et al., 2011; Sorell & Draper, 2012) and whether telecare will replace human care (Mort et al., 2015). In West Lothian, they found that people with lesser care needs appeared to benefit more from using telecare than persons in some kind of crisis (Bowes & McColgan, 2009). Sorell and Draper (2012) refer to users and carers in the Scottish telecare program who reported telecare to make them feel less anxious without feeling isolated. They suggest that 'independent living' implies aiming to keep carers out of the users' homes. When people are enabled to live independently by using telecare, it is most likely that they need less assistance from humans. People perceive being more in control when they do not depend on others, as I have also discussed previously in relation to quality of life and in paper 4. This is a highly relevant perspective in the present telecare

discussion and relates to aspects of quality of life and older people's perceptions of their position in life.

Surveillance and social isolation are aspects that contribute to acknowledging that telecare requires individual assessment and adjustment according to needs and abilities. How technology is regarded influences how it is planned for in community care services (Brender, 2006; Hofmann, 2013). Telecare *per se* does not ensure improved services to the service users as there are a variety of different aspects influencing the outcomes (May, Mort, Williams, Mair, & Gask, 2003). Telecare acts in social contexts (Essén, 2008; Rostgård, Remmen, & Christensen, 1990) and depends on other interacting elements in the context as is discussed in the submitted paper 3. These are all elements that have influence when elucidating and refining the programme theory.

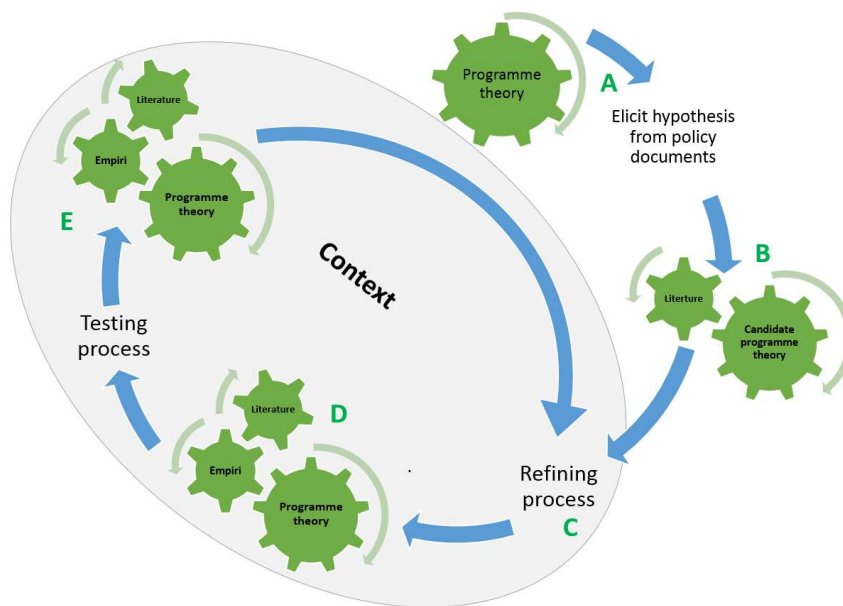


Figure 2 Depicting how I have used the programme theory refining process

The basic logic of this literature review has been to provide a comprehensive explanation of the subject, circumstances and respects in which a programme

theory works and in which it fails (Pawson, 2013) and to elicit candidate programme theories to guide the data collection and analysis. The candidate programme theories will be refined and tested using data from the evaluation in ongoing iterative processes as represented in the wheel of science (Figure 2).

Conclusion

The candidate programme theory served to guide the research. It reads ‘when people have telecare they feel safer and may be able to remain living in their own home for longer’. The candidate programme theory thus guided my initial literature review that in turn guided my data collection from stakeholders. The literature reviews illuminated important aspects within different stakeholders’ contexts that helped generate the programme theories. Entanglement theory supported a comprehensive understanding of the interactions occurring between users, telecare and different contexts and their influence on telecare acceptance. Knowledge about people’s usual preferences and reactions combined with previous results from telecare evaluations helped develop the programme theories. The interview data were also crucial in refining and confirming the programme theories.

Data from the different stakeholders led to several programme theories as discussed in paper 3 (in review), programme theories #1-6 and in chapter 5, programme theories #7-8. These programme theories followed in the wake of the initial programme theory, discussed in paper 4 (Berge, 2017) which originated from the hypothesis I discussed in the beginning of this chapter. Programme theories emerging from the stakeholders generated additional literature searches in an iterative process, doing several rounds in Figure 2. All the programme theories are listed in page 90, and a full discussion of how they emerged is provided at the end of chapter 4.

Chapter 4 Methodology and methods

Several theories have informed my work during this study. To understand the challenges we encountered in partnership working during the initial phases of the project, I started out using rational choice theory as presented by Barth (1966) (2007). This theory did not cover all aspects in the partnership; therefore, I included theories of trust and partnership working (Mohr & Spekman, 1994; Riggs et al., 2013; Sloan & Oliver, 2013). I discuss these theories in-depth in paper 1 (Berge, 2016a).

To develop my understanding of the interactions between telecare (technology) and society I explored Actor-Network Theory (ANT) and especially the works by Law (1992), Latour (2005), Mol (2010) and Callon and Latour (1981). I perceived the ANT approach to be very useful, but not sufficient in understanding and explaining significant interactions between human and nonhuman regarding telecare acceptance. In paper 2 (Berge, 2016b) I discuss how entanglement theory (Hodder, 2012) provides new insights in understanding mutual dependencies and entanglements between human and nonhuman, people and technology.

These theories have improved my understanding of context, in addition to illuminating the significance various elements hold in influencing interactions. Since I have discussed these theories thoroughly in the publications, I will not discuss them further here, but just emphasise that they are a part of the complete study. These theories have developed my thinking and are in accordance with the evaluation approach I use, which is realist evaluation.

In this chapter I discuss realist evaluation (Pawson & Tilley, 1997) which is my methodological approach. I argue how this approach enhances telecare evaluations and how it has enabled me to obtain a nuanced insight into when, why and for

whom telecare works – or not. I discuss the research design and the choice of methods for data collection, which adhere to realism in using multiple sources to gather knowledge from those holding it. Pawson and Tilley (1997) believe that knowledge of how a program works will differ from participant to participant and between researcher and interviewees, and that the ability to achieve the knowledge develops with growing insight. I therefore use sequential interviews and focus groups iteratively with literature searches to refine and eventually test programme theories. I explain how I have organised and analysed the data in order to be able to address the programme theories. My methodical reflections close this chapter. I have discussed realist evaluation in greater depth in my third paper that is in review.

Realist evaluation

Realism sits philosophically between positivism (we can see and understand the real world through direct observation) and constructivism (we interpret reality and cannot know for sure what its nature is). Realism thus agrees that there is a real world, which we interpret through our senses, but argues that we can improve our understandings of it because it is constrained by our interpretation from the knowledge we hold for the time being, and thus change in knowledge influences interpretation (Wong, Westhorp, Pawson, & Greenhalgh, 2013). Realism therefore acknowledges that our human brain will always shape and filter observations and as a result, our knowledge will always be partial and imperfect. There is therefore no such thing as ‘final’ truth or knowledge, as our knowledge can improve over time. Realism claims that both the material and the social worlds are real and can have real effects; and that it is possible to work towards a closer understanding of what causes change (Westhorp, 2014). Realism describes any manifestation of the belief that reality exists independently of observers but that those involved interpret it. Realism acknowledges fallibility, and argues that no programme will work for everyone, as it depends on the context (Pawson & Tilley, 1997). Realism can help understand the social world by acknowledging the existence of the external social

reality and its influence on human behaviour (Pawson, 2013). Realist evaluation allows the illumination of various stakeholders' experiences of implementing social programmes to identify emerging patterns that in turn improve understanding for future planning. Implementing social programmes in existing social settings, for example telecare into health and care services, is a complex intervention, as it produces different outcomes in different contexts (Pawson, Greenhalgh, Harvey, & Walshe, 2005).

Evaluating complex interventions

Implementing telecare in health and social services is described as a complex social intervention that impacts on service users, providers and organisational processes (Martin et al., 2008). The UK Medical Research Council (MRC) (2000) describes complex interventions in health care to involve a number of elements and their interactions that appear to be essential for the intervention to be effective. They do however emphasize that it is difficult to specify *the* active ingredient that causes the intervention to be effective. The MRC produced a framework for developing and evaluating randomized controlled trials (RCT) for complex interventions to improve health- the MRC-framework, which has been highly influential. However, due to some identified limitations, such as the need to acknowledge the impact of contexts, the framework has been revised and is now referred to as the MRC guidance on complex interventions (P. Craig et al., 2008). The MRC guidance no longer demands complete standardization, and it approves, now, of tailoring studies to match local circumstances. It acknowledges that the phases in complex interventions may not follow a linear sequence and that experimental designs are not always practicable. Experimental designs are, however, still preferred to observational designs. In other words, the MRC framework acknowledges that interventions may act differently in different circumstances according to differences in contexts; however, they do still prefer conventional methods of evaluating complex interventions.

In telecare implementations conventional methods, as preferred in the MRC guidance, appear to be unsuitable (Barlow, Singh, Bayer, & Curry, 2007). RCTs' core issue is that they rely on controlling all variables and aim to minimize confounding factors (Øvretveit, 1998). This is what is called a 'black box' evaluation, which is explained by Funnell and Rogers (2011:4) to be:

One that describes an evaluation that analyses what goes in and what comes out without information about how things are processed in between.

A complex social intervention, such as telecare, requires the contextual and intervening factors to be assessed as they influence its success or failure (H.-T. Chen, 1989). Therefore it is necessary to unpack the inner components of the intervention (Astbury & Leeuw, 2010). Unpacking the black box is what is referred to as 'theory-driven' evaluation. According to H. T. Chen (2012, p. 17):

Theory-driven evaluation is sharply different from another type of evaluation, called black-box evaluation. Black-box evaluation mainly assesses whether an intervention has an impact on outcomes.

He adds that black box evaluations do not focus on the 'transformation process' between the intervention and the outcomes.

Realist evaluation uses the notion 'middle-range theory' that originates from Merton (1967) as an explanatory theory that allows understanding of an event as a general case that can be explained in a broader connection (Pawson, 2013). A middle-range theory can be tested with observable data and is not abstract like the grand theories (Jagosh et al., 2015). Middle-range theories position themselves between grand theories and descriptions (Astbury & Leeuw, 2010).

Realist evaluation belongs among the 'theory-driven' evaluations and aims to understand the transformation process (Pawson & Tilley, 1997). The basis for a theory-driven evaluation is the programme theory or theories that guide the direction of the evaluation (Pawson, 2013) and is a systematic configuration of

stakeholders' assumptions about how the programme works (H. T. Chen, 2012). Theory-driven evaluation starts by clarifying the programme theory that describes the outcome that the programme is assumed to cause. Complex interventions involve multiple stakeholders in different positions that hold different ideas about what the intervention might achieve and consequently hold several programme theories (Pawson, 2013). Astbury and Leeuw (2010) cite a range of evaluators emphasizing the importance of investigating the underlying theories when evaluating social programmes and call for opening the black box in evaluation. The nature of telecare implies the need to look inside the black box as I have discussed and demonstrated in my paper 'Opening the black box in telecare: using Realist Evaluation methodology' that is submitted for publication and currently in review.

When implementing telecare in the health services we are, according to Pawson et al. (2005), dealing with complex social interventions that act on complex social systems. Realist evaluation is designed for evaluating social programmes as it recognises that there are many interwoven variables that operate at different levels, or contexts (Pawson, 2013; Pawson & Tilley, 1997) and should be a preferred approach for evaluating complex interventions where traditional evaluations often are less feasible (Westhorp, 2014).

Different telecare implementations will hold different variables and contexts and cause a variety of interactions to happen. This is why I have used the realist approach in this study. Realist evaluation asks not *if* the programme work but 'what is it that works for whom in which context to what extent and why' (Pawson & Tilley, 1997), which is the tenet of realist evaluation. Implementing telecare is implementing a social programme that intends to produce change. It is however not the programme *per se* that produces the changes but the people that are involved in various stages holding different roles (Pawson, 2013).

Realist evaluation is described by Westhorp (2014) as a way of thinking rather than a method. Using realist evaluation is hardly like following a cook book (Punton, Vogel, & Lloyd, 2016) and several researchers have acknowledged it to be challenging to operationalise (Dalkin, Greenhalgh, Jones, Cunningham, & Lhussier, 2015; Jagosh et al., 2014; Pawson & Manzano-Santaella, 2012). When using realist evaluation the researcher needs to be reflective and creative in applying it (Dalkin et al., 2015) which matches Pawson (2013:xii) who advises that '*Methods should be used with thoughtful adaptation rather than mindless replication*'. The approach can be successfully applied using a variety of qualitative and quantitative methods as long as they are appropriate for the issue studied. The choice of methods will shape the specific steps taken in conducting the evaluation (Pawson & Tilley, 2004). Realist evaluations always encompass three broad stages: *developing theory, testing theory, and refining theory* (Pawson & Tilley, 1997).

Realist evaluation is theory-driven

All interventions are rooted in a hypothesis to bring about a particular outcome; if we do X, then Y will happen. The hypothesis might be imported as for example the evaluation conducted by Manzano-Santaella (2011) in which she evaluated the hypothesis imported from a Scandinavian programme (fines reduce delays in hospitals) implemented in England. The hypothesis 'If hospitals (in England) use discharge fines as a financial incentive, then delays in discharge of patients are reduced'. The theory-driven realist evaluation implies that the evaluation starts with the underlying theory or theories of the changes that the implementation is expected to cause (Pawson, 2013). Manzano-Santaella (2011) used a broad and crude preliminary theory to highlight the anticipated changes, namely, 'fines reduce delays'. The programme theory was refined, through the evaluation process and led to a theory on how fines operate locally in practice. Theory dominates evaluation from its initial planning and may be traced from the heads of policy architects

through the hands of practitioners into the minds of programme subjects (Pawson et al., 2005).

A theory-driven evaluation focuses upon the causal mechanisms and the contextual factors that cause change in addition to focusing on the implementation of the intervention and its effectiveness (Marchal et al., 2012; Pawson, Greenhalgh, Harvey, & Walshe, 2004). Realist approaches assume that nothing works everywhere for everyone because context makes decisive differences to programme outcomes. The purpose of a realist evaluation is to assess why and how an intervention works, not only whether or not it works (Pawson & Tilley, 1997) and it takes barriers and facilitators in the local circumstances into consideration (Manzano-Santaella, 2011). Stakeholders inhabit different contexts and are likely to perceive the intervention differently, and thus there might exist multiple ideas how the intervention is expected to work. Therefore, there might be multiple programme theories as I have demonstrated and discussed in paper 3 (in review). The programme theories are useful in evaluation because they are transferrable while the programme is not.

The CMO configurations

Context (C), Mechanisms (M) and Outcomes (O) are key concepts that make up the CMO configuration (CMOc) that explains the if-then hypothesis and thus the programme theories. A *programme theory* will be applicable in different situations without the *theory* needing to be changed as demonstrated in the ‘fines reduce delays’ (Manzano-Santaella, 2011) where the programme theory is imported. The variables in action will influence the outcome of the programme, while the *intentions* of the implementation, the programme theory, may still be the same. The CMOc in hospital fines hypothesis (Manzano-Santaella, 2011) can be ‘If hospital

in England (C) use discharge fines as a financial incentive (M), then delays in discharge of patients are reduced'(O). Pawson (2013:22) explains:

'A CMOC is a hypothesis that the programme works (O) because of the action of some underlying mechanisms (M) which only comes into operation in particular contexts (C). If the right processes operate in the right conditions then the programme will prevail'.

CMO is a testable proposition that seeks to explain how the same programme resource is interpreted and acted upon differently by different participants in different positions (Pawson, 2013). From this follows the need to identify the programme theories for them to guide the evaluation (Funnell & Rogers, 2011).

There are always multiple mechanisms because different stakeholders have various ideas within the programme. These create different resources that activate different responses amongst the participants. Likewise there will always be multiple contexts because there will be a variety of different individual circumstances and conditions that form the action of the various mechanisms. There will also be multiple outcomes which will show the success and failure of a programme in relation to the underlying causal dynamics (Pawson, 2013), as I have discussed in paper 3 (in review).

Mechanisms, middle-range theories and demi-regularities

Mechanism is an accepted concept in evaluation research and refers to what causes the changes in the black box (Astbury & Leeuw, 2010). Mechanisms have an explanatory power and are defined as '*... underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest*' (Astbury & Leeuw, 2010:368). Mechanisms are the crucial linkage between cause and effect that provides a deeper understanding of why changes occur (Tilley, 2000). The participants that inhabit the programme make it work through their reasoning

about the resources provided in the programme (Pawson & Tilley, 1997), thus mechanisms include the resources and the reasoning. Because mechanisms operate differently in different contexts, changing the context (C) might trigger the 'right' mechanism (M) to give the desired outcome (O).

When the same mechanisms are operating in different contexts, the same middle-range theory can explain why certain outcome patterns occur ($C+M=O$), so-called demi-regularities (Pawson & Tilley, 1997). Jagosh et al. (2014) define demi-regularity in realist evaluation being '*semi-predictable patterns of program functioning*' and refer to Lawson's explanation of how human choice is partly predictable because of variations caused by differences in context. Middle-range theories explain how the context influences the mechanisms causing demi-regularities (Pawson, 2013). Mechanisms are often portable which means that they can be transferred to different contexts, and allow the outcomes to be compared. By using realist evaluation, the aim is to recognise patterns (CMOc) that can provide causal explanations for disparate outcomes from telecare.

Realist evaluation acknowledges that intervention programmes and policy changes do not work for everyone because people and contexts differ (Pawson, 2013; Pawson et al., 2005). Therefore, the same intervention should be expected to work differently when applied in different contexts or circumstances and by other implementers because different mechanisms have impacts on the different outcomes in the different contexts (Tilley, 2000). Social programmes have several components delivered in uncontrolled social settings in addition to their outcomes being dependent not only on the responses of the intended recipients but also on those implementing the programmes. The intervention *per se* is not making a complex intervention work (Pawson & Tilley, 1997). It is the people involved with their reactions to the intervention that make the real difference (Hewitt, Sims, & Harris, 2012). The advantage of realist evaluation is for research to discover what works for whom in what circumstances and in what respects and how (Pawson &

Tilley, 1997). Consequently this approach might provide a more usable and nuanced answer than using the simpler question 'does it work' as it makes it possible to distinguish between how different effects are caused by mechanisms and contexts (Pawson, 2013).

Evidence from success and failure

Opening the black box to explore what it is about telecare that makes it work, for whom, in what circumstance and why, it is equally interesting to look for what does *not* work (Pawson & Tilley, 1997). There is an overall tendency in research to avoid reporting on negative results and failures due to various reasons and consequently important knowledge is withheld from yielding evidence (Fanelli, 2011). In realist evaluation negative results and failures are as important as success when collecting evidence to explain why programmes succeed or fail overall (Pawson & Tilley, 1997). In telecare evaluation, different outcomes will provide a broader understanding of how to design future implementations. Testing the programme theories needs evidence from the different layers of context and from the stakeholders who are involved in aiming to identify mechanisms. H.-T. Chen (1989) argues that the worth of a social programme is difficult to judge without having information on the contextual and/or intervening factors, which help to make a program a success or failure. This leads back to the recommendations from the MRC guidelines and to the Whole System Demonstrator (WSD) where researchers use RCT, conclude that telecare does not work as intended (Chrysanthaki et al., 2013; Steventon et al., 2013) and question the usability of the RCT approach in complex social implementations (Hendy et al., 2012; Sanders et al., 2012). This is thoroughly discussed in paper 3 (in review).

Research design and data collection

This research follows the philosophy of realism that sits between positivism and constructivism, believing that the real world exists but that humans interpret it, and therefore knowledge plays a role in how the real world is understood. I build knowledge by iterating between literature studies and empirical data collection to test the hypothesis and understand how different programme theories emerge to be tested dependent on their contexts. Realist evaluation aims to build on multiple sources to acquire valid and reliable answers but according to Pawson (2013) all sciences have limited reliability, validity and generalisability as outcomes are dependent on different mechanisms in different contexts.

Pawson and Tilley (1997) advise evaluators to be attentive to the processes operating in different layers of context and the causal powers originating from reasoning and resources. The evaluators must aim to explore to what extent programme theory applies. Pawson and Tilley heavily emphasize this vital message (1997:159):

...the researcher's theory is the subject matter of the interview and the interviewee is there to confirm or falsify and, above all, to refine the theory.

The evaluators need to use the programme theories actively in aiming to refine them, as they constitute the units of analysis. The programme theory is the subject matter of the interviewer and therefore the researcher should ask the interviewees about *their* programme theories. Thus, in realist evaluation, the researcher is expected to abandon the neutral position (Kvale & Brinkmann, 2009) to engage with the interviewee and interact in a dynamic teacher-learner cycle (Pawson, 1996). Pawson and Tilley (2004) argue that the interviewee is there to respond to what the researcher needs to be able to test the programme theory. Different stakeholders hold different knowledge, and so it is essential to build on multiple sources to acquire valid and reliable answers, in testing the programme theories (Pawson, 2013). Creswell (2009) suggests incorporating validity strategies in the data collection by using multiple data sources such as; interviews, focus groups,

observation, and statistics. The evaluator needs to explore whether the ideas and assumptions underlying the intervention actually work. In other words, whether the programme does what it is supposed to do, and how it applies to the interviewees' experiences. The most common data collection strategies in realist evaluation tend to be qualitative interviews often in combination with other qualitative methods (Manzano, 2016).

Realist evaluation gives the opportunity to improve programmes by distinguishing between situations with effective or ineffective implementation (Pawson, 2013). It assumes that knowledge is a social and historical product, thus the social and political context, as well as theoretical mechanisms, need consideration in analysis of programme or policy effectiveness (Manzano-Santaella, 2011). Realist evaluation acknowledges a variety of methods as they will provide different kinds of data. Data diversity allows different things to be seen from different perspectives (Pawson & Tilley, 1997).

In my study, I have elicited the hypothesis: *'If telecare is used, then people are enabled to remain safe in their own home for longer'*. The hypothesis was the starting point for developing the programme theory that I have refined from empirical data and literature. The candidate programme theory *'When people have telecare, they feel safer and may be able to remain in their home for longer'* informed my data collection and drove the sampling choices (Emmel, 2013) together with the programme theories indicated at the end of chapter three.

Overview of my design

The research had several elements; focus groups with frontline staff (sequential and stand-alone), sequential interviews with users and relatives, observations from meetings and data from correspondence, as described in my papers. Table 1 (page

60) shows the timing of the different steps in the research process. In order to understand the experience of users and relatives I interviewed them at pre- and post-implementation stages; in total 45 interviews with 17 users (Table 11, page 75) and 10 with 6 relatives (Table 12, page 76). I conducted four focus groups with frontline staff at each of pre- and post-implementation stages (total 8) (Table 3, page 65), and an additional three focus groups with staff in special units at post-implementation stage (Table 10, page 69). These included the night patrol (NP), the provider-purchaser office (PPO) and the resource group (RG). In total, I conducted 11 focus groups.

The users, relatives and staff have different experiences that help to answer the research questions:

- How do users experience the influence of telecare in their everyday lives?
- How do relatives experience the influence of telecare in their everyday lives?
- How do staff in community care experience the influence of telecare in their working situation?

In turn, the experiences from the individuals influence other layers of context and have impact on the society as I have discussed in paper 3 (in review):

- What is the effect of telecare on society?

Table 1 Overview over the data collection

	Year 1												Year 2												Year 3												Year 4		
	Aug-12	Sept-12	Oct-12	Nov-12	Dec-12	Jan-13	Feb-13	Mar-13	Apr-13	May-13	Jun-13	Jul-13	Aug-13	Sep-13	Oct-13	Nov-13	Dec-13	Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14	Jan-15	Feb-15	Mar-15	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15
UI-1																																							
UI-2																																							
UI-3																																							
RI-1																																							
RI-2																																							
FG-1																																							
FG-2																																							
FG-oth																																							
RG-obs																																							
P-obs																																							
P-corr																																							
Months	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39
	UI-1	User interview #1								RI-1	Relative interview #								FG-1	Focus group #1									RG-obs	Resource group observations									
	UI-2	User interview #2								RI-2	Relative interview #								FG-2	Focus group #2									P-obs	Partner meeting observations									
	UI-3	User interview #3																	FG-oth	Focus group others									P-corr	Partner correspondation									

People with dementia

People with dementia were included in the research and in addition to the ethical approval, we sought advice from the chief county medical officer. Some of the respondents had reduced capacity to consent but were nevertheless included in the research. Of the three people concerned, one had a diagnosis of dementia and two had significant cognitive impairment, which was indicated by the staff members referring them. Even if the participants had cognitive capacity to give informed consent by the time of the first interview, their cognitive condition at the future third interview, about 10 months later, was unpredictable. The local project coordinator, the assessment team and the relatives cooperated closely in the recruiting process. Including people with dementia implied paying extra care to how I explained and repeated information to ensure their understanding (McKillop & Wilkinson, 2004). I attempted to use simple explanations and simply asked them to tell me about their everyday life. I repeated the information as often as required. I did not focus on nor ask about telecare when the persons themselves did not bring up that issue.

Anonymity

All participants in the study are anonymous. I requested the participants in the focus groups to exercise confidentiality about what appeared in the group. I used no names in the recordings and transcripts, only the identifier codes. The identifier key is kept separated from the data, in a password protected encrypted file. The recordings and transcript files are stored in a password-protected computer. All participants in interviews have an alias, and the participants in focus groups have a number to identify user and focus group.

Data management

All interviews and focus groups were audio taped using an iPad with RecorderPlus. In the focus groups, I additionally used a laptop with the software Audacity to ensure sufficient range for the recording. It was very helpful to use two devices, as there was often noise and disturbing sounds (laughter, coughs, etc.) in the focus group settings and thus a muffled voice in one device often appeared clear in the other. I transcribed all the recordings myself and therefore achieved a thorough knowledge of the material. The data collection covering the observations and the correspondence are referred to and discussed in paper 1. The data collection include email correspondence and field notes from 25 meetings between the partners during the first 18 months of the project, and field notes from additional 6 observations of meetings with the resource group (Table 1). I transcribed and coded all field notes in an iterative open coding process as elaborated in paper 1 (Berge, 2016a).

Focus groups

The initial focus group aimed to learn about the frontline staff context and their expectations and attitudes to using telecare, using realist concepts, to elicit their programme theories before they started using telecare.

The same two moderators participated in all focus groups. I was the moderator and thus responsible for facilitating the conversation. One of my Norwegian supervisors acted as the co-moderator, took notes to record the order in which the participants spoke, noting relevant body language and things happening that influenced the interview in other ways, such as whose mobile rang, who left the room etc. These notes were very helpful in the transcribing process and enabled me to link the voices to their identifiers (numbers). The two moderators had a brief discussion following each focus group as a summing-up.

The settings were quite similar in all focus groups. We sat at a table in a relatively quiet room at their workplace. Since most staff were on duty, some had to leave intermittently to follow-up on various tasks that needed attention. Each participant had a sign in front of them with their name on the side facing the participants, and the rules for the group facing themselves (appendix I). An overview over the focus group meeting dates are provided in Table 2.

Focus groups are useful when it comes to producing data concerning interpretation, collaboration and norms within social groups. The social interaction within the group is a source of the data (Halkier, 2002; Robson, 2011). Focus groups produce concentrated data concerning a specific phenomenon or topic and are usually less intrusive than field work or participatory observation (Krueger & Casey, 2015). When conducted correctly, focus groups may provide focus and depth (Halkier, 2002) and have the potential to uncover viewpoints that are otherwise difficult to access (Elwyn, Greenhalgh, & Macfarlane, 2001). To obtain the intended social interaction between the participants, my role was to introduce the topic then refrain from being active in the conversation (Halkier, 2002). The discussion might bring out different views and opinions that prompt the participants to contradict each other. I was therefore attentive to preventing the discussion from being dominated by strong individuals and aimed to keep the participants to responding to each other's statements (Krueger & Casey, 2015). Halkier (2002) emphasises the differences between group interviews and focus groups, with the first looking for answers on different questions, not on the interactions between the individuals, and the second having both social interactions and opinions in focus. The quality of the collected data is very dependent on the skills of the moderator (Halkier, 2002; Øvretveit, 1998).

The focus groups were designed to represent the typical frontline staff group (Elwyn et al., 2001). Each focus group covered one geographical location in the

municipality and included all who interacted, albeit in different roles, with the users in their homes: registered nurses (RN), state enrolled nurses (SEN) and home-helpers (HH). Table 3 (page 65) shows the focus group composition. Employees, employed during the last year were eligible. Being head or deputy head of department were exclusion criteria as leaders might influence the social interactions in a focus group (Halkier, 2002). Practical considerations influenced the participants as those on duty when the focus group was scheduled were most likely to participate, however, some turned up on their day off to participate in stage two after they had participated in stage one.

Focus group participants

The local project coordinator was the gatekeeper and arranged for the focus groups in cooperation with myself. We conducted all focus groups in their respective locations to ease accessibility during a busy working day. The staff had many years of experience in their current workplace, a mean time of 10.5 years, and wider experience as health personnel, mean time 16.5 years (Table 4 to Table 10, pages 66 to 69). The staff included two occupational therapists and one social educator but as they had the same level of education and carried out mainly the same tasks in this setting, they have been labelled registered nurses to avoid identification. There was only one male participant, the rest were female.

I have provided the identifiers to enable tracing the quotes. The codes indicate the various focus groups (FG1-FG4), whether it is a pre- or post-implementation group and the individual identifier of the participant. FG2-1-3 indicates it being focus group #2, at the pre-implementation stage (1) and individual #3. FG3-2-1 indicates the focus group #3, at the post-implementation stage (2) and individual #1. For those attending both pre- and post-implementation, both identifiers are provided in the post-implementation tables (Table 5, Table 7 and Table 9, pages 66 to 68).

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Table 2 Dates of meeting with focus groups

	FG meeting #1		FG meeting #2
FG1-1	08.03.2013	FG1-2	11.09.2014
FG2-1	19.03.2013	FG2-2	16.09.2014
FG3-1	03.04.2013	FG3-2	28.10.2014
FG4-1	23.04.2013	FG4-2	21.10.2014
NP	27.10.2014		
RG	06.11.2014		
PPO	03.02.2015		

Table 3 Focus groups participants

	Focus group #	Total # participants	Registered Nurses	State Enrolled Nurses	Home-Helpers
Pre-implementation stage 1 – 2	FG1-1 ¹	8	2	4	2
	FG2-1	9	3	4	2
	FG3-1	5	2	2	1
	FG4-1	6	1	4	1
Post-implementation stage 2 – 2	FG1-2	7	3	3	1
	FG2-2	11	4	5	2
	FG3-2	6	2	2	2
	FG4-2	4	1	2	1
Only post-implementation stage	NP ²	8	4	3	1
	RG ³	4	4	0	0
	PPO ⁴	2	2	0	0

¹ FG = focus groups # and indicating -1st and -2nd sequence

² NP = night patrol

³ RG = resource group

⁴ PPO = purchaser-provider office

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Eight registered nurses participated in the pre-implementation focus groups (Table 4) and 10 in the post-implementation ones (Table 5). In total eighteen registered nurses participated in the eight sequential focus groups.

Table 4 Registered nurses participating at pre-implementation stage

ID-number	Years in this department	Years in present occupation	Age
FG1-4	0-5	0-5	20-29
FG1-8	6-10	6-10	40-49
FG2-1	11-15	26+	50-59
FG2-2	16-20	26+	40-49
FG2-9	0-5	0-5	20-29
FG3-1	6-10	21-25	40-49
FG3-2	0-5	6-10	30-39
FG4-6	11-15	16-20	40-49

Table 5 Registered nurses at post-implementation stage

ID-number	Years in this department	Years in present occupation	Age	ID from pre-implementation group
FG1-2-1	6-10	16-20	40-49	
FG1-2-2	6-10	6-10	50-59	FG1-1-8
FG1-2-3	0-5	0-5	20-29	
FG2-2-1	6-10	6-10	30-39	
FG2-2-6	Not available	6-10	30-39	
FG2-2-7	16-20	26+	50-59	FG2-1-2
FG2-2-8	11-15	26+	50-59	FG2-1-1
FG3-2-1	6-10	16-20	40-49	
FG3-2-3	0-5	0-5	20-29	
FG4-2-3	21-25	21-25	40-49	FG4-1-6

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Fourteen state enrolled nurses participated in the pre-implementation focus groups (Table 6) and 12 in the post-implementation ones (Table 7). In total twenty-six state enrolled nurses participated in the eight sequential focus groups.

Table 6 State enrolled nurses participating at pre-implementation stage

ID-number	Years in this department	Years in present occupation	Age
FG1-1	11-15	26+	50-59
FG1-2	26+	26+	50-59
FG1-3	11-15	26+	50-59
FG1-7	0-5	16-20	40-49
FG2-4	21-25	21-25	50-59
FG2-5	6-10	16-20	60+
FG2-6	16-20	26+	40-49
FG2-7	11-15	16-20	40-49
FG3-4	11-15	21-25	50-59
FG3-5	11-15	11-15	30-39
FG4-1	6-10	16-20	30-39
FG4-2	11-15	16-20	50-59
FG4-3	0-5	0-5	40-49
FG4-5	0-5	6-10	40-49

Table 7 State enrolled nurses participating at post-implementation stage

ID-number	Years in this department	Years in present occupation	Age	ID from pre-implementation group
FG1-2-4	6-10	21-25	40-49	FG1-1-4
FG1-2-6	11-15	26+	50-59	FG1-1-3
FG1-2-7	16-20	26+	60+	
FG2-2-0	0-5	0-5	20-29	
FG2-2-2	6-10	16-20	60+	FG2-1-5
FG2-2-3	26+	26+	50-59	FG2-1-4
FG2-2-5	0-5	11-15	40-49	
FG2-2-9	16-20	26+	50-59	
FG3-2-4	6-10	16-20	40-49	
FG3-2-5	6-10	21-25	60+	
FG4-2-2	6-10	0-5	40-49	FG4-1-5
FG4-2-4	6-10	16-20	30-39	FG4-1-1

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Six home- helpers/assistants participated in the pre-implementation focus groups (Table 8) and six in the post-implementation focus group (Table 9). In total 12 home-helpers/assistants participated in the eight sequential focus groups.

Table 8 Home-helpers/assistants participating at pre-implementation stage

ID number	Years in this department	Year in present occupation	Age
FG1-5	6-10	6-10	20-29
FG1-6	6-10	6-10	40-49
FG2-3	0-5	0-5	30-39
FG2-8	6-10	6-10	50-59
FG3-3	0-5	0-5	50-59
FG4-4	21-25	21-25	50-59

Table 9 Home-helpers participating at post-implementation stage

ID-number	Years in this department	Years in present occupation	Age	ID from pre-implementation group
FG1-2-5	11-15	11-15	30-39	FG1-1-5
FG2-2-4	16-20	26+	60+	
FG2-2-5A	6-10	6-10	30-39	FG2-1-3
FG3-2-2	0-5	6-10	20-29	
FG3-2-6	0-5	0-5	20-29	
FG4-2-1	0-05	0-5	30-39	

In one location there appeared to be some misunderstanding as participants dropped in after the focus groups had started. I did not refuse the latecomers participation and it appeared that the only effect was that the group grew bigger than planned (Table 3, page 65). The discussions flowed well and the latecomers appeared not to disturb the group. There were interruptions in all focus groups, such as disturbances due to phones that needed to be answered, messages given to people that had to leave for a few minutes. This happened because people were

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on duty and had to respond when called for. It appeared that the participants were used to interruptions and appeared not to be distracted.

All disciplines participating in the additional post-implementation focus groups have been treated collectively to avoid identification and they are therefore not traceable (Table 10). I have therefore added information to their quotes about their experience and role. This includes participants from the night patrol (8), the resource group (4) and the purchaser-provider office (2). In total fourteen participants from the night patrol, the resource group and the purchaser-provider group participated in total three focus groups.

Table 10 Participants only participating at post-implementation stage

Years in this department	Years in present occupation	Age
0-5	11-15	30-39
0-5	11-15	40-49
0-5	6-10	30-39
0-5	0-5	20-29
0-5	0-5	20-29
0-5	0-5	20-29
0-5	0-5	20-29
0-5	0-5	30-39
0-5	16-20	30-39
0-5	16-20	40-49
11-15	26+	40-49
16-20	16-20	50-59
6-10	11-15	40-49
6-10	6-10	30-39

Each night patrol (NP) shift consist of three persons covering all districts and thus they operate over long distances. They might need 90 minutes to reach a user

when responding to an alert if they happen to be at the opposite end of the municipality.

The municipality is organised using the purchaser - provider model. The purchaser-provider office (PPO) manages and assesses the applications for community care. As telecare was a project, the resource group handled most of the telecare applications. This caused a new situation in which the two staff groups interacted with slightly blurred areas of responsibility. This situation resulted in some challenges that they solved during the project period.

The resource group (RG) consisted of dedicated personnel, four nurses and one occupational therapist, trained in telecare. They identified and assessed users, they informed all involved and planned and assisted in installation of the telecare equipment. Because they worked in different districts, they were crucial links in implementing and communicating with staff in their district. The resource group met once a month in 'resource group meetings' to discuss challenges and possible solutions, to learn from each other, and to coordinate and plan the progress of installations.

Interviews in realist evaluation

By choosing realist evaluation in this study, I have stated an initial expectation that telecare does not bring about the same outcomes for all involved (Pawson & Tilley, 1997). I aim to understand how differences in contexts influence the stakeholder's reasoning about the resources brought in (Pawson, 2013). This implies the need to explore latent resources in the users' context and understand how telecare may bring these to the surface (Manzano-Santaella, 2011). My focus has been on programme theories, and I have embarked in a teacher-learner circle with the interviewee. I have been very conscious in how I have presented the programme theory because I have been afraid to cause bias (Creswell, 2009) by influencing the

interviewees. The interviewees have usually been very conscious of why they have received telecare and have been eager to express their views of both positive and negative experiences. I have attempted to let the various interviewees openly voice their expectations and experiences to reduce threats to reliability and to increase trustworthiness. I have attempted to present the data so that the readers are able to make their own interpretations as my responsibility is to give a transparent picture of the situation (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013).

The quality of the interview depends on the researcher's creativity, sensitivity and skills (Kvale, 1997; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Realist evaluation is a methodology that is, as earlier noted, dependent on the researcher being creative when using it (Dalkin et al., 2015). This leaves much of the research dependent on how I have carried out the interviews, which make up a substantial part of my data collection and my ability to present the data and the results in a transparent way. This evaluation investigates various outcomes from telecare, looks for emerging patterns and thus adds transparency to how they develop from the users', relatives' and staff perspectives.

The baseline

The initial data collection serves to illuminate the context and to elicit the candidate programme theories. In paper 2 (Berge, 2016b) I demonstrate how literature from the pre-implementation stage commonly depends on interviewees discussing how they *think* telecare will affect them. I undertook pre-implementation focus groups with staff and interviews with users and relatives to establish a baseline. Research from post-implementation stages are lacking (Peek et al., 2014). I followed up the pre-implementation data collection by post-implementation focus groups and interviews, as will be described.

The interview participants – users

The project coordinator and the resource team that assessed the users also introduced them to the study, and asked if they were willing to participate. The users received the informed consent form that held the information about the project and the assessor telephoned them one to three days later to enable time for consideration and discussion with relatives, which they very often did. There is no record telling how many declined, only how many accepted.

According to realism, different participants have different knowledge. Therefore we aimed for participants to represent the wider sample of people that received telecare to learn their programme theory (Pawson, 2006b). Emmel (2013) argues that the researcher has to deliberately choose the participants in realist evaluation and therefore the term sampling is not appropriate in this methodology. The participants in this study are deliberately chosen to represent different contexts in which telecare is implemented. I aimed to provide a maximum variation drawn from the group that received telecare with regard to age, gender, marital status, health condition and ability to manage daily living. I tried to be as representative as I could but at the same time I had to be opportunistic because the composition of the group was constantly changing. The assessors informed me when they had a potential user that filled an identified gap. Frequent information exchange was necessary, as the time from assessment to installation typically did not exceed one week. When a user agreed to participate, I called them to make an appointment to interview them at home. I adjusted all appointments to suit the user's schedule and made sure they were able to contact me in case they had to reschedule or cancel. All interviews happened in the user's home except for two due to participants' current health. One user wanted to participate using the telephone. Telephone interviews were regarded as a useful alternative in interviewing (Carr & Worth, 2001). One younger person was interviewed in the institution where he stayed temporarily.

Table 11 shows an overview of the users participating in the interviews and the intervals in which they were interviewed. The users included three couples (shaded blue) where both spouses were present and participated during all interviews. Table 11 also shows the initial telecare equipment installed after the first interview but does not include any changes made during the project period. The telecare provided in the study is fully described in paper 4 (Berge, 2017). The users consist of two sub-groups, an 'ordinary' and a 'preventive' group. The ordinary group consists of users already using the community care service while the preventive group contains older people that do not already have any services from the community care. Users in the preventive group were either offered telecare instead of ordinary community care if suitable, or they asked for it themselves.

I used a topic guide (appendix II) in the first interview, aiming to collect information about the users' context, especially about elements that influenced their everyday coping, which in turn might affect why and how they would use telecare. This might in turn influence their reasoning about telecare, illuminating the mechanisms.

The interview participants - relatives

Relatives to the users of telecare often experienced some degree of risk related to the users. Relatives often supported them with various practical tasks with neither themselves nor the users perceiving them as being their carer (Phillips, 2007). The users and relatives gave and received support, help and care due to relations developed over many years, as part of a mutual relationship that changed according to variations in needs. Thus, this relationship might be at risk when the user's safety was at risk. The relatives' experience of the situation influenced the users and therefore I interviewed them to understand their role in telecare.

The relatives were chosen for the same deliberate reasons as the users, trying to achieve a maximum variation. In one case, the request was directed to a user's son while the daughter ended up being interviewed due to their internal agreement, and I did not perceive it appropriate to object. The recruitment otherwise followed the same process and procedures as that of the users. We had to choose the relatives from the group of users not interviewed due to the requirements from the Norwegian Social Science Data Services (NSD) (now named Norwegian Centre for Research Data) that assessed and approved the study.

Four out of six initial interviews with relatives took place in the user's home during the installation of telecare. Typically, the relatives were present to receive the same information as the user. While the technician installed and tested, I interviewed the relative in an adjacent room out of earshot of other people present. One relative wished to be interviewed on neutral premises and chose a quiet corner of a shopping centre café. One was a telephone interview due to the distance. The interviewees were daughters and one son of older users (Table 12, page 76) and one was the daughter of a couple with telecare. The telecare equipment indicated in Table 11 and Table 12 is what was installed after the initial interview.

I used a topic guide (appendix III) with the relatives to explore their context and to collect information about the challenges and expectations they perceived for their parents using telecare. The relatives' opinions are elements that might influence the user's reasoning about telecare, and thus could illuminate mechanisms.

Table 11 Overview of sequential interviews with users

Alias	Gender	Age at 1st interview	Marital status	Group	Interview No 1	Interview No 2	Interview No 3	Pendant	Smoke alarm	Movement sensor	Bed sensor	Fall sensor	Door sensor	Pull cord	Flood sensor
Nina	F	90	Unmarried	Ordinary	02.09.2013	07.10.2013	02.07.2014	1	1	1	1			2	
Kjell	M	91	Widower	Preventive	09.09.2013	14.10.2013	02.07.2014	1	1		1	1			
Hildur	FF	89	Widow	Preventive	16.09.2013	21.10.2013	17.09.2014	1		2	1	1			
Alida	K	84	Married/alone	Ordinary	18.02.2014	01.04.2014	13.02.2015	1	2						1
Paal	M	54	Unmarried	Preventive	10.03.2014	28.04.2014	25.03.2015	1	1						1
Petter	M	82	Married	Ordinary	01.04.2014	06.05.2014	10.03.2015		2			1		1	
Hulda	F	75						1							
Jens	M	92	Unmarried	Ordinary	22.04.2014	26.05.2014	11.03.2015		1	1	1	1			
Martha	F	91	Widow	Ordinary	22.04.2014	27.05.2014	12.03.2015		2	2	1	1			
Ingrid	F	88	Unmarried	Preventive	23.04.2014	27.05.2014	Died		1	1		1			
Gerd	F	88	Married	Ordinary	30.04.2014	10.06.2014	10.03.2015	1	2						
Hans	M	87						1	2						
Guri	F	79	Married	Ordinary	06.05.2014	10.06.2014	13.03.2015	1	2						
Ola	M	80													
Astrid	F	80	Unmarried	Ordinary	06.05.2014	10.06.2014	20.05.2015	1	2	2			1		
Sissel	F	47	Unmarried	Ordinary	15.09.2014	31.10.2014	21.08.2015	1	1						
Ivar	M	29	Unmarried	Preventive	13.10.2014	Moved	Moved		1	1		1			
Lisa	F	83	Married/alone	Preventive	10.11.2014	16.12.2015	30.09.2015	1	1	2	1				
Olga	F	75	Widow	Ordinary	28.11.2014	13.02.2015	30.09.2015		1	2		1		1	

Table 12 Interviews with relatives

Alias	Relative's gender	Relationship	User's sex	User's age at 1st interview	Marital status	Group	Interview No 1	Interview No 2	Pendant	Smoke alarm	Movement sensor	Bed sensor	Fall sensor	Door sensor	Pull cord
Laura	F	Daughter	F	86	Widow	Ordinar	11.09.2013	Died							
Mildred	F	Daughter	F	85	Widow	Preventive	23.04.2014	Withdrew		1	1	1	1		
Bergliot	F	Daughter	F	85	Widow	Ordinar	30.04.2014	13.03.2015	1	2					1
Helga	M	Son	F	87	Widow	Ordinar	27.06.2014	20.05.2015	1	2	2			1	
Ragna	F	Daughter	F	92	Widow	Ordinar	02.07.2014	27.05.2015	1			1	1		1
Tordis	F	Daughter	F	89	Married	Ordinar	17.11.2014	07.10.2015				1			
Rolf			M	90		Ordinar			1	2	2		1		

The second interview with users

During the initial interview I made appointments for the next one, to take place about 5 weeks later. I wished for the user to have lived in the home with telecare for that period. Some users had been away from home during this period, and then time was added accordingly. I prepared for the second interview by listening to the previous ones and noting down the issues raised by the users, their expectations, thoughts and worries. During the second interview I linked back to these topics to check out their relevance in the present situation. I usually started by asking how the last weeks had been for them, to tell what was important for them. While the first interview gave information about the context and the situation that needed change (Pawson & Tilley, 1997), the second interview provided knowledge about the CMOs and fed into refining the programme theory, thus the processes of analysis were iterative with interviews.

The final interviews with users

During the second interview with the users, I agreed with them how they wanted me to arrange for the third and last interview, about 10 months later. They usually wanted me to call them some weeks in advance to make the appointments. Two wanted me to make the appointments by mail a couple of weeks ahead of the interview and then call them to agree a time. The last interviews followed the same pattern: I listened to the interviews while having the transcript in front of me and noted the topics that emerged which highlighted mechanisms that I could follow and pursue. I was looking at exploring how the user reasoned about telecare and which outcome they perceived from it.

The final interviews with relatives

During the first interview with relatives, we agreed how to make appointments for the last interview. All wanted me to call them a couple of weeks beforehand, which I did. The relatives chose where the interview should take place and one happened at home, one at work, one in a neutral place (café) and the last via telephone due to the distance.

The final focus groups

I prepared for the focus groups by listening to the previous ones to be sure to follow up on their expectations, worries and comments despite the groups being differently composed due to who was available and on duty. I used the expression 'when I last talked to some of you...' or in the case where all participants were new, I said 'When I last talked to your colleagues, they said/ were worried/ expected/...' The groups were undertaken as the previous ones. As with the users and relatives, I tried to pursue how they had reasoned about the resources that telecare brought in and attempted to follow different themes that emerged. The staff discussed positive and negative outcomes from telecare.

I have carefully translated the quotations illustrating the topics discussed to ensure that the message in each quote is communicated. Thus, I have not translated them directly word for word, as the message could then have been lost (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015). I have conducted all interviews, additionally transcribed and analysed them in the native language, and therefore gained a thorough understanding of the interviewees, their contexts and cultures in where the interviews are given as Temple, Edwards, and Alexander (2006) argues important when research is conducted bilingually. This way I avoid known sources of translation errors in qualitative research (Al-Amer et al., 2015). Conducting all steps in the data collection and analysing processes myself in the

same mother tongue as the interviewees, also reduces some common threats to credibility that occur when interviews are presented in a different language than they are conducted (Al-Amer et al., 2015; Temple et al., 2006).

Analysis

The first step in this analysis refers back to the processes of eliciting and formalising the programme theories that underpin the implementation (Pawson & Tilley, 2004). The candidate programme theory that guided the initial focus groups and interviews was 'When people have telecare, they feel safer and may be able to remain in their home for longer'. The expected intention from the telecare intervention was that it brings about change, improved safety, and due to improved safety people can remain living at home. The realist approach guides my analysis which aims to uncover in what ways this change occurs (Pawson & Tilley, 1997). Pawson (2006b) describes four layers of contexts, as illustrated in Figure 3 in where an intervention will be implemented. Each layer is inhabited by stakeholders who perceive the intervention from their perspective. How an intervention works depends on the contexts and the stakeholders, which I have discussed in paper 3 (in review). Therefore, I started by exploring the layers of context in which the change was to happen and to identify which changes were expected to lead to safety. In telecare implementations there are multiple stakeholders holding different perspectives as further illustrated in Figure 3. For this study, I chose three major perspectives: users, relatives and staff.

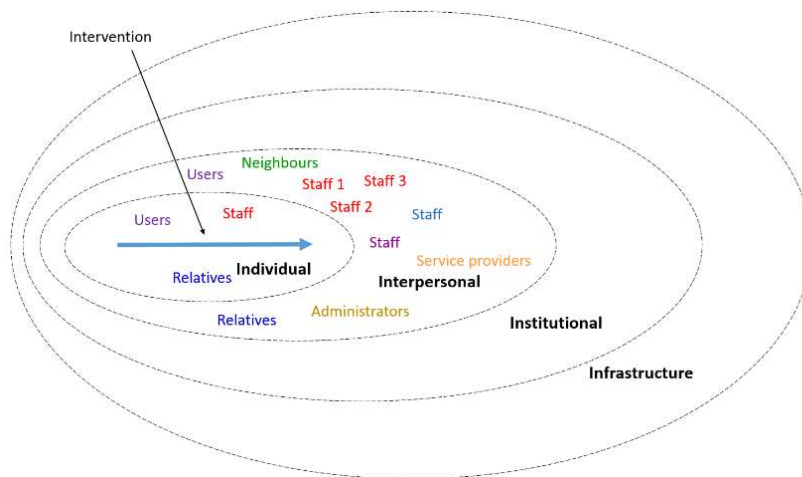


Figure 3 Stakeholders in contexts, inspired by Pawson (2006b, p. 32)

The initial focus groups served the purpose of identifying the staff context. Browning, Tullai-McGuinness, Madigan, and Struk (2009) suggest that staff play an important role in how telecare (the mechanism) is perceived by users. Staff members' own acceptance is suggested to be essential to whether the users accept telecare (Brewster, Mountain, Wessels, Kelly, & Hawley, 2014). Telecare is likely to influence the staff everyday work and their interactions with, for example, each other, users and relatives.

I started out using NVivo and, by coding the four initial focus groups thematically according to qualitative analysis, made nodes and sub-nodes for the various themes that emerged. Realist evaluation was novel to me and required a different way of conceptualising the data, which I initially did not realise. After struggling to understand the context from the themes that emerged, I realised that I needed a different approach. I followed the RAMESES discussion group (that includes most realists using the methodology, from Pawson and Tilley through to novices) that frequently discusses methodological questions and challenges in applying realist evaluation. Thanks to several others facing the same challenges as myself, I found answers and was guided to literature that made me realise that realist analysis needed its own specific approach (Jackson & Kolla, 2012). I also learned that my

initial attempt, the thematic approach frequently used in qualitative analysis (Polit & Beck, 2008; Robson, 2011), does not prove very beneficial in realist analysis (Westhorp, 2014) and that *thinking* in CMO configurations would be the most useful approach (Pawson & Tilley, 2004).

I recoded the four focus groups and, as this was a pre-implementation data collection, I focused on context and the expected outcome in which telecare would constitute the mechanism. The mechanism was not yet implemented, as these focus groups were undertaken, and so I focused on “what characterises the context” when I identified new nodes from staff description of their working context. I used memos to describe the nodes to keep them short and lucid. The new approach was more helpful and opened new insights to me about how the context influences staff expectations about how telecare might yield outcomes. I experienced how C’s, M’s and O’s appeared to link together when I switched to realist thinking.

The first focus groups indicated close connections between staff context and user’s context. One example is under the node ‘safety’ (Memo: user’s safety influences how staff perceive safety) from focus groups with staff:

FG4-1-1: For instance one user who is prone to falling, she is afraid of moving about, and I am anxious when I leave her because we won’t call in until the next week. I think it is easier with those who have several calls a day, because then I know they won’t lie suffering for days.

The focus groups provided some main themes that informed the candidate programme theory. The candidate programme theory presents telecare from an individual’s perspective; however, the staff included their perspective, as they had to relate to the safety issues with users on a daily basis. I searched the transcripts for indications about contexts and expected outcomes in addition to attempting

to identify possible facilitators and obstacles in the context that influenced the mechanisms.

The focus groups fed in to the knowledge base when starting the initial user and relatives interviews. These were coded in NVivo using the same approach as for the focus groups, following the candidate programme theories that emerged from the data. The nodes were commonly concurrent apart from a few differences; the staff included work satisfaction, while they and the relatives emphasised safety more than the users, who emphasized identity the most.

Realist evaluation is about theory testing and refinement and the CMO configurations (CMOc) that indicate how the programme activates the mechanisms to bring about change (Pawson & Tilley, 2004). These propositions bring together variations in mechanisms and in context that explain variations in outcomes and make up demi-regularities that can predict and explain outcome patterns. Realist evaluation thus develops and tests CMOc empirically. In analysing the second user interviews, the mechanism that was lacking in the first sessions was now implemented and the CMOc started to emerge. I looked for how the users reasoned about the resources and started to refine the programme theories.

The programme theories developed through the second interviews and in the third interviews with users, I refined and tested them. The relatives' programme theories were also refined and tested in the second and last interview. Both are presented in paper 4 (Berge, 2017). I looked for statements that identified how mechanisms worked in the specific context and how the reasoning influenced the outcome. I categorised the contexts, mechanisms and outcomes by the outcomes and then 'worked backwards' to illuminate how mechanisms worked differently in the various contexts. In this work, I also used large sheets of paper and colours to help map the CMOs. I encountered problems with NVivo not functioning and in one occasion lost input, a situation that made me reluctant to use it. I tried using

Excel which has proved useful in realist analysis (Punton et al., 2016) before finally coding the last focus groups using colours on papers. I used the programme theories and grouped statements according to how they confirmed or contested the theory in question.

The refined overall programme theory tested read ‘When people have properly adjusted telecare that matches their needs and abilities, they are and feel safer and may be able to remain in their home for longer’. CMOc from focus groups and interviews with users and relatives fed into this refined theory in addition to results from the literature searches.

Ethics

This research involved data collection from home dwelling users of the health care service, the majority being older people. I refer to them as vulnerable because they expressed that they felt vulnerable and unsafe due to age and/or diseases as I have outlined in paper 4 (Berge, 2017). Carrying out the data collection required me to seek ethical approval to secure that their rights and interests were not violated and that the research was performed according to ethical standards. The Regional Committee for Medical and Health Research Ethics (REC) firstly assessed the ethical application and then the Norwegian Social Science Data Services (NSD) (now named Norwegian Centre for Research Data) assessed and approved it. We received the approval March 6th 2013 from NSD that recommended that the research project be carried out, affirmation number 33469 (appendix VI) and approval for the results to be published. NSD also approved of the various informed consents from the participants (available on request), forms and topic guides used in the research (appendix II-V, pages 158-161).

The formal ethical approval sets standards for the informed consents and the topic guide and the performance of the research. It serves to emphasise the researcher's responsibility in respecting participants' anonymity, confidentiality and safety. This includes how data collection is undertaken, data storage and that data analysis is conducted rigorously and impartially according to the methodology. Research in care with vulnerable people requires constant reflection to ensure a high ethical standard. I followed the NSD standards and informed the participants at our first meeting, using the written approved information form that both parties signed. In addition, I repeated their right to withdraw without any reason at each encounter. I informed the participants orally in addition to the informed consent about publications and presentations that were planned from study and about precautions taken to ensure no individuals be identified. This also applied to the participants in the focus groups.

Reflections on data collection

The interviews are guided by the programme theory according to the realist approach. However, when reflecting back, I can see that I did not explicitly discuss the programme theories, probably due to my qualitative background and a desire to reduce bias by not influencing the topics for discussion in the interviews. The interviews therefore belong partly in the qualitative category and partly in the realist tradition. I tried to achieve understanding of the interviewees' programme theories in more subtle ways, by listening to them with careful prompts to discover how they reason about the resources offered by telecare. The interviews were, however, partly realist as the interviewees and the focus group participants were conscious of the aim of exploring experiences from shortcomings and strengths in telecare.

I visited people that I categorised as vulnerable in paper 4 (Berge, 2017) and was thus aware of signs of them being tired and needing to stop the interview. Such situations occurred only once, during a telephone interview with an ill person. This person was very eager to participate in the study as participating was an opportunity to influence further development of a service that would enable people to remain independent which, for her, had high priority. The persons I interviewed had a strong desire to remain at home and were eager to share their experiences about what worked or not, why and sometimes how to make improvements. Very often, I had to make them repeat what they eagerly told me before the interview started and I had turned on the recorder.

My impression from all interviews, except with one who said very little, was that they were surprisingly outspoken in sharing their experiences of telecare with me. Some used me as a messenger when they had questions, which they did not know where to direct. I appreciated this openness. Once a person mistook me for a journalist because the project was in the media at that time, and thus did not want to talk to me. When the misunderstanding was sorted out, I was welcomed in. People usually understood my role in evaluating how telecare worked and I made it a point of emphasising that I needed to learn what did not work for us to be able to improve the service.

One user with dementia welcomed me warmly for the first interview when a relative was present. Next time we needed some more time before I was accepted, as this user claimed to be “just a plain and ordinary person” and therefore was worried not to be able to answer correctly to a “highly educated person”. My experience from clinical nursing was helpful for me in choosing tactics to achieve the user’s trust even if I felt I was being somewhat intrusive at the very start. We sorted out the situation by chatting about things important to the user, which I told her was what I wanted to hear about. When finishing the interview, the user disapproved of me leaving as “chatting to me was just the same as chatting to any

other person". Naturally, the same thing happened when I returned the third time, almost one year later, and was sorted out in the same way.

Limitations to the realist evaluation

My knowledge in realist evaluation grew as I used it, and I realised the need for peer discussions. Working without other researchers being directly involved is likely to have been a limitation in carrying out this realist evaluation. If I were to do a similar evaluation, I would have two or three persons doing the interviews, each following up their interviewees. Then they would all have been involved in searching for C's, M's and O's, which might have taken the discussions to a higher level, expanding the perspectives of knowledge and experiences which would have strengthened the study. The discussions might then reach further than this evaluation has achieved.

Realist evaluation can be a huge task to undertake, and it is therefore necessary to limit the amount of programme theories to pursue, however challenging that may be. Telecare is a new area for realist evaluation and therefore field evidence to build on was lacking. I might perhaps have been too bold in setting out on a realist evaluation, but did not realise that when I started. Nonetheless, I am confident that there are findings in my study that would not have emerged using other methodologies.

If doing a similar evaluation again, I would emphasise the benefit of having the same focus group participants in pre- and post-implementation groups. I think that the discussions and reflections that start when the group discusses themes together in the first group develops over time and influences their opinions. I had a hunch that some themes were reflected upon more in groups consisting of

members that had participated previously, while to those that had not previously participated the themes appeared novel.

I have seldom seen the terms validity and reliability used in realist evaluation. This might be due to an acceptance that what works in one situation does not necessarily work in another (Tilley, 2000). The aim is to make transparent what works for whom in which situation and why (Pawson & Tilley, 1997). In realist evaluation it is essential to clearly show how things have emerged to enable the reader to understand how the CMOc have worked in this situation, as I have discussed in relation to realist review in paper 2 (Berge, 2016b). Being very clear about why choices are made and what has caused them, allows the readers to make their own judgements. It is therefore important for me to be very clear about the limitations of the study - this is what I found in this situation due to the methods I used with these particular stakeholders -and to try to show the CMOc and how they emerged. It is also necessary to be very clear that findings from one study are not transferable to another situation since the context and the participants will change and cause the mechanisms that telecare provides to work differently. The programme theories are however transferable and the evaluation will provide important information that might inform other telecare evaluations by showing how the CMOc have worked here. The CMOc will still need to be tested in the new settings.

The emergence of sub-programme theories

In my study, I have tried to show how the CMO patterns have emerged to allow readers to judge how I have used the data to reach my conclusions.

The hypothesis, *'If telecare is used, then people are enabled to remain safe in their own home for longer'* was elicited from national policy documents. This hypothesis guided the initial literature searches that led to the candidate programme theory,

'When people have telecare, they feel safer and may be able to remain in their home for longer'. I refined the candidate programme theory through pursuing eight programme sub-theories as they emerged from stakeholders' perspectives in focus groups and interviews. Pawson (2013) argues that there usually are more programme theories than are feasible to pursue in an evaluation. These eight programme theories represent various perspectives, #1 - #6 are fully elaborated in paper 3 (in review) and #7 and #8 are fully discussed in chapter 5. The aggregated data that emerge from different stakeholder's perspectives, feed into and eventually lead to the refined programme theory that is tested and confirmed: *When people have properly adjusted telecare that matches their needs and abilities (M), they are and feel safer (C) and may be able to remain in their home for longer (O).*

Programme theory #1 emerged from interviews with users who lived alone or with an equally vulnerable spouse. They shared a concern that they may not be able to alert someone for assistance, as is shown in paper 3 (in review) from two different users' perspective. The programme theory is: *Telecare will provide safety (O) by alerting and summoning help (M) in situations where the person cannot act themselves (C).* As fully discussed in paper 3 (in review) programme theory #1 was confirmed.

Programme theory #2 emerged from interviews with relatives and focus groups with staff. They highlighted how people with dementia encountered safety gaps when they were alone. Such safety gaps were difficult to avoid when continuing to live in familiar surroundings. The programme theory is: *Thoroughly adjusted telecare (M) can bridge safety gaps (O->M) caused by dementia that existing services from community care and contributions from relatives cannot provide (C) to enable the person to remain in familiar surroundings (O).* It is necessary to remember that in a realist view, things are not C, M, or O. They function as C, M or O in a particular part of the analysis (Westhorp, 2014) which is demonstrated

here. One outcome can influence or cause one or more outcomes or continue to function as a context or a mechanism as Pawson and Tilley (1997) demonstrate in their CCTV evaluation. Programme theory #2 was confirmed as discussed in paper 3 (in review).

Programme theory #3 then follows from #1 and #2, as the relatives are less anxious due to the users' safety being increased through telecare; this also emerges from the interviews with the users and the relatives. Programme theory #3: *Telecare will provide increased safety 24/7 (M), which will reduce anxiety for relatives (O) when vulnerable elders remain living in their own homes (C)*. Programme theory #3 was confirmed as discussed in paper 3.

Programme theory #4 follows from programme theory #2 and #3, as it might be regarded an outcome. In the interviews with the relatives, this was expressed to be an expected outcome from using telecare and a motivation to encourage using it. *Telecare (M) may improve documentation (O) of actual risks (C)*. Programme theory #4 was confirmed as fully discussed in paper 3 (in review).

Programme theory #5: *telecare (M) will provide increased safety 24/7 (O) + (M) and thus cover safety gaps (O) + (C) with vulnerable people who might experience adverse incidents (C)*. This programme theory emerges from interviews with users and relatives and emphasises the need to cover possible gaps in safety experienced by users and relatives. It exemplifies how various elements have different functions during the analysis, a reminder that CMOs are for analytical purposes only. Programme theory #5 was confirmed and is elaborated in paper 3 (in review).

In programme theory #6, the focus shifts to staff perspective and it emerges from focus groups with staff: *Telecare will provide increased safety 24/7 (M), which will*

reduce staff anxiety (O) when vulnerable people remain living in their own homes (C). This can be broken down further: *Telecare (M) will provide increased safety 24/7 (O).* This outcome, increased safety, then functions as a mechanism in reducing staff anxiety, a new outcome when vulnerable people remain living in their own homes. This way of depicting CMOs as dynamic functions in the analysis emphasises their role in supporting the programme theory in the evaluation. Programme theory #6 was confirmed as is discussed in paper 3 (in review).

The next programme theory #7, came from focus groups with staff that revealed their expectations about telecare being a means to ease their workload. #7 reads: *When people have telecare they will feel safe (C) and will not need the staff to call on them (O) -> (M) and thus the number of calls will decrease (O) -> (M) and cause the staff workload to diminish (O).* The CMOs change their function in this programme theory too. Programme theory #7 thus far was refuted due to incorrect adjustment of telecare and this is elaborated in chapter 5.

The staff raised concerns about whether telecare is ethical when used for people with cognitive impairment, resulting in programme theory #8: *Telecare is ethical in use (O) only when people understand how to benefit from it (C) and thus are able to consent to using it (M).* Programme theory #8 was refuted and is fully discussed in chapter 5.

To summarize, the programme theories pursued in this study are:

- #1 Telecare will provide safety by alerting and summoning help in situations where the person cannot act themselves.
- #2 Thoroughly adjusted telecare can bridge safety gaps caused by dementia that existing services from community care and contribution from relatives cannot provide to enable the person to remain in familiar surroundings.

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- #3 Telecare will provide increased safety 24/7, which will reduce anxiety for relatives when vulnerable elders remain living in their own homes.
- #4 Telecare may improve documentation of actual risks.
- #5 Telecare will provide increased safety 24/7 and thus cover safety gaps with vulnerable people who might experience adverse incidents.
- #6 Telecare will provide increased safety 24/7, which will reduce staff anxiety when vulnerable people remain living in their own homes.
- #7 When people have telecare they will feel safe and will not need the staff to call on them and thus the number of calls will decrease and cause the staff workload to diminish.
- #8 Telecare is ethical in use only when people understand how to benefit from it and thus are able to consent to using it.

Chapter 5 Findings: Staff perspective

The findings from this study are presented in this chapter and in the four papers, and together they create the whole picture. The findings from the partnership are fully presented in paper 1 (Berge, 2016a). The findings from new ways of assessing user acceptance are presented in paper 2 (Berge, 2016b). The findings from the first two papers discuss elements that influence telecare uptake, and in paper 3 (in review) I demonstrate how realist evaluation is beneficial as it facilitates understanding of how users reason about telecare causing them to accept or reject telecare. Paper 4 (Berge, 2017) highlights the importance of experiencing telecare and how users and relatives reason differently about it. In this chapter, I will focus on findings from the staff perspective. Staff findings related to partnership working are discussed in paper 1 (Berge, 2016a).

Introduction

The literature emphasises the important role staff play in telecare implementation and some claim the success or failure of the implementation to depend upon the staff (Willems et al., 2012). I have demonstrated the significance of user acceptance in paper 2 (Berge, 2016b) and partners' cooperation and interactions on telecare in paper 1 (Berge, 2016a), and therefore I am reluctant to single out one element or group to be credited with sole importance. I do however, acknowledge that staff, with their attitude and knowledge, significantly influence the implementation. The way staff introduce telecare is recognised to influence whether the users accept or decline telecare (Browning et al., 2009). This is supported by Brewster et al. (2014) who argue that it is necessary for staff to accept technology to enable them to provide correct information for the users to believe telecare to be beneficial to them. Staff attitudes towards telecare are therefore important to grasp to understand whether their attitudes change, why

they change or why they do not. It is also necessary to understand what influences how technology is perceived and how this affects telecare implementation. In their review on telehealth Brewster et al. (2014) conclude that staff acceptance is of utmost importance for implementation success, and they suggest staff knowledge to be the vital element. However, they call for more research concerning frontline staff as they found this to be scarce. My study provides experiences from users, relatives and frontline staff as they influence each other. This chapter reports from focus groups with frontline staff, conducted before and after implementation.

The candidate programme theory that guided the focus groups with staff was 'When people have telecare they feel safer and may be able to remain in their own home for longer'.

The pre-implementation focus groups

The initial focus groups served to illuminate the context in which telecare would be implemented and attempted to illuminate possible facilitating and hampering elements within the context. Context was not limited to locality but included all that was contextually significant, for example, interpersonal and social relationships (Pawson & Tilley, 2004). The quotations are examples of what was commonly said and illuminate the context in which telecare would be implemented.

Working conditions

All participants expressed their love of their work but emphasised that they were *very* busy. They appreciated the way that they were challenged personally and

professionally in responding to situations that occurred during the shifts, using and building expertise and experience. The community care staff were frontline staff working in the users' homes and included mainly registered nurses, state enrolled nurses and home-helpers. They followed individual schedules where the tasks for the shift were pre-decided. These schedules contained information about whom they were to visit and which tasks to carry out. The initial schedule usually changed during the shift due to unforeseen incidents. They often had to attend to unpredicted situations in which they had to use knowledge and experience. These situations increased the busyness. Several experienced staff, who had worked in community care for many years emphasised how their working situations had become increasingly busy during recent years. Several perceived this busyness to negatively influence the quality of their work. Among those describing the increased busyness and its influence on quality of work and in turn satisfaction, was one very experienced nurse:

FG4-1-6: I often leave work feeling that I've done a poor job because it's been too busy. You have very limited time with each user and it is actually not sufficient time to give the amount of help they need. You just have to hurry to see the next user. Therefore, the result sometimes is ... you know, poor I think it's poor-quality care when it is too busy.

Several staff emphasised how the group of users in community care had changed during the last decade. Users are now frailer and need more help. An increasing challenge raised by all focus groups was the growing number of users with dementia who often remained at home due to lack of nursing homes. These user groups needed considerable attention, care and time from the staff. In addition, staff perceived it to be unsafe to leave users with dementia alone, as their actions were usually unpredictable. Staff therefore felt themselves pulled between their scheduled work and the demands arising, which they experienced when visiting particular users, often amplified by their relatives' demands. These users usually objected to receiving help despite needing it, which in turn caused staff to use extra time negotiating to achieve their aim, to help them. These users often wanted to remain at home. Their relatives frequently supported their wish but

also realised the users' increased need for safety. The most usual solution to increase safety was to plan for frequent staff visits. Such solutions caused, in certain situations, the risk to increase rather than to decrease, such as when users were disturbed at night. The staff found it difficult to leave vulnerable users and perceived themselves responsible, but also unable to prevent risky situations, as they could not always be present.

FG3-1-1: Although we visit people with dementia frequently, we're unable to cover the entire day and night... The municipality tries to compensate for the lack of nursing homes and promises their relatives that we (community care) will spend a minimum time on each visit. But... quite often the person doesn't want us to help them. *They don't want it.* They want to manage by themselves but ...

Attitudes towards accepting community care

Receiving help from community care and becoming a user is not what older people wish for, and staff explained how they met people who tried hard to delay formal care. The staff experienced two motives that appeared to be two sides of the same story. The first issue being that several older people said that they were afraid of crossing the border to being a 'care recipient' because they were afraid of becoming a 'patient' and thus very dependent on others, and they did not want that. The staff were well aware that some users regarded their help to be quite intrusive, despite needing assistance; it caused the users to allow 'strangers' into their private spheres. Receiving help came at a high cost for their self-image. Receiving community care would include being dependent on another person, renouncing a piece of independence that affects identity, moving from being an independent person to becoming a patient and letting go of highly valued privacy. This coheres with what users themselves later expressed in interviews. The staff understood that users needed help but also why they rejected it. They saw telecare as an opportunity for people to accept help at an earlier stage without the high cost of giving up their independence.

FG2-1-6: Maybe then they'll accept they need help ... that it's easier this way (using telecare) ... because they may in a way function independently with it. Then they don't need us wandering about in their home as often. Some don't approve of us being there, you know.

The second issue is related as it concerns exposure to others when receiving help from community care. Staff said that several users perceived it to be very embarrassing when others, typically neighbours, learned that they were receiving help. Staff often heard users say that accepting help was equal to accepting that they were no longer able to cope by themselves, which they did not want others to see. The discussions in the focus groups related to both these components, as the staff perceived them to be related. The staff imagined telecare to offer less intrusive help in ways that influenced both these reasons for declining community care. Firstly the staff imagined telecare to support independent living, providing safety without needing to allow 'strangers' into the home unless in emergencies. Secondly, the staff imagined telecare to be more anonymous and thus it would not be that obvious for others when a user received help.

FG2-1-4: It (telecare) is quite an anonymous aid, isn't it? It's not on display outside the house, except if we're summoned. Then telecare is help that they (users) can receive without anybody knowing.

The staff anticipated that because of more users relying on telecare their workload would ease. However, when discussing why users often were reluctant to accept community care, the staff highlighted a group of users who insisted on having community care despite apparently being able to manage well by themselves. These users often lived alone with few or no regular visitors, and they had suffered an incident that had made them anxious. The staff perceived them to be taking precautions in wanting them to pop in.

FG3-1-1: We recently had a woman who needed help to get into bed. Then we learned that she got up and went to the toilet several times during the night. She managed to get back into bed herself. She felt it safe that someone was there every night otherwise she would be on her own.

Several staff highlighted that some users appreciated the community care calling on them, as they were the only people they saw during the week and enjoyed their company, however short. They discussed whether telecare would result in fewer visits and thus cause people to become lonelier and in turn unsafe. They agreed that they needed to be aware of this potential side effect. They also discussed whether lack of other options caused the users to cling to visits from community care and whether other options, like telecare, would change the users' preferences. In all groups, they expected there to be users who would not benefit from telecare as it would not be appropriate for everyone.

The context that emerges from the pre-implementation focus groups with staff, draws a picture of dedicated and experienced staff (Table 4-Table 10, pages 66-69) who were attentive to users' needs. Their shifts were busy with many users and minimal time for patients with special needs. When they had to leave vulnerable people alone due to other scheduled and urgent tasks, it negatively affected how they perceived themselves accomplishing their work. Many experienced having to work in a way that threatened quality of care and this feeling in turn negatively affected their work satisfaction.

Expectations of using telecare

In addition to the expectations emerging from speaking about their working situations discussed so far, the staff voiced several other expectations of telecare. These were mostly positive but they also had worries. They expected telecare to cause increased safety, which appeared to be their main objective as already discussed. Everyone had experiences of the inadequacies of present solutions such as social alarms, and expected more people to receive appropriate help in time with telecare, as they would not have to consider whether to call for assistance.

Most staff attended short training sessions as part of their preparation to start using telecare. There they received information about the intended outcomes from using telecare. They had therefore already be made aware of possible benefits from applying individually fitted sensors that matched users' daily activities. Most staff had several experiences of situations where users refrained from using the social alarm after suffering an incident. They identified five situations in where the present solution (social alarms) did not work. 1) Quite a few people did not dare to push the button due to the fear that they would cause a lot of fuss, especially when they expected someone to call on them in the near future. 2) Many people became disorientated due to suffering an incident and forgot they had the social alarm. 3) Several users did not wear the alarm when an incident happened and thus could not press the alert. 4) People with cognitive impairment did not understand what the social alarm was nor how or when to use it. 5) Some people were unable to push the button themselves due to the character of the incident.

FG4-1-6: I reckon telecare might cause improved safety when the users are unable to alert themselves, for example if they fall and remain on the floor. We usually have several users who're unable to alert themselves.

The staff also expected telecare to improve quality of care, especially in situations when they had to check on people during the night-time to ensure they had not left the house. These were usually people with dementia. Several users woke during these calls, and became scared due to 'strangers' being in their home. Thus, the side effect were often that the calls caused adverse situations similar to those they intended to prevent. All focus groups was concerned with how to improve safety at night.

FG3-1-2: When entering a home of a person with dementia during the night, you disturb them and might even wake them and cause them to wander off ... out.

Commonly the staff questioned older people's acceptance of technology in general and telecare in particular. They expected older people to be sceptical towards it and feared that the prospect of replacing carers with telecare would worry them. Many staff members expected improved acceptance of telecare from younger generations who they anticipated would be experienced in engaging with technology. Only a few expressed different views, believing that some older people would welcome assistance from telecare.

The staff worried about the way the media tended to make technology in care settings look as if robots would provide future care. The staff expected users to be unable to discriminate between telecare and futuristic visions and thus be negative towards telecare expecting it would cause them to receive depersonalised care from robots. Several focus group participants perceived their role in presenting telecare to be essential for the users to accept it and focused on the terms they used when presenting it.

FG4-1-1 Therefore, I think that using ordinary language, language that people understand, is extremely important. (Agreements from the group)

Their worries appeared to originate from their own experiences, and how they perceived telecare themselves when they first learnt about it. Several in the focus group said that they thought differently about telecare before having any information and that the language used in explaining telecare influenced how they perceived it. Before having any knowledge about telecare, they usually associated it negatively, as surveillance, and some were stunned to learn that they would have to use it in their work. A nurse explains her impressions this way:

FG1-1-8: Well, I think it depends on knowledge. Initially, when you hear *telecare*, you think surveillance, however, when you learn what this is all about, you think 'oh well, yes'. Therefore, I think it's extremely important to explain thoroughly to users and relatives what telecare includes, what it is and what it isn't.

The staff were conscious that some users might feel they were being monitored even if they had carefully explained what telecare was and was not. Some feared

that users might limit their activities because of the technology. The staff worried especially about people who had dementia. They worried that these users would be scared if the care centre talked to them from the home unit. Most staff therefore concluded that telecare most likely would not be suitable for people with dementia and in those cases would have to be installed prior to the user being too strongly affected by the disease. The discussion in the focus groups showed that their pre-implementation understanding of telecare was that it was a rigid tool, working in a set way, causing a set response. The staff were reluctant for telecare to be installed with people who may not understand what it does. One state enrolled nurse sums up what was a general opinion in all groups.

FG3-1-4: I think it (telecare) will be well suited for those who have had a stroke and want to manage mainly by themselves. I think they are ideal for telecare. They're prone to falling but they have a clear mind, in a way. They understand what's going on around them, I think they will be those best suited to have telecare....

Knowledge about the context

There are several safety gaps identified in the context in which telecare will act as a mechanism. These gaps cause anxiety and influence staff work satisfaction. The users that currently remain at home are frailer, older and have more diseases. Just a few decades ago, they would typically be in hospital or in a nursing home. The staff might act as facilitators supporting telecare if they perceive it beneficial to the users; however, if the user needs the social aspect of care they are sceptical about using telecare, as it will not provide the social interaction needed. Still, the staff expected telecare to replace some visits, typically at night, and thus anticipated that telecare would ease their workload. The staff regarded themselves as holding a significant role for users' acceptance of telecare, and were attentive to how they presented telecare so that users would accept trying it.

In addition to the candidate programme theory, the pre-implementation focus groups yielded information that produced additional programme theories from the staff perspective. These include two previously discussed in paper 3 (in review). Those are #5 'Telecare will provide increased safety 24/7 and thus cover safety gaps with vulnerable people that might experience adverse incidents'; and #6: 'Telecare will provide increased safety 24/7, which will reduce staff anxiety when vulnerable people remain living in their own homes'. I will develop the discussion further here and demonstrate how the programme theories link. When people feel safe they might not want somebody calling on them, and the staff expected the workload to decrease. Thus programme theory #7 might follow from other programme theories and also act as a driving force in the context. #7: 'When people have telecare they will feel safe and will not need the staff to call on them and thus the number of calls will decrease and cause the staff workload to diminish'. From the staff discussions about who is suitable for having telecare arises programme theory #8: 'Telecare is ethical in use only when people understand how to benefit from it and thus are able to consent to using it'. In the next section, I will refine and test the programme theories from data gathered in the post-implementation groups. This sequence covers in addition the night patrol, the purchaser-provider group and the resource group.

Post-implementation focus groups

Having explored the staff working context and their expectations of telecare, the post-implementation focus groups served to refine and eventually test the programme theories (#5-8) that emerged. Increasing safety is a major reason for using telecare, as there are gaps that ordinary community care services do not fill. Staff regard telecare from their perspective in the context in which they operate and interact as discussed in paper 3 (in review) (Figure 3, page 80).

When an unintended alert caused the community care staff to respond, they usually referred to it being a 'false alarm'. What they had in mind was 'an alarm without the user being in any need of assistance'. I have deliberately used the expression 'unintended alert'. Unintended alert covers situations where the user is not in need of assistance, however without stating the reason for the alert. 'False alarm' is technically not the right expression to use when the alarm activates as configured, however without mirroring the user's actual needs. In these cases the configuration needs to be adjusted to actual needs, as I discuss in paper 2 (Berge, 2016b). Another issue is the technical alarms that get no response from community care staff. This requires the call centre staff to have adequate competence to sort out which alarms need attention from care staff and which do not as I discuss in paper 1 (Berge, 2016a). If technical alerts are forwarded to community care staff, they will perceive the alerts to be 'false' as the user is not in need of assistance. The third issue occurs when sensors are not suitable for users in their situation. When the alerts are sorted out and routed correctly, the staff will need to respond to fewer unintended alerts. Correctly adjusted telecare that matches the users' abilities and needs might cause less unintended alerts and reduce staff workload. To adjust telecare correctly it is essential to understand why it is triggered.

Improved safety

During the initial focus groups, safety was a recurrent issue. Staff expected telecare to increase safety to all those involved; users, relatives and themselves. After having experienced telecare, they confirmed that it did increase safety with most users. They felt it was safer to leave users, as they were confident that telecare would alert if an incidence occurred. They referred in addition to users and relatives who perceived the situation to be safer and consequently felt more relaxed. The provider-purchaser office experienced a couple of users who relinquished assistance from community care because they preferred to manage

by themselves, as they perceived themselves to be sufficiently safe now that they have telecare.

PFG-1: In two cases, the users relinquished assistance from community care when they received telecare. They've received assistance (in showering) for some years because they felt unsafe when showering.

The staff had several experiences of telecare improving safety. They referred to how improved safety affected all involved, the user, relatives and the staff. In cases where people lived alone, with few or infrequent visitors, they especially noticed improved safety.

FG4-2-2: Sometimes we visit users just once a week. If we know they have telecare alerting if they fall, it improves our feeling of safety knowing that they won't be lying there a week. (...) It's easier to leave when I know they have telecare. Absolutely!

Without telecare, the staff worried that users would suffer incidents without being able to call for help and referred to several occasions where telecare had enabled early intervention:

FG3-2-3: One user suffered a stroke. I received the alert informing that he hadn't returned to bed after 20 minutes. I hurried out and found him lying on the floor. The ambulance arrived quickly. (...) He received help sooner due to having telecare.

The staff trusted telecare to alert if an incident happened and they found that increased safety of users reduced their level of anxiety when leaving a vulnerable user. Programme theory #6: 'telecare will provide increased safety 24/7, which will reduce staff anxiety when vulnerable people remain living in their own homes', is sustained. The discussions in the various groups highlighted that users with dementia were amongst those for whom the staff used to be anxious. Several focus groups discussed how decisions concerning people with dementia appeared to be continuous ethical dilemmas. People wanted to remain in familiar surroundings where they were happy and functioned to a certain degree. Relatives and staff understood the risk these users were exposed to, which the users

themselves did not appear to perceive. These situations were difficult for the staff to handle and they worried about which choice best would serve the user. Several users suffered when they had to move to a nursing home and the reduction in their well-being influenced both staff and relatives' well-being. From the experiences staff had from using telecare over 18 months, they realised that telecare did increase safety and thus improved opportunities for people to remain at home, even if they had dementia.

FG4-2-3: (...) Her only option was to move into a nursing home due to an incident with a hip fracture. For her to remain home, as she had dementia, the only possibility was with telecare, wasn't it?

Telecare for people with dementia

Initially staff were reluctant to install telecare with people with dementia whom they singled out as a group for whom telecare was neither suitable nor appropriate as they thought it would be unethical. The staff believed that a person had to understand the purpose of telecare, and suggested that this would be before the dementia became too serious. The staff were therefore surprised with the positive outcome for this user group, as this was contradictory to their expectations. They explained how their confidence in telecare grew according to their own understanding of its possibilities and limitations, and they emphasised the importance of the whole group of staff gaining experience and knowledge.

Choosing the right sensor proved particularly important for maintaining safety, especially for people with dementia. They discussed how some sensors would be better than others and how the choice of sensors depended on thorough knowledge about the users and their contexts, the disease and the technology. From the staff experience, door and movement sensors were useful, while they suggested avoiding bed sensors because many with dementia changed their daily rhythm and routines as part of the illness. For example, some did not sleep in the

same room each night and others did not go to bed until very late at night. Both changes would activate the alarms and could cause disturbance to the user. The staff judged telecare to improve user's condition in several ways and understood that it could also benefit those who did not have a clear understanding of what they received through telecare. Programme theory #8 'Telecare is ethical in use only when people understand how to benefit from it and thus are able to consent to using it' was refuted. When users could remain in familiar surroundings with telecare, they compared that with the users' reactions to moving away from their home. This registered nurse is an example illustrating how the staff changed their attitudes towards people with dementia and telecare.

FG1-2-2: Initially I thought this (telecare) wasn't the right thing for people with dementia. I thought it would confuse them, you know, the noise and the voice (from the home unit). However, when the call centre doesn't contact the user directly (telecare is silent), it works well for people with dementia too.

The staff also discussed whether it was correct to allow safety to overrule the users' own preferences.

FG4-2-3 Their remaining life is better living at home even if they might have lived longer locked in a nursing home. I think we must accept some insecurity.

Reduced workload

Programme theory #7 that reads; 'When people have telecare they will feel safe and will not need the staff to call on them and thus the number of calls will decrease and cause the staff workload to diminish.' The most striking information from the post-implementation focus groups, instantly voiced in all groups, was the increased workload caused by unintended telecare alerts. This was indeed an unintended outcome and contradictory to the staff expectations of eased workload due to fewer visits.

All staff, particularly the night patrol, expressed frustration due to telecare causing them extra workload due to numerous unintended alerts. Very often, the bed sensors caused the alerts, which typically happened at night, when the night patrol was on duty. There were only three persons, covering a large area and telecare thus caused their working situation to become challenging as they already had many scheduled tasks that also needed their attention. They described these new challenges with humour, however, emphasising that they had to take any alert seriously, as they did not know the actual urgency in the situation. There were alerts every night, to which they had to respond, causing other tasks to be set aside.

FGN-3: *Buckets full of bed-alerts!* (Laughter)

The night patrol staff perceived their situation much deteriorated due to telecare and in particular the alerts from the large number of the bed sensors.

Reasons for unintended alerts

The focus groups provided valuable information about the most frequent reasons as to why the unintended alerts occurred. They identified that the unintended alerts usually followed from new installations. One frequent reason occurred due to the bed sensor's positioning and/or configuration. The staff assessed the bed sensor to be too small in both breadth and length and therefore difficult to position correctly in bed. It often slipped out of position, which in addition called for adding an anti-slippery surface. One consequence from the sensor being too small was that some staff placed it wrongly because they did not realise its ideal location. Therefore, they put it lengthwise in the middle of the bed instead of across, leaving plenty of space on both sides and thus making it almost impossible for it to achieve the necessary body pressure, resulting in it sending an alert. This error often caused repeated alerts if not rectified.

Despite the alerts causing extra work, the staff exercised patience with telecare and regarded it as 'teething troubles' that they expected to cease. The staff, however, worried when the alerts influenced the users negatively. Some users experienced many unintended alerts, which made them tense and frightened, especially when the alerts woke them on several nights. The staff were eager to solve these situations and identified them as originating from gaps in user assessments, which could be difficult to make correctly at the start of the process. The situation improved along with increased experience and the staff accepted the need to accept some alerts in the process of obtaining correct adjustments. The resource group emphasised the importance of responding swiftly when learning about unintended alerts. This group was in charge of addressing the unintended alerts and was highly attentive to probable negative consequences.

RFG-1: I think it's particularly important to make corrections rapidly when the configuration doesn't match with the user's activity, otherwise it might cause disapproval. Unintended alerts actually cause the workload to increase and that puts telecare in a negative perspective.

Surveillance

Initially all focus groups had some worries concerning surveillance. The staff were less concerned about this issue when they had gained experience from using telecare for about 18 months. By experiencing telecare, they had changed their opinion and no longer regarded it as surveillance. However, if not adjusted properly, it caused alerts, which could lead to negative experiences. For example when the intervals for visiting the bathroom were too short, staff reported that the users tended to feel controlled. Exceeding the set time caused a response from the call centre, which gave the users the impression that the staff there always knew when they were out of bed, of which they disapproved.

FG2-2-8: Some had their bed sensors removed, I think *they* felt unfree, sort of (agreements): "I am not free to go to bed and get up when I want to" (agreements).

Correct adjustments matching the users' abilities and needs appeared to be essential for the users to perceive the sensors beneficial.

Social isolation

The pre-implementation focus groups revealed staff being worried that telecare would cause social isolation for users that typically had few visitors. This appeared not to be a problem as several users received telecare in addition to community care calling on them. They did, however receive fewer calls, typically dropping those at night. The users then avoided disturbance and the staff reduced the number of calls during a period with reduced staff capacity. Some users typically new to community care service, were offered telecare instead of the staff calling on them and thus did not miss anything. Staff had not experienced anyone feeling socially isolated due to telecare.

FG1-2-2: Many still receive services in addition, and then they see us anyway.

Telecare – worth the effort

The focus groups eagerly shared experiences, excitements and worries. They were clearly annoyed about telecare causing increased workload, challenges and problems; however, they remained optimistic and maintained a positive attitude. They perceived telecare in total to be a positive experience holding potentials that they had not yet fully utilised. They would not abandon telecare and return to the previous ways of offering community care service. According to them, telecare represented the future in supporting older people and thus enabling them to remain safely at home.

The resource group reported that the attitudes in the staff group had changed during this project. When telecare was new to them, they perceived it to be an effort and an extra burden but this gradually changed along with increased knowledge and experience. Presently the staff had started to make their own pre-assessments, targeting potential users. They introduced them to telecare, informed that it was available and offered to arrange for the local resource nurse to visit them for further information and assessment. In this way, all staff acted as an important referral route to the resource group who then would provide telecare. The resource group appreciated this cooperation from their colleagues.

RFG-1: They (the staff) are recruiting new users! They tell me how they've talked to people, promoted telecare, discussed particular challenges, and when the users show interest they call for me to visit them. This way we're all pulling in the same direction.

The quotation below sums up how the staff expected and aimed for telecare to work:

RFG-4: When telecare works as intended it is invisible. There are many users we do not hear anything from, and that is how it should be. Well working telecare alerts only when something is wrong.

Discussion

The overall programme theory was tested throughout all data collection, aiming to improve understanding of what works for whom, why and when. Realist evaluation highlighted how staff changed their opinion and what caused these changes. Programme theory #8, telecare is ethical in use only when people understands how to benefit from it and thus are able to consent in using it, was refuted. However, refining the overall programme theory might include all users regardless of the reason for needing telecare. Realist evaluation takes into account the dynamics and emphasises that each outcome should be understood in its

context. Changes in context influence how mechanisms work and impact on the outcome. The data collection throughout this study provided strong evidence that individual assessments and adjustments are essential and thus the overall programme theory was refined, reading ‘When people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer’.

This study includes pre- and post-implementation data collection from frontline staff that demonstrates their important role in implementing telecare, which supports findings from previous studies (Brewster et al., 2014; Browning et al., 2009; Willems et al., 2012). It also demonstrates how acceptance of and benefits from telecare depend on several interactions happening within telecare implementations, as I will discuss. The candidate programme theory was refined, and tested from the staff perspective.

Work satisfaction

Community care is busy, and today’s users have more complex needs and require more advanced care than just a few decades ago, this is also the situation in other industrialised countries (Hasson & Arnetz, 2008). The staff experienced distress because they had to tend to too many users during limited time, which in their opinion negatively influenced the quality of care. The staff perceived the tight schedules, and the risk when leaving vulnerable people, to be threats to quality of care that in turn affected their work satisfaction. Studies, albeit from hospitals, demonstrate in various ways how both user and staff safety and satisfaction relate to workload and the quality of the interaction between user and staff (Aiken et al., 2014; Dabney & Kalisch, 2015). The staff emphasised that they enjoyed their work, and mentioned especially their ability to influence and control their own job when they had to reschedule visits. They appreciated the culture with colleagues who supported and helped each other when necessary. These are qualities which have

been suggested protect from turnover and burnouts when work is demanding (Hayes et al., 2012; Hayes et al., 2006). The staff turnover at Lindås has been low over several years, as shown in Table 4 - Table 10 (Page 66-69). However, when nurses feel they are too busy to provide good quality care, they often consider leaving their job (Flinkman, Laine, Leino-Kilpi, Hasselhorn, & Salanterä, 2008). Correctly adjusted telecare might positively influence work satisfaction while, if incorrectly adjusted, it might have the opposite effect.

Staff work satisfaction was positively influenced by experiences of how telecare increased users' safety. From 18 months of using telecare, the staff had experienced several situations in which it had been demonstrated that telecare improved safety by alerting when, for example, a person had suffered a fall or left home during the night-time. Through repeated experiences, the staff gained confidence in how telecare worked and trusted it to alert according to configurations. Their understanding of the user-telecare interaction grew from experiences with using telecare over time, and in particular from situations when telecare did not work as intended (Law, 1992), causing unintended alerts

The staff relied on telecare alerting them if a user were to leave their home at odd times, and thus provide safety by summoning adequate assistance. Improving users' safety caused staff to perceive it to be less distressing to leave them alone as they relied on telecare to alert when necessary. Staff experienced increased work satisfaction by being able to provide better quality in care as the users were safer. They appreciated that they no longer caused users' adverse situations as previously, for example, when they sometimes woke them as a side effect to checking them at night.

Matching telecare to needs

All staff emphasised that telecare had to match the user's needs, which involved several interactions with a range of actors. The configuration of telecare sensors depends on the users giving correct information about their usual activity; on the assessor understanding and passing on the correct information; and on the technician to configure accordingly. There are several areas where errors can occur as I have discussed in paper 2 (Berge, 2016b). The staff confirmed this from their perspective, having experienced adjustments to be challenging and requiring knowledge, experience and much attention. I have discussed the significance of telecare matching needs for users to perceive it as useful to them in paper 3 (in review), and this is also demonstrated in other studies (Peek et al., 2016; Peek et al., 2014). Findings from users' perspectives suggest that when people have properly adjusted telecare that matches their needs and abilities, they are and feel safer and are able to remain home for longer. However, when the technology does not match their needs they stop using it (Peek et al., 2014) as my findings also show in paper 4 (Berge, 2017). The refined programme theory is confirmed: *'when people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer.'*

Consequences of sensor design

The bed sensors were especially challenging to adjust correctly and thus caused many alerts. These alerts occurred for several reasons; too short interval for the user to leave bed and return, and/or the sensor being activated too early in the evening, and/or was active for too long in the morning. This happened because the users went to bed and got up at different times than they had informed of, and/or needed more time when they left their bed during the night. The bed sensor reacted to pressure, and lack of pressure would activate the alert at set times. In addition to the challenge in configuring the bed sensor correctly, the design itself was problematic and questioned by the staff. They considered it to be

too small and made from material with a slippery surface that allowed it move itself. The most common reason for unintended alerts from the bed sensor happened due to the user's natural movements in bed during sleep (or when sleepless). The movements caused the sensor to slide out of position to areas with insufficient pressure. A common consequence when technology is not working as intended, is for users to attempt to adjust it themselves (Bouwhuis et al., 2012). This applied here too as the staff tried different solutions to stop the bed sensor from moving, by taping it to the mattress or placing it higher in bed, however without solving the problem.

Increase in workloads

The users typically receive telecare because they are prone to accidents. When the staff have to respond to alerts, they do not know what causes it, and thus they need to respond as if it is an emergency. Unintended alerts therefore increase workload and add unpredictability. Unintended alerts resulted from incorrectly adjusted telecare but also because the staff at the call centre were unfamiliar with how to respond correctly to them as I discuss in paper 1 (Berge, 2016a). In addition, some unintended alerts occurred due to technical issues. Unintended alerts may cause users to stop using telecare (Peek et al., 2014) which was also an experience in this project, emphasising the need to adjust telecare correctly. When telecare was included in community care services, the staff found that the unintended alerts caused stress and additional work. They experienced increased workload due to them, especially when the implementation was novel. Increase in workload due to telecare might negatively influence its uptake. The amount of unintended alerts decreased as the adjustments improved. However, despite having to attend to several unintended alerts, the staff perceived the users to be safer and therefore became less distressed when leaving a vulnerable user. Programme theory #6 is refined according to previous programme theories and sustained 'When people have *properly adjusted telecare that matches their need*

and abilities, then telecare will provide increased safety 24/7, which will reduce staff anxiety when vulnerable people remain living in their own homes’.

The staff demonstrated high tolerance for unintended alerts as long as the user was not annoyed or intimidated by them. If the alerts bothered or scared the user or the relatives the staff had less tolerance. The staff aimed to improve implementation by feeding back the knowledge and experience they gained. A useful response to unintended alerts would be to reassess the users and reconfigure the sensor. Post-implementation reassessments ought to be highly prioritised, as they are most likely to prevent unintended alerts.

The initial focus groups suggested that staff have a programme theory about reduced workload. #7 ‘When people have telecare they will feel safe and will not need the staff to call on them and thus the number of calls will decrease and cause the staff workload to diminish’. This programme theory will have to be refined according to #6, including the requirements to adjust correctly according to the user’s needs and abilities to be sustained. It thus reads ‘when people have properly adjusted telecare they will feel safe and will not need the staff to call on them and thus the number of calls will decrease and cause the staff workload to diminish’. Correct adjustments are essential.

The staff changed their attitude to telecare, as they grew more familiar with it. When they experienced it to be beneficial to users, they started to look for similar situations in which telecare could be useful as is also previously demonstrated from staff acceptance of telecare (Breivik, 2014). The responses from focus group participants also indicated how knowledge influenced their acceptance. Knowing the benefits and limitations developed a more realistic understanding of which challenges telecare could solve.

Ethical use of telecare

Another programme theory that emerged from the pre-implementation focus groups was #8, 'telecare is ethical in use only when people understand how to benefit from it and thus are able to consent to using it'. The staff realised that when telecare could summon assistance without frightening or annoying the user in any way, it could improve safety and thus support the user in remaining at home. Staff realised that the user could benefit from telecare without needing to interact consciously with any devices. To obtain this effect it was vital to adjust telecare to the user's abilities and needs otherwise it could cause the opposite effect, which led staff to reject it. Programme theory #8 is refuted because the experience demonstrated that correct adjustments of telecare might increase safety to people with or without their conscious interaction. The overall programme theory is refined to '*when people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer*', and emphasises the need to remember that the contexts are dynamic.

Dynamics in contexts

This programme theory included a significant aspect that needs to be acknowledged for telecare to continue to cause safety for all involved without unintended side effects. Telecare works in a dynamic context inhabited by dynamic stakeholders with ever-changing needs and abilities. Therefore, the reassessments of users must happen accordingly.

Cooperation with various other actors improved with increased knowledge in telecare. The resource group discussed challenges and solutions when they met and highlighted the need for cooperation in telecare. Apart from cooperating with staff in their own workplace, they also needed to cooperate with municipal actors

from disciplines that were new to them. Using technology requires new ways of working for staff (Moser & Thygesen, 2013) including cooperating with new partners.

The community care service aims to be seamless to the users and thus involving the call centre might add valuable perspectives to improve the service as is demonstrated from other studies (Roberts, Mort, & Milligan, 2012) and discussed in paper 1 from this study (Berge, 2016a).

Conclusion

The refined overall programme theory is sustained. 'When people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer'. However, nuances emerged that enabled discrimination between situations that worked well and those that did not work.

When vulnerable people had telecare, the staff experienced them to be safer because telecare had been demonstrated to alert and summon assistance when incidents occurred. Due to these experiences, staff trusted telecare and as a result, they were less anxious to leave users when they had to tend to others. Reduced anxiety influenced staff and improved their work satisfaction. Programme theory #6 'telecare will provide increased safety 24/7 (M), which will reduce staff anxiety (O) when vulnerable people remain living in their own homes (C)' was thus sustained. The increased safety becomes the mechanism in the context of vulnerable people living at home with telecare (and receiving community care) resulting in the outcome of reduced staff anxiety. This demonstrates how realist evaluation captures the dynamics in complex interventions; in this case, the

outcome (increased safety of users) becomes a mechanism causing yet a new outcome, reduced anxiety.

Telecare users were safer, and perceived themselves safe at home; however, for some telecare did not match their needs and abilities and thus caused unintended alerts. These alerts required staff to respond, causing them to reschedule and prioritise the alert without there being any actual need, resulting in increased workload. The staff had a programme theory, a driving force for them to commit to telecare, that telecare would reduce their workload. This did not happen, the staff experienced an increased workload. Programme theory #7 'when people have telecare they will feel safe (C) and will not need the staff to call on them (M) and thus the number of calls will decrease and cause the staff workload to diminish' (O) was refuted for the time being. However, this programme theory should be refined according to the overall programme theory and thus to include '*properly adjusted telecare that matches their need and abilities*'. Properly adjusted telecare will not cause unintended alerts and thus might reduce staff workload.

Another programme theory being refuted was #8: 'telecare is ethical in use only when people understand how to benefit from it and thus are able to consent to using it.' The staff changed their opinions as they realized it was possible to remain home, be happy and avoid moving without understanding the reason, telecare. As staff knowledge and understanding of telecare and its potential improved, this in turn caused better adjustments. The staff perceived telecare as being ethical (M) when users could live as they preferred (C), safe and happy in familiar surroundings without suffering negative effects from telecare (O).

Staff are significant in telecare acceptance. When they experience telecare to be beneficial to users, improving their safety, they facilitate implementation. Increasing knowledge and experience enable them to identify areas in need of

adjustment, and then they interact with users and telecare to continuously make improvements.

I have now presented all elements in this project and discussed them in their contexts. Now, I will move on to the overall discussion and show how these elements may be disentangled and understood in ways that allows for a more nuanced understanding of telecare.

Chapter 6 Discussion and implications

This chapter discusses the implications that the findings from my PhD study might have for policy, practice and future research. The thesis demonstrates how telecare produces different possibilities and challenges but it also reveals why each situation requires unique attention. The outcomes from telecare implementation vary according to how users perceive it to benefit them, whilst cautiously balancing the challenges versus chances to achieve the desired improvements in their situation. I demonstrate how telecare implementations can be traced from policy documents to individual context and highlight the impact individual acceptance has in achieving successful outcomes for society. Realist evaluation enables us to see how individual and infrastructural contexts influence each other, in mutual dependence, which I demonstrate in two papers, paper 3 (in review) and 4 (Berge, 2017) as is also depicted in Figure 4.

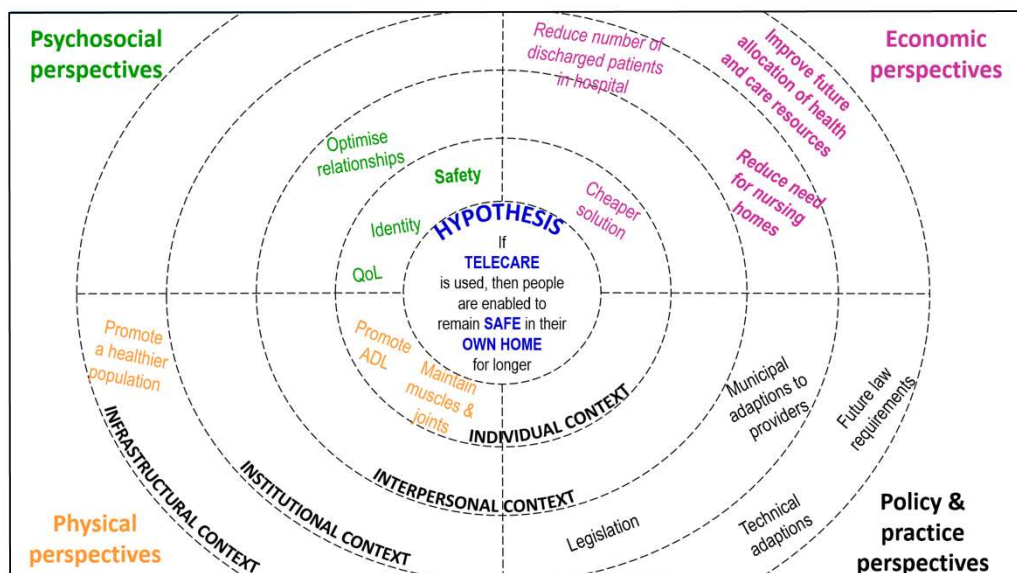


Figure 4 Contexts (Berge 2017 in review)

Cooperation influences telecare uptake – gap #1 in the literature

In paper 1 (Berge, 2016a) I identify and discuss the gap in the literature in relation to one of the reasons for slow uptake in telecare, i.e. problems in partnership working (Chrysanthaki et al., 2013; Greenhalgh et al., 2012; Milligan et al., 2011; Sugarhood et al., 2013). Literature reviews showed that partnerships in telecare often fail due to problems cooperating; however, the existing literature did not explore the impact of the partnership's internal complex social interactions. I pursued these gaps in the literature and suggested new ways of understanding partnership working in telecare in paper 1 (Berge, 2016a).

I argued that success in telecare partnerships depends on bringing together disparate knowledge and experience held by partners from different cultures. Different cultures hold different values that are part of what the partners bring, significantly influencing their choices and actions. Whether actions and choices are understood as rational or opportunistic depends on the partners' ability to recognize each other's underlying values. Rational actions and choices do not challenge trust, but perceived opportunistic behaviours do. Trust is vital for cooperation and influences further development of the partnership. Telecare is expected to constitute an important part of future health and care services (Kubitschke et al., 2010) and therefore understanding how telecare partnerships work is increasingly useful, as I demonstrate in paper 1 (Berge, 2016a).

Pawson (2006b) describes different levels of context into which interventions are implemented (Figure 4). Multi-stakeholder partnerships sit in the institutional context, where the stakeholders aim to adhere to governmental requirements from the infrastructural layer of context. In paper 1 (Berge, 2016a), I demonstrated how the stakeholders' individual and interpersonal contexts intertwine and consequently influence outcomes in the outer layers of context. This was the first paper from the study and it preceded my later approach to realist evaluation, however others have used the realist approach to demonstrate the importance of

trust in multi-stakeholder partnerships that addressed challenging public health problems (Jagosh et al., 2015), albeit not regarding telecare.

Telecare assessment influences uptake – gap #2 in the literature

In my second publication from this study (Berge, 2016b) I identify another gap in the literature and question the present ways of understanding and assessing telecare acceptance. User's acceptance is suggested to be another significant reason for slow uptake of telecare (Bouwhuis et al., 2012; K. Chen & Chan, 2011; Peek et al., 2014; Van Hoof et al., 2011). I identified and discussed three types of shortcomings of current assessments that used technology acceptance models (TAM) in assessing telecare acceptance. TAM is hitherto the most common model in assessing telecare acceptance, and I argue it is essential to recognise its shortcomings when applied to telecare. Three important aspects of telecare are not considered within TAM. The first occurs in dealing with user's views on telecare, which may be real or imagined, either of which affect acceptance, thus potentially hindering telecare use. The second concerns how humans and things relate to each other in ambiguous ways. The third is that users adapt to technology and/or adjust it to fit their purpose better. I argued that entanglement theory (Hodder, 2011, 2012) could cover these situations and demonstrated its advances on TAM by applying entanglement theory to the above aspects of telecare illustrated by situations from the literature. I concluded that understanding telecare acceptance retrospectively by using entanglement theory may improve how we assess telecare acceptance (Berge, 2016b). Challenges in understanding and assessing telecare acceptance continue to be debated (Cimperman, Makovec Brenčič, & Trkman, 2016; Peek et al., 2016).

Applying a new approach to telecare evaluation

Having demonstrated the need to assess telecare differently from technology acceptance and arguing that it is vital to understand that people reason differently about how they might benefit from telecare in paper 3 (in review), I applied realist evaluation to improve this understanding, as I demonstrate in paper 4 (Berge, 2017). Telecare does offer some possibilities that are otherwise difficult to achieve to sustain safety and support independent living, which users prioritised, however sometimes in unexpected ways. Realist evaluation showed why people reason differently about telecare. It illuminated how differences in people's contexts influenced their reasoning about possible benefits that in turn affect outcomes (Pawson & Tilley, 1997). The overall success from telecare depends on how each user accepts and utilizes it, as people will not use it if they do not like it (Bouwhuis et al., 2012; Peek et al., 2014). Applying the structured approach of realist evaluation enabled me to identify patterns in outcomes that followed from people's reasoning about the resources (mechanisms) that telecare brought into their context as I have illustrated in paper 4 (Berge, 2017). Realist evaluation enabled me to demonstrate how and why the users reasoned differently about the offered telecare equipment depending on their circumstances and how they perceived it to improve their situation. In this way realist evaluation produced richer answers that distinguished between for whom telecare worked, or not, why and in which circumstances, and thus illuminated the need for improvements. Using realist evaluation enabled discovery of the reasons for varied outcomes.

My research supports previous arguments stating that controlled designs like RCT cannot deal with the complexity in social interventions such as telecare (Barlow et al., 2007; Finch, May, Mair, Mort, & Gask, 2003; Greenhalgh & Russell, 2010). My research further demonstrates that it is essential to improve understanding of *why* telecare evaluations show disparate results as I discuss in paper 3 (In review) and in paper 4 (Berge, 2017) I demonstrate how realist evaluation enables this nuanced understanding. Previous telecare evaluations report disparate results,

either showing that telecare improve people's situations and enables them to remain living at home (Bowes & McColgan, 2013; Cartwright et al., 2011) or that telecare does not provide such support (Steventon et al., 2013). Varied results from different evaluations show different fragments of a complex reality (Tilley, 2000). In paper 3 (In review) I show how controlled designs do not look inside the black box to identify what it is that causes changes. I argue that it is necessary to identify significant interacting elements in the intervention by opening the black box; asking *how* telecare causes change, *for whom* and to *what extent* (Pawson & Tilley, 1997). Realist evaluation provides structured ways of addressing the elements that constitute the complexity by breaking down the contexts into layers and using the checklist, VICTORE (Volition - Implementation - Context - Time - Outcome - Rivalry - Emergence), to guide the search for explanations (Pawson, 2013) as I discuss in paper 3 (in review). This structured approach provides transparency and improves understanding of the complex and dynamic interplay of elements in a way that rigid approaches like RCT are not designed for.

Context: Appreciating everyday life

My research showed that telecare supported peoples' possibility to continue to live as usual, which was significant to them. Applying realist evaluation required me to firstly understand the context in which telecare is intended to make a difference as is described in the methodology. I explored the users' context through the initial interviews and learned how their context constituted their everyday life activities. This was the starting point for the implementation at the individual level. From several interviews, an image and a pattern emerged revealing how users also recognised potential risks and needs for improvements. The pattern adhered to the intention in the refined programme theory that reads; *'When people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer'*. The most important overall pattern that emerged was peoples' desire to

remain living in their own home. My research was able to show several distinctions in this pattern through the realist approach.

Similarly to previous findings, (Bergland & Slettebø, 2014; Haak et al., 2007) the users in my study preferred to remain in their home continuing with everyday activities. They appreciated to continue their long since established routines and to help others with contributions, however small, which they were able to do whilst living at home. These activities included, for example, housekeeping, baking, knitting and inviting family to coffee or dinner, and appeared to confirm their self-image and identity. These findings confirm results from previous studies suggesting that older people wish to remain at home, and that everyday activity proves positive for their well-being and in maintaining identity (Mahler et al., 2014; Parks, 2015; Sixsmith et al., 2014) which Wiles, Leibing, Guberman, Reeve, and Allen (2012) found important for older people to maintain independence and autonomy. In addition, the home itself holds memories and history that support identity and continuity (Young, 1997) and consequently remaining at home is very important to people with dementia (Parks, 2015).

People with cognitive impairment who live at home are found to have better quality of life than those living in institutions (Nikmat, Al-Mashoor, & Hashim, 2015). People moving from their home experience a change in their status from autonomous citizens to nursing home residents. Their physical and social environments change and affect identity and social interactions as they may become subdued in institutional routines and staff expectations (Kofod, 2008). Thus remaining at home has positive effects for the individual that telecare can support.

Regarding the infrastructural context (Pawson, 2013) the governmental aim concerns better allocation of resources (Helse- og omsorgsdepartementet, 2013) which may be achieved as the pressure on institutions such as nursing homes

eases when more people remain at home. This in turn will decrease expenditure as is discussed in paper 3 (in review).

Safety increases activity

My research found that when people continued their life at home, feeling safe, they consequently dared to be more physically active which they appreciated. The users perceived falling to be the main safety threat and many feared the consequences of a fall because no one would know of the incident. Very often, a fall caused them to review their safety situation. When people are afraid of falling their anxiousness tends to restrict their activity, which in turn increases the risk of falling (Fletcher & Hirdes, 2004; Friedman et al., 2002; Scheffer et al., 2008). When you live alone and have to trust your own ability to cope in any situation, it appears reasonable to try to avoid risky situations. The users, relatives and staff participating in my study perceived the users to be prone to falling, and they all feared the consequences if no one knew about the fall. Therefore, inactivity became a means to avoid falling as I demonstrate in paper 4 (Berge, 2017) despite activity being the better solution to maintain muscles and joints, as found in previous research (Fletcher & Hirdes, 2004; Friedman et al., 2002; Scheffer et al., 2008). The users were pleased with themselves for daring to be more physically active due to having telecare. They mentioned, for example everyday activities like walking to the mailbox, using the staircases and moving about more in the house. By keeping up daily domestic activities, they reduced inactivity (Berge, 2017).

Telecare influences identity and dignity

People in my study preferred to remain at home when they felt safe due to having telecare. Several expressed that they valued being in control of their life, being

able to choose and decide for themselves and being independent from others (Berge, 2017). My findings cohere with earlier findings suggesting that remaining at home provide benefits for people in itself. These include being in control, staying active and being able to engage socially which is found to be important for a person's identity (G. Craig, 2004; Sixsmith et al., 2014). Maintaining daily activities and routines, which is possible when remaining at home, are also found to support people's identity (Parks, 2015; Wiles et al., 2012). Being able to remain living in familiar surroundings at home, staying active doing everyday tasks is known to positively influence older people's lives (Mahler et al., 2014; Parks, 2015; Sixsmith et al., 2014). Further, this may keep people from being dependent on others which often is perceived a threat to their dignity (G. Craig, 2004; Wiles et al., 2012). Home *per se* supports identity and sense of self because it contains memories and routines that support people's cognitive capacity (Parks, 2015). This proved helpful for some users with dementia who remained living in their familiar surroundings longer when telecare provided safety and they benefitted from other services that helped them to manage everyday life. However, safety remained an important issue.

Relatives and staff appreciated when users maintained daily activities and felt safe, which in turn led the relatives and staff to perceive the situation as safer.

Ethical contradictions in dealing with risks and safety

My research demonstrates that when telecare functions as intended it promotes independence and increases safety for the user, which reduces anxiety for relatives and staff as I have discussed in chapter 5 and in paper 4 (Berge, 2017). Programme theories from various stakeholders' perspectives cohere, however emphasise slightly different views between users, relatives and staff. Programme theories #1, and #5 (see page **Feil! Bokmerke er ikke definert.**) concern improved

safety from the users' perspective, while #3 and #6 concern reduced anxiety for relatives and staff as a consequence from the user being safer. My research concluded that telecare might fill existing safety gaps because it provides safety at home 24/7. The people in my study often lived alone or with an equally frail spouse, whom they expected would be unable to call for assistance if necessary. They perceived their safety to be at risk, which caused them to question their ability to remain at home. This is similar to previous findings showing how lack of safety was a main reason for older people to move from their homes (Fonad et al., 2006).

When older people perceived their safety to be at risk, they and/or their relatives often made arrangements to improve safety. The options this far had been community care or moving, for example into sheltered housing or nursing homes. These options cause huge changes in people's lives, such as diminished autonomy (Kofod, 2008), and thus many people strive to avoid moving out of their home (Bergland & Slettebø, 2014; Kofod, 2008). The staff in my study describe in the initial focus groups how users refer to accepting community care as 'crossing a threshold' because it includes admitting 'strangers' access to their home and thus imposing on the users to adapt and adjust themselves to the service (Bowes & McColgan, 2013). The users perceive the next threshold to be accepting a move into a nursing home (Kofod, 2008). These steps are very significant and the users found telecare to provide a better alternative that fills a long acknowledged gap.

However, older people appear equally to fear being a burden to others. Their main aim is to stay independent and manage by themselves, and many strived to achieve this whilst they continued living at home. When relatives recognised their struggle, they worried that it was too risky to remain at home, as is known from previous studies (Buhr, Kuchibhatla, & Clipp, 2006; Kofod, 2008). The relatives often tried to increase safety by urging the older people to move into care. Older people might therefore be reluctant to confide in relatives as it might 'backfire' on

their attempt to remain at home. This was also the case with the older persons in my study as they were reluctant to expose their vulnerability to relatives, because they did not want them to worry.

The relatives, however, often appeared to be aware of their loved ones' risky situations. I have demonstrated how they were pulled between the older person's desire to remain at home prone to risky incidents and their own anxiety about the uncertainty in that situation. All the relatives in my interviews had experienced incidents that underpinned their anxiousness. In such situations, it is natural to seek increased safety (Olsson, Engström, Skovdahl, & Lampic, 2012). When the only option interferes in a way that is not acceptable to the person it concerns, the situation becomes delicate and challenging to both parties as is described in similar dilemmas (Greenwood, Habibi, & Mackenzie, 2012; Landau, Auslander, Werner, Shoval, & Heinik, 2010).

Telecare offered safety with less interference and therefore represented an acceptable solution to both parties, the older person and the relatives. It might be easier for users to more openly discuss their worries about safety, risks and anxiety when they do not need to put their life at home at stake. Equally, it might be easier for the relatives to suggest precautions when they do not cause the persons to give up their home and independent living. I have not discovered this topic to be previously discussed in literature. A somewhat similar situation is discussed by Olsson et al. (2012) who suggest relatives choose technology when they perceive it to increase safety. They suggest that the opportunity to create safety with technology overshadowed potential ethical problems. I argue from the evidence demonstrated in my research that telecare does not only promote safety for those who experience that outcome, but in addition supports independent living which many people prefer to other living arrangements. It is important that relatives also approve of the chosen solution as they have an additional personal aim to diminish their own anxiety as is previous found (Davies, Rixon, & Newman, 2013;

Mehrabian et al., 2015). Davies et al. (2013) found that relatives experienced less strain with telecare while Mehrabian et al. (2015) found that relatives felt safer and appreciated it more than the users did themselves.

Staff found that telecare increased the users' safety and extended the time people could remain safely at home. Staff referred to the ethical challenge they experienced when they had to leave vulnerable users, and described how that troubled them. The staff regularly had several users whom they were reluctant to leave alone as their behaviours were difficult to foresee. They perceived it to be easier to leave users who wanted to remain at home when they had telecare because they trusted the telecare to alert if necessary.

There is a challenge in how relatives, staff and older people themselves accept risk-taking in old age. The older people do not want to be a burden and believe themselves to be one when they remain at home and risk is high. Relatives influence their decisions and also tend to choose safety over independence contrary to the older person's priorities. Telecare increases safety and appears to reduce how users, relatives and staff perceive risks when the consequences are acceptable to users. It might be appropriate to question ethical aspects of *not* offering available services like telecare to people to consider when they need to improve safety.

The contribution made by relatives

The findings in this study demonstrate that relatives perceive telecare to increase safety, which was important for them to continue supporting older relatives to remain at home. In addition, my findings emphasise the importance of support from relatives for older people to be able to remain home as I demonstrate in

paper 4 (Berge, 2017). The cooperation between community care and relatives in this telecare study enabled an increase of time at home for the older person. There is an ongoing debate to what extent relatives should provide help. The common opinion in Norway is that the municipal services are responsible for providing care to the extent necessary, which is what the legislation requires. However, figures from the Norwegian IPLOS⁵ system show that about 40% of older persons who received community care also received informal care (Daatland et al., 2012). It is estimated that informal care constitutes about 50% of all care in Norway (Helse- og omsorgsdepartementet, 2011b). It is evident that support and care from relatives has been (Daatland et al., 2012) and will be important in enabling older people to remain at home (Helse- og omsorgsdepartementet, 2013). With the prospects of future demographics, the impact provided by informal care is likely to increase.

It is argued that society takes advantage of the efforts from relatives without providing them sufficient support to continue their work (Helse- og omsorgsdepartementet, 2011b). A similar situation appear to exist in several Western countries (Ahlström & Wadensten, 2011; Boisaubin, Chu, & Catalano, 2007; Greenwood et al., 2012; Shaw et al., 2009). Some predict that in the future people will refrain from taking on the responsibility of caring for their family as they do today (Milligan et al., 2011). The experiences from this telecare evaluation support previous studies (Davies et al., 2013; Mehrabian et al., 2015) indicating that telecare might positively influence relatives' commitment by diminishing their anxiety about safety, and thus might increase their willingness and ability to support their older relatives.

⁵ **IPLOS** refers to individual-based nursing and care statistics that in a standardized way describes needs for assistance to persons applying for or receiving care services in Norway.

Enduring the side effects

The users perceived more to be at stake than the relatives as the users risked losing their life at home, and thus they endured the side effects and yearned for telecare to work as intended. The users relied on telecare and they soon became confident about receiving help if an emergency occurred. This knowledge gave them peace of mind, and encouraged them to continue their daily life. Several users perceived telecare to provide safety 24/7, which surpassed any previous solutions they had experienced, such as occasional visits or phone calls. They therefore came to regard telecare as *the* essential element enabling them to remain at home as I have discussed in paper 4 (Berge, 2017). The literature discusses how people often stop using technology when they do not experience it to be helpful or if it annoys them (Bouwhuis et al., 2012; Peek et al., 2014; Steele et al., 2009). That was also the situation for some users in this study, to which I will return. What I found more interesting and previously not discussed is the extent to which some people endured severe side effects from telecare as I discuss in paper 4 (Berge, 2017). Some users endured disturbances caused by unintended alerts for a surprisingly long time. This included noises from the equipment, calls from the call centre staff and at times, typically at night, somebody letting themselves into their home to check on them. The users were annoyed, troubled and sometimes scared. They disliked being disturbed and they particularly disapproved of being a burden to the system (to the staff at the call centre or community care) or to relatives when they were the respondent. Typically, the users perceived themselves as responsible for the unintended alert and consequently for the respondent's increased workload. When being assured they were not a burden to the system, the users to a higher degree accepted being disturbed themselves. Bearing in mind that to some of these users telecare was *the* element that kept them from having to move, it is understandable that they accepted the side effects. The other option would include leaving the way of life they knew and valued. These examples can be seen as demonstrating how users reasoned that telecare made an essential difference that enabled them to continue living as they appreciated without having to make major changes in life.

Relatives often encouraged the older persons to try telecare, and the older people frequently relied on their relatives' advice. However, when encountering unintended alerts the relatives endured less (Berge, 2017). They were often the first to question whether telecare was a bad idea and often encouraged the user to stop using it. The users very often continued having telecare despite the advice from their relatives. However, relatives supported the users who wanted to continue having telecare, but emphasizing that it would be acceptable to quit whenever they wanted.

When the users recognised possible positive effects from telecare, their tolerance to side effects increased. It appeared to be a balance between older user's perceived usefulness and the effort associated with accessing these benefits that impact the adaptation process, as is suggested regarding ordinary technical devices (Karlsson, 2013). However, perceiving possible benefits from telecare appeared to be a strong driving force for continuing using it, not previously highlighted. Therefore, it is important to let potential users experience if and how telecare meets their needs.

Telecare embedded in daily life

Preconceptions about older people being negative about technology exist (Karlsson, 2013; Kerbler, 2013) but in my study older people's acceptance of telecare was high. When telecare worked well it became an integrated part of their home and life, to which the users seldom paid any attention. A staff member put it eloquently: *"... when telecare works as intended, it's invisible."* This is an indication of well-functioning networks (Law, 1992) which is a perspective I have rarely seen discussed in the telecare literature. I will therefore argue it to emphasise the importance of properly adjusted telecare.

Some users had to interact to turn the home unit off when they left the house, and on when they returned. Very often, they made that into a habit, like locking the front door. If they occasionally forgot, they accepted it being forgettable like any other task and did not feel embarrassed by the call centre contacting them, as I demonstrate in paper 4 (Berge, 2017). My research matches previous findings that suggest that when people realise the advantages and disadvantages in technology, their understanding gets more nuanced (Boise et al., 2013) and their attitude becomes positive when they perceive it beneficial to them (Karlsson, 2013; Kerbler, 2013). Age *per se* is not a barrier to using technology (Cartwright et al., 2011) but knowledge and understanding is essential in telecare acceptance (Kerbler, 2013) as my study also shows and refers to in papers 2 (Berge, 2016b) and 4 (Berge, 2017).

Staff attitudes to telecare

My research demonstrated that the staff embraced telecare when they experienced its positive impacts on the users' possibilities to remain at home. The staff endured extra workloads due to unintended alerts, which they considered to be 'teething troubles' that they expected to pass with improved experience and knowledge. On the other hand, they disapproved if telecare annoyed or scared the users. Then, they took action to make improvements, or in cases when they experienced telecare to be incongruent with the user's needs, they argued for its removal. In my study, the staff demonstrated the importance of having knowledge and experience that enabled them to handle telecare optimally. The findings from my research support results reported in other studies (Brewster et al., 2014; Saborowski & Kollak, 2015).

The staff in my study had more prejudices about telecare before they started using it, than when they had gained experience from it. When cooperating with telecare they discovered new and improved ways of offering assistance. This corresponds with previously reported findings from other studies (Bowes et al., 2014; Breivik, 2014) and underlines the need to ensure that staff achieve education and experience in using telecare as part of their approach to improve users' everyday situations at home. My research demonstrates that staff knowledge is vital as it influences their acceptance and that in turn influences how they present it to potential users. Thus they hold an important role in telecare dissemination, as is also suggested in other studies (Saborowski & Kollak, 2015).

Telecare's influence on social interaction

My research shows that the initial worries of staff about telecare causing social isolation diminished when they experienced telecare over time and improved their understanding of its benefits and shortcomings. Before they experienced telecare, staff worried that it would cause people to become socially isolated. It is a concern raised in the literature, whether telecare will replace human care (Mort et al., 2015). The staff adopted technological knowledge into their professional knowledge and improved their understanding about how telecare might contribute in different contexts. When the staff perceived telecare not to benefit a user they were truthful about it and acted accordingly. They were especially attentive to social isolation because they expected it to be a side effect. Staff were, however, well aware that some users preferred to manage without them 'running about' as long as they felt safe, while others enjoyed their visits. Even though none of the users in this study perceived having less contact with other people due to telecare, I cannot argue that this applies to everyone. Perceived loneliness in old age depends on several variables (Yang & Victor, 2011), it varies between countries, and is considered rare in Norway (Hansen & Slagsvold, 2015). People's

experience of using telecare is individual and to some it might not be the right solution, again highlighting the necessity for individual adjustments.

A flexible application in dynamic lives

My research emphasises the need to pay sufficient attention to the fact that the contexts are dynamic, and thus require careful individual tailoring to produce the intended outcomes. Individual tailoring includes acknowledging and planning for adjustments that occur because of changes in users' health and living conditions. Users, relatives and staff experienced several unintended alerts that occurred due to inappropriate adjustments, discussed in chapter 5 and in paper 4 (Berge, 2017). The staff that adjust the sensors have to understand each user's particular needs, their specific context and in addition the nature of, and the requirements from each sensor. This is a challenging task as humans do not live machine-like lives (Fisk, 2003) and in addition the users and their circumstances are dynamic and changing. Unintended alerts indicate a mismatch between the technology and the user's needs and/or abilities *at present*. The occurrence of unintended alerts might well indicate there has been a change that in turn requires adjustments, and should trigger reassessment.

Telecare acts in dynamic contexts and thus readjustments should be included in routines. The technology in this project required a technician to configure, install and reconfigure when making necessary adjustments. I have emphasised the importance and challenges in adjusting telecare correctly in paper 2 (Berge, 2016b) and this is also argued by others (Peek et al., 2014; Steele et al., 2009). Unintended alerts might cause users to quit telecare, and ignoring the need for adjustments causes disturbance in people lives. It is essential to anticipate readjustments, and to establish and incorporate them in daily routines. Thereby readjustments may be carried out swiftly with minimal consequences. This

perspective does not appear to be an issue in the existing literature. The problems that occur when technology does not match needs are discussed (Bouwhuis et al., 2012) but not the need to focus on readjustments as the users situation is dynamic, often unpredictable and consequently frequently changing.

The main reasons for readjustments concern the users and their context. The staff are familiar with the users, relatives and local conditions in the district, and as they call on several users, they are regularly in the area. As a result, they are more easily accessible and can therefore reduce delays in adjustments, which in turn minimizes the risk of unintended alerts. The staff, therefore, appear to be the most expedient in carrying out readjustments. This requires them to hold the appropriate knowledge to make adjustments.

The telecare interface should allow the community care staff to implement and adjust it when they hold adequate training. The users' needs and their contexts must be the focus, which requires a healthcare perspective in each situation. This implies that the telecare developers and suppliers have to produce technology that meets these requirements, and that the staff carrying out the adjustments get proper training and education. This in turn, influences the development of education in health and care professions, and calls for their adaption to a future in which telecare appears to constitute an important supplement to traditional care.

Telecare did not work for everybody

Significant knowledge from using realist evaluation includes knowledge about those for whom telecare does not work. Some users relinquished telecare when they perceived no benefit from it, and/or did not achieve increased safety. In

paper 4 (Berge, 2017) I have demonstrated how insufficiently adjusted technology commonly caused negative or unintended outcomes. On some occasions, the sensor's sensibility range was inadequate, for example, the bed sensor required the bodyweight to surpass 50 kilograms, which excluded some tiny women. These situations require the developers to make changes to the technology.

In other situations, the technology might have proven beneficial but when the users experience recurrent unintended alerts, some did not perceive their needs grave enough to withstand these side effects. A few users later changed their minds or their relatives persuaded them to make a second try, which often turned out better as the adjustments were better matched to the user's needs. This underlines my previous emphasis on the need for correct assessments and adjustments for each user. Correctly adjusted telecare is a prerequisite to achieving a well-working network of telecare (Latour, 2005; Law, 1992).

In situations when telecare does not work as intended, it becomes evident how telecare constitutes a part of a network (Latour, 2005) or an entanglement (Hodder, 2012). In paper 2 (Berge, 2016b), I argue how the relation between humans (users, relatives, staff etc.) and non-humans (telecare) can be perceived as an unstructured entanglement in which all involved become 'entrapped' (Hodder, 2014) and dependent on each other's actions. By taking the perspective of things, entanglement theory (Hodder, 2012) captures the mutual dependences and dependencies as I describe in paper 2 (Berge, 2016b:103). Correct adjustment of telecare (TH) depends on the user (and/or relatives) giving the correct information (HH) to the person assessing who must understand it correctly (HH) and forward the information, written and/or oral, correctly to the right person (HH). The circle starts again in giving and receiving information (HH), and then the correct configurations (TH) must be made to the telecare sensors that need to react as intended (TT) when a situation arises (HT). Hodder (2014:20) describes this

entanglement as humans getting: ‘... *caught in a double bind, depending on things that depend on humans.*’

In paper 4 (Berge, 2017) I demonstrate how incorrectly adjusted telecare caused a user to relinquish telecare whilst continuing to ‘suffer’ from trying it as she remained anxious long after its removal. Understanding this situation from entanglement theory as described by Hodder (2014), this is a likely result when trying to untangle the unpredictable interconnections in a situation. In the highlighted situation, there were unidentified influencing elements from the initial assessment that continued to cause influence. The user’s situation remained unsafe, the expectations of telecare failed, as she did not receive a solution that matched her needs and abilities, and instead of telecare easing the situation, it emphasised her vulnerability. She depended on telecare (HT) that depended on assessment (HH/HT) that did not meet her needs (TH) and thus caused unintended alerts (TT) that scared her (HT). It highlights the need to make thorough assessments of the situation as each implementation holds within it a potentially more severe interference than initially seen. There are in other words, various aspects caused by imposing telecare on older persons as well as imposing on them the prospect of moving. The reasoning about what to do must reflect ethical perspectives for each individual to ensure that the least intrusive option is chosen.

Entanglement theory offers possible explanations about the other major reasons discovered as to why some relinquished telecare. As I discuss in paper 4 (Berge, 2017) some users perceived it to be too intrusive to allow the community care staff admittance to their home in an emergency, even if that was the objective in case of alerts. These users appeared not to mind the technology *per se*, they disapproved of the idea of someone having access to their home, and thus they considered telecare too interfering to their privacy. Hodder (2011:182) argues the entanglement between human and non-humans to be:

‘... very difficult to predict – because so highly interconnected in so many dimensions and directions, entanglement is also practical and everyday – dealing with real forces as much as imagined ones.’

I have never seen these perspectives in telecare previously highlighted, however various reasons are given that cause people to stop using technological assistance, amongst others fear of social stigma and fear of social isolation (Allen, Foster, & Berg, 2001; Erber & Szuchman, 2015; Kang et al., 2010). Using the entanglement theory perspective emphasises that there are several aspects interfering and entangling in technology implementation (Hodder, 2012; Latour, 2005) which makes it important to analyse every situation to improve understanding (Pawson & Tilley, 1997). Accepting that the technology in telecare is but one part of the service and that the part that includes the responding human action might appear more intrusive to some is new and interesting, and needs further research.

Telecare – the safety piece in the jig-saw

My research has demonstrated how telecare can fill the safety gap that other services cannot. For vulnerable people to remain safe at home, they also depend on a variety of other issues to be covered. Such issues include basic personal and domestic needs like personal care, shopping, making food, eating, cleaning and social interactions. Community services like ‘meals on wheels’, day centres, cleaning services and personal help are other pieces in this jig-saw. The users explain how their everyday situation consists of different tasks and how safety has been the most difficult problem to solve, which I discuss in paper 3 (in review) and paper 4 (Berge, 2017). To provide the users with a realistic service to support them to manage everyday life, they need a tailored service in which telecare is an essential part that provides safety. I have not seen previous discussion about how telecare needs to interact with and to supplement other (community) services to match individual needs. Staff, relatives and users regarded telecare as an

additional service to improve the ability to remain at home. Most of them referred to telecare being the 'safety piece' of the jigsaw in the care service, whilst still realising its limitations in the context where other services contribute complimentary inputs.

Chapter 7 Conclusion

In this study, I have used realist evaluation to further understanding of telecare, a complex social intervention implemented in community care services. Realist evaluation enables a structured approach and by applying it, I have managed to identify and untangle significant aspects to telecare implementation and acceptance that are otherwise difficult to separate. I have opened the black box and illuminated how telecare involves and requires a variety of stakeholders and processes happening simultaneously in multiple contexts. Because I have used realist evaluation in opening the black box, I have been able to disentangle the complex social interactions that occurred and identify the elements that made telecare work, for whom and in which circumstances. I have demonstrated that telecare needs a structured evaluation approach that takes into account its complexity, comprised of multiple stakeholders and contexts.

A central concern of this project has been the range of stakeholders involved. I contributed to improved understanding of this issue by looking at telecare partnership working in a different way. The new understanding builds on theories in trust and partnership working and is informed by rational choice theory. I demonstrated how various stakeholders bring in disparate knowledge that is essential to their mutual goal and how they depend on understanding what guides other partners' reasoning and choices. These aspects constituted a challenge because the partners belonged to different disciplines and thus related to disparate realities that were sometimes conflicting despite their aim of benefitting from the mutual goal. Acknowledging these challenges and realising the need to understand what guides actions and choices should improve partnership cooperation.

Chapter 7 Conclusion

Telecare acceptance has so far been understood using various perspectives meant for other purposes, and which have consequently proved to be insufficient when used to assess telecare acceptance. In this study, I have demonstrated that telecare needs to be assessed in the social context in which it interacts, to include the users' views on telecare, both real and imagined; to recognise the ambiguous interaction between human and things; and to acknowledge the users intended and unintended adjustments and adaptations to telecare. When assessed in its rightful context and according to the specific user's needs, several perspectives emerged that helped to explain and understand the multiple elements influencing telecare acceptance.

Understanding the importance of assessing and adjusting telecare correctly and on an ongoing basis is another original contribution to knowledge. I have pursued different programme theories and demonstrated in paper 4 how they constitute patterns, or demi-regularities. Telecare operates differently with different users according to their needs, abilities and expectations. Telecare interacts in dynamic contexts and needs to be adjusted accordingly. My study suggests that we need to better understand how telecare assessments differ from other kinds of technology assessments.

The users typically wanted to remain living as independently as their circumstances allowed, and preferred to remain living at home. They wanted to avoid burdening others and many therefore strived to keep up appearances. People consider benefits against disadvantages when they have choices. When they could not manage safely by themselves, needing assistance or increased safety, their options were usually limited to community care and then the nursing home, depending on physical and/or cognitive needs. These options required them to yield privacy and/or independence, which many regarded as too heavy a price to pay and therefore postponed revealing their needs as long as they dared. Telecare represents a novel option that provides safety in addition to or instead

of community care. Vulnerable people in need of increased safety (C), use telecare that responds to incidents by summoning assistance (M) and thus provides increased safety that enables users to remain living at home with minimal interference according to their wishes (O). People reasoned differently about how intrusive they regarded telecare to be, usually considering it a less intrusive option.

People have disparate goals and some rejected both telecare and community care service. Using different programme theories, patterns emerged that demonstrated variations in CMOc as I show in paper 4. Users' reasoning about telecare and the service it implies and how it matches the users' context must be thoroughly assessed and telecare adjusted individually. It is essential to take into consideration that telecare interacts in dynamic contexts and thus requires readjustments according to emerging changes in needs.

Telecare offers solutions that appear to be more acceptable to users as they do not require them to move out of their own home. When users had tried telecare and experienced for themselves how it increased safety and thus provided opportunities the users valued, they appeared to endure surprisingly well the side effects from incorrectly adjusted telecare. The users had to experience its potential in order to endure these side effects, however better adjustments are necessary to reduce side effects and improve outcome. The users' alternatives to telecare brought them side effects that they regarded as more intrusive and limiting, such as adapting to other's routines and giving up independence. The users endured more side effects than relatives and staff, presumably because they had more to gain and less to lose by choosing telecare.

Relatives perceived that their whole situation was altered when they understood that the older person had increased safety due to telecare. Their situation eased because they worried less, being confident that telecare would respond if an

Chapter 7 Conclusion

incident happened. Before having telecare, the relatives usually worried because they understood the risks and feared for incidents.

The staff experienced increased work satisfaction due to having confidence in telecare. They found that vulnerable users were safer in their home and consequently perceived their work to be less of a strain despite experiencing increased busyness due to unintended alarms. The staff did not accept that users should have telecare when it disturbed them. In such situations, they called for adjustments or removal of the sensors involved. Staff knew users, their needs and abilities and following their increased knowledge in telecare, they better understood its possibilities and limitations. They understood how telecare could be applied to improve the users' situations. Gaining experience in telecare appeared to be necessary for all stakeholders to benefit optimally.

Before experiencing telecare, the staff worried that it would cause social isolation but they found that this was not a problem. The same applied to users and the relatives who often had long since established routines in calling each other daily. Telecare did not inflict negatively on social routines. People continued calling and visiting each other and were happy that the social situations no longer included checking if the older person had suffered an incident. The reduction in staff calls on users related to night-time visits and was not missed by users, and new users were offered telecare instead of staff calling on them.

Some people were already using community care and/or other municipal services but still experienced their situation as unsafe. For them telecare filled the gaps that other services could not do. Before having telecare, their only option would be to move into sheltered housing or a nursing home. Frail people that experience increased risk due to safety gaps (C), increase safety by telecare that covers these gaps 24/7 and summons help in response to an incident (M) enabling them to remain living at home (O).

Unintended alerts should be regarded as symptoms that telecare is not correctly adjusted at present, and thus their appearance is likely to identify the need for reassessment and reconfiguration, or a change in the devices provided. Unintended alerts are negative side effects that must be avoided as they distress people and cause some to refrain from using telecare. Unintended alerts increase workload to staff and given the severity in side effects, it is essential to reassess and reconfigure telecare rapidly. Consequently, the staff working in the area who know users and their context appear to be the right ones to undertake this task. They are more available and thus might complete the task more swiftly. I therefore argue that telecare needs to have a user interface that allows health care personnel to adjust it.

Some users did not experience telecare to be beneficial for them. These cases included, typically, a mismatch between the user's needs and abilities, and the installed telecare and how it was configured. Telecare needs to be understood as including a variety of elements constituting the *telecare service* to which a user might object, including other elements than the technology. The response to an alert is also part of the telecare service.

I have tested the refined programme theory: 'When people have properly adjusted telecare that matches their need and abilities, they are and feel safer and may be able to remain in their home for longer' and found it to be true. I have discussed the process towards its refinement. As long as the technology does not adjust itself, the community care staff need to be attentive to changes in the users or their context.

Limitations and next steps

Telecare was new to everyone in this study, not only to users, relatives and staff but also to researchers, the municipality and to the technicians. In addition, I used realist evaluation, which had never been used in telecare settings before and was new to most of the researchers involved in the study. These elements might have limited the implementation and the research as we learned as the project and the research developed. By establishing a new project, we have gained experiences that presumably will improve future research and learning as realist evaluation ideally requires more cooperation than was feasible here. In addition, the steps in realist evaluation could guide the project from the beginning in future research.

There are several aspects emerging from this evaluation that need further research. All findings need further scrutiny as telecare represents a dynamic area that is likely to develop with further experience and knowledge alongside technological developments. The possibilities that telecare might have for people with dementia and how telecare interplays with other services are examples of perspectives that need further research. The influence from telecare and technologies in healthcare services will need to be part of healthcare curricula, as healthcare personnel need additional knowledge to continue developing and improving areas where users can benefit. Last but not least, the rapid development of technology requires close attention as joint research between disciplines probably will be beneficial.

References:

- Ahlström, G., & Wadensten, B. (2011). Family members' experiences of personal assistance given to a relative with disabilities. *Health & social care in the community*, 19(6), 645-652.
- Aiken, L. H., Sloane, D. M., Bruyneel, L., Van den Heede, K., Griffiths, P., Busse, R., . . . Lesaffre, E. (2014). Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. *The lancet*, 383(9931), 1824-1830.
- Al-Amer, R., Ramjan, L., Glew, P., Darwish, M., & Salamonson, Y. (2015). Translation of interviews from a source language to a target language: examining issues in cross-cultural health care research. *Journal of Clinical Nursing*, 24(9-10), 1151-1162.
- Allen, S. M., Foster, A., & Berg, K. (2001). Receiving Help at Home The Interplay of Human and Technological Assistance. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 56(6), S374-S382.
- Ansell, C., & Gash, A. (2007). Collaborative governance in theory and practice. *Journal of public administration research and theory*, 18(4), 543-571.
- Astbury, B., & Leeuw, F. L. (2010). Unpacking black boxes: mechanisms and theory building in evaluation. *American Journal of Evaluation*, 31(3), 363-381.
doi:10.1177/1098214010371972
- Ballantyne, N. (2015). Human Service Technology and the Theory of the Actor Network. *Journal of Technology in Human Services*, 33(1), 104-117.
doi:<http://dx.doi.org/10.1080/15228835.2014.998567>
- Barlow, J., Singh, D., Bayer, S., & Curry, R. (2007). A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. *Journal of Telemedicine and Telecare*, 13(4), 172-179.
- Barth, F. (1966). *Models of social organization* (Vol. 23). London: Royal Anthropological Institute.
- Barth, F. (2007). Overview: Sixty years in anthropology. *Annual Review of Anthropology*, 36, 1-16.
- Bearon, L. B. (1996). *Successful aging: what does the 'good life' look like*. Paper presented at the The Forum.
- Berge, M. S. (2016a). How do we understand partnership working: Experiences from a telecare project. *Social Policy & Administration*. doi:10.1111/spol.12273
- Berge, M. S. (2016b). Telecare acceptance as sticky entrapment: A realist review. *Gerontechnology*, 15(2), 98-108. doi:10.4017/gt.2016.15.2.023.00
- Berge, M. S. (2017). Telecare - where, when, why and for whom does it work? A realist evaluation of a Norwegian project. *Journal of Rehabilitation and Assistive Technologies Engineering*, 4, 1-10. doi:10.1177/2055668317693737
- Bergland, A., & Slettebø, Å. (2014). Health capital in everyday life of the oldest old living in their own homes. *Ageing and Society*, 1-20. doi:10.1017/s0144686x14000877
- Beydoun, M., Beydoun, H., & Wang, Y. (2008). Obesity and central obesity as risk factors for incident dementia and its subtypes: a systematic review and meta-analysis. *Obesity Reviews*, 9(3), 204-218.
- Bishop, J. A. (2009). "The" 21st Century Specialization for Interior Designers.
- Boisaubin, E. V., Chu, A., & Catalano, J. M. (2007). Perceptions of long-term care, autonomy, and dignity, by residents, family and care-givers: the Houston experience. *Journal of Medicine and Philosophy*, 32(5), 447-464.
- Boise, L., Wild, K., Mattek, N., Ruhl, M., Dodge, H. H., & Kaye, J. (2013). Willingness of older adults to share data and privacy concerns after exposure to unobtrusive in-home monitoring. *Gerontechnology: international journal on the fundamental aspects of technology to serve the ageing society*, 11(3), 428.

- Borglin, G., Edberg, A. K., & Rahm Hallberg, I. (2005). The experience of quality of life among older people. *Journal of aging studies*, 19(2), 201-220.
- Bouwhuis, D., Meesters, L., & Sponselee, A. (2012). Models for the acceptance of tele-care solutions: intention vs behaviour. *Gerontechnology*, 11(1), 45-55.
doi:<http://dx.doi.org/10.4017/gt.2012.11.01.007.00>
- Bowes, A. M. (2007). Evaluating Technology for dementia Care. In A. Innes & L. McCabe (Eds.), *Evaluation in Dementia Care*. London: Jessica Kingsley Publishers.
- Bowes, A. M., Dawson, A., & McCabe, L. (2014). *RemoDem: Support for people with dementia in remote areas D.3: Evaluation report* (D3.1). Retrieved from
<http://www.northernperiphery.eu/en/home/>:
- Bowes, A. M., & McColgan, G. M. (2006). Smart Technology and Community Care for Older People: Innovation in West Lothian. *Scotland Edinburgh: Age Concern Scotland*.
- Bowes, A. M., & McColgan, G. M. (2009). Implementing telecare for people with dementia: Supporting ageing in place in West Lothian, Scotland. *Journal of Care Services Management*, 3(3), 227-243.
- Bowes, A. M., & McColgan, G. M. (2013). Telecare for Older People: Promoting Independence, Participation, and Identity. *Research on Aging*, 35(1), 32-49.
doi:10.1177/0164027511427546
- Bowling, A., & Dieppe, P. (2005). What is successful ageing and who should define it? *BMJ: British Medical Journal*, 331(7531), 1548.
- Breivik, E. (2014). *Business plan and deployment report* (D4.1). Retrieved from
<http://www.northernperiphery.eu/en/home/>:
- Brender, J. (2006). *Handbook of evaluation methods for health informatics*. Amsterdam: Elsevier Academic Press.
- Brewster, L., Mountain, G., Wessels, B., Kelly, C., & Hawley, M. (2014). Factors affecting front line staff acceptance of telehealth technologies: a mixed-method systematic review. *Journal of advanced nursing*, 70(1), 21-33.
- Browning, S. V., Tullai-McGuinness, S., Madigan, E., & Struk, C. (2009). Telehealth: is your staff ready to implement? A descriptive exploratory study of readiness for this technology in home health care. *Home Healthcare Nurse*, 27(4), 242-248.
- Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: clues for improving discussions with families prior to the transition. *The Gerontologist*, 46(1), 52-61.
- Callon, M., & Latour, B. (1981). Unscrewing the Big Leviathans How Do Actors Macrostructure Reality & How Sociologists Help Them. In K. Knorr & A. Cicourel (Eds.), *Advances in Social Theory and Methodology. Toward an Integration of Micro and Macro Sociologists* (pp. 277-303). London: Routledge.
- Carr, E. C., & Worth, A. (2001). The use of the telephone interview for research. *Nursing Times Research*, 6(1), 511-524.
- Cartwright, C., Wade, R., & Shaw, K. (2011). *The Impact of Telehealth and Telecare on Clients of the Transition Care Program (TCP)*: Southern Cross University-Aged Services Learning & Research Collaboration.
- Chan, M., Campo, E., Estève, D., & Fourniols, J. (2009). Smart homes—Current features and future perspectives. *Maturitas*, 64(2), 90-97.
- Chen, H.-T. (1989). The conceptual framework of the theory-driven perspective. *Evaluation and Program Planning*, 12(4), 391-396.
- Chen, H. T. (2012). Theory-driven evaluation: Conceptual framework, application and advancement. In *Evaluation von Programmen und Projekten für eine demokratische Kultur* (pp. 17-40): Springer.
- Chen, K., & Chan, A. (2011). A review of technology acceptance by older adults. *Gerontechnology*, 10(1), 1-12. doi:<http://dx.doi.org/10.4017/gt.2011.10.01.006.00>

- Chrysanthaki, T., Hendy, J., & Barlow, J. (2013). Stimulating whole system redesign: Lessons from an organizational analysis of the Whole System Demonstrator programme. *Journal of Health Services Research & Policy*, 18(1 suppl), 47-55.
- Cimperman, M., Makovec Brenčič, M., & Trkman, P. (2016). Analyzing older users' home telehealth services acceptance behavior—applying an Extended UTAUT model. *International journal of medical informatics*, 90, 22-31.
doi:<http://dx.doi.org/10.1016/j.ijmedinf.2016.03.002>
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., . . . Teri, L. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24(06), 856-870.
- Craig, G. (2004). Citizenship, exclusion and older people. *Journal of Social Policy*, 33(1), 95-114.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337(sep29_1), a1655-a1655.
- Creswell, J. W. (2009). *Research design*. Los Angeles: SAGE.
- Daatland, S. O., Veenstra, M., Kjellvik, J., Otnes, B., & Aksøy, H. (2012). Bærekraftig omsorg? Familien, velferdsstaten og aldringen av befolkningen.
- Dabney, B. W., & Kalisch, B. J. (2015). Nurse staffing levels and patient-reported missed nursing care. *Journal of nursing care quality*, 30(4), 306-312.
- Dalkin, S. M., Greenhalgh, J., Jones, D., Cunningham, B., & Lhussier, M. (2015). What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*, 10(1), 49.
- Davies, A., Rixon, L., & Newman, S. (2013). Systematic review of the effects of telecare provided for a person with social care needs on outcomes for their informal carers. *Health & social care in the community*, 21(6), 582-597.
- Davis, F. D. (1989). Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS quarterly*, 13(3), 319-340.
- Demiris, G., Hensel, B. K., Skubic, M., & Rantz, M. (2008). Senior residents' perceived need of and preferences for "smart home" sensor technologies. *International journal of technology assessment in health care*, 24(01), 120-124.
- Denton, F. T., & Spencer, B. G. (2002). Some demographic consequences of revising the definition of "Old Age" to reflect future changes in life table probabilities. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 21(03), 349-356.
- Department of Health (UK). (2011). *Whole System Demonstrator Programme: Headline Findings – December 2011*. London: Department of Health.
- Depp, C., Vahia, I. V., & Jeste, D. (2010). Successful aging: focus on cognitive and emotional health. *Annual review of clinical psychology*, 6, 527-550.
- Doughty, K., Monk, A., Bayliss, C., Brown, S., Dewsbury, L., Dunk, B., . . . Lowe, C. (2007). Telecare, telehealth and assistive technologies—do we know what we're talking about? *Journal of Assistive Technologies*, 1(2), 6-10.
- Dutton, R. (2009). 'Extra Care' Housing and People with Dementia.
- Elwyn, G., Greenhalgh, T., & Macfarlane, F. (2001). *Groups: a guide to small group work in healthcare, management, education and research*. Oxford: Radcliffe Medical Press.
- Emmel, N. (2013). *Sampling and choosing cases in qualitative research: A realist approach*: Sage.
- Erber, J. T., & Szuchman, L. T. (2015). *Great Myths of Aging*. Chichester: John Wiley & Sons.
- Essén, A. (2008). The two facets of electronic care surveillance: An exploration of the views of older people who live with monitoring devices. *Social Science and Medicine*, 67(1), 128-136.
- European Commission. (2012). Active ageing. Report. Special eurobarometer 378. In.

- Eurostat European Commission. (2012). *Europe in figures: Eurostat yearbook 2012*. Retrieved from Luxembourg:
- Evans, S., Fear, T., Means, R., & Vallyelly, S. (2007). Supporting independence for people with dementia in extra care housing. *Dementia*, 6(1), 144-150.
- Fanelli, D. (2011). Negative results are disappearing from most disciplines and countries. *Scientometrics*, 90(3), 891-904. doi:10.1007/s11192-011-0494-7
- Farquhar, M. (1995). Elderly people's definitions of quality of life. *Social science & medicine*, 41(10), 1439-1446.
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., . . . Huang, Y. (2006). Global prevalence of dementia: a Delphi consensus study. *The lancet*, 366(9503), 2112-2117.
- Finch, T., May, C., Mair, F., Mort, M., & Gask, L. (2003). Integrating service development with evaluation in telehealthcare: an ethnographic study. *BMJ*, 327(7425), 1205-1209.
- Fisk, M. J. (2003). *Social alarms to telecare: older people's services in transition*. Bristol, UK: Policy Press.
- Fletcher, P. C., & Hirdes, J. P. (2004). Restriction in activity associated with fear of falling among community-based seniors using home care services. *Age and Ageing*, 33(3), 273-279.
- Flinkman, M., Laine, M., Leino-Kilpi, H., Hasselhorn, H.-M., & Salanterä, S. (2008). Explaining young registered Finnish nurses' intention to leave the profession: a questionnaire survey. *International journal of nursing studies*, 45(5), 727-739.
- Fonad, E., Wahlin, T.-B. R., Heikkila, K., & Emami, A. (2006). Moving to and living in a retirement home: Focusing on elderly people's sense of safety and security. *Journal of Housing for the Elderly*, 20(3), 45-60.
- Friedman, S. M., Munoz, B., West, S. K., Rubin, G. S., & Fried, L. P. (2002). Falls and fear of falling: which comes first? A longitudinal prediction model suggests strategies for primary and secondary prevention. *Journal of the American Geriatrics Society*, 50(8), 1329-1335.
- Funnell, S. C., & Rogers, P. J. (2011). *Purposeful program theory: Effective use of theories of change and logic models* (Vol. 31): John Wiley & Sons.
- Gomersall, T., Nygård, L., Mihailidis, A., Sixsmith, A., Hwang, A. S., Hedman, A., & Astell, A. (2017). Network-based approaches for evaluating ambient assisted living (AAL) technologies. *Evaluation*, 23(2), 192-208.
- Greenhalgh, T., Procter, R., Wherton, J., Sugarhood, P., & Shaw, S. (2012). The organising vision for telehealth and telecare: discourse analysis. *BMJ open*, 2(4), 1-12. doi:10.1136/
- Greenhalgh, T., & Russell, J. (2010). Why do evaluations of eHealth programs fail? An alternative set of guiding principles. *PLoS Med*, 7(11), e1000360.
- Greenwood, N., Habibi, R., & Mackenzie, A. (2012). Respite: carers' experiences and perceptions of respite at home. *BMC Geriatrics*, 12(1), 42.
- Haak, M., Fänge, A., Iwarsson, S., & Dahlin Ivanoff, S. (2007). Home as a signification of independence and autonomy: Experiences among very old Swedish people. *Scandinavian Journal of Occupational Therapy*, 14(1), 16-24.
- Halkier, B. (2002). *Fokusgrupper*. Frederiksberg: Samfundslitteratur & Roskilde Universitetsforlag.
- Hansen, T., & Slagsvold, B. (2015). Late-Life Loneliness in 11 European Countries: Results from the Generations and Gender Survey. *Social Indicators Research*, 1-20. doi:10.1007/s11205-015-1111-6
- Hasson, H., & Arnetz, J. E. (2008). Nursing staff competence, work strain, stress and satisfaction in elderly care: a comparison of home-based care and nursing homes. *Journal of Clinical Nursing*, 17(4), 468-481.
- Hayes, L. J., O'Brien-Pallas, L., Duffield, C., Shamian, J., Buchan, J., Hughes, F., . . . North, N. (2012). Nurse turnover: a literature review—an update. *International journal of nursing studies*, 49(7), 887-905.

- Hayes, L. J., O'Brien-Pallas, L., Duffield, C., Shamian, J., Buchan, J., Hughes, F., . . . Stone, P. W. (2006). Nurse turnover: a literature review. *International journal of nursing studies*, 43(2), 237-263.
- Helse- og omsorgsdepartementet. (2006). *Mestring, muligheter og mening. Framtidas omsorgsutfordringer*. (nr. 25). Oslo: Helse- og omsorgsdepartementet, .
- Helse- og omsorgsdepartementet. (2009). *Samhandlingsreformen Rett behandling - på rett sted - til rett tid* (47). Oslo
- Helse- og omsorgsdepartementet. (2011a). *NOU 2011:11 Innovasjon i omsorg*. (978-82-583-1099-7). Oslo: Departementenes servicesenter, Informasjonsforvaltning.
- Helse- og omsorgsdepartementet. (2011b). *Når sant skal sies om pårørendeomsorg: fra usynlig til verdsatt og inkludert*. (NOU 2011:17). Oslo: Departementenes servicesenter.
- Helse- og omsorgsdepartementet. (2013). *Meld. St. 29 (2012–2013) Morgendagens omsorg*. Oslo
- Hendrie, H. C. (1998). Epidemiology of dementia and Alzheimer's disease. *The American Journal of Geriatric Psychiatry*, 6(2), S3-S18.
- Hendy, J., Chrysanthaki, T., Barlow, J., Knapp, M., Rogers, A., Sanders, C., . . . Bardsley, M. (2012). An organisational analysis of the implementation of telecare and telehealth: the whole systems demonstrator. *BMC health services research*, 12(1), 403. doi:10.1186/1472-6963-12-403
- Hewitt, G., Sims, S., & Harris, R. (2012). The realist approach to evaluation research: an introduction. *International Journal of Therapy and Rehabilitation*, 19(5), 251.
- Hirshbein, L. D. (2001). Popular views of old age in America, 1900–1950. *Journal of the American Geriatrics Society*, 49(11), 1555-1560.
- Hodder, I. (2011). Wheels of Time: Some Aspects of Entanglement Theory and the Secondary Products Revolution. *Journal of World Prehistory*, 24(2-3), 175-187. doi:<http://dx.doi.org/10.1007/s10963-011-9050-x>
- Hodder, I. (2012). *Entangled: An archaeology of the relationships between humans and things*. Chichester: John Wiley & Sons.
- Hodder, I. (2014). The Entanglements of Humans and Things: A Long-Term View. *New Literary History*, 45(1), 19-36. doi:<http://dx.doi.org/10.1353/nlh.2014.0005>
- Hofmann, B. (2013). Ethical challenges with welfare technology: a review of the literature. *Science and engineering ethics*, 19(2), 389-406.
- Jackson, S. F., & Kolla, G. (2012). A New Realistic Evaluation Analysis Method Linked Coding of Context, Mechanism, and Outcome Relationships. *American Journal of Evaluation*, 33(3), 339-349.
- Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., . . . Pluye, P. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC public health*, 15(1), 1.
- Jagosh, J., Pluye, P., Wong, G., Cargo, M., Salsberg, J., Bush, P. L., . . . Macaulay, A. C. (2014). Critical reflections on realist review: insights from customizing the methodology to the needs of participatory research assessment. *Research Synthesis Methods*, 5(2), 131-141.
- Joint Improvement Team. (2008a). *Seizing the opportunity. Telecare Strategy 2008- 2010*. Edinburgh.
- Joint Improvement Team. (2008b). *Telecare in Scotland: Benchmarking the Present, Embracing the Future*. Edinburgh: JIT.
- Kang, H. G., Mahoney, D. F., Hoenig, H., Hirth, V. A., Bonato, P., Hajjar, I., . . . Innovative, T. (2010). In Situ Monitoring of Health in Older Adults: Technologies and Issues. *Journal of the American Geriatrics Society*, 58(8), 1579-1586. doi:<http://dx.doi.org/10.1111/j.1532-5415.2010.02959.x>
- Karlsson, M. (2013). Elderly Users and New Technology: The Case of Care Homes and Other Contexts. In A. Hujala, S. Rissanen, & S. Vihma (Eds.), *Designing Wellbeing in Elderly*

- Care Homes* (pp. 204-216). Helsinki: Aalto University publication series CROSSOVER 2/2013.
- Kassner, E., Reinhard, S., Fox-Grage, W., Houser, A., Accius, J., Coleman, B., & Milne, D. (2008). *A balancing act: State long-term care reform*. Retrieved from Washington DC:
- Kerbler, B. (2013). The elderly and a remote home care: The case of Slovenia. *Stanovnistvo*, 51(1), 23-41.
- KMD Analyse. (2011a). *Digitalisering af ældreplejen - Potentialer og holdninger*. Retrieved from http://www.kmd.dk/da/om_kmd/kmd_analyse/Documents/KMD%20Analyse%20-%20Digitalisering%20af%20ældreplejen.pdf
- KMD Analyse. (2011b). *Kronisk sygdom - en digital samfundsdiagnose*. Retrieved from http://www.kmd.dk/da/om_kmd/kmd_analyse/Documents/KMD%20Analyse%202011%20-%20Kronisk%20sygdom%20-%20en%20digital%20samfundsdiagnose.pdf
- Kofod, J. (2008). *Becoming a nursing home resident. Unpublished doctoral dissertation, Technical University of Denmark, Copenhagen, Denmark.*
- Koivisto, J., Anttila, H., Ikonen, T., & Reiman-Möttönen, P. (2010). A systematic model for evaluating the patient aspects of health technologies. *Evidence and policy*, 6(1), 33-50. doi:<http://dx.doi.org/10.1332/174426410X482980>
- Krueger, R. A., & Casey, M. A. (2015). *Focus groups : a practical guide for applied research* (5th ed. ed.). Los Angeles: Sage.
- Kubitschke, L., Cullen, K., & Müller, S. (2010). ICT and Ageing: European Study on Users, Markets and Technologies, Final Report. *Brussels: Commission of the European Communities.*
- Kuyken, W., Orley, J., Power, M., Herrman, H., Schofield, H., & Murphy, B. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc sci med*, 41(10), 1403-1409.
- Kvale, S. (1997). *Interview : en introduktion til det kvalitative forskningsinterview*. København: Hans Reitzels Forl.
- Kvale, S., & Brinkmann, S. (2009). *Det kvalitative forskningsinterview* (T. M. Anderssen & J. Rygge, Trans.). Oslo: Gyldendal akademisk.
- Landau, R., Auslander, G., Werner, S., Shoval, N., & Heinik, J. (2010). Families' and Professional Caregivers' Views of Using Advanced Technology to Track People With Dementia. *Qualitative health research*, 20(3), 409.
- Latour, B. (1992). Where Are the Missing Masses? The Sociology of a Few Mundane Artifacts. In W. E. Bijker & J. Law (Eds.), *Shaping Technology/Buiilding Society*. Cambridge: The MIT Press.
- Latour, B. (2005). *Reassembling the Social : An Introduction to Actor-Network-Theory*. Oxford, GBR: Oxford University Press, UK.
- Law, J. (1992). Notes on the theory of the actor-network: ordering, strategy, and heterogeneity. *Systems practice*, 5(4), 379-393.
- Lunde, L.-H. (2012). *Alder ingen hindring: vekst og utvikling hele livet*. Oslo: Gyldendal akademisk.
- Mahler, M., Sarvimäki, A., Clancy, A., Stenbock-Hult, B., Simonsen, N., Liveng, A., . . . Hörder, H. (2014). Home as a health promotion setting for older adults. *Scandinavian journal of public health*, 42(15 suppl), 36-40.
- Manzano-Santaella, A. (2011). A realistic evaluation of fines for hospital discharges: Incorporating the history of programme evaluations in the analysis. *Evaluation*, 17(1), 21-36. doi:10.1177/1356389010389913
- Manzano, A. (2016). The craft of interviewing in realist evaluation. *Evaluation*, 22(3), 342-360. doi:DOI: 10.1177/1356389016638615
- Marchal, B., van Belle, S., van Olmen, J., Hoerée, T., & Kegels, G. (2012). Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research. *Evaluation*, 18(2), 192-212.

- Martin, S., Kelly, G., Kernohan, W. G., McCreight, B., & Nugent, C. (2008). Smart home technologies for health and social care support. *Cochrane database of systematic reviews (Online)*(4), CD006412-CD006412.
- May, C., Mort, M., Williams, T., Mair, F., & Gask, L. (2003). Health technology assessment in its local contexts: studies of telehealthcare. *Social science & medicine*, 57(4), 697-710.
- McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia*, 3(2), 117-125.
- Medical Research Council. (2000). *A framework for development and evaluation of RCTs for complex interventions to improve health*. London: Medical Research Council.
- Mehrabian, S., Extra, J., Wu, Y.-H., Pino, M., Traykov, L., & Rigaud, A.-S. (2015). The perceptions of cognitively impaired patients and their caregivers of a home telecare system. *Medical devices (Auckland, NZ)*, 8, 21.
- Merton, R. K. (1967). *On theoretical sociology: Five essays, old and new*: Free Press New York.
- Milligan, C., Roberts, C., & Mort, M. (2011). Telecare and older people: Who cares where? *Social science & medicine*, 72(3), 347-354. doi:10.1016/j.socscimed.2010.08.014
- Mohr, J., & Spekman, R. (1994). Characteristics of partnership success: partnership attributes, communication behavior, and conflict resolution techniques. *Strategic management journal*, 15(2), 135-152.
- Mol, A. (2010). Actor-network theory: sensitive terms and enduring tensions. *Kölner Zeitschrift für Soziologie und Sozialpsychologie. Sonderheft*, 50, 253-269.
- Moraes, J. F. D. d. (2005). Factors associated with the successful aging of the socially-active elderly in the metropolitan region of Porto Alegre. *Revista brasileira de psiquiatria*, 27(4), 302-308.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.
- Mort, M., Roberts, C., Pols, J., Domenech, M., & Moser, I. (2015). Ethical implications of home telecare for older people: a framework derived from a multisited participative study. *Health Expectations*, 18(3), 438-449.
- Moser, I., & Thygesen, H. (2013). Velferdsteknologi og teleomsorg: Nye ideale og former for omsorg. In A. Tjora & L. Melby (Eds.), *Samhandling for helse. Kunnskap, kommunikasjon og teknologi i helsetjenesten*. Oslo: Gyldendal Norsk Forlag AS.
- Nagel, S. K., & Remmers, H. (2012). Self-Perception and Self-Determination in Surveillance Conditions. *The American Journal of Bioethics*, 12(9), 53-55.
- Nikmat, A. W., Al-Mashoor, S. H., & Hashim, N. A. (2015). Quality of life in people with cognitive impairment: nursing homes versus home care. *International Psychogeriatrics*, 27(05), 815-824.
- Nygård, L. (2008). The meaning of everyday technology as experienced by people with dementia who live alone. *Dementia*, 7(4), 481-502.
- Oh, H., Rizo, C., Enkin, M., & Jadad, A. (2005). What is eHealth (3): a systematic review of published definitions. *Journal of medical Internet research*, 7(1), 1-12.
- Olsson, A., Engström, M., Skovdahl, K., & Lampic, C. (2012). My, your and our needs for safety and security: relatives' reflections on using information and communication technology in dementia care. *Scandinavian journal of caring sciences*, 26(1), 104-112.
- Parkhe, A. (1998). Building trust in international alliances. *Journal of World Business*, 33(4), 417-437.
- Parks, J. A. (2015). *Home-Based Care, Technology, and the Maintenance of Selves*. Paper presented at the HEC Forum.
- Pawson, R. (1996). Theorizing the interview. *British Journal of Sociology*, 47, 295-314. doi:10.2307/591728
- Pawson, R. (2006a). Digging for nuggets: how 'bad' research can yield 'good' evidence. *International Journal of Social Research Methodology*, 9(2), 127-124.

- Pawson, R. (2006b). *Evidence-based policy: a realist perspective*. London: Sage.
- Pawson, R. (2013). *The science of evaluation: a realist manifesto*. Thousand Oaks, CA: Sage.
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2004). Realist synthesis: an introduction. *ESRC Research Methods Programme. Manchester: University of Manchester*.
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review—a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research & Policy*, 10 (suppl 1), 21-34.
- Pawson, R., & Manzano-Santaella, A. (2012). A realist diagnostic workshop. *Evaluation*, 18(2), 176-191. doi:10.1177/1356389012440912
- Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. London: Sage.
- Pawson, R., & Tilley, N. (2004). *Realist evaluation*. British Cabinet Office.
- Peek, S. T. M., Luijkx, K., Vrijhoef, H., Nieboer, M., Aarts, S., Voort, C., . . . Wouters, E. (2017). Origins and consequences of technology acquirement by independent-living seniors: towards an integrative model. *BMC Geriatrics*, 17(1), 189.
- Peek, S. T. M., Luijkx, K. G., Rijnaard, M. D., Nieboer, M. E., van der Voort, C. S., Aarts, S., . . . Wouters, E. J. (2016). Older Adults' Reasons for Using Technology while Aging in Place. *Gerontology*, 62(2), 226-237. doi:10.1159/000430949
- Peek, S. T. M., Wouters, E. J. M., van Hoof, J., Luijkx, K. G., Boeije, H. R., & Vrijhoef, H. J. M. (2014). Factors influencing acceptance of technology for aging in place: A systematic review? *International journal of medical informatics*, 83(4), 235-248. doi:10.1016/j.ijmedinf.2014.01.004
- Phillips, J. (2007). *Care*. Cambridge: Polity Press.
- Polit, D. F., & Beck, C. T. (2008). *Nursing research: generating and assessing evidence for nursing practice*. Philadelphia, Pa.: Wolters Kluwer/Lippincott Williams & Wilkins.
- Punton, M., Vogel, I., & Lloyd, R. (2016). Reflections from a Realist Evaluation in Progress: Scaling Ladders and Stitching Theory.
- Richards, D. A., & Hallberg, I. R. (Eds.). (2015). *Complex Interventions in Health: An Overview of Research Methods*. London: Routledge.
- Riggs, E., Block, K., Warr, D., & Gibbs, L. (2013). Working better together: new approaches for understanding the value and challenges of organizational partnerships. *Health promotion international*, 1-14.
- Roberts, C., Mort, M., & Milligan, C. (2012). Calling for Care: 'Disembodied' work, teleoperators and older people living at home. *Sociology*, 46(3), 490-506.
- Robson, C. (2011). *Real world research*. Chichester: Wiley.
- Rostgård, M., Remmen, A., & Christensen, J. (1990). *Samfundet i teknologien*. Aalborg: Aalborg Universitetsforlag.
- Rowe, J. W., & Kahn, R. L. (1987). Human aging: usual and successful. *Science*, 237(4811), 143-149.
- Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *The Gerontologist*, 37(4), 433-440.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of personality and social psychology*, 57(6), 1069.
- Saborowski, M., & Kollak, I. (2015). "How do you care for technology?"—Care professionals' experiences with assistive technology in care of the elderly. *Technological Forecasting and Social Change*, 93, 133-140.
- Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S., Cartwright, M., . . . Hendy, J. (2012). Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study. *BMC health services research*, 12(1), 220.
- Sanderson, W., & Scherbov, S. (2008). *Rethinking age and aging*: Population Reference Bureau.
- Sanderson, W., & Scherbov, S. (2015). Faster Increases in Human Life Expectancy Could Lead to Slower Population Aging.

- Sarvimäki, A., & Stenbock-Hult, B. (2000). Quality of life in old age described as a sense of well-being, meaning and value. *Journal of advanced nursing*, 32(4), 1025-1033.
- Scheffer, A. C., Schuurmans, M. J., van Dijk, N., van der Hooft, T., & de Rooij, S. E. (2008). Fear of falling: measurement strategy, prevalence, risk factors and consequences among older persons. *Age and Ageing*, 37(1), 19-24. doi:10.1093/ageing/afm169
- Schein, E. H. (2010). *Jossey-Bass Business and Management : Organizational Culture and Leadership* (4th Edition ed.). Hoboken, NJ, USA: Jossey-Bass.
- Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., . . . Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13(20), 1-+. doi:10.3310/hta13200
- Sixsmith, J., Sixsmith, A., Fänge, A. M., Naumann, D., Kucsera, C., Tomsone, S., . . . Woolrych, R. (2014). Healthy ageing and home: The perspectives of very old people in five European countries. *Social science & medicine*, 106, 1-9.
- Slagsvold, B., & Solem, P. E. (2005). *Morgendagens eldre. En sammenlikning av verdier, holdninger og atferd blant dagens middelaldrende og eldre*. Retrieved from Oslo:
- Sloan, P., & Oliver, D. (2013). Building Trust in Multi-stakeholder Partnerships: Critical Emotional Incidents and Practices of Engagement. *Organization Studies*. doi:10.1177/0170840613495018
- Sorell, T., & Draper, H. (2012). Telecare, Surveillance, and the Welfare State. *American Journal of Bioethics*, 12(9), 36-44. doi:10.1080/15265161.2012.699137
- Steele, R., Lo, A., Secombe, C., & Wong, Y. K. (2009). Elderly persons' perception and acceptance of using wireless sensor networks to assist healthcare. *International journal of medical informatics*, 78(12), 788-801. doi:<http://dx.doi.org/10.1016/j.ijmedinf.2009.08.001>
- Steventon, A., Bardsley, M., Billings, J., Dixon, J., Doll, H., Beynon, M., . . . Knapp, M. (2013). Effect of telecare on use of health and social care services: findings from the Whole Systems Demonstrator cluster randomised trial. *Age and Ageing*, 42(4), 501-508.
- Stokke, R. (2017). " Maybe we should talk about it anyway": a qualitative study of understanding expectations and use of an established technology innovation in caring practices. *BMC health services research*, 17(1), 657.
- Sugarhood, P., Wherton, J., Procter, R., Hinder, S., & Greenhalgh, T. (2013). Technology as system innovation: a key informant interview study of the application of the diffusion of innovation model to telecare. *Disability and Rehabilitation: Assistive Technology*, 9(1), 79-87.
- Teknologirådet. (2009). *Fremtidens alderdom og ny teknologi*. Retrieved from Oslo:
- Temple, B., Edwards, R., & Alexander, C. (2006). *Grasping at context: Cross language qualitative research as secondary qualitative data analysis*. Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.
- Tilley, N. (2000). *Realistic evaluation: an overview*. Paper presented at the Founding Conference of the Danish Evaluation Society.
- Tsai, C.-H. (2014). Integrating Social Capital Theory, Social Cognitive Theory, and the Technology Acceptance Model to Explore a Behavioral Model of Telehealth Systems. *International journal of environmental research and public health*, 11(5), 4905-4925. doi:<http://dx.doi.org/10.3390/ijerph110504905>
- United Nations. (2004). *World Population to 2300*. Retrieved from New York:
- United Nations. (2013). *World Population Prospects The 2012 Revision, Volume I: Comprehensive Tables ST/ESA/SER.A/336*. Retrieved from New York:
- Urciuoli, O., Dello Buono, M., Padoani, W., & De Leo, D. (1998). Assessment of quality of life in the oldest-olds living in nursing homes and at home. *Archives of gerontology and geriatrics*, 26, 507-514.
- Van Hoof, J., Kort, H., Rutten, P., & Duijnste, M. (2011). Ageing-in-place with the use of ambient intelligence technology: Perspectives of older users. *International journal of*

- medical informatics*, 80(5), 310-331.
doi:<http://dx.doi.org/10.1016/j.ijmedinf.2011.02.010>
- Vassilev, I., Rowsell, A., Pope, C., Kennedy, A., O’Cathain, A., Salisbury, C., & Rogers, A. (2015). Assessing the implementability of telehealth interventions for self-management support: a realist review. *Implementation Science*, 10(1), 59.
- Vichitvanichphong, S., Talaei-Khoei, A., Kerr, D., & Ghapanchi, A. H. (2014). Assistive Technologies for Aged Care: Supportive or Empowering? *Australasian Journal of Information Systems*, 18(3).
- Wallace, W. L. (1971). *The Logic of Science in Sociology* Aldine Atherton.
- Westhorp, G. (2014). Realist Impact Evaluation: An Introduction. In: London: Methods Lab/Overseas Development Institute.
- WHO. (2011). *Global Health and Ageing*. Retrieved from Geneva:
- WHO. (2015). Health technology assessment. Retrieved from http://www.who.int/medical_devices/assessment/en/
- Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. (2012). The meaning of “ageing in place” to older people. *The Gerontologist*, 52(3), gnr098.
- Willems, C. G., Spreeuwenberg, M. D., van der Heide, L., & de Witte, L. P. (2012). Implementing Technology in Home-Care: Lessons Learned from Examples in the Netherlands. *Essential Lessons for the Success of Telehomecare: Why It's Not Plug and Play*, 30, 161.
- Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013). RAMESES publication standards: realist syntheses. *BMC Medicine*, 11(1), 21-35.
doi:10.1186/1741-7015-11-21
- Wong, G., Westhorp, G., Pawson, R., & Greenhalgh, T. (2013). *Realist Synthesis, Ramesis Training Materials*. Retrieved from
- Yang, K., & Victor, C. (2011). Age and loneliness in 25 European nations. *Ageing and Society*, 31(08), 1368-1388.
- Young, I. M. (1997). *Intersecting voices : dilemmas of gender, political philosophy, and policy*. Princeton, N.J: Princeton University Press.
- Øvretveit, J. (1998). *Evaluating health interventions*. Buckingham [England]: Open University Press.

Rules for the group discussion:

- You may speak as in an ordinary conversation
- Please respect confidentiality within the group
- Please speak one at the time
- Because this is recorded, please speak loud and clear
- There are no right or wrong answers
- Feel free to be honest
- It is important that all are able to voice their opinion
- It is important to hear all perspectives

Fold -----

Write your name here in capital letters, please

Fold -----

Write your name here in capital letters, please

Topic guide – user

The user and his/her social network

The purpose is to make the person tell about him/herself; who does s/he usually contact, when and how does this usually happen?

Coping with everyday life

The purpose is to get an impression of how the person copes with the different tasks and challenges that arise during a usual day and whether holiday seasons and vacations bring about extra challenges.

The need for help – and the person's responses to being in need for assistance

How did the person manage without help and was there any special occasion that provoked the need for help/home care? The purpose is to illuminate how the person managed without help, and his/her thoughts about, and attitudes to, receiving care and the reason why care is considered needed.

What is the person's thought about the assigned help?

How much and what does s/he know about the assigned help and what does s/he think about this health care service.

Topic guide relative

The person himself/herself and his/her social network

The purpose is to make the person tell about himself/herself and how s/he is in contact with the relative who is now being offered a new kind of service. The goal is to find out how and when this contact occurs.

Coping with everyday life as relatives

How does the person cope with the various tasks and challenges caused by his/her relatives during a day. It is relevant to find out if and when something causes further challenges, e.g. holidays and vacations etc.

The need for help - how is it perceived that the family member (wife / husband, father / mother etc.) needs community care

How has the interaction between the user and the relative been before they were offered community care and why did the need occur? The person's attitude to the fact that his/her relative has requested community care.

What do you think about the offered care?

What does s/he know about the offered care/service? What does s/he think about this? If this has not been a subject already during the interview, the positive and negative experiences related to technology and factors that are directly related to it (e.g. requests from central), will be asked for.

Topic guide focus groups

How will you describe your everyday working in community care?

Aims to learn which tasks they carry out are and how they do it. Additional aim is to learn about attitudes towards demands and expectations from users, colleagues and leaders.

The Lindås municipality is starting to use telecare, how do you expect it to influence your work and the service you provide?

All are informed about telecare and how it might work. They are also familiar with the test installations. What do they think about 'cooperating' with technology? What do they think about their own role? What are their opinions about using technology with persons in need of assistance?

FOCUS GROUP

Background questions to participants

Place of work and position

Workplace/department.....

Position..... Education

Approximate years in this position

Approximate years in today's position In this department.....

Employed ☐ temporarily employed ☐ Extra ☐

Work percentage

Gender

Female ☐ Male ☐

Age

Under 20 ☐

20-29 ☐

30-39 ☐

40-49 ☐

50-59 ☐

Over 60 ☐

For moderator (do not write here):

Focus group:day Date:time FromTo

Norsk samfunnsvitenskapelig datatjeneste AS
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Vår dato: 21.01.2014

Vår ref: 33469 HIT/LR

Deres dato:

Deres ref:

AFFIRMATION

33469

Teknologi som støtte i omsorgstjenestene

The Data Protection Official for Research at the Norwegian Social Science Data Services (NSD) finds that the processing of personal data in relation to the project "*Teknologi som støtte i omsorgstjenestene*" is in accordance with the Norwegian Personal Data Act, ref. our letter to Frøde F. Jacobsen on March 7th 2013.

Sincerely,


Bjørn Henrichsen


Hildur Thorarensen

Contact person: Hildur Thorarensen phone number: 55 58 26 54

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