Home-based Self-Care
Understanding and Designing Pervasive Technology to Support Care Management Work at Home

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PhD Dissertation

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A Dissertation
Presented to the Faculty of Science and Technology
of Aarhus University
in Partial Fulfillment of the Requirements for the PhD Degree.

by
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12th December 2013
Abstract

Demographic changes are challenging healthcare systems as well as societies around the world due to an increasing aging population and rapid propagation of chronic diseases. To deal with the consequences of these changes, more and more long-term care services are being implemented including home-based healthcare. To support self-care activities, an increasingly number of reminders and monitoring systems are being designed. However, most of these systems have been designed taking the healthcare professional’s perspective or targeting a specific treatment or condition that might not sufficient support the self-care management work at home. People need to know which care activities to perform, when to perform them, how to proceed and why these are important. While at home, an active lifestyle and comorbidity not only challenge self-care activities but also the use of self-care technologies in non-clinical settings. As such, sustaining daily care activities in the home (or other non-clinical settings) is challenging as they are becoming more and more intertwined into people’s everyday life. Thus, this dissertation is concerned about one major challenge in Pervasive Healthcare: the design of technology that fit into people’s everyday life.

Through a design research approach applying user-centered design methods and prototyping, the main focus of this dissertation is on exploring and providing a holistic understanding of the self-care work practices in non-clinical settings. Several home-based care practices are investigated to (a) further understand the self-care management work in non-clinical settings, and (b) inform future design of pervasive healthcare technology that accounts for people’s perspectives on self-care and everyday life. First, we explore two self-care practices of medication management and preventive self-monitoring to further study people’s perspectives on self-care both for health and illness. Second, we combine our initial studies with three additional studies of self-care practices: self-monitoring of pregnant women with pre-eclampsia and heart patients as well as home-based rehabilitation. This is done to examine similarities and differences among the studies.

While highlighting the importance of both the clinical and people’s perspectives in system design, this dissertation present a collection of user insights, new knowledge and several design implications, principles, recommendations as well as several conceptual tools. The different design and conceptual tools can enable a further understanding of self-care practices, support design of future pervasive healthcare technology, and facilitate designer’s reflective practices to explore particularities of people’s trajectories of care. We also discuss two design explorations that served as examples of how some of the design tools could be applied and extended by for example the Pervasive Healthcare and Health Informatics communities.

Finally, we reflect upon the application of the theory of practice and the concept of trajectory as lens for understanding self-care practices. We also present a future agenda to investigate self-care technology design that better account for people’s trajectories of care.
Résumé

Den stigende andel af ældre i befolkningen og den hurtige udbredelse af kroniske sygdomme udfordrer sundhedssektorer og samfundet verden rundt. For at imødegå disse udfordringer bliver flere og flere langsigtede omsorgs-services implementeret, heriblandt hjemme-baseret healthcare. For at understøtte egenomsorgsaktiviteter bliver et stigende antal påmindelses- og monitoreringssystemer designet. De fleste af disse systemer lider imidlertid under at være designet fra sundhedspersonalets perspektiv eller ved at være målrettet en specifik behandling eller sygdom, og er derfor ikke nødvendigvis tilstrækkelige til at understøtte egenomsorg i hjemmet. Folk har brug for at vide hvilke aktiviteter de skal udføre, hvornår de skal udføre dem, hvordan de skal fortsætte og hvorfor disse er vigtige. I hjemmet udfordrer en aktiv livsstil og komorbiditet ikke bare egenomsorgsaktiviteter, men også brugen af egenomsorgsteknologi i ikke-kliniske omgivelser. Det er derfor udfordrende at opretholde egenomsorgsaktiviteter i hjemmet (og andre ikke-kliniske omgivelser) da de bliver mere og mere viklet ind i folks dagligdag. På grund af disse udfordringer, beskæftiger denne afhandling sig med en af de største udfordringer i Pervasive Healthcare: design af teknologi der passer ind i menneskers hverdag.

Gennem en design research tilgang hvor user-centered designmetoder og prototyping er anvendt, er hovedfokus i denne afhandling på at udforske og give en holistisk forståelse for egenomsorgspraksisser i ikke-kliniske omgivelser. Adskillige hjemme-baserede omsorgspraksisser bliver undersøgt for: (a) at øge forståelsen af arbejdet med egenomsorgsstyring i ikke-kliniske omgivelser, og (b) at guide fremtidigt design af pervasive healthcare teknologier, der tager højde for almindelige menneskers perspektiver på egenomsorg og hverdagslivet. Først udforsker vi de to egenomsorgspraksisser: medicineringsstyring og præventiv selv-monitorering for at undersøge folks perspektiver på egenomsorg for både sundhed og sygdom. Dernæst kombinerer vi de første studier med yderligere studier: selv-monitorering af gravid kvinde med præeklampsii og hjertepatienter samt hjemme-baseret rehabilitation. Dette gøres for at udforske forskelle og ligheder mellem de forskellige cases.

Acknowledgments

There are so many people that I need to thank for their support during my three years of Ph.D. process. Family, friends, colleagues as well as people that I have met outside Aarhus.

At first, I would like to thank my supervisor Morten Kyng for giving me the opportunity to start this process as a Ph.D. student and supporting me in all the activities I could engage in and outside the office. For all our discussions, support and encouragement and for believing in my work during these years. Next, I would like to thank Erik Grønvall for accepting to be my co-supervisor after my qualifying exam and for being such a good friend and colleague. For all our discussions, feedback and for being always available when I needed to ask questions. For all our dinners and Friday’s bar as well as our long hours writing and working together. I would also like to thank Susanne Bødker and Olav W. Bertelsen for giving me the sense of belonging and always being there for me. For all the encouragement and support during these years. To my colleagues and friends from the Centre for Pervasive Healthcare and Department of Computer Science. In special to Lisa Wells, Susanne Wollsen, Lea Gulstav Dalgaard, Mark Surrow, Jesper Wolff Olsen, Tina Rudolph, Marianne Dammand for all the help, support and smiles I have received from them. And to all the participants in the Lev Vel consortium. For all our discussions, meetings, workshops and support to do this research.

To my dear friends and fellow Ph.D. students Vaida, Mads, Ubbe, Anders, Laura, Matthias, Pavel and Anna Maria for all your support and for finishing before me. For all the parties, dinners, coffee breaks, Friday’s bar and all good moments that we have shared together. To the rest of my other colleagues-friends from the different groups and in special to the UbiComp guys Allan, Mads and Robert who I interacted the most. In addition, I would like to thank all the great people at the HCI group in Vienna University of Technology. For all our lunch together, discussions, and support during my six weeks in Vienna. In special to Eva Ganglbauer and Florian Güldenpennig for being such a nice office-mates. And Francisco Nunes and Geraldine Fitzpatrick for all our discussions. I really liked my visit and looking forward to continue working with you. Thanks for making my stay so pleasant.

To all my friends in Ecuador, Trento, Aarhus as well as all around the world that I have met during these years in conferences or summer schools. In special to Cristina, Gonzalo, Maria Fernanda, Ragen, Andrea, Shivani, Paula, Adolfo, and Christian for all their support. For the ones in Aarhus thanks for showing me that there is a life after working hours.

Last but not least, special thanks to all my family including my mother, father, brothers, nieces, and grandpa for all their love and support during this process. In special my uncle Neicer, my aunt’s Vicky and Astrid and my cousin Karen for all the good food and family time in Spain. This dissertation is dedicated to my grandma Flor Maria for always taking care of me during these years. All of you have a special place in my heart, grateful for life.

Nervo Xavier Verdezoto D.
Aarhus, December 2013
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Part I

Summary
Chapter 1

Introduction

The increasing aging population and the rapid propagation of chronic, degenerative non-communicable diseases are challenging healthcare systems around the world (Kinsella & He, 2009; Trends, 2003; Mathers & Loncar, 2006; WHO, 2012; Health Metrics & Evaluation, 2013). Non-communicable diseases such as coronary heart disease, diabetes and musculoskeletal disorders (i.e. low neck and back pain) have increased the number of healthy years lost\(^1\) (DALYs) for people, especially the ones living in richer countries of North America and Western Europe as well as in Australia, Japan, and Uruguay (Health Metrics & Evaluation, 2013). What is more, a higher percentage of older adults in most developed countries implies a raise on healthcare costs as this population might experience age-related disabling conditions and comorbidity (Kinsella & He, 2009). For instance, a report from 2003 states that 80% of U.S. older adults over 65 years are living with one chronic disease and 50% are living with at least two chronic conditions (Trends, 2003). Thus, these challenges not only increase the burden on healthcare systems to provide universal healthcare but also on people and society in general as more and more caregivers are getting involved in the provision of care (Shirey & Summer, 2000; Anderson, 2007).

Universal healthcare is provided by healthcare systems around the world in different ways. There are a number of countries (e.g. UK and DK) in which healthcare is totally funded by the government, usually supported by tax revenues (Schabloski, 2008; Shah, 2011). Furthermore, there are countries with a more private model for healthcare (e.g. Switzerland) and the ones that apply a mixed strategy\(^2\) (e.g. Canada, France) to provide healthcare services (Schabloski, 2008; Shah, 2011). To illustrate the impact of the aforementioned changes in universal healthcare, consider Denmark that provides public healthcare services to everyone. The Danish welfare state is being challenged by demographic changes and the increase of non-communicable diseases - also called lifestyle diseases (Digital-Health, 2007) - as explained above. According to the United Nations, the Danish population aged 65 or over has

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\(^1\) Years of healthy life lost or Disability-adjusted life years (DALYs): It is a measurement to quantify the number of years of life lost as a result of premature death and disability caused by communicable (newborn, nutritional, and maternal) and non-communicable diseases or injury. See the report published by the Institute for Health Metrics and Evaluation for a complete definition (Health Metrics & Evaluation, 2013).

\(^2\) Funded partly by the government together with patients and/or private insurances.
increased from 385 thousands in 1950 to 925 thousands in 2010, and it is estimated to reach 1466 thousands by 2050 (United Nations & Social Affairs, 2013). Age-related disabilities and non-communicable diseases such as cancer, cardiovascular diseases, diabetes and respiratory diseases are challenging the Danish health care system (Europe WHO, 2012). In addition, modifiable biological (e.g. overweight, hypertension) and behavioral (e.g. smoking, physical inactivity, unhealthy diet) risk factors are having a great impact on the health of Danish population (Juel, Sørensen & Brønnum-Hansen, 2008). Either way, all models for deliver of care are being challenged and countries have started developing strategies to deal with the fast increment of healthcare costs (Prince-Market-Research, 2007; Kinsella & He, 2009).

To deal with the consequences of these challenges, healthcare systems are implementing more and more long-term care services such as nursing home and home-based healthcare (Shirey & Summer, 2000; Anderson, 2007). Especially the transfer of care from the hospital to a setting not supervised by healthcare professionals such as the home3, has promoted people’s participation in self-care management (Wilson et al., 2006; Rijken et al., 2008). As a result, people have engaged in self-care activities to learn how to cope with chronic conditions or as preventive care (Glasgow et al., 2001; Rijken et al., 2008). Indeed, a recent study in the U.S. shows this trend in which more and more people are starting to track health indicators (for themselves or a loved one) not only for managing chronic conditions but also as preventive care - to track the so-called healthy living activities e.g. weight, diet, or exercise routines (Fox & Duggan, 2013). In additions, the study reports the formal (using paper-based tools or technology) and informal (“in their heads”) ways in which tracking is accounted to support people’s care activities in everyday life (Fox & Duggan, 2013).

Nowadays, the active involvement of people in their own self-care management plays an important role not only for people’s care management but also for healthcare systems. Several researchers have pointed out the value of people’s participation as important “partners” in the deliver of care (Moore, 1995; Glasgow et al., 2001). For instance, the National Strategy for Digitalization of the Danish Healthcare Service has been launched to increase people’s involvement in prevention and treatment of diseases (Digital-Health, 2007). This digitalization strategy considers “citizens and patients as assets” expecting from them an extensive and active involvement in taking responsibilities in their own self-care management (Digital-Health, 2007). However, the partnership approach is often neglected in the clinical perspective resulting in new challenges due to for example an overemphasis on patient compliance4, empowerment and autonomy (Johannsen & Kensing, 2005; Montgomery-Downs, Insana & Bond, 2012).

At first, the whole notion of compliance is a “dead-end street” and exclude the patient as a partner when for example healthcare professional blame patients for noncompliance (Conrad, 1985; Moore, 1995). Next, the intensive focus on patient empowerment and autonomy rely on the patient choice rather than the partnership approach (Spoel, 2006; Wilson et al., 2006; Mol, 2008; Montgomery-Downs et al., 2012). In the so-called “logic of choice” (Mol, 2008), healthcare professionals can appear as mediators of health information - info(r)mersion process - looking for people’s actions and behavior change (Wyatt, Harris & Wathen, 2008). In this sense, people suffering from illnesses have to assume the role of ‘man-

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3 Williams (2002) refers to the transfer of care from formal settings (hospital) to informal settings (people’s homes) as changes in the “geographies of care”. She describes the challenges of this transfer by exploring its impact on the informal caregivers.

4 When for example people follow doctor’s orders and do what they actually say
agers’ of diseases in their daily life (Salmon & Hall, 2004) while health professionals have become info(r)mediators (Henwood, Harris & Spoel, 2011) in the care process. To some degree, these notions of compliance and empowerment (e.g. consumerism of health information and info(r)mediation) are failing to see the bigger picture of what it actually means for people to do self-care. For instance, not all people seek control or choice regarding their own care situation (Salmon & Hall, 2004), and some people might prefer a more dependent role rather than self-management (Woodward, 1998). As care responsibilities are being shifted to the lay people (Henwood, Wyatt, Hart & Smith, 2003; Spoel, 2010), it is important to recognized that unintended situations can appear such as stigmatization or depression that might have a negative impact on people’s health and challenge the treatment at home (Ciechanowski et al., 2003; Lin et al., 2004; Aarhus & Ballegaard, 2010).

As exemplified by the Danish digitalization strategy above (Digital-Health, 2007), the increased focus on people’s choice in healthcare has spanned from treatment of disease to preventive strategies. The intensive tracking of healthy living parameters (e.g. weight, diet and exercise) can be considered as an example of a self-agency model of self-management (Wilson et al., 2006) and the logic of choice. This way of quantification of health is usually framed as aiming for more and more “individual choice, ‘good behavior’, and self-care” in healthy living (Henwood et al., 2011). However, this over-emphasis on activity monitoring in self-care can also result in unintended situations such as obsession and stress (Andreassen, 2011; Lupton, 2013a). These can result for example in a negative health outcome as shown by a recent report in which healthy overweight people who lose weight have a 15 percent higher mortality rate than the ones who maintain their weight (Sørensen, Pedersen, Sandbæk & Overvad, 2013).

Thus, the partial and fragmented objectified picture provided by the logic of choice and the whole clinical perspective might hinder a general understanding of the caring process (Thomas, 1993). For instance, Thomas (1993) states that care is a complicated concept that should be understood along with seven dimensions: the social identity of the carer (e.g. mother, wife, nurse) and care recipient (e.g. able-bodied, dependent adults and children), its inter-personal relationships (e.g. family, friends, neighbors, contingent lay and professional), the nature of care (work activities and feeling states), the social domain (private/domestic or public), the economic character (paid or unpaid) and the institutional setting (e.g. home, residential institutions, hospital). Understanding caring as work and emotional labour can help to provide a bigger and comprehensive picture of people’s health management beyond compliance and the logic of choice. In this sense, both the clinical and individual perspectives are equally important in healthcare in the partnership approach. As explained by Mol, the experience of coping with either health or disease in self-care management is not a static process neither a product but rather a collaborative process and can not be achieved by the logic of choice.

...care practices tend not to be linear at all. Facts do not precede decisions and activities, but depend on what is hoped for and what can be done. Deciding to do something is rarely enough to actively achieve it... caring is a question of ‘doctoring’: of tinkering with bodies, technologies and knowledge - and with people, too (Mol, 2008, p. 14)

Mol (2008) describes the logic of care as a collaborative process in which care activities are
perform and negotiated by several actors (healthcare professionals, medication, machines, the frail (or healthy) person, and others involved) - and not in isolation - to improve a person’s care situation. She demonstrates how caring and its practices occur in the “messiness of mundane practices” of people’s life and explains the role of machines and technology as equal partner in supporting the serious and tedious care work (Corbin & Strauss, 1985) in everyday life. As pointed out by Timmermans and Berg (2003), technology is not a passive blank slate to be interpreted nor a super actor on its own. Instead, technology should be studied in practice analyzing how they mediate or interfere in people’s care management (Timmermans & Berg, 2003; Poland et al., 2005). As such, technology has been intrinsically incorporated and needed into care practices.

...technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care. (Timmermans & Berg, 2003, p. 104)

From the above, we can see the relevance of investigating self-care practices to inform technology design as technology is an important actor participating in the complex caring process. Now, we should turn our attention to this important aspect as technology is becoming more and more pervasive and embodied into people’s everyday life (Rogers, 2009; Kawser & Brush, 2013). Indeed, a body of work has focused on pervasive computing technologies for healthcare that support self-care management activities - for both health and disease - in non-clinical settings (Bhachu, Hine & Arnott, 2008; Rogers, 2009; Randell, Wilson & Fitzpatrick, 2010; Tentori, Hayes & Reddy, 2012).

Self-care technology can vary from simple medical devices (e.g. blood pressure and glucose monitors) to mobile and web self-tracking tools (e.g. MicrosoftHealthVault, patientslikeme.com) or a combination of different mechanisms and sensors named as “Quantified Self” solutions (e.g. Withings Scale, Fitbit, Jawbone Up) (Lupton, 2013b). More elaborated technology can include a mix of sensors and activity recognition efforts to implement for example Smart Homes and Ambient Assisted Living (SHAAL) systems (Jara et al., 2011; Demeris & Thompson, 2011; Tollmar et al., 2012). However, most of the aforementioned technologies might not sufficient understand and support people’s care trajectory if they have not acknowledged people’s perspective and the caring work at home (Ballegaard, Hansen & Kyng, 2008; Civan, McDonald, Unruh & Pratt, 2009; Storni, 2013).

On the one hand, traditional medical devices has adopted the medical model and the clinical perspective into technology design that for example focus on patient compliance (Storni & Bannon, 2011; Lavernet al., 2012). On the other hand, existing SHAAL and quantified-self initiatives have a strong technological focus in system design that prioritizes the objectivity of data and the logic of choice. SHAAL has focused on automation of care tasks and surveillance of inhabitants (Bratteteig & Wagner, 2013), whereas quantified self has focused on data collection and quantification of health (Swan, 2012). The nature of care as both work and feeling states might not be supported by these technologies if the objectified picture does not consider the value of the subjective input and expertise from both health professionals and people alike (Timmermans & Berg, 2003; Ballegaard et al., 2008; Civan et al., 2009). In this sense, technology might fail to support patient empowerment (Johannsen & Kensing, 2005; Storni, 2013) and therefore increase rather than support the care work at home (Aarhus,
Ballegaard & Hansen, 2009). As presented above, these can result in the aforementioned unintended situations (e.g. obsession, depression, stress, stigma, etc.) that might disempower rather than empower the individual performing self-care activities at home. Overall, it is important to understand and further study people’s perspectives and the role of technology in self-care work practices as well as getting insights from the clinical perspective to inform future system technology design. As we have seen, supporting the management of health and disease involve different conflicting perspectives in technology design as well as have implications for the society in general. As such, supporting self-care management can be categorized as a wicked problem for which there are not optimal solutions (Rittel & Webber, 1973).

To extend this body of work and address the aforementioned social or wicked problems, the focus of this dissertation: “Home-based Self-Care: Understanding and Designing Pervasive Healthcare Technology to Support Care Management Work at Home”, aims to contribute by providing a holistic view and understanding of home-based healthcare practices (for health and disease) to inform future system design of pervasive healthcare technology. Through a design research approach applying user-centered design methods and prototyping, the main concern of this dissertation focus on exploring and providing a holistic understanding of the self-care work practices in non-clinical settings to extend the work by (Mol, 2008; Bratteteig & Wagner, 2013). In this sense, my research investigates different home-based healthcare practices as key resources to study their implications for system design as suggested by (Rogers, 2009).

By doing this, we aim to further study the patient/citizen/people perspective (Ballegaard et al., 2008) aligned with previous efforts that have investigated caring in the “messiness of mundane practices” of people’s life and how technology can support care practices in non-clinical settings (e.g., Kanstrup et al., 2008; Mamykina et al., 2008; Preuveneers & Berbers, 2008; Aarhus et al., 2009; Civan et al., 2009; Aarhus & Ballegaard, 2010; Mamykina et al., 2010; Storni, 2011, 2013). But rather than focusing on a specific care practice, treatment, condition or a specific technology, this dissertation explore (self-)care work practices around the mundane day to day practices to get and in-depth understanding and overview of people’s care practices for both health and illness. Thus, the main contribution stands from providing a bigger overview of what is caring in practice and highlight the importance of both the clinical and people’s perspective in system design for self-care.

These concerns are examined in eight papers (four full published papers, one short published paper, one workshop paper and two manuscripts) that are presented in the second part of this dissertation. The focus of the papers is on understanding home-based care practices such as self-medication and self-monitoring. As explained above, self-monitoring care activities are becoming more and more pervasive in non-clinical settings not only for people with chronic conditions but also as preventive care (Tentori et al., 2012; Fox & Duggan, 2013). Furthermore, self-medication activities have been reported as one of the most complicated self-care activities especially with regard to older adults care (Codagnone, 2009). These two self-care practices constitute the basic for our empirical backdrop. In addition, this dissertation is concerned about the two major challenges in pervasive healthcare: 1) the shift from disease management to individual care management (from a centralized, reactive, information focus to a more pervasive, user and assistive focus); and 2) avoiding or delaying critical health situations - preventive care (Arnrich et al., 2010). I will return to all these concerns in
the following sections while describing the importance of understanding everyday practices in and around the care activities and the role of self-care technology at home.

Last but not least, I will present the description of our design explorations (MediFrame and SELMA) that transfer some of our user’s insights to technology system design. Our empirical work also provides a conceptual framework for understanding non-functional aspects of home-based healthcare technologies. Furthermore, the last two manuscripts are our first attempts towards a design framework and the use of theory based on the aforementioned self-care practices. The dissertation results in a collection of user insights, new knowledge and several design implications that are described in the following chapters. The first part of this dissertation presents an overview of my research by summarizing and discussing the work done based on eight papers. This overview also present future work and put the contribution in relation to the related work in self-care technologies. In the second part, the eight papers are included to complement the initial summary and to contextualize the work presented in this dissertation.

1.1 Research questions

The main research question associated to this dissertation is: How can we design pervasive self-care technology that support the self-care management work at home? In order to answer this meta-question, this dissertation focuses on the following specific questions regarding self-care work practices and home-base self-care technology design.

- What are the challenges of introducing self-care technology for heath and disease at home?
- Are there similarities and/or differences between health and disease care practices and how this can inform system design?
- How can we support designers of pervasive self-care technology to better account for the self-care management work at home?

To summarize the previous introduction, the individual care management is not only about the delegation of care to the care recipients, informal caregivers or technology (Bratteteig & Wagner, 2013). It is rather a dynamic process with people (care recipients and caregivers), information, knowledge and technologies (Mol, 2008). It is about getting and understanding of the multidimensional complexities that “empowerment” impose on people (Mol, 2008) rather than implementations of “watching over”, automatization of self-care activities (Bratteteig & Wagner, 2013), technology adherence and compliance (Moore, 1995; Henwood et al., 2003; Spoel, 2010) or quantification of health (Lupton, 2013a).

In this thesis summary, I - or what i better call “we” a multidisciplinary group of people - are interested on how the understanding gathered by investigating different health and disease home-based care practices can be translated into system design. First, as self-care work is intrinsically related to the situated “practices” (Schmidt, 2011), we investigate home-based care practices that occur in non-clinical settings but without focusing on a specific condition first. Then, using multiple case studies we seek to provide a holistic overview of home-based
care management practices for both health and disease. By understanding the self-care work at home, we aim to contribute to the conceptual knowledge regarding home-based self-care technology design providing: design principles, guidelines, tools, recommendations, and lessons learned. These design tools can be further investigated and applied by designers and researchers of home-based healthcare technology to: a) help designers in framing the design space, and b) facilitate a holistic overview of people’s trajectory of care. We aim to study further the citizen perspective (Ballegaard et al., 2008) regarding home-based healthcare technology accounting for the logic of care (Mol, 2008), towards the design of personalized self-care systems that support the self-care management work at home.

As an example of how the proposed design tools and insights can be used and further investigated, this dissertation further describes a design example - MediFrame - as a result of our user-centered design process and iterative prototyping. MediFrame is a tablet-based self-care application that incorporate both the citizen and health professional perspectives across the design process. MediFrame focus on facilitating the integration of a specific self-care activity (i.e. in this case medication management) into people’s everyday life. MediFrame has been used to get more knowledge about people’s self-care practices during the design process.

1.2 Research setting

Initially, the work presented in this dissertation is the result of my participation in the research Consortium called Lev Vel⁵ (in English Live Well). Lev Vel is a Danish initiative that was funded by The Danish Council for Technology and Innovation and The Capital Region of Denmark. This initiative is aligned to the National Strategy for Digitalisation of the Danish Healthcare Service (Digital-Health, 2007) that aims to increase citizen and patient involvement in prevention and treatment of diseases. I joined the Lev Vel Consortium as a PhD student in November 2010. I have participated in two of the three central innovation projects from November 2010 to February 2012. These projects are Preventive Self-monitoring and Add Ons to the Shared-Medication Card. The target group for these two project was mostly older adults. These projects provided most of the empirical background for my dissertation and I will provide more details in the following sections. From December 2012 to November 2013, I have been part of a small Lev Vel project concerning Rehabilitation and Self-monitoring based on findings encountered in the main two projects mostly as a secondary actor.

Based on the empirical findings from the initial exploratory phase, I enter into a reflective phase investigating similarities and differences with two additional cases of self-care (telemonitoring and home-based rehabilitation). The cases belong to two additional projects (Tele-Skejby and BDSI) from the Center for Pervasive Healthcare⁶ (CfPH). The Tele-Skejby was a tele monitoring project that investigated the care practices of heart patients (mostly older adults) and pregnant women with severe pre-eclampsia⁷ (pregnancy poisoning). BDSI

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⁵See http://lvvl.dk/
⁶See http://www.pervasivehealthcare.dk/
⁷Pre-eclampsia is a human-pregnancy-specific disease characterized by the occurrence of hypertension and proteinuria in a healthy individual after the 20th week of gestation (Eiland et al., 2012; Ghulmiyyah & Sibai, 2012).
was a home-based rehabilitation project that focused on older adults with vestibular dysfunction (chronic dizziness). My participation in this two projects was mostly analytical working and participating in discussions with the people involved in those projects and they served as additional cases to increase the pool of self-care practices and the empirical backdrop for this dissertation. This will be further described in the methodology section.

1.3 Research context

The content of this dissertation has been published in several academic venues such as Health Informatics (one short paper at IHI 2012 and one full paper at ICHI 2013), Pervasive Health (one full paper at PervasiveHealth 2013) and Ubiquitous Computing (one full paper at Ubicomp 2013), Cognitive Ergonomics (one full paper at ECCE 2013) and Human Computer Interaction (HCI - one workshop paper at NordiCHI 2012). While studying home-based healthcare technology, all the aforementioned research areas overlap. As we seek to study self-care work practices, there is a implicit area that I need to mention which is Computer Supported Collaborative Work (CSCW) that is highly related to the aforementioned areas and to the collaborative nature - at times - of self-care practices.

1.4 Outline of the Dissertation

In the following subsections, I provide a background section and a brief introduction of the methods applied in the different studies of self-care practices. Then, I describe the different case studies that provide the empirical backdrop for this dissertation. Finally, I will provide a summary of the contributions of this dissertation and its positioning in the related work before concluding and providing future work. The structure of the thesis is as follows.

- Background
  - The Self-care Management Work at Home
    * Understanding Self-Care Management Work Practices
    * Types of Self-Care Work at Home
    * Informing System Design
  - The Role of Technology
    * Home-based Healthcare Technology
    * Challenges and Opportunities
  - Summary and Discussion

- Methods and Home-based Self-care Cases
  - Phase 1: Explorative - Home-base Self-care Cases
    * Case A: Medication Management
    * Case B: Preventive Self-monitoring
  - Phase 2: Reflective - Multiple Cases
1.5 List of Papers

The list of papers that are considered in the main body of this dissertation are:

Chapter 1 Introduction

Paper 2 Nervo Verdezoto and Erik Grönvall (2012). Designing a Tablet Touch-Screen Interface for Older Adults. Workshop on How to Design Touch Interfaces for and with Older Adults: Identification of Challenges and Opportunities at NordiCHI 2012, Copenhagen, Denmark, 2012, p. 4.


In addition, there is another list of papers, manuscripts and ideas that i have been working on during my studies that i have not included in this dissertation:


In HCI, CSCW, and UBIComp, the understanding of work practices and people’s behavior is important for system design (Rogers, 2004, 2006, 2009, 2012; Schmidt, 2011; T. O. Andersen, 2013). For healthcare technology design, this understanding is crucial (Randell, Wilson & Fitzpatrick, 2010) for both clinical and non-clinical settings to adequately develop systems that support care management work.

In the clinical setting, care work practices are managed through spatial (J. Bardram & Bossen, 2005) and temporal (Reddy & Dourish, 2002) coordination in a highly distributed information space (González et al., 2005). In addition, healthcare professionals have the medical knowledge and are in control of care management activities while the patient plays a more passive role in the clinical setting (Fitzpatrick, 2011; Grönvall & Kyng, 2012). Several mechanisms have been implemented to support care work practices in clinical settings to improve care coordination and support local awareness of patients such as the use of mobile technology, implementation of health status summaries, use of cognitive artifacts (e.g. the whiteboard, doctor’s list) and nursing notes (Solberg et al., 1997; Vikkelso, 2005; Pabllo et al., 2008; Randell, Wilson, Woodward & Galliers, 2010).

Moving care from the clinic to an unsupervised setting such as the home, increases the challenges for ICT as the “home is not an extension of the hospital” (Fitzpatrick, 2011, p. 124). The home constitutes a different social world in which self-care is one more aspect that conform all the mundane activities that take place in people’s everyday life. For instance, people might have different roles during the day (e.g. father, carpenter, teacher, singer) and they are the experts regarding what is happening at home including self-care activities (Ballegaard et al., 2008; Civan et al., 2009; Storni, 2013). Moreover, people might not have the medical knowledge readily available at hand (Grönvall & Kyng, 2012) to interpret the repeated health information exchange during for example chronic care (Chen, 2011, 2013).

Yet previous research has shown the importance of multi-site workplace studies to unfold particularities between care settings (Randell, Wilson & Woodward, 2011). However, the home is a unique setting in which the self-care work differs in several ways from the hospital care work. Hence, it is highly relevant to get an understanding of everyday domestic practices including the self-care work practices to realize why, what, where and when technology...
might be useful to support people’s self-care work. By getting and in-depth understanding of self-care as an important type of work, we as designers can identify strategies and technology to support the complexities of self-care at home. In this sense, we can be able to see the bigger picture rather than focus on discrete self-care tasks. Thus, moving towards designing for “fit” in everyday life rather than designing for “fit for care” as extension of the clinical setting (Fitzpatrick, 2011, p. 125).

In this section, I will present the relevant related work associated to this dissertation. I will provide further details about the care management work practices outside the clinic. Then, I describe the different technologies that can be categorized as home-based healthcare technology and present the existing challenges. In addition, I describe opportunities that technology might provide to support self-care practices in non-clinical settings.

2.1 The Self-care Management Work at Home

In order to start describing the meaning of self-care work practices, let’s start by understanding the meaning of self-care. One of the oldest definitions of self-care is the one provided thirty years ago by the World-Health-Organization (1983).

Self Care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals. Seeking professional advice in Self Care is part of the continuum of trying to maintain good health and prevent disease. (World-Health-Organization, 1983)

A more recent definition provided by the World-Health-Organization (2009) extend the previous broad scope and it is more specific including topics such as: “health promotion; disease prevention; disease control; self medication, reactive and restorative care; referral for institutional/specialist care; and rehabilitation including palliative care”.

Self-care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider. (World-Health-Organization, 2009)

According to Rijken et al. (2008) self-care encompasses different types of self-care such as self-diagnosis, self-management, self-medication and self-monitoring. Furthermore, a more specific definition provided by Webber, Guo and Mann (2013) describes self-care in terms of seven domains and specific behaviors (health literacy, self-awareness of physical and mental condition, physical activity, healthy eating, risk avoidance or mitigation, good hygiene, and rational and responsible use of products, services, diagnostics and medicines). However, this last definition is aiming for a more objectified meaning to provide “tools to practice more effective self-care” activities (Webber et al., 2013).
Overall, these definitions introduce self-care as a broad category of activities that are intrinsically part of our everyday life. First, they touch upon the individual-health professional partnership that has a more visible role when an individual has to manage their health trying to cope with the challenges and complexities of managing health or disease at home. Second, these definitions states that Self-care activities might vary for example from doing nothing or taking analgesics to performing all the work that has to be done in managing health or disease at home. In this sense, we are interested in studying self-care management practices that are necessary to support people’s understandings of health and disease and the collaborative caring process between people, bodies, technologies and knowledge (Mol, 2008) as presented in the previous section. To study the caring process, we will focus on the day to day mundane practices around all the self-care management work practices that has to be done to improve health at home.

2.1.1 Understanding Self-Care Management Work Practices

In CSCW for example, the study of work practices has focused on understanding work as a resource that can inform system design (Blomberg & Karasti, 2013). Yet several studies of work does not necessarily inform design but rather provide for example full descriptions of the work practices that are considered useful for cooperative design (Kyng, 1995; Blomberg & Karasti, 2013).

After looking into the concept of self-care, now we should turn our attention to work practices. The self-care work is one of the most important type of work that is necessary in our everyday life (Corbin & Strauss, 1985; Bratteteig & Wagner, 2013) and that demands “skill and competence, stamina and effort, dedication and attention” (Schmidt, 2011) to enhance health and quality of life. Indeed, the - self-care work - performed by care recipients (and caregivers at times) can be considered as one of the primary cases of work that are “necessary and useful in a practical way” (Schmidt, 2011).

In a sense, the self-care management work can be described as a collection of self-care activities that people perform while taking care of themselves at home that requires “effort and concentration and presume mastery of all sort of technicalities” and as such “demands the best” (Schmidt, 2011). While talking about work in this sense, the term is related to the concept of activity talking about “the ways in which an activity is performed: ’artfully’, ’skillfully’, or of prerequisite competences” (Schmidt, 2011, p. 377).

At the same time, work is related to the concept of practice. Schmidt (2011, p. 377) describes a practice as “a species of regularly performed activity” and not as a particular activity. He says that a practice is something that “one learns and which one thereby eventually masters (or does not master)” (Schmidt, 2011). Furthermore, there is an important distinction between ‘practice’ and ‘practices’ that we should be aware of and that is explained by Reckwitz (2002) thought the theory of social practices.

‘Practice’ (Praxis) in the singular represents merely an emphatic term to describe the whole of human action (in contrast to ‘theory’ and mere thinking). ‘Practices’ in the sense of theory of social practices, however, is something else. A ’practice’ (Praktik) is a routinized type of behaviour which consists of several elements, interconnected to one other: forms of bodily activities, forms of mental activities,
‘things’ and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge. (Reckwitz, 2002, p. 249)

There are two central notions of practice as coordinated entities and as performance (Schatzki, 1996). In the first one, a practice is considered as “a temporally unfolding and spatially dispersed nexus of doing and sayings” (Schatzki, 1996, p. 89). In this notion, there are three main components that are needed to form the ‘nexus’ between the doing and sayings and thus coordinate them. These components are: understandings (of what to say and do), procedures (explicit rules, principles, percepts and instructions) and engagements (‘teleoaffactive’ structures embracing ends, projects, tasks, purposes, beliefs, emotions, and moods) (Warde, 2005; Schatzki, 1996, p. 89). In the second notion, practice is referring to the performance of the carrying out of practices - the performing of doing and sayings - that “actualizes and sustains practices in the sense of nexuses of doings” (Schatzki, 1996, p. 90). These two notions are summarized by Reckwitz (2002, p. 250).

A practice is thus a routinized way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood. (Reckwitz, 2002, p. 250)

In other words, practices only exist when all these elements (body, mind, things, knowledge, discourse/language, structure/process, and the agent/individual) are interconnected in a specific way and not in isolation (Reckwitz, 2002). Moreover, there is another important distinction that we should be aware of regarding practices. There are two types of practices: dispersed practices and integrative practices (Schatzki, 1996). Dispersed practices are the ones “widely dispersed among different sector of social life” (Schatzki, 1996, p. 91).

Their “dispersion” consists simply in their widespread occurrence across different sectors of social life, a breadth that, as noted, helps distinguish them from integrative practices. (Schatzki, 1996, p. 91)

Examples of dispersed practices are “practices of describing, ordering, following rules, explaining, questioning, reporting, examining, and imagining” (Schatzki, 1996, p. 91). Here, the performance of the doings and sayings only requires the first component of understanding in order to carry out the practice. These practices can be part of integrative practices and occurs in different domains in different ways. The integrative practices are “the more complex practices found in and constitutive of particular domains of social life” (Schatzki, 1996, p. 98) and are commonly understood as practices - as explained above by Reckwitz (2002, p. 250). Integrative practices are conformed by a “collections of linked doings and sayings” as a set of routinized bodily performances (Schatzki, 1996). In this sense, integrative practices are embodied into people’s everyday practices and can include different forms of dispersed practices. Examples of these complex practices are: business practices, cooking practices, banking practices, teaching practices, farming practices, cooking practices, and caring practices (taking care of oneself or of others) (Schatzki, 1996, 1997; Reckwitz, 2002).

Regarding self-care work integrative practices at home, I can mention for example an older adult taking medication to help control his blood pressure and a pregnant woman that has to monitor her glucose levels (caring for her and her baby). Both examples of self-care
integrative practices requires individual special attention and learning while managing care at home and as such depends on the person's needs that might change over time. Furthermore, care practices are also particular to a specific domain of social life (Schatzki, 1996) and thus caring at home is different from caring in a nursing home or in the hospital. Moreover, a number of dispersed practices can also occur as part of the integrative caring practices but performed in different ways. For instance referring to the older adult taking the medication, they might have to follow a set of rules regarding the medication about how and when to take it. Or, he/she might also need to read the instructions at least at the beginning of the medication intake and thus constitutes a dispersed practice. Similarly, the pregnant woman has to follow a set of rules or recommendation on how to use the glucose monitor at least before she master it.

These definitions and distinctions are important to have it clear before using them to inform system design. Now that we have reviewed the meaning of the self-care work management practices, we should turn our focus to the different types of work that are embodied in the aforementioned self-care work.

2.1.2 Types of Self-Care Work at Home

Self-care management work include performing different types of self-care work that have been identified by previous research regarding home-based healthcare practices. For instance, Grøn et al. (2008) refers to the “homework” as a set of activities that has to be done by care recipients in non-clinical settings while taking more responsibilities on their health. Taking the broad notion of self-care defined above, self-care work might vary from taking painkillers or doing nothing (Rijken et al., 2008) to all the “invisible work” performed at home when for example people turn into a “diagnostic agent” (Oudshoorn, 2008) or an “information courier” (Unruh & Pratt, 2008, p. 44) in self-care. Our interest relies on understanding all the self-care work practices that might be seen as invisible but that are burdensome for people performing self-care work.

To start with, there is an interpretation work that takes place while people try to understand and get meaning from health data (T. Andersen, Bjørn, Kensing & Moll, 2011). Furthermore, as a result of an active participation in self-care (Glasgow et al., 2001; Rijken et al., 2008), people engage in self-learning endeavors (Chen, 2010, 2011) to help themselves to cope with a disease. Moreover, Aarhus and Ballegaard (2010) shows how people engage in boundary work when for example they integrate or segment self-care activities into their everyday routines or while rendering/hiding self-care related objects (e.g. glucose monitors) at home. Recently, Bratteteig and Wagner (2013) makes the first attempt to categorize care work at home as an important and serious work by describing it using Strauss’ concepts of machine, safety and body work (Strauss, 1993). They describes how care recipients engage in machine, safety and body work when for example they adjust their body to a care-related machine (or devices) and follows the clinical recommendations on how to use it (Bratteteig & Wagner, 2013).

Additionally types of work include (anchored and unanchored) information work and alignment work. Klasnja et al. (2010) describes the information work as all the work that people do while managing health information in non-clinical settings. This might include the collection, integration and exchange of personal health information for themselves or for
sharing with informal and formal caregivers. At home, Moen and Brennan (2005) shows how people develop different storage strategies to help them to manage health information (including artifacts and information) such as “just-in-time” (available with individuals most of the times), “just-at-hand” (visible and readily accessible for the individual), “just-in case” (accessible but kept away for future use), and “just-because” (regarding health concerns with temporal relevance in the future). While these ‘anchored’ information work usually occur on specific and predetermined setting (the household), the unanchored information work occurs on the move for example while walking to the cinema in a setting with not sufficient resources to perform the work (Klasnja et al., 2010). Moreover, there is another type of information work that happens when for example a patient needs to bring information and handle interdependency across distributed care settings to “maintain the continuity of care” (Unruh & Pratt, 2008, p. 43-44). This effort done by patients to connect distributed care settings has been reported as “collaborate diagnostic work” by (T. Andersen, Halse & Moll, 2011, p. 6) as part of the patient homework that should be done.

Furthermore, Huh and Ackerman (2012) talks about the interactional work that takes place when for example patients share their illness trajectory as a member of a patient support group - ‘illness trajectory alignment work’ - aiming to build socially constructed meanings to get a personal meaning from the act of comparing and contrasting different personal experiences.

Finally, most of the aforementioned types of work has been found in specific studies regarding diabetes, cancer care and cardio vascular disease management practices. Even though these specific studies provides a better understanding of self-care practices while studying people’s perspectives on self-care and uncovering complexities (Ballegaard et al., 2008), it is still not known how much of these types of work span over different conditions or over health and much work is needed to provide a more holistic perspective on self-care (Mol, 2008; Bratteteig & Wagner, 2013). As described by Jensen and Allen (1994, p. 351), being healthy and / or having a disease involved a dialectic process (of comprehending, managing, connecting, normalizing and valuing) labeled as the “work-of-living” with health-disease. As people are into a spiral of managing the trajectory of health-disease (Jensen & Allen, 1994, p. 353), we argue that understanding the different types of self-care work as part of the trajectory work (Corbin & Strauss, 1985; Strauss, 1993; Strauss, Fagerhaugh, Suczek & Wiener, 1997) that people perform while doing self-care at home, can help us as designers to understand the more mundane practices around the self-care and to careful interpret them in designing system technology for home-based selfcare. As argued by (Chen et al., 2012; Fitzpatrick & Ellingsen, 2012), there has been limited work exploring the individual care management, the overall care trajectory (trajectory of health-disease) and the interplay of care activities across care settings. Our work will unfold some particularities throughout our case studies later on, now we will turn our focus on how can we use this understanding on work practices to inform system design.

2.1.3 Informing System Design

Besides the ongoing debate regarding the role of ethnography in ICT design (Plowman, Rogers & Ramage, 1995; Dourish, 2006; Crabtree, Rodden, Tolmie & Button, 2009; Blomberg & Karasti, 2013), the value of understanding work practices and people’s behavior have been

There are a number of strategies for transferring the knowledge from ethnography to design that relies on the analysis of work practices and technology in use such as insights, implications, specific design guidelines, design recommendations, and new prototypes (Plowman et al., 1995; Luff et al., 2000; Rogers, 2012). For instance, Kyng (1995) shows how representations of work can be useful for cooperative design to get a explicit understanding of the work situation and to remind the design team about the particularities of the work situation. Apart from the representation of work practices, Kyng (1995) describes the role of representations of the system being designed that should be grounded in user’s work practices to communicate and facilitate exploration of future use.

Besides the aforementioned empirical contribution, Dourish (2006) pointed out that ethnography can also provide analytical contributions while providing models or frameworks “for thinking about those settings and the work that goes on there” (Dourish, 2006, p. 549). In addition, there are initiatives for coupling ethnography and design (T. Andersen, Halse & Moll, 2011; Blomberg & Karasti, 2013) that focus on for example1:

…(1) the interleaving of work practice study and design representations, (2) the direct involvement of practitioners in developing analytic understandings along an extended temporal continuum of their work and technologies, (3) the iterative evaluation of technology-in-use, (4) the commitment to long-term engagement between designers and users that recognizes the inevitability of design-in-use, and (5) the positioning of design intervention as a necessary and equal partner in understanding the present and imagining the future (Blomberg & Karasti, 2013, p. 396)

In design research, several studies argue that design practices can play an important role as a method for inquiry that can help to bridge the gap between ethnography and design of future technology (Zimmerman et al., 2007; Koskinen et al., 2008; Mattelmäki & Matthews, 2009). For instance, T. Andersen, Halse and Moll (2011) uses design interventions as a strategy for questioning aiming to bridge from knowledge generation to for example design sketches of a healthcare system (MyRecord) relying on interventional assemblages in which the design researcher can “enact quick shifts in the mode of inquiry” (p. 7).

In particular in healthcare, Fitzpatrick and Ellingsen (2012) reports a review of the last 25 years of CSCW research in which most of the workplace studies include implications for system design. The review also reports that few studies has engaged in design explorations and that developing and evaluating technology in use is less prominent across multiple settings. Furthermore, the review states that a small number of studies focus on the conceptualization of frameworks of models for designing healthcare technologies (Fitzpatrick & Ellingsen, 2012). However, most of the existing frameworks, methods and models are based on studies from the clinical settings (e.g., Tang, Carpendale & Scott, 2010; J. Bardram & Doryab, 2011; Randell, Wilson, Woodward & Galliers, 2011). But there is a number of studies that

1See the review done by Blomberg and Karasti (2013) regarding the role of Ethnography in CSCW for a complete report.
have started to recognize the importance of the home setting in healthcare in order to propose a bigger view through frameworks and models focusing on for example: presenting a framework for user involvement based on the human-centered design model (Årsand & De-miris, 2008), presenting a model based on the technicalities of a specific system architecture (Vlahu-Gjorgievska & Trajkovik, 2011), and presenting a framework for high level analysis of collaborative processes in the health care sector (Heimly, 2010).

In this section, I have reported a body of work regarding the importance of understanding work practices and how this understanding can inform system design and beyond and why this is important in relation to self-care and home-based healthcare technology system design. Now, it is necessary to turn our focus to the role of technology, challenges and opportunities that it can provide to support the self-care work instead of adding more work to people’s everyday life.

2.2 The Role of Technology

As explained by Mol (2008), technology is playing an important role in the collaborative self-care process. Indeed, as we have described, moving healthcare from the hospital to the home has enabled people to for example get access to health information and technology to facilitate self-care management activities in non-clinical settings (Codagnone, 2009; Lewin et al., 2010). In this context, terms such as “patient-centric”, “patient empowerment” and “patient 2.0 empowerment” come into play to describe the possible benefits of the aforementioned shift of moving care from the hospital to the home (Bos, Marsh, Carroll, Gupta & Rees, 2008). As an example, “Patient 2.0 empowerment” is defined by Bos et al. (2008) as “... the active participation of the citizen in his or her health and care pathway with the interactive use of Information and Communication Technologies”.

However, shifting the responsibilities from the healthcare professional to the individual requires an in-depth understanding of the socio-technical complexities and side effects of introducing such technology in people’s everyday life (Fitzpatrick, 2011; Lupton, 2013a). For example, an ill person might experience more than one disease or have different activities in their active and busy everyday life that complicate the care management work at home (Corbin & Strauss, 1985; Anderson, 2007). In order to manage the work-of-living with health-disease, people might need confront several challenges and complexities of self-care work at home. Thus, it is argued that home-based healthcare technologies can provide several opportunities to enhance people’s abilities in managing health-disease (Randell, Wilson & Fitzpatrick, 2010; Tentori et al., 2012; Lu, Chi & Chen, 2013). In this section, we focus on the specific type of Information and Communication Technologies that aim to support self-care activities at home: home-based healthcare technologies. We will also describe the challenges and opportunities of home-based healthcare technologies to support the self-care management work at home.

2.2.1 Home-based Healthcare Technology

The application of ICT for healthcare in non-clinical settings i.e. home-based healthcare technology, has been reported by several studies regarding telemedicine, e-health, m-health, con-
2.2 The Role of Technology

Consumer health informatics, personal health informatics and pervasive healthcare. In particular, this dissertation started looking into the concept of Personal Health Systems (PHS) in which all the aforementioned research areas overlap. A PHS is defined by Codagnone (2009) as a system that is able to: “assist in the provision of continuous, quality controlled, and personalized health services to empowered individuals regardless of location”.

Three main areas of application of PHS have been identified such as chronic disease management, lifestyle management and independent living solutions (Codagnone, 2009). First, chronic disease management technology aims to support people with chronic conditions in their monitoring needs and related treatments. This technologies have been implemented to facilitate people to: a) monitor bio sensors values e.g. blood pressure, pulse oximeter, ECG (El Assaad, Topouchian & Asmar, 2003; A. Marshall, Medvedev & Markarian, 2007); b) manage specific illnesses e.g. diabetes, asthma (Farmer et al., 2005; Mamykina et al., 2008; Gupt et al., 2011; Jara et al., 2011); c) mental health problems such as bipolar disorder and dementia (J. E. Bardram et al., 2012; Vogt et al., 2012). Second, technology for lifestyle management includes prevention, early diagnosis, well-being, fitness, monitoring and support for identified health problems regarding for example weight (Tsai et al., 2007) and sleep (Choe, Consolvo, Watson & Kientz, 2011) or to provide awareness of for example physical activity (Consolvo et al., 2008). Third, independent living solutions for the elderly to age in place have included support for instrumental and enhanced activities of daily living (Mynatt & Rogers, 2001; Fausset et al., 2009). In particular, SHAAL systems and robot assistance are examples in elderly care (Demeris & Thompson, 2011; Beer et al., 2012).

However, most of the existing care technologies have been designed and implemented taking into account either a strong technological model that focus on surveillance, monitoring of activities, automatization of specific self-care tasks and objectified quantification of health (Jara et al., 2011; Demeris & Thompson, 2011; Tollmar et al., 2012; Bratteteig & Wagner, 2013; Lupton, 2013a). Or they have focused on the disease-centric model while paying attention to patient compliance and being driven by the health professional’s perspective (Moore, 1995; Henwood et al., 2003; Spoel, 2010; Ballegaard et al., 2008; Fitzpatrick, 2011; Storni, 2011, 2013). Thus, supporting people’s/citizen perspectives has been neglected to some degree (Ballegaard et al., 2008). As described by Fitzpatrick (2011), technology designed under the traditional model of medical care are unable to consider the “huge complexity and diversity of lived experiences at home” (p. 125). For instance, some people might be patients that need to follow a prescribed treatment at home and take an active role (Salmon & Hall, 2004), whereas another group of people might not feel comfortable taking an active role and prefer a dependent role (Woodward, 1998; Salmon & Hall, 2004). In addition, people at home could also be just healthy people with or without a general interest in their health and wellness, before becoming a user of a specific home-based healthcare technology.

As such, there is a body of work that have accounted for investigating people’s differences in managing health-illness care practices (e.g., Consolvo et al., 2008; Kanstrup et al., 2008; Mamykina et al., 2008; Preuveneers & Berbers, 2008; Aarhus et al., 2009; Civan et al., 2009; Aarhus & Ballegaard, 2010; Mamykina et al., 2010; Storni, 2011, 2013; Güldenpfennig & Fitzpatrick, 2013). In the following subsections, challenges and opportunities are described regarding home-based technology design.
2.2.2 Challenges and Opportunities

There are a number of challenges that has been identified by current research attempting to uncover people’s perspectives of care and support the self-care work caused by for example the disease, the treatment or the use of technology at home (Aarhus, Ballegaard & Hansen, 2009; Camerini, Giacobazzi, Boneschi, Schulz & Rubinelli, 2011). One of the main concerns is the issue regarding the acceptance and adoption of self-care technology in private homes as the home has not been designed as a place for care (Axelrod et al., 2009; Heart & Kalderon, 2011; Grönvall & Kyng, 2012).

Challenges include for example restrictions of space and place for care-related technology (Axelrod et al., 2009) and interference or difficulties for integration into people’s everyday life (Ballegaard et al., 2008; Fitzpatrick, 2011; Craven et al., 2013). There are also constraints regarding the installation and transportation of the technology (Grönvall & Kyng, 2012), reliability of the monitoring devices (Ashiful, Zarifi Eslami & Sikkel, 2012; Montgomery-Downs et al., 2012), and underestimation or not consideration of the individual health variability (Morris, Intille & Beaudin, 2005; Frost, Doryab, Faurholt-Jepsen, Kessing & Bardram, 2013). Furthermore, the lack of understanding of clinical terminology and health parameters (Morris et al., 2005), an increased focus on bio-values and symptoms oriented (Swan, 2012; Lupton, 2013b), and the lack of contextual information (Preuveneers & Berbers, 2008; Storni, 2011; Toscos et al., 2012; J. Bardram et al., 2013) challenge the use of home-based healthcare technology. Moreover, there are a number of issues regarding the aesthetics of the home as some monitoring devices can be perceived as disease-like (Aarhus & Ballegaard, 2010; J. Bardram et al., 2013) or has been designed in a way that catch inappropriate attention by other people in public (Nachman et al., 2010). Indeed, there is another privacy issue regarding the “big brother” effect (Milligan, Roberts & Mort, 2011). In addition, the lack of communication between multiple self-care devices (Toscos et al., 2012) caused by for example the use of closed source systems can limit the access to algorithms and personal health data (Montgomery-Downs, Insana & Bond, 2012). All of these challenges pose demands on people’s everyday life that can either support or increase the amount of self-care work performed in people’s everyday life (Preuveneers & Berbers, 2008; Aarhus et al., 2009; Aarhus & Ballegaard, 2010; Craven et al., 2013).

What is more, a number of negative and unintended side effects, as consequence of patient empowerment, at times caused by technology, does challenge the use of self-care technology at home (Storni, 2013). For instance, the fear of diagnosis labels i.e. stigmatization (Morris et al., 2005; Mulder et al., 2009; Aarhus & Ballegaard, 2010; Güldenpfennig & Fitzpatrick, 2013) or health-detrimental situations such as stress, obsession and depression (Ciechanowski et al., 2003; Lin et al., 2004; Andreassen, 2011; Lupton, 2012, 2013a). Additional side effects might include people’s feelings of alienation - “alienated by the technology” (Aarhus, Grönvall & Kyng, 2010) or negative emotional responses such as worrisome, disturbing, shameful, and frustration (Mamykina et al., 2010; Toscos et al., 2012; Huniche, Dinesen, Nielsen, Grann & Toft, 2013). Technology might fail to account for individual differences when for example people find complications on reducing the importance of their disease management to a game (J. Bardram et al., 2013) or having a machine replying to their suicidal thoughts with inappropriate messages (Farzanfar, Frishkopf, Friedman & Ludena, 2007).
At times, technology can be seen as intrusive in people’s everyday life when for example they are based on camera-based monitoring, positioning systems and microphones at home (Ziefle, Himmel & Wilkowska, 2011). To increase the adoption of these technology at home, they should be perceived as useful, simple and enable people to control them rather than providing the feeling of being controlled by the technology (Steele & Lo, 2009; Ziefle et al., 2011; Heart & Kalderon, 2011). Technology design should focus on designing for active engagement and reflection and not just as mediums for surveillance (Fitzpatrick, 2011).

Nevertheless, it is important to recognize that technology play an important role supporting people’s self-care work and that there is evidence of positive benefits of using technology for self-care. For example, while supporting people’s understanding and reflection of their own health conditions, technology has facilitated knowledge and enabled people to take an active role in the collaborative self-care process (Mamykina et al., 2008, 2010; Storni, 2011, 2013; Clemensen, Craggs, Marcussen, Petersen & Prior, 2013; Huniche et al., 2013). In this sense, people have increased their understanding about health and disease regarding how their bodies responds to certain behaviors and which factors affect self-monitoring values (Nachman et al., 2010; Mamykina et al., 2010; Toscos et al., 2012; Güldenpfennig & Fitzpatrick, 2013). This awareness has increased people’s feelings of competence while managing their disease as they master the necessary skills to cope with the specific disease over time (Mamykina et al., 2010). In this sense, technology has helped people to remember self-care activities and gain feelings of control over their disease and health situation to continue with their life (Aarhus et al., 2009; Aarhus & Ballegaard, 2010; Mamykina et al., 2010; Storni, 2011; J. Bardram et al., 2013; Clemensen et al., 2013). Furthermore, technology can enable people to find patterns about their health while enabling comparison of self-measurements over time through visualizations of health data (Preuveneers & Berbers, 2008; Toscos et al., 2012; J. Bardram et al., 2013).

Moreover, technology has also enable informal caregivers to take part of the caring process while rendering what is invisible for them ‘the current health situation of their love ones’ -(Aarhus & Ballegaard, 2010) and thus facilitating the sharing responsibility not only with clinics but also with family and friends (Aarhus et al., 2009). Positive benefits has been reported such as increased feelings of trust, security, and confidence while managing activities that fit people’s everyday life at home (Clemensen et al., 2013; Huniche et al., 2013) and positive emotional responses such as encouraging and reassuring (Huniche et al., 2013). Also, technology has facilitated the learning process from sharing experiences among peers (Mamykina et al., 2008; Glasemann, Kanstrup & Ryberg, 2010) that can result on increased individual motivation (Glasemann et al., 2010) and foster people’s identity construction while managing disease at home (Mamykina et al., 2010).

Finally, research has shown that mobile technology can offer several opportunities to support self-care activities in and outside the home setting increasing people’s acceptance while using self-care technologies (Pinsker et al., 2008; Bhachu et al., 2008; Tentori et al., 2012; J. Bardram et al., 2013). However, mobile phones and wearable devices suffer from some issues regarding the limited screen size (Massimi, Baecker & Wu, 2007; Bhachu et al., 2008) and the social stigma that can be attached to the device (Bhachu et al., 2008) when using these as tools for self-care. This is an important concern specially for older adults (Massimi et al., 2007). Here, touch-screen interaction offered by for example tablet devices can offer more opportunities while supporting older adults (Holzinger, 2003; Dewsbury, Rouncefield,
Touch-based interfaces can be easy to learn and adopt by older adults and easily fit their everyday activities (Häikiö et al., 2007) as for example tablets can fit in the limited space of people’s homes (Dewsbury et al., 2007). As such, tablet-based touch interfaces can be an alternative to embed technology into people’s everyday life as they can offer opportunities to remove the stigma attached to traditional self-care devices (Bhachu et al., 2008; Aarhus & Ballegaard, 2010).

2.3 Summary and Discussion

In brief, we have seen how technology can support self-care activities for managing health and disease at home (e.g., Ballegaard et al., 2008; Consolvo et al., 2008; Kanstrup et al., 2008; Mamykina et al., 2008; Preuveneers & Berbers, 2008; Aarhus et al., 2009; Civan et al., 2009; Aarhus & Ballegaard, 2010; Mamykina et al., 2010; Andreassen, 2011; Storni, 2011; Tentori et al., 2012; Toscos et al., 2012; Lu et al., 2013; Storni, 2013; J. Bardram et al., 2013). Home-based monitoring technology has facilitated the collection of health data in order to support both people and caregivers with self-care activities in non-clinical settings. Indeed, people have started to take an active role in their self-care management and have used technology to support their self-care practices such as physical activity, dietary intake or medication intake as explained by the examples presented above. As such, it is believed that mobile technology can support self-care management for different target groups including older adults and children (Bhachu et al., 2008; Toscos et al., 2012) as they can support mobility in and outside the home and thus can find space, place and be embedded into people’s everyday life that is one of the main challenges reported by several researchers (Ballegaard et al., 2008; Fitzpatrick, 2011; Grönvall & Kyng, 2012). This possible fit into people’s everyday life can help to remove the social stigma inherent in traditional self-care devices (Aarhus & Ballegaard, 2010) and thus contribute to the adoption of self-care technologies.

However, most of these good examples have focused on a specific disease, treatment or target group. In order to support people in their self-care work, we as designers of home-based healthcare technology should acknowledge that self-care is just one more practice of many that people have in their everyday life. We should recognize the challenges and opportunities that technology can offer to support all the work produced and moved as a result of the aforementioned shift of care. Informed by previous work, this dissertation aims to provide not only design tools such as requirements, design principles, opportunities and recommendation, but also to provide a holistic view of self-care practices at home. While recognizing and studying self-care work practices as one of the primary type of work in people’s everyday life, we aim explore the consequences of promoting people’s empowerment, also named the digital engaged patient (Lupton, 2013a), as well as the people’s perspective regarding self-care technology design (Ballegaard et al., 2008; Bos et al., 2008) but recognizing the value of multiple perspectives on self-care (Das & Svanaes, 2010). Most of current home-based healthcare technology (e.g. e-health) lack a proper consideration and understanding of the importance of people’s and health professionals perspectives and thus reported issues on usability and accessibility of these technologies (Goldberg et al., 2011). As we have seen, purely stand-alone devices (including quantified-self) for example have neglected one or both perspectives and thus might not be sufficient to support the individual performing self-care management work at home neither able to create meaningful value to
society (Gemert-Pijnen et al., 2011; Storni, 2013). What is more, technology can also result in different side effects that can be detrimental for people’s health rather than empowering people so to speak.

In the next chapter, we describe our methodology in order to study the self-care work at home and provide a description of the different case studies that have served to frame our contribution.
Chapter 3

Methods and Home-based Self-care Cases

This section contains a description of the research methodology of this dissertation. Since the overall aim of this dissertation was to get an in-depth understanding of self-care practices to inform system design, our studies are aligned to a design-research approach to a large degree to bridge the gap between understanding and designing. In addition, this dissertation has been informed by research on Healthcare, HCI, CSCW, and UbiComp as described in the previous section 2.

Rogers (2012) describes the turn to design as one of the main types of HCI contemporary theory. She explains how design has been a central topic for HCI research (e.g. user-centered design, interface design) since the 1990s. Similarly, Fallman (2003) describes HCI as a design-oriented discipline in which researchers engage in a design process (design, implementation and evaluation) of a specific interactive technology. To account for the context of use, there was a turn from controlled experiments to field studies to get a better understanding on the use, activities, and meanings attached to the designed artifacts (Koskinen et al., 2008). Hence, field studies and design have played an important role in HCI, CSCW and related research communities (Mattelmäki & Matthews, 2009). As such, the use of several design methods (e.g. scenarios, field studies, interviews, use cases and prototyping) have been widely applied not only for designers but also researchers (Rogers, 2004).

A more theoretical concern around the role of design theory and critical design started catching more attention during last ten years (Rogers, 2012). For instance, Fallman (2007; see also Fallman, 2008) explains how design-oriented research is different from research-oriented design in terms of the intended outcome of the design process. In design-oriented research, the knowledge that we as designers can gather with an iterative design process using the designed artifact as a means to contribute to that knowledge - research is the main focus of interest. Whereas in research-oriented design the focus of research relies on the complete implementation of the artifact as the main result - design is the main focus of interest (Fallman, 2007). Furthermore, some researchers started drawing attention to the complexity of design in HCI explaining how some design situations can be overwhelming for designers specially in “under determined” problems or “messy problematic situations” (Schön, 1983, p. 47) due to for example the overload of information sources (Lowgren & Stolterman, 2004; Stolterman, 2008). This in turn has provoked a shift from “prescription to reflection” (Rogers, 2012). As
such, design has been conceptualized as a reflective practice (Lowgren & Stolterman, 2004; Stolterman, 2008) based on Schöns’ work about the reflective practitioner in which design is seen as a generative work that involved a developmental process (Schön, 1983). To support designers in their reflective practices, there is a need to provide them with.

... (i) precise and simple tools or techniques..., (ii) frameworks that do not prescribe but that support reflection and decision-making..., (iii) individual concepts that are intriguing and open for interpretation and reflection on how they can be used..., (iv) high-level theoretical and/or philosophical ideas and approaches that expand design thinking but do not prescribe design action (Stolterman, 2008, p. 63).

Aligned with (Stolterman, 2008), Zimmerman et al. (2007) recognizes the need for usable tools to support designers and they introduced a model for interaction design research in HCI based on the research through design concept specified by (Frayling, 1993). They outline a model for designers that engage in wicked problems that might appear in HCI. Similarly to the “under determined” or “messy problematic” situations explained above, wicked problems are in essence planning problems that involved different stakeholders perspectives with no stopping rule and without a one-best possible solution (Rittel & Webber, 1973) provoking an overwhelming design complexity (Stolterman, 2008). The model aims to help designers to approach these extreme situations in order to discover new opportunities for technology by continually reframing the problem and focusing on describing a vision of a preferred state attempting to do the right thing (Zimmerman et al., 2007). However, Mattelmäki and Matthews (2009) emphasizes that research through design should not be understood as a method but rather seen as several ways in which “design methods, processes and products have been fundamental to (but not sufficient for) making a research contribution” (p. 4).

Similarly, Sengers and Gaver (2006) suggests that multiple interpretations can co-exist that might be useful to uncover aspects regarding the complexity and dynamics between the multiple stakeholders in the design process - in contrast to the strict view of one preferred interpretation. In fact, W. W. Gaver, Beaver and Benford (2003) highlights how ambiguity (of information, context and relationship) can be an important factor to help designers to consider different perspectives without enforcing the design of the right thing. Moving away from the right solution can provide a tool for both designers and users in which the focus is moved to how people appropriate technology in everyday life (W. W. Gaver et al., 2003). Furthermore, Fallman (2008) proposes a model for interaction design research as a triangle with three extremes: design practice, design studies, and design exploration. In particular, he describes design exploration as one most important that look into visions or ideals of the future rather than look for one preferred state or unique interpretation and thus resembles the connection between design research and HCI (Fallman, 2008, p. 17).

...Design exploration often seeks to test ideas and to ask “What if?” - but also to provoke, criticize, and experiment to reveal alternatives to the expected and traditional, to transcend accepted paradigms, to bring matters to a head, and to be proactive and societal in its expression (Fallman, 2008, p. 8).

These multiple interpretations and different visions of technology has been inspired by socio-technical approaches coming from Science and Technology studies (STS) (Pinch & Bijker,
3.1 Phase 1: Explorative - Home-base Self-care Cases

1987). As described by Sengers and Gaver (2006), STS studies are “interpretively flexible” in a sense that they focus on different (and multiple) ways in which people interpret and appropriate technology and its role in their life rather than only emphasizing designers or developer’s interpretations (Rogers, 2012). Indeed, STS has influenced design research for several years (Hanseth, Aanestad & Berg, 2004; Ingram, Shove & Watson, 2007) and thus other disciplines such as HCI and Participatory Design (Steen, n.d.; Storni, Linde, Binder & Stuedahl, 2012).

The nature of this dissertation is exploratory and by no means pretend to design the right thing. In contrast, we are interested in how the understanding of self-care practices can inform system design. Aligned with (T. Andersen, Halse & Moll, 2011), we are taking a design research approach in healthcare. First, we engage in two different cases of home-based self-care practices (medication management and preventive self-monitoring) to investigate challenges and opportunities for system technology design. As such, we also report on how design research methods helped us to generate knowledge through our iterative design process while moving between design exploration and design studies as described by Fallman’s model - see Phase 1 in Figure Figure 3.1. Second, we engage in a reflective “post-project” process that is reported as two different multiple case studies of self-care practices based on the empirical findings of the previous phase 1 (cases A and B in Figure 3.1) together with additional cases of self-care management support (self-monitoring of pre-eclampsia, diverse hearth conditions and home-based rehabilitation - cases C, D and E respectively in Figure 3.1) - Phase 2. In addition, we did our first attempt to use theory as lens to understand self-care work practices in a holistic way and Phase 3 will give a short discussion about that. All three phases are summarized in Figure .

![Figure 3.1 An overview of the different research phases](image_url)

3.1 Phase 1: Explorative - Home-base Self-care Cases

The first phase - Phase 1 - of this dissertation was done within a multidisciplinary group (e.g. medicine experts, computer scientists, business partners, and older adults) as described in Section 1.2. Phase 1 covers two exploratory studies of health-disease care practices aiming to get a better understanding of care practices to inform home-based healthcare system design. These self-care practices are medication management and preventive self-monitoring in non clinical settings as introduced in section 1.2. In the first case, we investigated older
adults medication management practices. In the second case, we investigated preventive self-monitoring practices among older adults (mainly healthy older adults). During this exploratory phase, we combined multiple methods (qualitative and quantitative) of enquiry as well as user-centered design methods. In our design-oriented research process, we move back and forth between the two extremes of Fallman’s triangle: design exploration and design studies. These two cases and their methods for data collection and analysis are summarized in the following subsections.

3.1.1 Case A: Medication Management

In the first case, we focus on getting an in-depth understanding of one of the most complex self-care practices in non-clinical settings: medication management practices. As described in the introduction of this dissertation, medication management is one of the most complicated self-care practices especially with regard to older adults care. But rather than focusing on a specific condition or treatment, we focus on self-care medication management practices to get a broader understanding but without a specific condition in mind. Our project work include both quantitative and qualitative studies as well as a compliance technology review that later extended to a user-centered design process moving back and forth between design explorations and design studies through iterative prototyping and user’s feedback. In the following, we summarize all the empirical work in terms of data collection and data analysis reported in Papers 1, 2, 3, and 4 respectively in (N. X. Verdezoto & Wolff Olsen, 2012; N. Verdezoto & Grönvall, 2012; Dalgaard, Grönvall & Verdezoto, 2013; Dalgaard, Grönvall & Verdezoto, 2013).

Quantitative Study

Initially, the project carried out 360 telephone interviews with older adults over 60 years old from two municipality in Denmark (Gentofte and Hillerød). Participants were recruited from a list of all citizens over 60 years old provided by the local governments and fulfilled the following requirements: participants manage their own medication, participants who have been prescribed medications at least for the last three months, and participants who take either more than once medication dosage (amount) or more than one prescribed medication a day (frequency). The Lev Vel stakeholders defined the 28 questions and contracted a market research institute to do the interviews. Questions touched upon participant’s medication intake (e.g. amount - how many medications - and frequency - how many times a day), participant’s medication information needs, participant’s mnemonic rules in medication management, participant’s compliance and noncompliance and participant’s use of technology.

Qualitative Study

The project also involved an initial qualitative study with nine older adults between 60 and 93 years old to confirm and further investigate medication management practices in older adult’s homes. Participants fulfilled the same requirements as in the previous study. Five of
them were recruited from the local healthcare workers in Gentofte and the rest from a pharmacy in Hillerød. Additional characteristics of this group include: daily medication intake between 1 to 32 doses. Four participants performed medication management by themselves and five received help from a nurse at home every second week. Two of them were additional assisted by their wives. One participant from the ones that received some sort of assistance was in the process of getting more independence regarding the medication management at home.

Compliance Technology Review

We also performed an extensive compliance technology review before the user-centered design process to get an overview of the broad market of current available technologies for medication compliance. Based on a compliance technology review (Dam, Agergaard, Herborg, Møldrup & Rossing, 2009) done by one of the Lev Vel partners Pharmakon, we confirmed if any technology from Pharmakon’s list are still available and extended the list with new available technology until January 2011. The information was collected over two months and include: product’s name, type, use and type of reminders, whether or not it enables mobility, technology level, image, website, form of distribution, availability of the technology, compliance monitoring and feedback and other sort of additional information. After the review was completed, a more focus review was performed for a number of selected technologies from the review the includes: product category, description (features and components), manufacturer, contact information, additional information and reviews if any.

User-centered Design Process

Next, we engaged into a participatory and user-centered design process with seven medication experts (two doctors, two healthcare workers, two pharmacists, and one developer from SMR), eight additional older adults (between 57 - 90 years old) and two/three researchers. The design process was informed by the previous studies, the compliance technology review and the related work of this dissertation regarding the opportunities that mobile technology can offer to support self-care activities.

First, we initially identify a set of 15 different concepts as a result of one initial workshop between all the partners involved in the project. Three tracks were defined and I engaged in the first track regarding the medication overview as part of the MediFrame concept - one of the concepts I initially suggested. Partners involved in the further design process for MediFrame were: Aarhus University (AU - Department of Computer Science), Alexandra Institute (AI),

1Jesper Wolff Olsen was the initial project leader and participated in the initial design process. After he left, Lea and Erik joined me in the project after a year.

2These concepts were: a pill reminder box, a physical medication card, MediFrame - a digital representation of the physical medication card, MediRoad - a context aware reminder application based on location information, squeezing “bracelet/watch” as physical reminder, reminder based on the iPod Nano design, RFID reminders, a medicine information dashboard, fancy pill sorter, session recorder for recording sessions with the pharmacy and/or GP, an online community for sharing information between citizens and GP, MediFilm - a personalized information film regarding citizen’s medications, MedicationDiary for registration of information about medications/treatments, compliance log regarding citizen’s medication taking behavior, MediWii - a wii game for improving medication compliance, a rule engine to generate and send reminders to citizens about medication events.
Chapter 3 Methods and Home-based Self-care Cases

Figure 3.2 User-centered design process: (a) involving medication experts; (b) understanding older adults routines; (c) getting feedback from older adults about our screen-based prototype.

Dansk Laegemiddel Information (DLI - Danish Medicine Information)\(^3\) and Trifork (software company). However, Trifork and DLI mostly played the role of medication experts. After the concept selection, we also did a literature review regarding tablet-based touch interfaces for older adults (N. Verdezoto & Grönvall, 2012).

Second, we carried out workshops and interviews with the older adults and medication experts as part of our user-centered design process. During the workshops with older adults, activities and discussions focused on: the same questions of the previous studies, participant’s daily routines including medication intake, getting early feedback regarding the vision, functionalities and goals of the MediFrame concept, and approach to technology by the older adults. During the workshops with medication experts, discussions and activities focused on: results of activities with older adults, gathering knowledge regarding the needed medication information at home, feedback and suggestions regarding the functionality, vision and goals of the different mockups and prototypes (Ehn & Kyng, 1991; Bødker & Grønbæk, 1992) of MediFrame. Additional meetings were held between researchers and medication experts when needed to further explore and confirm emerging situations from activities. All design decisions were based on the results from our diverse studies between researchers and medication experts though iterative prototyping (Bødker & Grønbæk, 1992). In brief, we moved between designing with medication experts and designing for older adults during our design process. Figure 3.2 illustrates some of our activities with older adults and medication experts.

Review on Design Guidelines for Tablet-Based Touch Interfaces

As part of the user-centered design process described in the previous section, we reviewed existing design guidelines regarding design for mobile devices, touch interfaces and older adults. The review includes: the Eight Golden Rules of Interface design (Shneiderman, 1987) that have been adjusted for mobile interface design (Gong & Tarasewich, 2004) and for the integration of multiple perspectives (Tarasewich, Gong, Nah & Dewester, 2008), the W3C review of accessibility for older adults W3C (2011), the Web content accessibility recommendations (WCAG) improved for older adults (Subasi, Leitner, Hoeller, Geven & Tscheligi, 2011), the 7 usability guidelines for websites on mobile devices (Warsi, 2007), touch-based inter-

\(^3\)DLI: http://min.medicin.dk/Artikler/Artikel/58#MASTER
3.1 Phase 1: Explorative - Home-base Self-care Cases

Figure 3.3 Affinity diagram of design guidelines.

faces design guidelines for older adults (Murata & Iwase, 2005; Jin, Plocher & Kiff, 2007; Kobayashi et al., 2011), and general guidelines for designing for older adults (Fisk, Rogers, Charness, Czaja & Sharit, 2009).

Data Analysis

The qualitative data from our previous studies was analyzed using content analysis (Patton, 2002; Braun & Clarke, 2006) and combined with the quantitative data. For instance, Braun and Clarke (2006) provides a step-by-step guide for conducting content analysis - 1) familiarization with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) reporting themes. Content analysis was used to identify the most relevant themes from the most frequently discussed and emphasized topics by the participants (both older adults and medication experts) and it was performed by the three researchers (Lea, Erik and me). Regarding the literature review on tablet-based touch interfaces, we combined them through an affinity diagram as illustrated by Figure 3.3.

3.1.2 Case B: Preventive Self-monitoring

In the second case, we initially focused on self-care monitoring practices in non-clinical settings (both health and disease) rather that focusing on a specific monitoring practice of illness. Our project work include both quantitative and qualitative studies as well as a user-centered design process moving back and forth between design explorations and design studies. The initial qualitative study made us focused on a specific target group of preventive self-monitoring practices that will be described in the following sections. In addition, the project involved a multidisciplinary group of people (e.g. three computer scientists, a nurse, an ethnographer, and two business managers as well as older adults). In the following, we
summarize all the empirical work in terms of data collection and data analysis reported in Paper 5 (Grönvall & Verdezoto, 2013b)\(^4\).

**Qualitative Study**

First, the initial qualitative study explored people’s motivation, perception and use of self-monitoring technologies in non-clinical settings. The initial data consist of two-hour semi-structured interviews with 10 adults (6 men, 4 female, aged 45-85) where six were living with their family and four were living alone. Among these participants, four were healthy, three had a chronic illness (one with diabetes and two with COPD - one of these two had a weak heart), two were in rehabilitation after cerebral hemorrhage and the last one had experienced breast cancer. The interview questions include: participants motivation and knowledge regarding their current health status, health data sharing needs, what motivate change behavior, participant’s use of self-monitoring technologies, participant’s experiences regarding self-monitoring technology.

**User-centered Design Process**

Next, we engaged into a user-centered design process. After the initial qualitative study, we focused on healthy people that would like to prevent fragility. We recruited ten participants between 65 and 84 years old from an activity center in Aarhus. Participants have an active lifestyle and perceived themselves as “healthy”. The design process was informed by the related work on self-monitoring technology. After the initial qualitative study, the collaboration started between Aarhus University, Alexandra Institute, Cure4You Technologies and Denmark Communications (Dencomm) focusing on healthy older adults.

First, we analyzed an initial set of health parameters suitable for self-monitoring at home from the Cure4You website. These parameters are summarized in table 3.1. From these parameters, we selected blood pressure (BP) for further investigation due to: 1) the level of complexity while taking the measurement based on the number of instructions that a person should follow to perform a valid measurement, 2) the relevance of BP as one of the most complicated risk factors in Denmark, and 3) the availability of BP devices in older adults’ homes.

The user-centered involvement extended to several workshops to investigate the challenges and opportunities to support preventive self-monitoring activities at home. Workshop activities explore why, how, and when participants could perform preventive self-monitoring as part of their everyday life. The first workshop focused in understanding blood pressure self-monitoring activities and a nurse was also engaged and explained to the participants the importance of preventive BP self-monitoring. The nurse explained causes, symptoms, consequences and actions to control high BP. Participants were asked to measure BP by themselves (see Figure 3.4a). Two participants left the project after the first workshop due to a high BP detected during the workshop. Second workshop focused on understanding older adult’s daily routines using a modified version of the Day Reconstruction method (DRM) reported by (Kahneman, Krueger, Schkade, Schwarz & Stone, 2004). In this workshop, we

\(^4\)Paper 5 has been pre-selected to appear in a revised form into the special issue in the journal Cognition, Technology and Work.
3.1 Phase 1: Explorative - Home-base Self-care Cases

asked participants to make drawings of their homes and list and order their daily activities (both morning and evening) on their drawings (see Figure 3.4b). Next, we asked participants to perform the BP self-monitoring activity as suggested by the nurse three days in a row - mornings and evenings - and registered the values on a paper-based template that we provided them. We also gave them a written version of the guidelines to perform a correct BP measurement at home that was translated to Danish from the original version provided by (Parati et al., 2010).

<table>
<thead>
<tr>
<th>a. Lung Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Peak expiratory flow</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. Heart Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Systolic Pressure</td>
</tr>
<tr>
<td>- Diastolic Pressure</td>
</tr>
<tr>
<td>- Heart Rate Pressure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c. Glucose Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Blood Glucose Level</td>
</tr>
<tr>
<td>- Glycosilated Hemoglobin</td>
</tr>
<tr>
<td>- Hemoglobin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d. Cholesterol</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Low-density lipoprotein, LDL (bad cholesterol)</td>
</tr>
<tr>
<td>- High-density lipoprotein, HDL (good cholesterol)</td>
</tr>
<tr>
<td>- Triglycerides</td>
</tr>
<tr>
<td>- Total Cholesterol</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>e. Weight and Body Mass Index (BMI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Weight</td>
</tr>
<tr>
<td>- Height</td>
</tr>
<tr>
<td>- BMI</td>
</tr>
<tr>
<td>- Waist</td>
</tr>
</tbody>
</table>

Table 3.1 Sample of Cure4You Health Data.

Based on the previous workshops, we engaged on a series of design explorations to further investigate the visualization and interpretation of BP values. In the third workshop, we presented our design explorations to the older adults apart from discussing participant’s experiences from the self-monitoring activity (see Figure 3.4c). The design explorations were represented as mockups (Ehn & Kyng, 1991) of different visualizations in terms of overview and details of BP values. Eight different pairs of visualizations were presented to them one by one to get feedback from the older adults as reported by (Beaudin, Intille & Morris, 2006). The last workshop was focused on getting feedback from older adults regarding a design concept that we started to work after the previous workshops to gain older adult’s attitudes towards self-monitoring (see Figure 3.4d). The design concept was SELMA, a personal and mobile application for preventive BP self-monitoring. SELMA was presented using a screen-based prototype on one screen without providing a hand-ons experience but rather to elicit older adult’s discussion. During each workshop, we always finished with a group discussion.

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5 Informally called bad cholesterol
6 Informally called good cholesterol
Chapter 3 Methods and Home-based Self-care Cases

Figure 3.4 Workshops: (a) understanding self-monitoring activities; (b) understanding older adults routines; (c) validation and visualization; and (d) older adults’ attitudes towards self-monitoring technologies regarding the activities that took place during the workshop.

Quantitative Study

Last, the project work also extended to a quantitative study (online survey) that included 165 completed respondents to confirm and further explore self-monitoring activities and workshop results on a broader population (aged 22-83). Questions were the same as in the qualitative study as well as questions regarding participant’s health status, personal information, and participant’s use and preferences regarding self-monitoring technologies at home.

Data Analysis

The qualitative data from our previous studies on self-monitoring was analyzed using an inductive and deductive content analysis (Patton, 2002; Braun & Clarke, 2006). As described by Braun and Clarke (2006), an inductive content analysis is a ‘bottom up’ approach in which themes are strongly identified in the collected day, whereas a deductive approach is a ‘top down’ analytic-driven way that provides a more focused analysis of a specific aspect of the data. Content analysis was used to identified the most relevant themes coming from our qualitative study and workshop activities (inductive) and the most relevant challenges coming from the literature (deductive) that were presented in section 2.2.2 (e.g. privacy issues, lack of understanding, issues with self-monitoring devices, etc.).

3.2 Phase 2: Reflective - Multiple Cases

In Phase 2, our work extended to a reflective “post-project” process in which we analyze multiple projects as cases of self-care practices. Based on our empirical findings from Phase 1, we considered more cases to investigate similarities and differences across cases as part of our exploratory and reflective process of self-care practices. The two initial cases were separately analyzed with three additional cases: tele-monitoring of heart patients, tele-monitoring of
pregnancy woman with pre-eclampsia and home-based rehabilitation. The description of the three additional cases and methods for analysis are summarized in the following sections.

3.2.1 Multiple Cases of Self-monitoring

In this exploratory and reflective phase, the main research method that has been adopted is a qualitative case study as empirical inquiry that emphasizes the study of closed-real life situations and how they unfold in practice (Patton, 2002; Yin, 2009). The unit of analysis were self-monitoring projects and they were purposefully selected to investigate health-disease self-monitoring complexities. Patton (2002) describes purposeful sampling as a number of information-rich cases selected due to the purpose of the study and available resources. The cases came from different projects at the Centre for PervasiveHealthcare. The self-monitoring cases were focused on: pregnant women with pre-eclampsia (i.e. pregnancy poisoning) - case C, frail older adults with different hear conditions - case D, and our preventive BP self-monitoring project - case B that was introduced in section 3.1.2. The three cases of self-monitoring (B, C, and D) are illustrated in Figure 3.1 at the beginning of this chapter. The data collection methods of each individual case as well as participants involved are summarized in table 3.2. This multiple case study is reported in Paper 6 and results are summarized in section 4.2.

In all three cases, we took a socio-technical approach as we were interested on how participants perceive, integrate and manage the self-monitoring activity as part of their everyday life as well as positive or negative effects. Data collection methods for case B - self-monitoring as preventive care - has been described in the previous section 3.1.2. Regarding cases C and D, the data collection methods focused on how the participant use and place the self-monitoring device at home, pros and cons of self-monitoring and participant’s experiences and motivation for self-monitoring. The additional questionnaire also includes questions regarding the care network, participant’s conditions, attitudes towards self-monitoring and the nature of the contact with healthcare professionals.

<table>
<thead>
<tr>
<th>Case of Self-monitoring</th>
<th>Health parameters</th>
<th>Data collection methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. Healthy older adults</td>
<td>blood pressure</td>
<td>Semi-structure interviews (n=8), workshops (n=4), online questionnaire (n=165)</td>
</tr>
<tr>
<td>C. Pregnant woman with pre-eclampsia</td>
<td>weight, blood pressure, pulse, CTG(^7) and proteinuria(^8)</td>
<td>Semi-structure interviews and fieldwork (n=6), paper-based questionnaires (n=66), workshops with healthcare professionals and pregnant woman</td>
</tr>
<tr>
<td>D. Older adults with different heart conditions</td>
<td>weight, blood pressure, pulse and ECG(^9)</td>
<td>Semi-structure interviews and fieldwork (n=7), paper-based questionnaires (n=83), workshops with nurses (n=2)</td>
</tr>
</tbody>
</table>

\(^7\)It refers to the fetal heartbeat and uterine contractions.

Table 3.2 Multiple cases of self-monitoring and their data collection methods.
Data Analysis

The data coming from these three cases were collected by a multidisciplinary group of researchers (computer scientist, ethnographers and Participatory Design experts). Data analysis was performed by Erik and me and we started with case C - pregnant woman - using an open coding approach. We iteratively identified the main concept for further exploration and several themes emerged from the data. Then, we added sequentially case D and case B to the analysis and performed a more focused coding using the emerged themes from case C. We then group all the themes with instances from all three cases and relate them with the literature reported in section 2.2. Themes were consistent in all cases of self-monitoring either as a challenge or a particular aspect of self-monitoring. Furthermore, our exploratory cross case analysis was performed with heterogeneous cases of self-monitoring to facilitate maximum variation (Patton, 2002). Additional interviews were conducted with four additional people to confirm some results from the analysis.

3.2.2 Multiple Cases of Self-care Activities

Taking a design research and socio-technical approach, this analyses focused on three different self-care practices rather that on a specific self-care practice as shown in the previous section. The unit of analysis were self-care projects that ended up with a designed artifact or utilized a stand alone device during the project work. Cases were purposefully selected to get an in-depth understanding of what concerns were in play and how our work was challenged and whether new insights were provided during each case. The main criteria for selection was the presence of one or more design rationales (influences from healthcare workplace settings or leisure) during our project work. The cases came from different projects at the Centre for Pervasive Healthcare. The three self-care projects were: medication management - case A, home-based rehabilitation - case E, and tele-monitoring of pregnant woman with pre-eclampsia - case C previously described. The data collection methods of each individual case as well as participants involved are summarized in table 3.3, reported in Paper 7 and results are summarized in section 4.2.

Data Analysis

We took a reflective learning approach from design research (Binder, 2002; Mattelmäki & Matthews, 2009) to perform a comparative analysis that was iteratively conducted by three researchers through several analysis sessions. The analysis focused on tensions caused by the different design rationales applied to the aforementioned cases. We retrospectively analyses our work in each project and several tensions emerged. At first, we arrange all information from our discussions using several analytic techniques as suggested by Miles and Huberman (1984). We started making a matrix of different categories and placing the tensions on it. The matrix was iteratively updated during our discussions meetings and was used to identify the themes coming from the different tensions. We also developed a rich case description as suggested by Yin (2009) to examine the complexity and relationships of the identified themes.

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*It refers to the protein level in urine.

9An electrocardiogram - ECG - is used to measure the regularity of heartbeats.
In addition, we used the themes to comparative analyze the cases.

<table>
<thead>
<tr>
<th>Case of Self-practice</th>
<th>Designed artifact/devices</th>
<th>Data collection methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Medication management for older adults with different conditions</td>
<td>MediFrame(^{10})</td>
<td>Fieldwork (n=9), telephone interviews (n=316), user-centered design methods - workshops and interviews with older adults (n=8) and medication experts (n=7)</td>
</tr>
<tr>
<td>C. Tele-monitoring of pregnant women with pre-eclampsia</td>
<td>off-the-shelf and project-specific monitoring systems</td>
<td>Semi-structure interviews and fieldwork (n=6), paper-based questionnaires (n=66), workshops with healthcare professionals and pregnant woman</td>
</tr>
<tr>
<td>E. Home-based rehabilitation for older adults with vestibular dysfunction(^{11})</td>
<td>LinkLights(^{12})</td>
<td>Participatory design activities with older adults (n=25) and physiotherapists (n=2)</td>
</tr>
</tbody>
</table>

Table 3.3 Multiple cases of diverse self-care practices and their data collection methods.

3.3 Phase 3: Applying Theory

During this phase, we take our initial step for applying theory to our empirical data. We performed a deductive content analysis (Patton, 2002; Braun & Clarke, 2006) supported by the concept of trajectory (Strauss, 1993; Strauss et al., 1997) to borrow terms as analytical tools for understanding the self-care management work at home. The concept of trajectory is defined by Strauss (1993) as:

…1) the course of any experience phenomenon as it evolves over time..., and 2) the actions and interactions contributing to its evolution. (Strauss, 1993, p. 53-54)

Even though the concept of trajectory born from studies in the clinical settings, several researchers (Aarhus et al., 2009; Chen, 2011; Huh & Ackerman, 2012) have started to apply and suggest the use of the concept in non-clinical settings to investigate for example illness trajectories. Examples of trajectory could be the aforementioned trajectory of illness, the trajectory of health, the trajectory of care or the trajectory of building a house as well as a biographical trajectory. The trajectory depends on the phenomenon under investigation that can be characterized through the trajectory management, trajectory scheme, trajectory projection, and trajectory phases (Strauss, 1993). As such, each trajectory is conformed by several phases. In self-care, the trajectory management involves all the entire process across all trajectory phases while conduction the trajectory scheme or specific care plan - trajectory work.

\(^{10}\) A tabled-based application to support older adults medication management reported in Paper 4.

\(^{11}\) It refers to a balance disorder that make a person to feel unstable and dizzy.

\(^{12}\) It is a modular rehabilitation tool to provide visual instructions to the patient to support rehabilitation of vestibular dysfunction. For further details consult (Grönvall & Kramp, 2011).
...The work that patients do is trajectory work in the service of managing and shaping aspects of their trajectories. (Strauss et al., 1997, p. 200)

As such the trajectory work is all the work associated to a specific trajectory of care that take place across clinical and non-clinical settings. For example in the case of illness trajectory, this becomes more evident as the information flow goes.

...from home residence into and through hospitals, and out again back to the home. When we consider such repeated cycles, it becomes apparent that patients are, as remarked earlier, working technologists, too, not only at home but in the hospital. (Strauss et al., 1997, p. 209)

Data Analysis

The concept of trajectory was used as a sensitizing concept to provide a “general sense of reference” (Patton, 2002) and as a tool for thinking as several other concepts used in healthcare (Doherty, McKnight & Luz, 2010). In our use of the concept and informed by the related work, we look for the several kinds of work (machine work, safety work, information work, interpretation work, comfort work, sentimental work, articulation work, body work, error work, dirty work, negotiative work) involved in the trajectory management as part of the trajectory work that take place at home. Instances that relate to any kind of work related to the trajectory work were extracted. The analysis was performed by the main author of this dissertation and only to the preventive self-monitoring case.

3.4 Summary and Discussion

In brief, we undertook a design-oriented research approach informed by the related work of this dissertation in HCI, CSCW, and UbiComp studies. The overall aim was to get an in-depth understanding of self-care practices to inform system design and our research through design methodology help us to bridge the gap between understanding and designing. As we were not looking to design the right thing, our work is more aligned with Fallman’s work Fallman (2003, 2007, 2008) and move back and forth between design explorations and design science as part of our user-centered design process. However, as stated by Mattelmäki and Matthews (2009), research through design is not a strict method but rather a collection of design methods, processes and artifacts necessary to make a research contribution. As such, we argue that our design-oriented research can be viewed as research through design as our work is based on a collection of methods that fall between the two extremes of Fallman’s triangle: design exploration and design science.

Furthermore, our research through design was divided in two phases. Phase 1 covers a diverse collection of methods to investigate self-care practices in non-clinical settings. Basically the practices of medication management and preventive self-monitoring are concerned in Phase 1. Regarding Phase 2, our work extended into a reflective learning phase in which multiple cases were analyzed in different ways. On the one hand, three different cases of the self-monitoring practices were analyzed through a case study approach in which the emerging themes were found using a bottom up strategy. On the other hand, three cases of
3.4 Summary and Discussion

diverse self-care practices (self-monitoring, home-based rehabilitation, and medication management) were iteratively compared as part of the reflecting learning process in which the artifact played an important role. Last but not least, in Phase 3 we attempt to use the concept of trajectory as a sensitizing concept and analytical tool to perform a deductive content analysis of self-care work in non-clinical settings.

3.4.1 Reflections on Methods

The epistemological position of design oriented research and research through design is aligned to the constructivist research paradigm (Cross, 2001; Findeli, Brouillet, Martin, Moineau & Tarrago, 2008). As explained by Schwandt (1994, p. 127), the constructivism paradigm focuses on the “meaning-making activity of the individual mind” in which each individual’s view of the world is as valid as any other. By focusing on real-world problems (wicked problems), the knowledge presented in this dissertation came from the information gathered through the different cases and through my experience of designing. Regarding the types of knowledge, Zimmerman, Evenson and Forlizzi (2004) presents a variety of knowledge opportunities (e.g. prototypical user needs, user’s insights, acceptance of design) from each phase of a user-centered design process while implementing research through design in HCI (Zimmerman & Forlizzi, 2008). In particular, theory on design and theory for design are the types of theory that are produced from design research and research through design (Zimmerman et al., 2010, p. 333). Our work has mainly produced theory for design taking the form of design guidelines, principles, recommendations, conceptual framework, implications for design, etc. that are presented in the next chapter.

The knowledge produced in our design oriented approach were complemented and supported by qualitative and quantitative studies as suggested by Mackay and Fayard (1997) due to the multidisciplinary nature of our research. In addition, we describe our design processes in detail while moving back and forth between design explorations and design science. While engaging as a reflective practitioner, the interaction with a multidisciplinary group of people moving back and forth between design explorations and design science have facilitated to get different perspectives and knowledge including.

...the kind of knowledge and user experience sought is the kind that cannot be obtained if design – the bringing forth of an artifact such as a research prototype – is not a vital part of the research process. (Fallman, 2008, p. 8)

Regarding the findings from multiple cases, we rely on analytical generalization rather than statistical generalization (Yin, 2009). Even though our methods complement each other and have been suitable for our cases, yet a further exploration of the field (Korn & Bødker, 2012) using the more completed design exploration (MediFrame) would have provided more insights regarding additional issues such as appropriation and emerging use practices. But, this was not possible due to the time frame and different constraints of the projects. In the next chapter, we will describe and discuss the results of the aforementioned phases regarding the diverse data collection and analysis methods.
Exploring Self-care Management Work in Non-clinical Settings

This chapter will focus on presenting the results from our diverse studies introduced in the previous section 3. First, we will describe the results of the two main exploratory cases of self-care practices that provide most of the empirical data for this dissertation: A) Medication management, and B) Preventive self-monitoring as described in Phase 1 (see Figure 4.1 - phase 1). Second, we will describe the results from our two multiple case analysis of self-monitoring care practices (non-functional aspects: people, knowledge, places, resources, routines, control and motivation), and different self-care practices (high level concerns: why, where, when and control in collaboration) - see Figure 4.1 - phase 2. Third, we describe the different types of self-care work (machine, body, safety, information, sentimental, comfort, interpretative, negotiate, articulation, error and dirty work) that we found while analyzing the self-monitoring project using the sensitizing concept of trajectory (see Figure 4.1 - phase 3). Let’s start with the two exploratory cases of self-care practices in the following Phase 1.

Figure 4.1 An overview of the results from the different research phases.
Chapter 4 Exploring Self-care Management Work in Non-clinical Set ...

4.1 Phase 1: Exploratory Cases of Self-care Practices

This section provides a summary of results of health-disease related care practices in non-clinical settings. At first, we will describe the complex care practice of medication management. We will show the result from our diverse studies and our user-centered design process. We also describe the results from our compliance technology review and point out a set of design guidelines that can be adapted for designing tablet-based touch interfaces for older adults. Next, we describe the case of preventive blood pressure self-monitoring and list a set of challenges and opportunities to support healthy people regarding preventive care.

4.1.1 Understanding & Designing for Everyday Medication Management

While being at home, people are responsible to continue the care treatment regarding self-care activities such as their own medication management. Medication management is one of the most complex self-care practices in non-clinical settings (Codagnone, 2009). For instance, people might suffer from more than one disease (Corbin & Strauss, 1985; Anderson, 2007) that increase the complexity of self-care practices at home as well as the number of prescribed medications they have to take on daily basis. Furthermore, medication intake at home become even more complicated when people gets older due to for example age-related symptoms that can also challenge the medication intake. Moreover, several technologies and paper-based strategies do exist to support medication management at home, however they have neglected the diverse practices that people have in everyday life and focused on either supporting a specific task or disease rather than supporting people in everyday medication management. In our study, we focus on studying how people deal with medication management in everyday life without focusing on a specific treatment or illness in order to get a holistic view of practices and uncover several specific particularities to inform the design of a personalized medication management system.

First, we introduce the results from our compliance technology review. Next, we will present the results from our initial quantitative and qualitative studies as well as the evolution of our main design exploration - the MediFrame Concept.

Compliance Technology Review

Regarding the adherence technology review, we reviewed in total 120 compliance technologies. From the initial list coming from Pharmakon, 28 out of 90 were not available anymore. We additional added 30 new technologies to the review. A total of 92 technologies were categorized as: 1) Electronic reminders - 22 (N. Verdezoto, 2011a), 2) Tablet-holders with electronic reminder - 14 (N. Verdezoto, 2011b), 3) Dosing aid with electronic reminder - 30 (N. Verdezoto, 2011c), 4) Automatic dispensers - 7 (N. Verdezoto, 2011d), 5) Non-electronic reminders - 5 (N. Verdezoto, 2011e), 6) Other types of technologies related to adherence - 3 (N. Verdezoto, 2011f), and 7) Other medical applications - 11 (N. Verdezoto, 2011g). Among the different technologies we listed: pill boxes, pill bottles, mechanical devices, mobile applications, several types of reminders, and paper-based medication lists, etc. Figure 4.2 illustrates an example from the review regarding tablet-holders with electronic reminders. Some of these tools were also found in older adult’s homes.
4.1 Phase 1: Exploratory Cases of Self-care Practices

Figure 4.2 Examples from our technology review.

We also performed a more focused review of eleven interesting technologies from the review. From electronic reminders, we further reviewed MedsLog, Medsy, Dosecat, MediRemind (see Figure 4.3), MotionPHR Health Record Manager, iPill Birth Control, MediReminder. From automatic dispensers, we further check Maya. From other sort of technologies related to adherence, we reviewed Raisin Personal System. And finally other two general applications: CardioTrainer and Instant Heart Rate. From this focused review, we were interested in common features of technologies such as types of reminders, system integration with personal computer or other mobile phones, additional components, history or log, cross platform applications, different versions and strategies to support the medication intake. Figure 4.3 shows an example of the data gathered for the MediRemind application. Further details on this can be found in (N. Verdezoto, 2011h).

Figure 4.3 A more focused review of MediRemind App
Challenges for Medication Management at Home

We now describe the results from our initial qualitative and quantitative studies. To illustrate the diverse challenges regarding medication management, I would like to introduce the following scenario based on a collection of stories from our empirical studies. The scenario illustrates a number of challenges that at time complicate people’s trajectory of care.

Ann is a 73 years old grandma who is living alone in her house near to the sea side in Risskov. She has been experiencing several diseases since ten years ago. In particular, diabetes, hypertension, osteoporosis and back pain. She has learned how to cope with her conditions but she has a lot of troubles keeping track of her medication intake. Recently, she has been visiting her doctor after she noticed rashes around her neck and legs. This is why she is taking up to 15 medications a day - at different times. For Ann, remembering to take and refill her medication is a big problem specially when her pharmacy substitutes her medication. What is more, she has to control her blood glucose and blood pressure several times a day that complicate not only her medication intake but also her everyday life. Ann is used to plan and attend different activities through the week outside her home. For example, she likes to visit the activity center and she often meet her friend Susanne for playing cards at her place. She likes traveling and to visit family and friends. She also likes walking around the sea side after lunch. As she is not always at home, she has to be attentive to what she eats, her medication dosages through her day and her self-monitoring activities to be able to continue with her planned activities. Furthermore, she does not really know what to do if she misses a dosage time and she has noted several questions on her agenda to ask her doctor but she forgets to ask while in the clinic. She knows that her doctor told her not to forget to take her medication but with several medications she would like to take a break on some of them that are difficult to swallow.

This scenario identifies a set of key challenges in Ann’s everyday medication management. Overall, Ann has problems taking her medication as she forgets or skips or just avoids the intake especially when she has other activities to attend during the day. In general, she needs more information at hand regarding her medication as she has troubles for example with substitute medication. Her doctor is not aware of what is hindering in her everyday medication management and all the challenges she has. In the following, we summarize the most relevant results from our diverse studies on medication management.

While managing medication management at home, older adults move along a continuum between total independence or total dependence. There are older adults who are in charge of their medication intake but there are others who received some sort of help from the care network such as a family member (spouse) or a formal help from a professional homecare worker. The assistance on medication management activities varied according to the individual’s health status and situation. In general, most participants expressed their willingness to actively participate in their medication intake activities.

Table 4.1 illustrates a summary of the most relevant results from our user studies. First, participants either intentional or unintentional non-adhere to the prescribed medication (see items a and b in Table 4.1). Reasons for intentional non-adherence are a lack of trust in the medication, fear to side effects, or when people perceived that their condition is under control. In particular, older adults have an active life style and they are not always at home and due to this irregularities in their routines they sometimes prefer to skip or delay a dose instead of missing a planned activity. Reasons for unintentional non-adherence are forgetfulness, misunderstandings of instructions or due to a human error when for example the
wrong medication is taken. One important thing is that our studies show that unintentional non-adherence does not increase with the number of medications but rather increase due to the frequency of medication intake during the day. In addition, medication intake is challenging when routines are broken when for example people are not at home or they receive visits from family or friends. And some participants have privacy concerns regarding taking medication in social settings (see item c in Table 4.1).

Furthermore, our participants have a high need of medication information and were proactively seeking for information (see item e in Table 4.1). For example, an important issue was the fact of substitute medication as participants are challenged when a medication changes its name. There also have problems when they receive different information from different members of the care network. Participants were actively seeking for information in different sources such as the Internet, pharmacies or through the patient medication leaflet. Some participants consider highly important to get in touch with their physicians when they lack information or get confused by different sources of information. Moreover, there are caregivers that can support the medication intake at home. Spouses or nurses were partly involved in some cases but participants recognized that this support is not always stable over time (see items f in Table 4.1).

<table>
<thead>
<tr>
<th>a. Intentional non-adherence</th>
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<tbody>
<tr>
<td>- 23% of participants from quantitative study (QS)</td>
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<tr>
<td>- Mistrust on medications effects, fear of side effects, irregularities in everyday life</td>
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<table>
<thead>
<tr>
<th>b. Unintentional non-adherence</th>
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<tbody>
<tr>
<td>- 34% of participants from QS forgets to take medications</td>
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<tr>
<td>- Forgetfulness, misunderstandings of instructions, outside the home, human error</td>
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<tr>
<th>c. Breakdown of routines</th>
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<tr>
<td>- 56% of participants from QS rarely bring medication outside</td>
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<tr>
<td>- 30% have privacy concerns taking medication in public</td>
</tr>
<tr>
<td>- 24% take medication outside home several times a month</td>
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<tr>
<td>“When I’m not home in the evening I take my medication when I return. I never bring my medication out of the house...”</td>
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<tr>
<th>d. Mnemonic rules</th>
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<tr>
<td>- 79% of participants from QS do something special to remember</td>
</tr>
<tr>
<td>- 26% take medications in connection with meals</td>
</tr>
<tr>
<td>- 22% have a visible storage system for medications</td>
</tr>
<tr>
<td>- 36% have a pill dispensing box</td>
</tr>
<tr>
<td>- Refill is seldom included in routines</td>
</tr>
<tr>
<td>“I have a little dispenser lying on the table. So I cannot avoid seeing it”</td>
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<tr>
<th>e. Information about medication</th>
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<tbody>
<tr>
<td>- 75% of participants from QS have a high need for information</td>
</tr>
<tr>
<td>- 58% are proactively seeking for information</td>
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<tr>
<th>f. The heterogeneous care network</th>
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<tbody>
<tr>
<td>- Informal/formal caregivers (e.g. spouses, nurses, others)</td>
</tr>
<tr>
<td>“...I have figured out, that I should make him eat them [the medication] together with the dinner. It can’t be later as then he goes to bed...”</td>
</tr>
</tbody>
</table>

Table 4.1 Challenges for medication management at home.
Finally, most participants distinguish between over the counter and prescribed medications and implement their own home storage system for medication that is sometimes visible to support their mnemonic rules (see items d in Table 4.1). In addition, some participants forget whether or not they took a medication or order a new medication when they run out. To support remembering, participants attach the medication intake to their meals and some have gotten a portable pill dispensing box. For further details please refer to Papers 1, 2, 3, and 4 respectively in (N. X. Verdezoto & Wolff Olsen, 2012; N. Verdezoto & Grönvall, 2012; Dalgaard, Grönvall & Verdezoto, 2013; Dalgaard, Grönvall & Verdezoto, 2013).

Medication-Specific Requirements in Practice

As we took into consideration both perspectives coming from medication experts and older adults as the main stakeholders during our design explorations, we encountered a number of medication specific particularities that challenge the medication intake in unsupervised settings such as the home. Table 4.2 illustrates a condense number of specific particularities that came from our interaction with medication experts and older adults and from the knowledge gathered from our previous studies.

As we described in the previous section, the complexity of the medication intake does not increase due to the number of medication but rather with frequency a person takes medications during the day. Indeed, we found a person during our design process that was prescribed until 35 medications. The complexity increase as medications have different formulations such as creams, eye drops, injections and not just pills. During our design process medication experts became aware of several issues from our collection of studies and we further discussed several themes that are illustrated in Table 4.2.

To start with, we have seen that participants were challenged when the medication changes its name. Medication experts confirmed this and became aware of why people might get confused and stop taking medications. Medication experts stressed that people should know whether or not they have received a substitute medication (see item a in Table 4.2). Furthermore, during our workshop on participant’s homes, we became aware that there were some medications that were not listed by participants during our activities. Participants expressed that they did not list their according to need medication because it is up to them to decide how and when to take it as they are not taken them on regular basis (see item b in Table 4.2). Medication experts stressed that people should document all their according to need medication to get a complete overview of their medication intake. Moreover, while discussing the results of our diverse studies with the medication experts, there were some particularities that were unfolded. As it is normal that people follow the instructions regarding how and when to take a medication, there are medications that can actually be delayed as the case of diuretic medication (item c in Table 4.2). Medication experts emphasizes that it is true that some medication can be delayed and adjusted to people’s daily routines but they vary according to the medication and the rest of prescribed medication around the intake.

Furthermore, we discussed about the importance of medication information available at hand at home (see item d in Table 4.2). Medication experts stressed that people should get a complete overview and knowledge regarding their prescribed medication for each person in the home. Specially when routines are not stable, people should have the information at hand to take the decision whether or not to skip or take a medication and avoid misunderstanding
### 4.1 Phase 1: Exploratory Cases of Self-care Practices

#### a. Substitute medication

“I don’t know the name because it’s something new every time you buy - it is different drug. It’s called something different every time (...) So I took the wrong pills, I couldn’t figure it out”

#### b. According to need medication
- Medications that should be taken when needed and not on daily basis e.g. painkillers

#### c. Delayed medication intake
- The case of diuretic medication

#### d. Overview and knowledge about medication
- Administration instructions, food interactions, daily medication intake, and preventive medication

#### e. Doctor’s insights in people’s medication management
- Regarding intentional and unintentional non-adherence issues

<table>
<thead>
<tr>
<th>Table 4.2 Medication-specific requirements in practice at home.</th>
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<tbody>
<tr>
<td>coming from different sources. One issue discovered by medication experts was the role of preventive medication when a person is old as avoiding them can help to reduce the complexity of the medication intake. Another issue was that people should have the instructions about why, when and more important how to take a medication. Additional information as food interaction is highly relevant to have it at hand. Last, medication experts became aware and were hindered by so much information that are not available to them (see item e in Table 4.2). They value the information coming back from the home because it helps them to assess and become aware of issues regarding intentional and unintentional non-adherence to support people’s trajectory of care.</td>
</tr>
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</table>

### The Evolution of the MediFrame Concept

At first, we combined our previous studies with the technology review and defined a set of functional (integration, reminder, tracking, mobility, medication information search, navigation, sharing, flexibility, control) and non-functional (security, safety, performance, privacy, and user interface) meta-requirements. For further details on meta-requirements, please refer to Paper 1.

When we selected our MediFrame concept for further exploration, we started a literature review on tablet-based touch interfaces. We reviewed existing design guidelines for mobile devices, older adults and touch interfaces. In total, we revised 31 guidelines and were categorized as follows: 17 design guidelines for visual and interaction design, 4 design guidelines regarding information organization, and 10 conceptual considerations. Regarding visual and interaction design, guidelines touch upon topics such as text-related factors, icons, links, visual warning messages, buttons, type of input, visual cues, manual dexterity, screen scrolling, system status, etc.. Regarding the information organization, guidelines touch upon the following topics: consistent grouping of related information, menu structure, design for optimal access and design for top-down interaction. Last, the conceptual considerations are related to common topics such as: informative feedback, user control, good dialog design,
error prevention, reduce short-term memory, consistency, flexibility, design for limited and split attention, support user goals. These 31 guidelines can be adapted for tablet-based touch interfaces and can help designers to frame the design space. We have tested so far some of the guidelines during our design process. Further details on the guidelines for tablet-based touch interfaces are reported on Paper 2 - (N. Verdezoto & Grönvall, 2012).

At the same time, we also started our design explorations that were informed by all our studies and related work. We used several scenarios and started working on low fidelity mockups. In particular, we saw MediFrame as a mobile tablet application and we focused on a specific set of the aforementioned meta-requirements (integration, reminder, tracking, mobility, medication information search, navigation, sharing, control, privacy and user interface) during our design explorations. After several iterations working with several design materials, several metaphors were explored. One of these was the clock, Figure 4.4 shows several iterations around the clock metaphor. For example, Figure 4.4a shows one of our first design ideas that came out from a workshop with a medication expert and interaction designer from one of our project partners. After working on initial ideas, we move to paper-based representations (see Figure 4.4b) and then move to paper-based high fidelity representations (see Figure 4.4c). For each design idea, we move back and forth between design explorations and initial design studies while asking feedback for our design explorations to a multidisciplinary group of experts (Computer Scientist, Ethnographers and a Graphic Designer). Another metaphor was the medication cabinet (see Figure 4.5a). However, this metaphor was left out for several reasons. For example, trying to allocate medication intake along the 24h in the vertical axis (initially inspired but Benjamin Franklin’s Daily Schedule) was an issue encountered by the aforementioned experts apart from the limitations on the number of medications and medication categories (horizontal axis).

An additional workshop was held with the medication experts (See Figure 4.6a) and four older adults to get further feedback from our different explorations explorations. Even though they all agree that using the clock metaphor can be helpful to manage their medication, they found several drawbacks. As with the medication cabinet, the clock was also challenged by the complexity of participant’s medication intake (daily dosages 1-32 medications at the time of these explorations). Participants said that it was not precise regarding the radial position of the medication. Timing was also an issue as the clock can only enable

![Figure 4.4](image.png)  
**Figure 4.4** Design explorations using the clock as metaphor: (a) initial idea; (b) low fidelity mockup; and (c) high fidelity representation of the clock.
12 hours that complicate the color coding amount the 24 hours a day. Thus, these metaphors were left. As suggested by the first evaluation with the experts, we focused on finding a balance between metaphors and the complexity of the medication intake. Figure 4.5 shows a different design exploration that explore the balance between metaphor and a touched-based interface to show an overview of the medication intake and address its complexity. It uses a color coding for arranging medication across the day according to the different dosages time (morning, noon, evening, night). In the top of the interface, there is the picture and name of the person taking medication and the contact information of the doctor for two reasons. First, participants expressed that they would like to get a sense of authority behind information. Second, they would like to get a sense of ownership of the application and get customizable information according to their own health situation. This mockup received the most positive feedback from medication experts and older adults thus becoming the first version of the MediFrame concept. However, there were concerns about simplicity of the interface and too much information at times.

After several design iterations (design explorations & design studies) with our group of expert including medications experts and project partners, we decided to get feedback from older adults (see Figure 4.6b). In this version, our design exploration supports the user’s information seeking behavior based on Shneiderman’s visual information seeking mantra “overview first and details on demand” (Shneiderman, 1996) to avoid the visual clutter for older adults. To get a better understanding of participant’s medication information seek-
Chapter 4  Exploring Self-care Management Work in Non-clinical Set …

...ing needs at home, we leverage upon Bate’s model for - active\(^1\) and passive\(^2\) - information seeking behavior (Bates, 2002).

Insights from our user studies and our iterative design process feed back to MediFrame to focus on sustaining people’s medication management care practices (planing, informing, reminding). Based on the Model-View-Controller design pattern, we move to the development of a high fidelity prototype. It has two main components (offline processing and MediFrame App) to provide an integration of two different services - the Shared Medical Record\(^3\) (SMR) and the Danish Medication Information service\(^4\) (DMI). The basic functionalities for MediFrame are: Calendar, Medication, Diary, Reminder, According to Need, Settings and Take Medicine. For instance, Figure 4.7 illustrates the Calendar interface that provides an overview of people’s medication intake in relation to their planned activities highlighting overlaps between those activities that can challenge the intake. Based on the specific particularities found in our studies (see Section 4.1.1), it provides different level of aggregation of information and possibilities to adjust or delay the medication intake. The last version of MediFrame’s Calendar and Taking Medicine interfaces were also evaluated by an older adult regarding the information seeking behavior (See Figure 4.6c). Further details are described in Paper 4. Now, It is time to present our second case’s results!

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\(^1\) Active information seeking occurs when an individual is actively looking for information in a directed (looking for particular information - searching) or undirected (looking randomly - browsing) manner.

\(^2\) Passive information seeking occurs when an individual is not looking for information and it can be either directed (alert and monitoring of things that can be interesting) or undirected (learning by just being aware without a particular interest).

\(^3\) SMR enables people to get access to an individual prescribed medication.

\(^4\) DMI enable access to medication’s images and related medication information.
4.1 Phase 1: Exploratory Cases of Self-care Practices

Figure 4.7 The MediFrame’s Calendar Interface - overview of medication intake in relation to people’s planned activities.

4.1.2 Preventive Blood Pressure Self-Monitoring

As described in Section 1, people are getting more and more interested in preventive self-care activities not only for diseases but also for people with a general interest in wellbeing. Prevention involves all sort of actions performed by an individual that aims to “delay disease or slow its progression” (Mallery & Rockwood, 1992). There are several preventive health measures such as primary (i.e. immunization and health promotion), secondary (early detection for asymptomatic diseases e.g. cancer, hypertension, dementia) and tertiary (rehabilitation to decrease disability and slow deterioration caused by symptomatic but unreported illness) interventions (Stults, 1984; Kane, Kane & Arnold, 1985; Mallery & Rockwood, 1992). Indeed there is a shift in society from managing a disease when it appears to being a proactive health manager to avoid disease as long as possible and losing independence in life. For people over 60 years old, loss of independence, moving into nursing home is a major concern as they would like to stay at home as long as possible with family and friends (Prince-Market-Research, 2007). But not only older adults can reach that point, also healthy people today can be really sick tomorrow due to an increase of asymptomatic diseases. In this
Chapter 4 Exploring Self-care Management Work in Non-clinical Set …

Case, preventive healthcare activities can benefit people ranging from healthy to frail people and special attention should be given to people between those extremes (Stults, 1984). Rather than focusing on frail people, we focused on people who are independent enough to carry preventive health self-care activities to get a better understanding of these practices and the role of self-monitoring technologies as preventive care.

After this brief introduction about prevention, we would like to introduce the following scenario based on a collection of stories from our empirical studies on preventive self-monitoring. The scenario illustrates a number of challenges that complicate people’s effort towards preventive care in everyday life and thus people’s trajectory of care.

Thomas is a 67 years old man who is living alone in the north part of the city. He is interested in health and wellbeing and that’s why he visits the activity center everyday day. He usually attends some activities organized in the activity center or he and his friends organize join together meetings either for lunch or bowling every second week. We invited Thomas as participant of our project. During the project work, he was really interested in preventive care activities. Specially, when the nurse explained that high blood pressure is the silent killer. Hence, he became more aware and thus decided to continue in the project. He learned about the symptoms, consequences, possible actions and how to measure blood pressure. During the first workshop, he helped his friends with the measuring task by for example placing the cuff in the right position and remembering the measuring rules to his friends. However, his agenda was full when we asked him to perform self-monitoring at home. As suggested by the nurse, we asked him to do self-measurement three days in a row mornings and evenings. By looking at his agenda, he noticed that his evenings were full during the next week. When he found the time, he informed us and we brought the monitoring device to his place. As part of the self-monitoring task, he took the measurement (in some occasions more than once) and wrote down on a paper-based template his BP values. During our discussion after the task, we asked him why he took more than once the measurement and he replied that he wanted to be sure that his values were correct. However, he told us that he could not figure out the meaning of the values by just looking at them. He was a bit concern because he knew that one of his friends left our project after she noticed high BP values and entered to treatment. He also told us that it was not that difficult to follow the measuring rules in the morning but it was difficult to do it in the evening specially when he was not at home. As such, he for example skipped an evening measurement while bowling and told us that he did not want to bring the BP device with him because his friends might think that he is sick when he is not.

This scenario identifies a set of key challenges in Thomas’ preventive self-monitoring activities. At first, he got problems while trying to understand and get meaning from the BP values. He also had problems trying to follow the measuring rules especially when he was involved in other activities during the day and he was not at home. Even though he was motivated to do the measurements, he was not conformable doing it outside his home. In the following subsection, we will present these challenges and other important issues in preventive care that are illustrated in Table 4.3.

Challenges for Preventive Self-Monitoring

Preventive self-monitoring activities are performed either by people with chronic conditions or healthy people to either slow the progression of diseases or delay the onset of any condition respectively. In our qualitative study, 131 out of 165 participants stated that they do not have any chronic condition and 86 of them own a self-monitoring device. There is a trend in
which more and more people are becoming active participants in their own healthcare management as presented in Section 1. Our study confirmed this not only showing how people without any chronic condition are interested in healthy living but also further uncovering the challenges that people encountered while trying to perform preventive self-care monitoring activities as part of their everyday life.

<table>
<thead>
<tr>
<th>a. Rule complexity</th>
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<tbody>
<tr>
<td>- Too many rules including time-constraining rules</td>
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<tr>
<td>- Lack of time to complete a correct measurement</td>
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<tr>
<td>- Problems developing and adjusting routines to suit measuring rules</td>
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<tr>
<th>b. Reliability of the Measurements</th>
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<tbody>
<tr>
<td>- Lack of contextual information</td>
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<tr>
<td>- Technical or human error</td>
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<tr>
<th>c. Interpretation, Understanding and Health Awareness</th>
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</thead>
<tbody>
<tr>
<td>- Difficult to get meaning just from BP values</td>
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<tr>
<td>- Lack of support for interpretation</td>
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<tr>
<th>d. The Sharing activity for Prevention</th>
</tr>
</thead>
<tbody>
<tr>
<td>- 69% of participants from the quantitative study would share their health data with physicians if needed</td>
</tr>
<tr>
<td>- Dealing with health-related issues in public</td>
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<tr>
<td>- Other activities get a higher attention</td>
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<table>
<thead>
<tr>
<th>e. Motivational sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Feelings of Independence</td>
</tr>
<tr>
<td>- Personal interest on health and social relationships</td>
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<tr>
<td>- Perceived performance on daily activities</td>
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<tr>
<th>f. The role of the Doctor for Prevention</th>
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<tr>
<td>- Advisor or supportive role</td>
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<tr>
<th>g. The use of Self-monitoring technology</th>
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<tr>
<td>- Automatic vs manual data collection</td>
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| h. The Home as a distributed information space       |

| i. Visualization of BP values                        |

**Table 4.3 Challenges for preventive self-monitoring practices at home**

Table 4.3 illustrates a summary of the most relevant results from our study. First, participants learned how to take a correct BP measurement. However, they encountered problems to follow the measuring rules especially during the evenings due to for example: a) too many rules, b) time-constraining rules that request more effort and attention from participants, c) interference with other planned activities in or outside the home (see item a in Table 4.3). The rule complexity has also consequences regarding the reliability of the measurements due to for example the lack of time to perform the correct measurement (see item b in Table 4.3). The reliability is also comprised due to the lack of contextual information around the measured values. Contextual information add meaning to the measured values enabling interpretation and understanding when for example values can be off the normal situation. In addition, technical and human such as battery life and hand-written mistakes respectively can also compromise the reliability of the measurements taken at home. After getting a cor-
rect measurement, how people get meaning and understand their own bio-values play an important role in self-monitoring (see item c in Table 4.3). Even though, participants were able to use the self-monitoring device they got problems regarding an overall understanding of the current health situation.

Furthermore, participants did not feel comfortable performing the preventive self-monitoring activity in public spaces (see item d in Table 4.3). For example, they either perceive that missing a measurement might not evolve to any life-threatening situation or want to avoid stigmatization or sick labels. In general, participants would not like to involve other people in their preventive activities unless it is necessary as a confirmation step with immediate family or their physicians. Moreover, participants want to keep their independence as long as possible as they sometimes dislike to depend on others (see item e in Table 4.3). Participants did not want to stop their normal activities and get motivated by their performance on doing this and that. As such, they have increased their interest on their health management to continue with their life and their wishes of a future healthy aging. In addition, the role of the doctor is shaped for prevention and in most cases it is perceived as an advisor or coach that supports people’s healthy living activities (see item f in Table 4.3).

Furthermore, the home is one example of a complex information space in which different activities can be either done in the same place or at the same time (see item h in Table 4.3). Moreover, it turns out that older adults relies on the textual representation of the BP values rather than icons or abstract representations of the values (see item i in Table 4.3). Participants found particularly usable the color encoding to attach meaning to BP values.

The evolution of the SELMA prototype

The insights coming from our study helped us to move back and forth between design explorations and the different design studies. We tested the different visualizations with older adults and then moved back to the next iteration. Regarding the overview of BP values, Figure 4.8 illustrates different design explorations based on the previous findings. In Figure 4.8a, the focus is on providing meaning for the BP readings by displaying morning and evenings BP values and the use of color coding charts. However, BP values were omitted to avoid visual clutter. Since participants rely more on visual values than icons, another iteration (see Figure 4.8b) focused on providing a balance between the visual clutter and participant’s requirements. Figure 4.8b shows an overview of both diastolic and systolic BP in combination with contextual information (the cup of coffee is an indicator of caffeine). In addition, the textual representation of measurements for the current day are visualized using a sliding window (see the green rectangle in Figure 4.8b).
4.1 Phase 1: Exploratory Cases of Self-care Practices

Figure 4.8 Overview of BP: (a) morning and evening systolic BP; and (b) systolic and diastolic combined with contextual information - indicator of caffeine.

After several iterations, the SELMA concept appeared as a personal mobile application for preventive self-monitoring aiming to increase the individual’s health awareness and understanding of people’s health status. Based on the individual’s self-assessment of risk factors proposed by (Bellingham & Cohen, 2001), the following design iteration incorporated support for the three basic steps necessary for lifestyle change: a) assessment of risk factors, b) plan your possible changes, and c) take action (Bellingham & Cohen, 2001). Figure 4.9a illustrates several options connected to the aforementioned steps. But rather in focusing just on actions regarding BP, we envisioned a digital frame that can provide the individual’s health “status summary” (Solberg et al., 1997) at home in which several health parameters can be chosen and personalized such as blood pressure, cholesterol, blood glucose, lung capacity, and weight as illustrated in Figure 4.9b in the left menu. Figure 4.9b also shows the overview visualization with different check boxes to make visible or hide the respective line on the chart. It also shows pre-defined goal values and general suggestions to lower BP values.

Figure 4.9 Next iterations: (a) shows actions and suggestions for tracking BP; and (b) a more general overview with several levels of granularity.

Last, Figure 4.10 shows our last design exploration regarding the visualization of BP de-
tails based on the insights from our study using the color coding and the contextual information. As we described in Section 3.1.2, our details and overviews design explorations were evaluated by older adults. However, the next iterations that combine them were just evaluated by the project partners and not with older adults due to lack of time (Christmas season). Thus, we did not engage into a high fidelity prototype in this case. However, our design explorations have been informed by our studies and provides insights on possibilities to visualize overview and details of health data as well as diverse challenges for preventive self-monitoring.

![Blood Pressure screenshot](image)

**Figure 4.10** Our last design exploration for SELMA that focus on BP details.

### 4.2 Phase2: Reflections on Multiple Self-care Cases

This section provides a summary of results regarding our multiple cases of self-care practices in non-clinical settings. Our reflective phase combines our two aforementioned cases of medication management and preventive self-monitoring with other cases of self-care (as illustrated in Figure 4.1). First, we will describe the multiple case study of self-monitoring projects. Second, we will describe our reflections on home-based healthcare technology design through three different cases of self-care. Now, we move into the results of these two studies respectively.
4.2 Phase 2: Reflections on Multiple Self-care Cases

4.2.1 Three Cases of Self-monitoring Practices

Our cross-case analysis came out with seven themes that provide a holistic understanding of important non-functional aspects of home-based healthcare technology design. Themes were identified in all cases either as a relevant aspect or a potential challenge during self-care monitoring practices. These themes are: people, resources, places, routines, knowledge, control and motivation. All these themes refer to nonfunctional aspects and conform and conceptual framework for understanding the dynamic of self-care practices and the role of these aspect on self-monitoring technology design. In the following, we will summarize these themes in relation to our cases and further details can be found in Paper 6 (Grönvall & Verdezoto, 2013a).

People

Unsurprisingly, the individual performing self-monitoring is one of the main actors involved in self-care management. In all three cases (pregnant woman with pre-eclampsia, patient with heart conditions and healthy older adults), we observed that participants put their monitoring needs in the background in order to reduce their focus on a specific condition. Furthermore, there is the immediate care network such as family and maybe the closest friends who also play an important role in self-care (Consolvo, Roessler & Shelton, 2004; Fox & Duggan, 2013). In contrast, the extended care network such as neighbors, friends or distant family members rarely get involved in self-care activities. The healthcare professionals are also involved as remote partner in the two first cases (pregnant woman and patients with heart conditions) whereas the perceived healthy older adults if necessary they would involve their physicians in their preventive care practices.

Resources

One of the main resources in self-monitoring practices is the self-monitoring device. People learned how to use the self-monitoring devices in order to support care practices at home. In our cases, we have observed that people attach different meanings to different devices used for self-monitoring. Devices that are perceived as illness-related are more likely to be hidden at home than devices perceived as wellness devices. Even a neutral device like a computer can get an illness connotation when used for illness management and participants prefer to use their now personal devices. Additional resources also include calendar, notebooks or other digital or paper-based documentation tools used to keep track of their measurements (Chen, 2010, 2011; Fox & Duggan, 2013). Moreover, the measuring guidelines on how to conduct a correct measurement are highly important resources that should be available for people performing self-monitoring at home. The illness connotation on devices and the measuring rules are issues tightly connected to where people perform the activity - places.

Places

As we have seen, the different themes are also interrelated as they affect or get affected by the rest non-functional aspects. Indeed, resources put several constraints in people's
homes regarding when and where participants performed their measurements (Axelrod et al., 2009; Grönvall & Kyng, 2012). There are several distinctions between performing the self-monitoring activity in public or in private. The healthy group preferred to do it at home whereas people with a condition and following a treatment would do it when necessary. However, it depends on the social environment and even people with chronic conditions like our heart patients might not feel comfortable performing the measurement outside the home. However, the pregnant women were more opened about the place regarding taking self-measurements outside the home. Participants were also concerned about issues such as size and mobility of self-monitoring devices as for example they would prefer devices that can be easily transported and not occupied much space in their homes. In addition, a device that is mobile can provide opportunities to facilitate the integration of the self-monitoring activity to people’s routines.

Routines

The integration of self-care activities into people’s everyday life is an important challenge that have been reported in previous studies (Ballegaard et al., 2008; Aarhus & Ballegaard, 2010; Chen, 2010; Fitzpatrick, 2011; Craven et al., 2013) and in our two initial studies (Dalgaard, Grönvall & Verdezoto, 2013; Grönvall & Verdezoto, 2013b) and in general discussed in Section 2.2.2. Indeed, integration of the self-monitoring activity in the morning routines was doable and with less complications in comparison with evening routines in the case of preventive self-monitoring. This case also shows how the measuring guidelines support getting a reliable measurement but also put restrictions to people’s routines as there are time-constrained rules that people have to follow. However, there are individual differences that we should take into account even if the integration in morning routines seems doable. People might have different starting point for their morning routines or have other activities that can provoke a breakdown of routines as some heart patients experienced. For instance, a heart patient could not perform the measurement before he started his morning routines outside home because the self-measurement was scheduled considering the health professional perspective and activities and not his personal on. Furthermore, people would prefer to do the measurements in the morning so that they can continue with their planned activities as the case of pregnant women and their spouses and thus continue with their normal day without given so much attention or being worried about the measurement.

Knowledge

While managing disease at home, people engage in learning endeavors trying to cope their conditions becoming the experts in day to day self-care management (Ballegaard et al., 2008; Chen, 2010). In our three studies, we have observed that important aspects of this learning experience are connected to the self-monitoring activity. By rendering physiological health parameters as visible, the measured-values become an important tool for reflection (Mamykina et al., 2008) providing an understanding of what is happening inside an individual’s body. People start reflecting in their bio-values and see how they affect or get affected by their everyday activities. At times, the learning experience can be also shared with the intimate care network as the case of the pregnant women and heart patients with their partners. In this case, the intimate care network can also get an understanding of their
loved one’s health situation and provide a more personalized help to cope with conditions or needed activities.

**Control**

In our studies, we have identified different types of control. First, the personal feelings of control gained over their own health situation that for example can facilitate the self-monitoring activity regarding where and when to make the measurements (Grönvall & Kyng, 2012). An individual level of control in one’s life is also manifested when for example people try to control the effects of a disease in their everyday life (Mamykina et al., 2008; Aarhus & Ballegaard, 2010). As an example, the pregnant woman get more control over their everyday activity supported by her knowledge regarding her bio-values and decide what to do or not even if that includes to manipulate their values while transferring to the hospital to avoid a perceived unnecessary visit. Second, there is a type of control taken by the intimate care network as they became more aware of their loved one’s care situation. For example, an spouse can at times exert some rules over their partners. Third, there is a distribution of control in our two cases where healthcare professionals were present as they could loose some control due to for example intended (manipulation of bio-values) or unintended (forgetting) situations at home. Last, the system can at times exert control over some aspects of people’s life when for example its physical properties restrict the freedom of place the device anywhere or people’s routines get affected by the device.

**Motivation**

In our three cases, we have observed different types of motivation. First, the healthy older adults that were motivated by their personal desire to keep their current health status. Heart patients motivated by the desire of improving their current health status. Third, pregnant women motivated by their personal desire of maintaining her and his baby health status. Last, the intimate care network is also motivated by the desire of increased improvement of their love one’s health status. Indeed, individual motivation is necessary while managing health conditions (Gläsemann et al., 2010), however the perceived effect of a specific self-care activity is different between healthy people and people living with any chronic conditions. As such, healthy older adults showed in general less motivation than pregnant women and heart patients due to for example more tangible and practical benefits such as avoiding visits to the hospital and rather focus in other activities in their life.

We have presented the results of our multiple case study of self-monitoring practices based on three cases: pregnant wowed with pre-eclampsia, heart patients and healthy older adults. The analysis came out with seven themes that point to important non functional aspects of home-based healthcare technology. All themes are related and conform a conceptual framework that can facilitate the understanding of self-care practices beyond the specific activity of self-monitoring towards a holistic view of what it means to perform self-care activities in everyday life and how different populations can different or be similar in managing health and disease at home. In the following, we now continue with the second study that focus on reflections of home-based healthcare technology design extended the previous focus on self-monitoring practices.
4.2.2 Three Cases of Home-based Healthcare Technology Design

Our cross-case analysis this time resulted on an identification of four high level concerns that we consider critical and highly relevant for designing home-based healthcare technology design. These concerns are:

- Why do or should a person use a specific support system?
- When do we or should we use a support system?
- Where do we or should we use a support system?
- Control in collaboration aspects in a support system

These concerns came from a comparative analysis of three projects (medication management, home-based rehabilitation and tele-monitoring of pregnant woman with pre-eclampsia) previously introduced in section 3.2.2 and discussed in the previous sections to present the aforementioned high level concerns. We revisited each project and reflected upon their empirical material using different analytical techniques (as explained in the previous chapter) to re-position these high level concerns in our work analyzing similarities and differences on how healthcare activities are supported in people’s everyday life. As described before (see Section 3.2.2), we wanted to investigate how the presence of one or more design rationales (influences from healthcare workplace settings or leisure) are or can be balanced while designing for home-based healthcare. A more elaborated discussion was provided in Section 2 regarding the challenges that different perspectives (e.g. professional’s and people’s) bring to home-based healthcare technology design. Further details can be found in Paper 7 (Grönvall, Kyng & Verdezoto, 2013).

Why

First, we reflected upon the differences between why people perform self-care activities and how these reasons are different from performing any other work or leisure activity. Along the previous sections, we have seen people have different motives to perform health or disease related activities and how any other activity get at times more relevance or priority in people’s everyday life. One difference is the immediate feedback coming from work and leisure activities in contrast to self-care activities in which benefits might need more time to be recognized. Even though some medications can provide a direct feedback within minutes or hours after intake such as painkillers, there are a lot of medications and rehabilitations programs that do not provide this immediate feedback. As such, the individual motivation gets affected by positive or negative effects including side effects that challenge the performance and results of the self-care activity. Individual differences should be considered as some people are challenged when self-care activities are tedious or time-consuming and they all have a different personal experience (Chen, 2010). In our two cases of medication management and home-based rehabilitation, we have observed different complexities including a lack of understanding of why they have to perform a specific activity and thus people can intentionally non-adherence to the specific treatment (Sabatâe, 2003). Even though most older adults have a low motivation either by non-perceived benefit or considered themselves as too
old, few participants find personal motivation from other sources such as the social network conformed by family and friends. In the case of the pregnant women, a strong motivation was perceived as they received immediate benefits from the self-care activity such as avoiding to be hospitalized and indeed they do not want to put their baby at risk. However, taking the measurement at home sometimes took about 45 minutes that affected her and her loved one’s normal routines.

When

When to perform a self-care activity depends on each individual’s motivation, the type of activity, the current health situation and the context of the activity. In this sense, performing a self-care activity is different and at times more complex than performing a work or leisure activity. Most self-care activities are time-restricted and need to be integrated into people’s everyday life as they are usually dependent of other routines and activities such as before going to bed or before having breakfast (Palen & Aaløkke, 2006; Fitzpatrick, 2011). But self-care activities can also interfere with other important non-health related activities such as work (e.g teaching) in which people might not want to cross the boundary between work and private life and thus avoid self-care activities until they can find available time for them (Aarhus et al., 2009; Aarhus & Ballegaard, 2010). In all three cases, self-care activities at times are time-restricted and thus require a lot of planning trying to find the time to perform the medication intake, rehabilitation exercises and the self-monitoring activity. These activities also depend on the context such as the intake of diuretic\(^5\) medication that needs to be planned considering the availability of a bathroom. In diverse tele-monitoring projects, we have also observed how the time for a specific self-care activity is managed by healthcare professionals rather than considering people’s everyday life as if they were in the clinic rather than at home.

Where

Self-care activities are more complex at times than other work or leisure activities that are performed most of the times on a stable physical setting rather than distributed over time (as presented before) and over places. In all three cases, we have observed how people get challenged by the physical surroundings while performing self-care activities. For example, the treatment is challenged when a medication is not brought along while leaving the home as older adults did not like to take medication outside the home due to privacy issues. Or a rehabilitation or self-monitoring tool can not be easily transported in and outside the home as it was difficult for older adults and pregnant women to find a suitable place for them at home and follow the provided guidelines for measuring or rehabilitation. Even if these sort of support can be mobile and easy transportation (Grönvall & Kyng, 2012), unintended situations such as stigmatization can occur due to the perceived aesthetics of these support - digital or not (Aarhus & Ballegaard, 2010). This was more common among older adults that prefer to perform self-care activities at home than in public spaces. In contrast, pregnant women were more opened to do it even if they do not like to make the measurements outside

\(^5\)It is a medication that increases the production of urine
the home. However, additional restrictions of the physical setting as Internet coverage or power supply made it more difficult.

Control in Collaboration

Control in collaboration is usually present in self-care activities in asymmetric ways (Aarhus et al., 2009; Grönvall & Kyng, 2012) as experienced in our three cases in which healthcare professionals prescribed a specific treatment plan and patients are expected to follow that plan. Even though the monitoring system was implemented taking the healthcare professional’s perspective, pregnant women developed strategies to recover or remain in control of different aspects of their lives that get affected by the self-care activity. As such, pregnant women started to manipulate the measured bio-values to avoid unnecessary visits to the hospital under her individual’s perspective. Similarly in the medication management case, older adults wanted to keep control and they preferred to document their medication intake by themselves and use the tool to share their data with physicians if necessary or during consultations. In the rehabilitation case, older adults did not want to share information about when and where they performed the self-care activities to the healthcare professional and retain the control over their own activities. As such, control in collaboration in self-care is very different from control in collaboration for work or leisure activities. Even if there are activities in which people engage without a saying, most work and leisure activities are symmetric and negotiated towards a shared goal or common interest that it is difficult to perceived in the aforementioned self-care cases.

In brief, we have presented two analysis of multiple cases of self-monitoring (pregnant women, heart patients, healthy older adults) and self-care practices (medication management, home-based rehabilitation, tele-monitoring) in this subsection. The first analysis of empirical material from the aforementioned three cases of self-monitoring present seven themes (people, resources, places, routines, knowledge, control, and motivation) as important non-functional aspects in home-based healthcare technology. The second analysis came out from a reflection learning process in which we identified four high level concerns and revisited the three diverse cases of self-care to exemplify our concerns. Before introducing a further discussion on the results from the individual cases (medication management and preventive self-monitoring) and the multiple cases of self-monitoring and self-care, we will move to discussing the different types of work that we found while revisiting the empirical material from the preventive self-monitoring case to further use this results in the discussion section of this chapter along with the other cases.

4.3 Phase 3: Different Types of Work Involved in Self-monitoring

This section provides a summary of the results regarding the different types of work that we found in the preventive self-monitoring project. In this last phase, we engage in a reflection process and revisit the empirical data from the self-monitoring project to uncover the different types of self-care work (as illustrated in Figure 4.1). We use the concept of trajectory as a sensitizing concept to look for the several kinds of work (e.g. information, body, sentimental, machinery, and comfort work) involved in the trajectory management that conform
the trajectory work performed in non-clinical settings. Rather than being prescriptive or restrictive, the concept of trajectory is exploratory opening opportunities for interpretation and reflection about the specific domain under investigation. In the following, we will summarize these types of work in relation to our preventive self-monitoring case and further details can be found in Paper 8 (N. Verdezoto, 2013).

4.3.1 Machine Work

People engage in machine work while operating a specific self-monitoring device and they usually (and preferable) learned how to operate them from a healthcare professional (Strauss et al., 1997, p. 45) or by themselves. For instance, a participant from the qualitative study engaged in machine work while acquiring and operating a BP self-monitoring device after a diagnosis of hypertension. This work includes all the activities for string up and taking down, maintenance and storing of a specific device - machine tending as described by (Strauss et al., 1997, p. 45-53). For instance, a participant from the qualitative kept the blood pressure self-monitoring device in the closet readily available if needed. While performing the self-measurement, our workshop participants also engaged in machinery work when setting up and operating the device. In contrast to body work where the focus is the body, in machine work the focus is the technology and the activities around it to make them work. Machine work also involve transporting machines or bodies to perform the measuring activity (Strauss et al., 1997, p. 54). For instance, one of our participants preferred to go to the doctor’s office to take the measurement, whereas the healthy older adults brought the device to the home. In the first case, going to the doctor’s office to perform the self-measurement would involve other types of work as articulation of work (see Section 4.3.8) since some arrangements might need be done in advance. The main task on machine work is connecting the device to the person to perform the self-measurement activity or “connecting work” as defined by (Strauss et al., 1997, p. 55). It might sounds trivial but it actually requires considerable skills, time and effort while following the measuring rules. Our participants needed to place the cuff to their own arm and the cuff should be long enough to encircle the arm several times as well as positioning the arm at heart level and rest for five minutes before the measurement. If the cuff is misplaced the accuracy of the measurement can be compromised and thus lead to a wrong value or diagnosis. For instance, if the bladder is too small (undercuffing) there would be an overestimation of BP or so called “cuff hypertension”, whereas if the bladder is too large (overcuffing) there would be a underestimation of BP (O’Brien et al., 2003; Parati et al., 2010) and thus provoke other types of work like error work. Machine work might also involved other types of work such as comfort and composure work at times depending of the self-measuring situation. Machine work can increase if the person needs to use more than one self-monitoring device according to their condition. Last, machine work also involves monitoring and information work as participants monitor and record the device’s information.

4.3.2 Body Work

Strauss et al. (1997, p. 261) distinguishes three types of body work as: working with other people’s bodies (e.g. dress designers), working with one’s own body (e.g. self-care, dieting, singers, etc.) and working together with our own bodies and with other people’s body (e.g. climbing, cooking with a friend, etc.). As self-monitoring is performed on people’s bodies,
most of the body work is performed having the body as the main focus of attention regardless the health or illness condition. For example, a participant from the qualitative study expressed how difficult it is to exercise and another stated that it would be easier if exercise could be inserted into the working hours. Even if participants do not perceive doing exercises as part of the treatment plan as work, their body work is necessary work in the context of trajectory work for a specific trajectory of care (Straus et al., 1997, p. 261). However, there are different levels of types of body work that are accommodated according to the individual’s care trajectory and the specific treatment plan. For example, the body work performed by our participants with chronic conditions is different from the one performed by our healthy older adults in terms of quantity and frequency of the self-monitoring activity according to the treatment plan that can vary from several weeks to the rest of their lives. In our workshop with the healthy older adults, the nurse suggested to perform the BP self-monitoring activity for 3 days in a row mornings and evenings up to 4 times a year for prevention. Furthermore, the measuring guidelines also require other different types of work from people including body work while using the self-monitoring device. People have to manage their posture (sitting, lying or standing) and their arm position (at the level of the heart) while placing the cuff and bladder. As illustrated in Figure 3.4a, during the first workshop when participants learned how to perform and use the self-monitoring device, they also engage in body work while helping each other to accomplish the task. In general, all the aforementioned types of work would involve some sort of body work as long as they include body tasks (Strauss et al., 1997, p. 261).

4.3.3 Comfort Work

Comfort work is the work done to minimize or prevent discomfort (e.g. body conditions and sensations) in both clinical and non-clinical settings (Strauss et al., 1997, p. 106). From our qualitative study, we have observed several people with different roles engaging in comfort work. First, the people performing self-care at home that for example have bought a self-monitoring device or are taking (preventive) medication. Second, the care network also engages in comfort work at home from giving motivation statements to support the self-care activity. Third, healthcare professionals also perform comfort work when for example people prefer not to be that independent and go to the doctor’s office. For example, a participant from the qualitative study visited the doctor’s office every third month to take all the measurements because it was perceived as very comforting due to the supportive role of the nurse. From the workshop, we could see how participants engage in comfort work while supporting each other with the measurement and its respective interpretation. Also the nurse was performing comfort work during the initial workshop. Furthermore, discomforts can be also caused by the technology for example when the cuff was too small or too big or too tight to the arm causing tingling or itching, etc.

4.3.4 Safety Work

Safety work is the work done to manage and prevent the potential dangers (disease related) and risks (technology or treatment related) of a specific trajectory of care that requires “alertness and skills in preventive, monitoring, and rectifying action” (Strauss et al., 1997, p. 71). As such, safety work is tightly related to the previous machine work and it also takes place
4.3 Phase 3: Different Types of Work Involved in Self-monitoring

when people perform self-care activities at home. In our case, workshop participants for example were trained in safety work of self-monitoring by the nurse who explained what, why, and how to perform blood pressure self-monitoring. She explained to participants and researchers the importance of the measuring guidelines, posture, arm position and the correct use of the self-monitoring device to avoid measurements errors. Due to blood pressure variability, she also recommended to take the measurement more than once to check the values and also to take the measurement from both arms the first time. The role of the nurse was necessary to learn different particularities and issues that can result in errors regarding the accuracy of the gathered values. By analyzing the reported bio-values from the self-monitoring task, we have observed how older adults at home took the measurement more than once and in some cases from both arms when selecting the arm to start taking the measurements. In addition, one of the BP devices had a low battery and the participant requested another one. From the quantitative study, we also noticed that older adults are willing to buy self-monitoring devices as long as they have been tested beforehand. Even though, the group of participants during our workshops perceived themselves as healthy, one of our participants left our project because she got high BP values and visit her doctor as suggested by the nurse and entered to treatment. Of course the safety requirements for self-monitoring of health are different according to one or more illness conditions due to the complexities of each disease that increases the physical dangers and risks.

4.3.5 Information Work

Information work include all the managing efforts (e.g. handling, processing) of information before, during and after the task that are integral to the different types of work that compose the trajectory work (Strauss et al., 1997, p. 255). During our workshops we have different sources of information. At first, the nurse informed all the participants about symptoms, consequences, possible actions to control high blood pressure as well as how and when to perform the self-measurement. She also brought some pamphlets to the older adults. Furthermore, the measuring guidelines became an important resource to carry out the self-measurement task. In addition, older adults registered all the measurements in a paper-based template together with comments on the activity and values as necessary. Managing all these verbal or written information constitutes most part of the information work (Klasnja et al., 2010) attached to self-monitoring. It also varies according to the trajectory of care and the different types of work that need information to get them done.

4.3.6 Interpretation Work

Interpretation work include all the activities that take place when people try to get meaning from their own health data (T. Andersen, Bjørn et al., 2011). In our case, interpretation work was observed while analyzing the self-reported data from our participants. They used several strategies to make comparisons, understand and confirm their blood pressure values. However, some of them reported difficulties because they forgot the reference values to categorize their own values provided by the nurse. In our first workshop, we noticed that all participants got problem trying to understand the meaning of the value displayed by the device. The nurse played an important role to support interpretation including an explanation of the variability of BP values taken from both arms. Interpretation work, at times, also
goes beyond the bio-values to consider the context surrounding the self-measurements. As explained by the nurse, if the measuring guidelines are not followed the bio-values would not be accurate and context information is needed to avoid misinterpretation and over or under estimation of BP values that can lead to a wrong diagnosis.

### 4.3.7 Sentimental Work

Sentimental work is all the work that is present in the aforementioned types of work that affect people’s emotions. There are different types of sentimental work: interactional work and moral rules, trust work, composure work, biographical work, identity work, awareness context work, and rectification work (Strauss et al., 1997, p. 132). Some of the these types of sentimental work were present in our study. For instance, some participants from the qualitative study pace themselves to keep active and for example do some walking or shoveling the snow. Pacing as a relevant rule can also build trust and increase people’s confidence. Furthermore, composure work was perceived when people performed the self-measurement by themselves while following the measuring guidelines. They needed to sit down and wait for 5 minutes before taking the measurement. During that time, our older adults engaged in composure work keeping them calm to accomplish the activity. In addition, the nurse engaged in biographical work during the first workshop while establishing a relationship with participants asking questions about their lifestyle in relation to BP self-monitoring.

### 4.3.8 Articulation Work

Articulation work is all the work that has to be done to coordinate all the different tasks in a proper sequence or scheduling that takes place either at the hospital or at home (Strauss et al., 1997, p. 153). In our project, most of the articulation work was done by the older adults since the self-monitoring activities took place at home. First, older adults are the managers not only for the preventive care trajectory work but also for all the trajectory work that are aligned with the different types of work that occurs at home (first level). Second, older adults were also the ones who set up and used the self-monitoring device and supervised themselves while following the measuring rules. Third, they were also in charge of the operationalization of articulation work while actually carrying out the self-measurements and the tasks related to the measuring rules. As older adults are the experts of what is actually happening on their homes, they performed different levels of articulation work at times. One of the main issues was planning the self-monitoring activity around all other scheduled activities in the busiest lives of older adults. As we saw in our drawing activity, evening routines are not stable and challenge the self-monitoring activities as our participants prioritized other non-health related activities. From our qualitative study, we saw that articulation of work is more complex when performing chronic illness trajectory work due to the character of illnesses, more actors involved in the management of disease, and more technology involved.

### 4.3.9 Error Work

Another interesting type of work is the so called “error work”. Strauss et al. (1997, p. 242) defines error work as the different tasks involved in “in preventing, minimizing, defining, de-
tecting, covering up, rectifying, estimating the consequences of, and so on, mistakes”. Every self-care activity and the different types of work are potentially exposed to different sort of errors that also vary along with the different trajectories of care. In our case, we have observed how the healthy older adults take the self-measurement more than once or double check the position of cuff and bladder and the measuring guidelines. While this was seen during the learning process, they also did that during the self-monitoring task in their homes. While analyzing the different data registered by them, we could see that they take more than once (in some cases three or four times) the measurement and in some occasions in different arms.

4.3.10 Dirty Work

Dirty work is another special type of work that can be present in all types of work that are perceived as physically or socially unpleasant (e.g. unchallenging, exhausting or stressful, dangerous, physically or symbolically dirty) (Strauss et al., 1997, p. 247). In our qualitative study for example a participant stated that doing exercises or sports were not fun and that exercises were another duty attached to their everyday life. Another participant also expressed that performing non-funny things increased the risk of “becoming sick”. Dirty work also includes all the tedious tasks around the self-monitoring activity. For example, some healthy older adults also reported some complexities around the measuring rules that in some cases were boring for example, resting on the table for 5 minutes. Again, dirty work also vary according to the individual trajectory care and its phases (Strauss et al., 1997, p. 249).

4.3.11 Negotiative Work

Negotiative work can take place around all the different types of work and involves various kind of well-articulated task to carry out negotiation to achieve some agreements (implicit or explicit) regarding a specific topic (Strauss et al., 1997, p. 267). In our case, we have found two different types of negotiation: inner and outer negotiation. Inner negotiation takes place when people negotiate with themselves and play an important role in health or disease management. People at home performing self-monitoring need to define what, how, and when to perform the activity. In our qualitative study, as a result of his inner negotiation a participant became an anti-smoker after the illness, and another thinks about food and its relation to health and exercise to decide what to eat. This internal process is ongoing specially for people with a specific illness that need to control diet and do exercises. Another example includes a participant saying that he would forget about the consequences of alcohol in a social environment and engage in drinking having the possibility to get new friends. It also occurs for example when a participant decided to move to a nursing home to be close to his children as well as deciding to avoid the self-measurement in the evenings while attending other planned activities or not bringing the device outside the home. Outer negotiations were more apparent during our workshop when people talk and agree who is helping each other with the measurement. Or during our discussions when a participant told us that he discussed his values with his spouse and thus decided to take more than one measurement in morning or evening. Also when a participant arranged to take the self-measurement at the doctor’s office instead of the home. Thus, negotiative work take places all the time in all
trajectories while interacting with people or with ourselves as well as get affected and affect the other types of work.

4.4 Summary and Discussion

In brief, this chapter has presented our findings from our studies of self-care practices. First, we have presented the challenges that older adults have regarding medication management activities in relation to their everyday life (see Tables 4.1 and 4.2). In addition, we presented the results of our compliance technology review as well as the design guidelines review for tablet-touch based interfaces. We have described our user-centered design process with medication experts and older adults moving back and forth between design explorations and design studies. We have explored and framed the design space through several low-fidelity (mockups and screen-based prototypes) and high-fidelity prototypes that have resulted in the further implementation of the MediFrame concept.

Second, we also presented the findings from the preventive self-monitoring case in which several challenges were listed (see Table 4.3). Even though we considered different target groups in our initial qualitative study, our user-centered design process just focused on healthy older adults to investigate the challenges and opportunities of preventive blood pressure monitoring. We investigated older adult’s routines and their perceptions towards self-monitoring. We employed different design explorations for visualizations of blood pressure data. A nurse was also involved and helped to provide relevant information to participants regarding preventive BP self-monitoring. All our participants were able to take their own self-measurements. Our findings from our activities and design visualizations fed back to the SELMA concept. Even though the last version of SELMA was shown to our participants to elicit discussions, it has not yet been evaluated. However, our case of preventive self-monitoring provided several insights that made us move on to our reflective phase and compare multiple case studies of self-monitoring.

Third, we carried out our multiple case study of one specific self-care practice (self-monitoring) with different populations (pregnant woman, healthy older adults and older adults with heart conditions) that resulted in a conceptual framework composed by several themes (people, knowledge, places, resources, routines, control, and motivation). These themes represent “non-functional aspects” of self-monitoring technology and were present in all three cases and thus reached analytical generalization as suggested by (Yin, 2009). These themes constitutes a conceptual framework for understanding the dynamics of self-monitoring practices and provide a holistic view of self-care practices at home that goes beyond tracking of health parameters.

Fourth, we moved to another cross-case analysis reflecting on different self-care projects (medication management, self-monitoring and home-based rehabilitation). While analyzing the different design rationales in the aforementioned projects, our analysis resulted in the identification of four high level CSCW/HCI concerns (why, when, where, control in collaboration) for designing home-based technology. There are similarities and differences across the different cases regarding why, when, where and the kind of control experienced while performing self-care practices at home. These concerns can be used to help designers to identify particularities of specific cases to further frame the design space and later on to evaluate
different design explorations (mockups, prototypes) while having in mind the individual’s perspective without neglecting for example the healthcare professional’s perspective.

Fifth, we have used the concept of trajectory to explore the trajectory work that occurs while performing self-monitoring in non-clinical settings. Informed by the related work reported in section 2.1.2 and the concept of trajectory, we identified different types of work in our preventive self-monitoring case which include both healthy and people with chronic conditions. These types of work are machine work, safety work, information work, interpretation work, comfort work, sentimental work, articulation work, body work, error work, and dirty work. As such, the self-care management work at home for self-monitoring includes these different types of work that sometimes are not perceived or recognized as work in non-clinical settings. Moreover, these different types of work can be used to provide an in-depth understanding of the different actors, dangers, risks, possible disruptive conditions and in general issues that can challenge a successful self-care plan at home.

Finally, while at the hospital the healthcare professionals are in charge of the trajectory work and have the necessary knowledge and resources to manage and shape people’s care trajectories, the situation is totally different when people engage in self-care trajectory work by their own. At home, people have to engage in diverse self-care activities that most of the time involve the use of some sort of technology (Bratteteig & Wagner, 2013). As we have seen in our cases, people tend to learn how to manage and shape their own trajectory of care by their own regardless their health or illness situation. For example, both frail and healthy older adults as well as pregnant women engage in different types of self-care practices at home as we have seen in this chapter. Informal and formal caregivers also get involved in people’s care trajectories especially when a person is not able to take part of the self-care division of labor at home (Corbin & Strauss, 1985). In our medication management case, some participants move along the continuum between dependence and independence. As such, the care network starts playing an important and active role in the trajectory work performed at home. Another example is related to the pregnant woman’s husbands as they become more and more aware of what is happening with their child. In contrast to the hospital that has been designed to adequately support care management activities, the home has not been designed as a place for care (Axelrod, 2009; Heart & Kalderon, 2011; Grönvall & Kyng, 2012). In the home there are different lines of work that take place and most of the time the central focus of attention is not per se self-care (Corbin & Strauss, 1985; Aarhus et al., 2010). We have seen how an active lifestyle challenge health and illness self-care activities and people’s trajectory of care as people are not always at home or they have different non-health activities to attend. While investigating people’s perspectives (Ballegaard et al., 2008) in health and illness, we have seen several similarities and differences that have been reported in this chapter. A bigger picture is provided while considering different perspectives of health and disease self-care practices uncovering several specific challenges and opportunities of self-care. Furthermore, some of the themes and concerns have been previously reported by previous work (Palen & Aalekke, 2006; Ballegaard et al., 2008; Axelrod et al., 2009; Aarhus & Ballegaard, 2010; Chen, 2010; Fitzpatrick, 2011; Grönvall & Kyng, 2012). However, they have not been discussed as a whole in home-based healthcare as they have focused on a specific target group and/or a specific disease. These themes can support reflective practices of designers while applying them for understanding on the specific domain at hand.
This chapter have summarized the results from our diverse studies in detail. In the following chapter, a more elaborated discussion as well as a summary of paper’s conceptual contributions and lessons learned are provided to support the self-care management work at home.
Chapter 5

Summary of Contributions and their positioning in the Related Work

At first, this section presents a summary of conceptual contributions and lessons learned from our diverse studies according to the three aforementioned phases while understanding and designing home-based healthcare technology. Furthermore, the second part of this chapter discusses and positions the conceptual contributions in relation to the existing related work in self-care technology. Next, the third part of this chapter provides a more elaborated discussion of the diverse results using the concept of trajectory and the theory of practice to provide a more in-depth understanding of the relations and application of the presented contributions.

The work presented in this dissertation is placed to a large degree under the umbrella of Personal Health Systems that involves a multidisciplinary context covering several research areas such as Health Informatics and PervasiveHealth communities (health-related) as well as HCI, UbiComp and CSCW communities (non-health specific). Figure 5.1 illustrates an overview of the different conceptual contributions and lessons learned from this dissertation that will be described in the following sections.

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lessons learned</td>
<td>Lessons learned</td>
<td>Lessons learned</td>
</tr>
<tr>
<td>Use of Tablets by Older Adults</td>
<td>Design Recommendations to Support the different Modes of Self-monitoring Use</td>
<td>Designing For Healthcare in Everyday Life Implications for Design</td>
</tr>
<tr>
<td>Interface Design for Medication Management</td>
<td>High-level CSCW/HCI Concerns for Home-based Healthcare Technology Design</td>
<td>Different Types of Work in Self-care</td>
</tr>
<tr>
<td></td>
<td>Design Principles for Pervasive Healthcare Medication Management Systems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Designing Opportunities for Preventive Home-based Blood Pressure Self-monitoring</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Additional Contributions: Reviews of Compliance Technologies and Design guidelines for Tablet-based Touch Interfaces</td>
<td></td>
</tr>
</tbody>
</table>

Figure 5.1 An overview of the different conceptual contributions and lessons learned from the different research phases.
5.1 Conceptual Contributions from our Three Phases

5.1.1 Phase 1: Contributions from the Exploratory Cases

The two initial cases of medication management and preventive self-monitoring provided the basis for all the contributions of this dissertation. In the following, we present a summary of contributions and lessons learned from these two specific cases.

Functional and Non-functional Meta-requirements for Pervasive Healthcare Medication Management Systems

Based on our findings and results from our different activities (compliance technology reviews, initial user studies, related work) summarized in Section 4.1.1, we present a set of functional (integration, reminder, tracking, mobility, search, navigation, sharing, flexibility, control) and non-functional (security, safety, performance, privacy, user interface) meta requirements towards the design of Pervasive Healthcare medication management systems (see Paper 1, p. 113). These meta-requirements are summarized in Table 5.1.

<table>
<thead>
<tr>
<th>Functional Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>- F01 Integration: multiple sources of information</td>
</tr>
<tr>
<td>- F02 Reminder: portable and customizable reminders</td>
</tr>
<tr>
<td>- F03 Tracking: register and follow up medication intake</td>
</tr>
<tr>
<td>- F04 Mobility: support of medication intake in and outside home</td>
</tr>
<tr>
<td>- F05 Search: active medication information search</td>
</tr>
<tr>
<td>- F06 Navigation: provide free navigation regarding multimedia content</td>
</tr>
<tr>
<td>- F07 Sharing: enable customizable modes for sharing information with caregivers</td>
</tr>
<tr>
<td>- F08 Flexibility: regarding the storage of medication</td>
</tr>
<tr>
<td>- F09 Control: enable the user to control and customized functionalities</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-Functional Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>- NF01 Security: enable secure authentication</td>
</tr>
<tr>
<td>- NF02 Safety: provide, restore and log status information in case of failure</td>
</tr>
<tr>
<td>- NF03 Performance: short response time and high availability</td>
</tr>
<tr>
<td>- NF04 Privacy: take into account user’s privacy concerns</td>
</tr>
<tr>
<td>- NF05 User Interface: easy to use, balance on interfaces, touch instead of typing, use of images</td>
</tr>
</tbody>
</table>

Table 5.1 Functional and Non-functional meta requirements.

Design Principles for everyday Medication Management Systems

Based on our findings, from our medication management case, summarized in Section 4.1.1, six important and specific particularities were identified for everyday medication management (according to need medication, the substitute medication, the medication informational order, the adjustment of the medication intake, the shared responsibility and the heterogeneous care network) that provided the basis for our design principles (see Paper 3, p. 127).
Table 5.2 presents five design principles for future design of pervasive healthcare medication management systems (PHMMS) based on the aforementioned particularities.

| Design Opportunities for Preventive Home-based Blood Pressure Self-Monitoring |
|---|---|
| The design of PHMMS that enhances the individual medication overview by visualizing, documenting, and supporting the use of **substitute** and **‘according to need’** medication. |
| The design of PHMMS that supports the **shared responsibility** by providing the individual’s local awareness and enhancing the physician’s local awareness of medication intake taking advantage of the individual medication overview. |
| The design of PHMMS that sustains the **medication informational order** to enhance individual’s sense making and reflection. |
| The design of PHMMS that supports the **adjustment of medication** intake according to prescription times, people’s routines, and the respective time interval in and outside the home. |
| The design of PHMMS that sustains and allows (both **amateur** and **professional** caregiver) to play an active role in people’s medication intake by providing caregiver’s local awareness taking advantage of the individual medication overview. |

**Table 5.2** Design Principles for pervasive healthcare medication management systems (PHMMS).

**Design Opportunities for Preventive Home-based Blood Pressure Self-Monitoring**

Based on our findings summarized in Section 4.1.2 from our preventive self-monitoring case, Paper 5 (p. 149) discusses two design opportunities for pervasive healthcare blood pressure self-monitoring technology. The first design opportunity is “Rethinking Preventive Self-Monitoring of Health Parameters towards a Positive Experience”. As we described above, there are different sources of motivation that go beyond the self-measuring activity and there are several challenges that complicate preventive activities. The idea of rethinking the design of preventive self-monitoring that can provide a positive experience to facilitate the integration of these activities with everyday routines as well as decrease the stigma attached to most of the existing self-monitoring devices. One strategy could be to explore the social aspects of people’s everyday life to increase motivation and promote preventive self-monitoring activities at home. The second one is “Supporting the Active and Informed Citizen”. This came from the idea to support active and informed citizen with a general interest in health and wellbeing to perform the self-monitoring activity and facilitate interpretation of health data to increase the individual health awareness. One strategy could be using visualizations and tagging techniques to enhance individual’s health awareness and support people’s reflection processes.

**Additional Contributions**

The first one is related to the review of compliance technology (electronic reminders, tablet-holders with electronic reminder, dosing aid with electronic reminder, automatic dispensers, non-electronic reminders, other types of technologies related to adherence, other medical applications) summarized in Section 4.1.1 and reported in Paper 1 as well as in a project report (N. Verdezoto, 2011h) that contains seven appendices (N. Verdezoto, 2011a, 2011b, 2011c,
The second one is related to our review on design guidelines for tablet-touch interfaces summarized in Section 4. Our review considered existing design guidelines for mobile devices, older adults and touch interfaces. In total, we revised 31 guidelines and were categorized as follows: 17 design guidelines for visual and interaction design, 4 design guidelines regarding information organization, and 10 conceptual considerations as illustrated in Table 5.3. These 31 guidelines can be adapted for tablet-based touch interfaces and can help designers to frame the design space for their future solutions (See Paper 2, p. 121).

<table>
<thead>
<tr>
<th>a. <strong>Visual and Interaction Design</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Visual design considerations (text-related factors, naming labels and icons, links, visual warning messages, button spacing, intended target size for touching)</td>
</tr>
<tr>
<td>- Interaction design considerations (input by selection, temporal constraints for user input, clear visual cues, manual dexterity of target group)</td>
</tr>
<tr>
<td>- Visual-Interaction and Navigation considerations (intended target location, screen scrolling, clear indication for selected items on the interface, avoid repetition in the navigation, enhance visibility and accessibility for important actions, clearly indicate the system status)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. <strong>Information Organization</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>natural and consistent grouping of related information, menu structure, design for optimal access and design for top-down interaction</td>
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</table>

<table>
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<tr>
<th>c. <strong>Conceptual Considerations</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>provide useful and informative feedback, keep user in control, good dialog design, error prevention, reduce short-term memory, speed and recovery, consistency, adaptability and flexibility, design for limited and split attention, support user goals</td>
</tr>
</tbody>
</table>

Table 5.3 Design guidelines for tablet-based touch interfaces.

Lessons Learned from MediFrame and SELMA Design Processes

Table 5.4 illustrates some lessons learned from both MediFrame and SELMA design processes based on our observations and our different studies presented in Section 4. Most of our participants have some sort of experience with different types of technology for both medication management and self-monitoring. While using tablet technology with older adults (item a in Table 5.4), providing an introduction to the technology before our workshops activities was a good strategy to engage older adults in our activities. In addition, the review of design guidelines were useful and help us to frame the design space. As there is not previous work to our knowledge suggesting design guidelines for tablet-based touch interfaces for older adults, we have adapted the guidelines to our case and tested some of them that help us to take decisions and re-design parts of our interface.

While designing for medication management using tablet-based touch interfaces (item b Table 5.4), we involved different stakeholders that emphasized the importance of providing a clear overview of the medication regimen. After trying several metaphors that were challenged by the complexity of our participant’s medication needs, we moved away from the metaphor idea focusing on reducing the information clutter on the screen. We used several strategies (images, user’s identity, information seeking) across low and high fidelity proto-
types to find the balance between complexity of the medication regimen and information seeking needs. *MediFrame* was designed to support planning and reminding of medications by combining information (prescribed medications and people’s activities) across settings (item c Table 5.4). For instance, *MediFrame* calendar’s interface provides directed (monitoring, awareness) and undirected (browsing, search) medication information according to Bate’s model of information seeking behavior. In addition, the *MediFrame* take medicine’s interface is concern about documenting and providing an overview and knowledge about medication (item d Table 5.4). Documenting can be useful to support doctor’s information seeking needs and the overview and knowledge at home can help people to get the right information to support their medication intake. Last, regarding the different weekly and details visualization of blood pressure data from SELMA (item d Table 5.4), our participants found the visual encoding of different BP values (low, normal, borderline, high and very high) as useful. For overview, they preferred line charts instead of icons and bar charts. Papers 4 (p. 137) and 5 (p. 149) provided a more elaborated discussion on lessons learned from our different studies.

<table>
<thead>
<tr>
<th>a. From the Use of Tablets by Older Adults</th>
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</thead>
<tbody>
<tr>
<td>- Introduction of Tablet Technology</td>
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<tr>
<td>- Application of Design Guidelines for Touch-based Interfaces</td>
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</table>

<table>
<thead>
<tr>
<th>b. From the Interface Design for Medication Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>- The use of images</td>
</tr>
<tr>
<td>- Addressing the complexity of medication intake</td>
</tr>
<tr>
<td>- Providing user’s identity</td>
</tr>
<tr>
<td>- Facilitating the information seeking on the interface</td>
</tr>
<tr>
<td>- The use of low and high fidelity prototypes</td>
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</table>

<table>
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<tr>
<th>c. From Designing for Planning and Reminding the Medication Intake</th>
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<table>
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<tr>
<th>d. From Designing to Provide an Overview and Knowledge about Medication</th>
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<tr>
<th>e. From the Blood Pressure Visualizations</th>
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Table 5.4 Lessons learned during the MediFrame and SELMA design processes.

5.1.2 Phase 2: Contributions from the Multiple Cases

Based on the findings from our two cross-case studies of self-monitoring and self-care practices reported in Section 4.2, we will now present a summary of all contributions from these multiple cases in the following subsections.


In Section 4.2.1, we present the results from our first multiple case study of self-monitoring practices: pregnant women with pre-eclampsia, older adults with diverse heart conditions and preventive care. The cross-case analysis came out with seven themes (people, knowledge, places, resources, routines, control and motivation) that together conform a conceptual framework to facilitate the understanding of non-functional aspects of self-monitoring technologies as well as the dynamic and complexities of self-care practices in non-clinical
settings. In Paper 6 (p. 161), we identify and present a discussion regarding different modes of self-monitoring use (individual and care network, demo, wellness and illness use) associated to many of the aforementioned themes. These three modes exemplifies how people use self-monitoring technologies at home and we argue that self-monitoring technology should offer flexibility to support a variety of use in non-clinical settings.

Properties of Home-based Self-monitoring Technology

Based on the identified modes of self-monitoring use and the presented non-functional aspects, we suggested three properties that self-monitoring technologies should account to support the different modes of use and self-monitoring practices at home. These three properties are: the individual and care network’s local awareness, assess and assist the individual health locus of control and the active information seeking and reinforcement. First, we suggested that pervasive healthcare technology should be able to provide the individual and the care network with a sense of local awareness through the application of information sharing, learning and reflection techniques. Second, we discuss an important system quality regarding the importance on how to support or suppress the different actor’s levels of control (internal, external, and by chance) in home-based technology design. We suggest that pervasive healthcare technology should support people’s active information seeking behaviors and reinforce the application of the measuring guidelines as well as capturing all the relevant contextual information. By doing this, technology can support the self-monitoring informational order in non-clinical settings that can facilitate the individual and care network’s involvement in home-based care practices. Paper 6 provides an in-depth discussion for each of these properties.

High level Concerns for Home-based Healthcare Technology Design

In Section 4.2.2, we introduced our second cross-case analysis during our reflection phase. We revisited there specific projects related to three different self-care practices (medication management, home-base rehabilitation, and self-monitoring). We further present 4 high level CSCW/HCI concerns (why, when, where, control in collaboration) related to home-based healthcare technology design while discussing the different design rationales that were present in each project. Even though the aforementioned concerns have been reported before in the CSCW/HCI communities, they play and important and critical role in the pervasive healthcare technology design that we discuss in Paper 7 (p. 173). First, we provided an rich description of the aforementioned cases including the different settings and actors involved in each self-care project. Second, we argue that these four concerns can help designers to find a balance between the different design rationales and perspectives as well as increasing their awarness while designing home-base healthcare technologies to fit in people’s everyday life. Paper 7 provides an in-depth discussion for each of these properties.
5.1 Conceptual Contributions from our Three Phases

Designing for Healthcare in Everyday Life - Implications for Design

Based on the four high level concerns, some preliminary implications for design has been provided for pervasive healthcare technology designers. Our preliminary\textsuperscript{1} list of implications are presented in Table 5.5.

\begin{itemize}
  \item Home-based healthcare technology should be designed to provide a clear and easily perceived benefit for the individual while balancing multiple perspectives to increase peoples’ motivation.
  \item Home-based healthcare technology designers should understand individuals’ activities and what effects inserting healthcare activities might have on everyday life.
  \item Home-based healthcare technology should balance the number of constraints, making healthcare activities more flexible and easier to integrate in people’s everyday life.
  \item Home-based healthcare technology should support people in re-scheduling and planning their healthcare activities so that they can perform them where and when they prefer.
  \item ICT support for healthcare activities should be designed with an understanding of what control is provided, removed or altered within a collaborative entity through its implementation. Home-based healthcare technology should increase the activity awareness of users, care network and designers on how people do workarounds to retain or gain control not provided to them by the designed system.
\end{itemize}

\textbf{Table 5.5} Healthcare in Everyday Life - Implications for Design

5.1.3 Phase 3: Contributions from the Analysis of Trajectory Work

In Section 4.3, we present a rich description of different types of work (machine work, safety work, information work, interpretation work, comfort work, sentimental work, articulation work, body work, error work, dirty work, negotiative work) identified in the preventive self-monitoring case based on the concept of trajectory and the related work (see Section 2.1.2). These different types of work are embodied in the self-care work and together conform the trajectory work associated with people’s self-care activities in non-clinical settings. The main contribution here is to highlight the presence of the different types of work in self-care and make them visible. However, we have not reached the stage to provide implications for design but rather provide an example of how the trajectory work at home can be analyzed and the different interpretations that can increase designer’s awareness providing a different (top-down) holistic perspective. Paper 8 (p. 187) provides an in-depth discussion for each type of work.

\textsuperscript{1}Preliminary because they are coming from Paper 7 (p. 173) that is in preparation for submission
5.2 Positioning in the Related Work

The work presented in this dissertation have exemplified how the self-care work differ in several ways from the hospital care work. At first, our work is positioned under the umbrella of personal health systems while investigating the challenges and opportunities to support the self-care management work at home (see Section 4.1.1). As described in our Background section (see Section 2), our work is aligned to previous work (e.g., Palen & Aaløkke, 2006; Consolvo et al., 2008; Ballegaard et al., 2008; Kanstrup et al., 2008; Mamykina et al., 2008; Preuveneers & Berbers, 2008; Aarhus et al., 2009; Civan et al., 2009; Aarhus & Ballegaard, 2010; Chen, 2010; Mamykina et al., 2010; Fitzpatrick, 2011; Storni, 2011; Grönvall & Kyng, 2012; Storni, 2013; Güldenpfennig & Fitzpatrick, 2013) that have investigated health-illness care practices as well as the citizen perspective (Ballegaard et al., 2008). However, most of the existing work have focused on specific disease management practices such as diabetes care management. Instead of focusing on specific disease management, we have focused on investigating the complexity of medication management practices regardless of the disease and preventive self-monitoring care practices. By doing this, we have uncovered for example specific medication particularities (e.g. according to need medication, the substitute medication, the medication informational order, the adjustment of the medication intake, the shared responsibility, the heterogeneous care network, the complexity of measuring rules, different motivational sources, the home as a distributed information space, etc.) that are important to consider in everyday medication management (see Table 4.2 for a complete list) and preventive self-monitoring practices (see Table 4.3 for a complete list). These particularities aim to help designers to account for a bigger understanding of self-care activities in non-clinical settings as suggested by Mol (2008) while considering multiple perspectives on self-care (Das & Svanes, 2010). A more detailed description of challenges and opportunities from our cases can be found in Papers 5 (p. 149), 6 (p. 161), and 7 (p. 173).

We have acknowledged the existing challenges of home-based healthcare technology (see Section 2.2.1) while also presenting a set of challenges from our different cases. As the main idea was to support pervasive healthcare technology designers, we have provided a set of tools such as design principles, guidelines, recommendations and lessons learned from our cases. We have acknowledged and complemented prior work on design guidelines for home-based healthcare technology. These guidelines include: principles for home-based medication management (Palen & Aaløkke, 2006), for the design of personal health applications (Siek et al., 2011), implications to support self-reflection (M. L. Lee & Dey, 2011) and medication reminders (Y. S. Lee et al., 2009). For instance, Mulder et al. (2009) highlight the importance of considering human values in the design of pervasive healthcare technologies. Ballegaard et al. (2008) proposes designing for continuity, understandability and learning while considering the individual perspective. A more detailed description of guidelines in relation to previous work are described in Papers 1 (p. 113), 3 (p. 127), 4 (p. 137), and 7 (p. 173).

Even though there are some frameworks, methods and models to support pervasive healthcare designers (e.g., Tang et al., 2010; J. Bardram & Doryab, 2011; Randell, Wilson, Woodward & Galliers, 2011), most of them target the design of technology for a specific clinical settings. However, some researchers have started to consider the home setting (e.g., Årsand & Demiris, 2008; Heimly, 2010; Vlahu-Gjorgievska & Trajkovik, 2011) most of them have a strong technological focus. In a recent CSCW review for healthcare, Fitzpatrick and
Ellingsen (2012) reports that few studies engaged in design explorations and that there is a lack of work on conceptualization of frameworks and models for designing healthcare technology. Thus, apart from providing design guidelines, we support designers in their reflective practices by providing conceptual tools to support reflection and decision-making as suggested by (Stolterman, 2008, p. 63). Our empirical contribution extended previous work by providing tools for thinking (Dourish, 2006, p. 549) that help to understand the self-care work that take place at home. Our non-functional aspects and high CSCW/HCI concerns do not prescribe but rather support reflection grounded in our empirical case data that can help designers to get an in-depth understanding of self-care practices and the trajectory of care at hand. As some researchers have argued (Chen et al., 2012; Fitzpatrick & Ellingsen, 2012), there is limited work exploring the overall trajectory of care, these conceptual framework and concerns can help designers to explore particularities of specific trajectory of care. Last, the different types of work provided by Strauss (Strauss et al., 1997) can also serve as a reflective tool based on concept of trajectory and abstracts concepts of work that can provide a broader understanding of self-care practices at home. Even though some of the types of work have been already investigated in CSCW research on specific settings (Fitzpatrick & Ellingsen, 2012; Blomberg & Karasti, 2013), their understanding as a whole can provide a holistic perspective to further study the self-care work at home (Bratteteig & Wagner, 2013) for both health and disease as we have presented in Section 4.3 and suggested by (Mol, 2008). A more detailed description of conceptual contributions on frameworks, concepts and concerns is presented in Papers 6 (p. 161), 7 (p. 173) and 8 (p. 187).

5.3 Summary and Discussion

In this chapter, we have provided a summary of the different contributions of this dissertation. We have presented a set of tools such as requirements, design guidelines, conceptual tools and high level concerns to support pervasive healthcare system designers in their reflective practices as suggested by Stolterman (2008, p. 63). Furthermore, we have positioning our contribution along the related work that has been previously introduced in Section 2.

In addition, the non-functional aspects (people, knowledge, places, resources, routines, control and motivation), the list of concerns (why, when, where, control in collaboration) and the different types of work (machine work, safety work, information work, interpretation work, comfort work, sentimental work, articulation work, body work, error work, dirty work, negotiative work) in self-care are explanatory rather than prescriptive and can support designer’s reflective practices by for example enabling them to further explore these different concepts for future technology design (Rogers, 2012) while supporting people’s trajectory of care. Furthermore, our research prototypes can be seen as implicit theoretical contribution (Zimmerman et al., 2010, p. 314) as they have embedded knowledge and describe a vision of a preferred state (Zimmerman et al., 2007, p. 498) and thus they constitutes facts of our research through design process (W. Gaver, 2012, p. 944). All the knowledge gathered through our design oriented approach that have been described in this chapter can be extended and applied for different researchers and designers across the different communities while designing self-care technologies.

Now, we want to focus on an additional discussion using the theory of practice (described in Section 2) as lens for getting a further understanding on self-care practices and its implica-
tions for home-based healthcare technology design. Next, we also discuss the different types of self-care work in relation to the different cases and its implications for system design.

5.3.1 Using the Theory of Practice to Understand Self-care Practices

The theory of practice (Schatzki, 1996; Reckwitz, 2002) has been applied in other HCI research areas such as sustainability using practices as a unit of analysis or a unit of design (Kuijer, Jong & Eijk, 2013; Ganglbauer, Fitzpatrick & Comber, 2013). Using practices as a unit of analysis for example can provide a further understanding of everyday practices as well as on how “designed artifacts shape and are shaped by the contexts in which they are used” (Ingram et al., 2007). As discussed in Paper 7, self-care practices are different from other work or leisure practices. Even if some preventive self-care practices can provide a direct benefit as any other work or leisure practices, most of the self-care practices specially while managing a chronic condition are less evident and will have long-term benefits. In this dissertation, we have reported both health and illness related self-care practices based on our different cases. As the home is a complex setting and has been not designed as a place for care (Fitzpatrick, 2011; Grönvall & Kyng, 2012), we need to understand all the complexities and practices that occur at home and around the self-care practices in order to design pervasive healthcare technology that actually support self-care practices instead of increasing the complexity of the self-care activity (Aarhus et al., 2009). Thus, this is our attempt to start exploring the use of the sociological theory of practice to understand self-care practices in order to support designers while using high-level theories to expand design thinking as suggested by (Stolterman, 2008, p. 63).

To start with, recalling Ann’s and Thoma’s scenarios our findings pointed out and confirmed how self-care practices are affected by internal and external factors (e.g. people, knowledge, places, resources, routines, control, motivation, character of the disease, physiological factors, etc.) that sometimes resulted in unintended consequences such as deceiving behavior (e.g. pregnant women) and stigmatization (e.g healthy older adults) as described in Paper 6. To further understand self-care practices, it might be useful to reflect on dispersed and integrative self-care practices. For instance, medication management at home is a critical integrated practice with a specific set of routine practices such as planning, storing, medication routines, intake and refill practices. Regarding preventive self-monitoring at home, it was also a integrated practice with a set of routine practices on planning, storing, performing the measurement. Around medication management, our participants mostly use agendas or calendars to do their planning. They usually go through their prescribed medication list and include them in their agenda if any to support the reminding of the medication intake. However, sometimes their busy lives with work or leisure activities (e.g. trips or visits) resulted on breakdowns of routines. Their medication routines depend on several personal, social, and contextual factors like for example where and when to take the medication as well as the storing area of medications (distributed or central storing around the home). Mnemonic rules like taking medications with meals plays an important role. Furthermore, refill medications was another issue caused by forgetting or lack of planning.

A common disperse practice among all our cases was the practice of “having an active lifestyle”. Most of our participants assign higher priority to this practice than to the previous mentioned integrated practice increasing the opportunity to miss a medication intake or a
self-measurement activity. Recalling the concept of caring explained in Section 1, caring as an emotional labour (Thomas, 1993) can be considered a dispersed practice that take place on different integrated practices in different ways. But caring as work (Thomas, 1993) should be considered as an integrated practice in which several dispersed practices take place such as ”having an active lifestyle”, ”looking for information”, ”reading instructions”. Furthermore, the dispersed practice of “having an active lifestyle” sometimes were non-negotiable as in our preventive self-monitoring because they continuously engage in social activities. In the medication management, participants try to find a balance between work activities and self-care activities engaging in boundary work while integrating or separating practices (Aarhus & Ballegaard, 2010) that sometimes resulted on skipping the medication dose or just forgetting to do so.

Therefore, self-care practices from our cases can be defined as a collection of interconnected practices - both dispersed and integrated - that can take place both in and outside the home. Strategies to support both dispersed and integrated practices can be seen around the Calendar interface of MediFrame as an example to support planning of medication intake around other planned activities in people’s everyday life. By doing these, dispersed and integrated practices are interconnected and visible to support the medication intake. Another strategy this time in the SELMA prototype that make visible the integration of self-monitoring practices with contextual information regarding the practices around the measurements. Furthermore, additional support for the integrated practice of self-monitoring could be the reinforcement of measuring guidelines (see Paper 6) and rethinking self-monitoring technology towards a positive experience (see Paper 5). By doing this, the accuracy of the measurement would not be compromised and the risk of causing stigmatization can be reduced while focusing on a positive experience and the aesthetics of technology to provide a ”cool gadget” (Güldenpfennig & Fitzpatrick, 2013) rather than the typical standalone medical technology. Designing for self-care integrated practices might include support for planning and reminding as well as providing and overview and knowledge of for example medication intake at hand (see MediFrame Paper 4). Supporting storage of medication and self-monitoring devices can facilitate self-care practices. Last, we should provide support for both the informal and formal care network while documenting and sharing personal health data as needed. To some degree, some of the aforementioned strategies can inform system design of future pervasive healthcare technology. It is all about considering the individual personal experiences and everyday lives, the specific situation at hand and the role of different perspectives as technology is more and more pervasive and embodied into people’s everyday life (Rogers, 2009; Kawsar & Brush, 2013).

5.3.2 Using the Different Types of Work to Understand Self-care Work

Even though the concept of trajectory came out from studies in clinical settings (Strauss, 1993; Strauss et al., 1997), some researchers have used the concept of trajectory to understand self-care practices around disease management (Aarhus et al., 2009; Chen, 2011; Huh & Ackerman, 2012). These previous CSCW studies have focused on studying Illness trajectories of a specific target group that is one of the main examples of trajectories of care. Illness trajectory is defined as the.

…flow from home residence into and through hospitals, and out again back to the
home. When we consider such repeated cycles, it becomes apparent that patients are, as remarked earlier, working technologists, too, not only at home but in the hospital. (Strauss et al., 1997, p. 209)

While at the hospital people take a more passive role in the care trajectory management, at home they are the main actors in managing and shaping their own trajectory of care for health or disease. As such, the work that people perform at home while managing health or illness is trajectory work that is associated to a specific trajectory management. The trajectory management involves all the entire process of managing a trajectory of care that can include different care trajectory phases that occur while conducting a specific care trajectory scheme. The trajectory scheme refers to the specific care plan designed to achieve an individual or shared care goal (Strauss, 1993; Graham, Cheverst & Rouncefield, 2005). In our different projects, we have observed how people engage in several self-care activities that are part of the individual care trajectory work either for health or disease. Most of the current care management technologies mainly focus on supporting the trajectory scheme by implementing for example reminders and self-tracking applications for a specific disease management or behavior change (Tentori et al., 2012). However, we have observed that managing health or disease goes beyond tracking health parameters. People might have different needs and health and illness are not mutually exclusive, a person can be healthy and suddenly experience an illness or disability or a person can be healthy while having an unhealthy lifestyle. Thus, it is important to understand the work of living with health or disease as part of people’s everyday life.

Strauss provides a number of different types of work that can facilitate the understanding of trajectory work in both clinical and non-clinical settings (Strauss et al., 1997, p. 209). For instance, while clinical safety work is the central focus of attention in the clinical setting regarding the safety of patients, healthcare professionals and environment in general (Strauss et al., 1997, p. 69), this work is also important when care is moved from the hospital to the home. Safety work is highly related to the machinery work, the character of the disease if any, and the treatment plan or trajectory scheme. The different types of work from Strauss and the related work (machine work, safety work, information work, interpretation work, comfort work, sentimental work, articulation work, body work, error work, dirty work, negotiative work) in self-care monitoring have been described in Section 4.3. While designing home-based healthcare technology, the understanding of these abstract concepts of work can provide a greater understanding of the different self-care activities at home as well as point out to possible problematic trajectories of care. The dynamic of the different types of work vary according to the trajectory of care, trajectory phases and trajectory scheme. These types of work used as analytical tools to uncover the self-care work at home might provide a possible list of issues that should be accounted for when designing self-care technology.

Accounting for the different types of self-care work can render visible what it seems invisible or implicit while managing health or disease at home. For instance, a lot of this implicit work took place in the case of the pregnant women performing self-monitoring at home. They not only engage in sentimental work but also their partners while performing self-monitoring at home. On the one hand, if the measurements were not able to be sent during the morning pregnant women and their partners increase their feeling of worrisome and planned their day around the measurement. Husbands not only worry about the child’s wellbeing but also about their partner’s health status. However, it is difficult for them to
5.3 Summary and Discussion

do something about as, in contrast to pregnant women, they have not direct connection to the child’s health status. These types of sentimental work has not been considered in technology system design especially if the technology is driven by the healthcare professional’s perspective rather than focusing on people’s perspectives. It is important to recognized that the different types of work are intertwined that one might require or affect another one in a positive or negative way. Thus, making the implicit work visible can help designers to identify unintended situations that might disempower individuals rather than empower them.

Furthermore, in our preventive self-monitoring case in order to perform machine work participants needed to do other types of work like negotiative work or information work according to the specific situation. They needed to negotiate to themselves for example whether or not to bring the self-monitoring device to a social event. And they need to know not only the measuring rules but also the necessary information to interpret and understand the meaning from the BP values. In addition, an error while performing machine work and the self-measurement can have consequences in other types of work like safety work or sentimental work. Carefully accountability for all these different types of work in the situation at hand can help designers to get a bigger understanding and avoid unintended situations as they can also be technologically induced. Thus, it is important to assess and assist these different types of work in order to manage and shape trajectories of care.

Moreover, the non-functional aspects and high level concerns can help designers to get further understandings of people’s trajectories of care and uncover the key challenges of developing technological support for each specific case. For instance, the understanding provided by these concepts can help designers to identify when the trajectory of illness might be inappropriate to consider for the design of self-care technologies. In additions, all these concepts (non-functional aspects, concerns and types of work) can be used as tool for thinking or analytical tools to help designers to address the tension regarding for example data collection process or asynchronous power relations while using self-monitoring technology. For some of our participants, a manual collection support their interpretation of health data that can be restricted by automatic methods to increase reliability of data. However, some participants have preferences about automatic data collection. Analyzing the self-care work at home, can help designers to identity the pros and cons of these processes focusing on each individual case but having a holistic view of the different factors and concerns that can affect people’s trajectory of care.

In brief, this chapter present the summary of the different contributions of this dissertation and positioning them in the related work. In addition, we have discussed the importance of providing a holistic perspective to cover health and disease self-care practices. Next, we have explored the theory of practice and the different types of work as tool for thinking that can provide a further understanding about self-care work at home. All the presented tools can better support designers to account for the self-care management work at home.
Conclusion and Future Work

This chapter provides a general summary regarding the work presented in the first part of this dissertation. Next, the main contributions are listed and the main conclusions are presented. After the main conclusions, future work on understanding and designing pervasive healthcare technology to support self-care management work is described.

6.1 General Summary

To start with, the first chapter (see Chapter 1) of this dissertation introduces demographic challenges as well as the role of people’s active involvement in self-care management and related consequences. Next, we introduce some initial definitions of caring and state the relevance of understanding self-care practices to inform system design. Then, we introduce different perspectives of self-care technology and its important role in self-care management. Research questions as well as a short description of the research context and setting are provided. Last, the outline of this dissertation as well as the main list of papers that conform this dissertation are provided at the end of this chapter.

In Chapter 2, we present the related work associated to this dissertation. We start by introducing some definitions regarding self-care to continue presenting the self-care management work at home while describing self-care management work practices and different types of self-care work. By doing this, we present how studies of work are usable to inform system design. Next, we present the role of the home-based healthcare technology as well as some challenges and opportunities of technology to support people’s self-care activities in everyday life.

In Chapter 3, we describe our methodology to explore and investigate the self-care management work in non-clinical settings. Taking a design research approach in healthcare, this dissertation has moved back and forth between design explorations and design studies to support the intrinsic dialog between understanding and designing for self-care. As the nature of this dissertation is exploratory, our process has been carried out in three different phases. In Phase 1, we engaged in two different cases of medication management and pre-
ventive self-monitoring at home to investigate challenges and opportunities for pervasive health care technology design. In Phase 2, we engage on a post-project reflective process in which we combine different cases of self-monitoring care practices (of pregnant women with pre-eclampsia, older adults with different heart conditions, and healthy older adults) as well as different cases of self-care practices (medication management, tele-monitoring, and home-based rehabilitation) based on the results from Phase 1. Based on a reflecting learning approach, we comparative analyze the different cases looking for similarities and differences. In Phase 3, we use the concept of trajectory as a sensitizing concept as well as a tool for thinking using the different types of work defined by Strauss to further analyze the empirical data from our preventive self-monitoring case. All the methods per each phase are reported in this chapter.

Chapter 4 reports the different results from the aforementioned phases while exploring the self-care management work in non-clinical settings. First, we introduce the challenges in everyday medication management as well as the results from our compliance technology review. Medication specific requirements in practice based on specific particularities as well as the evolution of the MediFrame concept are explained here. Second, we describe the challenges of preventive blood pressure monitoring as well as the evolution of the SELMA concept. After the results from phase 1, we move on to describe the results from the cross-case analysis from phase 2. We present seven themes (people, knowledge, places, resources, routines, control and motivation) that together conform a conceptual framework to understand non-functional aspects of home-based healthcare technology. Then, we present four high level concerns (why, where, when, control in motivation) that came out while revisiting three self-care projects. These concerns are exemplified using the three cases while presenting how different design rationales take place in each case and how these concerns can help designers to be aware and balance those design rationales while designing for home-based healthcare. Last, we describe the different types of work (machine work, body work, safety work, sentimental work, information work, interpretation work, comfort work, negotiate work, articulation work, error work and dirty work) that we found in the self-monitoring project that can facilitate the further understanding of self-care work in non-clinical settings.

Chapter 5 presents a summary of contributions and lessons learned based on our different cases. From the exploratory cases, we present functional and non-functional meta-requirements for pervasive healthcare medication management systems (PHMMS) as well as a set of design principles for future design of PHMMS based on several specific particularities (according to need medication, the shared responsibility, the adjustment of the medication intake, the medication informational order, the heterogeneous care network, and the substitute medication). We also present design opportunities to support preventive blood pressure monitoring and additional contributions such as the results form the two reviews (compliance technology and design guidelines for tablet-touch based interfaces) were also presented. Several lessons learned from our design processes were also highlighted in this chapter. These lessons cover topics from our experience on the use of tablet technology with older adults as well as the challenges on the interface design for complex medication management. We discuss the calendar and the take medicine interfaces and how they support planning and reminding the medication intake at home as well as providing an overview and knowledge about medication at home. Additional lessons learned from our different visualizations and feedback from older adults were presented regarding blood pressure self-monitoring. From the multiple cases, we provide the conceptual framework based no non-functional aspects of
home-based healthcare technology as well as some design recommendations to support the different modes of self-monitoring use that we found (individual and care network, demo and wellness and illness use). The aforementioned high level concerns were also presented here together with some preliminary implications from design for designing for healthcare in everyday life. Last, the description of the different types of work and its relation to self-care and how they might relate to each other were presented as well as the use of the theory of practice to understand self-care practices (both dispersed and integrated practices).

6.2 Conclusions

The main problem that has been addressed in this dissertation is how to design pervasive healthcare technology that support the self-care management work at home for both health and disease management. We have presented a set of challenges from our different cases that shows the importance of looking beyond single strategies (reminders and tracking) to provide a holistic understanding of what it means to perform health or disease management activities as part of people’s everyday life. Our findings have provided a set of tools ranging from design opportunities, principles and recommendations to high-level considerations to support designers in their reflection processes. We have observed some similarities and differences across our cases. For example, there are similarities in the way that all non-functional aspects are present in the different cases of self-monitoring. However, the differences stems from the particularities of people’s experiences for each case. These different concerns and aspects are to some degree interrelated and serve as a tool for reflection to open us discussion and uncover issues regarding health and disease management. The methodological significance stems from the interpretive nature of our cases that have provided in-depth insights on health and disease self-care practices claiming for analytical generalization. However, this empirical generalization should not be confused with statistical generalization since it is not relevant for our studies and would not provide more in-depth insights of the situation at hand as positivist studies are decontextualized from the self-care practices.

We have observed that there are different types of work and the dynamics of different care trajectories. We have seen how people move along the continuum from being independent to being totally dependent and how different self-care actors can get involved in individual self-care practices. Even though the medication management and preventative self-monitoring share some challenges such as the understanding the self-care activity or complexities integrating those activities into everyday life, both groups have different motivations and constraints that can affect the trajectory of care at home.

In addition, to further understand the different trajectories of care and the self-care management work at home, our conceptual framework based on non-functional aspects and the high level CSCW/HCI concerns are not prescriptive but rather open to help designers to reflect on the situation at hand by playing with these high level concerns and non-functional aspects to support their decision making processes. By doing this, designers can use them to interpret their own self-care unique situation and figure out how they can be understood and applied for each individual case. Each theme and concern deserved special attention, however the idea was to provide a holistic view of health and disease self-care management activities to supper system design. In addition, our practical tools (design opportunities, design principles, design recommendations) provide guidance in the design process by help-
ing designers to frame the design space for a specific situation. Some of the tools have been already applied in some of our design explorations (MediFrame, SELMA) as an example of how to work with these considerations providing new visions for the future but that can take another different form according to the new situation. However, more user studies are needed in order to see how people might see the benefits of using a supportive system in real settings.

Furthermore, we have seen that through the lenses of practice, self-care practices can be understood as a combination of both dispersed and integrated practices and they both should be supported by system design. By doing this, a broad overview of different practices can be uncovered around self-care practices. In addition, the different concepts of work can also provide a rich description that can support designers to expand their design thinking processes and uncover unintended situations that can then help to inform system design. All the presented tools can better support designers to account for the self-care management work at home. Even though our findings can be transferrable to other age groups due to the analytical generalization, they are far from complete and further research should be done to uncover more particularities on disease and health management in order to support the serious self-care work at home.

6.3 Future Work

As part of the future work, one basic idea is to continue investigating particularities in people’s health and disease management as we have seen above, getting more understanding from the citizen’s perspective. By exploring more cases of self-care, we can perform more cross-case analysis to see similarities and differences that can inform future design of pervasive healthcare technology. In addition, our lessons learned, insights and guiding principles can help us to move to other different ways to implement a different support system to help people to manage and shape their own trajectories of care.

From a more analytical perspective, continue working with the concept of trajectory getting more understanding of the trajectory work that take place at home can inform system design. As well as it can be interested to see how the concept of trajectory can be powerful enough to be applied not only for analysis but also for design of self-care technologies. The concept of trajectory and the different types of work can provide a broader understanding of people’s self-care work at home and for example can be applied to the empirical data from the medication management case to get a more in-depth description of different types of work.

Apart from exploring the concept of trajectory for analysis and design, we argue that the theory of practice can also help designers as a tool for thinking while designing for complex self-care practices. Understanding and designing to support dispersed and integrated practices, can help designers to get the bigger picture rather than focusing on simple strategies (reminders and tracking) that might fail to capture the holistic sense of self-care activities.

Another example of future work is on the use of the aforementioned concerns and aspect on understanding and designing for a specific self-care situation. It could be possible to apply the non-functional aspects, that came from the multiple cases of self-monitoring, to the understanding of a different self-care practice as medication management. In addition, further research is needed in how to balance the different perspectives on self-care that can
lead to for example negative, little, moderate, or high health outcomes as presented in Figure 6.1. For instance, how should we bridge the gap between boundaries of care while taking into considerations multiple perspectives in home-based healthcare technology?

![Figure 6.1 Possible Health Outcomes and Degree of Accomplishment.](image)

Furthermore, self-care practices and the use of technologies is becoming more and more embodied into people’s everyday life as we have seen in this dissertation. As such, it will
be worth to look at other theories or concepts such as embodiment (Dourish, 2004) and how embodiment can be applied for understanding and designing self-care technology. This can be challenging as embodiment in HCI bring different and critical perspectives for the design of technology from “down-to-earth interpretations to more philosophical ones” as presented in a recent TOCHI issue (P. Marshall, Antle, Hoven & Rogers, 2013).

Moreover, I have listed two ongoing ideas for publications that I am working on (see Section 1.5). In that list, the papers Fourth and Fifth are the ones I am referring to and that are not part of this dissertation because they are not mature enough. Paper Fifth refers to a paper idea in which the compliance technology review in combination with our user studies can be used to describe the ecology of artifacts for medication management. And paper Fourth concerns to a CHI review of 30 years of self-care technologies that came out from my six weeks visit to TUVienna. We reviewed about 800 titles and abstracts before we selected the papers that will be included in the review that I will continue after I submit this dissertation. The review focus on challenges, opportunities, methodologies, trends, and design implications of 30 years of publications in CHI and relevant associated conferences (e.g. CSCW, UbiComp, ECSCW, PervasiveHealth). Another idea was to focus on looking at how and what theories are being applied for understanding and designing technology for self-care.

As technology for self-care is becoming more and more pervasive to our everyday life, it is important to look back in order to move forward as expressed by Kierkegaard:

…”It is quite true what philosophy says; that life must be understood backwards. But then one forgets the other principle: that it must be lived forwards. Which principle, the more one thinks it through, ends exactly with the thought that temporal life can never properly be understood precisely because I can at no instant find complete rest in which to adopt a position: backwards. (Kierkegaard, S., 1843)

As Kierkegaard expressed, we should be mindful with the task at hand in this case self-care practices. Avoiding breakdowns and distractions while performing self-care activities can facilitate to get them done. However, people should get time to perform them but without being worried or obsess with the results. It is important to be able to see the big picture and technology should support them to get a holistic view of what is going on regarding their current health situation. Not only showing bio-values but showing the complete summary or picture with relevant contextual information at hand. Different trajectories of care will probably have different phases, depending on the phase the activities should be accounted and facilitated towards a better health outcome. Perhaps the review will be the first step to reach a broader understanding while combining the existing literature that can provide us with trends and paths for future technology design for self-care.
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Personalized Medication Management: Towards a Design of Individualized Support for Elderly Citizens at Home

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Published in the Proceedings of the 2th ACM SIGHIT International Health Informatics Symposium (IHI 2012), January 28-30, Miami, USA, 813–817. ACM Press.
Personalized Medication Management: Towards a Design of Individualized Support for Elderly Citizens at Home

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ABSTRACT
Several technologies have been developed to support people’s medication management, including pillboxes, specialized software applications, reminders and paper-based medication lists. Several of these technologies were discovered in older adults’ homes during user studies carried out with the main purpose to help them to manage their medications and recall challenges. We confirm that a considerable number of older adults integrate their medication treatments into their daily life routines, and that the lack of knowledge, caregiver’s support, medicine outside the home, forgetting medication intake, complexity of medication regimen were equally important challenges. One of the major findings was the issue related to substitutions, as older adults get confused due to the volatile information that they receive regarding their medications. We define basic requirements in order to address these issues towards the design of a personalized medication management system. We further describe our initial stage in a participatory design process as part of the ongoing Lev Vel Consortium.

Categories and Subject Descriptors
H.5.2 [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

General Terms
Design, Human Factors, Management

Keywords
Healthcare, medication management, senior adults

1. INTRODUCTION
The older population will increase rapidly over the next generation in European countries. By 2020, 25% of the European population will be over 651 implying an increase in age-related illnesses, chronic diseases and disability conditions as well as an increase in the number of care services carried out at their homes. Similarly, a study published by the Healthy Aging Forum at the end of 2009 states that 20% of the population in the U.S. will be over 65 by 2030 due to various factors, such as, chronic diseases, functional limitations, and thus, increasing the healthcare costs exceptionally.

Furthermore, adherence2 to medication has been identified as a worldwide problem among people with chronic conditions [7]. The World Health Organization (WHO) has reported intentional3 and unintentional4 mistakes related to adherence where intentional non-adherence appears as a significant problem during long-term therapies (e.g. diabetes, hypertension, asthma). Moreover, WHO has identified five different factors that affect adherence as follows: 1) Socio-economic condition (e.g. socioeconomic status), 2) Health-care system (e.g. lack of knowledge, poorly developed health services, short consultations, etc.), 3) Disease therapy (e.g. complexity of treatments, long distance from the treatment settings), 4) Characteristics of the disease (e.g. duration of the disease, inadequate understanding) and 5) Patient-related (e.g. poor health education, forgetfulness, lack of information, etc.). These factors have a considerable effect on adherence across different health care actors. Thus, self-management strategies of treatments are required to wholly support people with their varied care needs (e.g. children, older adults, people with disabilities).

The work presented in this paper is part of the Lev Vel Consortium5. The overall aim of this Danish initiative is to enable and increase participation in citizen’s own care management by establishing a strategic partnership between companies, research institutions, municipalities and hospitals. The initiative is aligned to the National Strategy for Digitalisation of the Danish Healthcare Service6. The main

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IHII’12, January 28–30, 2012, Miami, Florida, USA.  
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2Adherence is defined by WHO as “the extent to which a person’s behavior - taking medications, following a diet and/or executing life-style changes, corresponds with the agreed recommendations of a health care provider”
3Intentional reasons for non-compliance include misunderstanding of side-effects, fear of addiction, etc.
4Unintentional reasons for non-compliance include forgetfulness, misunderstanding of instructions, etc.
5Lev Vel Consortium http://www.lvvl.dk/
6The National Strategy for Digitalisation of the Healthcare
purpose here is to describe our initial stage towards the design of a personalized medication management system (PMMS) to support senior citizens at home. A list of requirements has been defined based on a literature review, a compliance technology study as well as qualitative and quantitative user studies. Our initial prototyping phase has considered some of these requirements during an iterative design process for the design of a mobile application, identifying challenges that are discussed in the next sections. The paper is structured as follows: section 2 presents the methodology; section 3 defines a basic list of requirements for a PMMS; section 4 presents our initial approach and prototyping stage towards the implementation of a mobile PMMS application; section 5 concludes, and explores how the concept can be extended and requirements can be applied in the development of future healthcare technologies.

2. METHODOLOGY
To identify user requirements for a PMMS, our basic approach is to take into account the current solutions available in order to analyze differences, advantages and disadvantages of these technologies. Moreover, the results of the initial user studies within the Lev Vel Consortium have shown to be a valuable source of information. Additionally, design principles from previous work are considered and reported in the following subsections.

2.1 Adherence Technology Review
Pharmakon published a report on the growing market of adherence technologies in 2009 [9] listing technologies available before 2008. Additionally, they implemented a pilot project to identify and categorize existing adherence technologies. We have reviewed Pharmakon’s original list and added new technologies from December 2010 to January 2011. Figure 1 illustrates a total of 120 compliance technologies classified using Pharmakon’s initial categories, allowing us to make a distinction between technologies in terms of availability as follows: 1) Electronic reminders, 2) Tablet-holders with electronic reminder, 3) Dosing aid with electronic reminder, 4) Automatic dispensers, 5) Non-electronic reminders, 6) Other types of technologies related to adherence, and 7) We added other medical applications. The updated list includes various technologies that people use to support their medication intake such as software applications (e.g. web applications, reminders, mobile applications), pill boxes, pill bottles, mechanical devices, healthcare systems, etc. The information collected from these technologies includes: product name, product type, number or daily reminders, type of reminders (e.g. sms, emails, lights), mobility (e.g. low, medium, high), compliance feedback, compliance monitoring, technology level (e.g. low, medium, high), image, webpage, price, form of distribution, availability and additional information.

A further review was done for the next group of technologies as follows: 1) Electronic reminders (e.g. MedsLog, Medey, Dosecat, MediRemind, MotionPHR, Birth Control, and MediReminder), 2) Automatic dispensers (e.g. Maya), 3) Other types of technologies related to adherence (e.g. Service 2008 - 2012 - action plan 2 - establishes tools that provide services and improve opportunities for citizen’s involvement in their own healthcare treatments”.

Similar technologies were not considered in order to avoid repetition and overlap information.

Figure 1: Compliance Technology Review

2.2 The Initial User Studies
Considering the target group defined by the Lev Vel Consortium, an initial user needs assessment was conducted in February 2011. A total of 325 senior adults were involved in two different studies described in the next sections.

2.2.1 Quantitative User Studies
316 telephone interviews were collected from two towns in Denmark. The participants fulfilled the following requirements and constraints to participate in the study: 1) Citizens from Hillerød or Gentofte, 2) Age groups between 60 - 69 (younger group), 70 - 79 and over 80 years old (older group), 3) Citizens that perform their medication management themselves, and 4) Citizens who use prescribed medications for at least three months and take either more than one tablet (quantity) or more than once a day (frequency).

2.2.2 Qualitative User Studies
Nine senior adults over 60 years old were interviewed at home. They all fulfilled the criteria regarding medication intake as the previous study. Additional characteristics as follows: 1) Age between 60 and 93 years old (3 men and 6 women), 2) Daily tablet intake between 1 and 32 tablets, and 3) Level of assistance regarding their medication intake, that is, 4 people sort their own medicines, 5 receive help from a nurse at home and 2 of these get an additional help from their wives. One specific case was in the process of getting back the responsibility of medication self-management.

Raisin Personal System), and 4) Other general applications (e.g. CardioTrainer, Instant Heart Rate). This review gave us a better understanding of the current situation as a baseline related to these technologies.
2.3 Design Principles

Healthcare technologies should allow citizens to control their own healthcare activities rather than being controlled by the technology [2, 10]. Several design principles have been reported in previous work considering the citizens’ perspective [3] for developing healthcare technologies. Current practices for managing medications include: 1) Situating medications within routines, 2) Other reminders (e.g. family, one’s own body), 3) Exerting control over the regimen, and 4) Autonomous medication management [6]. For instance, a considerable group of elderly people build their own medication management systems relying on spatial features, temporal rhythms and routines [8, 13]. In addition, several scenarios were analyzed using audio interface features to support vision impaired elderly in their medication management [5]. Similarly, multiple channels for reminders have been explored to be important for users into a home-centered medication reminder system [6], in which participants consider the mobile phone as the most useful device for reminding functionality. Particularly, the notification functionality is considered as intrusive, impractical and costly for the younger group. Privacy and availability issues are the main concern regarding the TV as a medium for medication reminder [6].

Healthcare systems should consider an iterative participatory design (PD) process. Designing for continuity, understandability and learning [3] can increase participation in their own healthcare management. Recently, a web-based Personal Health Application (PHA) has been implemented considering these dimensions in a PD approach [13] into a laboratory setting environment. Besides their limitations (small sample sizes - four users in most of the user studies and differences in participating roles), they provide guidelines for the future PHA technologies. These guidelines include: 1) Prioritize performance over preference, 2) Work with all stakeholders and try to find a balance between metaphor and textual information (e.g. users got confused using the kitchen counter metaphor), and 3) Require minimal interaction steps to perform basic medication management tasks. Similarly, some design implications should be considered such as needs for customizable reminders, information search, value of portability for developing a medication reminder system [6]. Moreover, the mismatch between professional and patient understanding of medication management (e.g. reconciliation task) should be taken into account to avoid conflicts between stakeholders [13] during design process.

These design principles would be considered in our participatory design approach. We expect to deploy several tools for senior adults to be tested in a real setting environment (at home) by providing customizable information.

3. REQUIREMENTS

Moving medical treatments to senior adults’ home implies several challenges [6] for healthcare technologies. There are several requirements (e.g. home, users, healthcare sector, etc.) that should be considered towards the implementation of a PMMS. We have defined basic functional, Table 2, and non-functional, Table 3, requirements based in our adherence technology review (section 2.1), literature review.

Refers to specific functionalities of the system.

Refers to specific qualities/constraints of the system.

3.1 General Findings

The general findings from our initial user studies (section 2.2) are explained as follows:

- There is a big overlap between the user studies (qualitative and quantitative) results (see table 1).
- 34% of the participants are unintentionally noncompliant and 23% are intentionally noncompliant.
- Non compliance does not increase with the number of pills-quantity, but with the number of times a day-frequency the person is taken medication.
- The intentionally non compliant has a greater need for information than the rest of the participants.
- The participants own and use a lot different technologies including mobile phones (78%), computers and Internet (58%).

The most important findings are summarized and combined on Table 1. Moreover, a comprehensive description of findings is out of scope of this paper and it would be presented in detail as a report within the Lev Vel Consortium [1].

<table>
<thead>
<tr>
<th>Table 1: Combined results of the user studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Complexity of Medication Regimens</td>
</tr>
<tr>
<td>- 38% take more than 3 different medicines</td>
</tr>
<tr>
<td>- 20% take medicine more than 3 times a day</td>
</tr>
<tr>
<td>B. Forgetting Medication Dose</td>
</tr>
<tr>
<td>- 34% have forgotten to take their medication</td>
</tr>
<tr>
<td>C. Habits and Routines</td>
</tr>
<tr>
<td>- 79% do something special to remember their medicine</td>
</tr>
<tr>
<td>- 26% take their medicine in connection with meals</td>
</tr>
<tr>
<td>- 22% have a visible medicine stored system</td>
</tr>
<tr>
<td>- 36% have bought pill dispensing box.</td>
</tr>
<tr>
<td>D. Lack of knowledge about medicine</td>
</tr>
<tr>
<td>- 75% have a high need for information</td>
</tr>
<tr>
<td>- 58% are proactively seeking information regarding medication (41% Internet, 36% leaflet, 10% pharmacy)</td>
</tr>
<tr>
<td>E. Remembering</td>
</tr>
<tr>
<td>- 12% have troubles remembering whether or not they have taken their medication</td>
</tr>
<tr>
<td>- For some citizens it is hard to remember to order new medicine before they run out</td>
</tr>
<tr>
<td>F. Medicine outside the home (mostly the younger group)</td>
</tr>
<tr>
<td>- 24% take medicine outside home several times a month</td>
</tr>
<tr>
<td>- 30% have privacy concerns taking medicine in public</td>
</tr>
<tr>
<td>G. Support for caregivers</td>
</tr>
<tr>
<td>- For people (e.g. nurses, spouses, etc.) who play a very active role in medication management</td>
</tr>
</tbody>
</table>

4. CONCEPT AND ITERATIVE DESIGN

MediFrame is one of the concepts defined for the Lev Vel stakeholders during the participatory design process. It is a digital frame that shows relevant information to citizens about their medication-taking behavior. We use basic scenarios to explain our concept, getting a better understanding of it’s utility and possible issues of a medication management system for senior adults. The following scenarios are described using hypothetical data and users (Anita):
### Table 2: Functional Requirements

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>F01-Integration</td>
<td>Capability to provide customizable information from heterogeneous source of current information (e.g. citizens information, right prescriptions considering substitutions).</td>
</tr>
<tr>
<td>F02-Reminder</td>
<td>Capability to provide portable, customizable and/or context-aware reminders - habits and routines play an important role.</td>
</tr>
<tr>
<td>F03-Tracking</td>
<td>Capability to register and follow up medication intake information over time (e.g. daily use, before run out, non-prescribed medication).</td>
</tr>
<tr>
<td>F04-Mobility</td>
<td>Capability to support medication intake outside the home or in different places inside the home (due to routines and privacy concerns).</td>
</tr>
<tr>
<td>F05-Search</td>
<td>Capability to support multimodal and multimedia medication information search (e.g. daily dose).</td>
</tr>
<tr>
<td>F06-Navigation</td>
<td>Capability to provide free navigation with multimedia content (e.g. images, text, video).</td>
</tr>
<tr>
<td>F07-Sharing</td>
<td>Capability to support customizable remote access to the information that users want to share with their caregivers (e.g. spouses, relatives, nurses).</td>
</tr>
<tr>
<td>F08-Flexibility</td>
<td>Capability to support a systematic storing of medicine inside and/or outside dispensers (e.g. medicine can be stored in many different places).</td>
</tr>
<tr>
<td>F09-Control</td>
<td>Capability to allow user to control functionalities considering different levels of users.</td>
</tr>
</tbody>
</table>

### Table 3: Non-Functional Requirements

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>NF1-Security</td>
<td>Capability to support secure authentication within heterogeneous sources of information (e.g. log in, encrypted wireless communication).</td>
</tr>
<tr>
<td>NF2-Safety</td>
<td>Capability to provide, restore and log status information (e.g. right medication, right dose) in case of failure (e.g. power off, system crash).</td>
</tr>
<tr>
<td>NF3-Performance</td>
<td>Capability to support short response time and high availability.</td>
</tr>
<tr>
<td>NF4-Privacy</td>
<td>Capability to support medication intake considering privacy concerns to preserve personal dignity (e.g. reminders, sharing information).</td>
</tr>
<tr>
<td>NF5-User Interface</td>
<td>1) Easy to use, 2) Right balance between metaphor and textual information 3) Multimodal interaction 4) Users prefer images, 5) Typing is not a good input for older adults 6) recognized value of in-home accessories 7) Behavior reminders</td>
</tr>
</tbody>
</table>

1. Anita arrives home around 10 AM and she receives a reminder on her MediFrame indicating that it is due time to take one dose of Acetoxyl. In addition, Anita does not remember whether or not she took her morning medication. She was able to see her daily medication intake summary.

2. Anita receives a reminder from her MediFrame (only because she has not taken it yet). It is noon and it is time to take 1/2 dose of Halcion. She is curious and wants to know more information about her medicine’s side effects. She was able to see the relevant information about her medicine.

3. Anita is in the kitchen completing her morning routine taking her morning medication. She is in a hurry and needs to register her intake in the minimal interaction steps. The MediFrame’s place reminder is activated according to the previous configuration. She was able to register her medication intake while completing her morning routine without login in the system using the place reminder.

### 4.1 Low Fidelity Mockups

Our target group have been using different technologies (e.g. mobile phones, computers, internet) during their daily life. Thus, we decided to implement our MediFrame concept as a mobile application for a tablet mobile device. We have considered most of the requirements defined in Section 3 into our paper-based prototypes. Several iterations have been done in order to cover medication management issues. Place and time were considered as important features for our visual interface. Metaphors to cover this features were explored such as a medication cabinet (Figure 2a) and the clock time (Figure 2b) interface considering user routines. For instance, the clock metaphor has been used in several context such as location and activity awareness [11, 12] and medication reminder [13]. The medication cabinet consist of two dimensions, time of medication routines representing 24 hours and medication categories displaying medicines in different areas of the clock. A different approach (Figure 2c) shows a balance between metaphor, place and time where the daily summary relies on touch interaction and a color code was used to distinguish medication time (morning-blue, noon-yellow, evening-magenta, night-grey) from the general user interface.

### 4.2 Initial Evaluation

Several workshops were conducted to brainstorm on our ideas in order to evaluate and qualify multiple concepts and prototypes. We utilized low-fidelity paper prototypes and a multidisciplinary group of experts composed by Computer Scientists, Graphic Designers, Interaction Designers and Ethnographers during our initial iterations. Additional workshops were conducted to show our concept and initial prototypes to a) Two health care workers, b) Two nurses working in the municipality home-care department, c) The head of the home-care department from Hvidovre municipality, d) A doctor specialized in healthy ageing from Bispebjerg Hospital, and e) Four senior adults. All sessions were recorded and a tablet mobile device was used to explain our MediFrame concept by showing several mockups.

The main concerns were related to simplicity, support for caregivers, integration capabilities and forecasting capabilities for medicine intake. Overall, the group thought of our mockups as a helpful solution to manage medication, not only for the elderly themselves, but also for healthcare professionals. This initial feedback was generally positive and several issues were reported regarding medication information and usability. Moreover, we argue that more information is needed during our participatory design process, and more detailed workshops with senior adults are planned to take place in our next iteration. The initial feedback is be considered further in a separate workshop between designers and stakeholders to incorporate the most important concerns in our concept.
5. LOOKING FORWARD

We described basic requirements towards the development of a PMMS for older adults. We introduced our MediFrame concept in order to apply these requirements into real life scenarios. Furthermore, an expert review is necessary to avoid possible conflicts between stakeholders and to identify usability issues. We argued that there are no solutions to cover all types of adherence problems, however, a feasible combination of these technologies, considering the basic requirements, can in fact support elderly to manage their medications, and that a user acceptance study should be considered in the design process. This work can therefore be applied in several directions. For one, there are several ongoing concept implementations in our Lev Vel Consortium, which are considering those as basic requirements during the design process. However, regardless of their health conditions, senior adults play an important role in their own healthcare management and they should have an active participation during the design process. For instance, our next steps are considering several workshops, mockups testing and participant observations moving to high-fidelity prototypes that would involve citizens. Moreover, we are looking into the integration with the Shared Medicine Card\textsuperscript{15} to get updated information about citizens’ prescriptions that would help us to address some of the issues that are described in this paper.

6. ACKNOWLEDGMENTS

We would like to thank all professionals and participants involved in the ongoing Lev Vel Consortium for their cooperation. Lev Vel is funded by The Danish Council for Technology and Innovation and The Capital Region of Denmark.

7. REFERENCES


\textsuperscript{15}Danish service which provides current information about people’s medication.
Designing a Tablet Touch-Screen Interface for Older Adults

by Nervo Verdezoto & Erik Grönvall

Published in the Proceedings of the Workshop on How to Design Touch Interfaces for and with Older Adults: Identification of Challenges and Opportunities at NordiCHI 2012, October 14-17, Copenhagen, Denmark.
Designing a Tablet Touch-Screen Interface for Older Adults

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ABSTRACT
Sustaining daily, unsupervised healthcare activities in a private home setting can challenge, among others, older adults. In this paper, we discuss experiences from designing the tablet based mobile application MediFrame with the aim to support older adults’ medication management at home. In relation to MediFrame’s touch interface design, we discuss existing guidelines that can be adopted for touch interfaces and we use MediFrame to illustrate an implementation of such guidelines.

Author Keywords
Touch Interfaces, Older Adults, Participatory Design, Tablet, Mobile

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Human Factors; Design; Management

INTRODUCTION
In two projects, we have investigated older adults and their needs regarding medication management [1] and preventative self-monitoring activities [2] at home. In the two projects, we have applied a Participatory Design (PD) approach. However, as shown in other research [3, 4], the use of PD in designing healthcare solutions for older adults in unsupervised settings such as the home can be challenging. Still, the two projects have managed to carry out a diversity of workshops and other PD related activities to inform the project work.

As a result, we herein describe challenges and opportunities to design touch interfaces for and with older adults, and present design considerations that can be used by designers of touch interfaces for older adults.

Research has shown that touch screen interactions are more suitable for novice older computer users rather than keyboard or mouse input devices [5]. Indeed, touch interfaces provide simple interaction for people with low or no computer literacy [6]. They can be easy to learn and adopt by older adults besides their physical or cognitive capabilities [7]. Furthermore, touching has been reported as an intuitive and natural way of interaction and well suited for tasks that need to be integrated into people’s everyday lives [7] provided that they do not require continuous touch-contact such as games [8]. However, using touch-based interaction on mobile phones can embed challenges for older adults such as a limited screen size [9], small buttons, and difficulties using the phone’s keypad [7]. Therefore, tablets with touch-technology can be an alternative that accommodates older adults’ demands in terms of screen size, device weight, reduced complexity and portability [10]. In addition, apart from allowing direct, natural and mobile interaction techniques that are preferred by older adults [7, 11] tablets can also fit into the limited space of older adults’ homes [7, 10, 12]. Furthermore, in diverse studies of older adults and their use of tablets such as an iPad or Samsung Galaxy Tab we have observed, similar to [4], that such technology have the opportunity to prevent stigmatization when supporting older adults’ healthcare activities within and outside the home as these tablets are not perceived as healthcare or ‘illness-related’ technology.

DESIGN CONSIDERATIONS
As part of the project work, we have reviewed existing design guidelines that are important to consider when designing for mobile devices, touch interfaces and older adults provided by: a) the web accessibility review for older adults provided by the W3C [13] and WCAG improved recommendations for older adults [14]; b) Shneiderman’s Eight Golden Rules of Interface Design [15] adjusted for mobile interface design [16] and for integrating individual and organizational perspectives [17]; c) the Seven Usability Guidelines for websites on mobile devices [18]; d) specific guidelines of touch-based interfaces for older adults provided by [12, 19, 20] and d) general design guidelines for older adults provided by Fisk et. al. [21]. We combined and summarized these guidelines so that they could be
adapted for touch interfaces using an affinity diagram in three main categories. These categories group a total of 31 guidelines as follows: 17 guidelines for Visual and interaction design, 4 guidelines regarding Information organization and 10 guidelines as Conceptual considerations. These categories will now be presented.

**Visual and Interaction Design**

This category includes several guidelines regarding the visual presentation of information as well as interaction recommendations. People interact with data represented through the interface. And, some guidelines also cover the visual-interaction relation and navigation that can be adapted to touch interfaces.

**Visual Design Considerations**

The main goal of this specific set of guidelines is to minimize the visual clutter [21] by showing essential information [18] to the users considering sequence changes, critical information and feedback [14]. In addition, designers should consider touch-device specific constraints such as screen size and user’s capabilities to provide accessibility to all screen elements (e.g. button, label, list, icons) when designing for older adults.

The visual design considerations include: 1) text related factors such as a) font size e.g. less than 12-point should be avoided; b) font type e.g. avoid italics or underlining text as they are difficult to read; c) uppercase text leads to slowed reading; d) contrast ratio and color selection to maximize contrast e.g. black text to white background or white text on black background; e) avoid short wavelength contrast (blue-violet-green) specially for signaling important information; f) avoid colored and watermarked backgrounds for text displays areas e.g. black text on blue background [13, 21]; 2) naming labels, icons, and links should be defined using familiar language to older adults [14]; 3) three-dimensional and virtual reality displays should be minimized [21]; 4) icons/symbols are preferred when older adults are familiar with their implicit meaning, they should be easy discriminable and might not be a good option for warning messages [21]; 5) use of repetitive visual warning messages instead of one that remains on the interface for longer time [21]; 6) an acceptable intended target size for touching is 16.5mm² [12, 19] and it should not be less than 8mm [20]. If a better reaction time performance is needed, an acceptable larger size of 19.05mm² can be used when designing for adjacent buttons, and 11.43 mm² when designing an isolated button [19]; 7) button spacing should be between 3.17mm to 12.7 mm for adjacent buttons. Older adults preferred a spacing of 6.35mm and large spacing implies an increment on the reaction time [19].

**Information Organization**

This category describes four considerations regarding the information organization that can be adapted for touch interfaces. These considerations include: 1) natural and/or consistent grouping of related information [21]; 2) menu structure that takes into account user’s capabilities, task demands, and medium of presentation (e.g. screen size) [21]; 3) design for “top-down” interaction - breadth versus depth menu structures – a shallow information hierarchy can work better for older adults [13, 21]; and 4) design for optimal data access [17].

**Conceptual Considerations**

General existing guidelines for interface design and mobile devices can be applied and adapted to touch-based interfaces to target older population. These considerations include: 1) keep the user in control; older adults want to control their own activities rather than being controlled by technology. Touch-based interfaces should be designed in such a way that older adults can control interaction except for emergency notifications that the user has set up in advance [14, 16]; 2) provide useful, real and informative feedback. Feedback can be visual, haptic or auditory. Older adults can take real feedback to guide on their next steps on the interface [15, 16, 21]; 3) good dialog design to yield closure among sequences of...
MEDIFRAME: FOLLOW UP ON THE GUIDELINES

We initially explored several metaphors such as the ‘medicine cabinet’ and the ‘clock’ to explore possibilities with arranging medicine and reminders. An initial evaluation to qualify our MediFrame concept was performed by a multidisciplinary group of experts including nurses (see Figure 2a), healthcare workers, a doctor and four older adults [1]. The project participants agreed that it is very challenging to make an interface that works for everyone. They stressed that simplicity is the key to success and that users might not want or need too much information on the screen. Based on feedback from our participants, we rapidly move to a new set of mockups considering the previous set of guidelines. Figure 2b presents our revised design of the ‘Take Medicine’ interface that was tested with three senior adults using a screen-based prototype for a tablet mobile device. Older adults use this particular interface of MediFrame to register their daily medicine intake. Moreover, we gave them a quick introduction about how the iPad works before they explored our prototype. It turns out to be a really important step to discover older adults’ attitudes and barriers towards technology. After this evaluation, we decided to implement a high fidelity prototype of MediFrame. A cross-platform application using the Model-View-Controller design pattern and the SenchaTouch framework [23] was developed and tried out.

Our initial user’s feedback states that older adults rely on images regarding their medicines. Thus, we have combined each medicine’s image with buttons to allow users a simple identification and registration of the medicine intake. Figure 1 shows part of the current version of the ‘Take Medicine’ interface considering the previous user’s concerns and some of the previous guidelines.

Figure 1: Iteration of "Take Medicine" Interface Design

actions that clearly convey the current system status [15, 16, 21]; 4) error prevention, simple handling, and reversal of actions [15, 16, 21]; 5) reduce short-term memory and cognitive loads minimizing the need for scanning and providing memory aids [15, 16, 21]; 6) design for speed and recovery allowing users to start, stop, and resume applications [16]; 7) consistency of the interface design across platforms and devices [16], for example, using a standardized format for warning, error messages and buttons (e.g. same location and/or same actions) [21]; 8) allow adaptability, flexibility of different user level and personalization based on user’s needs [15, 16, 21]; 9) design for limited and split attention - providing redundant information using auditory (e.g. sound, speech) and tactile (e.g. vibration) output can be beneficial for older adults when augmenting warning signals. A complete description of auditory and haptic guidelines for older adults are provided by [21]; and 10) provide system tools to support user goals [21].

MEDIFRAME: FOLLOW UP ON THE GUIDELINES

Furthermore, we have verified some of the guidelines during our preliminary evaluations. Firstly, we removed the main menu from the current of the ‘Take Medicine’ because our users got confused having more visible functionality than needed. This validated the guideline “do not repeat the navigation…” Secondly, we changed the ‘Take all doses’ (i.e. medicine) button to a ‘Done’ (i.e. task complete) button (see red circle in Figure 1) to add a confirmation step and yield closure to avoid the laziness effect of pressing the “Take all” button without taking all medicines as expressed by our medicine experts. Finally, we combined textual information with a visual representation indicating the number of medicines to take for each specific dose. This redundant information of how many medicines to take was preferred by users over the textual representation (i.e. a picture of three pills rather than just showing the number 3 to indicate the current dose – see Figure 1). Moreover, the ‘Take Medicine’ interface clearly distinguished all selected items and our users easily recognized buttons by their appearance (button perceived affordance).

DISCUSSION AND CONCLUSION

It is important to consider all stakeholders involved in older adults’ activities to get insights from different perspectives. For instance, our stakeholders have recognized the utility of MediFrame not only for older adults but also for healthcare professionals and family members involved in older adults’ healthcare activities. Indeed, our design process has moved between two continuums of designing with (e.g. medicine experts, older adults) and designing for older adults. Moreover, it is important to take advantage of tablets aesthetical properties when introducing touch-based technology in older adults’ home. These properties can
provide several opportunities and special focus should be given to the “non-usage” state of systems. To illustrate this, we have conceptually proposed that MediFrame can work as a picture frame showing family photos when it is not in use. In general, our users agreed that simplicity is a key factor. They recommended that designers should be aware about privacy and security issues regarding their critical information when designing for a dynamic context such as the home. In addition, our review can serve as starting point to derive specific guidelines or frameworks to help designers of touch interfaces that target older adults.

Furthermore, using low fidelity prototypes allowed us to get a rapid awareness regarding the knowledge, expectations and capabilities of our users. In addition to this, our introduction to the touch device provided us with a first positive contact during our evaluation. However, our screen-based prototype also embedded problems related to its current state and challenged our older adults when separating the prototype’s vision from its limitations. We expect to get more insights during the next evaluation of our high fidelity prototype regarding the applicability, validation and use of the herein discussed set of guidelines.

ACKNOWLEDGMENTS
We would like to thank our colleagues and all participants, especially the elderly citizens involved in our project and the Lev Vel Consortium for their cooperation. Lev Vel is funded by The Danish Council for Technology and Innovation and The Capital Region of Denmark.

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Accounting for Medication Particularities: Designing for Everyday Medication Management

by Lea Gulstav Dalgaard, Erik Grönvall & Nervo Verdezoto
Published in the Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth 2013), May 5-8, Venice, Italy, 137–144. IEEE Press.
Abstract— Several projects have shown that self-management of medication in private homes can be challenging. Many projects focused on specific illness-related approaches (e.g. diabetes) or practical issues such as how to handle medication while travelling. However, designing for everyday medication management involves more than just specific illness-related strategies and should take into account the broad set of activities conforming people’s everyday life. This study investigates how older adults manage their medication in everyday life. To inform the design of pervasive healthcare medication management systems (PHMMS), the study calls for attention to medication-specific particularities that account for: according to need medication, the heterogeneous care network, the substitute medication, the medication informational order, the shared responsibility and the adjustment of medication intake. These medication particularities can enhance the individual’s medication overview and support the understanding of medication intake in everyday life. The study also presents five design principles for future design of PHMMS.

Keywords - Medication management; Qualitative; Quantitative; Personalized; User-centered Design; Older Adults.

I. INTRODUCTION

Older adults who live independently in their private homes are often responsible for their own daily medication intake. Based on an iterative, user-centered project, and qualitative and quantitative studies this paper discusses how older adults manage their medication outside of clinical settings, such as private homes. Taking into account how medication-specific requirements can inform support systems for everyday medication intake and administration, this paper presents design principles to consider when designing such systems for older adults’ homes and everyday lives.

The target group for our project is older adults who are able to manage their medication at the moment but might need assistance in the future. To illustrate challenges in everyday medication management for older adults, we now present a scenario based on a collection of experiences derived from our user studies:

Ann is 73 years old; she lives alone since her husband died two years ago. She suffers from a range of illnesses including diabetes, osteoporosis, back pain and hypertension. As a result, she takes up to 19 medications a day, spread evenly throughout the day. Indeed, Ann finds it hard to remember to buy new medications as all packages contain different amounts of medication and so it happens that she runs out of medication. Another challenge for Ann is when the pharmacy substitutes her medication, due to a cheaper price. Ann likes the cheaper price, but the new medication’s name sometimes confuses her.

Ann takes great pride in going to the local elderly center to follow their activities, including bingo events and ‘eat together’. Her son Thomas lives in the same town and he, and her two grandchildren, visit her every second week. When home alone, Ann usually remembers to take her medication. However, when Thomas and the grandchildren visit her, she tends to forget her pills during their stay. When Thomas cooks for her, he usually cooks very differently from what Ann usually does and she knows that she has to pay attention to what she eats with some of her medication. Ann really doesn’t know what to do when she forgets a dosage of medication, sometimes she takes a double dose at the next scheduled time and sometimes she just skips it. She has planned to speak with her doctor about this, but when at the clinic she never remembers to ask. Furthermore, Ann’s doctor is not aware that Ann does not take her hypertension medication once in a while when she visits her neighbor for evening tea. Overall, Ann has problems taking the medication when her routines are broken, for example when she stays a bit longer than planned at the elderly center, or when she has visits or visits friends.

This scenario identifies the following key challenges in Ann’s daily medication management: forgetting to buy and take medication, the breakdown of routines, the lack of medication information at hand, handling substitution medication and her doctor’s lack of insight in her medication adherence. These challenges are discussed in this paper.

That people (of all age groups) forget their medication and the amount of medication that they have to take are common causes to non-adherence to a prescribed regimen [1]. It might sound trivial, but in our study we have encountered older adults taking up to 35 pills a day. To sustain a correct medication regimen is even more complex when prescription medication also includes for example creams, injections and eye drops. According to the World Health Organization (WHO) [2] common reasons why people do not comply with a prescribed medication regimen are for example forgetfulness, deliberately not following the prescription, not being able to handle the number of medications, fear of side effects and problems.
interpreting the instructions on how to take the medication. This non-adherence is connected with large costs for both the individual and society [3].

In the following, we present related work and our user studies. We then report on findings that provide insights for the design of future pervasive healthcare medication management systems (PHMMS), and discuss particularities of medication management that have not previously been discussed as a whole. The findings call for designing a PHMMS for non-clinical use that not only supports monitoring and reminders, but also provide individualized support facilitating for example the individual’s understanding of, and reason for, medication intake. A desired effect is to move away from compliance and adherence and move towards concordance [4] through a dialogue with the healthcare professionals. Finally, we extract five design principles for the design of PHMMS to support older adults’ everyday life and their medication needs. These design principles are directly related to the key challenges exemplified in the scenario above based on our user studies.

II. RELATED WORK

This section reports on the medication process and technologies as strategies for medication management. We also describe known design principles for medication management and previous work on patient-healthcare collaboration.

A. The Medication Process

Medication intake and administration is a complicated endeavor. In a clinical setting, a prescribed medication is measured, administered, evaluated and adjusted by healthcare professionals [5]. Through for example mobile technology, healthcare professionals can be supported in their medication administration routines [6]. Indeed, in order to improve care coordination, physicians have used cognitive artifacts to support local awareness of patients [7] and nursing notes to generate the patients’ medication overviews [5]. People in non-clinical settings are however expected to engage in self-care activities such as self-diagnosis, self-management, self-medication and self-monitoring [8]. A supported medication self-management can facilitate the move across boundaries (e.g. when an individual moves between the clinic (i.e. being a patient) and the home (being a parent or spouse)) to defeat identified physical, psychological, cognitive, economic, social and cultural barriers found in self-care [9]. Today people use diverse strategies to support their home-based medication regimens such as: reminders, tablet-holders, dosing aid, automatic dispensers, software applications, pill boxes (with or without technology), and paper-based medication lists [10].

B. Technologies and Strategies for Medication Management

A mix of sensor and self-reporting techniques have been investigated to support people with diabetes [11, 12]. Studies have shown that medication management routines are highly personal, and non-frequent activities such as travelling that challenge established routines [11, 13]. Palen and Aaløkke [14] argue that individual strategies and routines can support people to integrate medications into their everyday lives. However, these strategies work best in stable, daily routines. Medication management systems such as CollaboRhythm [15] and Colorado Care Tablet [16] have applied clock metaphors in their user interfaces to provide a known concept into the design. However, the clock metaphor may be challenged due to complex medication needs [10].

1) Reminders: Systems to support medication intake usually involve different forms of reminders. Designing medication reminders is complicated due to the heterogeneous nature of the receiver; people with different abilities and needs in medication management [17]. Reminders exist in both simple and more elaborated forms. Simple reminders include SMS texts/warnings, voice messages and mobile web applications [18]. SMS based systems usually apply a ‘fire and forget’-strategy; the reminder has been sent but do not require a feedback of the user’s action after being received. More elaborated reminders range from smartphone apps to activity recognition systems. For instance, the app UbiMeds allows integration of a Personal Health Profile to upload a person’s prescribed medication [1] while PillboxApp provides medication list management and overviews [19]. In Pillboxie the user can setup and receive medication reminders [20]. In the app MedBox users can download images of, or take photos of their own, medication [21]. And, activity recognition systems explore how activity and proximity can be used to remind a user [22]. These activities can be ‘sleeping’ or ‘waking up’ and proximity refers to where the user is when being reminded.

2) Augmented medication pillboxes: A number of augmented pillboxes exist such as MedTracker [23] and the smart pillbox [13]. A pillbox is not always a sufficient solution, and other tools such as calendars come in play when trying to understand medication challenges [13]. SmartDrawer is an example of a combined ‘medication drawer and reminder’-system based on RFID technology [24], and specific Caregiver modules have been developed to allow caregivers to monitor the medication intake among for example older adults [25]. GlowCaps [26] is a cap that fits on normal prescription bottles and handles automated reminding and records date and time when it is opened. Movipill [27] creates a persuasive game for older adults to address adherence issues.

C. Design Considerations for Medication Management

Existing design guidelines to support medication management include: 1) principles for home-based medication management [14], 2) guidelines for the design of Personal Health Application [16], 3) implications for medication reminders [28], and 4) recommendations to support self-reflection [13]. We acknowledge and complement the previous set of design considerations through the medication specific particularities that we identified in our work.

D. Patient-Healthcare System Collaboration

A range of remote monitoring projects supporting the communication between patients at home and the hospital has been developed [29, 30]. Others have focused on collaboration between actors (both professional and amateur) in care networks to provide best possible care across organizational
and social settings [31]. Collaboration often takes place among actors that share a common goal and values. Different rhythms and goals among the collaborative partners can be challenging. Indeed, persuasion, trickery and even force are all part of working out a collaboration and this process is shaped by for example existing power structures [32]. To be aware of, and design for organizational and individual differences while supporting collaboration seems important. Negotiating medication intake in terms of concordance [4] may be one fruitful strategy.

However, different levels of illness and age-related symptoms challenge a successful intervention [16] and existing, technological aids might not always be sufficient to sustain a successful home-based medication regimen. Based on the related work, we investigated how to improve both medication consumers and physicians’ local awareness across care settings (e.g. patient-doctor communication and cooperation) to contribute and enhance the individual ability of managing medication in non-clinical settings.

III. USER STUDIES

This project integrates qualitative studies and a quantitative survey to establish an understanding of older adults’ medication management. The work extended into a user-involved design process including interviews, creative workshops with older adults, developers of the Shared Medication Record (SMR), medication consultants and pharmacists (i.e. medication experts) (see Figure 1). The SMR is a Danish, national service that allows health actors and citizens to access people’s prescribed medications.

The quantitative study included 316 telephone interviews. Participants were recruited from a list of all citizens over 60 years old provided by the local governments of two Danish municipalities. They fulfilled the following requirements: 1) they manage their own medication, 2) they have been prescribed medications for at least the last three months and 3) they take either more than one medication dosage (amount) or more than once a day (frequency). The project partners defined the questionnaire and contracted a market research institute to perform the study. Questions touched upon the participants’ amount and frequency of medication intake, their compliance and noncompliance, their mnemonic (assisting memory) rules in medication management, their medication information needs and use of technology.

The qualitative user study has been conducted to qualify, confirm, and further investigate aspects of the quantitative study. This study touched upon the same questions as the quantitative study and included nine older adults. They all fulfilled the same requirements as those of the quantitative study. The participants were between 60 and 93 years old (two males and seven females), and their daily medication intake varied from 1 to 32 doses including pills, creams, eye drops and injections. Four participants managed their own medication, while five received assistance from a nurse every second week. Two of them were additionally assisted by their spouses. One participant who received assistance expressed a sincere will to return to an independent medication management.

As part of the participatory and user centered design process, we carried out workshops and interviews with additional seven older adults (five females and two males) and seven medication experts. The older adults were between 57 and 87 years old and their daily medication intake varied from 1 to 35 doses. During workshop activities, these participants were asked to write down their daily routines, including their medication intake on a paper-based calendar. Interview questions touched upon the same questions of the previous studies and approach to technology at home. The medication experts were two healthcare workers, two doctors, a developer from SMR and two pharmacists.

IV. EVERYDAY MEDICATION MANAGEMENT

The results of the user studies show several similarities between the participants in the qualitative and quantitative studies. In all, our user data confirms that the participants are often challenged in their day-to-day medication management. We now present the most relevant themes from our diverse user studies. The themes emerged as being the most frequently discussed and emphasized topics by the project participants.

A. Medication Intake at Home

The diversity in applied strategies to manage medication among these participants illustrates a continuum where older adults in periods can get help from different care network actors. Such assistance can change over time, both increasing and decreasing the amount of help received from both professional (e.g. a homecare worker) and amateur (e.g. a family member) members of a care network (see Figure 2).

When an older adult returns from a hospitalization s/he might be assisted in managing (parts of) the medication for a period, and later, as the situation stabilizes, returns to a self-managed situation. Or s/he might get more help over time, due to more complicated medication regimen. Such support may be
initially provided by a spouse and later a professional homecare worker. Moving along the continuum (the arrows in Figure 2), towards a more individualized medication management, can e.g. 1) take place as a medical condition is improving or stabilized or 2) facilitated by a (technological) intervention or 3) a combination of the previous two.

1) Intentional non-adherence: Intentional non-adherence occurs when people intentionally decide not to follow a medication regimen. The quantitative study shows that 23% of the participants intentionally do not follow the prescribed regimen for different reasons. Some quit their medication intake if they believe it does not work or due to (fear of, or experienced) side effects or mistrust in the medication. This group has a greater need for information than the rest of the participants. Others skip their medication because of irregularities in their everyday lives. One participant said: “If I’ve eaten late, I’m skipping my evening medication because I don’t want to stay up two hours more just to take my medication”. Others are intentionally not following the treatment if they feel that their disease is under control.

2) Unintentional non-adherence: Unintentional non-adherence occurs when people do not follow the medication regimen without an explicit will to do so. The quantitative study shows that 34% of the participants do not adhere to the medication regimen because of forgetfulness, misunderstanding of instructions, they are busy or not being at home. A participant said: “I have my doctor’s medication in the bathroom. Because to begin with I forgot those blood pressure [medications]... that wasn’t so good. I did that often”. Furthermore, our study shows that unintentional non-adherence does not increase with the number of pill quantity, but with the frequency a person takes the medication. Unintentional non-adherence is not necessarily because of forgetfulness but can be the result of a human error. A participant described one such event as she took her medication while visiting a church. Due to the bad illumination she took the wrong pill from her medication ‘travel-pack’. While she tried to adhere, she made a mistake due to the pills’ similar appearance and the surroundings’ bad illumination.

3) Breakdown of routines: The qualitative study confirms that medication has a great impact on the participants’ everyday lives. Most of their daily activities are adapted to the medication intake, just as the medication intake is regulated according to different activities. One participant says: “When I’m not home in the evening I take my medication when I return. I never bring my medication out of the house”. This is confirmed in the quantitative study where 56% of the participants rarely bring medication outside their homes, and 30% have privacy concerns taking medication in public. However, 24% of the participants take medication outside their home several times a month. When participants are not at home and routines are broken, the risk of forgetting a medication dosage increases.

4) Mnemonic rules: It is natural that people create different routines to remember their medication. An older woman says: “I have the little dispenser lying on the table. So I cannot avoid seeing it”. Indeed, 79% of the participants in the quantitative study do something special to remember their medication such as taking the medication with meals (26%) or having the medication visible (22%). In addition, 36% have bought a pill-dispensing box. Most participants distinguish between real (prescribed) and ‘unreal’ medication (‘over the counter’-medication and vitamins) as they place them in different locations. However, the routines seldom include the less frequent actions related to everyday medication management such as the refill activity. For example, participants are challenged when it is time for medication refills, a participant told us that “It’s always hard to get hold of the doctor, and it’s always in the morning that I miss it [forget to refill medication] and then it takes 20 phone calls before I get through…”.

5) Information about the medication: The qualitative study participants are challenged when the medication’s name changes, for example when a pharmacist substitutes one medication with another. The participants also find it challenging when provided different information from for example a nurse and a doctor. A participant said: “The nurse told me that I don’t have to take them all... but my doctor said you have to... and then who do you listen to... I have to listen to my doctor right?” 75% of the participants in the quantitative study have a high need of medication information and 58% were proactively seeking medication information. The main sources of information were: the Internet 41%, the patient medication information leaflet 36% and the pharmacy 10%. Two participants from the qualitative study emphasized the importance of calling their physician to get medication information.

6) Supporting a heterogeneous care network: As discussed, and visualized in Figure 2 above, medication management is not only a private affair. Nurses, spouses and other family members can at time have an active role in older adult’s medication intake. This form of support was directly observed in the qualitative study. For instance, a spouse said: “...I have figured out, that I should make him eat them [the medication] together with the dinner. It can’t be later as then he goes to bed...”. However, this support is not always stable over time and the participants preferred as much independence process as possible in their own medication management.

B. Medication-Specific Requirements in Practice

As illustrated in the ‘Related work’ section, numerous studies have examined adherence in non-supervised settings such as private homes. However, to support medication intake in non-supervised settings one has to consider a range of exceptions and special situations, which can be hard to depict for a design team. For example, during the user involvement (see Figure 1), specific medication particularities emerged that can challenge medication consumers in everyday life. As a result, the project’s medication experts became aware of, and
could further unfold such situations and how the following particularities can challenge an individual medication regimen.

1) Substitute medication: As illustrated above, participants were challenged when the medication’s name changed. Similarly, medication experts expressed that many different medications exist with the same effect but under different names and manufacturers. In Denmark, it is the pharmacy that offers these substitute medication. The pharmacist might do this to lower the medication’s cost. While this indeed can help the wallet of any medication consumer, it can also add complexity in the medication management. For some medication, the prices changes often, leading to regularly changes in medication brand and naming. This is confirmed in the qualitative interview where a participant told us: "I don’t know the name because it’s something new every time you buy - it is a different drug. It’s called something different every time (...). So I took the wrong pills, I couldn’t figure it out”.

2) ‘According to need’ – medication: Not all medication is taken regularly, or it is up to the individual to decide when to take it. The medication experts confirmed this. Indeed, “According to Need”-medication is not suited for reminders. It can be a medication that is prescribed by the doctor, for example a cream, but that the patient should apply only when needed and not on a day-to-day basis. For example, a participant had, at times, been prescribed up to 12 different types of so-called ‘according to need’-medications that she could take if necessary. Also, she was only allowed to take a specific amount each day, which complicated her medication management. The experts emphasized the importance of documenting “According to Need”-medication intake, to get a more complete overview of an individual’s medication intake.

3) Delayed medication intake: Analyzing the user-study material, the medication experts emphasized the need to take medication within a certain time interval. A participant noted the importance of taking her painkillers at a specific time, because when she forgets, her pain increases and the pills will no longer be as helpful. However, some medication can be taken later than prescribed. A participant was informed that it was possible to delay the intake of so-called “water pills”, that increases the production of urine (diuretics). So, the participant started to adjust the water pill intake, making sure there was a bathroom nearby after the medication intake. Also, a morning medication may be taken at lunchtime or at the evening and medications that are taken more sporadically can, occasionally, be taken within a week’s time. Other medication should be skipped if a dosage is missed. Indeed, the recommendations for delayed medication intake, varies with each medication and depends on what other medications are taken.

4) Overview and knowledge about medication: The medication experts emphasized the importance of providing an overview and knowledge about medication at home. This becomes more critical if there is more than one individual following a medication regimen at home, and even more critical if they are prescribed the same medication. The experts stated that it is necessary to provide an individual medication overview for each person in the household. Taking a medication can be so integrated into older adult’s routines that a registration of whether or not they have taken a specific dosage is needed. For instance 12% of the participants had problems remembering whether they have taken the medication. Indeed, a dosage of medication can be prescribed for several times during a day and the registration on daily basis can facilitate an overview of medication intake for both people and practitioners over time. For example, a participant was prescribed 32 medications during a day and at different times (7/11am and 12/16/18/22pm). She found it difficult to take the medication (at the right time) and get a comprehensive overview of her medication intake. As illustrated above, a medication consumer occasionally receives different messages from different healthcare professionals regarding when, how and why to take a specific medication. This also challenges the understanding of the medication, the prescribed regimen and reduces medication adherence.

People are also prescribed preventive medication. This medication aims to decrease the risk of future health condition, for example stroke. Medication experts stressed that people should be informed about the effects and reasons of preventive medication as they also increase the complexity of the medication regimen. A medication expert said, “It [preventive medication] is great if you are young but not when you are 85 years old”. Moreover, the experts stated that fine-grained information such as “do not crunch the pill” or “shake the bottle before use” or “to wear gloves when taken the cream” is extremely important and should be accessible to people. It is very important that a person has access to the correct and necessary medication information, such as administration instructions and food interactions. A participant explained that there are types of food that she should not eat together with her medication but she doesn’t really know which.

5) Doctor’s insights in everyday medication management: The medication experts emphasized the importance of the doctor-patient relationship and the doctor’s insight in patients’ everyday medication management. This insight is considered valuable both in situations of adherence and non-adherence. Today, the doctor usually lacks this insight in different ways; first, when patients are unintentionally non-adherent without later becoming aware of this, they naturally cannot tell their doctor. For example they might have misunderstood a prescription, and hence take just one out of two prescribed doses a day. Second, if the patient intentionally skips the medication, both doctor and patient would benefit from sharing this information. The patient might have planned to consult the doctor on this matter, but might forget this during the consultation. Indeed, many participants in our study bring notes to remember what to talk about with their doctor. Third, a patient follows a regimen, but wishes to consult the doctor about experienced side effects or challenges with integrating the prescribed medication into his/her daily routines. For example, a participant was prescribed a cholesterol pill at night.
but she was taking it during the evening with dinner because she worked at night. A medication expert commented on this, stating, “those [cholesterol] pills are not allowed to be taken together with food”.

V. DESIGNING ACROSS CARE SETTINGS

The findings show the importance of both medication consumers and experts’ involvement to reveal new challenges in supporting medication management practices. In this section, we discuss challenges, opportunities, and a set of design principles for pervasive healthcare medication management system (PHMMS). These design principles complement the pre-existing guidelines (See Related work) to account for individual and medication particularities to better support older adults’ medication intake across care settings.

A. Individual Medication Overview

The number of pills, different types of pharmaceutical formulation and frequency of dosage describe the complexity of medication regimens. Indeed, medication comes in different shapes and forms. Some have special markings while others are more anonymous in their appearance. Also, there could be a potential mismatch between the prescribed medication and the medication handed out to the person at the pharmacy – so called substitute medication. Moreover, some “according to need”-medications have restrictions on how many doses can be taken within a specific time frame. Therefore, documenting “according to need” intake could support a person in keeping track of this medication and could help to identify a change in the medical condition. These in-home and medication particularities can enhance the individual medication overview and improve the physician’s local awareness [7] regarding the prescribed care plan at home.

Our findings suggest the design of PHMMS that enhances the individual medication overview by visualizing, documenting and supporting the use of substitute and ‘according to need’ medication. This implies an automated update about what medication the doctor has prescribed and what the pharmacist actually has handed out. For example, a person might still have some medications left, when buying the new substitute medication and hence both the prescribed and handed out substitution medication must be made visible to people at home. The use of ‘according to need’ medication should also be reported and attached to the individual medication overview. This is something not found or spoken as a concern in the related work of this paper. This complements [14], that calls for a distinction between real and other medication (i.e. supplements). Indeed, substitute or ‘according to need’ medications are real medications and should be accounted for medication management technologies.

B. Shared Responsibility

Doctors are in charge of defining a specific care plan based on their expertise and the patients’ treatment goals. However, the care plan is sometimes given to patients without discussing its consequences or without the physician knowing what is happening in the patient’s everyday life. This can result in only a minor improvement or even a negative health trend. The medication experts emphasized that doctors should inform, and discuss with, their patients about the reasons and consequences of each prescribed medication, including preventive medication. Limiting the number of preventive medication can be favorable, especially for older adults with a complex medication regimen. Here concordance [4] can evoke a shared responsibility that fosters an active participation from both settings. Aligned with [13], collaboration and sharing of behavioral data among the care network members are needed. Health care providers should promote, motivate, encourage and follow up on people according to mutual goals. Still, people should take responsibility to perform self-care activities and to report back to their health providers. In a clinical setting, physicians have improved their local awareness about the health status of their patients using cognitive artifacts [7]. However, when a patient is at home, the lack of knowledge between consultations about what happens in the home hinder a complete overview of the medication intake. For instance, sharing issues about general problems and unintentional non-adherence can enable a patient-doctor dialogue about this issue and hence both the doctor and the patient should be aware of the patient’s challenges in following the prescribed medication regimen. Sharing issues about intentional non-adherence can enable the patient to document why a medication has not been taken as prescribed, for example due to the fear of side effects. Therefore, a care plan can be improved by gathering people’s expertise regarding the home context, obstacles, facilitators, implications, feelings and in general details of individual’s behavior [13]. Thus, the local awareness in non-clinical settings can be seen as all factors that affect a medication intake activity and that can be used to expand physician’s local awareness to promote and improve care outcomes.

Our findings suggest the design of PHMMS that supports the shared responsibility by providing the individual’s local awareness and enhancing the physician’s local awareness of medication intake taking advantage of the individual medication overview. In this sense, the individual medication overview turns into a cognitive artifact [7] that can facilitate the shared patient-doctor responsibilities across care settings.

C. Beyond Capturing, Reminding and Monitoring Medication Intake at Home

Clearly indicated in our study, there is a need for updated, validated and especially relevant medication information from trustable sources. People are actively searching for medication information from different sources (e.g. Internet, patient medication information leaflet, pharmacy). However, the participants did not want a complete “Patient medication information leaflet”. Consistent with [28], our results show that pervasive healthcare medication management technology should support active information search from trustable information sources. Preferably, but still technologically out of reach, the information should always be tailored showing only what is relevant for each individual at any given time and
situation. Fine-grained details are necessary to support self-medication as stated by medication experts. This has strong implications for the design of pervasive healthcare medication management technology. The integration of these different sources can facilitate a sense making and self-reflection process. Hence, supporting an active search go far beyond the passive capturing, monitoring and reminding functionalities in much existing medication management technology. People should know what to do, if for example a medication is forgotten, to maintain the right medication informational order. The medication informational order refers to the all aspects (e.g. who are the sender and receiver, how the trustable medication information is delivered, what type of medication information is interchanged – instructions, side effects, food interactions) of the information flow between care settings [32], that should be available at hand to support the medication activity.

Our findings suggest the design of PHMMS that sustains the medication informational order to enhance individual’s sense making and reflection. The informational order complements the gathered knowledge (e.g. people’s routines, available spaces, individual’s behavior) from the home [13]. A proper combination of the medication informational order and gathered knowledge from the home can enhance the individual medication overview and provide a sense of local awareness. The individual local awareness can be enhanced by applying information visualization techniques as proposed by [13]. In doing this, individuals get the ability to explore, compare and analyze their own medication intake through the individual medication overview. This principle also complements [16] that focuses on interface messages in medication management systems. The right phrasing, visual representation, terminology, individual’s behavior and the medication informational order can assist a more complete sense-making and reflection process to facilitate the individual’s understanding of the current care plan.

D. From Medication Adherence to Integrated Adherence

The home is not designed as a place for care and people might live out different roles, and activities, at home compared when they are in a clinical settings [33]. Thus, it is important to support people to insert the medication activity into their daily routines and their available space at home. There are a high number of participants who attach their medications to their habits and routines and, indeed, it seems that medication management is more complex when older adults have an active lifestyle as 1) people are not always at home or in the vicinity of their medications when it is time to take their medication and 2) some people feel uncomfortable bringing medication outside their homes. Furthermore, the mnemonic rules show that when routines are broken, remembering a medication dose is a common problem. In addition, forgetting to request new medications, as they are about to run out increases the risk of non-adherence. Consequently, people do not know what to do if a medication is forgotten - should for example the missed dosage be skipped or a double dosage consumed the next schedule time, and will it be possible to delay a specific medication intake. Besides the necessity of customizable reminders [28], an integration of the daily medication regimen with a person’s daily activities can promote adherence when daily routines are broken. This integration can facilitate the reminding process, as people should receive reminders when it makes sense according to their needs to prevent unintentional non-adherence.

Our findings suggest the design of PHMMS that supports the adjustment of medication intake according to prescription times, people’s routines and the respective time interval in and outside the home. This principle calls for an attention to the specific reminder time interval in which a certain medication can be taken. Recognizing, and designing for, this medication-intake interval would allow an individualized adjustment of people’s medication intake. This adjustment accounts for planning, reminding and supporting the intake, identifying activity-medicine conflicts to hence adjust the intake (according to pre-established rules) to suit people’s lives. This complements customizable reminders guidelines provided by [28]. As explained above, this goes beyond simple reminders, as the medication informational order should also be available at hand. Furthermore, technology should help remind people to order/re-order new medication as it is about to finish and whether or not a delayed medication intake is possible.

E. The Heterogeneous Care Network

Both the older participants and the medication experts have discussed the importance of 1) motivation and 2) to be continuously encouraged to follow a medication regimen. As illustrated in Figure 2, the older adults in our studies received both amateur and professional medication support. From this perspective, the network of actors surrounding an older adult with a complex medication regimen plays an important role in supporting adherence and motivation. But, supporting the coordination of cooperative care work at home is not an easy task as relatives and clinicians have their own values, rhythms and attitudes [34]. For example have [13] suggested the use of data annotation to support collaborative task sharing to avoid misinterpretations. Medication management technology should sustain both amateur and professional care providers to play an active role in the older adult’s medication intake and provide them with a sense of local awareness.

Our findings suggest the design of PHMMS that sustain and allow (both amateur and professional) caregivers to play an active role in the people’s medication intake by providing caregiver’s local awareness taking advantage of the individual medication overview. The overview is important to provide caregivers with local awareness as people move away from an independent care situation (see Figure 2).

VI. CONCLUSION

This paper shows the importance of looking beyond single strategies and solutions (e.g. medication reminders or pillboxes – technological augmented or not) targeting a specific subset of users or illnesses. Rather, there is a need to develop a more complete understanding of what it means to
live with an illness and to be in need of medication management support in everyday life. This paper discusses six important particularities of everyday medication management (according to need medication, the heterogeneous care network, the substitute medication, the medication informational order, the shared responsibility and the adjustment of medication intake) that have not, to our knowledge, been adequately discussed within the Pervasive Healthcare community. Our findings suggest that generating a more complete and individual medication overview, that accounts for the individual’s and medication particularities discussed in this paper, can: 1) provide both care receivers and (amateur and professional) care givers with an understanding and local awareness of the medication intake; and 2) expand the physician’s local awareness of the current care plan.

Our findings come from a project working with older adults, but they may be transferrable to other age groups as well. From the aforementioned particularities, we introduce five design principles (see Section 5: Designing across care settings) to support designers in developing future pervasive healthcare medication management systems.

To deal with some issues presented in this paper, might require a national investment (e.g. infrastructure for medication information or technological frameworks) to integrate solutions and systems from different levels of the healthcare system. However, while such a development might be out of reach for most designers and developers, it is important to be aware of the herein presented issues and their impact on pervasive healthcare designs. Furthermore, the presented findings are most likely far from complete, and we encourage the Pervasive Healthcare community to continue discovering and understanding particularities of peoples’ everyday medication management. To preserve an independent care situation as long as possible, we suggest moving away from solutions focusing on one specific strategy such as reminders, towards solutions that consider the wider spectra of issues existing in everyday medication management.

ACKNOWLEDGMENT

We would like to thank all colleagues and reviewers that, through their feedback, have helped to improve the paper. We also thank all LevVel participants for their cooperation.

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Abstract—Healthcare activities in private home settings that are not supervised by a healthcare professional can challenge older adults. To support such unsupervised care activities, an increasingly number of reminders and monitoring systems are designed. However, most of these systems target a specific treatment or a specific condition. In this paper, we discuss experiences from designing the tablet-based application MediFrame. MediFrame is a personal medication management system to support older adults in non-clinical settings such as the home. The paper describes the user-centered design process and the resulting tablet application. We show how MediFrame can be used to support adherence in medical treatments through fieldwork informed use scenarios. Based on early qualitative feedback, we also discuss lessons learned and how designers can support a holistic medication experience for an older adult's everyday life.

Keywords—medication management; design; tablet; older adults; user-centered design

I. INTRODUCTION

The World Health Organization (WHO) [1] reports that adherence to long-term therapies is around 50% in developed countries and even lower in developing countries. For instance, about half the people subject to prescribed medication fail to take their medications accordingly [2, 3]. In the US, medication related problems had a cost of approximately $177 billion in 2001 alone [4]. According to the same study, this cost was doubled from 1995 to 2001. Better adherence to a prescribed treatment together with documentation of use and side effects is one way to help both the individual and society to control this cost.

Institutional care is more resource-demanding compared to home-based care [5] and moving from an independent to a dependent life situation is a major concern among people over the age of 60 [6]. To address this, the healthcare system tries to enable citizens to remain self-sufficient. A prolonged independence can reduce healthcare costs while helping people to sustain a dignifying, independent lifestyle [7].

The Danish welfare state provides free healthcare while motivating citizens to take responsibility for their own health and lives [8]. A new, Danish, national funded initiative is the Shared Medication Record (SMR) [9]. It provides physicians and care professionals at different locations such as hospitals, the general practitioners out-clinic and municipality care workers with access to all people’s prescribed medication. SMR is also accessible to people through the Internet. In the project, we examined how to support older adults in their everyday medication management. We developed user-centered extensions, or add-ons, to the SMR. Our work leverages previous research that demonstrates how electronic medication monitoring data can benefit pharmacists and physicians as it empowers them to adjust patient treatment plans [10].

This paper presents the iPad-based prototype MediFrame that aims to postpone the transition across care settings by supporting people’s everyday medication intake. In the following, we present related work, our user-centered design process with older adults and medication experts, the MediFrame application and its early evaluation phase. The main contribution is the presentation and discussion of the design of mobile medication management support for older adults in everyday life. Finally, we present a MediFrame use scenario and discuss lessons learned regarding medication management support for older adults in everyday life.

II. RELATED WORK

A. Mobile Technology and Older Adults

The use of smartphones and their built-in sensors has become widespread when supporting older adults’ daily activities. However, one disadvantage of mobile phones may be the limited screen size when an older adult is expected to use screen-based interaction [11]. Here tablets with touch-technology can be an alternative [12, 13]. Research has also shown that touch screen interaction is more suitable for computer-novice older adults rather than using keyboard or mouse [14]. Furthermore, touch-based interfaces suite activities that should be integrated into people’s everyday lives [15]. Touch interfaces can be easy to learn and adopt by older adults besides their physical or cognitive capabilities [15]. In addition, tablets can also fit into the sometimes limited space of older adults’ homes [12].

Indeed, integrating healthcare technology into older adult’s homes can be challenging [16]. People tend not to put too much emphasis on their illnesses while at home, and assistive technologies that prevent stigmatization are preferred by many users [17]. When designing healthcare technology for the home, it is important to consider how people arrange things and activities at specific places to maintain the order of the home [18]. In this sense the aesthetics of the home plays an important role [18] and tablet
cases, covers and sleeves can provide several opportunities to allow a more personal and aesthetical fit in private homes. Modern, mobile technologies, such as tablet-computers can prevent stigmatization through its design and additional 'non-healthcare use'.

B. Technology for Medication Management

A set of physical and digital artifacts are available to support people’s medication intake, such as reminders, pillboxes, software applications, tablet-holders, automatic medication dispensers and paper-based medication lists [19]. An example is the SmartPill web application [20]. It presents the medication level in the blood and can send SMS-warnings if a medication dosage have not been taken in time. MovPill [21] creates a persuasive, medication adherence game for older adults by combining mobile technology and pillboxes. Others examples of augmented physical objects for medication management are MedTracker [22] and the smart pill box [23]. SmartDrawer combines a physical drawer with a RFID-based reminder functionality [24]. GlowCaps [25] is a medication container cap that uses light, sound, or telephone calls to remind a user to take medication and calls if a refill is needed before the prescription runs out. GlowCaps also provides a monthly adherence report to family members or the general practitioner.

Apps for the iPhone can for example provide medication list management and overview [26] or setup and receive medication intake reminders [27]. Most of these systems use a generic medication image (i.e. an iconic pill), but [28] allow users to download the actual image of pills or take photos of their own medication.

C. Patient-Physician Collaboration and Information Sharing

How to enable an effective patient-physician communication has been widely studied [29-31] and recognized as a key factor in increasing treatment compliance [1, 30]. To successfully carry out agreements, the collaborative partners rely on a shared intention within the group [32]. The facilitating technology can be seen as one actor in such collaborations. At clinics, information exchange is composed by information seeking, documentation and patient education [33]. Using modern telecare solutions, communication can include locations outside of the clinical setting [34] and mobile phone-based diaries have been used to support for example everyday diabetes management [35].

D. Design Implications for Medication Management

Design implications for medication management systems include (from [36]): 1) to pay special attention to placement, readability, and terminology of instructions and confirmations; 2) to prioritize performance over preference when designing interfaces for personal health applications; 3) to present individual’s health information by finding a balance between textual information and design metaphors; 4) to provide automated mechanisms to perform basic medication management tasks but requiring minimal interaction steps; 5) to consider all stakeholders to address possible conflicts and avoid misunderstandings between each stakeholders; 6) to explore and understand individual’s unique practices for health information management; 7) to provide the possibility to add more functionalities as users master the basic ones; (and from [37]) 8) to provide customizable reminders; 9) to facilitate information search; 10) to recognize the value of portability for the reminding; 11) to allow users to retrieve information about the context; (and from [23]) 12) to provide low-level details regarding an individual’s behavior; 13) to allow collaborative sharing and exploration among members of the care network; 14) to support annotation of health-related information before sharing to avoid misinterpretations; (and from [38]) 15) support distribution and personalization according to spatial arrangements that sustain routines; 16) consider privacy and ethical considerations; 17) consider a broader scope of health to extend the context of a patient-physician interaction; and 18) provide a mechanism of inference for remote assistance.

Our work emphasizes the need to support the medication information exchange across care settings. We focus on both the documentation of medication intake and the understanding of people’s medication information seeking needs at home. To do this, we build upon Bates’ model for information seeking behavior [39] composed by: a) active information seeking including browsing (undirected active) and searching (directed active); and b) passive information seeking including monitoring (directed passive) and being aware (undirected passive). By facilitating people’s medication information seeking, MediFrame aims to support the medication information exchange, especially when people are away from the clinic and their physician.

III. DESIGNING FOR MEDICATION MANAGEMENT

First, the project initially carried out a quantitative study with 316 older adults over 60 years of age and a qualitative study with 9 older adults (aged 60-93) [19]. This initial fieldwork revealed that the lack of knowledge about medication, forgetting the medication intake, complexity of the medication regimen, taking medication outside the home, the lack of support for caregivers, and substitution of medication are important challenges for older adults.

Second, we reviewed existing mechanisms and technologies used to support peoples’ medication intake. Our review included electronic reminders, tablet holders and dosing aids with electronic reminders, automatic dispensers, and non-electronic tools such as paper-based medication lists and pillboxes [19]. We found some of these artifacts in older adult’s homes. These technologies might support people in different ways but also present disadvantages such as lack of usability and knowledge regarding people’s daily activities (routines or not), and a too generic support (e.g. reminders, pillboxes) that might not be enough for people with a complex medication regimen. Based on our initial fieldwork and this review, we defined a set of functional (integration, reminder, tracking, mobility, medication information search, sharing, flexibility for systematic storing of medication, control) and non-functional (security, safety, performance, privacy, user interface) meta-requirements for the design medication management systems [19].
Third, MediFrame was designed following a user-centered design process [40]. This process involved older adults, medication experts and researchers. Eight older adults (aged 57-90) and seven medication experts participated in several workshops (two-three hours’ sessions). The medication experts were two doctors, two healthcare workers, two pharmacists and a developer from SMR. The MediFrame design team was informed by the initial user meta-requirements and the related work in which tablet technology seems to provide several opportunities for home-based healthcare technology. Workshops together with the older adults involved 1) discussions about how participants manage their own medication, the amount of medications and the frequency of the medication intake, strategies to remember a medication dose, current technology to support the medication intake and their need of medication information, 2) identification of older adult’s daily routines including their medication intake by filling a paper-based weekly calendar, and 3) early feedback regarding the functionality and goals of MediFrame based on early prototypes. Workshops together with medication experts involved 1) discussions about the results of the workshop activities with older adults, 2) gathering knowledge regarding medication information for example the exact definition of a dosage, the use of generic and active substances and the right phrasing for a medication dose, and 3) feedback and suggestions on the functionality, vision and goals based on early and revised prototypes of MediFrame. Additional meetings were held between the researchers and the medication experts to further explore and confirm specific situations that emerged from previous activities.

All design decisions were based on the results and feedback from the workshop activities. Now, we further describe our initial list of requirements and design process.

A. Initial MediFrame List of Requirements

Based on the related work and the tablet technology the project defined the initial list of requirements for MediFrame. We focused on a specific set of the aforementioned meta-requirements [19]:

1) **Integration:** MediFrame should integrate validated medication information from trustable sources (e.g. the “patient information leaflet”). This also implies an automatically update of prescribed medication (by doctors) and handed out medication (by pharmacist) to provide information about substitute medications.

2) **Reminder:** MediFrame should provide customizable reminders to each person’s medication regimen and in accordance with their daily activities including the medication refill reminder.

3) **Tracking:** MediFrame should document the patient’s medication intake or lack of it over time. This tracking information includes issues about intentional non-adherence and regarding the current medication regimen such as side effects or reasons for skipping a dose.

4) **Mobility:** MediFrame should support medication intake in and outside the home especially when daily routines are broken.

5) **Search:** MediFrame should facilitate an active medication information search from trustable sources (e.g. “patient information leaflet”).

6) **Sharing:** MediFrame should allow users to play an active role in the user’s medication intake.

7) **Control:** MediFrame should let the users decide when to start or stop sharing their medication information and receiving reminders.

8) **Privacy:** MediFrame should allow users to preserve their personal dignity by giving them control over functionalities that can rise privacy concerns such as reminders and sharing information.

9) **User Interface:** MediFrame should be able to support several doses of medication per day with different type of formulation considering the capabilities and limitations of tablet technology.

B. Exploring the design space

We initially investigated several metaphors such as the “medication cabinet” and the “clock” to explore possibilities of arranging medications and reminders [19]. We used a number of early low fidelity prototypes [41] to elicit discussions and get early feedback from participants. These prototypes were manifested in several design drawings and mock-ups that in combination with the tablet device allow us to get a rapid user feedback on our MediFrame concept. We additionally reviewed existing guidelines for mobile devices regarding touch interfaces and older adults to frame our design space. A total of 31 design guidelines were classified as guidelines for visual and interaction design (17), information organization (4) and conceptual consideration (10) that can be adapted for tablet-touch interfaces [42].

C. Iterative Prototyping

During our design iterations, the low fidelity prototypes moved from early sketches, to screen-based prototypes and finally into a more interactive high fidelity prototype. Figure 1 shows an example of a low-fidelity prototype during test. To support user’s information seeking, we based some designs on Shneiderman’s visual information seeking mantra “overview first and details on demand” [43] to avoid the visual clutter for older adults.

Applying Bates’ model, the workshops focused on understanding how people relate to interface features and information (e.g. phrasing, icons, layout, navigation).

Figure 1. Testing our screen-based prototype

Bates’ model was applied to MediFrame during the iterative design process to discuss and revise previous interfaces relying on user’s information seeking behavior.
D. Additional Requirements

A number of unforeseen challenges emerged through our design work, for example the case of the so-called “according to need”-medication [40]. According to need medication is medication that you do not take according to a schedule, but rather when there is a perceived need. Pain-killers can for example be prescribed as “according to need”-medication. During our user workshops it was revealed that the older adults did not perceive this type of medication as ‘real’ medication and therefore they did not keep track of it. Also, the older adults did not document why they did not take a medication. The medication experts emphasized the importance of getting this sort of information from the older adults, to better adjust the prescribed regimen. These specific challenges were further discussed with both the medication experts and the older adults and investigated using low fidelity prototypes as illustrated by Figure 2.

After a 10-month user centered design process, our empirical study suggests five design principles that account for medication specific particularities (according to need medication, the heterogeneous care network, the substitute medication, the medication informational order, the shared responsibility and the adjustment of medication intake) in practice for everyday medication management [40]. Then, we initiated the high fidelity prototype development phase.

IV. THE MEDIFRAME APPLICATION

Informed by the related work and medication specific particularities [40], MediFrame aims to support unsupervised everyday medication intake allowing users to 1) plan their medication intake on a day-to-day basis. Also considering other scheduled activities such as work or leisure; 2) retrieve information about each medication they are prescribed; 3) get reminders when to take their medications; 4) get documentation and support in their medication-related dialogue with their general practitioner, and 5) support the intake of “according to need”-medication.

In addition, MediFrame relies on the user’s active search of medication information. When applying Bates’ model to MediFrame; prescribed, substitute and “according to need”-medication are considered main, directed information. And relevant medication information such as side effects or instructions is considered undirected information.

As stated before, the project has the national, upcoming Shared Medical Record (SMR) service in mind. Even if the medication information is available to the citizen through a web service, the SMR’s security model does not at this point allow a seamless mobile integration. Hence our application works with offline data records, identical to the online version of SMR. In addition, MediFrame integrates a Danish Medication Information (DMI) service, made available online by one of the project partners [44]. This service allows us to show images of each commercially available medication in Denmark and collect information such as the medication’s effect, possible side effects and when and how it should be taken (i.e. the Patient Information Leaflet).

A. MediFrame System Architecture

MediFrame is a web (cross-platform) application based on the Model View Controller (MVC) design pattern. It uses the Sencha Touch Framework [45] to access native device APIs and is embedded as a native shell (using PhoneGap [46]). The cross-platform approach allows MediFrame to be deployed on other mobile devices and platforms in the future, but is currently being evaluated using the Apple iPad.

Two main components describe the system architecture of MediFrame: 1) the offline processing, and 2) the MediFrame App (see Figure 3).

1) Offline processing: It is necessary to preprocess and re-structure the data that comes from the two Danish services: SMR and DMI. This is managed by the Data Miner. The Data Miner generate JSON files to instantiate the data model for the MediFrame App.

2) MediFrame App: The MediFrame App is the tablet application developed using the MVC design pattern. The status and the application’s data are stored using SQLite in the tablet device. Furthermore, the application defines and combines the controllers, views and models to provide the user with different functionalities. Each functionality has its own controller and view classes (e.g. CalendarController-CalendarView) except from the main Controller Application which manages the MainView of the application, the TakeMedicineView and MoreInfoView.

B. MediFrame Functionalities

As a result from the cooperative design process, MediFrame implements the following functionalities:

1) Calendar: This function provides an overview of the scheduled medication intake (see Figure 4) in relation to other planned activities (e.g. a private or work agenda). People can adapt and personalize their medication intake based on this information. For example, the user can ‘at a
glance’ identify medication and activity overlaps that can challenge adherence. The user is also allowed, within given timeframes, to adjust and reschedule the medication intake to suit his/her everyday activities, especially when routines are broken. The interface provides different levels of aggregation: per day, week and month. It also provides details on demand by selecting each medication from the calendar. In addition, it can import events from personal calendars (e.g. google calendar). We implemented the calendar using the FullCalendar Javascript library [47].

2) Medication: This function makes the user and potential caregivers able to get an overview, and retrieve information, about all prescribed medication. The medication information (i.e. the Patient medication leaflet) and images are retrieved through an online service (DMI) to be used by the DataMiner (see Figure 3). The medication list can be filtered, providing different views for example “today’s medication” or “all prescribed medication”. It provides details on demand by selecting each medication.

3) Diary: This function allows the user to document information about the medication and experienced side effects in a diary-style log. It also provides a mechanism to automatically log several medication-related events such as an updated medication list, reminders, and medications not taken according to plan. Hence, it provides an overview of these events during the medication administration activity.

4) Reminder: This function provides users with medication reminders when it is time to take medication or a refill is needed. A reminder can be set to be active (sound and visual) or passive. In passive mode, MediFrame presents itself as a digital picture frame and the reminder-signal is a specific picture that appears on the screen (e.g. a picture of a flower). Seeing the signal (i.e. the flower) the user taps the screen to start the interaction with MediFrame. The specific cue-image is repeatedly displayed on the screen until the user takes action.

5) According to Need: This function allows the user to document the use of “according to need” medication. Here the user starts by selecting a symptom or condition rather than a medication (see Figure 2). MediFrame then informs what prescribed medication to use in this particular situation. The registration of “according to need” medication is also documented in the Diary.

6) Settings: MediFrame allows the configuration for some of the above-mentioned functions. For example, it allows the user to personalize each medication’s reminder respecting the limitations imposed by each medication. For instance, organizing all morning medications by selecting the prescribed medication according to the specific time frame. Helping users to set reminders and medication time according to their own needs.

7) Take Medicine: This function allows the user to register the medication intake at specific times a day by tapping each medication button (see Figure 5). When a user taps the (“I”)nformation icon, relevant medication information is displayed regarding the selected medication. It also allows the user to manage potential substitute medication by highlighting this medication in the interface. All selected medication are clearly displayed on the interface. Furthermore, a confirmation step is added by a “Done” button replacing a prior “Take all doses”-button from earlier versions. In addition, the “progress bar” provides feedback about the status of the current medication intake at hand. When tapping the “Done”-button, it provides a motivational feedback if all scheduled medications have been taken accordingly, otherwise, it asks the user to register (by selection) the possible reasons for skipping the current dosage as presented in Figure 2.

V. EARLY EVALUATIONS

A. Concept Validation

An initial MediFrame concept validation was performed together with the medication experts and four older adults [19]. They stressed that simplicity is the key to embrace as many diverse users as possible and that users might not want or need too much information on the screen. While concerns
emerged that MediFrame could be difficult to use by people with motor impairments and dementia, the evaluation team stressed that in such cases MediFrame could be useful for the healthcare professionals and care providing family members.

Based on the feedback, we found that older adults rely on the use of images (e.g., visualizing two graphical medication icons instead of writing ‘take 2 pills’) and medication experts suggest providing user’s identification (i.e., the user should have his/her name clearly written within the interface – this is especially important when more users, e.g., a couple, share the tablet) as main features of the interface.

### B. Testing the Screen-based Prototype

The medication experts were concerned about how to visualize and support a complex medication intake, for example when a large number of different medications should be taken at the same time. We decided to address this complexity on the “Take Medicine” interface by displaying up to 10 prescribed medications at the time, providing a balance between information granularity and overview. After an iterative user-driven refinement of our mockups, we performed a user test of the “Take Medicine” interface with older adults using a screen-based prototype as illustrated by Figure 1. We visited three older adults and asked them to explore our interface using the iPad tablet. We provided an introduction to the tablet technology prior to the user test.

Based on the participant’s feedback, new issues emerged. First, users got confused having more visible functionality than needed. Second, participants tend to press the “Take all doses” button without pressing all the medications in the interface. Third, the screen-based prototype embedded interaction-limitations that confused our users. Fourth, the redundant information provided by a combination of textual information and visual representation (i.e., a picture of three pills rather than showing the number 3 to indicate the current dose) was preferred over the textual representation. Finally, the interface features such as font size, text and buttons were well accepted by older adults as they could distinguish for example all selected items or recognized buttons by their appearance (button-perceived affordance).

### C. An Evaluation of the High Fidelity Prototype

Considering the results of the previous evaluations, we now started evaluating the current high fidelity prototype focusing on the understanding of user’s information seeking needs. We visited an older adult to get an initial feedback from our “Calendar” and “Take Medicine” interfaces. She was 87 years old and she has never used a tablet device before. First, we asked the participant to write down her weekly activities and her prescribed medication on a paper-based calendar. We used this information to configure the Calendar to represent a real situation. During the test, we evaluated both the Calendar and “Take Medicine” interfaces.

1) Calendar Interface: The calendar interface was perceived as a good overview of scheduled activities and prescribed medication (directed information). However, we observed that the participant did not detect the scrolling possibility within the interface while seamlessly working with the other interface elements, such as buttons, etc. Furthermore, the undirected information in the calendar such as the status of the prescribed medication (i.e., whether it is planned, taken or ‘in conflict’ with another activity) is perceived as useful information. Regarding a possible conflict between a planned activity outside the home (e.g., playing cards) and the scheduled medication, the participant said “It would be very useful to know from this [MediFrame] that I should take it [the medication] with me”.

2) “Take Medicine” Interface: The “Take Medicine” interface was perceived as a good overview of prescribed medication that should be taken at a specific time of a day (directed information). The participant understood the name and dosage of each medication. However, she got confused when she noticed one incorrectly written medication in the interface. This shows the complexity with for example handling substitute medications that regularly can change names. Furthermore, the undirected information in the interface, such as side effects and what the medication is for, which appear when the user presses the additional medication (“I”)nformation icon, was perceived as important. The participant said: “If I have doubts about it… if I shouldn’t take to many of them then I would look at it ([“I”]nformation icon) to find out if it is not good to take it more than once a day”. The participant stressed that information regarding how long a person should take a medication, and whether it is temporarily or not is desirable. She said “it would be nice to know… if you have to change it [medication] after a while or if I should continue for the rest of my life”.

As a result, it was clear that MediFrame relies on the user’s active search and browsing of information. In general, the results were positive regarding the overview of information. The participant said “I think this [MediFrame] is very good even thought I am against technology...”.

### VI. MediFrame Use Scenario

We developed envisioning and use scenarios during our design process to explore and validate our concept. The MediFrame functionality, to a large extent, enables these scenarios. We present a use scenario based on experiences from our design process to illustrate the use and benefits of MediFrame.

It is early Tuesday morning and Ann wakes up and has to take her Alendronat (bisphosphonate) for her osteoporoses half an hour before she eats her breakfast. Ann wakes up around 7 o’clock every morning and has configured MediFrame to remind her to take her medication immediately when she wakes up. MediFrame opens up the ‘Take Medicine’-view. Ann confirms taking the Alendronat by tapping on its icon. If Ann makes a mistake, for example tapping the wrong medication she can simply ‘undo’ the action by tapping the erroneous selection once again. Now Ann concludes the activity by tapping “Done” as no other medication is scheduled now. MediFrame plays a comfortable melody to confirm the action, which makes Ann confident in her medication intake.

Later today Ann is going to the elderly centre to play bingo from 10 to 12 AM. Today Ann and her friends are...
staying at the centre afterwards to eat lunch together. Before she leaves her home she opens up the MediFrame Calendar-view and becomes aware that she should bring her noon-medication (for her back pain and diabetes) as her daily activity and scheduled medication are overlapping. Ann collects her noon-medication in her purse and leaves for the elderly center.

In the evening Ann’s son Thomas and her grandchildren are visiting for dinner. Thomas is cooking dinner. Ann notices a head of cabbage and recalls some complications eating cabbage with her daily intake of anticoagulant medication (Marevan). She activates the Medication-view where all her medication is listed. Here Ann can see a detailed description of each medication, when to take it, how much to take, side effects and what kind of food/drinks she should avoid when taking it. Ann selects Marevan and a part of its patient information leaflet is presented and confirms that she should not eat cabbage because it contains vitamin K, which reduces the effects of the anticoagulant medication.

The grandchildren are having a sleepover at Ann’s house the same night, which means that Ann spends some time finding the mattresses and making their beds. Because of this breakdown of her normal routines, she questions whether she took her evening medication after dinner or not. MediFrame can help Ann to recall her medication intake as this is registered in the Diary-view. Hence, she checks My Diary that confirms she indeed has taken her evening medication. MediFrame makes Ann feel secure in her daily medication management and she can go to sleep not worrying about it.

The presented scenario illustrates several challenges in Ann’s medication experience. In addition, the scenario shows how MediFrame can support Ann’s medication intake especially when the routines are broken. We now discuss and present the lessons learned during our design process.

VII. DISCUSSION AND LESSONS LEARNED

Based on our observations and the input gathered during our design process, we will now discuss lessons learned during the MediFrame design process.

A. The Use of Tablets by Older Adults

MediFrame facilitates the transition between the clinic and the home by supporting people to manage their daily medication intake. The older participants in our study did not previously use smart phones and tablets. However, all were positive about using a tablet that can help them gain more information about their medication. So far, they have used pillboxes, reminders and paper-based forms to track their prescriptions. Medication experts expressed a positive feedback as MediFrame can be seen as a tool that can mediate the communication between care settings. They emphasized that it is useful to know what is happening with older adults at home between consultations. One nurse commented that “It [MediFrame] can be a way to know why they are not taking their medication as we [nurses and general practitioners] don’t know why they come back after few weeks of discharge from the hospital”.

1) Introduction of Tablet Technology: It turns out to be a good strategy to give older adults an introduction to the iPad technology – how it works and how they can use it – before the test. This introduction helps us to discover their attitudes towards the technology as such. In one of our workshops testing a screen-based prototype, one participant (woman, 90 years) kept her distance to the tablet at the beginning of the activity. But after receiving the introduction she was curious about the tablet and engaged in our workshop.

2) Guidelines for Touch Interfaces: We have considered existing guidelines for designing touch interfaces provided by: 1) related work areas such as user interface design, mobile interface design and usability and accessibility for mobile devices, 2) specific work on touch-based interfaces for older adults, and 3) guidelines to design for older adults [42]. However, no previous work has suggested how to improve the design of tablet-touch interfaces that target older adults. Consequently, we have adapted the existing guidelines and validated some of them (e.g. “do not repeat the navigation…” to frame our design space. For instance, we decided to remove the main menu from the “Take Medicine” interface after the screen-based evaluation as users got confused having more functionalities than needed. Unsurprisingly, conceptual considerations such as “keep the user in control”, “good dialog design…” and “reduce short-term memory and cognitive loads…” [42] also apply for the design of tablet-based interfaces for older adults, but their application get a more important role in the healthcare context. For example, we changed the “Take all doses” (i.e. medication) button to a “Done” (i.e. task complete) button to add a confirmation step and avoid the laziness of pressing the “Take all” button without selecting all medications one by one. This concern was also discussed by our medication experts who support our design decisions.

We suggest that a further formal validation of the existing guidelines should be iteratively done through the use of prototypes to suit and design for older adults. In addition, a short, but concise, introduction to tablet technology and its use should be provided to users that have no previous experience of such technology (as our older adults) to enhance their participation in user tests.

B. The Taking Medicine Interface - Simplicity is the Key

As mentioned in section 4, the MediFrame design involved different actors during the design process. In particular, medication experts were concerned about the complexity of the medication regimen. They emphasized that a clear overview that contains all medications for a specific time should be visible to older adults on the screen. Previous work has applied the medication clock metaphor for medication management on a mobile device such as CollaboRhythm [48] and Colorado Care Tablet [36]. However, we found that the clock metaphor might be challenged due to the complexity of our older adults medication intake [19]. Indeed, the older adults in our study are taking up to 35 medications distributed across the day at different times. This complexity challenged our interface design as we moved away from our initial idea of metaphors as also suggested by [36] through the use of the diverse low-
fidelity prototypes. In addition, the medication experts stressed that simplicity is the key and that users might not want, or need, too much information on the screen.

The “Take Medicine” interface provides directed, active, medication information (search) by giving an overview of a specific time’s medication dosages at a glance. This facilitates the registration of the medication intake. An undirected active medication information (browsing) is provided by giving access to more relevant specific medication information by selecting the (“T”)information icon. This can support the medication intake by providing relevant information such as instructions of how to take a medication. Directed passive medication information (monitoring) is provided by the overview where the selected/taken medication changes color and a progress bar provides overview. An undirected passive medication information (awareness) is provided by medication reminders and warnings as a user wants to skip a medication.

1) The use of images: After our first users’ feedback (older adults and medication experts), we found that older adults rely on images regarding their medications. A medication expert said, “you [older adult] don’t need big pictures of the drug in this overview. Small size may be good enough”. Even though the use of images helps users to identify medications, the complexity of the medication intake was not addressed in early prototypes.

2) Addressing the complexity of the medication regimen: Medication experts see MediFrame as a medication checklist that can help them to track and remember whether or not the older adults have taken all medications for a specific time, specially during a complex regimen. Based on the Shneiderman’s visual information seeking mantra [43], we provide a medication overview where older adults need to register their medication intake. Considering the medication complexity and medication experts’ feedback, we defined a list with up to 10 medications that can be displayed for a specific time on the screen. For instance, one of our older adults took 5-6 different pills, 5-6 times a day. MediFrame is expected to support her medication intake.

3) Providing user’s identity: Medication experts expressed that “it is very important to see the name of the person which the information concerns”. Especially if the system can help more than one person. For example, spouses play an active role and there are cases in which the couple are taking the same medications (i.e. diabetes medication) as supported by our empirical material.

4) Facilitating the information seeking in the interface: Considering the feedback from the older adults and the discussions together with the medication experts, we took several design decisions to improve the visual information seeking. For example, the main menu was removed from the “Take Medicine” interface, a combination of textual information with a visual representation of the number of medications to take for a specific dose was provided, and a clearly distinction of all selected medications was applied.

5) The use of Low- and high-fidelity prototypes: The early paper-based prototypes supplied user feedback and helped us to identify different design problems. The early prototypes also challenged our participants as they had problems separating the MediFrame vision from the embedded limitation in the early prototypes. For example, they found that a tablet reacted “incorrectly” to their actions, as the system was not fully developed.

We suggest that a medication overview that supports the registration of user’s medication intake should be designed to support the four modes of information seeking behavior at a glance (i.e. no scrolling required): browsing, monitoring, searching and awareness. Designers can follow the information seeking mantra by applying and validating existing and generic guidelines for user interface to provide a medication intake overview at a glance. By doing this, designers can work around the technology constraints such as the limited screen size of a tablet device to find a balance between complexity and information seeking needs.

C. The Calendar Interface - Planning and Reminding the Medication Intake at Home

MediFrame aims to help people plan their medication intake by combining information across care settings. First, MediFrame uses data from the Shared Medication Record [9]. This information is currently generated at a clinical setting. Second, it uses data from people’s scheduled everyday activities that is generated in non-clinical settings.

Based on our fieldwork, we have encountered participants that do not have well-established everyday routines. Recalling Ann’s use scenario in the previous section, there are active older adults that have activities outside the home for example at the activity center. One participant showed us her agenda in which she writes all her appointments such as visiting friends, consultations, trips, and church visits. To provide medication awareness, monitoring, browsing and searching according to Bates’ model [39], the Calendar interface provides an overview of the current and daily medication intake combined with people’s scheduled activities (see Figure 2). The calendar provides directed active medication information (search) by giving an overview of several dosages of medications during the day or a week. This facilitates the planning and adjustment of medication intake when Ann needs to go out. An undirected active medication information (browsing) is provided by giving access to the specific medication information (e.g. what is this medication used for?). This information is provided when users search for that knowledge and tap of specific medication. Directed passive medication information (monitoring) is provided by the calendar using different colors for the medication icon. This helps users to remember whether or not they have taken a medication, and follow up their medication intake or look for conflicts between medication intake and planned activities like the red pill icon on the screen. Finally, undirected passive medication information (awareness) is provided by the calendar by giving warnings for possible conflicts between future medication intake and scheduled activities apart from the red color pill. The participant also experienced small problems regarding the scrolling in the calendar.

We suggest that a calendar interface for medication management should be designed to provide an overview of medication intake at a glance (limiting the scrolling as much
as possible) that supports the four modes of information seeking behavior: browsing, monitoring, searching and awareness. In doing so, MediFrame (or another similar application) can improve the visual perception and the information sense-making process. The overview can later be used as a cognitive artifact [49] that allows people to get a complete overview to recall a medication intake, plan (e.g. move and adjust a medication dose) and manage (set reminders) possible conflicts or breakdowns between medication intake and planned activities. Indeed, automated reminders of daily events and calendar mobility within and outside the home have been reported as important features to support calendaring routines at home [50].

D. Documenting and Providing an Overview and Knowledge about Medication at Home

As illustrated in Figure 5, the “Take Medicine” interface registers 1) the medication intake, and 2) information why a user might have skipped a dose. This can inform a later dialogue between the individual and the physician. During our evaluations, medication experts expressed the necessity of presenting the right additional information or instructions when supporting the current medication intake. While the Patient information leaflet is always distributed together with the medication, this information is not always available at hand. The leaflet might have been thrown away, misplaced, or not always easily to understand by the reader. The leaflet text is often rather small, something that can also challenge an older adult in comprehending the text.

We suggest that a medication overview that supports the registration of medication intake should be designed to integrate, and visualize, relevant parts of the medication leaflet in an understandable manner. To do this, it is important to get an understanding of the user’s information seeking needs in order to apply the information seeking mantra on the interface. By considering user’s information seeking behavior, designers can provide a more complete and fresh experience-based interaction schema as suggested by [51]. Moreover, helping users to document all the specific medication particularities at home and in practice can support physician’s information seeking according to specific care plan. This documentation can bridge the gap between laypeople and health professionals that exist between consultations due to the lack of knowledge about what is happening at home during a medication treatment.

VIII. CONCLUSIONS

We have presented the table-based reference implementation MediFrame. Naturally, an implementation of medication support can take many other forms and MediFrame represents only one attempt to interpret and work with a challenging group as older adults. As MediFrame is not a disease-specific application, MediFrame targets most medication situations including ‘according to need’ and substitute medications.

Our cooperative design process with older adults and medication experts helps us to define the main functionalities (calendar, medication, diary, reminder, according to need, taking medicine) for such a system, aiming to support medication management activities at home. We have described how MediFrame implements two of these functionalities in detail (calendar and taking medicine) and our lessons learned during the 10 months design process. The existing design guidelines that can be adapted for tablet-touch interfaces need to be further validated with users to see how the visual information seeking can be improved but getting a better understanding of the user’s information seeking needs. These strategies can help designers to improve tablet-touch interfaces for older adults supporting a holistic medication management activity and facilitating the information exchange between patient and doctors.

We argue that it is beneficial that a system automatically updates the individual medication; however, this automation provides new design challenges. For example, substitution medication handed out by the pharmacy can make the automated update process more complicated as the provided medication is different from the one written on the original prescription. While much research is still needed, this paper has shown the importance of looking beyond single strategies and solutions targeting a specific subset of users or diseases. Rather, there is a need to develop a more complete understanding of user’s medication information seeking needs in everyday life.

From our perspective, future work includes a more extensive evaluation of MediFrame and to investigate novel ways of working and implementing, integrated solutions to support older adults’ everyday medication management.

ACKNOWLEDGMENT

We would like to thank our colleagues and all participants, especially the elderly citizens involved in our project and the Lev Vel Consortium for their cooperation. Lev Vel is funded by The Danish Council for Technology and Innovation and The Capital Region of Denmark.

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Understanding Challenges and Opportunities of Preventive Blood Pressure Self-Monitoring at Home

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Understanding Challenges and Opportunities of Preventive Blood Pressure Self-Monitoring at Home

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ABSTRACT
The herein presented study explores socio-technical complexities that may occur when introducing preventive health-measurement technologies in older adults’ daily routines and everyday lives. Using mainly blood pressure measurements in private homes, the study applied qualitative and quantitative methods to understand existing challenges and uncover opportunities of self-monitoring technologies to support preventive healthcare activities among older adults. Emerging challenges from our study were: rule complexity for self-measuring, reliability of measurements, interpretation, understanding and health awareness, the sharing activity for prevention, motivational sources, the role of the doctor for prevention, older adult’s use of technology, the home as a distributed information space, and visualization of health data. An awareness of these challenges can help designers to develop better tools to support people’s preventive self-monitoring needs compared with existing solutions. Furthermore, supporting the active and informed citizen can improve older adult’s care abilities, awareness and activation towards preventive care.

Author Keywords
Preventive care; self-monitoring; home-based technology.

ACM Classification Keywords
H.5.m [Information Interfaces and Presentation]: Miscellaneous.

General Terms
Human Factors; Design; Management.

INTRODUCTION
The Danish social welfare state provides equal access to health care services for everyone. However, demographic changes challenge the Danish healthcare system as the population gets older and consequently age-related illnesses and chronic diseases follow. One example of an increasing age-related illnesses among older adults is high blood pressure (BP) [37]. For a general adult, high BP or hypertension is defined as a condition in which the systolic blood pressure (SBP – blood pressure when the heart is beating) is equal to, or greater than, 140 mmHg and/or a diastolic blood pressure (DBP – blood pressure when the heart is relaxed) is equal to, or greater than, 90 mmHg [29]. In Denmark, high BP is placed in the top five list of health risk factors [16] and according to the World Health Organization (WHO), high BP increases the risk of heart diseases and stroke [37]. WHO also defines high BP as one of the most prominent health risk factors in developed countries (among others such as obesity, high cholesterol, and tobacco consumption) [37]. In Denmark, 16% of the men and 19% of the women have severe hypertension, and high BP has reduced the life expectancy of Danes by 9 to 6 months (numbers from 2007) [16]. To address challenges related to an increasing older population, such as high BP, there is a neo-liberalistic idealism to motivate Danish citizens to take responsibility of their own lives and healthcare management [27].

Institutional care is more resource-demanding compared with home-based care [11] and for people over 60 years old, moving from an independent to a dependent life situation is a major concern [19]. As a consequence, enabling citizens to be self-sufficient and sustain an independent lifestyle is one preferred strategy to reduce health care costs [5]. Shifting from a disease to a (proactive) individual health management promotes both home-based and preventive healthcare in society [4, 34]. Home-based self-monitoring technologies can be one way to support a continuous independent lifestyle among for example older adults. Home-based self-monitoring of diverse health parameters can also limit the ‘white coat’-phenomenon [29]. The ‘white-coat’-effect occurs for example when a person shows higher BP values at the hospital due to anxiety of being in a clinical environment, or vice versa (normal readings at the hospital and high values at home). This phenomenon has been identified to be particular evident in the older population, together with specific BP conditions (i.e. isolated systolic hypertension, hypotension, postural and postprandial hypotension, and pseudo hypertension) [29]. The variability of BP and its importance [39] for older adults makes BP a suitable candidate for studying self-monitoring technologies.

The purpose of this study is to explore socio-technical challenges of using preventive self-monitoring technologies. Through a research and innovation consortium [23], we have investigated the role of home-based preventive self-monitoring technologies with a focus on BP monitoring. The project served to a) gain a better understanding of preventive self-monitoring activities done by Danish citizens (e.g. older adults), b) collect people’s concerns and attitudes regarding preventive self-monitoring technologies, c) get an overview of what challenges people have when performing preventive self-monitoring activities, and d) explore and uncover opportunities to facilitate preventive self-monitoring activities.

In this paper, we present challenges that emerged from our BP study related to: the rule complexity for self-measuring, reliability of measurements, interpretation, understanding and health awareness, the sharing activity for prevention, motivational
factors, the role of the doctor for prevention, older adult’s use of technology, the home as a distributed information space, and visualization of health data. Then, we propose a set of design opportunities for preventive self-monitoring technologies that can facilitate their integration into older adults’ homes and everyday activities.

Before introducing our user studies, we will discuss related research focusing on older adults, non-clinical care management, and preventive self-monitoring technologies.

**RELATED WORK**

This section describes the aging process, the concept of preventive care, and introduces preventive self-monitoring technologies.

**The aging process**

The World Health Organization (WHO) states that there is a necessity to “reinvent our assumptions of old age” to promote healthy living [38]. As suggested by Fisk et al. [10], we acknowledge aging as a process within three dimensions (biological, psychological, and social) and that age is also task-context dependent. Fisk et al. also state that chronological age is suitable only as a marker for behavioral changes. Furthermore, Rockwood et al. [31] state that older adults in a clinical setting have different needs regarding the use of healthcare services. Rockwood et al. redefined the concept of frailty as a dynamic model in which the balance between assets (e.g. health, attitudes, resources) and deficits (e.g. illness, disability, dependence) can help to determine people’s independence level. Thus, an unstable balance between assets and threatening deficits can be used to identify frail older adults [31]. According to their model, a 50 years old adult who might have experienced a severe deterioration of function (biological, psychological, or social) due to for example cancer might fall in the group between healthy and frail older adults. As older adults can experience different healthcare needs [26, 31, 33], special attention should be given to older adults who fall between the two groups (healthy-frail) as they most likely can benefit from preventive care activities [33].

**Preventive care**

Mallery et al. [26] define prevention (in a healthcare context) as any action that “delays disease or slows its progression”. Preventive health measures include primary, secondary and tertiary interventions [33]. Primary prevention focuses on decreasing the risk of an illness to appear (i.e. immunizations and health promotion). Secondary prevention focuses on early detection and treatment, especially for asymptomatic diseases (e.g. cancer, hypertension and dementia). Tertiary prevention focuses on rehabilitation to slow deterioration and decrease disability of symptomatic but unreported illnesses by using a comprehensive assessment of function (i.e. physical, psychological and social) [18, 26, 33].

Kane et al. [18] present four main areas of interventions for preventive strategies: 1) specific conditions or illnesses that result in dysfunction (e.g. cardiovascular diseases, cancer), 2) risk factors that can be categorized as unhealthy behaviors rather than illnesses (e.g. smoking, lack of exercise, unhealthy diet), 3) conditions that require caregivers’ interventions (e.g. depression, drug abuse, visual and hearing impairment), and 4) dealing with consequences of caregiving and medical care (e.g. drug side effects, function disability of overprotective environments) [18]. Furthermore, it is important to understand the differences and similarities between prevention and promotion in healthcare [6].

Many health promotion measures (e.g. for older adults) are related to primary or tertiary prevention and aim for behavioral change in older adults at risk or to improve their functional capacity [6, 26]. However, lifestyle changes or preventive care activities (e.g. healthy diet, regular exercise, avoiding alcohol or smoking) might be sufficient for some, but not all, healthy older adults. As older adults are not a homogeneous group, preventive care that aims to modify a risk factor after its effects has been identified might not be effective, especially for frail older adults [18]. An older adult with a diagnosed symptom may need monitoring and an individual assessment, including medication adherence-support, to control a specific condition (e.g. high BP [37], diastolic dysfunction [36]) and avoid excessive or insignificant treatment [29]. For example are people over 80 propense to diastolic issues (a lack of arterial-blood oxygen when the heart is relaxed) [36].

Furthermore, similarities and differences between chronic-illness management and prevention do exist and have been analyzed by Glasgow et al. [13]. They also investigated whether or not the chronic care model (CCM) proposed by Wagner [35] is suitable for prevention. Similarities include: a) ongoing planned care with “proactive follow-up”; b) complexity due to multiple health behavior changes or risk factors; c) illness/reactive care is inadequate; d) active patient involvement is required; e) patient activation tailoring shared decision making with physicians is important. Differences include: a) visits to the doctor for prevention are less frequent than for chronic illnesses; b) patients with chronic illnesses have stronger motivation to change health behaviors; c) patients’ care needs are greater for chronic illness care (e.g. medication adherence [7]); d) prevention often happens outside the medical culture; and e) prevention is less often tracked [13]. Although differences and similarities do exist, Glasgow et al. [13] suggest that an extended version of CCM can be suitable to understand, improve and develop preventive care. Our study recognized these similarities and differences to better understand preventive self-monitoring practices at home.

**Preventive self-monitoring technology**

In comparison with disease management technology, preventive healthcare technologies have been less studied [4]. However, examples do exists such as Beaudine et al. [3] that use mockups of diverse visualizations to reveal user reactions to home monitoring for proactive health and wellbeing. One of the most common examples about prevention is accident detection (e.g. falls) that has been addressed using sensors and algorithms [9]. Furthermore, self-monitoring of health parameters, as part of primary prevention, has been tightly coupled with health promotion and challenges related to lifestyle and behavior changes [20]. In secondary prevention, the concept of embedded assessment have been introduced by Morris et al. [28] to promote the early detection of health conditions. Early detection should integrate monitoring, compensation, and prevention to provide a value beyond the assessment to address clinical (e.g. infrequent, delayed and limited focus of assessment) and individual (e.g. privacy concerns, complex terminology, self-monitoring devices constraints, fear to diagnosis of diseases) barriers [28]. In addition, tertiary prevention is exemplified by monitoring how often and how well instrumental activities of daily living are performed by aging adults [21].

However, these technologies might not be enough to support preventive health self-monitoring as this might require: 1) a better
understanding of preventive self-monitoring needs [25], and 2) a proactive activation of people’s self-care abilities [13, 35] for prevention to complement the role of the “informed, activated patient” [35]. Based on the related work, we investigated challenges that older adults can experience in day-to-day preventive self-monitoring.

**USER STUDIES**
The study integrated qualitative studies and a quantitative survey across the following three main steps. First, an initial and exploratory phase to define a relevant target group was conducted using interviews and cultural probes. Second, we selected a specific health parameter of interest (i.e. blood pressure) for our study. We conducted several workshops, semi-structured interviews and blood pressure self-measurement activities in people’s homes. Finally, the third step was based on a quantitative study for data verification and further exploration. These three main steps are described in the following subsections.

**Defining our target group**
An initial qualitative study took place including ten participants (four women, six men) with an average age of 61.8 years (SD 11.95). Since chronological age was not a central issue, participants were selected according to their relation to the Danish healthcare system matching the three levels of preventive health measures (i.e. primary, secondary and tertiary prevention [33]). Four participants were categorized in the primary prevention group (one healthy without diagnosis and three taking preventive medication and in risk of getting into treatment), three participants were categorized to be in the secondary prevention group (people with chronic diseases that have changed their lifestyle to prevent further deterioration due to the illness), and three participants in the tertiary prevention group (two people in physical therapy after arterial thrombosis and one previous cancer patient). Participants were interviewed regarding their motivation in relation to the knowledge they had of their current health status, their health data sharing needs, what motivates them to change behavior, their use of self-monitoring technologies at home, and their experience regarding self-monitoring technology being perceived as beneficial or not. Additional material (photos taken by the participants using disposable cameras) was collected as probes.

**Exploring challenges**
Based on knowledge from the previous step, we decided to focus on people that are motivated to maintain an existing healthy condition and avoid the decay or the onset of illness, i.e. prevent fragility. We then recruited a new group of participants from a local activity center. The participants were ten active older adults and perceived themselves to be rather ‘healthy’. They were between 65 and 84 years old. At the activity center our work extended into a user-involved design process including interviews and workshops together with the older adults. We investigated challenges and attitudes towards the preventive action of blood pressure self-monitoring. We selected BP for analysis of self-monitoring due to its complexity (number of instructions to follow in order to perform a valid measurement), importance (relationship with other risk factors in the Danish context), and its availability (e.g. presence of blood pressure devices at older adult’s homes) identified through the initial photography probes.

**Understanding self-monitoring activities**
An early goal for the project team was to get a better understanding of self-monitoring activities and its importance regarding older adult’s own health status. The workshop participants received an introduction to BP (causes, symptoms, consequences, actions to control BP) and how to measure it by the nurse affiliated with the project. During the workshop participants were asked to take their own BP (see Figure 1a) and they all engaged in the activity using a digital BP device. A group discussion was performed during and after each activity. Findings from the first workshop indicated that the complexity of the BP rules challenged self-monitoring activities.

**Understanding older adults’ routines**
A second workshop was conducted after two weeks. We employed a modified version of the Day Reconstruction Method (DRM) [17] to further investigated older adults’ daily routines. We applied our modified DRM to explore difficulties and possibilities in integrating BP measurement activities in everyday routines.

As part of the workshop, participants engaged in a drawing and
reflection activity regarding their homes and daily routines (see Figure 1b). In detail, the workshop participants were asked to: a) draw a sketch of their homes (see an example in Figure 2a), b) list their activities before they leave home (in the morning or when they consider their morning to be concluded) and after they arrive home (in the afternoon, or when they perceive that they started their ‘evening’ activities), c) order the activities using numbers on the drawing. One researcher gave an example of how to draw the sketch of the home and how to list the activities before the drawing activity started. One senior needed assistance from a researcher to conduct the task. After the activity, participants shared their sketches and routines. This was followed by a group discussion about the possibilities and implications of using self-monitoring technologies across their daily activities.

Performing a self-measurement task
Findings from the second workshop revealed differences between older adults’ morning and evening routines. In general, the evening routines were less homogeneous and stable due to an active lifestyle. Therefore, we further investigated how older adults could perform self-monitoring activities at home and the participants were requested to perform BP self-measurements until the next workshop.

The participants were provided digital BP devices and were asked to measure and register their own BP for at least three days (mornings and evenings) in a row during a one week period (as suggested by the nurse and according to existing guidelines on how to perform a correct BP measurement at home) [30]. These guidelines (e.g. do not smoke, drink coffee, eat or consume alcohol half hour before the measurement) were given verbally and on a paper to the participants. The participants also received a paper-based template where to register and log their BP values. The template included fields such as date, time, higher value (systolic pressure), lower value (diastolic pressure), pulse and a space for additional comments i.e. which arm they used to take the BP (see Figure 2b).

Validation and Interpretation of BP values
To share their experiences regarding self-monitoring and to validate the previous findings, the workshop participants were invited to a third workshop. At the workshop, the participants presented the collected BP information, the BP rules they had applied and difficulties during the task.

Next, we investigated what and how BP information can be presented to older adults in an understandable way. The participants were given eight different color image-pairs, combining weekly and daily measurement overviews to elicit feedback regarding visualizing data from self-monitoring technologies as suggested by [3]. Examples of these weekly and daily overviews are illustrated in Figure 3. For example, the weekly BP overviews were represented in three different formats using: 1) encoded charts with icons, circles, starts and squares without specifying an exact value (see Figure 3a); 2) vertical and horizontal bars (see Figure 3b); and 3) line charts (see Figure 3c). Furthermore, the daily overviews were represented by four different formats using: 1) icons to represent a specific BP values (see Figure 3d); 2) text values of BP (see Figure 3e); 3) speedometers visualizing BP values (see Figure 3f); and 4) encoded charts using BP values (see Figure 3g). These weekly and daily visualizations were combined and one pair was shown at the time. The participants commented and gave feedback on the presented visualizations. Finally, the participants engaged in a group discussion about how to visualize and facilitate interpretation of health data for citizens that have no previous knowledge of medical data.

Quantitative study
The workshops provided a deeper understanding of the challenges related to self-monitoring activities, especially for independently living older adults that like to prevent fragility. However, we wanted to include a broader population to further explore self-monitoring activities and the workshop results. We developed a
quantitative study (a Danish web-survey) that touched upon the same questions as the initial qualitative study. The survey also included questions regarding current health status (e.g. any chronic disease) and personal information (e.g. age, gender, location). We received 191 responses to the survey, but only 165 were completed and considered in our analysis. Participants were adults between 22 – 83 years old.

CHALLENGES OF PREVENTIVE SELF-MONITORING
In our quantitative survey, 131 respondents (out of 165) do not have any chronic disease and 86 of these participants own a health self-monitoring device. This indicates that people without any chronic condition are interested in their own health, keeping a desire ‘to stay young’ as long as possible. In the study, nine themes emerged from a combination of the most relevant topics and discussions sprung out of from the workshops and other user activities (inductive) and the most relevant issues regarding self-monitoring (e.g. lack of contextual information, privacy issues, difficulties understanding clinical terminology, attitudes and perceptions of people about self-monitoring, and problems with measuring devices [1, 28, 30, 34]) from the literature (deductive). The nine themes related to home-based self-monitoring were: 1) rule complexity, 2) reliability of the measurements, 3) interpretation, understanding and health awareness, 4) the sharing activity for prevention, 5) motivational sources, 6) the role of the doctor for prevention, 7) the use of self-monitoring technology, 8) the home as a distributed information space, and 9) visualization of BP values. We now present the nine challenges that emerged from our study and how to support a successful integration of preventive BP self-monitoring in everyday life.

Rule complexity
The first challenge for preventive BP self-monitoring is rule complexity. Rule complexity relates to the rules a person must adhere to guarantee a valid (BP) measurement. For example should one sit and rest for 5 minutes before taking the BP. Our workshop participants mentioned several difficulties in measuring BP in accordance with the established rules. A challenge was that they did not (perceive to) have enough time to correctly take a measurement (and hence apply to the rules of rest before a BP measurement or other time-constraining rules such as not eating, drinking or smoking 30 minutes before the measurement). Indeed, older adults may have other activities than self-monitoring to attend during the day.

When examining the self-documented data from the monitoring activity at home, it was clear that all participants performed their morning BP measurements. However, some participants experienced difficulties integrating the evening measurements into their lives and hence omitted the evening measurements. Thus, developing and adjusting routines to suit the BP rules was complicated during the evening due to for example an active lifestyle. Indeed, a male participant with a very active social live could not find the time to carry out the preventive measurement task for three days (2 measurements a day) in a row (this configuration was suggested by the project nurse). He said “I cannot do it this week [looking at his agenda], maybe next week I can try...”. Analyzing the drawings the workshop participants made of their homes and the herein situated activities confirmed the characteristics of morning and evening measurements. We found in general that the morning routines were more established than the evening routines, as they appeared more stable and were easy to recall for the participants.

Reliability of the measurements
This challenge concerns the reliability of measurements taken by laypeople in their homes. Due to for example rule-complexity in conducting valid home-based measurements and the lack of contextual information during the measurements, the reliability of the measures can be compromised. For instance, the participants had to take more than one BP measurement to assure and verify their measurements. Four of the participants performed the measurement two or three times in a row on either one or both arms (this being contextual information). Even though we asked them to write down such contextual information (e.g. if they have rested, talked or smoked before or during the measurement) that can indicate non-adherence to the rules, the only information they wrote down was about which arm the measurement was from. When the contextual information is missing or misleading, readings can show an erroneous value, without being explained why, that might not reflect the current condition. For example, the readings might show hypertension stage one, but this could be related to missing information (e.g. the participant did not follow the guidelines and did not report the rule non-adherence) around the measurement. We also observed that measurements could be unintentionally done in a non-correct fashion, for example due to a misplaced cuff on the arm. We additional found possible misreporting due to handwriting mistakes or a non-functional device.

Interpretation, understanding and health awareness
People should not only become aware and understand the consequences of unintentional mistakes or misreporting that can compromise the reliability of the measurements. They should be able to interpret and understand the meaning and consequences of the measurements. From the initial qualitative study, a participant said “the weight scale shows too much. Could my weight be a side effect to the pills? I can feel and see that I have gained weight”. From our workshop activities it became clear that the participants were well aware of, and understood, the importance of lowering their BP if they were measured with a high BP. However, how to lower the BP was less understood and the participants were interested in knowing more about how they could decrease their BP value.

In general, participants could use the BP measuring device provided by us after a limited initial training. However, moving from a correct device usage to a proper understanding of the measurements (i.e. the numeric values of the BP) was more challenging. While the participants managed to take a proper measurement, they failed to understand, or interpret, the acquired values. For instance, half of the participants had their BP value over the normal level when they did their first measurement and hence the nurse asked them to repeat the measurement on the opposite arm to compare the BP values. The nurse suggested that the lower value (taken from either of the two arms) should be considered as the reference point for future measurements. The nurse stated that a higher value in a specific arm is due to an obstruction of the arteries in the side of that arm. The nurse played an important role explaining the meaning of the values in each arm and the importance of taking the measure at least twice a day (morning and evening) three days in a row.

When reporting the BP measurements using the provided paper-based templates, participants use symbols (e.g. lines and ‘+’- signs) to group them and identify values within the normal BP range. The participants also took additional readings from both
arms to compare and understand the BP values and hence support the interpretation. Furthermore, an understanding of their current health situation can support older adults in getting a sense of health awareness towards maintaining or achieving a better health status. A participant from our qualitative study stated “For many years I forgot about exercise. 5-6 years ago I had a case of slipped discs. I have avoided surgery with the help of painkillers and exercise”. Thus, an interpretation and understanding of the current health situation can help older adults to achieve better health outcomes. In general, we confirmed that high blood pressure is indeed a non-communicable disease as people may not be aware that they have a high BP. As previously stated, two participants left the project after becoming aware of their high BP.

The sharing activity for prevention
The workshop participants all had concerns about sharing illness-related information and performing measurement-activities outside the household. It was for example not acceptable to perform BP measurements at a friend’s house or at a restaurant, not even if they went to a more private space such as the restroom. It should be noted that the measurements were related to preventive monitoring, rather than monitoring of an identified illness. This can have, as a minimum, two effects: 1) the older adults did not feel that it was a matter of “life or death” if they did or did not perform the BP measurement, and 2) they did not like to deal with health-related issues (preventive care) if their activities (planned or not) could be miss-understood as illness-related. This was confirmed by the qualitative study. For example did one participant state “I'm not interested in coming off as being sick, because I'm not”. In general the respondents from the quantitative study were not willing to share their own health information and preferred to not involve others in their health management. However, 63% of participants mentioned that they would like to share their data with their physicians if needed. In contrast, some participants from the qualitative study shared the interpretation task with someone from the immediate family, for example a spouse, to add a confirmation step and see if the measurement was correctly taken.

Motivational sources
When the workshop participants understood the importance of BP measurements, they further asked questions and showed more interest in our activities. In the project, we identified three main motivational sources. The first one came from the individuals and their feelings of independence. A participant from the qualitative study expressed "To have to be dependent on others I don't like that. I would rather be able to do it myself." In particular, the older adults in the qualitative study expressed major concerns regarding the feeling of being independent. A participant said, “It is hard to have to depend on others, and to continue to do so". The second motivational source derives from social relationships and a general interest in health. For instance, the qualitative study participants mentioned reasons for why to engage in preventive self-monitoring. A female participant said that (she and her companion) would like to continue to be able to take care of their grandchildren, love each other and live their lives. In the quantitative study, 42 participants had acquired a self-monitoring device due to a general interest in their own health.

The third motivational source came from the performance of daily activities. Participants expressed a desire to continue being able to do the things they normally do and remain in their homes as long as possible. For instance, a participant from the qualitative study expressed “Going out and shoveling snow##I was surprised by how well it went. Our house is in a corner area, so there was a lot of snow. But I wanted to do it! I am a little stubborn. I have to continue to be able to do the things I have always done”. This was confirmed in the quantitative study where 43 participants (out of the 110 respondents that owned a self-monitoring device) use monitoring devices for prevention as they would like to remain ‘as young as possible’ and monitoring their health can help them to achieve that.

The role of the doctor for prevention
The quantitative study shows that 75% of the participants that use self-monitoring devices for prevention would like to use them as a supplement of the existing health services (e.g. counseling, doctor visits, etc.). But only 60% would use them as a substitute. Older adults are more reluctant to replace primary healthcare with self-monitoring technology. However, the study shows that older adults are willing to acquire new self-monitoring technologies to maintain or improve their health, but only after the technology has been out on the market (22% of the older respondents) for a while and been tested on beforehand (30% of the older respondents).

During preventive care activities, the role of the doctor can take a more advisory function. The study showed that participants did not consider involving the doctor unless they are really sick or their measured values are not within the normal range. Here, doctors can help in the interpretation of the measured values or support and follow up on people that perform preventive care activities. Such activities might support people to get self-confident with preventive self-care activities. A participant from the qualitative study expressed "The last two years we have been able to get health checked through the company. But I always knew approximately how my health was, but it is always nice to be confirmed in your believes and get a self-esteem boost. It also shows that the way I chose to live ... that I don't really need to make any changes. By getting several checks you can also see a trend, which tells me where I'm heading. That is a good indication".

The use of self-monitoring technology
The workshop participants had a rather general understanding of technology. They all had mobile phones and modern household appliances. They were to some extent interested in computers, as they all followed a beginner’s computer class at the activity center where we arranged the workshops. The participants (except from one, that later withdraw from the project) did not have previous experience using a BP measurement device at home. However, they could all use the digital, off-the-shelf BP measurement device after its introduction.

From the quantitative studies, we could see that health-monitoring technologies have presence in people’s homes. Heart rate, BP monitors and pedometers were the most frequently available devices among the 131 respondents without chronic conditions. Furthermore, they would prefer to automatically measure: 1) physiological parameters such as weigh and blood pressure (89), 2) their diet (74), 3) wellbeing parameters such as depression, stress, etc. (44), 4) cognitive functions such as memory, analytical skills, etc. (43). 24 participants replied that they would not like to measure any health data about themselves.

Regarding older adults, participants would prefer to automatically measure physiological parameters (47), diet (24), wellbeing (18),
cognitive functions (21) and 12 older participants replied that they would not like to measure any health data about themselves.

In addition, BP devices were also found in people’s homes during the initial qualitative study through the collection of cultural probes. This confirmed our selection of BP as the main health parameter for this study.

The home as a distributed information space
When the project participants drew sketches of their homes, it was possible to observe how the older adults visualized and communicated their routines. After analyzing the drawings, four similarities emerged: 1) there are common places for specific routines among the participants (e.g. brushing the teeth or hair happens in the bathroom), 2) morning routines are more established than evening routines (as explained above), 3) activities can occur in one or more places (e.g. reading the newspaper), and 4) more than one activity can take place at the same time (e.g. eating breakfast and reading the newspaper).

Visualization of BP values
Our workshops revealed that older adults have some difficulties understanding BP readings. Even though they could perform the measurements, they experienced difficulties interpreting the resulting values (as described above). Thus, we explored different ways to enhance their understanding of BP data using mockups visualizations.

In this activity, we explored two levels of information, the weekly overview and the detailed view of measured values from the current day as illustrated in Figure 3.

Weekly overview
First, participants found the visual encoding of the charts useful. They used it as an indicator of the meaning of the different BP values such as low, normal, borderline, high, and very high (see Figure 3a). A workshop participant expressed “it is simple and easy to understand...”. However, they felt that the charts were not precise when the BP values are not shown and they would like a combination with the line charts (see Figure 3c).

Second, participants found the simplicity of the line chart useful. However, some participants did not find the dots in the curve as relevant. For example, one participant commented, “...maybe you can add the smile-faces on the curve”. This presupposes that people might need to know the different meaning of the smile-faces if they are associated to the home-based measurements.

Third, participants agreed about a simple way to see the actual value of the measurement through the bar graphs (see Figure 3b). However, they did not understand the meaning of the values and suggested that the pillars could relate or have indicators or some mechanisms to present the meaning of the value.

Daily details
First, participants found the icons useful but also indicated some problems with the iconic data representation (see Figure 3d). A workshop participant expressed “It is simple, appealing and funny, and it is easy to understand but not precise”.

Second, participants relied on text values as they allowed them to simply extract and see the actual measurement-value (see Figure 3e).

Third, some found the speedometer useful (see Figure 3f) saying that it is ‘kind of’ ok since the blood pressure is like a speedometer. One participant said “it [blood pressure] goes up and down”. However, they also agreed that in some cases a speedometer might not be precise.

Finally the participants found the color indicators of the encoded bars – “red-toned bars” useful and perceived them as a good strategy to show the daily measurements. A participant said, ”The idea of the daily overview is kind of ok” (see Figure 3g).

DESIGN OPPORTUNITIES FOR PREVENTIVE BLOOD PRESSURE SELF-MONITORING
The findings indicate that current (BP) self-monitoring technology cannot fully support the needs of preventive self-monitoring in practice. The complexity of the rules that should be followed to guarantee valid BP measurements and the lack of contextual information may for example compromise the reliability of the measurements. Even though participants were able to take the (morning) measurements in a complex distributed information space such as the home, they failed to interpret and understand their measurements.

In this section, we discuss design opportunities for home-based self-monitoring that aim to enhance people’s abilities for self-care and promote preventive self-monitoring activities at home.

Rethinking preventive self-monitoring of health parameters towards a positive experience
Most monitoring devices have been designed taking the clinician’s perspectives into account to help people, including older adults, to monitor health parameters to gain control and/or prevent illness and disabilities [28]. However, current monitoring devices have, to a large degree, neglected personal perceptions and the motivation that make people control their health and wellbeing. Exploring the social aspects of people’s everyday life can increase motivation to perform self-monitoring (e.g. RunWithUs [12]). As described earlier, there are different motivational sources that people have that go beyond the actual self-measuring activity. Older adults want to be independent as long as possible and continue with the activities they are used to, stay longer in their own place, etc. The social environment is really important, as older adults want to stay active and be able to visit friends, attend the activity center, travel or take care of their grandchildren. To not consider older adults’ motivational factors might negatively influence the use of preventive self-monitoring in everyday life. Most of the participants considered preventive self-measurements as an individual activity that should be performed at home and not in a social environment. The participants feared they might be perceived as ill when they are not.

Furthermore, the complexity of the rules associated with bio-measurements turns the preventive self-measurement tasks into a complex endeavor that interfere with everyday activities. Hence, considering the peculiar characteristics of preventive self-monitoring, there is a need to provide older adults and society in general with a positive experience regarding self-measurement activities. Creating a positive experience may imply rethinking preventive self-monitoring as a tool that can allow people to achieve their personal goals driven by their own motivation. A positive experience associated with the use of preventive self-monitoring technology can facilitate a better integration with older adults’ daily routines. This integration might facilitate older
adults’ participation in self-care activities and should be considered from the beginning of the design process [14]. Indeed, as Bannon [2] proposed more than 20 years ago, we should consider humans as actors and not factors.

In society, a positive experience might increase the sharing of health information with close family members and friends as monitoring can be seen, for example, as a wellness activity thus avoiding stigmatization.

Supporting the active and informed citizen

In order to support the active and informed citizen while performing BP self-monitoring at home, healthcare technology designers should (re) consider the role of older adults as proactive people [32]. Furthermore, a proper understanding of why people follow a health intervention (e.g. using prescribed medication or doing self-monitoring) is needed not only to enhance the individual health awareness but also to facilitate its integration in people’s everyday life [7]. As stated in this paper, older adults want to interpret, understand and get meaning from the measurements in relation to their current health status. Thus, self-monitoring can support this learning activity [8]. In doing so, the role of the doctor is shaped to support this interpretation process (as preferred for some of our participants) or to confirm their personal interpretation and understanding of the current health situation. To facilitate the interpretation and understanding of health data, visualization techniques can be used to provide older adults with the needed information at hand to improve health awareness [22]. For instance, our visualization activity reported that older adults rely on text values rather than icons. They want to know the exact values even if they do not understand their meaning. The workshop participants valued the visualizations as they gave both an overview and details of BP data (see Figure 3g).

By showing a combination of charts and a color scheme representing BP levels (low, normal, borderline, high, very high) visualizations complement and enrich the actual BP value on the monitoring device. A graphical interface that combine encoded and line charts (as suggested by participants) can provide a clear overview embedding temporal dimension (logging and sense making of BP data) to support older adults self-reflection processes.

Furthermore, the lack of contextual information inherent to the monitoring devices provides opportunities for Ubicomp and context-aware technologies to support self-monitoring practices of health data in and out of a complex distributed information space not only for chronic care [15] but also for preventive care. Self-monitoring technology for preventive care should provide the opportunity for older (and younger) adults to enter into a reflection process, regarding their health data and help them to take action on their own (current and future) health situation. Existing efforts on guidelines for data collection towards supporting self-reflection [24] of personal information are not yet reflected or available in self-monitoring devices at older adult’s homes. We suggest that a simple tagging functionality of contextual information (e.g. whether the measurement was taken before or after the breakfast or if the person has been drinking alcohol or coffee before the measurement) can help older adults to reflect and understand the dynamic nature of their measurements. The tagging functionality can also serve as a tool for validation of the reliability of the measured data and to enhance the user’s health awareness of their current health situation. Thus, using visualization and tagging techniques can facilitate the interpretation of health data and support the active informed citizen to learn about their own health.

All these aforementioned opportunities can support older adults’ health education and self-learning activities regarding preventive care.

CONCLUSION

In this paper, we have explored preventive self-monitoring activities in non-clinical settings for older adults. The study has focused primarily on BP measurements, but some of the herein presented findings may be applicable to other bio-monitoring scenarios. However, this should be further studied and understood as people might use diverse self-monitoring technologies for prevention.

Successful home-based, preventive health monitoring can be highly beneficial for both the individual and society. However, our study reveals a number of challenges that can lower the positive impact of these measurements, or even making them impossible. An example challenge is how to achieve a successful integration of the guidelines into an individual’s daily routines. If a successful integration can be made, opportunities such as a better understanding of what life-situations affects the body both positively and negatively can be obtained.

To support a successful integration of health self-monitoring (e.g. blood pressure) into older adults everyday lives one have to consider the individual motivational factors, the home as a distributed information space, and how health information are presented. For our participants, a precise representation of the BP-values was of utmost importance to facilitate the interpretation and understanding of ones’ health.

The findings from our study call for rethinking preventive self-monitoring of BP (and possibly other health parameters) to generate a positive user-experience by considering older adults’ perspectives, needs and desires. One way to provide this positive experience is by supporting the active and informed citizen in order to improve older adults’ health awareness while supporting their independence at home. These opportunities may be transferrable to other age groups, as more people are becoming aware and starting preventive care activities before they get older.

ACKNOWLEDGMENTS

We would like to thank all professionals and participants involved in the Lev Vel Consortium for their cooperation. Lev Vel is funded by The Danish Council for Technology and Innovation and The Capital Region of Denmark.

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by Erik Grönvall & Nervo Verdezoto

Published in the Proceedings of the ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp 2013), September 8-12, Zurich, Switzerland, 587–596. ACM Press.
ABSTRACT
Monitoring of health parameters in non-clinical settings is one strategy to address the increasingly aging population and age-related disabilities and diseases. However, challenges exist when introducing self-monitoring activities in people’s everyday life. An active lifestyle can challenge the appropriation of healthcare technologies and people with comorbidity may have diverse but co-existing monitoring needs. In this paper, we seek to understand home-based health monitoring practices to better design and integrate them into people’s everyday life. We perform an analysis of socio-technical complexities in home-based healthcare technologies through three case studies of self-monitoring: 1) pre-eclampsia (i.e. pregnancy poisoning), 2) heart conditions, and 3) preventive care. Through the analysis seven themes emerged (people, resources, places, routines, knowledge, control and motivation) that can facilitate the understanding of home-based healthcare activities. We present three modes of self-monitoring use and provide a set of design recommendations for future Ubicomp designs of home-based healthcare technology.

RELATED WORK
This section presents challenges of home-based monitoring focusing on user acceptance and how monitoring systems are inserted into everyday life. We also describe people’s care management routines in non-clinical settings.

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ACM Classifications
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Design; Human Factors; Management.

INTRODUCTION
Ubicomp technologies for healthcare are becoming more widespread, both in clinical settings and at home [28]. However, as reported by Arnrich et al. [2] two major challenges in pervasive healthcare are: 1) the shift from disease management to individual care management (e.g. from a centralized, reactive, information focus to a more pervasive, user and assistive focus); and 2) avoiding or delaying critical health situations (i.e. preventive care). Available off-the-shelf self-monitoring technology can support the aforementioned shift from managing illness to maintaining wellness through preventive care [28]. Technologies for self-monitoring include both wearable and non-wearable sensors, fill-in forms and guides for managing health and illness. Such technologies can provide integration with mobile and web applications [28] and allow people to collect and reflect upon their own personal health [18]. Examples include blood pressure monitor devices, Fitbit mobile Apps and devices (e.g. Flex, Zip) and Microsoft HealthVault. These technologies aim to improve quality of life by empowering people to take an active role in their own health management [10, 27]. However, most of these technologies have not been designed with a sufficient understanding of people’s needs and home-based practices [1, 19, 21]. Consequently, there is a risk that the amount of care management work increases instead of supporting and integrating care activities into everyday life [32].

Three home-based self-monitoring projects have served to investigate people’s illness and preventive health practices and self-monitoring needs. The cases of self-monitoring are: 1) pre-eclampsia (i.e. pregnancy poisoning), 2) diverse heart conditions, and 3) preventive care. The cases have served to analyze socio-technical challenges and dynamics of self-monitoring practices in non-clinical settings.

Challenges of Home-Based Monitoring Technology
How technology can support a patient’s transition from the hospital and back home has been widely investigated [1, 5, 13, 17, 21, 32]. Challenges can emerge as care and rehabilitation move into private homes and people that suffer from comorbidity or weakened by age are expected...
to engage in self-monitoring of their health. Challenges include the acceptance of technology in private homes [13], to find space, or a place, for the care technology within the home [4] and within everyday life [5] and how patients can transport and install medical and rehabilitation devices in their homes [13]. Challenges also include the reliability of self-measurement [3], clinical barriers to early detection (e.g. lack of knowledge about people’s everyday life), and individual barriers to early detection (e.g. underestimation of health variability, fear of diagnosis labels and stigmatization [31], privacy [21], lack of understanding clinical terms and health parameters) [22].

Many older adults do not perceive that healthcare technologies can significantly improve their lives [15]. However, Clemensen et al. [10] report a positive influence in quality of life, safety, acceptance and empowerment when home monitoring fits into a person’s everyday life. Older adults prefer technology that enhances personal and decision-making abilities over surveillance technology [21]. Designing for healthcare technology adoption, features such as simplicity, a person’s ability to control the technology and its perceived benefits should be considered [15, 27]. People tend to accept being a ‘patient’ at the hospital but when returning home (now as citizens) they have more preferred roles such as spouse, sportsman or parent [13].

**Care Management outside the Clinic**

Care management is complicated in both clinical and non-clinical settings. Home-based care involves both temporal and spatial arrangements and people apply home-made strategies to manage for example their medications [23]. Through boundary work people render objects invisible/visible and integrate/segment healthcare activities [31]. Indeed, care management in peoples’ everyday lives is highly context dependent (e.g. their home, activities, specific needs and desires) [1, 5, 8, 9, 23, 31]. The home-setting is an example of a complex and distributed information space that has been less studied as a place for care in comparison with the clinic [28]. Also Chen [9] shows the importance of patients’ health information use at home and how patients engage in self-management and self-learning activities during chronic care. There is a need to better understand healthcare activities across care settings [28], but also how technology can support home-based care activities and its integration into everyday life [5, 32]. Care activities can be both private and collaborative. A care network (e.g. family, friends, etc.) may get involved in everyday care of for example frail, older adults [11, 17]. The lack of understanding of home-based care practices where the individual living at home is the expert rather than the healthcare professional [5, 8, 9] can result in no, or even negative, effects on a person’s care management and life.

**Self-Monitoring Technology for Individual Care Management**

A range of self-monitoring systems have been developed to support people’s active involvement in their wellness and disease management [17, 28]. These systems include monitoring of vital signs, diseases, treatments and mental disorders [2, 20, 28, 32]. Simultaneously, self-monitoring of health parameters for wellness or lifestyle management has been tightly coupled with behavioral change such as losing weight and physical activity awareness [28]. An integration of these technologies with a Personal Health Record (PHR) can facilitate the collection [27] and self-reflection [18, 20] of health information at home. However, most systems focus on one particular illness, treatment, lifestyle problem or user-group (e.g. older adults) [13]. In addition, if guidelines for measuring bio-values (e.g. home blood pressure monitoring [3, 14]) and contextual information [14, 28] are not considered in self-monitoring designs, the quality of the measured values cannot be guaranteed.

As exemplified this Related Work section, we must better understand how self-monitoring activities are situated in people’s everyday life. The three case-studies enabled self-monitoring activities at home with the aim to support people’s health management [28]. Instead of focusing on a specific population or self-monitoring device, we investigate home-based care practices. We include both healthy and frail people to get a broad understanding of non-functional aspects in everyday self-monitoring activities. This understanding has implications for future personal and home-based healthcare technology designs.

**METHODOLOGY AND CASE STUDIES**

We undertook an exploratory case study approach [24, 30] that emphasizes the study of close-real life situations and how they unfold in practice. The three cases were purposefully selected (purposeful sampling [24, 30]) to reveal socio-technical challenges and dynamics of self-monitoring practices in non-clinical settings. Figure 1 provides an overview the cases and their involved main actors, devices, locations and internal relationships.

Initially, we undertook an exploratory case study [30] of the pregnant women with severe pre-eclampsia (pregnancy poisoning). These pregnant women monitor their condition at home instead of being admitted, or constraint to do daily visits to the hospital. Our work developed into a multiple case study [30] by adding two different cases (heterogeneity sampling suggested by [24]) to further challenge and extend the socio-technical conceptual framework derived from the initial case study (as suggested by Yin [30]).

![Figure 1. The cases and their socio-technical configurations.](image-url)
Then, we describe the data analysis followed by a report on our findings and the common elements across the cases that conforms the socio-technical conceptual framework. The socio-technical conceptual framework helps us to investigate both home-based illness and preventive self-monitoring practices across the cases (see Figure 3).

Self-monitoring Cases

Our initial two cases investigated self-monitoring needs among 1) pregnant women with pregnancy poisoning and 2) frail older adults with different heart conditions (see Figure 1 - left). In the first case, the women performed self-monitoring activities during a specific period of time (from weeks up to months) until childbirth. In the second case, heart patients (mainly older adults) used diverse self-monitoring devices to monitor their condition until it stabilized or for the rest of their lives. The third case considers healthy older adults that should perform voluntarily preventive self-monitoring (see Figure 1 - right).

Self-monitoring of pre-eclampsia

We examined a project, investigating the impact self-monitoring had on pregnant women diagnosed with pre-eclampsia (i.e. pregnancy poisoning) or, in some cases PROM (Premature Rupture of the Membranes). The project was conducted by a consortium, including a university hospital that recruited and equipped pregnant women with both off-the-shelf and project-specific monitoring systems. One of our project-interests was how these women integrated, perceived and managed their measurements as part of their everyday lives and potential positive/negative outcomes of the monitoring activities. We followed the women at the hospital, as they received and learned to use the monitoring equipment and later in their homes. Each morning the women measured weight, blood pressure, pulse and CTG (i.e. the fetal heart and uterine contractions). They also measured the protein-level in the urine and compiled an online questionnaire (e.g. if they experience headache or not). Due to the time-consuming CTG measurement (done by placing sensors on the woman’s belly - see Figure 2 right) the daily measurements took about 45-60 minutes to complete. The system sent the results to the hospital midwife for evaluation. The midwife sent a mobile phone text-message to the women if everything was OK. If not, the woman had to visit the hospital and repeat the measurements in a more controlled environment. If a woman with pre-eclampsia is not tele-monitored, she may have to visit the hospital every day or be hospitalized.

We made interviews with six of the pregnant women and their midwife. Our work included semi-structured interviews (an interview guide was developed based on early fieldwork at the hospital) and fieldwork in the pregnant women homes. The interviews focused on how the women used and placed the monitoring equipment at home, how they integrated their measurements into their everyday lives, motivation, experiences of use, the (nature of the) contact with the hospital, pro and cons with monitoring. We also developed a questionnaire handed out to women at the genecology and pre-eclampsia ambulatory waiting rooms at the hospital. The questionnaire took about 15 minutes to compile. The questions were informed by the outcome of the early interviews and fieldwork. Among other things the questionnaire addressed the women’s personal relations (e.g. availability and nature of a care network), their contact with the healthcare system, their condition and their perception of, and attitude towards tele-monitoring. A total of 66 compiled questionnaires were collected during 1 1/2 month. The answers helped us to update the interview guide and validate results from the qualitative study. The workshops dealt with 1) the healthcare professionals’ perspectives and requirements on home-based monitoring, and 2) the pregnant women’s needs regarding home-based monitoring, how they have adapted their everyday life and how they relate to their condition through the monitoring.

Self-monitoring of heart diagnoses

We examined a project, investigating the impact self-monitoring had on (mainly older) adults with severe heart conditions. The project was conducted by a consortium including a university hospital that recruited and equipped heart patients with both off-the-shelf and project specific monitoring systems. Our interest in the project was on how the heart patients integrated, perceived and managed their measurements as part of their everyday lives and potential positive and negative outcomes of the monitoring activities. All patients had a severe, possibly life threatening diagnose and they should make daily bio value measurements to monitor their health. The heart patients measured their weight, blood pressure and pulse. Some patients also conduct ECG measurements. The patients were instructed to perform measurements and fill out an online questionnaire (e.g. if they felt a tendency to faint or not) each morning. The system then sent the data (using 3G) to the hospital for evaluation. If the hospital-nurse discovered something not being as expected, she contacted the patient.

We followed seven heart patients at the hospital and in their homes. Similarly to the previous case, our work included semi-structure interviews and fieldwork related to the patients’ monitoring activities. The interviews were recorded and transcribed. The interviews touched upon similar questions as the interviews with the pregnant women. A questionnaire was also handed out to heart patients at the heart ambulatory to better understand how these patients perceive their illness, its impact on everyday life and self-monitoring. 83 replies were compiled during 1 1/2 month. The answers helped us update the interview guide and validate results from the qualitative study.

Figure 2. Case participants performing self-monitoring.
We also did workshops and field studies with two nurses enrolled in the project. The workshops dealt with the healthcare professionals’ perspectives and requirements on home-based monitoring. The nurses also demonstrated the software used to handle the patient-generated data.

**Self-monitoring as preventive care**

We conducted a project to investigate healthy older adults’ attitudes towards preventive health monitoring. The study engaged eight older adults to discuss their perspectives on health and preventive health monitoring as part of their everyday lives. Participants were recruited from an activity center. The older adults participated in workshops to explore why, how and when they could best perform and integrate blood pressure self-monitoring in their everyday lives (see Figure 2 left). Their everyday routines and activities were identified and rules related to successful blood pressure measurements (e.g. do not eat 30 minutes before the measurement and sit and rest without talking five minutes before a measurement) were put into relation to their daily activities and rhythms. Participants were also asked to do blood pressure measurements at home (both morning and evening) for three days in a row within a one-week timespan.

A web questionnaire was developed to better understand how people perceive and use preventive self-monitoring technology. We collected 165 questionnaires (responders’ age: 22-83 years old). Questions were related to motivation in health management and lifestyle changes, the need of information about the current health condition, sharing of health data, what ‘general’ self-monitoring technologies do people have at home and the notion of assistance and surveillance in home-based health monitoring. Further details regarding this project can be found in [14].

**Data Analysis**

Apart from the investigated participant (e.g. care receivers and healthcare professionals), each case also included a multi-disciplinary group of researchers (e.g. computer scientists, ethnographers and Participatory Design (PD) experts). Minimum one of the two authors worked with each case and hence participated in the case-specific data generation and analysis. In this paper, the initial analysis focused on the first case (i.e. the pregnant women), before starting the comparative analysis across cases. The initial analysis was guided by an open coded approach conducted by each author with a computer scientist and PD background. Non-functional aspects of self-monitoring technologies were identified as the main concept from the initial analysis and thereof represent the main concept for further exploration. The initial themes that emerged around this concept were: people, resources, places, routines, knowledge, control and motivation (see Figure 3). These themes constitute the initial lenses for the socio-technical conceptual framework that we used to further investigate the temporal and distributed nature of health related self-monitoring activities in everyday life.

We sequentially added the second and the third case and performed a comparative analysis across these cases. To allow comparisons, a more focusing coding of the aforementioned non-functional aspects was performed based on data from the additional two cases. Data was grouped into themes to facilitate the search of instances of the non-functional aspects and relate them to the current literature of home-based monitoring. The occurrence of the themes across the heterogeneous cases indicates consistency and reveals the shared themes.

The three cases provide a heterogeneous self-monitoring population with different ages, interests, and health conditions. This heterogeneity provides the maximum variation [24] that allows us to comparatively extract shared themes by focus on the non-functional aspects of self-monitoring technology. The themes were 1) present in all three cases and/or 2) identified as a particular challenge or aspect of health monitoring at home. As suggested by Yin [30], the three direct replications of the themes support an analytical generalization. Additional interviews were held with four additional persons to discuss illness and wellness devices (respondent validation [24]).

**CARE MANAGEMENT SITUATED PRACTICES**

Our cross-case analysis revealed seven specific themes (people, resources, places, routines, knowledge, control and motivation) related to home-based self-monitoring (see Figure 3). Previous work shows the importance of some of these themes in the home setting (see Related Work [4, 5, 8, 11-13, 23, 31]). All themes were present in our studies and together they established a socio-technical conceptual framework that facilitates an understanding of 1) the non-functional aspects in self-monitoring technologies, and b) the dynamic complexities of situated practices within self-monitoring and the interrelation of these practices in non-clinical settings. These themes will now be presented.

**People**

The reasons for doing home-based self-monitoring vary as do the people that benefit from such activities. We have observed that people take different stances towards their health, illnesses and measuring devices and how they integrate these in everyday life [5]. An individual that must make daily measurements for a long time to monitor a life-threatening disease is in a different situation compared with someone doing preventive check-ups few times a year. Aligned with [31], it is evident in all cases that the participants do not like to focus on their condition and keep their monitoring needs in the background (both mentally and physically). A woman with a heart diagnose with...
I then told my husband, that I cannot stand it – that it should be a ‘hospital room’. I don’t want that. The care network can play an important role in home care management activities [11, 12]. Yet most participants only involve the immediate family and maybe their closest friends in their health management. We named these people the intimate care network (see Figure 1). The heart ambulatory questionnaire revealed that over 90% of the respondents involved the immediate family in their illness management. However, an extended care network, such as friends, distant family members or neighbors [11] rarely get involved - at any level. Only 12 (out of 83) discussed their health with the extended care network and six indicated that they do not include anyone in their health management. The questionnaire from the preventive case shows similar, but more restrictive data as most respondents preferred to only share health data with a healthcare professional and only 15% wanted to share health data with family and friends. The healthcare professionals also represent an involved (but remote) partner in the hospital-initiated cases.

Resources
Self-monitoring devices are main resources in personal health management. From the preventive case questionnaire, devices for measuring blood pressure and pedometers have a notable presence in people’s home. However, we have noticed that some people attribute different meaning and function to different devices. One heart patient said: “I can see a point in, having something [monitoring equipment] that is not related to something with the hospital…”. There seems to be a mental difference on devices that are perceived as general devices (e.g. a laptop), wellness devices (e.g. body weight scales and pedometers) and ‘illness devices’ (e.g. blood pressure and blood glucose monitors). For instance, people tend to leave wellness devices visible (for one-self and others) compared with devices more connected with illness around the home. The heart ambulatory questionnaire revealed that 53% would hide the blood pressure monitoring device but only 16% would hide the body weight scale. In a tele-monitoring project, four participants were individually shown pictures of diverse tools for health management (e.g. a blood pressure device, Nordic walking sticks, computer, body weight scale, thermometer). The participants preferred to leave wellness-related devices more visible and hide more illness-related devices. Also, a generic device such as a computer would keep its ‘non-illness’-connotation when used for illness management – in this case tele-monitoring. For example, one participant did not like to have a special-made computer for tele-monitoring visible at home and prefer to use her personal computer instead.

Some participants in our three cases used calendars and notebooks as documentation tools [8, 9]. Others lacked a history log in the devices, but still did not keep a separate log. Also, measurement guidelines (e.g. a person should rest and not talk five minutes before a measurement) on how to perform a correct measurement becomes a resource (and possible constraint) in the self-monitoring activity [3, 14].

Places
Aligned with [23, 31], many participants in the three cases created or adapted a place for their measurements. However, the measurement guidelines provide different constraints on both the activity and place. The constraints are meant to ensure validity of the measurements. Our cases confirm the distinctions between public and private places when doing the self-monitoring activity [31].

If the measuring system is mobile, it can ease transportation and allow self-measurements outside the home, for example at work, during vacations or trips. However, the healthy older adults raised privacy concerns when we discussed the possibility to perform measurements outside the home. It seems that a bigger acceptance of self-monitoring occurs within the boundaries of the home for healthy people whereas frailty people tend to do it when it is necessary [31]. Still, they might not feel comfortable doing such measurements in all ambient and among all people and hence prefer to stay home instead of visiting friends or attending social activities. A heart patient that should visit a relative’s birthday and stay the night said: “…there I thought, should I bring it [the monitoring system] or not, no… you [intending himself] do not bring it”. However, some pregnant women brought their measurement system on vacations and were in general more open to perform monitoring outside their own homes. Consistent with [13], a higher acceptance towards self-monitoring has also been noticed if monitoring equipment can be freely positioned within the home. The questionnaires also show that many people are afraid that a tele-medicine system would be too spacious and could not “just be placed anywhere”. A pregnant woman told us: “Well, I have a need for, like, that it [the monitoring system] could fit…and not fill the whole room…I really like to have a nice home and so… If it had been a big machine…but now, when it can be put away into a box… Then one can bring it out when one should use it instead of that if should fill ones’ life”.

Routines
As described by [5, 8, 12, 23, 31], implementing self-care activities into everyday life relates to how people actually live and organize their lives. In our cases we observed that people have the most stable routines in the morning. At a workshop in the preventive case [14], participants were asked to make floor plan drawings of their homes and then tag activities to the different locations and their individual order. By analyzing the drawings and discussing them at the workshop, it was clear that the morning routines were more homogeneous (from day to day, and among participants) compared with the afternoon/evening routines. While the measuring guidelines (as resources) support the reliability of the measurements [3] they can also challenge the integration or insertion of the self-monitoring activity in people’s everyday life. There are specific rules on how one should behave, not only during, but also before a blood
pressure measurement for example. A person should not smoke, drink or eat in a specific interval before the measurement. It might sound trivial, but for some of our preventive care participants, just to consider measuring blood pressure twice a day (for a three day period) seemed impossible due to for example the breakdowns of routines [12]. They could do the measurements in the morning, but had severe challenges integrating their ‘afternoon or early evening’-measurements in their everyday lives due to other (distributed) activities already planned in this time period such as bowling and playing bridge. These activities were something they did not easily want to give up, or reschedule. A participant expressed “You can be completely worn down after meeting with a friend, but it brings me so much joy to do it”. These activities included other people – making rescheduling harder or even impossible. In the mornings, the measurements could more easily be integrated into the current routines and other people did not need to be included or know about the measurements. Exceptions did occur, as one heart patient liked to go fishing in the very early morning and do the measurements before that, something that was not technological possible. Indeed, finding a solution that ‘fits all’ is challenging in a heterogeneous patient group [8, 31] that might possibly have just one thing in common - their illness.

Another aspect was to allow oneself to forget about the condition to continue with one’s normal day [5]. One pregnant woman explained this, saying that after the morning measurement “they [she and her partner] could forget about the condition until the next day”. If the measurement had been in the afternoon, the whole day would be planned around this event and might create worry as they would not know if the values would be good or not.

Knowledge
Align with [5, 8], we have identified an important aspect of learning about oneself and one’s condition directly connected to the act of self-monitoring. A central source of knowledge is the measured bio-values and how they unfold over time. Through the measured values people can start to reflect on the results and its correlation to their routines and day-to-day activities [5]. For example if a person has been drinking to little (or too much) water one day, the next day’s bio-values may reflect this. A pregnant woman told us “...it helps us [woman and partner] that we feel that we can do something with the illness” and another explained that “...it’s cool that you can do something yourself and not just go to the hospital and say: Fix me”. By rendering bio-values visible, that normally are invisible, the person is provided with a tool for learning through reflection to help understanding his or her own body and condition. A participant told us that: “one learns more when you do it [the measurements] yourself instead of when a nurse does it”. The learning aspect can on instances go beyond the self-monitored person to also include people in the vicinity, such as a spouse. While creating awareness for the care network has been investigated by [11], an active support for the intimate care network learning was not present neither in the diverse cases, nor in the Related Work. By learning for example what makes a partner feel better or worse, one can provide better care and get a deeper understanding of why a person might be tired one day. A pregnant woman said: “It creates a feeling of security, also because I do believe, when he cannot really feel the child, as I can... I can feel the child and so... I know now what to react on, but when he cannot even know, if she kicks or not, or if I gain sufficient weight, than he can see these values... and see that everything is ok...”. The gained knowledge includes not only an interpretation of bio-values but also how they effect and be affected by everyday activities. While self-monitoring provides an instrument for learning through reflection [20], none of the systems in the three studies were designed to facilitate learning and reflection for either the individual or people close to the patient (see people). For instance, the healthy older adults used different mechanisms (e.g. additional readings, grouping values, symbols) to support their understanding of bio-values.

Control
In the three cases, we have observed mainly four aspects of control; 1) the (perceived) gain in control for the person subject to self-monitoring; 2) the control that is distributed to people close to the monitored person; 3) the removal of control from the healthcare professionals (when applicable) and 4) control retained by the system.

First, an increased personal control can facilitate freedom regarding when and where to make measurements [13]. If one does not regularly have to go to the hospital and meet up at specific hours, one may better accept and integrate the measurements (e.g. creating routines) in everyday life. One heart patient expressed this stating that: “I have nothing against surveillance if it is for ‘good’, where it can help you. They can monitor me as much as they like... If I just do not have to go to the hospital only once... If I only have to go to the hospital 12 times a year it is fine”. The personal level of control also relates to the control of one’s life and the role of illness in that life [20, 31]. For example, some of the pregnant women have reported using their condition as an excuse not to do things they do not feel like doing (like go grocery shopping or meeting someone). Similarly, we encountered situations where a person manipulated values to prevent a trip to the hospital. For example, the pregnant women should urinate on a special paper strip that reacted to the level of protein in the urine. This value was manually read and entered into the monitoring system. The scale is analogue as the paper strip change color based on the protein level (similar to a litmus PH-test). The obtained non-discrete value allows for interpretation of the results (knowledge). This interpretation allows the women at times to prevent going to the hospital or not. Another strategy was to drink more water to adjust the urine protein level. One of the women said: “so then I drank a lot of water, and then it [the value] was not that high, and I didn’t have to be hospitalized...”. To increase accuracy, one might vote in...
favor for a completely automated system. However, the individual can feel more involved, and learn more about their values when they manually input data. A pregnant woman said: “Yes, one should of course do the actual work at home, at the hospital there is a nurse that does it all, so there one is a bit more tranquilized in the situation. Here [at home] you should do it all by yourself. But one has also more control and one also shows more interest; one should by oneself understand and know (…)”.

Second, some control was also given to (or taken by) people close to the monitored person. The bio-data became a tool, for example for the fathers-to-be to imply ‘rules’ on the pregnant women. As they worried about the child and the woman they could say, backed by the bio-values, that the woman should not do specific activities, rest more etc. A pregnant woman’s partner told us: “She decides all the time, but if I feel that, based on the results, that, if I see the results are not good I can say this to her, we can talk about it, it is not good to do [an activity] more”.

Third, a distribution of control became an effect of the self-monitoring. As described above, the patient gained control while the healthcare professionals lost some levels of control. Still, the healthcare professionals are remotely present in the two hospital cases. They were positive to tele-monitoring, but also stated that they did not like all patients to use it as 1) not all were suitable for it and 2) they did not like to spend all their time in front of computers but rather meet patients.

Last, a system takes control of some aspects of the patient’s life when entering to the home. Aligned with [31], the removal of control was manifested by the physical properties of the devices (e.g. size, portability, power, 3G coverage) that constraint the place and people’s routines.

**Motivation**

Motivation is highly individual and complex by nature. In the three cases, we have observed different types of motivation. First, a healthy person motivated by the desire to maintain health and wellbeing. Second, a heart-patient motivated by the desire to get well or achieve a better health state. Third, a pregnant woman motivated by the desire to maintain health and the wellbeing of her child. Last, the immediate family and friends motivated by the desire of improvement in a loved person’s health.

The results of pro-active measurements may be noticeable first years after its initiation and this can effect motivation. In our cases, the healthy person supposed to engage in pro-active monitoring expressed less motivation compared with the other groups. In contrast, the direct benefits for a heart-patient or a pregnant woman doing monitoring at home were more evident. For example did they save trips to the hospital and could have a more active lifestyle as described above in control. Another participant said “I’ve gotten an increased focus on taking care of my health so that my wife and I will grow old together – live healthy!”.

**MODES OF SELF-MONITORING USE**

Many of the themes are associated with specific properties of self-monitoring technology - the main resources to support self-monitoring activities in people’s everyday life. For example, self-monitoring devices can have a visible or invisible position at home and people create, adjust and attach the monitoring activity to their routines. People engage in self-learning and reflection to acquire a sufficient knowledge through monitoring activities to perform health monitoring and to understand how their everyday life affects and get affected by the self-monitoring activity.

Clearly indicated in our studies, people want to be in control of their own situation as long as possible and they might have different motivation for doing so. Self-monitoring devices are primarily designed to support the individual to play an active and collaborative role in his/her own self-care management. The analysis of the themes enables us to identify different use modes of Ubicomp technologies for self-monitoring.

**Individual and Care Network Use**

Especially in the two non-preventive cases it is evident that the technology is developed mainly for two people: the healthcare professional and the monitored person. Indeed, self-monitoring devices often lack a more situated support for the care network [11] (e.g. a monitored person may live with other people). While other people may not share a monitoring need, our cases show that people in the proximity of a monitored person may need better support and could be a better used resource in the care situation. An empowered care network member may for example provide better assistance to the monitored person and better learn and get knowledge about the overall situation. When shared, information about one’s health is to a large degree connected with a feeling of security and safety. Some participants in the two non-preventive cases perceived a benefit if others know about their current health-status. This was generally not the case in the preventive care case. Most pregnant women include the becoming father by going outside of the system and sent SMS’s or emails to inform him about her current health status. However, privacy is a main concern and the sharing of health data is a delicate matter. The monitored person should decide whom to include and how in their personal health management.

**“Demo” Use**

Another sort of inclusion-feature discussed in our cases, especially in the two cases with prescribed measurements, was the possibility to allow others [16] to try out and perform measurements with the device(s). To allow a partner, child or a group of friends to test a monitoring device can allow a more open discussion and understanding about the measurements and illness. In the illness related cases, this is not currently possible as all data is sent to the hospital and therefore must be performed at specific times and only by the patient. When role-based access control is not enough [16], something as simple as a demonstration-function where the device is used but does not transmit the values could prove useful. For example, a simple game-
function (i.e., gamification—not necessarily of the actual measurements but in a demo-mode) could help explain and demystify the measurements to children, or even make the measurement something fun in a group of friends rather than something one should hide or do alone.

**Wellness and Illness Use**

There seem to be differences on how people appropriate healthcare technologies into their everyday life. Some people care for example more about the appearance of their homes while others do not. There also seem to be a balance between what is practical in everyday life and hiding an illness. It also seems like the more severe one’s condition is, the more one accepts. The participants have mentioned the aesthetics of the device as an important aspect to facilitate the appropriation process. For example should a monitoring system not communicate illness or be ‘hospital-looking’. A similar aspect derives from the culturally embedded perception of a particular device. In interviews people have been more open to having a bodyweight scale visible in the bathroom than not in everyday use. An image of a purpose-made ‘hospital-looking’ computer system would have been hidden away when not in use. Indeed, tools for wellness (or tools that do not communicate ‘illness’ or ‘hospital’) seem more easily integrated into people’s lives compared with illness-related devices. Given the above mentioned, attention should be given to not only functional aspects but what a monitoring system or device communicate, both in use and non-use situations. This aspect of healthcare devices needs further investigation. The reason for why a device is hidden or not is perceived by a household is complex. But in diverse projects, people seem to prefer wellness devices and technology that ‘everybody have’ for example due to fear of stigmatization [31].

**SUPPORTING MODES OF SELF-MONITORING USE**

We have identified and exemplified different modes of self-monitoring technology use in which people take and share their measurements. For example 1) individual and care network use, 2) demo use and 3) wellness and illness use. Self-monitoring technologies should not be designed to support just one mode of use but offer flexibility and support a range of uses. This could be a way to lower stigmatization and normalize devices for self-monitoring, especially regarding illness-related monitoring. We will now discuss properties of self-monitoring technologies to support the described modes and care situated practices.

**Individual and Care Network’s Local Awareness**

People engage in self-learning and self-reflection endeavors to get a sense of their current health status. Besides the efforts to provide design features to facilitate data collection during the maintenance and discovery phases of self-reflection [18], most self-monitoring technologies lack mechanisms to help people to make sense of their data. Here, data does not only include bio-values but also all the knowledge that can be gathered at home such as people’s routines and contextual information. A proper combination of all these information can support a self-reflection process and provide local awareness for the individual and the intimate care network [11, 12]. People sharing the household (intimate care network) with monitored individuals in our cases have talked about the possibility to learn about the other person’s illness and how to be able to assist this person through the reasoning and reflection that comes from sharing the measurements. Today this awareness and learning have been an emergent property in use, rather than a designed feature. As Bates [6] states most learning comes “through being aware and monitoring” as a result of the interaction with one’s friends and the actual social or physical surroundings. We observed that the pregnant women were the only group actively sharing and discussing health data not only with their partners but also with for example their parents.

In all cases, the visualization tools were not designed to enable local awareness and learning, neither for the individual nor the care network. However, in some aspects the pregnant women perceived the monitoring system to be more beneficial for their partners than for themselves as it provides the partner with a tool that render what is for them ‘invisible visible’. Although the visualization of bio-data (e.g. pulse, blood pressure and the child’s ECG) can provide for example the intimate care network with an understanding of what is going on. Ubicomp monitoring technology designs could benefit by further acknowledging people in the direct vicinity of an individual doing home-based monitoring. Ubicomp technology can also help the intimate care network with learning endeavors and provide them with a sense of local awareness. For example, exploring ways to improve social connectedness through physiological data [26] or enhancing the PHR by creating common information spaces [7] to support and facilitate information sharing, reflection and learning for both the individual and care network in non-clinical settings.

**Assess and Assist the Individual Health Locus of Control**

As described earlier, there are different aspects of control and/or lack of thereof during non-clinical health monitoring. As care moves out of the hospital and into people’s everyday lives there is a shift in control among the involved actors. When designing Ubicomp technologies for home-based healthcare, how to support or suppress the different actors’ level of control over a situation can be an important system quality that might impact both the individual and the care network. While people might refuse to use over-protective or surveillance technologies [21], we have observed that technology have also helped to provide people with control in their everyday lives. It is important that the control of one’s life remains with, or is returned to,
the individual. Our findings show that a person can gain an “internal health locus of control” [29] not only through reflective thinking [20] but also if the system allows some flexibility in when, where and how measurements should be performed. At the same time, the external health locus of control [29] associated with the healthcare professionals at the hospital decreases over the monitoring person and the measurements. This shift in control and how it affects the involved stakeholders and the overall care situation might differ when designing for frail people and not all people may be capable to handle a high level of control.

Especially among the pregnant women, we observed how they intentionally manipulated the reported values to get a higher internal locus of control of their life situation. However, frail people such as older adults might benefit from a setup where the control (internal and external) is shared among the involved actors or, in severe cases, put into the hands of others (external locus of control) such as for example the healthcare professionals. Furthermore, especially in the preventive case we also observed that healthy older adults might experience a chance-type health locus of control [29] as they think they are too old for health interventions. Furthermore, the fathers-to-be gained a multidimensional health locus of control [29] (i.e. internal and external) as they got access to the women bio-values. Also, they got in a position where they could take, or be permitted, some of the woman’s control as they started questioning her decisions and habits. On some occasions this control were taken, and on other occasions given or negotiated as some women also expressed comfort in having someone taking ‘tough’ decisions for them.

In the described cases, we have seen examples of how an increased personal control has benefitted the individual performing home-based monitoring. Designing for an increased internal locus of control can indeed support appropriation and use of home-based monitoring devices for both frail and healthy people. Furthermore, designers of Ubicomp technology should not only consider the needs of the individual but also the role of the care network. In this sense, the individual and the care network should be seen as proactive people [25] of self-monitoring technologies. As described above, providing and maintaining the individual and care network’s local awareness can help Ubicomp technology to assess and assist the individual health locus of control (internal, external or by chance). In doing so, the individual and the care network (intimate or extended if applicable) are able to gain health locus of control, share the responsibility [12] and identify atypical situations (e.g. cheating, obsession) in which a reinforcement (especially when chance health locus of control occurs) or a suppression of the health locus of control is preferred. This can avoid unintended consequences of a continued monitoring such as stress [19] provoked by the monitoring activity. Such stress can be perceived as a loss of internal health locus of control, in which the care network needs to become aware of, and gain more control over the situation.

**Active Information Seeking and Reinforcement**

The contextual information of measurements and the guidelines for bio-measurements play an important role in an individual’s care management. To maintain awareness (individual or intimate care network) of the situation, people engage in active information seeking activities such as directed searching and browsing [6] to support their self-learning and self-reflection processes. We observed that a manual entry of bio-values supports the understanding of the current health condition. However, frail people might benefit from a setup where data is inserted into the system automatically. Participants that got feedback from the hospital about their measurements appreciated this as they were always looking for a response to get a feeling of security and safety during the day. Even though some of the current technologies on the market (e.g. Withings blood pressure device) inform the individual about the existing guidelines, they do not enforce the user to comply with these guidelines nor help to interpret the values. Ubicomp technologies can help by supporting the active information seeking, reinforcing the application of the guidelines, and capturing relevant contextual information. In this sense, capturing all this information together with the individual and care network’s local awareness can help Ubicomp technologies to support the informational order [12] needed to perform self-monitoring activities at home. Knowing that all the necessary information is available at hand can motivate the individual to continue doing self-monitoring and support the intimate care network to get involved in the care activity. This can also be beneficial for the healthy (preventive) group as they can become more aware about the role and importance of the guidelines besides the meaning of their bio-values.

**CONCLUSION**

Although each non-functional aspect (people, resources, places, routines, knowledge, control and motivation) presented deserves further research, this paper provides a holistic perspective that we argue is important to consider when designing for home-based health monitoring. Through a cross-case analysis of three cases, we show the role of these seven non-functional aspects. We also identify and discuss three modes of self-monitoring use at home: the individual and care network use, the demo use and the wellness/illness use. Based on our findings, we suggest moving away from passive monitoring and surveillance to solutions that assess and assist the individual health locus of control and enforce active information seeking. By doing so, a sense of local awareness of the current health situation can be provided to both the individual and the care network through learning and reflection in non-clinical settings.

To our knowledge, these non-functional qualities have not been adequately discussed as a whole within the Ubicomp community. We hope the findings presented in this paper can inspire to future research and provide home-based healthcare technology designers with knowledge about the use of self-monitoring technology in the home setting. However, the presented findings are far from complete and
many challenges remain when designing home-based healthcare technology. We encourage the Ubicomp community to continue exploring and understanding socio-technical complexities involved when introducing home-based health technologies in people’s everyday life.

ACKNOWLEDGMENTS
We would like to thank the CPH and especially the diverse participants from the LevVel and Tele-Skejby projects. We also thank all partners and colleagues that have contributed to the diverse projects and the data collection.

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Designing for Healthcare in Everyday Life: Caught between Work and Leisure

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Unpublished manuscript. This paper is in preparation for submission to an HCI Journal.
ABSTRACT
In this paper we consider the design of ICT-support for healthcare in everyday life. Increased unsupervised care at home has brought attention to the difficulties encountered when trying to develop healthcare systems for the home. Our work reveals a need to further understand the setting that is being designed for: the private home. When we design for home-based healthcare we need a deep understanding of the home and everyday life healthcare activities to balance inflow of design rationales from healthcare workplaces, like hospitals, and from home-based leisure, like games. To help designers of everyday home-based healthcare, we present and discuss four concerns (why, when, where and control in collaboration) that emerged in our analysis of challenges in three of our projects. In our experience these concerns help designers to focus on aspects where design rationales from healthcare workplaces and leisure respectively are not sufficient and may even point in other directions than what is helpful for home-based healthcare.

Author Keywords
Healthcare; Design; Concerns; Home; Work; Leisure.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Design; Human Factors; Measurement.

INTRODUCTION
The use of technology at home is becoming more and more pervasive. Also, more and more technology move from the workplace and into people’s homes and becomes mundane in all aspects of life rather than mere work tools [31]. As such, much technology is used for both work and private situations - also simultaneously [34]. The transfer of workplace-originated technology into private homes now takes place ‘a mass’ within the healthcare sector. Systems designed mainly for or by healthcare professionals’ move into patients’ homes where they are expected to support patients and healthcare professionals alike. Numerous papers on telemedicine and tele-care projects illustrate this development (for example [16, 24, 37]). However, introducing healthcare technology in the home is usually different from introducing such technology in a workplace (for example a hospital) or introducing non-healthcare-specific technology in the home. As described below some of these differences relate to training, IT-support and who the active part is.

Healthcare professionals have or can be provided extensive training in novel healthcare ICT designs. In a clinical setting these systems also become embedded in an environment where skilled IT-support is usually available. When system designers do acknowledge patients, or other people visiting a hospital, they usually perceive the hospital as an environment where the professionals, and not the patients, are the active part, e.g. in making a new booking. Patients come to the hospital to get cured, and the professional care workers are in control of these situations. On the other hand, many home-based healthcare designs require an active patient without a formal healthcare education who may receive none or only limited training regarding the use and functionalities of home-based healthcare devices. In addition, technological support is seldom available ‘in-house’ at the patient’s home.

Furthermore, the home is seldom designed to be a place for care and in many situations the patient also prefers to live out other roles (e.g. the spouse, parent or football trainer) than the patient-role [29]. Furthermore, healthcare professionals usually do not have a deep understanding of what is happening regarding a specific care plan at home [4, 29]. Instead, the patients and their close family-members becomes the experts of the situation and setting [4] and are mainly the ones in control of care activities at home [29]. As we noticed in one of our projects on understanding medication management practices at home [20], one older woman was prescribed a cholesterol pill to take at night. However, as she was working night-shift, she instead took the pill in the evening together with her dinner. What she had not been informed about was that this specific medication should not be taken with meals. This example shows the challenge of integrating her prescribed
medication into her daily routines and the lack of the doctor’s insights into her everyday medication management. Our example also demonstrates the importance of a detailed understanding and elaboration of both the citizen’s [4] and the health professional’s perspectives when designing ICT support for home-based healthcare.

Indeed, ICT-support for healthcare to a large degree originates from professional settings such as hospitals. Furthermore, designs from these professional settings influences home-based healthcare designs. For example, these influences were observed when examining an e-monitoring project [50]. In this project we followed pregnant women doing bio-measurements at home. These measurements should be done and transmitted to the hospital every weekday morning to suit the healthcare professionals’ schedule (they needed to analyze the results etc.) rather than the everyday rhythms and plans of the becoming parents. Moreover, the measurements should not be transmitted during the weekends as no one would look at the values and hence if out of range, react on the deviation.

Another design strategy followed by diverse projects (e.g. [11, 59]) is to apply elements from leisure to inform everyday healthcare designs, for example through Serious Games projects [36] and Gamification [22], making rehabilitation and treatments more motivating, engaging and ‘fun’. However, ICT support for healthcare at home is different from ICT support for leisure at home. We first note that when designing for leisure the user experience and “the fun factor” are often key design aspects [38]. However, in healthcare, different issues are often at stake and “the fun factor” might not be sufficient to fully support healthcare activities at home. As described in one of our projects supporting home-based rehabilitation at home [28], we initially designed for an engaging experience by embedding components of play and gaming into the design. However, to make the rehabilitation tool accepted and attractive to use and even get the rehabilitees to accept it into the private homes other design aspects had to be considered. We ended up designing a foldable device so it did not take up too much space when not in use and we also considered what role the device could take when not used as a rehabilitation tool (after all, the active rehabilitation training is just a small part of a 24 hours day).

Many projects on ICT support for home-based healthcare (and more generally on “healthcare outside healthcare workplaces”) apply design-rationale from “healthcare workplaces” as well as from leisure activities (see Figure 1). However, we often need to supplement these perspectives to fully support people doing care activities at home, as illustrated by our previous examples. We argue that we need to embrace home-based healthcare designs in their own right. The associated research question is: How can the influence of design-rationales be balanced in home-based healthcare?

To explore this question, we have analyzed empirical findings from three of our projects related to 1) Medication Management [20]; 2) Home-based rehabilitation [28]; and 3) Tele-monitoring [50]. And then performed a cross-case analysis on similarities and differences of how healthcare activities are supported in people’s everyday lives. We identified four high-level CSCW/HCI concerns that embraced most of the challenges and further relate to relevant existing literature on ICT supported healthcare for the home. These concerns are:

1) Why do or should a person use a specific supportive system?
2) When do we or should we use a support system?
3) Where do we or should we use a support system?
4) Control in collaboration aspects in a support system.

When examining a rationale influence.

By exploring and considering these concerns, designers can identify strategies to balance the tension between the different design rationales that are applied to home-based healthcare. Aspects of these concerns have previously been discussed in CSCW-literature for different domains but as we will return to in the analysis section of this paper, they have not been elaborated in relation to ICT-designs for home-based healthcare.

We will now present related work, our research approach and our three cases. We then perform a cross-case analysis that allows us to discuss the aforementioned four CSCW concerns, followed by a conclusion.

RELATED WORK
First, we consider the implementation of technology in people’s lives in general. At the workplace, time fundamentally belongs to the employer who can decide what technology should be used or not (e.g. shared calendar systems) [12]. At home, there is not always such a clear incentive why a specific technology (such as a shared online calendar) should be used [12] unless the users can see a direct benefit of using the proposed technology [27]. Furthermore, as we design for a workplace and professional use of technology, we tend to know the context and what we can expect from the use setting in terms of available resources etc. [42]. A private home and its inhabitants represents a more heterogeneous environment where people may even lack the space for introducing novel technologies as their homes are crowded with a lifetime collection of objects and memories [2]. One interest in home-based designs relates to how it can provoke and inform workplace technology designs [19, 43]. However, as pointed out by
Bertelsen and Petersen [9] few have studied the impact technology can have on non-work situations, for example our erotic life. Indeed, the home and domestic life challenge prevailing assumptions about workplace technology design in which activities should be understood in context rather than one action at the time [43, 52]. As technology move from the workplace and into the home, we must understand the mechanisms behind technology appropriation outside of the workplace [3] and the established rules of interaction between professional and amateur users [12].

The following subsections use Figure 1 and describe the design rational flow that occurs across the multi-site (e.g. hospital) and home settings. We will depict relevant work from each setting (i.e. the boxes in Figure 1) and pay attention to the current flow of design rationales from work and leisure (i.e. the arrows in Figure 1) that influence design for home-based healthcare.

Technology and the Multi-site Healthcare Settings

In a clinical setting, care activities occur in a collaborative environment that provides continuous coverage of patient care through the coordination of local awareness [14, 45]. For example physicians have used cognitive artifacts to get a sense of local awareness of patients at the clinic [45]. The clinic setting is a good example of a distributed information space [26] in which care activities are managed by arranging spatial [5] and temporal [47] coordination to support clinical work practices [8]. In addition, Fitzpatrick et al. [25] recently reported a review of 25 years of CSCW research in healthcare in which most of the reported workplace studies give implications for design and only few studies present design explorations. She reports that developing and evaluating systems in use is less prominent across multiple settings and that a small number of studies propose frameworks or models for design of healthcare technologies [25]. Although most existing frameworks, methods and models target the design of ICT support for a specific care setting such as the hospital [6, 46, 51], some studies have started considering the interplay between care settings and the importance of the design of collaborative systems to provide care services closer to the patients’ homes [32, 54, 60].

Technology and the Home-based Healthcare Setting

When designing ICT solutions for home-based healthcare, there are several conflicts and challenges that need to be solved, in particular related to home-hospital collaborations [1, 29, 35, 58]. For instance, pervasive healthcare should move away from looking at specific disease management aspects to focusing on the individual’s care management [1]. It is important to recognize the expertise, level of control and activities that exist in both home and clinical settings [29], and at the same time cater to these without ignoring the repeated clinical-home information flow [13]. Different roles cater for care within the home in different ways and with different motives [10]. While a professional home-care worker or doctor act out a profession and a professional role, amateur care givers such as next-of-kin may provide care out of love or the perceived need to pay back for care received as a child [15]. Sharing of tasks among the different (professional and amateur) care providers are often reciprocal by nature; one is expected to return a favor in kind [10]. Moreover, healthcare technology should acknowledge the home-setting as a place for care [29], internal and external factors that affect self-efficacy of patients [60], and how it fits into the limited space of people’s private homes and their everyday lives [29]. Furthermore, healthcare technology should acknowledge the routines and the cooperative work of the home [18] to preserve its order [57], support coordination and avoid undesired interruptions [7].

Technology transfer from healthcare setting to home

Several design guidelines have been proposed to support technology transfer between care settings. For instance, Robach et al. [48] proposed guidelines to support planning, assessment and performance of tele-home care in order to improve the quality of care. Årsand et al. [60] proposed guidelines for end-user involvement in design of patient-centric e-health applications. Designing for continuity, understandability and learning have been proposed by [4]. In addition, Siek et al. [49] provide guidelines for future Personal Health Applications and [33] discuss design implications for reminder systems. Also, design principles for home-based medication management systems that accounts for everyday activities, medication requirements in practice, and temporal, spatial and informational ordering have been provided by [20, 41]. Furthermore, [39] emphasize that designers need to incorporate human values into the design of pervasive health applications, especially as many people want their healthcare activities to be invisible at home – both literally and psychologically [57].

Guidelines and strategies can help designers emphasize the home and home-based treatments in healthcare designs. However, designers still have to deal with the tensions between the demands of healthcare in everyday life and design rationales coming from both workplace and leisure. The four concerns presented in this paper may help designers bridge this gap. We now introduce our research approach followed by the empirical cases and a cross-case analysis of the three cases of home-based healthcare design.

RESEARCH APPROACH

The three cases described in this paper are all based on a Participatory and user centered design approach where we alternated between fieldwork, workshops and design work. To get a better understanding of the challenges encountered we decided ‘post-project’ to analyze the three cases individually and together to get an in-depth understanding of what concerns were in play and how our work challenged and provided new insights to these concerns. The three authors held several analysis sessions and
eventually the list of issues were condensed to the following concerns: why, when, where, and control in collaboration. Through the analysis we added new facets to the work on these concerns of CSCW. This in turn helped us to better understand the unique nature of each case and some implications for design.

The three cases were selected based on their relevance for home-based healthcare. The main selection criteria included the presence of one or more influences of design rationales from a healthcare workplace setting or from leisure. In all three cases, participants carried out healthcare activities at home and there was heterogeneity of the stakeholders. The information gathered from the cases were complemented with, and related to, the existing literature regarding home-based healthcare.

Now, we return to the three cases: 1) Medication Management, 2) Home-based rehabilitation, and 3) Tele-monitoring. First, we describe the cases and the individual analysis of the concerns in each case. Secondly, in the next section, we further explore the tensions between different design rationales through a cross-case analysis.

**Case 1 – Medication Management**
This case contributed to our understanding of the importance of the following three concerns: why people should take their medications and where and when these medications are prepared and administered.

We conducted the project to investigate and support people’s medication management in everyday life. An outcome of the project was MediFrame, a tablet-based app to support older adults in their everyday medication management [21]. The project applied a User Centered Design approach and ran for over two years. Early project work included both a quantitative survey (316 telephone interviews with medication users over the age of 60) and qualitative studies (9 older adults taking 1-32 medication doses a day). The work extended into a user-involved design process including interviews, creative workshops with older adults, a developer of health ICT infrastructure, medication consultants and pharmacists. As part of the design process, we carried out workshops and interviews with additional seven older adults (aged 57-87, 1-35 doses a day) and seven medication experts. The study identified a need to put attention to medication-specific particularities such as “according to need medication” (prescribed medication that should not be taken at specific time-intervals but when needed, e.g. pain-killers and sleep medication), the use of the heterogeneous care network available close to a person, the substitute medication, and the patient-doctor shared responsibility. For an in-depth description of the project, please consult [20, 21].

In the project, we observed that many people do not know exactly why they take their medications and have a rather vague understanding of what each medication actually does. This has been reported to have a direct negative influence on medication adherence and treatments [56]. To help people in their medication management it is important that they know why they take each medication. To prevent fear of side effects, non-prescribed ‘drug holidays’ [55] and other intentional and unintentional non-adherence situations, the individual undergoing a medication treatment should have relevant medication information ready at hand, in an understandable format. For example, the Patient Information Leaflet provided with each medication can be lost, not easily understandable, or simply not available when needed. However, MediFrame provides this.

Many reminders and medication dispensers aim at supporting people in when to take medicine [33]. In such support it is important to consider what possible other activities take place at the time of medication intake. MediFrame integrates a person’s everyday calendar into its interface and overlays an overview of what medication to take and ‘when’ with respect to other scheduled activities. Potential conflicts between pre-scheduled activities and medication intake can be identified at a glance. Many conflicts can be resolved for example by re-scheduling activities or adjusting the time for medication intake within an allowed time range. Where a person will be at the time of medication can further challenge adherence [41]. It might be that the place itself limits the possibility to adhere or the medication is not brought along. The joint calendar and medication overview helps the planning ahead.

**Case 2 – Home-based rehabilitation**
This case gives emphasis to why, where and when the rehabilitation is performed as relevant concerns when designing ICT-support for home-based rehabilitation technologies.

We conducted the project to investigate and support home-based rehabilitation for older adults affected with vestibular dysfunction, a sort of dizziness condition. Older adults suffering from vestibular dysfunction can feel nausea and risk to fall. It’s not uncommon that vestibular dysfunction patients become isolated, as they fear to fall when outside of their homes where they cannot find support from furniture’s and walls. An outcome of the project was LinkLights, a modular rehabilitation tool designed to fit into people’s home and everyday life. It is a foldable device with sixteen multi-color LEDs in each module designed to provide visual instructions to the user. The project applied a Participatory Design approach and ran for 30 months. The PD activities included 25 older adults and two physiotherapists. The different PD activities took place in the special fall-clinic at the hospital where the vestibular patients went once a week. However, to have an impact, the rehabilitation has to be performed on a daily basis. As a consequence, most PD activities took place in the intended use setting (i.e. in the older adults’ homes). For an in-depth description of the project, please consult [28, 29].
In the project, we observed that many of the people undergoing the rehabilitation had only a rather superficial understanding of why they should perform the different prescribed exercises. They knew it was for their dizziness condition, but they could not perceive that they got better from the rehabilitation exercises. In fact, the effect is delayed as one has to do the exercises for some months before a positive effect is perceived. The rehabilitation-exercises should be performed daily but are very repetitive (and hence perceived as boring), and many feel nausea and tiredness afterwards. Nausea and tiredness cannot easily be ‘designed away’, but LinkLights creates a more interactive, engaging experience and offers variation in the exercises.

As a result of daily rehabilitation exercises, some people either felt sick or very tired afterwards. Hence, it is important that people carefully plan when to conduct their daily rehabilitation. Furthermore, if a person does not do the exercises, for example due to forgetfulness or other activities it is important to catch user’s attention and remind them to do the exercises. Indeed, LinkLights does this through softly pulsing its LEDs.

The concern of where a person with vestibular dysfunction performs the rehabilitation is two-fold: 1) where the rehabilitation should take place within the home and 2) where outside the home, for example on vacations. As the rehabilitation provokes dizziness and nausea, people risk falling as they perform the exercises. Therefore, the rehabilitation should be done preferably while standing in a corner, with a chair in front of oneself. The walls and chair provides protection if one is about to lose the balance. However, many of the older adults we met had problems finding a suitable corner in their homes as they were crowded with furniture and other objects. Previous research has also indicated the problem of implementing ICT in older peoples’ homes as they can be so ‘crowded’ [2]. If rehabilitation should be carried out on a day-to-day basis, for a long period of time (as is the case of the vestibular rehabilitation) one must consider places outside the home as possible spaces for rehabilitation. Tools to be used in the daily rehabilitation must therefore be mobile and functional outside a person’s home. LinkLights is autonomous and mobile, designed to function at any location within or outside the home. LinkLights runs on batteries that can last for several days of normal use, and its foldable design makes it compact during travel.

**Case 3 – Tele-monitoring**

The third case underlines the importance of understanding the nature of **Control in collaboration** in people’s healthcare activities when designing ICT-support for tele-monitoring.

We examined the project, to investigate the impact self-monitoring had on pregnant women diagnosed with pre-eclampsia (i.e. pregnancy poisoning). The pregnant women measured their weight, blood pressure, pulse and CTG (a measurement of the fetal heart and uterine contractions). They also measured the urine protein level and compiled an online questionnaire. All participants performed their measurements daily. For the women this took up to 45-60 minutes due to a time-consuming CTG measurement (done by placing sensors on the woman’s belly). Our interest in the project was for example on how the women integrated, perceived and managed their measurements as part of their everyday lives and potential positive and negative outcomes of the monitoring activities. In total we followed six pregnant women in their homes and at the hospital. Interviews and fieldwork related to the patient’s monitoring activities were conducted in their homes. We also did workshops and field studies with the midwife. A workshop was also done with two of the pregnant women. As part of the project, we also developed a questionnaire handed out at the hospital to other pregnant women with pregnancy poisoning to better understand how they perceive self-monitoring, their illness and its impact on everyday life. The questionnaires were placed in the waiting room and we collected 66 compiled questionnaires from the pregnancy ward during 1 1/2 month. For an in-depth description of the project, please consult [50].

While the women were overall very positive about being tele-monitored and the level of freedom provided to them, we also observed negative aspects of the tele-care. The tele-care system acted as an extension of the hospital and healthcare sector into the pregnant women’s lives. The women should go to the hospital for further examination if their daily measurements indicated a possible worsening of the gestational poisoning. Most bio-data were submitted automatically, but in addition a questionnaire had to be completed. For example, the women should report if they had a headache, and if ‘yes’, was it worse than the day before. To remain in control of their lives, and not to have to go to the hospital too often (requiring about 3-4 hours of their day), some women intentionally reported incorrect answers. For example, they quickly learned that a ‘2’ on a urine protein scale was ok but ‘3’ was not. In this situation they could report a ‘2’ instead of a ‘3’. They did this intentionally and based on how they perceived the situation.

The collaboration supported in most tele-care solutions such as the one described above, is between a care professional and a person in need of care. These systems are based on initiatives from within the healthcare sector that influence the design rationale of most tele-care systems. In our case, the care receiver (e.g. the pregnant woman) remains in the patient-role while at home. The collaboration between the healthcare sector and the women is done mostly considering the health professionals’ availability and needs. In the gestational poisoning project, a woman can see some but not all bio-data as she performs the daily measurements at home. Aligned with [4], the pregnant women have mentioned during workshops and interviews that they would like to also have access to the
remaining bio-data. Based on input from the healthcare professionals, the current system does not allow that.

**EXPLORING THE TENSIONS BETWEEN THE DEMANDS OF HEALTHCARE IN EVERYDAY LIFE AND WORKPLACE AND LEISURE DESIGN RATIONALES**

After considering the influence of each of the aforementioned four concerns in the three specific projects, this section presents the results of a cross-case analysis focused on the impact of the concerns across the cases. The concerns not only consider the citizen’s perspective (such as [4]) but also takes into account the collaboration with healthcare workplace settings [44] and relations to leisure.

**Why**

The reason why we do, or do not engage in healthcare activities differs in many respects from why (or why not) we work or do leisure activities. In work and leisure our reasons and motives are often firmly embedded in our culture, social networks and personal preferences. To earn a living, have fun, to socialize or to express (or improve) one’s talents or skills are important aspects of work and leisure. Healthcare activities on the other hand are rarely done with the purpose of earning money, socializing, or having fun. We rehabilitate an injury, undergo a specific treatment, or manage a chronic condition based on a doctor’s diagnosis and instructions. Much work or leisure activities that we perform also provide rather direct feedback. When playing video games we have fun ‘instantly’. We invite friends for dinner and get appreciation for our cooking while they eat. At work we also get positive and negative feedback at meetings and informal encounters with colleagues or clients. However, home-based healthcare activities often don’t provide such direct feedback. While painkillers and other strong medications can provide a rather instant effect, much medication and rehabilitation do not. Also, some treatments do provide a direct effect, but a negative one (e.g. nausea or tiredness) that can put the personal motivation in performing these treatments at risk. Indeed, from a patient’s perspective such healthcare activities are not done for leisure but are rather considered both time-consuming [17], boring [23], and costly [53]. Contrary to what many healthcare professionals believe, the wish ‘to get well’ or ‘to remain well’ is quite often not enough for a person to undergo (home-based) treatment. According to a study by WHO, only about 50% of people prescribed treatment for chronic diseases in developed countries follows the given directives [56]. Furthermore, many home-based healthcare activities are done alone and can hence not leverage on social interaction and stimuli. In both the medication management and home-based rehabilitation cases we observed that people had a rather low motivation (that got worse over time). Also, the reason why they should perform a specific healthcare activity was not always clear or merely understood on a superficial level. This is known to influence adherence negatively, for example in medication management [20]. If the perceived effect of a treatment (e.g. a medication or rehabilitation) is delayed, this can further challenge an understanding of why the treatment should be performed and hence there is a risk that the treatment is forgotten or overlooked. We have also observed less motivation among some older adults to perform treatments (e.g. home-based monitoring) as they consider themselves to be ‘old’ and do not see the direct benefit of changing behavior as, in their own words, ‘they will soon die anyway’. However, a few of the older participants had a strong personal rehabilitation motive such as be able to pick up a grandson at the bus stop after soccer training. Also the pregnant women showed a strong motivation, as they care for their unborn children and directly benefited by not needing to make daily visits to the hospital, or even be hospitalized. For people not having such direct, or personal, motive we observed much less motivation. The herein presented cases indicate challenges in why we perform healthcare activities and how this is different from everyday work or leisure activities.

Our findings across the cases suggest that a further understanding of why, or why not, people engage in healthcare activities is needed to design ICT support for home-based healthcare. Home-based healthcare technology should be designed to provide a clear and easily perceived benefit for the individual while balancing multiple perspectives to increase people’s motivation.

**When**

The time when we select, or have to perform an activity highly depends on the very nature of the activity and the situation at hand. Some activities that we perform as part of our everyday life, such as many work activities are rather stable over time. Even if we have different meetings and work-related tasks from day to day, it is not unusual that people have the same work hours for many years. There are few constraints on leisure activities such as reading a book, having coffee with friends or playing video games. We choose to perform leisure activities either by finding time for them through planning or more spontaneously, when we feel like doing them. On the contrary, prescribed treatments are rarely to be done when we ’feel’ like it. Indeed, healthcare activities such as taking medications, following a rehabilitation program or using tele-care must be integrated, or inserted, into a person’s pre-existing everyday life. To insert such healthcare activities in everyday life can be challenging as there is a risk that they interfere with other activities.

In one of our former projects with pregnant diabetics, challenges were identified on how to insert a healthcare activity in everyday life. For example one teacher did not like to stop her teaching to take her insulin [57]. She continued teaching her class and afterwards went into the bathroom to take the injection. She did not feel comfortable either interrupting her work activity or taking the insulin in front of her class. Similarly, all three cases contained
different elements of time constraints and planning. For example should medications be administrated at specific times of the day, rehabilitation should be performed at specific time intervals and in tele-monitoring the hospital expects home-based measurement results to be delivered at specific times of the day. In diverse, ongoing tele-monitoring projects we have observed that physicians tend to instruct patients to perform home-based bio-monitoring or care at specific times. Thus, the physician manages the patients’ time in a similar way as in the clinic, mainly taking his/her own work schedule into account and not the patients’ everyday routines. However, people do not only stay at home, ready to perform healthcare tasks. People visit friends, do shopping and travel. These activities can collide with the prescribed care. However, in some situations there might be more aspects to consider than finding the time to perform rehabilitation or take medication.

Additional constrains further challenge the activity, for example that a specific medication should be taken 30 minutes before a meal. This usually requires a high degree of planning and scheduling. A part from psychological barriers that can challenge an integration of treatments in everyday life, treatments can also have negative medical side-effects that can challenge everyday life activities. As observed in our study, for example diuretic medication (water-medications) intake needs to be planned so that a bathroom is available after the intake. Similarly, healthcare activities can from one perspective be categorized as activities we should perform at specific times and for a specific duration, when there might be other scheduled or preferred activities we would like to perform. This was also observed in a self-monitoring project in which rules for correct measurement of blood pressure conflicted with, and constraint, older adult’s everyday activities [30].

The herein presented cases indicate challenges related to when we perform healthcare activities and how they differ from everyday work or leisure activities. When to perform healthcare activities is not only important in clinical [51], but also in non-clinical settings. In non-clinical settings, it may be challenging to insert healthcare in ongoing activities for example due to an active lifestyle [30] or privacy concerns [40]. Home-based healthcare technology designers should understand individuals’ activities and what effects inserting healthcare activities might have on everyday life. Moreover, our findings suggest that ICT support for healthcare activities should be designed to allow the individual to reschedule, or adapt the prescribed regimen so it fits with other everyday activities. Home-based healthcare technology should balance the number of constraints, making healthcare activities more flexible and easier to integrate in people’s everyday life.

Where
For many work and leisure activities, the physical setting plays an important role. Activities often have a specific place where they are carried out. For instance, we cook dinner in the kitchen, we play football on the football field, and we have our office for work. While the physical settings for many (but not all) work and leisure activities are rather stable, the settings for home-based healthcare activities are more diverse, and the relations between setting and activity are more complex. Few dedicated spaces exist for treatments in our everyday life. The home is not designed to be a place for care [58] and people are reluctant to configure these private spaces to embrace their treatments [29]. Healthcare activities can also be physically distributed, as they might also have to be conducted at work, at school, at the sports club or while on vacation. This means that many healthcare activities such as doing specific rehabilitation exercises or taking insulin might have to be conducted outside the privacy of the home [57]. Furthermore, some treatments put requirements on the place of execution. If a specific rehabilitation tool or medication is not brought along or not even usable in a specific location (there might not be 3G coverage or a rehabilitation tool cannot easily be transported) the treatment plan is challenged. When implementing assistive technology it can also be hard to find the physical space in private homes [2], and even when the space exists the fear of stigmatization or simply aesthetical considerations make it challenging to integrate treatment and rehabilitation into everyday life. Still, the home can provide a sense of privacy that makes healthcare activities doable in an unsupervised setting.

The diverse users in the three cases were all, at different levels, challenged by the where to perform healthcare activities. Medication had to be brought along when outside of the home, something some people did not appreciate out of privacy concerns. For example, some of the participants in the Medication Management case did not like to take medication outside the privacy of their own home. When the medication was brought along, it had to be remembered and properly identified to ensure adherence. The rehabilitees in the home-rehabilitation case were even challenged by locating a suitable place within the home where they could perform the rehabilitation in line with the provided guidelines. Some of the pregnant women described challenges related to visiting friends or being on vacation while being monitored. They describe challenges in locating a stable 3G connection for the required Internet connection and electricity for the monitoring and communication equipment. Also, as the measurements could take up to an hour, the setting should allow them this time, something maybe not possible at a restaurant or elsewhere where the 3G coverage and required electricity were present. Participants in other tele-monitoring projects we have conducted have hesitated in doing bio-measures outside of the home, even if they can be ‘alone’ in a private location. In comparison, the pregnant women were more open to perform monitoring outside the home compared with these and the herein presented other two cases.

The presented cases indicate challenges related to where we perform healthcare activities and how they differ from
everyday work or leisure activities. ‘Where’ to perform healthcare activities is not only important in clinical settings [5, 51], but also in non-clinical settings such as the home. In non-clinical settings, our findings suggest that ICT support should be tailored to the specific requirements existing in different homes. However, some healthcare activities are done outside the home, and we should design to support privacy in public contexts. Home-based healthcare technology should support people in re-scheduling and planning their healthcare activities so that they can perform them where and when they prefer.

Control in collaboration

Collaboration in professional settings is usually facilitated through a shared understanding among colleagues and specific collaborative tools such as file-sharing software and shared calendars [12]. Also, collaboration in work or leisure often involves a shared goal or common interest. For instance, we collaborate with colleagues at work to keep a deadline or with friends when playing online games. Moreover, there are few activities that an (adult) person enters without having any control or saying. Either an individual has full control, e.g. what that individual does the following Saturday, or shared control where if, when and how a specific activity will be carried out is negotiated, for example at work or within a relationship. In many companies, employees also have a say in what kind of tasks are relevant and how to carry out given assignments. In contrast to many work and leisure activities, the nature of control in collaboration during healthcare activities is asymmetric and provides less possibility for control by the patient [29] – especially when the activities are not privately funded.

In the medication management case there was no active monitoring tool developed that transmitted levels of adherence to a healthcare professional. The medication takers preferred to have a tool that allowed them to document their adherence-rate and reasons for non-adherence, much like a diary. The adherence data could then be shared with a doctor during a face-to-face consultation, but on the patient’s and not the physician’s initiative.

In the rehabilitation case the rehaiblities preferred an offline tool, and they did not want the physiotherapists to exactly see when and how much rehabilitation they performed on a day-to-day basis. They demonstrated that retaining control was important, and that the designed solution provided them with a high level of control.

The system that enabled the women with gestational poisoning to do remote monitoring was specified by the hospital and the healthcare professionals. The system became an extension of the hospital that reached into the pregnant women’s homes and everyday lives. The women, independently of each other, developed diverse strategies to remain in control of their lives. One such strategy was to manipulate the values transmitted to the hospital. By transmitting values ‘within range’ the women could remain at home and continue their scheduled activities rather than going to the hospital for further examinations. Indeed, the women’s collaboration with the hospital was affected by the distribution of control designed into the system.

Most technological support for collaboration between doctors and patients staying at home are built to support the (homogeneous) health professionals’ needs, rather than the needs of the (heterogeneous) group of patients [10]. At the hospital, the health professionals normally take over much of the individual control for the patient. Negotiating control comes into play when healthcare is moved into private homes as to a large extent healthcare related collaborations are imposed on people rather than deriving from people’s own choice. A person with diabetes can maintain control over some health promoting activities such as how and when to exercise, what to eat, etc. However, he or she must always prepare to take insulin [57].

In an early tele-monitoring project, which will remain nameless, a first version of the system allowed the doctor to turn on a live video stream from a patient’s home at any time. From the hospital setting, the doctor was used to always being able to check up on the patient at any time (by just opening the door to the patient’s room), and the doctor felt that this was also necessary in the tele-monitoring setting. However, this feature violated normal privacy concerns, and it also shows how vulnerable technology can render a patient while at home by removing the control of one’s (private) life.

The herein presented cases indicate challenges related to the nature of control in collaboration as we perform healthcare activities and how they differ from everyday work or leisure activities. The notion of control in collaboration has an important role when performing healthcare activities in both clinical and non-clinical settings [29]. In non-clinical settings, our findings suggest that ICT support for healthcare activities should be designed with an understanding of what control is provided, removed or altered within a collaborative entity through its implementation. Home-based healthcare technology should increase the activity awareness of users, care network and designers on how people do workarounds to retain or gain control not provided to them by the designed system.

Based on the herein presented cases and detailed discussions, we have demonstrated the relevance of the four concerns as a tool for a deeper understanding of specific conditions of instances of healthcare in everyday life. We have done so by presenting different aspects of the four concerns and how they come into play and affects home-based healthcare. The relationship between these concerns, the three cases, and the effect these concerns have on the diverse cases can be seen in Table 1. The above-made presentations of each case allow us to understand issues at stake when designing for home-based care. It should be
pointed out that the impact levels in Table 1 stem from the direct cases and not general assumptions. For example is it clear in our presented cases on Medication management and Home-based rehabilitation that why the case participants should followed a prescribed treatment must be understood and supported. However, due to specific conditions regarding the pregnant women and their condition that resulted in a high level of motivation, the impact of ‘why’ is lower. However, this is not necessarily the case in all Tele-monitoring cases. Indeed, it may very well be the opposite. While much design influence for home-based healthcare come from work and leisure, we argue through our presented cases and the provided analysis, that designers must better understand and take into consideration; 1) that designing for home-based care is different than designing for work or leisure; and 2) the positive and negative aspects of using design-elements from work and leisure in home-based care designs.

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Table 1: Role and relationship between the diverse concerns and the cases. Impact level: H=High; M=Medium; L=Low.

CONCLUSION
In this paper we have presented aspects regarding four concerns important to consider when designing ICT for home-based healthcare. Using the three cases and the resulting four concerns, we argue that everyday life and healthcare in the citizen’s perspective have their own set of characteristics and should be put in the forefront when designing ICT support for home-based healthcare. The concerns may be used throughout a design project, initially to help understand the specifics of the case at hand and later to evaluate design ideas, concepts and prototypes.

Many healthcare activities require that we step outside of our normal, everyday activities and focus on something different – our illness and treatments. This set them apart from work and leisure, and consequently how we design for them. We should apply, but wisely and only when appropriated, design rationales from work and leisure in home-based healthcare designs according to the specific target group and settings. Our findings state that a deep understanding is required not only from the use cases, but also from the actors and the multi-health settings involved. We argue that it is possible to design ICT systems for home-based healthcare that embody more equal types of collaboration among the people involved, i.e. systems that support citizens and empower them to be an active part, make decisions, to control the way they use home-based healthcare, and to influence their treatments in clinical settings. However, doing so requires a shift in attitude among those involved, so that idle talk about patient-centric systems and empowerment is replaced by the will and the capability to develop concrete systems delivering exactly that. This in turn requires a better understanding of how (home-based) healthcare ICT systems impact the activities of those involved. Furthermore, we should support an ongoing (re-)negotiation between the planning and processes at clinical settings on the one hand and the control exercised by citizens on the other. However, the task ahead is huge and much more work and practical experience is needed.

We encourage designers and developers to further consider how rationales from healthcare workplace settings and leisure activities may influence future design concepts and solutions – and to pay attention to the aforementioned concerns (why, when, where and control in collaboration) to get a profound understanding of each particular case or situation when developing home-based healthcare solutions.

ACKNOWLEDGMENTS
BLINDED FOR REVIEW

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Understanding the Care Management Work at Home: The Case of Self-Monitoring

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Unpublished manuscript. This paper is in preparation for submission to a CSCW Journal.
Understanding the Self-care Management Work at Home: The Case of Self-monitoring

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ABSTRACT
It is important to understand both the setting and the individual everyday life when designing healthcare technology for unsupervised settings. However, most of these technologies are being designed without an in-depth understanding of the self-care management work at home. Based on qualitative studies, related work and taking into account the notion of trajectory, this paper shows how both frail and healthy people perform self-care management work at home. By doing this, the paper also introduces several challenges and call for attention to the different types of work (machine, safety, information, interpretation, comfort, sentimental, articulation, negotiative, body, error, and dirty work) that are tightly associated to the individual care trajectory work at home.

Author Keywords
Care management work, care trajectory, self-monitoring.

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION
It is argued that UBICOMP technologies for healthcare provide several opportunities to support care activities for both clinical and non-clinical settings (Tentori et al. 2012). In non-clinical settings, these technologies have increased the access to health information and tools to support self-care activities (e.g. chronic disease or lifestyle) in and outside the home. Self-care technology range from medical devices (e.g. blood pressure and glucose monitors) and simple mobile and web self-tracking tools (Tentori et al. 2012) to “Quantified Self” systems (e.g. Fitbit, Jawbone Up, Nike Fuel, WakeMate, Withings Scale). In addition, more elaborated technology includes the application of activity recognition algorithms and a mix of sensors to implement for example Smart Homes and Ambient Assisted Living (SHAAL) systems (Demiris and Thompson 2011). However, most of these technologies might not sufficient understand and support people’s care trajectories if they have not acknowledged the citizen perspective (Ballegaard et al. 2008; Storni 2013) to support the serious care work at home (Bratteteig and Wagner 2013).

On the one hand, medical devices have been designed considering the medical model driven by health professionals (Storni 2013). On the other hand, existing SHAAL and quantified-self initiatives have a strong technological focus in system design. SHAAL systems have focused for example on automation and inference of activities of daily living and surveillance (Bratteteig and Wagner 2013; Demiris and Thompson 2011). Whereas quantified-self systems have focused on data collection and quantification of a variety of health and wellbeing variables such as diet, exercise patterns, alcohol, tobacco consumption, etc. (Lupton 2013; Swan 2012; Tollmar et al. 2012). If home-based healthcare technology neglects the citizen perspective, it might fail to support patient empowerment (Storni 2013) increasing rather supporting the self-care management work at home (Aarhus et al. 2009). The complexity of the self-care work increases when people experience more than one disease or have an active lifestyle with different activities in their everyday life work (Corbin and Strauss 1985). This can turn the self-care management work into a complicated endeavor not only for care recipients but also for caregivers that perform or support care activities at home (Bratteteig and Wagner 2013; Dalgaard et al. 2013). The lack of understanding of the self-care management work in home-based healthcare technology design can result in unintended situations such as obsession, stress, stigmatization or deceiving behavior (Aarhus and Ballegaard 2010; Grönvall and Verdezoto 2013; Lupton 2013).

The aim of this paper is to get a better understanding of the complexities of performing care management work in non-clinical settings by care recipients “self-care work”. Our study extends the related work (Bratteteig and Wagner 2013) by exploring the concept of trajectory its different types of work associated to it (Strauss et al. 1997) to further understand the self-care management work as part of the trajectory work that needs to be performed at home. The main contribution of this paper is to highlight the different types of work (machine, safety, information, interpretation, comfort, sentimental, articulation, negotiative, body, error, and dirty work) that are manifested along the self-care trajectory work at home.

THE CARE MANAGEMENT WORK AT HOME
In non-clinical settings, the self-care management work does not only include the “homework” of performing care activities (Aarhus et al. 2009), but also all the “invisible work” that takes place when for example people become a “diagnostic agent” at home (Oudshoorn 2008). People engage in interpretation work (Andersen et al. 2011) and...
self-learning endeavours (Chen 2011; Grönvall and Verdezoto 2013) while trying to understand and get meaning from health data. Aarhus and Ballegaard (2010) shows how people engage in boundary work when managing a chronic disease at home, moving between two continua of segmentation/integration (of care activities) and visibility/ invisibility (of care-related objects). Bratteteig and Wagner (2013) applies Strauss’ concepts of machine, safety and body work (Strauss et al. 1997) to describe the care work performed by care recipients when for example they adjust their body to a technical care-related device following clinical safety recommendations. As the home has not been designed as a place for care (Bratteteig and Wagner 2013; Grönvall and Kyng 2012), previous work has also reported the importance of integrating healthcare activities as part of people’s everyday lives (Ballegaard et al. 2008; Dalgaard et al. 2013). Furthermore, the self-care management work is affected by the character of the disease, routines, activities, places, individual’s health locus of control, availability of resources, acquired and needed knowledge, and people’s motivation (Aarhus and Ballegaard 2010; Ballegaard et al. 2008; Chen 2010; Dalgaard et al. 2013; Grönvall and Verdezoto 2013). In addition, there has been limited work exploring people’s temporal trajectory of care and the interplay of self-care activities across care settings (Chen et al. 2012; Fitzpatrick and Ellingsen 2012). For instance, Aarhus et al. (2009) and Chen (2011) have applied the concept of “illness trajectory” to get an understanding of care work practices in non-clinical settings. The trajectory concept is defined by Strauss (1993) as “1) the course of any experienced phenomenon as it evolves over time..., and 2) the actions and interactions contributing to its evolution”. The trajectory work is all the work associated to managing and shaping a specific trajectory of care across care setting (Corbin and Strauss 1985; Strauss 1993; Strauss et al. 1997).

APPROACH
Aligned with (Doherty et al. 2010), we use the concept of trajectory as a “tool for thinking” to get an understanding of the care management work at home. After identifying the trajectory work as the main theme of the paper, we use it as a sensitizing concept to provide a “general sense of reference” (Patton 2001). Informed by the related work, we then apply the concept to the data coming from a case study project of health self-monitoring. Instances that relate to this concept were extracted from the transcripts and analyzed using the different types of work (machine, safety, information, comfort, sentimental, articulation, negotiative, body, error, and dirty work) and trajectory patterns (i.e. trajectory phasing, trajectory scheme, trajectory projection, and trajectory management). Each theme was related to the literature.

The project was open-ended and involved a multidisciplinary group of people (e.g. three computer scientists with PD background, a nurse, an ethnographer, and two business managers). Participants included both healthy and frail older adults to add heterogeneity sampling as suggested by” (Patton 2001) to further investigate the care management work in non-clinical settings. The project work included: a) an explorative qualitative study, and b) a user-centered design process, and c) an exploratory quantitative study. First, the initial qualitative study explored people’s motivation, perception and use of self-monitoring technologies in non-clinical settings. The initial data consist of two-hour semi-structured interviews with 10 adults (6 men, 4 female, aged 45-85) where six were living with their family and four were living alone. Among these participants, four were healthy, three had a chronic illness (one with diabetes and two with COPD - one of these two had a weak heart), two were in rehabilitation after cerebral hemorrhage and the last one had experienced breast cancer. Second, the user-centered involvement consisted of semi-structure interviews and four workshops with eight additional healthy older adults over 60 to investigate challenges and opportunities to support preventive self-monitoring activities at home. Workshop activities explore why, how, and when participants could perform preventive self-monitoring as part of their everyday life. Third, the quantitative study (online survey) included 165 completed respondents to confirm and further explore self-monitoring activities from a broader population (aged 22-83). For further details please refer to (Grönvall and Verdezoto 2013).

THE SELF-CARE TRAJECTORY WORK AT HOME
The self-care trajectory work is all the work associated to a specific trajectory of care. As explained by Strauss et al. (1997), “… the work that patients do is trajectory work in the service of managing and shaping aspects of their trajectories” (p. 200). Informed by the related work and Strauss concept of trajectory, we look for several kinds of work (machine, body, comfort, safety, information, interpretative, sentimental, negotiative, articulation, dirty, error ) involve in the individual’s trajectory management as part of the trajectory work that take place at home. The self-care trajectory work should be understood as a combination of the different types of work as follows.

Machine Work
People engage in machine work while setting up and operating a specific self-monitoring device (Strauss et al. 1997) as part of the trajectory work at home. For instance, a participant said ”I bought a blood pressure device after I was diagnosed with a high blood pressure. I wanted to be able to check it myself: I used it when my heart starting beating away, but I don't do that anymore. It is just a comfort and safety to know, that it is in the closet if I need it”(See also Comfort and Safety Work). Machine work involves all sort of activities from connecting the body to the device to arranging a proper maintenance and storage place for the devices. Participants from our workshops engage in machine work while performing the self-measurement by placing the cuff to their arms and following the measuring rules either by themselves or by helping each other. Machine work also involved other types of work at times such as comfort, safety, sentimental, information and articulation work. For example, a participant preferred to visit the doctor to perform the measurement because it was comforting but the visit needed to be arranged in advance (articulation work).
Body Work

While performing body work, the body is the main focus of attention (Strauss et al. 1997) regardless the health or illness condition. For instance, a participant said: “I would like it if exercise could be worked into the everyday life, maybe even just 15 minutes. It would also make the culture of doing exercise stronger if it was brought in to be a part of the work day”. As such, exercise constitutes body work as participants wish and look for integration of care activities into their daily activities. Body work can add an extra work to people’s everyday life. A participant said, “I have to bring exercise in as an extra thing - pull myself together. Exercise is something I have to do, because I have to and not because it is fun. Sports and exercise are not fun, and it’s not something I do because I want to - it is a duty”. The level of body work changes according to the individual health or illness conditions in terms of the quantity and frequency of the self-monitoring activity and the treatment/intervention plan. For instance, the nurse suggested preventive blood pressure measurements for 3 days in a row, mornings and evenings, u to 4 times a year. Furthermore, we observed how participants engaged in body work while managing their posture, arm position while and following in general the measuring rules.

Comfort Work

People engage in comfort work to minimize any possible discomfort cause by their health or illness conditions that can be performed either by the individual or by members of the care network (Strauss et al. 1997). As we described above in machine work, having a blood pressure device in the closet brings comfort, as it is ready available if needed. For instance, some participants do not mind to move to a more supervised environment to bring comfort and keep social relationships. A participant said “I would like to search for an elderly apartment in the commune of Gentofte. I would like to move there, so I can be closer to my kids”. In addition, healthcare professionals also perform comfort work as well as closest family and friends while conducting self-monitoring. For instance, an older participant said “I get blood tests and so on taken at the doctors, by the nurse. It is very comforting because she cares a lot about what she does. I’m up there every third month and I look forward to going up there. ‘Come here and we will help you’. I myself have changed my medication, and she was very proud of that”. Discomfort can be caused by the technology as we observed during our workshop, some participants engage in comfort work helping each other to place the cuff as in some cases the cuff was to tight to the individual’s arm. However, technology can also bring comfort if the benefits can be perceived. For instance, a participant said: “I’m completely comfortable with the monitoring equipment. If it can help me, I would like to use them”.

Safety Work

People engage in safety work when they learned how to manage and prevent potential dangers and risk regarding the self-care activity at home (Strauss et al. 1997). In our case, the nurse taught our participants safety work regarding what, why, and how to perform blood pressure self-monitoring at home. She explained to our participants the importance of the body posture (e.g. sitting without crossing the legs), arm position at heart level and measuring guidelines to avoid errors or misinterpretations. She recommended taking measurements from both arms and registering the one with the lower value and repeating the measurement to confirm the values. We observed this during the self-measurement activity while checking the reported BP values. Some participants took the measurement from both arms and also more than once to confirm the values. From the quantitative study, we saw that older adults are willing to buy self-monitoring devices as long as they have been tested before. And from the qualitative study, just having the blood pressure device in the closet bring safety to participants as described above in machine work. Furthermore, people can be aware and try to manage the possible dangers and risks around themselves and take decisions according to their personal situation. For instance, a male participant expressed “I used to be able to do everything myself. You only use the doctor, when you are really sick (...) it is probably a typical male-point of view that I have, about not going to the doctor unless you broke an arm or something”. Deciding to go or not to the doctor has an implicit safety work that can be crucial depending of the healthcare situation (see also sentimental work).

Information Work

People engage in information work while managing all sort of information before, during and after the self-care activity take place (Strauss et al. 1997). From our workshops, participants engage in information work when the nurse informed them about BP self-monitoring including possible symptoms, consequences, possible actions to control it and how and when to perform it. The nurse gave them some additional pamphlets. Older adults also registered all the measurements and made some comments to their readings. Managing all verbal and written information is part of the information work at home as described by (Klasnja et al. 2010).

Interpretative Work

Interpretation work no only take place in the clinical setting (Andersen et al. 2011) but also in non-clinical settings. People engage in interpretation work for example while trying to get meaning from their own self-measured bio-values. In our project, participants used several strategies to make comparisons, understand and confirm their BP values. This interpretation also considers the context around the measurements as explained by the nurse. Knowing if the person does not follow the measuring rules and for example drinks coffee or alcohol around the measurement can help to determine under or over estimation of BP values. The reference values explained by the nurse played an important role, as it was the basis for older adults to interpret and understand the meaning from the values. Thus, self-learning and self-reflection activities occur as a result of the interpretation work. For instance, we observed how a participant reflected back to the weight scale values wondering if the gained weight was a result for example of a medication side effects. In addition, external factors as a result of the individual interaction with the social
(see also sentimental work) and physical environment can provoke interpretation work. For instance, a participant commented: "Many of my good friends disappear, and then I think to myself ‘How are you really doing?’". Or from external factors that can vary from for example reading an article in the media (e.g. newspaper, websites) to for example temporal weather conditions (see adaptive work).

**Sentimental Work**

People engage in different types of sentimental work as explained by Strauss et al. (1997): interactional work and moral rules, trust work, composure work, biographical work, identity work, awareness context work, and rectification work. For instance, composure work was observed when people performed self-measurements by themselves following the measuring rules. Some participants try to increase their own confidence and build trust by pacing themselves (interactional work) with their normal activities. A participant said: "Going out and shoveling snow – I was surprised by how well it went. Our house is in the corner area, so there was a lot of snow. But I wanted to do it! I am a little stubborn. I have to continue to be able to do the things I have always done". In addition, the nurse for example engaged in interactional work while establishing the relationship with our participants by asking questions about their life style in relation to BP self-monitoring. There is also sentimental work associated with people’s aims to continue with good health and wellbeing and avoid health problems that can interfere with their everyday life. A healthy participant said "It would be nice if I am so fresh - that I can still row kayak, be in vigor and have the energy to stay active. Keep my life as it is now - here where I live. I would like to travel, go to art museums and experience and read". Most participants live an independent care situation and wish to maintain their relationship with family and friends as long as possible. A participant said "I need to be healthy and well in 10 years when my grandchildren are going to learn to ride their bikes". As a consequence of the interaction work, reciprocity behaviors can occur (positive or negative). A participant said in a positive way "It is hard to just receive and not being able to give back".

As part of the care trajectory projection that involves “visions of future action” (Strauss 1993) regarding the personal health experience, people also engage in sentimental work. This vision might be individual or collective as people value their social relationships along the care trajectory phases. While preparing for the future, some participants want to stay in their own house and to keep their social network and be able to take care of themselves. A participant said, "My boyfriend and I shall grow old together. We shall laugh, hold hands, go out to cafes, take small and larger vacations, take care of grandchildren, have long deep conversations, make love - live life. I hope we stay fresh and mobile". Visions of the future are related to personal questions about "Where am I going? And what will I have to do to reach my goals".

**Articulation Work**

People engage in articulation work when they have to coordinate all the different activities that take place at home (Strauss et al. 1997). At the top level, older adults needs to manage the self-monitoring work as well as other lines of work that are present at home. Then, older adults used and supervised themselves in relation to the self-monitoring activity. While at home, older adults operationalize articulation of work while carrying out the measurements and following the measuring rules especially in relation to all other scheduled activities in their daily life. Articulation work is more complex for people with chronic condition as the number of actors involved in the different levels increase.

**Negotiative Work**

People engage in negotiative work while negotiating implicit or explicit agreements regarding a specific topic (Strauss et al. 1997). We found two types of negotiation (inner and outer) while performing self-monitoring at home. For instance, our participants engage in inner negotiations while prioritizing social activities instead of health. A participant said (while watching a picture that shows a glass of wine) "Drinking habits, community, information - awareness about the potential damage of alcohol - even though alcohol is a very strong social factor/drug, that creates new friendships and such. In a social relation I will probably forget about the just mentioned, factors". A difficult negotiation might occur when lifestyle changes are requested (negative lifestyle behaviors or changes that affect participant’s everyday life such as skipping appointments with friends or planned holidays). Another example takes place while people try to pace themselves to accomplish something (see sentimental work). For instance, a frail participant said "The goal so far is to reach some sort of walking function with a stick. That I would like. Then I could walk around. It is so hard to get around. I don’t expect to ever walk around outside again, but then again I don’t know if I will ever walk at all!". Furthermore, we observed an outer negotiation when healthy participants have to deal with the social worlds around them while performing preventive self-care activities. For instance, some healthy participants feared stigmatization when self-monitoring activities conflict with other planned activities. A participant expressed that he would not take a self-monitoring device to his bowling activity, as he was not interested in being labeled as a sick person.

**Dirty Work**

People perform dirty work when for example engage in physically or socially unpleasant activities (Strauss et al. 1997). In our case, some participants did not like to depend on others. For instance, a participant said: "Suddenly you are so dependent of others. That is very unpleasant" (see sentimental work). As we described above in body work, some participants considered that exercises added an extra work is added to their everyday life and that they were not pleasant to do. Another participant stressed: "When I do to many things that I don’t think are fun, then I have a risk of becoming sick!". Activities can be boring at time and challenge the self-care activity at home. For example, resting 5 minutes...
before taking the measurement were perceived as tedious for some participants.

**Error Work**

People engage in error work while preventing, minimizing, defining, detecting, covering up, rectifying, and estimating the consequences of mistakes (Strauss et al. 1993). Our participants perform several preventive activities while taking the measurements at home. For instance, we could see that they performed the measurement more than once both during the workshop and during the self-measurement task.

**Adaptation Work**

We have named adaptation work to the work that is done by people while adapting to the current trajectory of care. For instance, a participant performed adaptation work while changing a behavior to suit the new conditions or treatment plan: “I’ve become an anti-smoker after I became ill. I tell people that they should quit smoking and I’ve sent my son to a quit-smoking class”. Maintaining a personal health experience involves relearning typical life routines, accommodating atypical activities and a reevaluation of personal expectations (Chen 2010). The adaptation can also be affected by external factors such as weather conditions and people adapt themselves to the new conditions. For example, a participant said “It is very much in relation to food that I think about health and exercise. During the summer when I have lots to do I don’t worry so much about it - it is more now in the winter time”. During the adaptation work, we observed that people have issues with loosing or getting control (Grönvall and Verdezoto 2013) while adapting themselves to the new situation. A participant said “I don’t want to be a burden to others - just because you are a little sick you don’t necessarily need help”.

**DISCUSSION AND CONCLUSION**

Our findings introduce the following challenges. At first, even if participants are aware of the consequences of specific lifestyle behaviours, some participants prioritize social experiences and desires. The more independent participants rely on self-monitoring to check and control their individual health status. Consistent with (Andersen et al. 2011), participants engaged in interpretation work either by themselves or by involving other people in the care network. For prevention, participants are likely to share their bio-values either with the doctor (that has a secondary role as an advisor) or with their spouses. But most of them did not like to take the measurement in public due to fear of stigmatization especially the healthy older adults. Negotiation of boundary work not only takes place when managing a disease at home (Aarhus and Ballegaard 2010), it also occurs when people manage preventive healthcare activities. We have observed inner and outer negotiations when people for example have to engage in other everyday activities while still carrying on the trajectory scheme or treatment plan (Ballegaard et al. 2008; Dalgaard et al. 2013). Aligned with (Aarhus and Ballegaard 2010), self-monitoring activities take place either integrated or separated from people’s everyday life. Some participants integrate their care management work to their everyday life especially when benefits of self-monitoring can be more perceived as in the case of the non-healthy older adults.

In non-clinical settings, the care plan or trajectory scheme (Strauss 1993) is contextualized to the list of self-care activities that people perform while at home. For example, a care plan for an individual with diabetes might contain prescribed medication and self-monitoring activities and a complete detail of food that the person is able to eat or not. While performing a self-monitoring activity, the trajectory scheme is tightly related to the monitoring schedule and conditions of measurement that have to be captured over time. For instance, the guidelines for measuring were important for both participants and the nurse during the self-monitoring activity to support the interpretation work.

As we have seen, several types of work take place as part of the self-care work at home. Most technology mainly focuses on supporting the care trajectory scheme specified by the health professional. Beyond supporting the care trajectory scheme, designers of self-care technology should recognize the different types of work that take place at home and how one of them can affect the others. These types of work are highly intertwined and are not only attached to the technology but also to people’s desires, visions of the future and their social relationships that affect the self-care management work at home. As visons are not an “end” (Strauss 1993), understanding the citizen perspective (Ballegaard et al. 2008) can help people to reflect back and refocus shaping actions during the care trajectory phases to establish, maintain and assess the right (spatial, temporal, work, sentimental, technological, informational, moral and aesthetic) order (Strauss 1993) in people’s trajectory of care when needed.

Furthermore, we have observed that the complexity of the monitoring activity increase with comorbidity. Here, the care trajectory scheme can establish tensions between the individual everyday life and the care activity when an extra work is added to their everyday life. Before implementing technical solutions to support a specific treatment or condition, designers should consider and understand all lines of work (Corbin and Strauss 1985) in people’s everyday life. For instance, one way to deal with this challenge is to support planning of care activities as part of people’s everyday life (Dalgaard et al. 2013). Supporting the third level of articulation of work “planning and coordinating” between the trajectory and everyday work (Bratteteig and Wagner 2013), can alleviate the tensions between the care activity and people’s everyday life. As a result, the monitoring activity can be planned, moved and adjusted according to the people’s everyday activities, needs and care setting. Accounting for all explicit and implicit types of work in people’s everyday life would help designers to identify the main issues in people’s trajectories of care.

Finally, understanding the care management work in non-clinical settings can for example help designers to identify several opportunities when the “trajectory of illness” might be inappropriate to consider for the future technology design. The presented findings are far for
complete, however, they suggest that a more holistic view is needed to understand and support people’s self-care management work at home.

ACKNOWLEDGMENTS
Blind for review.

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