

# CAREMAP- PLATFORM TO SUPPORT AND EMPOWER INFORMAL CAREGIVERS

# CAREMAP- PLATVORM OMASTEHOOLDAJATE VÕIMESTAMISEKS JA TOETAMISEKS

MASTER THESIS

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Tallinn 2024

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# Department of Mechanical and Industrial Engineering THESIS TASK

Student:	Terje Losvik, 221862MADM
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#### Thesis topic:

CareMap- platform to support and empower informal caregivers CareMap- platvorm omastehooldajate toetamiseks ja võimestamiseks

#### Thesis main objectives:

1. Conduct literature review and field research about careburden of informal caregivers

2. Utilizing design interventions to identify and understand the pain points and needs of informal caregivers guided by caregiver stress theory

3. Utilizing design thinking methodology with co-development to propose design concept

#### Thesis tasks and time schedule:

No	Task description	
1.	Literature review	
2.	Participatory research	
3.	Living Lab preparation and conducting testing	16.08.24
3.	Concept creation and design finalisation	02.12.24
4.	Finalisation and submission of the thesis	30.12.24

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#### ABSTRACT

Our goal is to live happy, active and healthy.

During life, people come across different life situations, one of which can be, for example, a family member born with disability or falling ill. Those family members who need care are usually cared for by a close family member.

If the need for care appears when a family member becomes ill, for example with dementia, the caregiving process typically begins with a sense of duty and compassion, but as time progresses and the demands of caregiving intensify, the weight of responsibility can evolve into a significant burden.

Caregiver burden encompasses the physical, psychological, emotional, social and financial challenges faced by individuals providing care for loved ones with chronic illnesses, disabilities, or age-related conditions. This multidimensional phenomenon significantly impacts caregivers' well-being, potentially leading to a decline in physical health, emotional distress, social isolation and financial strain. Influencing factors include the intensity and duration of care, the caregiver's relationship with the care recipient, available support systems, and the caregiver's own health and resources.

Addressing caregiver burden is essential for sustaining caregivers health and enhancing the overall caregiving experience, emphasizing the need for systemic support and interventions.

As the population is aging and age-related conditions are growing, it is also accompanied by the growing share of informal caregivers in the healthcare and social systems, and thus demand for social and health services is also increasing.

In order to alleviate the growing burden caused by the ageing population on the healthcare system, the author of this thesis has designed a concept for reducing the careburden by implementing design thinking principles.

Co-designed with caregivers, CareMap- AI-driven internet platform was designed to reduce informal caregivers careburden by implementing welfare technology into the care process. CareMap-platform for decision-support, is scalable and empowers caregivers by providing personalized care plans, welfare technology recommendations and decision-support tools tailored to each stage of the caregiving journey. This platform also integrates Living Labs as demo centers, enabling caregivers to explore, test and adopt welfare technology solutions, fostering a supportive and efficient caregiving environment.

By utilizing human-centered design principles, welfare technology and social services can be effectively integrated to create holistic, caregiver-focused system that improve care outcomes while reducing caregiver burden.

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Stakeholders are engaged as active participants in the process, contributing their knowledge and experiences. This approach emphasizes that services are not simply delivered but are co-developed, ensuring that solutions are dynamic, responsive and aligned with the evolving needs and contexts of the stakeholders.

Keywords: human-centered design, design thinking, service co-development, caregiver burden, informal caregiver, welfare technology

### List of terminology

**Caregiver burden** (in estonian *hoolduskoormus*) is a multi-dimensional response to the physical, psychological, emotional, social, and financial stresses associated with caring for someone, typically with a chronic illness, disability, or age-related frailty. For the purposes of this study, the term "care burden" is used throughout as a synonym.

**Dementia** is an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living. Dementia is one of the major causes of disability and dependency among older people worldwide. It can be overwhelming, not only for people who have dementia, but also for their carers and families, who globally provide the majority of care and support (WHO, 2013).

**Informal caregiver** (in estonian *omastehooldaja*) is a person of any age who cares (mostly free of charge) for a family member or loved one who has a chronic illness, disability or other long-term health condition or care need, doing so outside of professional or official work (Riigikantselei 2017: 9).

**Intellectual disability** is a permanent condition that manifests itself in childhood. A person with intellectual disability needs continuous, ongoing support to cope with everyday life. Intellectual disability is a condition, that requires ongoing support from others throughout life (Raudmees, n.d.).

**Welfare technology** refers to technologies that help individuals, especially the elderly, disabled, or those requiring long-term care, achieve a higher quality of life . These technologies aim to promote independence, everyday functioning, and well-being. In this context, 'technology' means technologies within the social and health sectors in particular, which focus on care, prevention and slowing down of functional deficits and deterioration, compensation and rehabilitation (Sosiaali- ja terveysministeriö, 2010).

# 1. BACKGROUND AND MOTIVATION FOR THE RESEARCH

Health systems of the future will be put under significant pressure because of several demographic developments. Advanced economies are struggling with ageing populations with longer lifespans, which may present issues like increased susceptibility to non-communicable diseases, a shrinking work-force, and increasing long-term care costs (Mogensen, 2021, p. 7), as well as an increase in care burden. Current and future megatrends, the total underfunding of the social sector, an ageing and shrinking population, changing employment relations, increasing pressure to use flexible forms of work, the high risk of poverty - combined with regional concerns - keep the focus on a crucial question for the development of society and the economy: what changes in public policy are needed to meet the needs of people, the economy and the labour market, while ensuring increased welfare and the sustainability of social protection systems. In this research, the author focuses on the care burden of informal caregivers and how to reduce care burden through improved services, products and interactions. The author focuses on people with dementia and intellectual disability in this work because these conditions are very challenging and demand significant commitment and time resources from caregivers. It follows from the study that to empower informal caregivers, integrated and innovative services must be developed and their availability must be ensured (Varik et al., 2020). Like other European countries, Estonia is also facing a challenge in terms of how it provides services for the growing number of older people and the associated rise of those living with long term health conditions into old age. The motivation for writing this thesis stems from the recognition that in Estonia, individuals with caregiving responsibilities face an unequal and overwhelming care burden, there is a lack of supportive services, which further isolates them from the labor market and social life. Almost two-thirds of those who have taken on this role today would like to go to work instead; this must become possible through the provision of services to those in need (Turu-uuringute AS, 2022, p. 50). Many of whom would prefer to participate in the worklife are often constrained by the time and commitment required to care for their loved ones. The social sector needs the widest and highest possible attention. Investment in social protection must increase. Clear but ambitious targets are needed. The best social protection is when people can work or otherwise participate in society. Many of whom would prefer to participate in the worklife are often constrained by the time and commitment required to care for their loved ones. The research seeks to offer solutions how can caregivers maintain their current quality of life and be able to participate actively in social life, be healthy and able to work for a long time (Mastik

& Lannes, 2021) and which would benefit both caregivers and care recipients, contributing to the overall sustainability of the social and health sector.

# **1.1** Research problem and objectives

If it unfortunately happens that a family member ends up in a situation where he needs care, the caregiver may face a situation of confusion and uncertainty.

The report published in 12.04.24 by Estonian National Audit Office confirms that considerably clearer guidance is needed in Estonia for adults in need of social care and they are left on their own when seeking support. If people in need of care doesn't know what assistance is available, where to get it and how to get it, they're likely to miss out on it (Riigikontroll, 2024).

This research aims to contribute to the field by bridging the gap between the needs of informal caregivers and the capabilities of healthcare technologies and social services. It also seeks to support innovation in the social system, by initiating and supporting cooperation between the social sector as a potential user of technology and the technology sector as a provider of technological solutions, as stated in the Green Book "Increasing the use of technology in a person's everyday life to support coping and well-being at home " which states that there is a need to develop an ecosystem within the social system (Sotsiaalministeerium, 2020).

By focusing on human-centered design principles this study intends to offer actionable insights into developing more effective, integrated solutions that can significantly reduce the caregiving burden and enhance the well-being of caregivers. This approach has not only the potential to improve individual caregiver experiences but also to inform broader policy and practice in healthcare and social service provision.

This research also aims to contribute to the strategies outlined in the Estonia 2035 action plan and the Welfare Development Plan goals, including, first of all, to reduce the care burden of informal caregivers.

The application of design thinking in co-developing quality health and social services is the innovative aspect of this study.

The main research problem for the study is formulated as:

how can the care burden of informal caregivers' be reduced so they can work or otherwise participate in society.

More specifically the main research problem was formalized into more concrete initial research question that first guides the literary study:

What are the primary needs, challenges and preferences of informal caregivers in relation to social services and welfare technology? This question seeks to uncover the detailed landscape of caregiver experiences, focusing on their interaction with technology and social services.

#### In what ways can human-centered design (HCD) principles be utilized to enhance the integration of welfare technology and social services for informal caregivers?

This question explores the application of HCD methodologies to create a cohesive solution that bridges technology and service provision, tailored to the caregivers context.

The **main objectives** of the research are to identify and understand the key challenges faced by informal caregivers, particularly those caring for individuals with dementia or intellectual disabilities with a focus on how well current services meet the needs of informal caregivers and the elderly population, to develop actionable insights for improving service delivery and resource accessibility for informal caregivers through the application of human-centered design and design thinking principles.

That means to understand the specific requirements, obstacles and preferences of informal caregivers and to assess the current landscape of healthcare technologies and social services available to caregivers.

Another objective is to evaluate existing solutions and identify gaps in meeting the needs of informal caregivers, focusing on areas for improvement through humancentered design and to produce information about the human centred design in social services and design a solution that addresses the identified needs and challenges of caregivers, leveraging the strengths of both technology and social services.

## **1.2 Research approach**

This study uses a qualitative methodology. Qualitative approaches allow room to be innovative and to work more within researcher-designed frameworks (Creswell, 2009, p. 35) and qualitative approaches use multiple forms of data collection and analyzing methods, such as open-ended observations, interviews and documents (Creswell, 2009, p. 182), which all are used in this study. Qualitative research methods are vital in this study for understanding the complex, subjective experiences of service users and providers of social care. Interviews and case studies allow to explore perspectives, motivations and the context of social care delivery, offering insights into how services can be improved to better meet the needs of users. In a systematic research process the theoretical framework, empirical fieldwork, and case analysis all evolve simultaneously.

# **1.3 Hypothesis**

The hypotheses for this thesis are formulated based on the selected topic and an analysis of the existing services provided by local municipalities. These assumptions will be evaluated in the research's conclusion to determine their relevance.

Before delving into detailed research on the social care sector and its operations, the study presents the hypotheses.

#### The hypothesis for the thesis is

- The lack of clear guidance and information significantly increases the caregiving burden for informal caregivers of individuals with dementia and intellectual disabilities.
- Automation of routine monitoring through advanced healthcare technologies reduces the care burden on informal caregivers.
- Social workers and family doctors are inadequately equipped with the knowledge and resources to reduce the care burden on informal caregivers, due to a lack of targeted services and insufficient awareness of available welfare technology solutions.
- Informal caregivers remain unaware of potential support options due to insufficient dissemination of information and knowledge.
- Providing improved support and services for informal caregivers will enable them to maintain a balance between caregiving responsibilities and employment, contributing to their overall well-being and societal participation.

## 2. METHODOLOGY

The methodology chapter serves as the cornerstone of the research, providing a detailed roadmap of the methods used in this study. It is an articulate demonstration of the research design's logic, validity and alignment with the study's objectives. The choice of methodology is guided by the research questions and the theoretical framework underpinning the study.

#### 2.1 Theoretical framework

The theoretical framework for this study on integrating social service concepts with welfare technology to reduce care burden involves several theories and models that explain how technology can enhance social services in healthcare settings and the subsequent effects on reducing care burden. This framework provides a foundation for understanding the relationships between technology, social services and care burden.

#### 2.2 Human-centered design

Human-centered design (HCD) is a framework focused on understanding human needs and how design can respond to these needs. With its systemic humane approach and creativity, human-centered design can play an essential role in dealing with today's care challenges. 'Design' refers to both the process of designing and the outcome of that process, which includes physical products, services, procedures, strategies and policies. The resulting design is understandable and usable, it accomplishes the desired tasks and the experience of use is meaningful and pleasurable. Characteristic of HCD is its holistic, systems approach towards human needs, ensuring that solutions fit the dynamics of the (complex) sociotechnical system the user is part of (Melles et al., 2021, p. 37).

In this study three key characteristics of HCD which related to the context of social and healthcare are addressed-understanding people, early and continuous stakeholder engagement and a systems approach. The emphasis of HCD is on human needs and how design can respond to these needs. Understanding people, how they think, how they behave and how they are influenced by their environment (i.e. their sociotechnical system) is therefore conditional before the actual development of an intervention can start. For highly complex matters such as patient safety and quality of care HCD may provide a much needed systemic and humane perspective to develop meaningful innovations to improve safety and quality. HCD relies heavily on qualitative research methods and user studies (Melles et al., 2021, p. 38). Applying HCD principles in developing healthcare technologies and services ensures that the interventions are user-

friendly and effectively meet the needs of care recipients, caregivers and healthcare providers, leading to more significant care burden reduction.

#### 2.2.1 Service dominant logic

As Vargo and Lusch introduced it, a transformative worldview in marketing, known as service-dominant logic, which redefines the prevailing perspectives in the field. According to the service-dominant logic, service provision- instead of physical products - is the fundament of all economic exchange. For example cars render transportation services (Vargo & Lusch, 2004) or welfare technology render social services. The open process nature makes service development more difficult in comparison to closed internal R&D driven product development. In a service-dominant economy, the core is based knowledge competence on (Vargo & Lusch 2004). According to Patricio et al the emergence of complicated service systems requires new interdisciplinary service development methods. They present that service development should happen on multiple levels, combining new service development, interaction design, and the emerging field of service design. In addition to the need for research collaboration between different disciplines, successful service development practices of today require another type of collaboration with the users of the service (Patrício et al., 2011).

#### 2.2.2 Design thinking process

In the health- and social care service design process, consideration of persons experience is a priority since the improvement of care quality can be achieved only through an understanding of persons needs.

Design thinking is a problem-solving approach that combines empathy, creativity and rationality to meet user needs and drive innovation. It's increasingly recognized as a powerful tool for tackling complex challenges across various industries, leading to innovative solutions that might not emerge from more traditional approaches. Design thinking is a non-linear, iterative process that teams use to understand users, challenge assumptions, redefine problems and create innovative solutions to prototype and test (*What Is Design Thinking (DT)?*, 2016).

Design thinking in healthcare is a promising approach to intervention development, implementation, and dissemination that may increase the acceptability and effectiveness of health care interventions by actively engaging patients and providers in the design process and rapidly iterating innovation prototypes to maximize success

(Altman et al., 2018) and design thinking can help stakeholders create products and practices that are more humane, efficient and equitable (Ku & Lupton, 2020, p. 6). Design thinking process by Interaction Design Foundation involves five phases-empathizing, define, ideate, prototype and testing (*What Is Design Thinking (DT)*?, 2016).



Figure 1. A non-linear process of design thinking (*What Is Design Thinking (DT)*?, 2016)

The integration of design thinking into the health and social care service design process marks a significant evolution towards more human-centered care. The essence of this approach lies in its prioritization of understanding individual needs as the foundation for enhancing care quality. By leveraging empathy, creativity, and rationality, design thinking serves as a versatile problem-solving method that transcends traditional boundaries to address complex challenges across industries, including social- and healthcare.

Design thinking relies on our ability to be intuitive, to recognize patterns, to construct ideas that have emotional meaning as well as being functional (Turk et al., 2022).

#### 2.2.3 Caregiver stress theory

Caregiver stress theory provides a conceptual framework for understanding the sources of stress for caregivers and the impact of caregiving on their mental, emotional and physical health. The study by Bastawrous considers caregiver stress theory to be relevant to the field of caregiving. By understanding how 'burden' factors into the stress process researchers can gain greater insight into the variables that affect and are affected by the construct (Bastawrous, 2013).

The importance of distinguishing between objective and subjective burden is highlighted when 'caregiver burden' is considered in context of the stress process. Pearlin's stress process model suggests that stressors and resources exist which affect individuals' well being. Within this model, primary stressors, secondary stressors and mediators interact in a way which ultimately impacts the individuals' well being outcomes. When applied to caregiving, 'caregiver burden' takes on the form of a primary stressor, which is affected by the caregiver's background and the caregiving context (Pearlin et al., 1990). In turn, as a primary stressor, 'caregiver burden' interacts with secondary stressors, which consist of role strains and dissatisfaction factors (self-esteem, mastery, etc.). The secondary stressors influence outcomes such as depression and anxiety. In this model, the interaction between the primary stressors, secondary stressors and outcomes is mediated by coping strategies and social resources (Bastawrous, 2013).

Research on caregiver burden underscores the intricate dynamics between stressors and the well-being of caregivers (Figure 2). Importantly, the role of coping strategies and social resources as mediators in this process highlights the potential for intervention and support. It can be concluded that social support not only aids in improving the wellbeing of caregivers but also enhances the quality of care provided to recipients, affirming the significance of addressing caregiver burden through the lens of stress theory.

Recognizing and addressing these stressors based on the insights provided by caregiver stress theory can lead to strategies and interventions aimed at reducing the overall burden on caregivers.



Figure 2. Pearlin et al.'s Stress Process Model

#### 2.2.4 Informal caregiver persona and journey mapping

In healthcare settings journey mapping is a relatively new approach that has been adapted from customer service and marketing research. It is gaining increasing recognition for its ability to organise complex multifaceted data from numerous sources and explore interactions across care settings and over time. Medical journey mapping involves creating narrative timelines, by incorporating markers of the patient experience with healthcare service encounters. Integrating diverse components of the patient healthcare journey provides a holistic perspective of the relationships between the different elements that may guide directions for change and service improvement (Ly et al., 2021). Journey maps can be used to help identify process pain points and highlight opportunities for improvement across various settings and contexts. Further, the visual findings of journey mapping activities can assist service providers and implementation scientists in effectively deploying resources to expand services or establish operational risks (Joseph et al., 2023).

#### 2.2.5 Living Lab

The aim of testing within a Living Lab hypothesis is to develop a service that integrates technology into the daily lives of caregivers. Living Labs allow for testing in real-world settings, providing a more accurate representation of how a service will perform under everyday conditions for service users. This can help identify practical challenges and user behavior patterns that might not be visible in controlled environments.

At the forefront of the Living Lab methodology is a co-creation approach, which seeks to integrate research and innovation processes into real life settings with service and product users. Ultimate aim of social living lab is to promote enhancement of community well being through shared exploration, experimentation, co-creation and evaluation in relation to particular social concerns (Wong & Curbelo, 2020).

A Living Lab has the endeavour to support the innovation process for all involved stakeholders, from manufacturers to end-users with special attention to SMEs, with the potential users in the centre in their real world context. To be able to create value for customers and users, it is important to understand their needs and motivations as well as how these needs can be met by an innovation. This focus gives organisations an opportunity to increase the level of innovation and to decrease the risk of developing something that customers do not want. Living Lab processes support the process of understanding if the customer or user has a need for a service and how intense their attraction or repulsion for that service is in the real-world context. Living Labs can support processes by allowing users to elaborate with the service in their context to

determine if it provides a value for them. In addition, a Living Lab can also provide insights about how users perceive value. These insights can guide the innovation process to deliver innovations that are perceived as valuable from a business and a customer perspective (Ståhlbröst & Holst, 2012., p. 5).

Multi-stakeholder collaboration and knowledge sharing is a critical factor to successful Living Labs and user engagement, motivations and expectations are critical inputs to create and sustain a fertile Living Lab context.

Living Labs can be characterized in multiple ways and serve several purposes. They are both practice-driven organisations that facilitate and foster open, collaborative innovation, as well as real-life environments, where both open innovation and user innovation processes can be studied and experimented with and where new solutions are developed. Despite the multiple different implementations, Living Labs share certain common elements that are central to the approach. Following principles are core within Living Lab methodologies: active user involvement, real-life experimentation, multistakeholder and multi-method approaches. As shown in the figure 3, the Living Lab methodology consists of the following elements:

Multi-method approaches: there is no single Living Lab methodology, but all Living Labs combine and customize different user-centred, co-creation methodologies to best fit their purpose. User engagement is rooted already in the origins of Living Labs, the key to success in any activity is to involve the users already at the beginning of the process. Multi-stakeholder participation: even if the focus is on users, involving all relevant stakeholders is of crucial importance. These include all the quadruple helix actors: representatives of public and private sector, academia and people. Real-life setting: a very specific characteristic of Living Labs is that the activities take place in real-life settings to gain a thorough overview of the context. Co-creation: typically, especially in technology projects, activities are designed as top-down experiments, benefiting from users being involved as factors rather than actors.



Figure 3. Elements of Living Lab (Malmberg et al., 2017, p. 12)

The Living Lab approach strives for mutually valued outcomes that are results of all stakeholders being actively engaged in the process from the very beginning so that users become equal contributors and co-creators rather than subjects of studies. Living Labs are complex multi-stakeholder constellations where a multitude of activities take place. Three main building blocks within Living Lab projects can be distinguish-exploration: getting to know the 'current state' and designing possible 'future states'; experimentation: real-life testing of one or more proposed 'future states'; evaluation: assessing the impact of the experiment with regards to the 'current state' in order to iterate the 'future state' (Malmberg et al., 2017, p. 12,14).



Figure 4. Phases of Innovation Process (Malmberg et al., 2017)

As there is a need to bring more innovation to social care, by fostering environments where academic research, business interests and user needs intersect, Living Labs can drive innovation in welfare technology. This often leads to breakthroughs that might be difficult to achieve in more traditional research and development settings and overall Living Lab methodology supports the creation of health and social services that are not only innovative and technologically advanced but also user-friendly and contextually relevant. This approach is particularly important in health and social services where the impact on human lives and well-being is significant and as Vink states design labs are essential for driving systemic innovation in complex fields like healthcare. Their success hinges on collaboration, systemic thinking, and iterative experimentation while addressing challenges like funding and resistance to change (The Design Thinking 101 Podcast, 2023.).

#### 2.2.6 Service co-development interventions in health and social care

In the scientific literature on design, co-design refers to the whole design process and co-creation to the temporary creative mindset for exchanging of ideas, experiences, expertise, within a co-design process. Co-design is a process in which the planning, adjusting tools and facilitation is built on a mindset based on collaboration. Co-creation can take place within co-design processes but focuses much more on the collective creativity of involved users and stakeholders. From that perspective co-design is among the practices in which co-creation is concretized (Mattelmäki & Sleeswijk Visser, 2011).

The present thesis overlooks the variances among methods and concepts, employing the term 'development' as a holistic term for interventions.

This chapter delves into the idea of service co-development interventions through insights from the organizational and management studies, marketing and design research.

The term service co-development highlights the dominance of services in the present economy. Services play an increasingly central role in the global economy, driven by the major technical and regulatory changes that are shaping this transformation. Structural shifts in the world economy, brought on by rapid technological developments, have placed services - especially those involving information and communications technologies (ICT) - at the heart of economic transformation. Services production is a dominant economic activity in all countries of the world, regardless of their level of development. The sector represents 67% of world GDP (Weltbank & World Trade Organization, 2023, p. 13) and according to the Vargo & Lusch (2004, p. 3), the value of physical products can be seen through the services that the resources can render.

In this research, development goals in empirical instances are framed as services. Co-production occurs when citizens actively participate in the design and delivery of public services. Historically, co-production has also played an important role in the study and understanding of social welfare services, particularly due to the intricate relationship between the needs of, often vulnerable, service users and the service delivery system (STROKOSCH, 2021, p. 2). Co-design is a collaborative process that actively seeks knowledge from participants own life experience. In the designing process stakeholders should be active participants in co-designing process, not just emphatic observers (Ku & Lupton, 2020, p. 24). Keeping stakeholders informed and engaged and clarifying the added value of design work to the stakeholders (Melles et al., 2021, p. 43) will increase the commitment of the stakeholders to the project, create ownership among stakeholders of solutions and improve implementation.

Co-design are mainly driven by the objective to create better and more effective solutions, create more inclusive processes and enhance stakeholders engagement. Systems are shaped and directed by different purposes, worldviews and the interpretations people develop of their reality. Working to make these values, beliefs and meanings tangible, and creating a space for conversations, will lead to shared and agreed solutions, even if temporary ones, as necessary in value networks. In this process service design adopts a pluralistic and inclusive approach to system design, based on the belief that systems cannot be completely understood or designed, but that they can be interpreted via a collaborative process (Sangiorgi & Prendiville, 2017, p. 57).

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### **3. BACKGROUND RESEARCH**

In the rapidly evolving landscape of global health and social care, the phenomenon of care burden has emerged as a pivotal area of concern. This chapter delves into the versatile dimensions of care burden, weaving through its statistical outlines, policy frameworks and the lived experiences of individuals who got into caregiving situations. At the heart of this chapter lies a critical examination of the current situation, marked by demographic shifts, economic constraints and evolving social norms that collectively intensify the pressures on care systems worldwide. As populations age at an unprecedented rate, the demand for long-term care services escalates, stretching the capacity of existing health and social care infrastructures and spotlighting the indispensable role of informal caregivers. These caregivers, often family members, find themselves at the crossroads of personal obligation and systemic inadequacy, bearing a disproportionate share of the emotional, physical and financial toll. Informal caregivers perceive their situation as permanence and they experience a sense of being tied-in, being always alert, unappreciated, feeling trapped, like a prison, pulled in all directions, and at times, being in an unreal situation. These feelings manifest together with emotions of distress, hopelessness, depression, tiredness, exhaustion, frustration, guilt, negative thoughts, loss of patience, and isolation (Huisman et al., 2022).

The situation is further complicated by the gendered nature of care work, which predominantly impacts women, thereby perpetuating existing inequalities and limiting economic and personal development opportunities.

#### 3.1 About caregiver burden

A disproportionately large burden of care falls on informal caregivers. In Estonia, approximately 30,000 women and 17,000 men have care obligations (Riigikantselei, 2017, p. 3)

According to the data of the European Carers Association (Eurocarers) even 35,100 women and 24,500 men in Estonia have care obligations. (Eurocarers 2023).

The burden on carers is high, both in providing care and in paying for care.

The illness of a family member changes the family's relationships and the previous way of life. In addition to the new role of caregiver, one must fulfill one's previous roles, which are often accompanied by burden and emotional stress. Often, the caregiver is a specific relative who takes responsibility for decisions related to care. Since she has researched more about the disease, she also has to support other relatives emotionally and help them get an understanding of the disease. The care burden is perceived as more stressful when the care is intensive and there is no experience (Varik et al., 2020). People stay out of the labour market because of the care burden (according to the Labour Force Survey, 8,000 people are away from the labor market and 5,000 work part-time) or are burdened with caring for loved ones in addition to working full-time. High caregiving burden affects the carer's own health, and the carer may become cared for himself/herself because of the burden. Such a situation does not guarantee the dignity of carers and cared-for-persons and, in addition, generates indirect costs for the state – lost tax revenue, additional burden on the health care system, financial support for people's subsistence etc (Riigikantselei, 2017, p. 3).

The aging of the population in the European Union is one of the most important medium and long-term challenges facing all member states (Uusküla, 2021, p. 7).

Estonia is also a country with an aging population. Although the population has stopped declining in recent years, the share of people aged 65 and over in the population has been on a steady upward trend: while in 2007 this age group accounted for 17.3% of the total population, by the beginning of 2021 the share had risen to 20.3%, and by 2035 the share of pensioners is projected to rise to 25.1%.

At the same time, the health indicators of the Estonian population are lower than the EU average – both life expectancy at birth and the number of healthy life years are lower in Estonia than in the EU average. Over the last 15 years, the proportion of people aged 16 and over in Estonia with long-term health conditions has increased (from 40.2% in 2007 to 47.3% in 2021).

There has also been an increase in the proportion of people with an official disability, including in younger age groups: between 2007 and 2021, the proportion of people with a disability in the total population increased from 8.6% to 11.0%, with an increase from 2.7% to 4.0% in the under-16s, from 4.5% to 7.8% in the 16–62 age group, and from 26.4% to 27.5% in the 63+ age group.

The ageing of the Estonian's population and worsening health indicators mean that the proportion of people in need of long-term care will increase, also in younger age groups. According to the "Survey on activity limitations and care needs of the population" conducted in 2020, 17% of the population aged 16 or over used the support of a close relative or formal (care) services because of a health problem or activity limitation, with 14% using only the support of a close relative, 1% using only formal services and 2% using both the support of a close relative and formal services.

This shows that a large part of the care burden falls on the cared-for-person's relatives or acquaintances (informal caregiver). Problems include the disproportionately high care burden of informal caregivers, inadequate social guarantees (including the amount of carer's allowance and inconsistent payment practices) and the poor availability of care services (e.g. actual demand for home services exceeds supply by almost seven times) (Sotsiaalministeerium 2022:4–5). Research commissioned by Social Ministry states that 220,000 – 255,000 people in the age above 16 in Estonia take care of their loved ones (Turu-uuringute AS, 2020) but relatives and acquaintances are also ageing, and may in the future need help themselves and no longer be able to provide care.

Although other EU member states face similar challenges from an ageing population, there is no common understanding of what changes should be made to social systems in the short term.

The report of the European Social Policy Network recommends that the development of formal care, in particular home care and care institutions resembling homes, should be a priority for countries (Uusküla, 2021, p. 9).

Norwegian health policy encourages older citizens to remain at home for as long as possible and to stay active and fit (Helsedirektoratet, 2021).

# Quality of the life of the caregivers who are taking care of person with dementia and intellectual disability

The number of people with dementia in Estonia is unknown because the disease is underdiagnosed and epidemiological studies have not been conducted. Based on data from other countries, Alzheimer Europe estimated that in 2025, approximately 26,216 (2.01% of the population) people with dementia live in Estonia (Varik, 2022). As the dementia progresses, the care requires more time, energy and physical exertion from family members, and care may take a few hours per week or day or be around the clock (Varik 2022, p. 10). The course of dementia and the resulting increase in care burden can be described with the Allen Cognitive Level model (Champagne, 2020) which is a standardized assessment tool to assess cognitive function (Evans, 2023). In Figure 5 can be seen how care burden increases as cognitive levels decline.



Figure 5. Allen Cognitive Levels by author

In case of intellectual disability (approximately 2% of the population) people with this condition need ongoing support to cope with everyday life (Raudmees, n.d.). Although this condition is acquired by birth, the caregiving burden for individuals with intellectual disabilities changes over time rather than remaining static. Care burden evolves due to various factors, including the developmental needs of the individual, societal support systems and the caregiver's own capacity to manage their role. Due to the above and leaning on caregiver stress theory it can be concluded that caregivers, in their duty of caring for loved ones with these syndromes, frequently experience emotional, physical and financial challenges. Therefore, it can be estimated that 4 percent of the Estonian population is, to varying degrees, excluded from both the workforce and active participation in social life. Long-term care may as well give rise to a higher risk of health problems such as cardiovascular disease and a greater number of physical health decline problems and also, caregivers may feel shame, frustration, anger, guilt, sadness, loneliness, social isolation and anxiety or depression (Varik, 2022, p. 19). In addition to being excluded from the labor market, these same people may also find themselves in need of help (Iva, 2017) and can also become care recipients and thereby create an even greater economic burden on the state. However, when family caregivers are well supported in the social protection system (e.g. have informational, emotional and instrumental resources), it can offset the difficulties they experience. This leads to the provision of higher quality care and better functional recovery and community reintegration of the individual with disabilities. Conversely, when family caregivers lack support and resources, they experience greater financial, physical and psychosocial costs and this can ultimately compromise the quality of care they are able to provide (Bastawrous, 2013). The quality of life for caregivers of individuals with dementia and intellectual disabilities is profoundly influenced by the evolving demands of care. Dementia care, marked by progressive cognitive decline, increasingly requires greater time, energy and physical effort, leading to significant emotional, physical and financial challenges for caregivers. Similarly, caregiving for individuals with intellectual disabilities, though a lifelong role, is shaped by changing developmental needs and societal support systems. As care burdens intensify, caregivers often face heightened risks of health problems, emotional distress, social isolation, and economic strain, sometimes becoming care recipients themselves.

#### **Economic value**

Informal caregivers play an important role in sustaining national healthcare systems. People with a care burden are and will continue to be an important resource for municipalities, covering part of the assistance that the local government would otherwise have to provide to people in need of care. In Canada, the unpaid care provided by family caregivers results in approximately \$25 billion in annual cost savings for the health care system. This amount is a striking \$350 billion in the U.S. With the percentage of those 65 and older expected to double in the next 25–50 years, it is reasonable to anticipate that the economic value of family caregiving will increase as well (Bastawrous, 2013) which gives reason to believe that informal caregivers are a vital part of healthcare systems worldwide, providing the majority of long-term care in the community. Their contributions significantly reduce the burden on formal healthcare services and institutions. On the other hand informal care can be associated with substantial time costs and can result in considerable adverse health effects in informal caregivers as a result of they can end up to be care recipients themselves.

Although loved ones should not bear the burden of care themselves, the real situation forces them to do so, because there are often no suitable and necessary support services. It is still preferred to develop institutional care services instead of home living support services, which are considerably more expensive. A person's only choice is generally a carehouse where the person must pay for the services. Although at the same time some people could stay at home if they had support services (Sotsiaalministeerium, 2020).

Although the start-up and investment costs incurred are significant, the cases below show that the gains that can be achieved at an individual level are large, both in the form of increased quality of life and avoided resource use.

# 3.2 Overview of social services and welfare technology for caregivers in Estonia

The provision of social services, social benefits and other assistance is organized by the local government of the person's place of residence entered in the population register. Although the local municipalities task is to organize social assistance, people's awareness of the general organization of social welfare and social services (including home services) offered by local municipalities is low (Sotsiaalkindlustusamet, 2022, p. 36). People are not always aware of the opportunities and responsibilities of the state and local governments to provide support in case of need, the safety net is porous both within the field and when transitioning, for example, from healthcare to social care or social care to the labor market (Mastik & Lannes, 2021).

At the present time it is not clear what kind of support local governments and other parties must offer to people with a care burden, as the level of informal caregivers care burden and what support caregivers need have not been assessed in Estonia, nor has the organization of care or time for taking care of family member been evaluated. This means that local governments have no overview how many people with a care burden live in the territory of their administrative unit, how big is their care burden and what kind of help informal caregivers need. There are no supportive services developed to empower and support informal caregivers as well trainings suitable for intervention programs. The social welfare system needs to pay attention to helping and supporting people with a care burden. Services and training are needed for meaningful and systematic field development both in the city of Tallinn and throughout Estonia (Abiks hoolduskoormusega inimesele, 2022).

There are few services offered for informal caregivers. For example Tallinn city government ordinance nr 25 "Sotsiaalteenuste osutamise tingimused ja kord" from 01.07.2021 states three services for informal caregivers to reduce care burden. Substitution of caregiver is a service to reduce care burden and the aim of this service is to support the caregiver in order to enable her or him short breaks or usage of free time. The service is enabled 2–16 hours per month. Formal caregivers movement to and away from the client is calculated also in these hours. Tallinn city government ordinance nr 25 § 22 states another service – daycare for the people with memory disorders. According to a conducted telephone interview with one carehome manager, in present time 3 daycares in Tallinn offer this service with approximately 20 service providing contracts are concluded. Third service according to the Tallinn city government ordinance nr 25 § 19 is home service. Through the home service, it is possible to order food and household items to home (Tallinna Linnavolikogu, 2023). Carer benefits for informal caregiver are determined by disability that has been established by the Social Insurance Board and ranges in amount of 50-100 eur per month (Tallinna Linnavolikogu, 2024). 56,000–76,000 caregivers would need additional assistance in the form of services (Haljasmets et al., 2021, p. 16).

The attitude towards possible help from the public sector (municipality), which would ease the work of caregivers and improve the situation of the person being cared for, is not widespread.

More and more new smart solutions are appearing in the social field that support person's ability to cope at home (e.g. home sensors, medicine dispensers, alarm buttons). At the same time, it is found that the potential users (municipalities, end-users) don't know about them and according to the survey of care needs conducted in 2022, only 2% of 861 participants were using some kind of assistive devices (Turu-uuringute AS, 2022, p. 59), so the smart solutions have not managed to be rolled out to the wider public (Nordic Welfare Centre, 2019). Service providers often have to do advertising and outreach to make existing services visible so that those in need start

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using them (Sotsiaalkindlustusamet, 2022, p. 36) and getting advice on the use of technical aids is one of the greatest benefits (Kõre et al., 2019).

# 3.3 Reducing caregiver burden with welfare technology. Insights from abroad

Since the awareness of welfare technologies in Estonia is very limited, that means there is no knowledge how welfare technology can support, what technology is developed and available for individuals with cognitive or intellectual impairments to live as

independently as possible at home and at the same time to reduce the caregiving burden on informal caregivers, the author draws on experiences from countries that have successfully integrated welfare technology into the daily lives of caregivers.

This sub-chapter delves into how different countries harness innovative technologies to significantly reduce the care burden on caregivers. The showcase examples of successful technology implementations that have lightened the caregiving load are presented as examples from countries like Finland and Norway because these countries, like Estonia, also face significant demographic challenges and therefore it is appropriate to explore the health technologies implemented in the aforementioned countries on reducing care burden.

In this work the author focuses on solutions that aim to reduce the caregiving burden on challenging behaviour which arise from dementia and intellectual disability challenges. The most frequent behaviors among people with dementia and intellectual disability are aggression, agitation, wandering, apathy and disturbed sleep (Anderson et al., 2020), difficulty to understand behavior, aswell as not coping with daily living tasks. All these factors mentioned beforehand are significantly reducing the quality of life of the caregivers.

Globally, there are numerous solutions available on the market aimed at addressing these challenges.

Technology for assessing and predicting behaviors may provide greater quality of life for both care recipients and their caregivers (Anderson et al., 2020) reducing caregiver stress, giving them a feeling of security in their daily lives and in different care situations.

Each example in this chapter will provide insights into the effectiveness of these technologies and their impact on reducing caregiver stress and workload. Through global insights, the aim is to inspire and inform stakeholders involved in the deployment of healthcare technologies, highlighting not only the challenges but also the vast opportunities for reducing the care burden worldwide.

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Welfare technologies and digitization can be used for many purposes – to increase the safety of care recipients, daily coping, ease the work and well-being of caregivers. Also the usage of welfare technology contributes to avoiding the costs and frees up time (Figure 6) when welfare technology is used providing informal care as shown in a study conducted in Norway.



Figure 6. Amount of avoided costs and freed up time when welfare technology is used providing informal care (Helsedirektoratet, 2021, p. 7).

The results of the Norwegian National Welfare Technology Program shows that for caregivers the biggest gains for using welfare technology are linked to an increased experience of freedom, independence, dignity and flexibility in everyday life (Helsedirektoratet, 2021, p. 6).

One potential strategy to make caring sustainable for caregivers is to make greater use of welfare technology and the studies found that for example sensor alarms improved safety of care recipients, reducing the need for intervention by caregivers (Choi et al., 2024).

National Welfare Technology Program conducted in Norway started from year 2020 showed that security alarms, patient notification system, electronic medicine dispensers, location technology (GPS), E-locks and digital supervision played a big role in reducing care burden reported by caretakers (Helsedirektoratet, 2021).

Next, the author mapped the assistive technologies that are used in the care of persons with dementia and intellectual disability in Finland.

Table 1 is showing different care needs matched with corresponding devices and their features. This table details how each device addresses specific care needs, enhancing real-time safety for care recipients.

Care need	Device	Features	Health condition	Source
Wandering	GPS watch	Ensures the care recipients safety in real time. With it, care recipients can safely exit the room or building and stay in the fresh air. If a person gets confused, he can use the watch to contact helpers himself. The watch helps to identify the location coordinates of a lost person in real time, even if the person does not know how to use the device. The perimeter can be set so if the user leaves the set respective person will be notified.	Memory disorders, intellectual disability	Everon OY, CarersUK, Norwegian National Welfare Technology Programme
Disturbed sleep	Door sensors	Provide real-time information on care recipients exits during night. System can be set as needed, for example for a certain period of time to receive notifications about when the care recipient leaves the room orproperty. The the respective person will receive a notification about exit. Sensors are mounted to doors. Easy to install no cabling required	Memory disorders, intellectual disability	Everon OY, CarersUK
Safe cooking	Stove guard	The product measures the temperature from the stove and gives a pre-alarm in case of a potentially dangerous situation. If the warning is not acknowledged, the stove guard alarms and cuts off the power to the cooker so the product can be used safely and it does not require any action from the user. Stove guard can be useful for people who may not otherwise be able to react to an emergency alarm and are living independently or spending long periods of time alone in the home. Depend of on the stove easy to install no cabling required	Memory disorders, intellectual disability	Innohome, Carers UK
Falls	Digital presence	OnOn's digital presence is a sensor-based system. Continuous monitoring of the environment gives the care recipient and caregiver a sense of security without identifying the person. OnOn is a passive system – no need to press a buttons. The technology is based on the recognition of changes in the environment. The system can be configured in such a way that the system recognizes when a person has fallen or cannot get up from the floor, when a person gets out of bed or leaves the room. Since the person cannot be identified, the system complies with the Data Protection Act. Easy to install no cabling required	Memory disorders, intellectual disability	Everon OY, CarersUK
	Improve or maintain		Memory disorders,	Evondos
Taking medications	health condition	Reminds the person to take the medicine	intellectual disability	OY

Table 1. Devices addressing specific care needs. By author.

All solutions listed in the table 1 are reducing care recipients dependence on a caregiver, increasing peace of mind and decreasing caregiver workload as well as support care recipients security.

Security alarms, patient notification system, electronic medicine dispensers, location technology (GPS), E-locks and digital supervision play a big role in reducing careburden reported by caretakers in Norway National Welfare Technology Program (Helsedirektoratet, 2021) as well as social robots and companionship technology which provides redirection during emotionally difficult times, as well as facilitating positive shared moments and for later stages of dementia in caregiver-caregivee interaction to lessen caregivers emotional burden (Moharana et al., 2019).

Digital services have been rapidly developed in recent years to address global healthcare and social welfare challenges. Digital services have been proposed as one solution to address problems in terms of accessibility, availability, and costs in healthcare (Härkönen et al., 2024) but technology demands a value-added service around it, which typically is a service in the social and health sector. As the manufacturer of technology is often not the service provider – partnerships are needed (Holappa & Merilampi, 2022, p. 24).

Since 2011, in Norway community health care services have been encouraged to integrate digital assistive technology in the home care services to increase quality and efficiency in the health services and to reduce costs. More than 300 municipalities have

joined the Norwegian national project to implement digital assistive technologies such as global positioning system (GPS), electronic medicine dispensers, and electronic door locks. Results from these trials demonstrate the potential economic benefits that can be realized within the home care services. Expectations of the potential of technology to support older adults at home and the home care services are therefore high, however, it is contingent on usability and acceptability (Holthe et al., 2022).

#### 3.4 Problem owners

At the heart of the caregiving narrative are two principal figures: the informal caregiver and the care recipient. These individuals are the direct problem owners. With the direct problem owners as a focal point, the stakeholder mapping as a strategic tool to visualize this ecosystem will be created (Figure 7). This process will not only highlight the reciprocal relationship of various stakeholders but also reveal the potential pathways through which support and resources can be mobilized to alleviate the care burden.

Reducing the care burden on informal caregivers requires the involvement of a broad network of stakeholders beyond the immediate circle of caregivers and care recipients.

These important stakeholders outside including municipalities (district governments in Tallinn), social workers, first level healthcare providers, technology developers, and support organizations play critical roles in shaping the caregiving landscape. The task of Tallinna district governments and other local municipalities is to offer primary guidance and support, while social workers are primary specialists who provide information about the services offered by municipalities – the municipal social worker collects information and evaluates the need for assistance using an assessment tool. After assessing the need for help, the social worker introduces the service system to the person in need of help, and based on the need for support, the social worker connects the person in need with a suitable support provider (Sotsiaalministeerium, 2021). Technology developers introduce innovations that can streamline caregiving tasks and improve communication, first level healthcare providers serve as the frontline in health management and prevention and MTÜ Elu dementsusega and support association for people with intellectual disabilities offer emotional support to caregivers.

The more distant problem owners, such as the Ministry of Social Affairs and the broader health and social care system, play instrumental roles in the ecosystem of caregiving, directly impacting the ease of caregiving tasks through early intervention and consistent support. The ministry of Social Affairs, responsible for shaping social policies and programs, has the power to address systemic barriers to effective caregiving, implementing measures that can significantly lighten the care burden. The health and

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social care system at large encompasses the infrastructure and resources necessary for comprehensive care, influencing the availability, quality, and affordability of support services for caregivers and recipients alike. These stakeholders address the care burden from a systemic and policy-driven perspective.

Each group of stakeholders involved has its own set of needs and constraints (Darzentas & Darzentas, 2014).



Figure 7. Stakeholder map by the author

#### 3.5 Conclusions of the background research

The background research has given an overview of caregivers and the challenges of being a caregiver. The findings show that there are technology applications available to support the informal caregivers of persons with dementia and with intellectual disability. The technology applications mostly contribute to lower the care burden and therefore may contribute to reducing social isolation and reducing caregiver stress.

Informal caregiving provides substantial economic value, saving billions in healthcare costs annually as seen in examples from Canada and the U.S. However, this economic benefit comes at a personal cost to caregivers, who may face health decline and economic hardships due to their caregiving roles. There is an evident gap between the demand for care services and their availability. Policies have not sufficiently kept pace with the increasing care needs, leading to inconsistencies in care support and allowances. The European Social Policy Network suggests prioritizing the development

of formal care services to address these challenges. As the population continues to age, it is imperative to focus on sustainable care solutions that include services to support caregivers and integration of advanced technologies to reduce the burden on caregivers ensuring at the same time care recipients safety and well-being.

These findings underscore the complex impact caregiving has on the well-being and highlight the need for comprehensive support systems and services to address these multifaceted challenges.

The Figure 8 visually illustrates a conclusion of the background research which shows that without sufficient social services, caregivers face a significant risk of falling out of societal systems, including active participation in work and social life.



Figure 8. System wiew by author

The background research emphasizes the urgent need for comprehensive, humancentered solutions that combine technology and formal care services. These solutions must prioritize caregiver well-being and ensure their continued participation in society while also safeguarding the safety and quality of life of care recipients.

#### **4. PARICIPATORY RESEARCH**

First step of participatory research involved reaching out to the social departments of district governments in Tallinn. On behalf of the author Tallinn Welfare and Health Department sent out targeted emails to the social departments of district governments in Tallinn in order to establish a dialogue, inviting them to become co-developers in this research and to provide the author with contacts of informal caregivers for interviews. District governments social departments are the primary institutions to which a person in need of help could turn when the need for help arises. As no responses followed, the author took the next step of contacting the heads of the social departments by phone to facilitate the contact between author and informal caregivers. Unfortunately there was no interest to contribute by Tallinn district governments social departments. As a next step the author made the call among the authors network and in total, 12 interviews were conducted – 7 interviews with the caregivers (2 of them were interviews and were observed in a caregiving situation), 3 interviews with social workers and 2 interviews with family doctors.

Qualitative data were collected by using semi-structured interviews. The results of the interviews are summarized and elaborated further. The transcribed interviews can be found in Appendix 2.

#### 4.1 Interviews with the informal caregivers

To conduct semi-structured qualitative interviews in research, a flexible interview guide was developed, including a list of open-ended questions and topics to ensure that all the necessary areas were covered while allowing for the natural flow of conversation. This approach facilitated a deeper understanding of participants perspectives, experiences and insights. The questions were designed to be broad enough to encourage participants to express their thoughts freely but specific enough to address the research objectives. Informal caregiver interview guide in Estonian can be found in Appendix 1. All interviews started with an introduction about the overall study subject and the thesis topic. All participants gave their consent to be interviewed. Interview participants were assured that they will remain anonymous. All the participants' answers were transcribed during the interview and each interview lasted on average one hour. The transcribed interviews can be found in Appendix 2. All interviewees were women.

#### 4.2 Interviews with the social workers

As district government social workers are the main mediator between informal caregivers and the social system, 3 interviews were conducted with them.

Social workers were asked about their experiences with caregivers and care recipients with dementia and intellectual disability and also their experiences with healthcare technology to reduce care burden. The transcribed interviews can be found in Appendix 2.

# 4.3 Interviews with the first level healthcare provider

For informal caregivers who need guidance, referrals, or prescriptions, family doctors are usually the first and easiest point of contact.

The caregiver is bringing her loved one to the family doctor to seek help regarding the need for help that has arisen; therefore 2 interviews were conducted with family doctors. The transcribed interviews can be found in Appendix 2.

#### 4.4 Conclusion of the interviews

The interviews were highly emotional because of the nature of the topic. Also access to informal caregivers was difficult.

Finding oneself suddenly thrust into the role of a caregiver can be an unexpected journey, marked by a profound sense of responsibility coupled with uncertainty. This transition, often occurring without warning due to a loved one's illness or a sudden change in their ability to care for themselves, brings with it a myriad of challenges.

The interviews with caregivers of individuals requiring 24/7 care due to various health conditions — intellectual disabilities and dementia — reveal profound insights into the challenges faced by caregivers and the limitations of current care solutions. These insights underscore the urgent need for more tailored, empowering and technologically advanced care options to support both care recipients and their caregivers.

From these interviews, several key themes emerged:

**Lack of suitable services for caregivers.** Caregivers express a significant gap in available services for individuals with dementia and intellectual disabilities, particularly as people with intellectual disabilities age. The transition from school-age services to adult care poses challenges, with care homes often lacking empowering and

developmentally appropriate activities. Also there are lacking services for people with dementia or caregivers don't know about the services offered.

**Safety concerns.** Both intellectual disabilities and dementia raise serious safety concerns, including risks of wandering, falling and accidents related to household appliances. Caregivers are left to manage these risks with limited or no support, often resulting in constant stress.

**Technological solutions.** While some caregivers have turned to technology, like alarm buttons, these solutions often fall short. They may not be suitable for the cognitive abilities of the care recipients or fail to provide the necessary level of monitoring and alerting that caregivers need or cause extra stress.

**Systemic barriers.** Navigating the local municipalities and governmental support systems can be confusing and frustrating. All caregivers emphasized a lack of clear guidance, support, and accessible information on available services. This situation often leaves caregivers feeling alone and without resources.

**Caregivers work and personal life.** The caregivers' personal lives, health, and employment are profoundly impacted. The demands of caregiving result in physical and emotional exhaustion, isolation, and strained relationships. Caregivers desire solutions that allow them to maintain some semblance of personal life while ensuring the safety and care of their loved ones.

The findings highlight a critical need for comprehensive, customizable care solutions that address the unique needs of individuals with intellectual disabilities and dementia and their caregivers. Recommendations could include using technology for giving care- implement reliable, user-friendly technology solutions tailored to the specific safety concerns associated with each health condition, such as wearable devices for wandering, alerts and smart systems for accident prevention. Technological solutions could be critical in ensuring the safety and well-being of care recipients, particularly those who are with intellectual disability, may be elderly or have dementia. Various technologies can address these concerns by enhancing monitoring, ensuring safety, and providing emergency alerts.

Also streamline access to information and support from governmental and local municipalities are important, ensuring caregivers are aware of and can easily navigate the options available to them. It is important to advocate for policy changes and increased funding to support the development and accessibility of services and technologies that cater to the nuanced needs of this population.
## 4.5 Research question

Despite the availability of welfare technology designed to support caregiving, informal caregivers, family doctors, and social workers are unaware of these solutions. This lack of awareness limits the potential for welfare technology to alleviate the care burden placed on informal caregivers and healthcare professionals are unable to recommend or integrate these resources into care plans effectively.

Therefore the research question of this thesis is how to put welfare technology in efficient use to reduce caregiver burden.

## **5. DESIGN PROCESS**

As welfare technology is not just a measure in itself, it requires the design of a completely new service or service component within existing service. Chapter 5 describes the concept creation in co-development practices.

Bringing a design thinking approach, service design has emerged as a human-centred, creative, iterative approach to the creation of new services in a process of exploration, creation, reflection and implementation (Sangiorgi & Prendiville, 2017, p. 53). This design process takes a holistic, human-centered approach to creating resources that empower informal caregivers, social workers and family doctors to understand, access and adopt welfare technology effectively. Strengths of design thinking include rapidly developing a deep understanding of user needs and then communicating them in ways that are emotionally engaging and actionable (Bhattacharyya et al., 2019).

The importance of involving end-users in this process is critical — individuals living and working within a specific context have a deep understanding of the challenges they face and the intricacies of the environment in which these challenges are embedded (Bird et al., 2021).

Author's "Call for interest" brought together 3 caregivers, social worker and family doctor and herewith a user advisory group (UAG) was established. Author placed UAG at the heart of thesis guiding activities from a user perspective. UAG plays a major role in identifying and understanding the key user needs of the digital solutions to be developed during the project (Turk et al., 2022).



The design process in this thesis is divided into four phases as shown in Figure 9

Figure 9. The design process. By author

## 5.1 Living Lab intervention

This sub-chapter presents the Living Lab intervention, a hands-on, participatory approach aimed at introducing welfare technologies to informal caregivers taking care of individuals with dementia and intellectual disability. The intervention sought to explore and assess how welfare technology could support caregivers in their roles, reducing the demands and pressures of continuous monitoring and caregiving tasks because by integrating welfare technology into caregivers daily routines, the aim is to create a safer, more supportive and less burdensome caregiving environment and also welfare technology tools can enhance access, understanding and adherence enabling better stakeholder engagement and integration of care (Turk et al., 2022).

A living lab can be defined as "an experimentation environment in which technology is given shape in real life contexts and in which (end) users are considered 'co-producers'" (Colomer et al., 2014).

The purpose of Living Lab intervention is, first, to identify and evaluate welfare technology solutions that can be seamlessly integrated into caregivers routines. Secondly, to assess their effectiveness in enhancing the quality of life for both caregivers and care recipients, with the goal of creating a new service for caregivers.

The ultimate goal is to empower these individuals with greater independence and coping mechanisms, while simultaneously enabling caregivers to balance their caregiving duties with personal and professional commitments. By fostering an environment where caregivers can either remain in or return to the labor market, this approach not only enhances individual well-being but also contributes to broader socio-economic stability.

Vink has indicated that Labs operate as testing grounds where hypotheses can be validated through iterative experiments and they are not just about creating new products or services, but about addressing systemic challenges and improving the overall structure of systems, such as health and social care (The Design Thinking 101 Podcast, 2023.).

Aimed at reducing the physical and emotional strain on caregivers providing informal home care for loved ones, the author of the thesis, as facilitator in Living Lab, collaborated with welfare technology producers Everon, Innohome and Evondos, who provided support.

Manufacturers of welfare technologies were mapped according to the health situations of care recipients.

It is important to remember that by integrating welfare technology into caregivers daily routines, the aim is to create a safer, more supportive and less burdensome caregiving environment and also welfare technology tools can enhance access, understanding and adherence enabling better stakeholder engagement and integration of care (Turk et al., 2022).

The intervention took place in the private homes of three caregivers who are currently caring for family members with health conditions like dementia and intellectual disability.

According to the care recipient's health condition and care burden of caregivers a welfare technology in Living Lab was included as follows:

- GPS watch Everwatch produced by Everon OY to make sure that loved ones are safe when they go wandering.
- Door sensor produced by Everon OY to not disturb the sleep of caregiver or family members.
- Stove guard for safe cooking produced by Innohome.
- To prevent falls Onon digital presence produced by Everon OY.





Figure 10. Welfare technology in Living Lab testing

Then caregivers were asked to deploy and test a variety of welfare technologies with the goal to create an understanding whether the selected welfare technologies reduce caregiver stress and thereby improve the quality of life of the caregiver and care recipient.

As objective metrics for success the "Before and after" questionnaire was created (Appendix 6) with following questions to measure intervention impact – reduction in caregiver stress levels and increase in their free time; satisfaction ratings from caregivers regarding the ease of use and helpfulness of the technologies. This questionnaire provides a structured way to compare caregivers experiences before and after the implementation of welfare technology, helping to assess the overall impact of the Living Lab and identify areas for further improvement.

Before starting to deploy and test, participants were asked to fill out the 'Before' part of the questionnaire.

# 5.1.1 Summary and conclusion of the Living Lab intervention

The insights gained from the Lab can significantly inform the scalability of these technologies for wider adoption in home caregiving scenarios.

Once the tasks were completed, participants were asked to fill out a questionnaire. Based on the "Before and After" questionnaire summary, the impact of the Lab intervention on informal caregivers are the following:

- 1. Exhaustion/burnout frequency: Caregivers reported feeling less exhausted or burnt out after the intervention, with an average improvement of 1.75 points.
- 2. Safety when leaving care recipient alone: Caregivers felt significantly safer leaving the care recipient alone after the intervention, with an average increase of 2.00 points.
- Anxiety/worry about care recipient: Caregivers experienced a reduction in anxiety or worry about the care recipient, with an average improvement of 1.75 points.
- Sleep interruptions to check on care recipient: Caregivers reported waking up less frequently at night to check on the care recipient, showing an average improvement of 2.50 points.
- 5. Confidence in using technology: Caregivers confidence in using technology to assist with caregiving tasks increased, with an average improvement of 1.50 points.
- 6. User-Friendliness of welfare technology: Caregivers found the welfare technology more user-friendly, with an average improvement of 2.00 points.

Results can be attributed that the intervention had a positive impact on reducing caregiver stress and increasing their confidence and sense of security through welfare technology.

In addition to good award criteria, the municipalities should strive for welfare technology to be awarded before compensatory services. By putting the focus on independence and self-management already early in the process, this will help to reduce the need for more complex services in the future. Therefore, it should be a goal for municipalities that welfare technology should be the first choice, especially for new clients (Helsedirektoratet, 2021, p. 41).

## 5.2 Co-development workshop

Co-developing a digital, human-centric information solution with relevant stakeholders has been a central objective in addressing the research objective – how to put welfare technology in efficient use to reduce caregiver burden.

The purpose of the co-development workshop is to bring together UAG to collaboratively address the critical gap in information flow about welfare technology. Despite the positive impact welfare technology has had on reducing caregiver burden, the insights from the interviews of caregivers, social workers and family doctors and from Living Lab intervention reveal that information about these technologies **does not effectively reach or move between** all key stakeholders.

Given the communication gap identified, a leading question for the co-development workshop is how can we simplify the sharing and accessibility of welfare technology information among all stakeholders to support informal caregivers with the goal to reduce caregiver burden.

This question highlights the integration of key stakeholders and the core goal of leveraging welfare technology to effectively support informal caregivers.

The co-development workshop can prioritize exercises that explore communication channels, shared resources, and collaborative strategies to bridge this information gap.

The workshop aims first to identify barriers to communication through exercises, the workshop allows each stakeholder to express their unique communication challenges and needs. This creates a shared understanding of why information flow is currently limited and helps pinpoint specific obstacles that each role faces in sharing or accessing welfare technology information. Secondly, co-development empowers participants to collaboratively brainstorm tools and practices that could facilitate smoother communication about welfare technology. These solutions are developed by the people who will actually use them, making them more likely to be practical, relevant and easily adopted, that means design practical solutions for information sharing. Thirdly, the workshop fosters trust and empathy among caregivers, social workers, and family doctors, creating a foundation for ongoing communication and collaboration. This relational aspect is key to implementing any information-sharing solution effectively, as each group understands and values the role of the other.

When describing the caregiver journey, the caregivers' needs were mapped, input from phase 2 (Figure 9) was used, and it also served as input for persona creation. Following exercises were tailored to this insight.

#### Exercise 1. Co-developing personas and the caregiver journey

The insights gathered from participatory research were used to create a user persona and the purpose of visualizing a persona, Maria was created (Appendix 3).

The narrative in caregiver journey map unfolds through the lens of a caregiver persona, bringing together touchpoints from various caregiver experiences to form a caregiving journey. Maria, the caregiver, is just beginning to navigate the complexities of her role. Maria had always been close to her mother, a woman known for his sharp mind and independent spirit. When she first began showing signs of forgetfulness, she thought it was just part of aging. But as her confusion worsened and behavior became more erratic, she realized something more serious was going on. After several difficult months, Maria decided it was time to consult their family doctor. During that visit, the family doctor confirmed what Maria had feared—her mother was showing early signs of dementia. The diagnosis hit hard. While the doctor explained the medical side of the condition, outlining the progression of dementia and prescribing medications to help manage symptoms, there was something glaringly missing- any advice on how Maria could cope as a caregiver. She asked about support services, thinking there must be something to help lighten the load but the doctor had no such recommendations. She sympathized with her situation but simply not much she could offer in terms of reducing the care burden. Maria walked out of the office with a prescription for her mother, but no roadmap for herself—no guidance, no resources, no support.

<u>The growing burden.</u> As her mother's condition deteriorated, Maria found herself drowning in responsibilities. Mom began needing help with everyday tasks—dressing, eating, and managing personal hygiene. Nights became sleepless as her mother wandered around the house and in some time even went out of the appartement. Maria was constantly on alert, fearing she might hurt himself. Without any professional support or services to help, Maria's role as a caregiver quickly became overwhelming. The family doctor, while empathetic, couldn't point her to any concrete solutions. Maria was left to navigate this all alone, balancing her mother's increasing needs while trying to manage her own household.

<u>The emotional and physical toll.</u> The emotional toll of caregiving was enormous. Watching her mother—a woman who had once been so full of life—lose touch with reality was devastating. Some days, she didn't recognize her. Other days, he would become angry and agitated, making it difficult to calm her down. Maria's heart ached, knowing she couldn't reach her the way she once could. But it wasn't just the emotional burden; it was the physical toll too. Maria spent hours each\_day caring for her mother, all while trying to keep up with her job and family. She had no\_time for herself, no time to rest

or recharge. Each day felt like a marathon she hadn't trained for, and the exhaustion was catching up with her. There were moments when she thought, " If only there were some support services in place, I could manage this better. I could breathe"; But there were none. And no one, not even her family doctor, had the resources to point her toward relief.

<u>Financial pressure and burnout</u>. To make matters worse, the financial burden was growing. Maria had to cut her work hours to care for her mother, leading to a decrease in household income. Meanwhile, her mother's needs kept increasing—special equipment, medications, home modifications. Every unexpected expense was another layer of stress. With no formal caregiving services to reduce her workload, Karin began to burn out. There was no one to help, no respite in sight. The isolation was crushing, and she felt abandoned by a system that didn't acknowledge the incredible burden she was carrying. She loved her mother deeply, but the lack of support services left her feeling trapped and exhausted.



Figure 11. Maria's user story. By author

Along the way, the story highlights potential paths and choices, representing the common scenarios that many caregivers might face. These include various decision points that alter the caregiving journey in response to unexpected events and challenges. The persona- Maria's story is a framework to explore the realities and potential variations in the caregiving experience, emphasizing the adaptability and resilience required in this role.

Designers use journey maps to imagine a user's interaction with a device or service or to break down the components of the current offering (Ku & Lupton, 2020, p. 92). An initial version of the informal caregiver journey ( Appendix 4 ) was created based on interviews of caregivers, social workers and family doctors.

The caregiver journey map not only illustrates the extensive responsibilities and challenges faced by informal caregivers but also highlights critical gaps in support and resources that, if addressed, could improve the quality of life for both caregivers and their care recipients.

The caregiver journey map provides a human-centered perspective that focuses not just on the medical needs but also on the broader experience of the care recipient and caregiver. This holistic view helps family doctors, social workers and caregivers better understand the day-to-day realities and emotional nuances that might otherwise be overlooked in standard assessments. Created journey map links caregivers encounters longitudinally, promoting continuity and a holistic understanding of care across settings and over time.

Journey map allows stakeholders and caregiver family members to gain a deeper empathy for the care recipient and caregiver. By visually capturing the emotions, challenges and daily activities, stakeholders can better understand and address the complexities of caregiving. In addition, caregiver journey mapping allows healthcare providers, the social system and family members to gain a deeper empathy for the care recipient and caregiver. Mapping gives a holistic view and goes beyond medical symptoms to include emotional and social dynamics, providing a comprehensive view of the care recipients and caregiver's lives.

Insights gained from the journey map also inform policymakers about the needs and challenges faced by care recipients and caregivers, leading to better policies and support systems. The opportunity to focus on a caregiver as a co-developer of digital health design solutions is well supported by methodologies such as design thinking that utilizes a human-centered approach (Turk et al., 2022).

The caregiver journey mapping exercise led to the conclusion that the needs and challenges faced by caregivers include navigating limited access to information, inadequate municipal support, and overwhelming responsibilities. Caregivers struggle with emotional stress, financial strain and the progressive dependency of care recipients, leading to burnout.

#### Exercise 2. Affinity clustering map of information and communication barriers

Information about welfare technologies does not effectively flow between all key stakeholders. To address this issue, exercise 2 will be conducted to identify and categorize specific communication barriers faced by UAG and categorize them to find common themes.

This exercise led to a categorization of barriers by UAG (Figure 12), helping to identify that caregivers struggle with awareness and isolation, social workers with fragmented communication channels and role ambiguity, and family doctors with a focus on clinical priorities and privacy concerns. All three segments barriers were awareness, fragmented communication channels and time constraints.



Figure 12. Communication challenges by UAG

#### Exercise 3. Future visioning - imagine an ideal caregiving ecosystem

In this exercise UAG were asked to describe or sketch their vision of an ideal caregiving ecosystem in the focus on how welfare technology, communication, and support systems could transform the caregiver experience. The output was to identify actionable steps to work toward this vision.

Ideal caregiving ecosystem scenario was created by UAG and is illustrated below.



Figure 13. An ideal caregiving ecosystem by UAG

In this ideal ecosystem, the caregiving journey is no longer an isolated struggle, but a collaborative effort, powered by integrated welfare technology and a network of conscious stakeholders working together to ensure well-being and peace of mind for all involved.

All participants at the end of the co-development workshop had a 10 minute personal reflection exercise, where each participant pointed out one insight that was most important to them.

Results from the three exercises and personal reflection collectively highlighted the following:

- Current caregiving systems suffer from fragmented communication, lack of information and awareness about welfare technology and emotional strain on caregivers. Simple source of information and resources for caregivers is needed that lists available welfare technologies with use cases, instructions and also funding options.
- 2. Informal caregivers face a non-linear, emotionally difficult journey that requires more robust support mechanisms, like spaces (Living Labs) where caregivers can experience and test welfare technologies before adoption.
- 3. A technology-integrated ecosystem with centralized platforms, tailored resources, and healthcare professionals/caregivers decision-making can reduce caregiver burden.
- 4. The co-development process was defined as understanding the co-creative nature of value and empowering stakeholders in the development work. The understanding of the significance of co-development in services is recognized by all stakeholders involved.

These findings emphasize the need for a human-centered, technology-enabled caregiving ecosystem that bridges gaps in communication and empowers all stakeholders.

Three exercises which were carried out in co-development workshop, provided input for the conclusion that welfare technology supports the caregiving process. To make better care management decisions and reduce care burden, information about welfare technology must be accessible via centralized platform by healthcare professionals and caregivers. To support healthcare professionals and caregivers there must be a possibility to get hands-on guidance about welfare technology which can be provided by the Living Labs, allowing the caregivers to feel confident and comfortable with the setup and therefore the future customer journey was created by UAG.

The future customer journey (Appendix 5) described in the co-development workshop, the customer needs mapped in the second stage of the thesis, and the problems identified in the field of social care served as an input for creating the design proposal.

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Stakeholders involvement in the co-designing process provided valuable insights into all areas of the solution and paved the way to create a practical and complete response to the caregivers challenge.

# 5.3 The concept

The concept's vision is to empower informal caregivers, social workers and family doctors with a unified platform and hands-on testing and learning environment that simplifies access to welfare technology, reduces caregiver burden and enhances collaboration.

### Overview

The concept integrates an **internet platform** with a Living Lab (*tervisetehnoloogiate demokeskus*), creating a dual resource ecosystem designed to meet the specific needs of caregivers, social workers and family doctors. This solution addresses the three main goals identified in the co-development process:

- 1. Delivery of information about welfare technologies
- 2. Personalized advice and practical support
- 3. Coordination and communication among stakeholders

Through an intuitive, user-centered design, the platform and Living Lab enable stakeholders to discover, test and adopt welfare technology solutions tailored to real-world caregiving scenarios.

### **Core Features**

**1. Internet platform**. The platform acts as a digital knowledge hub and communication tool for stakeholders. It includes:

- <u>Centralized resource library</u>. Comprehensive, searchable database of welfare technologies categorized by caregiving needs (e.g., mobility aids, remote monitoring tools).

- <u>Personalized recommendations</u>. An AI-based assessment tool that suggests welfare technologies based on user-specific caregiving scenarios, needs and challenges.

- <u>Expert consultation portal</u>. Users can schedule virtual consultations with technology specialists or healthcare professionals to receive personalized advice. The platform connects users with professionals, including healthcare specialists, occupational therapists, assistive technology consultants and product experts.

- <u>Community forum</u>. A moderated space where caregivers, social workers and doctors share experiences, tips and insights about welfare technology use.

- <u>Feedback mechanism</u>. The aim of this feature ensures that the platform evolves in tandem with technological advancements and the requirements of its users. Healthcare professionals and informal caregivers who use welfare technologies purchased through the platform can provide feedback and users can share their experiences, covering key aspects such as ease of use, effectiveness, durability and user satisfaction. They can also report challenges or suggest improvements. Caregivers can log their experiences with welfare technologies, which are analyzed to continuously improve platform content and recommendations.

For unstructured feedback, advanced algorithms analyze text data to identify recurring themes, common pain points or frequently praised features. The feedback mechanism creates a transparent, user-centric system that prioritizes caregivers' needs.

**2.Living Lab.** Lab complements the platform by offering a physical and virtual space for experiential learning and technology trials. It includes:

-<u>Technology demonstration and trial center</u> – a space where users can interact with and test welfare technologies before adoption.

Hands-On training sessions – (virtual)workshops and live demonstrations for caregivers and professionals to learn how to set up, use and troubleshoot welfare technologies.

-<u>Caregiver-Doctor-Social worker collaboration workshops</u> – facilitated sessions that foster communication and coordination for integrating welfare technologies into care plans.

As shown in the study a visit to an interactive showroom demonstrating welfare technology products and solutions increased the perceived general knowledge and value of welfare technology among the participating test group. The number of participants confirming the potential of welfare technology to contribute to municipal operation areas increased in seven out of eight areas after their visits (Gustafsson & Sandsjö, 2020).

#### 5.3.1 Conclusion of the concept generation

By integrating a dynamic platform with an engaging Living Lab, this concept fosters a supportive ecosystem where caregivers, social workers and family doctors can collaborate, learn and adopt welfare technologies to improve caregiving outcomes and reduce caregiver burden.

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# 5.4 How does the concept work on the previously mapped caregiver journey?

The proposed concept aiming to directly address the challenges and needs identified throughout the informal caregiver journey. The intervention consists of organizing resource gathering systems by integrating them into one platform and recommending resources according to the specific needs of informal caregivers. A welfare technology demo center supports the platform.

By overlaying proposed concept onto the mapped experiences of Maria — a 56-year-old caregiver for her mother suffering from memory disorders — the concept seeks to reduce caregiver burden and improve access to essential information and support.

The integrated platform addresses pain points like lack of information and lack of coordinated services by offering centralized, easily accessible information about welfare technologies tailored for caregivers needs, while the Living Lab provides a hands-on, supportive environment to empower both caregivers and healthcare professionals.

This approach ensures that informal caregivers, like Maria, have access to a holistic support system at every stage of their caregiving journey, from the discovery of the health condition to ongoing care management.

The design concept has been transferred into a design concept user story, illustrating how the integrated platform and Living Lab align with and improve the previously mapped caregiver journey. This user story demonstrates how the concept provides tangible benefits, from the discovery of the health condition to ongoing care management, by addressing key challenges such as access to information, emotional support and coordination of services.

The design concept user story is presented visually in the appendix 7, showcasing how the proposed solution seamlessly integrates into the caregiver's journey to deliver impactful results and improve the caregiving experience.

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# 6. DESIGN PROPOSAL- "CAREMAP". PLATFORM FOR CAREGIVERS AND HEALTHCARE PROFESSIONALS

With CareMap, caregivers no longer have to walk a caregiving journey alone or in uncertainty. CareMap is like a GPS for caregiving, it does not take away the challenges, but it empowers users with clarity and direction. It ensures caregivers always know where they are, where they're going and how best to get there, even when the journey feels uncertain.

Based on future customer journeys compiled in co-development workshops, new opportunities were identified to reduce caregiver burden. The description of the design proposal is based on the ideas proposed in the co-development workshop, the interviews conducted and the literature reviewed and thus the problems and opportunities were identified in the system. The CareMap concept emerged as a response to the identified challenges and opportunities, guided by ideas generated during the co-development workshop.

CareMap incorporates a centralized health advisor platform for decision-making, offering tools and resources tailored to each stage of the caregiving experience and enabling caregivers to explore, test and adopt solutions through Living Lab demo centers.

CareMap is not only an outcome of participatory design but also a reflection of caregivers, social workers and family doctors' experience.

The main function of CareMap is to recommend tailored care plans with a decisionsupported AI-driven system and suggest welfare technologies for the caregiving process. Also CareMap is scalable that means it is designed to evolve as caregiver needs change over time.

## 6.1 Interfaces of CareMap

To gain a comprehensive understanding of the interfaces and functionalities, it is described through an example profile of the user. Maria is an informal caregiver of her mother who has Alzheimer's disease. She struggles with balancing her caregiving responsibilities, work and her own mental well-being. Maria first learns about CareMap during a consultation with her family doctor, Dr. Anders.



Dr. Anders introduces Maria to CareMap and helps her sign up. Together, they review Maria's caregiving situation and in the designated place they describe Maria's mother's health condition, emphasizing that her mother forgets to turn off the stove while cooking.

Figure 14. Digital mockup of CareMap, by the author



As Alzheimer's disease is developing during the life, Maria ticks the appropriate point and as she has to check on her mother 3 times a day, it will be noted in the system.

AI analyzes the provided data and categorizes it in either low severity, medium severity or high severity case.

By pressing "next", using the input data CareMap generates a customized value proposition.

Figure 15. Digital mockup of CareMap, by the author



Accordingly, "Kitchen Basic Safety", which is a monthly subscription package, is offered to Maria.

In this package a **smart stove safety device** that automatically turns off the stove after a set period of inactivity and detailed information about its features and benefits, is proposed.

Access to a video tutorial that demonstrates how the device works and how it can prevent accidents, is available.

Figure 16. Digital mockup of CareMap, by the author



Now Maria is asked in order to continue to agree to the terms.

Figure 17. Digital mockup of CareMap, by the author

ayment Method     Mapp       PayPal		~
PayPal     Google Pay     Apple Pay     Credit Card     Debit	ayment Method	Mapp
Google Pay     Apple Pay     Credit Card     Debit	O PayPal	
O Apple Pay O Credit Card O Debit	Google Pay	
O Credit Card	O Apple Pay	
O Debit	O Credit Card	
	O Debit	

Once agreed with terms, Maria is guided to proceed to the payment phase. It is possible to choose between several payment options.

Figure 18. Digital mockup of CareMap, by the author



CareMap has helped Maria make a decision and already in the evening Maria will be contacted by CareMap team and a time to install the device will be agreed.

Figure 19. Digital mockup of CareMap, by the author

As dementia syndromes worsen over time and cannot be stopped with treatment and in case the mother's condition evolves, CareMap remains scalable from low severity to high severity as shown in appendix 8.

That means continuous adaptability— with care recipient profile updates. As health changes, new and relevant recommendations for welfare technology will be received.

Key features of the platform summarized:

- AI-Driven care plan recommendations
- Welfare technology recommendations
- Scalable support
- User-Friendly and intuitive interface
- Seamless integration of welfare technologies into daily care routines
- For decision making, there is the option to use the Living Lab on-site demo center or video tutorials about the recommended device.

## 7. DISCUSSION

This study was aimed to investigate how the caregiver burden can be reduced so caregivers do not fall out of the social protection system and remain active in work and social life.

The results of the study show that the findings from interviews with caregivers highlight systemic issues, including insufficient services, safety concerns, technological inadequacies, and systemic barriers. Empirical validation through Living Lab interventions demonstrated measurable improvements in caregiver well-being, including reduced exhaustion, increased confidence in technology, improved safety and less anxiety. The co-development workshop revealed that the lack of effective information sharing about welfare technologies limits their adoption in the caregiving process.

The CareMap platform is a product of a collaborative design process. Insights from codevelopment workshops, interviews with stakeholders (caregivers, social workers, and family doctors) and literature review were instrumental in identifying the problems and opportunities within the caregiving context. The platform is designed to evolve with changing caregiver needs, ensuring its long-term utility and relevance.

CareMap directly impacts challenges mentioned above by providing comprehensive solutions like AI-driven care plans, tailored welfare technologies and intuitive user interfaces. This ensures caregivers are better supported in their roles, reducing stress and improving outcomes for care recipients. Results from Living Lab validate the practical benefits of welfare technology, showing how it can effectively alleviate caregiver burden and enhance caregivers quality of life.

The importance of this work also lies in the fact that it can facilitate policy and systemic change because findings advocate for changes in how welfare technology is integrated into caregiving systems, including prioritizing technology before more complex services. Further studies are needed to explore how to implement welfare technology into social protection systems, focusing on developing frameworks that align with existing policies and addressing barriers to adoption within governmental structures.

## 7.1 Feedback

Feedback is an essential component of the design and development process, as it ensures that the final solution aligns with the needs, preferences and pain points of the target users. By actively seeking feedback, designers can evaluate whether the proposed solutions effectively address the intended problems, enabling iterative improvements to the design. As Wynn and Maier (2022) highlight, feedback is fundamental to validating the relevance and functionality of a design, ensuring that it meets user expectations and resolves the challenges it aims to address.

For the feedback author approached caregivers who are participating in support groups and introduced the goal of the feedback session which was to understand how caregivers interact with the platform.

Open-ended questions to encourage responses were created by the author and were presented to five primary stakeholders – caregivers.

First, the author explained that the prototype being tested today is a platform designed to help caregivers to implement welfare technology to care process in order to reduce their care burden.

It was further explained that this is a prototype, so features are not functional yet. Preliminary version of the CareMap concept were then presented to stakeholders for feedback and features and functionalities were revised to incorporate feedback.

The following feedback was received from a feedback session. The platform recommendations were relevant to their specific caregiving situations, but several caregivers requested for a broader range of options tailored to the specific conditions – some caregivers pointed out pain points related to administering medication to care recipients. Also logs for tracking care activities were mentioned.

Caregivers agreed that the platform interface is user-friendly and accessible, and they did not find it overwhelming.

As a result of the feedback, it can be concluded that testers have received the platform well and are ready to use it.

# 8. CONCLUSIONS

This research underscores the big challenges faced by informal caregivers of individuals with intellectual disabilities and dementia, highlighting the urgent need for systemic, technological and policy innovations to alleviate the care burden.

The hypothesis of this research was that the lack of clear guidance and information significantly increases the caregiving burden for informal caregivers of individuals with dementia and intellectual disabilities. The findings highlight that the lack of structured and practical guidance not only increases stress levels but also limits caregivers' ability to effectively navigate health and social systems and provide optimal care. In the thesis, these gaps were addressed, as they are essential for reducing caregiver burden.

The second hypothesis of the research stated that the automation of routine monitoring using welfare technologies can reduce the care burden for caregivers. The study findings supported this hypothesis, demonstrating that sensor technologies, GPS-watches, and AI-based monitoring systems significantly alleviate the workload of caregivers. By streamlining routine tasks and providing real-time updates, these technologies enhance efficiency and allow caregivers to focus on other essential aspects of care. This evidence underscores the potential of welfare technology to ease the physical and emotional strain on caregivers, thus reducing their careburden.

Next, social workers and family doctors do not have enough knowledge and resources to help reduce the care burden on caregivers. This is because there are not enough targeted services and they are not fully aware of the welfare technology solutions available. The research findings confirmed this hypothesis, revealing gaps in training, resource allocation and familiarity with innovative welfare technologies among these professionals. This gap in awareness makes it harder for caregivers to get the help they need.

Finally, the author's findings confirmed the hypothesis that if informal caregivers remain unaware of potential support options due to insufficient dissemination of information and knowledge, providing improved support and services for informal caregivers will enable them to maintain a balance between caregiving responsibilities and employment, contributing to their overall well-being and societal participation.

In order to integrate welfare technologies into the daily life caregivers, to reduce the care burden, the CareMap platform was co-developed with caregivers, social workers and family doctor. This participatory method actively involved caregivers, social workers

and family doctors in the design process, ensuring that solution are practical, relevant and directly responsive to user needs.

With CareMap caregivers can manage their caregiving responsibilities better, leading to less stress, more stability in their work life and better mental health. CareMap also benefits society by allowing caregivers to stay engaged in the work life and contribute economically and socially. By addressing the root causes of caregiver stress, CareMap empowers informal caregivers to thrive, ensuring they can fulfill their roles with resilience and confidence. Benefit for individuals and society underscores the possibilities of CareMap as a tool for reducing caregiver burden and fosters a supportive ecosystem that evolves alongside caregivers needs.

## 9. SUMMARY

The study emphasizes the potential of welfare technologies, which, when effectively implemented, can significantly reduce caregiver burden and stress, improve quality of life and enhance the safety and well-being of care recipients. Interventions such as Living Labs and co-development workshops underscore the value of a human-centered design approach. By prioritizing holistic approach, trust and collaboration, human-centered design bridges gaps in communication and facilitates the development of tools and practices tailored to the real-world challenges faced by caregivers.

## 9.1 Eestikeelne kokkuvõte

Käesolev magistritöö keskendub omastehooldajate olukorrale Eestis, nende väga ebamõistlikult suurele koormusele lähedase eest hoolitsemisel ja sotsiaalhoolekande sektori innovatsiooni ökosüsteemi panustamisse.

Vananev rahvastik, vähenev tööjõud- see kasvatab nõudlust sotsiaal- ja tervishoiuteenuste järele. Seetõttu on kvaliteetsete, uuenduslike, inimkesksete ja tõhusate sotsiaal- ja tervishoiuteenuste arendamine ja pakkumine kogu sotsiaalsektori jätkusuutlikkuse jaoks hädavajalik.

Kes meie eest tulevikus hoolitsema hakkab- on teema, millele peame vananeva rahvastiku tingimustes ühe rohkem ja rohkem mõtlema. Ühe lahendusena pakub autor oma töös välja heaolutehnoloogiate laialdasemat kasutuselevõttu ja rakendamist hooldustoimingutes koduses keskkonnas. Just dementsuse-sündroomide ja intellektipuuete korral on heaolutehnoloogiate rakendamine andnud positiivseid tulemusi omastehooldajate hoolduskoormuse vähendamisel. Käesolev magistritöö ongi suunatud eelkõige nende omastehooldajate, kes hooldavad dementsusega ja intellektipuudega lähedast, hoolduskoormuse vähendamisele. Dementsus tekib elu jooksul ja on progresseeruva kuluga, mistõttu suureneb ka omastehooldajate hoolduskoormus, intellektipuue on sünnijärgne ning varieerub kergest kuni sügava puudeni. Eelnimetatud terviseseisundid vajavad suures mahus hooldust ja järelevalvet omastehooldaja poolt ning hoolduskoormus võib olla seesugune, et omastehooldaja on täielikult isoleeritud ning ei saa osaleda tööelus ega isiklikus elus. Avalikud teenused (KOV, riik) eelpool mainitud terviseseisundite puhul omastehooldajatele puuduvad. Arvestades, et Eesti on vananeva elanikkonnaga riik, on lähiaastatel oodata hoolduskoormuse osakaalu suurenemist inimestel kes hakkavad hoolitsema kodus oma lähedase eaka, puudega või krooniliselt haige inimese eest.

Oma töös jõudis autor järeldusele, et teadlikuse puudumine piirab hoolekandetehnoloogia potentsiaali leevendada hoolduskoormusega inimeste stressi ja koormust. Ilma asjakohase teabe ja juhisteta olemasolevate tehnoloogiliste vahendite kohta seisavad hoolduskoormusega inimesed jätkuvalt silmitsi väljakutsetega, mida saaks muidu leevendada, samas kui tervishoiutöötajad ei saa neid ressursse tõhusalt hooldusplaanidesse soovitada ega integreerida.

Omastehooldajad on valmis heaolutehnoloogiaid kasutama ja sotsiaaltöötajad ja perearstid on neid valmis soovitama hoolduskoormuse vähendamiseks kuid keskset info-keskust teabega milliseid tooteid turul on saadaval, koos toetava võimalusega tehnoloogilisi lahendusi füüsiliselt katsetada, huvigruppidel ei ole.

Tulenevalt eeltoodust kaasas töö autor disaini protsessi kaardistatud ja asjakohased huvigrupid ning rakendades inimkeskse disaini põhimõtteid, arendati välja internetiplatvorm, mis toimiks teabekeskusena konseptsioon- kasutajasõbralik (information hub) tervishoiutöötajatele, kohalikele omavalitsustele ja kokku heaolutehnoloogiate omastehooldajatele, viies nad ressurssidega ja abivahenditega hoolduskoormuse vähendamiseks. Konseptsiooni põhjal disainiti ka prototüüp, millest nähtub, et platvorm on praktiline, skaleeritav ja jätkusuutlik. Internetiplatvormi toetuseks on olemas ka tervisetehnoloogiate demokeskus (Living füüsiline mis olemuselt keskkond kus Lab), on oma on võimalus hoolekandetehnoloogiliste lahendustega tutvuda ja neid katsetada.

Eeltoodu põhjal võib väita, et teenused mida sotsiaalsektoris pakutakse, on mõjusad kui nende arendamisel kasutakse inimkeskse disaini ja disainmõtlemise meetodeid. Disaini roll sotsiaalteenuste väljatöötamisel on olulise tähtsusega, seesuguselt saab arendada sotsiaal- ja tervishoiu sektoris teenuseid ja tooteid, mis on inimkesksed, ligipääsetavad ja effektiivsed.

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# APPENDICES

# Appendix 1. Informal caregiver interview guide in Estonian

Uurija ja uurimuse tutvustamine

Demograafilise informatsiooni küsimine

- Sugu
- Vanus
- Elukoht (KOV täpsusega)

## INTERVJUU KÜSIMUSTIK

1. Palun kirjeldage oma ööpäeva omastehooldajana

## Väljakutsed ja vajadused

- 2. Millised on teie suurimad väljakutsed omastehooldajana?
- 3. Kas ja kui siis millised on need tegevused mis on teie jaoks eriti rasked ja / või stressirohked?
- 4. Mis osas te vajaksite kõige enam tuge?

### Toetussüsteem

- 5. Kas ja kui, siis millist toetust te saate KOV-ilt, teistelt pereliikmetelt, sõpradelt? Kas on veel keegi kellelt saate abi?
- 6. Millist toetust saite KOV-ilt kui sattusite omastehooldajaks?
- 7. Kas te olete kursis milliseid teenuseid KOV pakub omastehooldajatele?

## Abivahendid sh tehnoloogilised

8. Kas te kasutade hetkel abivahendeid sh tehnoloogilisi abitehnoloogiaid. Kui, siis milliseid ja kuidas need teie hoolduskoormust mõjutavad?

9. Milline võiks olla selline abivahend, sh tehnoloogiline abivahend mis võiks hoolduskoormust vähendada.

## Ideaalne lahendus

10. Kui saaksite luua teenuse või abivahendi, sh tehnoloogilise, mis aitaks teie hoolduskoormust vähendada, milliseid funktsioone või tuge see hõlmaks

### Mõtted

11. Kas te sooviksite midagi muud öelda oma kogemuste kohta omastehooldajana

12. Kas teil on mõtteid kuidas saaks omastehooldajate mõeldud teenuseid parendada

# **Appendix 2. Transcriptions of the interviews**

#### Transcriptions of the interviews with the informal caregivers

#### Caregiver (CG) 1

Care recipients (CR) health condition- intellectual disability. Need for care 24/7. Main problems according to CG are no services suitable for CR.

Care need increases by age because CR gets physically more capable. When CR went to school, it covered CG working days now CR is adult and possible service is care home. In care home there are no empowering activities so from a human and development point of view CG don't want to put CR to care home. Only if there is absolutely no other possibility CG sometimes temporarily takes CR to care home.

Main care is to follow that CR does not run away from home. It could happen via window or door. Door can be locked but windows cannot be locked so that CR can't open them. When CR runs away it is extremely difficult to locate CR. Usually the police will be involved. Very worrisome are the night where CG sleeps "one eye open" because of possibilities of CR running away. Also, CR can make simpler dishes but attention is easily lost when cooking and many times there has been a risk of fire due to not turning off the stove.

As CG works in district government social department there was no need to ask for guidance of district government because and there are no services offered by district government with such health condition. CG has possibility to work from home but there is no personal or social life.

Ideal solution according to CG could be service where CG can sleep and work and leave CR at home safely not to worrying that GR burns down the house or runs away and CG can at least go to walk or shop.

### CG 2

Care recipients (CR) health condition- dementia. Need for care 24/7

CG turned to district government social department because CG have heard that they could help. District government then suggested the alarm button. That did not worked because of dementia CR does not know when to push the button. That is only healthcare technology that CG knows.

CG experiences physical and emotional exhaustion because CG has to go to work so CG leaves CR at home. CR is staying most of the time in the bed but because CR is physically able to walk there is need to know if CR leaves the bed because there is a risk of falling. At the present time CG drives home on lunch breaks to check on CR. Because CG thinks that at carehome are poor service CG does not want to put CR at carehome. There is constant concern about CR safety.

Ideal solution according to CG could be service where CR is safely at home while CG is at work. It could be some technical solution by which CG knows if CR is leaving the bed so CG can drive home.

### CG 3

Care recipients (CR) health condition- dementia. Need for care 24/7

GR is taken care by two CG. Main concerns forgetting taking medication and turning off the stove when cooking.

Usual day – one CG drives to CR in the morning and gives medicine. Also, in the evening the same routine. CG looking for place at carehome because they fear that one day the flat will be burnt down.

CG did not knew where to turn- the Tallinn city government, to the district council, to which department. Accessibility to information on services is extremely confusing. It seemed to CG that different departments were duplicating each other, CG was led from one department to another. The social department of district government itself did not offer any options or services and CG did not knew what to ask.

Ideal solution according to CG is something that cuts the power of the stove and reminds to CR to take medications.

#### CG 4 and 5

Two care recipients (CR) – spouses. Health condition one - memory disorders ( need for care 24/7), health condition two- 100% visual impairment ( can manage but need for care with making food).

CR-s is taken care by two CG. One CG is living in the same household with CR. Day starts at 4 am – CG has not be able to sleep properly for years, sometime sleeps standing. No personal life for years. Only manages to go to work. Work quality is suffering. Feels that cant tolerate the situation anymore but cant give up also.

Other caregiver helps afternoon, mean time CR-s are staying at home alone.

Because one CR has 100% visual impairment CG-s cannot allow strangers (helpers) in to appartement because CR can be scared of strangers.

CR with memory disorder is staying most of the time in the bed because of the nature of disease but sometimes can come out of bed and therfore is a risk of falling and risk of fractures.

District government has not find the solution to situation.

Ideal solution- to know when CR leaves the bed or leaves bed and notification of falls.

#### CG 6

Care recipients (CR) health condition- intellectual disability. Need for care 24/7.

CR can run away any time of the day. CG can't sleep in the nights because scares that CR runs away and puts oneself and fellow people in dangerous situation. CG don't want to put CR into institution. Because the health condition is permanent and has lasted decades CG has not got no help from local municipalities because there is no service for adult person with intellectual disability. District social department offered substitute No friends also don't want to look after CR because the don't want to take any risks that CR could run away. Need is to locate CR when there has been running aways. In the nights some gadget is needed when there is running aways, that notifies CG if CR has runned away. CG feels frustrated over situation.

#### CG 7

Care recipients (CR) health condition- dementia. Need for care 24/7.

Looked the door because there was need to go to work otherwise CR will go wondering. Zero time for children. Feels that situation is desperate.

CG has not turn to district government social department because have heard that they can't help. No additional help CG does not receive. CG used camera but it helped only during day. Then CG only looked at camera and it confused and disturbed to work. Challenges were night when CG was sleeping and CR went wondering. Several times has involved the police to locate CR. Don't want to put into institution because people are dying there- according to CG. There has been decline in physical health. Need for something that notifies when CR goes wondering at nights also something that helps to locate CR.

#### Transcriptions of the interviews with the social workers

Social worker 1. Works in district government social department.

There is no good solution or services for caregivers who has to take care of people with memory disorders or intellectual disability. They can only offer substitute caregiver for amount of max 16 hours per month (including substitute caregiver travels to and from informal caregiver) or day care.

Social worker does not know do people in need know that first institution where to turn if need for care appears is district government.

Only healthcare technology social worker knows is alarm button that a person in need can call for help. Cannot name any healthcare technology that could contribute to the safety of a person in need of care if it is a memory disorder or intellectual disability.

Social worker 2. Works in care hospital for last 14 years.

Can't name any service offered by local municipality for health conditions like memory disorders or intellectual disability. District governments contacts also the care hospital in order to ask can they take some care recipient in to service. Social worker experience is that caregivers taking their loved ones to hospital, but very rarely, so they can take the time off. The service costs 21,79 euro/ 24 h. Care recipients want to physically move but there is a danger that they get lost or are dangerous for themselves.

Only healthcare technology social worker knows is alarm button that a person in need can call for help. At the same time, it is not suitable for a person with memory disorders, because he does not know how to use it so this kind of functionality is not suitable for the above-mentioned health conditions. Good results could give GPS trackers witch carereciepent can't remove, medication reminders, automatic switches to turn off stoves, sensors when there are movements from the doors.

Social worker 3. Works in municipality social department.

Social worker stresses the need for collaboration with healthcare professionals and need for a broader array of services specifically tailored to support caregivers of individuals with memory disorders. She points out that caregivers often face significant challenges in balancing their caregiving responsibilities with personal commitments, such as employment. The lack of comprehensive support services means many caregivers are unable to engage in work or social activities without worrying about the safety and wellbeing of their loved ones.

The social worker admits to a significant gap in her knowledge regarding healthcare technologies that could assist caregivers in managing their care burdens. She notes her inability to recommend specific technological solutions that could alleviate some of the daily challenges faced by caregivers of individuals with memory disorders. The social worker expresses a strong interest in learning about and adopting technology that could make caregiving more manageable and improve the quality of care provided.

#### Transcriptions of the interviews with the family doctors

Doctor 1

This is really a challenging situation. Caring for someone with memory disorders, like dementia, is incredibly demanding, both physically and emotionally. Unfortunately, when it comes to navigating the healthcare and social support systems, it can be confusing—there aren't always clear pathways, especially when the caregiver is unsure where to start.

To be honest, I often find myself in the same position as the caregiver—unsure of exactly where to refer them for help. The healthcare system focuses on the patient's medical needs, but there's no dedicated system for managing the caregiver's burden, especially in cases like memory disorders where the care can become overwhelming. In the case of memory disorders, though, there are specific needs—like respite care, specialized dementia support, or even help with daily tasks that the caregiver might not be able to manage alone. But, unfortunately, I can't always say with confidence where those services are easiest to access. The social support side is critical, but it feels fragmented. I really empathize with caregivers in this situation—they're doing their best in an environment where clear guidance is lacking. We need better systems to help both the patient and the caregiver navigate these kinds of challenges.

#### Doctor 2

Caregivers feeling overwhelmed but unsure where to turn. It's crucial to recognize that the caregiver's health is just as important as the patient's. If the caregiver burns out, both of them will suffer.

There are no clear guidelines where to refer the patient in need of help. Family doctors follow the health condition of patients but not caregiver's, in the sense of care burden. Has proposed to turn to the social service department but don't know whether to Tallinn city government or district departments.

## Appendix 3. User persona



## MARIA

Age: 56

Occupation: teacher (masters degree) Living arrangements: lives in apartment with mother Married, husband works in Finland Personality and interests: theatre, travelling, reading Role: informal caretaker of her 82-year old mother diagnosed

Welfare technology: door sensor, GPS-watch, stove guard

with Alzheimer's disease

## Moms health condition

Alzheimer disease, hypertension Mom goes wondering, forgot to take medication, forgot to turn off the stove

#### Moms medication

Anticoagulant , donepezil

#### Familydoctor concern's

No services to reduce caregiver stress, there is nothing I can do for Maria. I can write a prescription for Marias mom but I am not sure does mom takes the medication.

#### How I like to interact with healthcare professional

Preferably In person or via Teams, sometimes via phone, because private matters I don't want to discuss over email. Communication, collaboration could be better. Help for reducing careburden I have to ask myself, otherwise it won't happen

#### My most trusted advisors

Friends, google search, hairdresser

#### Frequency of routines

My work starts at 8 AM, at lunch break I drive home to look that mom has not left appartement, has not turn on stove and has taken her medication

#### Pain points / problems

Social : can't go to theatre, can't travel because mom needs constant supervision

Psychological: feeling frustrated

How I feel about these problems: autonomy challenges, can't participate in social life, lack of sleep does not allow me to be as productive I want at work, familydoctor has no solution for my problem- how to reduce the stress from caregiving
## Appendix 4. Initial version of the informal caregiver journey



#### Appendix 5. The future caregiver journey



# Appendix 6. "Before and after" questionnaire

Informal caregiver	1		2		3		4	
1. Caregiving Experience	Before	After	Before	After	Before	After	Before	After
How frequently do you feel exhausted or burnt out as a result of caregiving?(1 =								
Rarely, $5 = $ Almost Constantly)	4	3	5	4	5	2	4	2
How safe do you feel leaving the care recipient unattended for a short period of time								
(e.g., running errands)? (1 = Very Unsafe, 5 = Very Safe)	1	4	1	5	4	5	4	4
2. Emotional and Physical Well-Being								
How often do you experience anxiety or worry about the safety of the care recipient?								
(1 = Never, 5 = Constantly)	5	4	5	1	3	1	4	4
3. Safety of Care Recipient								
Have you experienced incidents where the care recipient wandered or became lost?								
(1 = Never, 5 = Frequently)	2	2	5	2	5	1	4	3
How often do you wake up during the night to check on the care recipient? (1 =								
Never, 5 = Constantly)	4	3	5	1	6	1	4	4
4. Technology Use and Usability								
How confident are you in using technology to assist with caregiving? (1 = Not								
Confident, 5 = Very Confident)	3	4	4	. 4	3	5	1	4
How user-friendly did you find the welfare technology solutions provided during								
the Living Lab? (1 = Very Difficult, 5 = Very Easy)	1	3	2	. 5	2	. 5	4	4
Have the technologies provided during the Living Lab helped you manage your time								
between caregiving and other responsibilities (e.g., work, family, personal								
activities)?(1 = Not at All, 5 = Significantly)		4	2	5	4	5	4	4
Do you feel that the welfare technology provided has improved the quality of life for								
both you and the care recipient?(1 = Not at All, 5 = Significantly)		5	2	4	3	5	5	5
What additional support or services would you need in order to start using and adopt	that		why I was		I can sleep at		give	
welfare technology? Open question	someone		not told		night, local		familidoctor	
	could		before that		municipality		knowledge	
	recommend		technology		could pay for		that there is	
	to me,		can notify me		it		technology	
	nobody know		that X has				available so I	
	what is		gone out				can at least	
	available						work for half	
							a day	
	1	1	1	1	1	1		1

### Appendix 7. User story with CareMap



#### MARIA

Age: 56

Occupation: teacher (masters degree) Living arrangements: lives in apartment with mother Married, husband works in Finland Personality and interests: theatre, travelling, reading Role: informal caretaker of her 82-year old mother diagnosed with Alzheimer's disease

Welfare technology: door sensor, GPS-watch, stove guard

#### Background

Maria is taking care of her mom Maie. Maie is a former teacher and she has always been fond of walks outside as well as making food.

Maria is very worried that mom can go wandering, falls or leaves the stove on.

Maria takes Maie to family doctor. According to information from epicrisis doctor decides to use welfare technology platform "CareMap", introduced in "Eesti arst" magazine.

# Introduction of welfare technology by family doctor

In appointment Doctor logging herself in to "CareMap" platform and with simply ticking off three choices, she receive the matches that meets compliance to Maie's health condition. Doctor has decided to assign Maie a GPS watch, door sensor and stove guard.

Sensors fixed to doors and windows can send an alert if Maie enters/ exits doors and/or windows. They can be attached to cupboards, a fridge door or interior doors to monitor daily use and send an alert when motion is not detected during a certain time period or throughout the day.

Stove guard cuts off the power to the cooker and it does not require any action from the user.

GPS-watch helps to identify the location coordinates in real time if Maie gets lost even if Maie does not know how to use the device. The perimeter can be set so if the Maie leaves the set Maria gets notification in her phone.

Maria wants to get acquainted with the functionality of the recommended welfare technologies and enters the virtual Living Lab connected to "CareMap".

#### Winnings

Previously, Maria check on Maie several times throughout her work day and do not sleep very well at nights due to worrying about whether Maie is wandering about.

After adopting welfare technology, she makes only one home visit every lunchtime.

This has freed up capacity for her to work more productively and sleeps peacefully at nights.

In the longer term, it can also contribute to avoiding costs in the form of postponing nursing home stays.

# **Appendix 8.** CareMap scalable view

