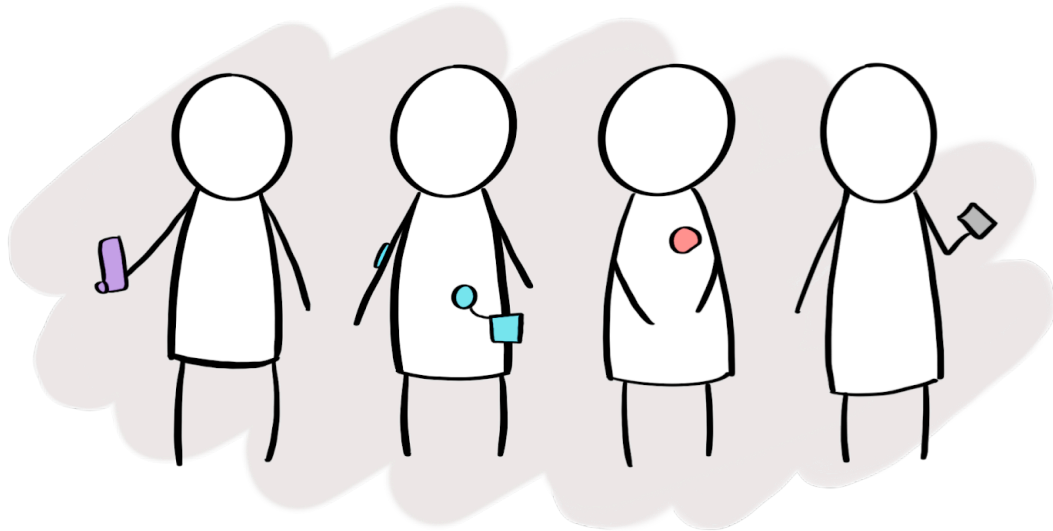




CHALMERS
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Expectations on future digital healthcare services

A study on hopes, fears and ideas expressed by citizens with asthma, diabetes, heart failure and the public in general

Master's thesis in Industrial Design Engineering

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MASTER'S THESIS 2022

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Cover: Illustration by Ellen Friborg, the studied user groups

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Abstract

This study compares the self-care practices of four user groups in Sweden with different health conditions, and identifies their expectations on future digital healthcare services. The purpose was to find out how Sahlgrenska University Hospital should develop their services, by means of Internet of Things and data collection, so that such services are well-received among Swedish citizens.

Semi-structured comparative interviews were conducted with individuals living with asthma, type 1 diabetes and heart failure respectively, to elicit their hopes, fears and ideas on future digital healthcare services in relation to their self-care practice. The same was elicited from citizens in general through a survey. Transcripts and free-text answers were analysed in broad themes using thematic analysis, which were used to compose possible scenarios and considerations for future development by Sahlgrenska University Hospital.

The study presents 34 themes of expectations in five categories: political context, organisational context, contact with healthcare, digitalisation, and data collection and sharing. To address these expectations, ten areas of considerations were formulated; five for convenient healthcare contact, and five for accepted health data collection and sharing. The expectations between user groups appeared to vary based on three main factors: 1) self-image in relation to health condition, associated with willingness to adopt digital healthcare services; 2) degree of interaction with healthcare, associated with how well an individual navigates within the healthcare system; and 3) previous meaningful experience of collecting and sharing health data with healthcare and using digital devices, associated with willingness to use digital healthcare technology and share such data.

The study indicates that no one, regardless of health conditions, wants more things to mind, carry or manage. Instead, future digital healthcare services should be uniform, minimalistic and automatic in design, as well as personalised, purposeful and supportive in order to facilitate proactive care among Swedish citizens.

Keywords: *Digital healthcare, Digital healthcare services, Attitudes, Expectations, Practice theory, Swedish healthcare, E-health, User study*

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We would also like to direct a warm thank you to all of the people who in different ways voluntarily have contributed to or participated in this study, with a special remark to Riksförbundet HjärtLung, Svenska Diabetesförbundet and Unga Allergiker. Thank you!

A handwritten signature in black ink, featuring a large, stylized 'C' and 'S' that loop together. The name 'Cedrik' is written in a smaller, cursive script across the middle of the signature.

Cedrik Sjöblom

A handwritten signature in black ink, written in a cursive style. The name 'Ellen Friborg' is clearly legible, with the 'F' and 'R' being particularly prominent.

Ellen Friborg

Glossary

Expressions

Citizens	The individuals that make up the Swedish population
Healthcare	The organisation(s) that provides care for citizens
Health worker(s)	Personnel who work within healthcare
Digital healthcare (services)	Digital efforts to achieve or maintain citizen's health
Health records	Records that document a patient's interactions with healthcare (Swedish: <i>Sjukvårdsjournaler</i>)
Primary care (centres)	General care centres (Swedish: <i>Vårdcentraler</i>)
Secondary care (centres)	Specialist hospitals
User group(s)	Any or all of the participating groups of citizens
Care group(s)	Any or all of the participating groups representing citizens with chronic diseases
Respondent(s)	Any or all of the participating groups representing citizens in general

Acronyms

SU	Sahlgrenska University Hospital
VGR	Region Västra Götaland
R&D	Research and development
IoT	Internet of Things
SKR	Swedish Association of Local Authorities and Regions (Swedish: <i>Sveriges Kommuner och Regioner</i>)

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1 Introduction

This first chapter introduces the master's thesis by presenting its background, purpose, objectives and scope.

1.1 Background

Demographic predictions show that the ageing population of Sweden will increase in relation to the share of people in the labour market (SCB, 2022; Framtidskommissionen, 2012). As public healthcare suffers from both limited tax funds and a shortage of healthcare workers, this places unreasonable demands on future healthcare as it would strain the resources available to provide care for everyone (Socialstyrelsen, 2021).

To maintain quality of healthcare given these circumstances, the Swedish Government and the Swedish Association of Local Authorities and Regions (*Swedish: Sveriges Kommuner och Regioner, SKR*) regards digital healthcare as a powerful tool and has set out a vision for Sweden to become the best in the world in making use of the possibilities of digitalisation and e-health by 2025 (*Vision e-hälsa 2025, 2021*). In their strategy to reach this vision, they mention several motivators for digitalisation of healthcare, concerning both the individual care recipients and the healthcare organisation (*Regeringskansliet & SKR, 2020*). First of all, digitalisation is seen as a means to make healthcare more individualised, giving the patient increased control over their own health and life situation, as well as facilitating ways of communication. As for the organisation, benefits such as increased equality, effectiveness and accessibility are emphasised, along with the possibility for improved working conditions.

The Centre of Digital Health (*Swedish: Centrum för Digital Hälsa*) at Sahlgrenska University Hospital (SU) is currently investigating the area of digital innovations within healthcare in the project sensLAB Fas 2. The goal of sensLAB Fas 2 is to find out how to gather and manage health data through Internet of Things (IoT) sensors, to create the prerequisites for future ways of providing care.

An on-going practice used in Region Västra Götaland (VGR) and by the healthcare industry in Sweden is self-monitoring, where patients themselves can measure and monitor their health from home, either with products provided by the healthcare or with their own smart applications (*SKR, 2022a*). This practice of self-monitoring is currently increasing within the healthcare provided in VGR. While this relieves the pressure on healthcare, it is a practice that is initiated at a later healthcare stage when the patient already has become ill.

The issue that SU therefore would like to investigate further, is how digital innovation, with a focus on IoT and data collection, could be used for preventive healthcare – such as early discovery of disease or early diagnosis – rather than reactive, to lessen the overall pressure on healthcare. To support this investigation, and guide future development efforts in a direction that would be accepted by the citizens, this thesis was initiated to explore the Swedish citizens' expectations on future digital healthcare services.

1.2 Purpose

The purpose of this master's thesis project is to convey a better understanding of the Swedish citizens' expectations, including hopes, fears and ideas on future digital healthcare services, with the aim to provide insights on how their health concerns can be solved better and earlier through digital efforts.

1.3 Objectives

The objectives of this thesis are:

- To present insights on citizens' expectations on future digital healthcare services, and how these might be influenced by their current care practices to maintain good health, regarding both self-care and when in contact with healthcare.
- To present suggestions on how citizens' expectations could be addressed, including insights for Sahlgrenska University Hospital to consider when proceeding with their efforts to facilitate early discovery with digital health technology.

1.4 Project scope

The scope of this thesis is limited in terms of target group, what types of diseases to consider for early discovery, and our client's interest in data collection and ambitions for implementation.

The target group are Swedish speaking citizens between 25-44, who are assumed to better express detailed demands on digital technology as they have long experience and skill with digital devices from a young age (SCB, 2019).

The thesis addresses health in terms of non-communicable diseases and non-acute conditions, to better allow for early discovery among individuals. The focus is on preventative care in terms of early discovery and less on self-monitoring and long-term prevention, as the latter two areas are more mature according to our client.

SU has an interest in having citizens collect and share their health data with healthcare via IoT. This interest is guiding the study but does not have any predetermined influence on the result. The result will focus on the desired healthcare experience as interpreted from the citizens' expectations. Furthermore, the results will not take technical feasibility, including data security, into direct consideration. Presented ideas should not be dismissed as impossible given the contemporary circumstances, but rather as plausible future directions which could challenge the status quo within the next five to ten years.

2 Related work

The following chapter presents information about digital healthcare and the Swedish healthcare system, as well as previous research on attitudes towards digital healthcare.

2.1 What is digital healthcare and e-Health?

Sweden’s National Board of Health and Welfare (*Swedish: Socialstyrelsen*) defines e-Health as the usage of digital tools and digital information exchange to achieve and maintain health (Hälsa, 2021). This includes digital prescriptions, video calls with doctors or medical equipment (Om ehälsa, 2019), and covers both the technology used by the healthcare personnel, for example during surgeries, as well as devices used by the care recipients such as mobile health applications or activity bracelets.

The term e-Health also encompasses multiple interventions, covering telemedicine, telehealth, mobile health (mHealth), electronic medical or health records (eMR/eHR), big data, wearables and artificial intelligence (AI) (WHO, n.d.). The first three interventions concern the feasibility of remote healthcare services, for example via mobile phones, video calls or remote monitoring of vital signs. eMR/eHR and big data concern different kinds of data collection and tracking, while AI is a tool for analysis of data.

2.1.1 Applications of digital healthcare

Within these broad descriptions of e-Health, there exists a wide range of digital healthcare services, targeting different interaction points with healthcare as well as different medical fields. Based on substantial market analysis by Milde & Locher (2021) and Sweden’s National Board of Health and Welfare (Socialstyrelsen, 2019a), digital healthcare solutions can be grouped by means of phone calls, webpages, mobile applications, video calls, medical equipment and consumer products (see table 2.1).

Table 2.1: Digital healthcare solutions.

COMMUNICATION OR ASSESSMENT	
Phone calls	Health advice, Appointment booking
Web pages / Mobile applications	Appointment booking, Prescription renewals, Information and health advice, Chatbots for information search
Video calls	Appointments where testing or physical examination is not required
MEASUREMENT OR TREATMENT	
Medical equipment	Assistive tools provided by healthcare for medical purposes: <i>Portables</i> , e.g. Insulin pump <i>Wearables</i> , e.g. hearing aid <i>Implants</i> , e.g. pacemaker <i>Digestibles</i> , e.g. medicine
Consumer products	Assistive tools owned by the patient, for purposes other than medical purposes, Smartphones or smartwatches with health applications and measuring capabilities

When data is collected and measured through digital devices such as portables, wearables, implants or digestibles, they are called digital biomarkers, which then could be used for explaining, influencing or predicting health-related outcomes (Digital Biomarkers, n.d.). Such solutions constitute a prerequisite for implementing IoT within healthcare.

Sweden’s National Board of Health and Welfare (Socialstyrelsen, 2019a) expresses integration of AI as the next chapter in digital healthcare. According to them, the application of AI within healthcare is still in its infancy, with only a few applications in operation, but they also state

that the area is currently highly researched. The current applications are image interpretation, automatic classification, decision support for health workers, among others.

The future development of digital healthcare could be illustrated by the development of diabetes care. Decades ago, patients' only alternative was to manually measure their blood glucose level and adjust their insulin intake accordingly through a manual injection. Today, there exist glucose meters and insulin pumps that automatically measure and inject continuously. Mobile applications for monitoring these devices are already on the market, and the treatment is believed to advance to a complete automated closed-loop solution, i.e. an artificial pancreas (Milde & Locher, 2021).

In general, technological advancements and implementations appear to converge towards a more automated healthcare system, with automatic means of health analysis and treatment for both patients and health workers.

2.1.2 The Swedish public healthcare system

The context for this thesis is public healthcare in Sweden. A typical *healthcare cycle* consists of first contacting healthcare, who then assesses the need for investigation, conducts investigation, assesses the need for action, conducts or prescribes action, and later conducts follow-ups before the cycle either continues or ends (Socialstyrelsen, 2019a). This cycle can have one or several iterations at one or several healthcare centres.

The main interaction-points between public healthcare and the population is the Healthcare guide 1177 (*Swedish: 1177 Vårdguiden*) which provides citizens with advice via phone, web-guides and chat on how to take care of yourself and where to go when seeking assessment or treatment (Om 1177 Vårdguiden, 2021), and primary care centres providing the general treatment or initial assessments that can result in referral to secondary care centres (i.e. hospitals) if specialised assessment and treatment is needed (Socialstyrelsen, 2016). Due to the recent Covid-19 pandemic, video meetings with health workers became a necessity and a chatbot was developed to address the intensive information need (Chatbot Covid-19, 2020).

Complementary to the aforementioned cycle, Swedish healthcare strives to lessen the care demand with proactive measures: Longtime prevention of endemic diseases by encouraging lifestyle changes (Socialstyrelsen, 2018c), screening and early discovery of symptoms in seemingly healthy individuals to lessen the health consequences (Socialstyrelsen, 2019b) and self-monitoring to detect worsening health conditions in already diagnosed individuals (Milde & Locher, 2021).

2.2 Attitudes toward digital healthcare

Previous research relating to Swedish citizens' attitudes about digital healthcare primarily presents quantitative results, such as the degrees of trust and positivity (Kantar Sifo, 2018a, 2018b; SKR, 2022b, 2022c; E-hälsomyndigheten, 2021), and pros and cons (Trolle Lagerros et al., 2019; Tuulasvirta & Milenova, 2020) while few concern how citizens reason about their attitudes (Nymberg et al., 2019; Fadhel & Nilsson, 2019).

2.2.1 Degree of trust and positivity

Each year, the Swedish Association of Local Authorities and Regions releases a study on the Swedish citizens' attitudes, trust and perception of Swedish healthcare. Results from the latest edition show that 81% of citizens are positive towards using the Healthcare guide 1177 and roughly 70% are positive towards using digital solutions to support self-care (SKR, 2022b). The

30% of citizens who are negative towards consultation and treatment with digital technology (SKR, 2022b) are foremost older citizens (SKR, 2022c). Older citizens in contrast hold the highest trust for Swedish healthcare in general according to a study by Kantar Sifo (2018b). Younger citizens rate healthcare ineffective to a higher degree (Kantar Sifo, 2018a) and expressed that digital services facilitate their life, while the opposite is true for respondents over 50 years old (SKR, 2022c). Overall, the studies conclude that the more experience citizens have with digital services, the more positive they are towards such services (SKR, 2022b; Fadhel & Nilsson, 2019; E-hälsomyndigheten, 2021).

2.2.2 Pros and cons

Besides degrees of positivity, there are several opinions among the Swedish citizens concerning concrete advantages and disadvantages with digital healthcare. One of the main advantages is increased accessibility of healthcare (Kantar Sifo, 2018a; Trolle Lagerros et al., 2019; Tuulasvirta & Milenova, 2020), including the aspects of flexibility, efficiency and economics when not having to travel from home or work as well as a lowered barrier to initiate contact with healthcare (Fadhel & Nilsson, 2019; Trolle Lagerros et al., 2019; SKR, 2022c). The benefits of reducing physical contact in favour of avoiding contagion were also mentioned, as well as shorter waiting times at the care centre (Kantar Sifo, 2018a; SKR, 2022c).

Besides these advantages, Fadhel and Nilsson (2019) also found that there seems to exist a scepticism that digital healthcare would be equal to the physical, traditional one. Furthermore, their findings also showed that a reason for not choosing the digital option would be of a political manner, from a belief that digital care is mainly utilised by the private sector.

2.2.3 Health data collection

Regarding the Swedish citizen's attitude towards collecting and sharing health data with healthcare, a study made by Belfrage, Lynöe and Helgesson (2020) showed that there exists a broad willingness to let one's data be used. An important condition was however the ability to influence how the data is used. However, what could also be seen from their study was that a majority of the respondents would put the ability of influence aside if it meant supporting medical progress. Most of them would also risk unauthorised access of their health data to avoid a situation where healthcare could not access the right information to provide them appropriate care.

2.2.4 Covid-19 as a catalyst

While some of the reviewed literature was published before the Covid-19 outbreak at the beginning of 2020, the number of recent literature on Swedish citizens' current attitudes on healthcare is scarce. It is however clear that the corona pandemic has given the digitalisation of healthcare a boost, regarding transition to new ways of working, an increased number of digital healthcare meetings and an extended use of self-monitoring (Post och Telestyrelsen, 2021; Cederborg, 2020). Along these changes, it also appears that the Swedish citizen's attitudes towards digital healthcare has been affected positively (Post och Telestyrelsen, 2021; Tuulasvirta & Milenova, 2020).

This boost is further confirmed by Dahlgren et al. (2021), who when investigating the consumption of digital healthcare during the pandemic, saw that the pandemic has worked as a catalyst toward a digital transition within healthcare. Even in periods with lower contagion, there were a higher degree of remote meetings than before the pandemic, something that they believe will sustain in the future.

3 Research approach

In this chapter, relevant theory is described to understand the research approach of the thesis. This includes theory on social practices and expectations, and also information about the studied user groups living with chronic diseases.

3.1 Understanding behaviour with practice theory

The theoretical framework for this study is practice theory, a social theory in the cultural subset of theories, as refined by Kuijer Lenneke (2014) in her doctoral thesis. Practice theory, which describes people as carriers or performers of practice, represents a way of deconstructing and understanding society. Practice, widely cited from Reckwitz (2002), is:

"a routinized type of behaviour which consists of several elements, interconnected to one other: forms of bodily activities, forms of mental activities, 'things' and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge. A practice – a way of cooking, of consuming, of working, of investigating, of taking care of oneself or of others, etc. – forms so to speak a 'block' whose existence necessarily depends on the existence and specific interconnectedness of these elements, and which cannot be reduced to any one of these single elements."

The practice framework, as presented by Lenneke, consists of three elements and the links between them: competences, meanings and material. Alternative terminology are skills, images and stuff, which will be used in this thesis (see figure 3.1). While the elements are described in separation below, they mutually alter each other as part of the practice. This implies that the links between the elements are just as important as the elements themselves, to understand practices.

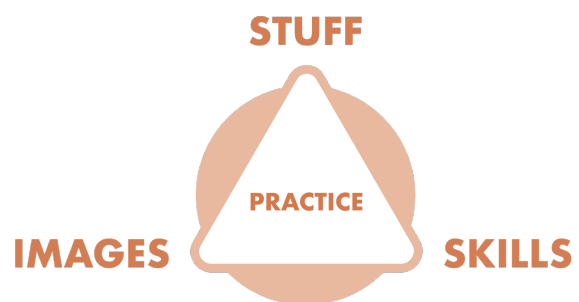


Figure 3.1: The practice theory framework.

Since a practice is socially shared, it is considered to be carried by a varying number of changing practitioners over time rather than owned by either of them. However, each so-called performance by each practitioner contributes to the practice and how its configuration changes over time. Ultimately, a practice will cease to exist if there is no longer anyone to carry it.

3.1.1 Stuff – The what

Stuff constitutes the tangible elements that are used in practices. For instance, items, infrastructure, equipment, software, and natural objects like trees, air and the body itself are considered stuff. Without them, practices would not be possible, and their inclusion make practices more uniform over time due to their tangibility. However, practices cannot be changed by mere introduction of new stuff.

3.1.2 Skills – The how

Skills are learned routines through which the practices are carried out. This includes competencies and socially shared knowledge of e.g. feeling, doing, recognizing, reacting and evaluating. Competences are not considered inherent to the performer, but instead distributed and subject to the interaction between the performer and their tools.

3.1.2 Images – The why

Images are what provides the relevance of engaging in practices. This includes socially shared meanings, such as associations, norms, values and ideas related to the practice. These meanings vary among people and even more so between cultures.

3.2 Defining expectations

The concept of ICE – ideas, concerns and expectations – is a patient-centred consultation method used to elicit the perspective of patients (Tate & Frame, 2019). As well as being used during appointments by practising healthcare workers, it is used as a framework in research aiming to provide insights and improve patient-doctor communications (Matthys et al., 2009; Burggraf et al., 2019, Freilich et al., 2019; Whitaker, 2021).

For this study, ICE was used to structure data gathering (e.g. formulation of questions) and helped nuance the concept of *expectations* into its three components: *Expectations* was defined by the study as the citizens' *hopes* given the current state and direction of healthcare; *concerns* as the citizens' *fears* and worries; and *ideas* as the citizens' own *ideas* on alternative scenarios (see figure 3.2). By using a concept familiar to healthcare, it was assumed that resulting insights would be easier to interpret by SU.

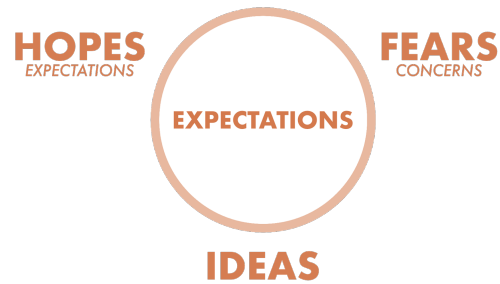


Figure 3.2: The ICE concept.

3.3 Studying specific care groups

Instead of studying health behaviour “in general”, Lenneke (2014) recommends that practices should be framed as activities that are neither too narrow nor broad, to facilitate comparison between alternative ways of conducting a practice. To achieve specificity, three different care groups with chronic diseases were selected.

- A. Citizens with asthma
- B. Citizens with diabetes
- C. Citizens with heart failure

These three groups were selected based on their complementary and long-term experience: While group A tends to have relatively milder complications, group B and C live with more severe conditions. Between the latter two, group B provides themselves with medical care each day based on self-monitoring, while C is using self-monitoring tools to provide healthcare with daily data which they can act upon.

The assumption was that these three groups, thanks to their different healthcare practices, have different attitudes, characteristics and expectations on healthcare – both digital, specific to their condition, and in general. Furthermore, the groups are specific yet widespread enough to cover a larger share, i.e. 14%, of the Swedish population. Thus, should improvements be made for these care groups, it is assumed to have a larger impact on the healthcare system in general.

3.3.1 Asthma

Asthma is a condition where the mucous membranes in the windpipe swells due to chronic inflammation, the surrounding muscles around the windpipe contract and sticky mucus forms and results in difficult breathing and coughing (Astma 2021a; Astma, 2021b). The disease is common across all ages and affects about 800 000 people in Sweden (Socialstyrelsen, 2020), of which five percent suffer from severe asthma (Tunsäter & Bjermer, 2021).

Asthma is typed as either allergic or non-allergic. The former is caused primarily by allergens such as pollen, nuts and fur, and is more common among children. The latter is primarily caused by irritants such as car emissions, tobacco smoke, strong smells, and cold air as well as physical exertion and stress (Astma, 2021a). Although people with allergic asthma can become worse from both allergens and irritants, asthma in general is said to be caused by a combination of heritage, environment and lifestyle factors. Common symptoms, among others, are sudden breathlessness, prolonged cough, whistling breathing sound, heavy breathing and coughs during exercise (Astma, 2021b).

Asthma symptoms are experienced differently, but most commonly described as “breathing through a straw” or “a pressure on the chest” (Astma, 2021a). Although symptoms can last from minutes to hours or longer, the intensity varies from severe to negligible (Astma, 2021b). However, becoming “used to” the asthmatic condition can cause chronic damages on the windpipes. During a severe, so-called, asthma attack, a person’s heightened effort to breathe increases their body’s need for oxygen, which if not met, may lead to oxygen deficiency (Astma, 2021a) which in turn can cause bodily functions to deteriorate.

Asthma is treated with anti-inflammatory medicine such as cortisone – which makes the windpipes less sensitive to irritants or allergens – and medicine which makes the windpipe widen by relaxing the surrounding muscles. While most people can live without major symptoms by regularly breathing in cortisone with an inhalator, both types of medicine are recommended to live an as healthy life as possible with asthma (Astma, 2021a). It is also important to note that cortisone is most effective over time and not as a quick solution. In addition to medication, lifestyle changes, such as leaving workplaces with high exposure to allergens and irritants, are recommended.

3.3.2 Diabetes

Diabetes is one of the largest endemic diseases in the world and around five percent of the Swedish adult population have it (Socialstyrelsen, 2018a), equal to about 500 000 individuals. The disease can, if not treated well, lead to other heart and vascular diseases that in turn may cause premature death.

Diabetes is a collective name for a number of diseases that cause excessive blood sugar levels (Diabetes typ 1, 2022). Although recent research suggests that categorising diabetes in five types would benefit treatment practices (Diabetes, 2018; Ahlqvist, 2018), two traditional categories are acknowledged and used internationally: type 1 and type 2 diabetes (Socialstyrelsen, 2018a). For type 1 diabetes, the body has ceased production of insulin that is necessary to absorb glucose from the blood (Diabetes typ 1, 2022), while type 2 diabetes is due to decreased tolerance for glucose which only reduces the body’s insulin production (Diabetes typ 2, 2019).

Type 2 diabetes, which is most common, often develops during adulthood. With changes to food and activity habits, individuals could live an almost unaffected life while having a limited need for medication (Diabetes typ 2, 2019). Type 1 diabetes, on the other hand, often develops during juvenile years and requires the individual to control and regulate their blood sugar levels by injecting insulin throughout their life (Diabetes typ 1, 2022). They can do this manually, using

a glucose meter, disposable test strips and insulin syringes. There are also a range of more digital and automated devices that can continuously measure the blood sugar level (i.e. glucose monitors) and continuously regulate the insulin flow (i.e. insulin pumps). About 50 000 individuals in Sweden have type 1 diabetes (Diabetes i siffror, 2020).

While individuals with type 2 diabetes have regular meetings with primary care yearly (Diabetes typ 2, 2019; Socialstyrelsen, 2018a), individuals with type 1 are often in contact with the secondary care, including check-ups and a range of sample takings with both doctors and nurses (Diabetes typ 1, 2022). In addition, individuals with either diabetes benefit from eating regularly, exercising and avoiding alcohol and smoking (Diabetes typ 1, 2022; Diabetes typ 2, 2019). Other self-treatments for both types are to take extra good care of your feet and teeth, the former since a lowered blood flow results in decreased sensitivity in the feet and the latter because of higher levels of blood sugar.

3.3.3 Heart failure

Heart failure is a condition where the heart no longer manages to pump around the blood that the body needs, either due to the heart muscle's ability to contract is weakened or that it cannot relax as it should (Hjärtsvikt, 2020). Around two percent of the Swedish population are living with heart failure (Socialstyrelsen, 2018b), equal to roughly 200 000 people based on current population, and it is an endemic disease that becomes more common with increasing age (Hjärtsvikt, 2019).

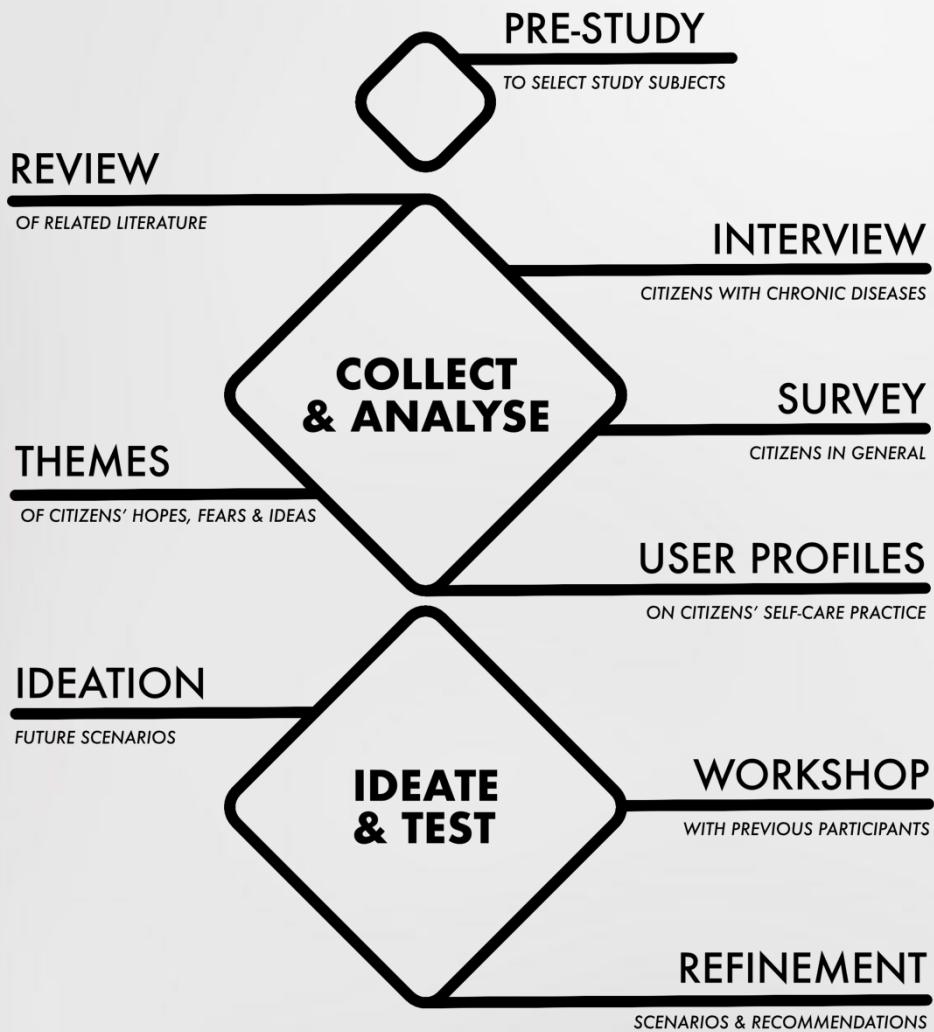
Heart failure is caused by underlying diseases such as hypertension, angina or diabetes (Hjärtsvikt, 2020). Common symptoms are tiredness, breathlessness and edema, and long-term heart failure also affects other organs, such as the brain, and functionalities of the skeletal muscles or the kidneys.

Most individuals with heart failure can be treated with medication to ease their symptoms, avoid healthcare visits and increase their quality of life (Hjärtsvikt, 2019). There are also a number of lifestyle changes that they can make to feel better. For example, through appropriate exercise and by avoiding alcohol. However, the prognosis of the disease is always severe and it is common with repeated need for medical visits (Socialstyrelsen, 2018b), and individuals with a more severe diagnosis could be in need of a pacemaker or implanted defibrillator (Hjärtsvikt, 2020).

Furthermore, it is the severity of the heart failure that determines how much the individual's life is affected by the disease, but most people can live about the same as someone without heart failure. However, if the disease worsens and the symptoms get stronger, it could be difficult to cope even with moderate physical activity (Hjärtsvikt, 2020).

4 Process and method

In this chapter the process of the thesis is presented along with used methodology and its adaptations and purposes. Themes of expectations and user profiles were derived from data gathering, which included literature reviews, interviews and a survey. Based on said outcome, scenarios and considerations for future development of digital healthcare services were formulated, tested and refined through ideation and a workshop.



4.1 Pre-study

In the initial phase of the project, a pre-study was performed to narrow the studied target group into specific patient groups with diagnosis and treatment that supposedly would benefit especially well from digitalisation.

Seven specialists and managers within cardiology, orthopaedics, internal medicine, research & development, and digitalisation were consulted separately during a brief phone interview. The first three interviewees were selected based on initial recommendations from SU, while the remainder were contacted based on recommendations from the preceding interviewees.

During a five-minute interview, each interviewee answered what kinds of healthcare visits they believed could be conducted in other ways than on-site, and gave examples of these visits and related patient groups. After a review of the mentioned patient groups, three were selected based on their complementary healthcare practice and their prevalence in the Swedish population.

4.2 Data gathering

Followed by the pre-study, data was gathered by two literature reviews – one with focus on the studied user groups and another with focus on digital healthcare – followed by user studies through qualitative interviews and a quantitative survey.

4.2.1 Literature reviews

A literature review is a method to systematically study existing research and other published information on a specific topic (Thomas & Hodges, 2010), and has a number of different purposes depending on the nature of the project. For example, to identify key information within a topic, finding out what is already known about a topic or just updating basic knowledge.

For this project, two literature reviews were conducted. The first aimed to explain digital healthcare in terms of what it is, how and where it is applied, as well as presenting existing research on Swedish citizen attitudes towards it. The purpose was to give an introduction to, and understanding of, the area as well as finding out what research on expectations towards digital healthcare that already had been conducted. The literature was gathered by using Google Scholar and Chalmers Library Database, with keywords such as *digital healthcare*, *expectations*, *attitudes* and *Swedish healthcare*. Due to national and cultural implications that can affect expectations and attitudes, only literature that addressed Swedish healthcare was reviewed.

The second literature review aimed to present information related to the diseases of the studied user group. Information was primarily gathered directly and summarised from web pages and reports by Swedish authorities, (e.g. Healthcare guide 1177, Sweden's National Board of Health and Welfare). The purpose was to summarise basic "hard facts" related to these diseases, so that the user studies could focus on softer user values.

4.2.2 Interviews

Interviewing is a qualitative research method based on asking questions to users to elicit their thoughts, attitudes, motivations, experiences and behaviours towards certain areas (Karlsson, 2007).

A total of 15 interviews were performed, of which five were held for each of the three user groups: citizens with asthma, diabetes and heart failure (see table 4.1). The interviewees were primarily recruited with the support of national associations related to each care group, while four interviewees were recruited through snowball sampling and convenience sampling. The former sampling involves participants recommending other participants, and the latter involves approaching individuals directly (Lavrakas, 2008).

The purpose of the interviews was to gather qualitative data from the care groups, with the aim to find out what distinguishes each user group in how they take care of themselves and with this what expectations they have on future healthcare. The interviews were semi-structured, including both open and closed questions with probing to allow the interviewees to elaborate their answers further (see Appendix A). All interviews were held via the digital software Zoom, besides two which were held via phone call and on-site respectively. They were audio recorded to support recollection and facilitate later analysis.

Table 4.1: The interviewed citizens with chronic diseases.

ASTHMA	DIABETES*	HEART FAILURE**
A1: Engineer aged 25-34	D1: Health Worker aged 35-44	H1: Student aged 35-44
A2: Lawyer aged 25-34	D2: Rehab Worker aged 35-44	H2: School Worker aged 55-64
A3: Store Personnel aged 25-34	D3: IT Consultant aged 25-34	H3: Social Worker aged 55-64
A4: Student aged 25-34	D4: Marketer aged 25-34	H4: Job-seeker aged 55-64
A5: Student aged 25-34	D5: Salesman aged 25-34	H5: Technician aged 55-64
*All interviewees had diabetes type 1 **Rare condition at a younger age		

4.2.3 Survey

A survey is an indirect question-based method, where users answer questions in a pre-written or computerised questionnaire. They are primarily used for gathering data from a bigger set of people, validating results from interviews or gathering data from people difficult to reach physically (Karlsson, 2007).

One survey with 20 questions was formulated, with an even share of text answers and rating answers (see Appendix B). The share was decided to make the survey less time-consuming to fill in for respondents, while at the same time allowing for in-depth answers. The survey was distributed via 10 community groups, on the social media platform Facebook, related to cities in Region Västra Götaland. The cities were decided to represent the full range of urban regions of different population sizes.

The survey targeted citizens aged 25-44 and received a total of 100 responses. It was purposefully designed to acquire a quantitative picture over average care habits and expectations on digital healthcare, and assess the similarities and differences between them and the care groups, regardless of health condition or in relation to a certain diagnosis.

4.3 Analysis

To process and analyse the gathered data concerning the participants' expectations, a comprehensive thematic analysis was conducted along with making user profiles based on the practice theory, distinguishing the care groups and their self-care practice.

4.3.1 Thematic analysis

To analyse the data from the interviews, a total of three thematic analyses were conducted, one for each care group respectively. A thematic analysis is a method where data is organised and described by identifying, analysing and reporting themes within it (Braun & Clarke, 2006).

These analyses were adapted toward the practice theory, with the three elements as categories: stuff, skills and images. Within these deducted categories, themes emerged inductively during the analysis. When the three analyses were finished, the results were summarised jointly under each identified theme. When the themes had been established, free form answers from the citizen survey were incorporated into the themes, while the multiple-choice questions were statistically summarised (see Appendix C). As a qualitative study, the number of citizens did not impact the relevance of specific themes, which instead were chosen to represent the areas of expectations.

The main purpose of the thematic analyses was to see what expectations the different care groups had on future digital healthcare services, and to map these into themes. Another purpose was to see similarities both between the care groups as well as between the individuals within the care groups, and if these similarities resulted in the same expectations.

4.3.2 User profiles

A user profile is a method for describing who the users, who are to be designed for, are and what they want to achieve (Sherratt, 2020). In line with the objective of the study, user profiles have been designed for each care group based on the practice theory.

Four user profiles were created based on the thematic analysis, one for each user group. Each profile consists of a descriptive text that conveys their behaviour in relation to taking care of their health, divided into sections about the role of healthcare, self-care and the group's distinction compared to the other user groups. The text is illustrated with a triangle that summarises the self-care practices surrounding their specific health condition. The triangle is composed of stuff (e.g. healthcare infrastructure, medicine, products) skills (e.g. awareness, knowledge, routines) and images (e.g. conceptions of healthcare, disease and self).



Figure 4.1: User profile layout for self-care.

The purpose of the user profiles was to provide insights on the user groups' self-care practices, to highlight differences between them, as well as to find possible distinctions relating to certain types of expectations.

4.4 Ideation and evaluation

From the gathered data, analysis and user profiles, ideation took place continuously throughout the project on how to meet these expectations and solve issues related to them. A workshop was also held with two participants to refine ideas and ensure that their expectations were in line with the interpretations from the analysis.

4.4.1 Ideation

Ideation is a way to manifest your understanding of a problem and can be conducted for many purposes, such as communicating insights or preparing for product development (Wikberg-Nilsson et al., 2021), of which the former aligns with the purpose of this thesis. For this study, brainstorming and scenarios were used as ideation methods. While brainstorming is a group activity where ideas emerge through discussion (Wikberg-Nilsson et al., 2021), scenarios are user-centred narratives intended to explore the meaningfulness of products or services in a person's life (Hanington & Martin, 2019).

Three ideation efforts were done with different intended outcomes. The first one was a longitudinal brainstorming effort in tandem with learning more about participants' self-care practice and expectations during analysis. The outcomes are tightly coupled with the ideas and beliefs that they have explicitly mentioned, for example betterment of existing healthcare services. The second effort was a brainstorming session related to early discovery of diseases and health data collection devices, in line with the client's ambitions to leverage IoT. The third and final effort was to formulate several ideas into scenarios that describe meaningful interactions between citizens, healthcare and digital services. All ideation was primarily conducted on the visual collaboration platform Miro, with digital post-it notes and mind maps.

The purpose of the ideation overall was to find ways to illustrate the insights in an actionable way. As this thesis in itself is a pre-study for SU's future efforts, it was considered more appropriate to express the final ideas in terms of values and usefulness rather than metrics.

4.4.2 Workshop

To ensure that gathered expectations and insights had not been misinterpreted, all interviewees were asked to participate in a workshop, of which two interviewees were able to attend (see Appendix D). During the workshop, two scenarios were presented that targeted areas of improvement that emerged during the study. The participants also got to comment on how to refine the ideas within the scenarios.

The workshop was held over Zoom, and the scenarios were presented one at a time, where the participants had the chance to first think for themselves and then freely express their spontaneous reactions, before a joint discussion led by a facilitator.

5 Expectations

This chapter answers to the first objective of this thesis. It begins by presenting user profiles based on how citizens with asthma, diabetes, heart failure and citizens in general practice self-care, followed by a thematic arrangement of their expectations.

5.1 User profiles on self-care

The following sections present a user profile for each user group with asthma, diabetes, heart failure and citizens in general, see figure 5.1, 5.2, 5.3 and 5.4. They describe behaviour in terms of self-care practices related to their specific health condition.

5.1.1 Asthma self-care

Healthcare. The main healthcare contact for the participants with asthma is the Asthma & Allergy Clinics, and more specifically its asthma doctors, allergists and nurses. Depending on the severity, check-ups are done yearly to examine their lung health with a spirometric device. For the participants with mild asthma, the main role of healthcare is to prescribe medicine (e.g. inhalers, pills), while for those with severe asthma, healthcare provides regular support in understanding and treating frequent and worsening complications.



Figure 5.1: User profile of asthma self-care.

Self-care. During their day-to-day life, ways to avoid complications include customising their environment and lifestyle. Minor changes (e.g. open/close windows, cleaning, fragrance-free products), increased awareness of surroundings or both are sufficient for the participants with mild asthma to avoid complications. The participants with severe asthma require major changes (e.g. preferring car over bicycle, indoor activities, mucus-decreasing diets, using medical-grade air purifiers at home). Besides learning what adaptations work well, all of the participants learn what triggers their asthma and how and when to take their medicine. Furthermore, they all maintained some sort of exercising routine (e.g. sports, walks, cardio training, healthcare-provided exercises) while also assessing their bodily reactions as to not overwork themselves, both in and out of training. They experience a prejudice that people with asthma are “attached to their inhalator”.

Distinction. The participants with asthma, compared to those with diabetes or heart failure, have many more circumstances that can trigger complications, of which many are out of their own control. For example, outside conditions like cold temperature and pollen, and lifestyle choices of others such as having pets or using perfume. As such, they avoid complications by adapting to external factors to a larger degree. Furthermore, while people with diabetes and heart failure accepted interview requests, plenty of people with asthma turned it down. Two of the participants expressed that they initially wanted to say no because their asthma complications and associated healthcare contact were negligible, and that their experience would not be valuable for this study.

5.1.2 Diabetes self-care

Healthcare. The contact with healthcare for participants with type 1 diabetes usually consists of a few yearly visits to diabetes doctors and nurses. At least one of the visits consists of a routine medical examination of feet and eyes, since complications are common for these body parts. Most of the visits are however more focused on having a dialogue with the healthcare personnel, together evaluating the treatment and disease. The dialogue could be in relation to diet and physical engagement, but is often individualised towards what the patient wants to prioritise at the time.

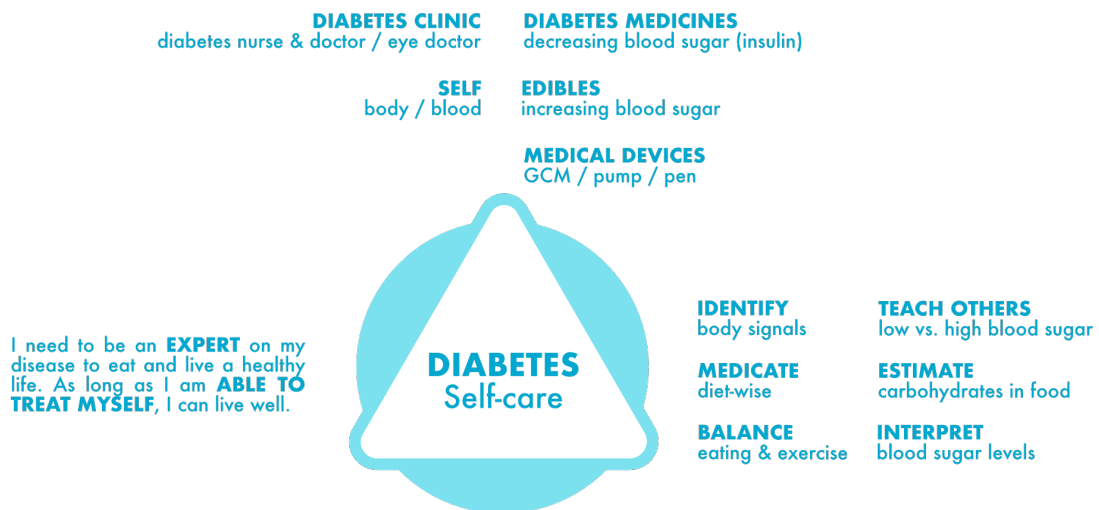


Figure 5.2: User profile of diabetes self-care.

Self-care. The daily treatment is mainly to oversee their blood sugar levels and adjust their insulin intake accordingly. All of the participants had an automatic measurement of their blood sugar levels through a continuous glucose monitor (CGM-meter) attached to their body, which then sends the data to an application in their smartphone. Most of the participants had insulin pumps connected to the CGM-meter that adjusts the insulin injections automatically, while some injected manually with insulin pens.

Apart from using the medical equipment, the participants also expressed having developed great knowledge on their bodily reactions to low versus high blood sugar levels. They also know how to regulate it without insulin intake, by adjusting carbohydrate intake or engaging in physical activities. With this, they have gathered a fundamental knowledge about carbohydrates levels in most common food and they usually carry Dextrosol, a glucose supplement, as a back-up with them. Besides the mentioned treatment and awareness, the participants expressed that the disease does not affect their lifestyle to a larger extent. All of them however mentioned how planning and routines facilitate the management of the disease.

Distinction. The participants with diabetes, compared to those with heart failure and asthma, to a higher degree expressed having vast knowledge of their disease, the treatment and how it affects their body and well-being. Their healthcare interactions were more of a coaching dialogue, and the participants that had lived with diabetes for longer periods (20+ years) even expressed having a better understanding of their own disease than the healthcare personnel, both in daily treatment and during acute conditions.

5.1.3 Heart failure self-care

Healthcare. The main healthcare contact for the participants with heart failure are Heart Clinics, and more specifically its heart failure doctors, nurses and pacemaker specialists. The participants either already had or plan to receive a pacemaker, with or without a built-in defibrillator (ICD). They have regular examinations of the heart (i.e. with electrocardiogram) and the pacemaker, ranging from one to four times per year depending on past health assessments. Some have received a transmitter unit that sends data from the pacemaker to the clinic, for themselves or healthcare personnel to notify each other and follow-up on any irregularities. After their initial diagnosis, the participants were all provided scheduled group exercise fit for their condition by the heart clinic. When their health condition improved, they were no longer offered this exercise.

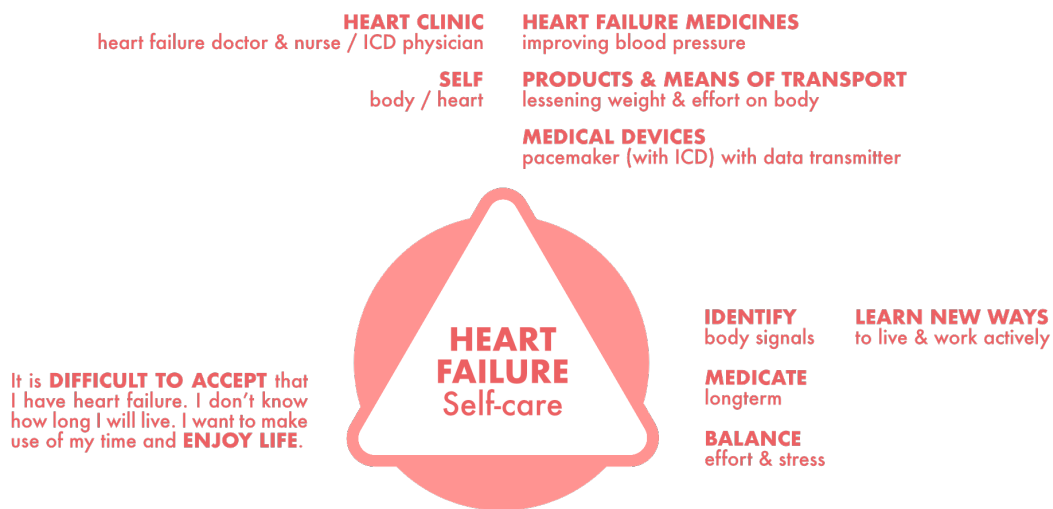


Figure 5.3: User profile of heart failure self-care.

Self-care. During their day to day life, ways to avoid complications are to make use of things or do things which lessen the stress on the body (e.g. lifts, e-bike, sack carts, walking slower, avoiding hills). Furthermore, the participants all expressed the benefits of exercise and how important it is to find new ways to be active, but expressed difficulty in keeping exercise routines in place and how they preferred when the exercise was scheduled by healthcare. One participant had joined an outdoor exercise group at a local heart-failure organisation, which was led by the same instructors that previously had provided them exercise via the heart clinic. All participants with heart failure had learned to assess their bodily reactions as to not overwork themselves, and to identify different signals from the heart and body, and adjust their activity levels accordingly.

Distinction. The individuals with heart failure, compared to those with asthma or diabetes, express existential reflections to a larger extent (e.g. making use of the time they have left in life). As heart failure is rare at a young age, only one participant was aged between 25-44. This individual specifically expressed how heart failure care does not fit for those who still have young kids and are pursuing a work life.

5.1.4 General self-care

Healthcare. Survey respondents' contact with healthcare is to a higher degree located to browsing health related information online (i.e. *at least once a month to at least once a quarter*), compared to contacting healthcare by calling 1177, using e-services or visiting on-site (i.e. *occasionally during a year*). In other words, they spend more time on assessing their health condition given online resources and less time in direct contact with healthcare.

Furthermore, eight out of ten respondents express having a good or very good self-awareness about their health condition. Regarding what they identify as signals to contact healthcare, respondents primarily mentioned long-term illness that will not go away, obvious illnesses in terms of visible, perceptible and sudden, and advanced and acute illnesses. Less common mentions included being encouraged by relatives and experiencing illnesses that limit their capacity to live and work.

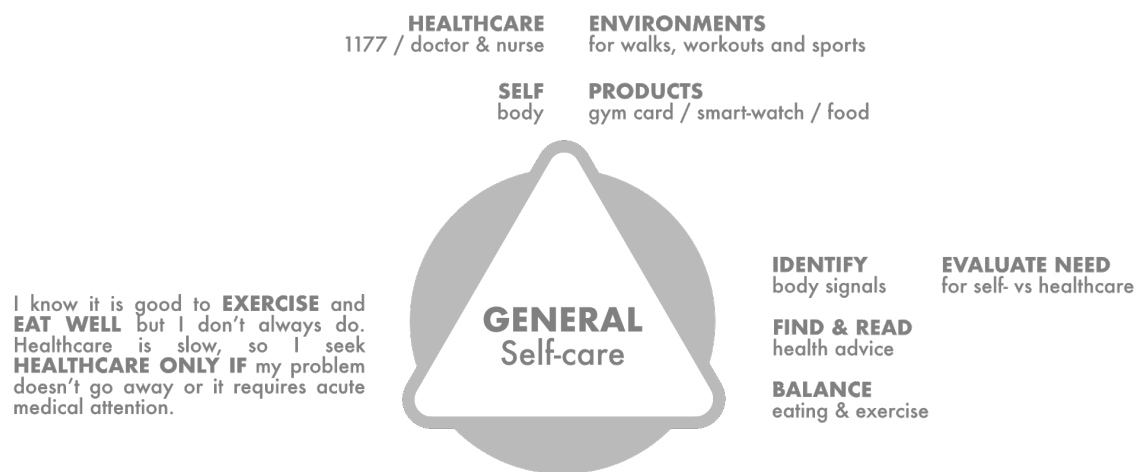


Figure 5.4: User profile of general self-care.

Self-care. The most common response on how to take care of one's own health were to engage in physical activities as well as to think about eating properly. Physical engagement included a span from shorter daily walks to hours of weekly exercising at a gym or in sports. With this, common stuff to own is workout clothes, equipment, activity watches and gym memberships. Responses on how to eat properly ranged from occasionally avoiding food, such as sugars or snacks, to following a more restrictive diet and eating vitamins, but no particular stuff was mentioned to support this other than one person using a dietary application.

A lower number of respondents also mentioned stress-handling, mindfulness and recovery as important factors of self-care, where one tool used for this was mindfulness applications. Additional areas within self-care that were mentioned concerned routines and stuff related to hygiene and less severe health issues treated from home (e.g toothpaste, thermometer).

Distinction. The survey respondents, compared to the interviewed care groups, described more general stuff relating to maintaining their health. In addition, their health condition was expressed to not justify the use of more invasive treatment, for example the belief that measuring their health data would not improve their lives significantly.

While it was possible to distinguish between respondents with or without (unspecified) chronic diseases in the survey, this distinction is not made throughout the thesis. The only three significant differences were that the respondents with chronic diseases mentioned their specific aids and medicines, that they do on-site visits and use healthcare e-services to a higher degree, and that they were more positive towards digital aids and health data collection.

5.2 Expectations on digital healthcare

Expectations, including hopes, fears and ideas, elicited from the user study, were grouped in themes and sorted into five categories (see table 5.1). First, is the *political context* that forms the current boundaries of healthcare services and their organisation. Expectations here centre around economics and resources, providing information about what direction that the citizens want to set for future healthcare.

Affected by the political context, is the healthcare organisation and their practical execution. Within this *organisational context*, expectations concern working conditions and the role of healthcare personnel. A predominant sub-category in the organisational context, is the *contact with healthcare*, where expectations concern interaction and means for citizens to get in and keep contact with healthcare.

Digitalisation gathers expectations in areas where citizens believe digital efforts could make room for improvements and also where they believe it to be problematic. The sub-category *data collection and sharing* contains expectations to take into extra consideration when designing for digital healthcare that makes use of IoT.

Table 5.1: Themes of expectations.

Political context		Digitalisation	
Healthcare in general	●●●●	General attitudes	○●○●
Research & development	●●●●	Fast & efficient healthcare	●○●○
Public & non-bureaucratic healthcare	○●○●	Human & accurate healthcare	●○●○
Public & free healthcare	●●●●	Overuse of healthcare	○●○●
Equal healthcare	○●○●	Difficulties for minorities	○●●○
Shorter waiting times	●○●○	Digital meetings to complement	●●●○
Competent healthcare	●○●○	Remote prescription renewals	●○●○
		Self-tests at home	●●●○
		Unified health record system	●●○●
		Digital research & development	○●○●
Organisational context		Data collection and sharing	
Sound staffing & conditions	●○●○	Meaningful purpose	●●●○
Care over administration	●●●○	Secure data sharing	●●●○
Proactive healthcare	●○●○	Transparent collection	●●○●
Individualised healthcare	●●●○	Minimalistic & automatic	●●●○
Support with self-care	●●●○	Custom & justified	○●○●
Personal healthcare & continuity	●●●○	Personalised & limited feedback	●●●○
To be approached well	●●○●		
Contact with healthcare			
Reaching the right person & place	○●○●		
Alternative means of contact	●●●○		
Custom appointment booking	●●○●		
Improved app & web experience	●●●○		

Asthma	●○●○
Diabetes	○●○●
Heart failure	○●●○
General	○●○●

5.2.1 Political context

The political context concerns expectations that form the current boundaries on healthcare services and its organisation, see table 5.2.

Table 5.2: Themes within a political context.

Healthcare in general		Equal healthcare	
Research & development		Shorter waiting times	
Public & non-bureaucratic healthcare		Competent healthcare	
Public & free healthcare			

Healthcare in general

Expectations on whether healthcare would become better, worse or stay the same in the future were scattered among the care groups and survey respondents. From the survey, a mix of diagnose specific concerns were mentioned, of which the most common was a wish for improved psychiatric care. Other concerns were related to gynaecological diseases, pregnancy, stress disorders, and social stigma of obesity within healthcare. Individual expectations related to these areas were a fear of psychiatry only becoming a means of receiving pills and being stored away, and to fear giving birth due to insufficient maternity care.

I expect fast and appropriate care when I need it.
/ Survey respondent

Research & development

All care groups expect that research and development (R&D) will lead to better medicines and treatment methods. Specifically for the citizens with diabetes, it was expected that improvements will make the disease “disappear”. This expectation was related to a desire, that was also expressed by those with asthma and heart failure, to live an unhindered life without their illness and a concern that they will not receive better care without R&D. Individual examples of this concern were fears that vital medicine and devices would not be improved and wishes for increased competition in medtech to push R&D.

*I think diabetes will be a welfare disease that disappears.
[...] Not that you cure it, but that you might implant
something [...] and then you live a normal life.*
/ Individual with diabetes

Public & non-bureaucratic healthcare

On a political level, survey respondents expressed an experience of regional public healthcare being a bureaucratic and slow-moving organisation. Those characteristics were expressed to obstruct healthcare from being at the forefront in research and development, compared to private actors. Specific mentions of obstructions were the Swedish Public Procurement Act (Swedish: *Lagen om offentlig upphandling, LOU*) in combination with tendencies to set unreasonable goals within tight budgets.

*I am also concerned that bureaucracy and politics, such
as LOU, will prevent healthcare from ever being at the
forefront of technology, with the exception of
university hospitals.* / Survey respondent

Public & free healthcare

Survey respondents do however desire that healthcare remain state-owned so that care and medication can be provided at a reasonable cost. This connects to a concern that access to healthcare, if privatised, would become a matter of economic class. The survey respondents expressed strong beliefs that the strained healthcare was causing people to seek care from private actors. Given the current financial compensation system where “money follows the patient”, they also expressed beliefs that private actors attracted and managed the more simple cases at a faster rate, leaving public healthcare with more complex cases and less financial resources. Furthermore, concerns were expressed that profit-driven motives could lessen the quality of healthcare.

I am concerned that the staff at the region's hospitals are so pressured that the alternative is to consider private care to get a doctor who has time to listen.

/ Survey respondent

Regardless of the public and private aspect of healthcare, the survey respondents feared that healthcare would become costlier. For example, increased prices per visit or treatment. This was also expressed by all care groups related to their medicines and medical devices. In addition, the survey respondents wish for increased allocation and improved distribution of resources as they believe the lack of financial resources will be a growing problem due to increasing care needs for different reasons (e.g. in general, relative to an ageing population or relative to resource-intensive diseases due to poor lifestyle choices).

It would be awful if it were like in the US where it costs so much money, if people cannot afford to take their insulin.

/ Individual with diabetes

Equal healthcare

The survey respondents desire equal access to high-quality healthcare, independent of where they decide to live geographically in Sweden. Their desire is linked to concerns that resources, including competent staff, are being concentrated in larger cities and that it affects their access to primary care (*Swedish: Vårdcentraler*), smaller hospitals, emergency centres and ambulance service. While they urge access to the aforementioned primary healthcare services, they expressed an understanding that specialist healthcare cannot be spread out in abundance. Another aspect of equal healthcare is gender, coupled with an expressed hope that women-specific diseases would receive more attention in research due to concerns of being less prioritised.

More competent doctors to smaller towns and health centres, who remain in the town or workplace and do not change workplaces because they want a larger hospital or variety.

/ Survey respondent

Shorter waiting times

The survey respondents were concerned whether healthcare would have time and space for them if need arises, related to their desire for more efficient care with shorter queues and reasonable waiting times. This desire was also strongly expressed by the citizens with asthma.

Individual examples of this desire were to extend opening hours, to receive feedback from previous appointments faster and that people should not feel they need to hold off from seeking care until their problem becomes acute. Furthermore, the survey respondents expressed a need for transparency on how priorities are made on who gets treated first and why it takes time while in a waiting room.

I am worried that there will continue to be long queues and inaccessibility-issues to get in touch with healthcare.
/ Survey respondent

Competent healthcare

Relating to faster healthcare, it was however emphasised among the citizens with asthma that competence criteria for new personnel must not be compromised to cut waiting and queue times. The survey respondents expect healthcare personnel to be highly competent and professional so they can provide appropriate treatment and care. This desire is related to their concern that the competence within healthcare may lack in the future.

Individual examples are the fear of not being offered appropriate help, that healthcare students are not provided enough experience before they begin working, and that the broad surface-level competence among the doctors at primary care centres may complicate and delay correct diagnosis.

I worry that more doctors at primary care centres who are general practitioners, and do not have the deeper knowledge, can lead to you not getting a diagnosis until it may be too late. / Survey respondent

5.2.1 Organisational context

The organisational context, which is affected by the political context, concerns the healthcare organisation and their practical execution, see table 5.3.

Table 5.3: Themes within an organisational context.

Sound staffing & conditions		Support with self-care	
Care over administration		Personal healthcare & continuity	
Proactive healthcare		To be approached well	
Individualised healthcare			

Sound staffing & conditions

The survey respondents expressed a deep concern about staff shortage. They expressed fears that working conditions result in high levels of stress and difficulties to cope for the personnel. In addition, the citizens with asthma expressed a strong wish for more allergists, especially with a deeper knowledge of severe asthma. This wish was connected to the oncoming retirement of many allergists.

Above all, we should not have to be the caregivers for our healthcare staff in order for the healthcare system to work in the end. / Individual with diabetes

Individual examples of the staffing concern are fears that working conditions increase stress-related mistakes, that people avoid and leave the profession and that they ultimately result in longer care queues. Furthermore, they wished to increase the number of healthcare personnel, their salary and status if that meant they could give better care for the number of patients.

The care staff must have a reasonable workload so that they have the strength, time to learn from each other and have fun at work. / Survey respondent

Care over administration

Both survey respondents and all care groups expect and wish for healthcare personnel to spend their time on actual care and collaboration with colleagues instead of administration and paperwork. Individual examples of this wish were the suggestions to have medical secretaries relieve nurses and doctors, an extended mandate for nurses to relieve doctors, and more efficient health record systems. This way, it was expected that each healthcare profession would be enabled to use their core competencies to provide care.

If we talk about healthcare in general, I would probably like to reduce the administration [...] so that there is more focus on actually caring and, yes, taking care of patients and healthcare. / Individual with diabetes

Proactive healthcare

The survey respondents and citizens with asthma and diabetes expressed wishes for more proactive healthcare, in terms of preventing diseases, by discovering symptoms early or by keeping your chronic disease at bay. This is related to their desire that healthcare should have less focus on medication. Individual examples are the wish for more preventative health examinations, to receive advice and support in health-improving changes to lifestyle and habits, and the fear that life-style diseases would increase costs across society as a whole.

I hope healthcare will be more preventative and not just remedial. / Survey respondent

Individualised healthcare

Related to proactivity, both survey respondents and the care groups expressed wishes for more individualised healthcare and treatment. The care groups specifically desired that healthcare should focus more on the patient as a whole rather than solely on their diagnosis. Similarly, survey respondents wished for care based on their conditions and circumstances. For both care groups and survey respondents, the individual aspect was mentioned in terms of bodily parameters, such as weight, length, metabolism and genetic profile.

I expect and hope that care will be individualised. That there will be even more focus on the patient as a whole and not just diagnoses. / Individual with asthma

The individual aspect was also mentioned in terms of asking for the priorities of the patient instead of assuming them. This was exemplified by a citizen who felt empowered by their wheelchair, but was met by healthcare personnel who were more focused on lessening their need for it.

It was not a problem for me to use a wheelchair. What was a problem for me was that I could not hang out with my friends and that I could not go to school. But the focus was always on how healthcare could get me out of the wheelchair, while I was more of the opinion that it's a tool for me to do some more things at least.

[Ask me] 'What is the problem for you as a patient?'

/ Individual with asthma

Similarly, the citizens with diabetes wished to be treated more as experts on diabetes and equals with whom health workers can have a dialogue with, since their extensive experience with treating themselves enables them to reach appropriate conclusions on how to treat their own complications. Furthermore, they wished to get all their treatment from their specialists, as they experience inconsistent treatment and understanding from primary care on how diabetes affects and is affected by other diseases in general.

You get placed very much in a box. 'You have type 1 diabetes and then you should do this'. I want it] a little more individualised. / Individual with diabetes

Related to individualised healthcare practice, all care groups and survey respondents also expressed desire for more alternatives to adapt their healthcare. Besides being expressed on a general level – “Free choice wherever suitable” – the desire was primarily mentioned in connection with choosing format and frequency of appointments.

Support with self-care

Also related to individualised healthcare, all care groups desired to receive support in how to better take care of themselves, for example with clear advice on exercise and dietary habits, and support in understanding whether their current health condition depends on illness or current life situation (e.g. pregnancy, age).

The citizens with heart failure expressed desire to be offered scheduled and tailored exercise from healthcare, related to the concern that exercise is good but difficult to get going with on your own. A concern mentioned by a younger individual with heart failure was that care activities do not suit their age group. They further described how difficult it is to live with heart failure at a working age, as it affects their ability to work and take care of family members. Although the former is the presumed responsibility of labour unions, it is an important aspect to consider in terms of individualisation.

[In the beginning] I got physiotherapy. Damn how good it was. I think we should all have that, so expand that concept and make the training facilities bigger. [...] It has increased the quality of life, I think, for many to get out and get going with exercise. Now I can work out whenever I want, yes, but I do not want to. So, it doesn't happen. / Individual with heart failure

Among the citizens with diabetes there was a specific wish for a fast track during emergency visits, as they often know how to treat their complications and just need brief support from healthcare before they can continue taking care of themselves. They also wished for automatic treatment technology so they would not have to depend on others, related to a fear that elderly care – with high staff turn around – would fail to care for them if they become demented and unable to care for themselves.

But when you're such an expert on your own illness, I just want to say 'throw in two litres of drip and I'll be fine again'. Then it's like 'No, you have to go through the usual triage and sit and wait'. But if you just pour me this, you don't have to hospitalise me.
/ Individual with diabetes

The citizens with severe asthma would like more healthcare personnel and people in general to be aware that the severe asthma – although uncommon – exists, as they experienced a lack of awareness and related knowledge. They also expect to be able to care for themselves more independently, and wish for an easier way of knowing the status of their health, as this could be difficult sometimes. They also wish to not have to keep track of their medical history themselves.

I could die [...] Not many people get that, and I have noticed that people may not understand the seriousness. I have been exposed to people trying to test if I get sick, maybe by wearing a lot of perfume and then I get really ill. But then usually that prejudice disappears when they see how unwell I actually get. Afterwards it often happens that this is completely reversed and they become very understanding instead. / Individual with asthma

Personal healthcare & continuity

Both care groups and survey respondents desire a more personal relationship and continuity with the same healthcare personnel over time, related to an experience of having to rebuild trust and comfort while repeating yourself every time your care contacts are swapped with other personnel. This also related to a concern that personal contacts will become less and less common. The citizens with asthma and heart failure expressed the benefits that you would not have to remember your medical history, knowing that your doctor is well aware and familiar with your health and feeling safe in knowing who you will meet next time. Individual examples from survey respondents were the feared lack of dedicated personnel with good insight into individual long-term patients and their past health record.

And maybe there are a lot of things I don't know are important, that can affect [the treatment], and miss to tell. I become a filter of my medical history. The times I've had the same doctor have been really valuable because then they have been able to say, 'You have had this before'. If you'd gone to different psychologists every time it wouldn't have worked. I feel that should apply to doctors as well. Like you used to have your family doctor, I would have liked that.
/ Individual with asthma

To be approached well

The survey respondents expressed a strong desire for their health concerns to be better addressed by healthcare, related to concerns that they are not always taken seriously nor properly followed up, and experiences with hasty conclusions leading to being erroneously sent home or diagnosed. Individual examples are the desire to be believed in and become more involved through dialogue, and the fear that being offered the right help will happen only if you have committed relatives that push through for you while you are too sick and exhausted.

Similarly, the citizens with asthma and diabetes expressed a belief that healthcare workers, due to their constrained working conditions, are forced into a position where it appears desirable for them to solve a patient's problems without having to request help from colleagues. The belief was related to experiences where individual healthcare workers express their advice and conclusions with uncertain-sounding wordings.

Everyone wants to be this good individual. [...] If a health worker says 'I think you can do this' to me, who has had diabetes for thirty years, I see red and become afraid of society. In general, I think you should be able to admit that you don't have full knowledge and that you request assistance from colleagues. It has a bit to do with stress, not wanting to bother colleagues because they have their asses full of other things.
/ Individual with diabetes

5.2.3 Contact with healthcare

Within contact with healthcare, expectations concern interaction and means for citizens to get in and keep contact with healthcare, see table 5.4.

Table 5.4: Themes concerning contact with healthcare.

Reaching the right person & place	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Custom appointment booking	<input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/> <input type="radio"/>
Alternative means of contact	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/>	Improved app & web experience	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/>

Reaching the right person & place

The survey respondents hoped for easily accessible and transparent healthcare, and expressed concerns that it would become more difficult to get in touch with and receive care in the future. Furthermore, they desire to quickly reach the right place and the right level of care, instead of spending time and effort on navigating and being sent between different care units.

Individual examples were the desire for care centres in general to become better at forwarding patients, to have a contact person with good knowledge on how to navigate the healthcare system, to have a better information system that makes it clearer whom a patient should contact for what, and a more accessible primary care so people do not opt for emergency clinics instead.

I want it to be easier to get the right contact quickly, to avoid being passed around between healthcare centres.
/ Survey respondent

Alternative means of contact

Regarding accessibility, all care groups desire alternative ways of contacting healthcare, depending on the urgency or complexity of their health concern. Means of contact were exemplified with written communication (i.e. chat, mail), voice communication (i.e. phone calls, video meetings), and self-service (i.e. booking time slots, searching for info). An individual wish was for there to exist a fast-track to get answers on simple questions.

I want to have contact more easily without physical contact points. Be able to ask questions and get answers without having to call or physically visit.
/ Survey respondent

This desire was also expressed by the survey respondents, in terms of being able to ask questions and get answers without having to call or visit healthcare. In other words, written communication was expressed as being an easier and more accessible means. An individual example of this desire was the idea to answer questions about a health concern through e.g. an app, and then automatically be forwarded to speak to the right person.

I wish that I could choose whether I wanted a phone call, video or a physical meeting. / Individual with asthma

Custom appointment booking

Specifically for booking appointments, the citizens with diabetes and asthma wished to decide on time slots that suit them instead of being assigned a predetermined time slot that could very well be difficult to adapt to and require unnecessary contact with healthcare. Although humble that it could become more complex to manage in healthcare as it is now, they expressed that being able to book time slots themselves really would improve their healthcare experience and make it easier to prepare for healthcare appointments. The survey respondents also expressed the same wish, in terms of making it easier to schedule and reschedule healthcare meetings in advance through the web.

I also find it quite tiresome that when they send a meeting time, I am expected to be free at that time and must adapt my daily life to that time. Sometimes it results in rather big consequences when I can't, and I must wait two months to get a new appointment. That doesn't seem quite reasonable. Well, it works if it's once a year, but not when, like me, you have quite a lot of health care contacts and suddenly the health care visits themselves affect my life as much as the illnesses themselves. / Individual with asthma

Improved app & web experience

The care groups and survey respondents wish that the Healthcare guide 1177 and related public healthcare apps and websites would have more uniform appearances and navigation, especially between sub-pages for different care centers. This is related to a concern that it is difficult to find what you are looking for despite being young and well-oriented with computers. Individual examples of this wish is to have all personal health information gathered in one place, and that the Healthcare guide 1177 should provide more automatic functionality to increase ease of use.

I hope they solve the 1177 app first, because it's a jungle! [...] Really, it's a bit too many steps to go to the right menu, log in under the right menu, go to the next menu and there select between care units, search for your city, go in and choose the right department out of 11 possible ones. / Individual with diabetes

5.2.4 Digitalisation

Digitalisation concerns expectations in areas where citizens believe digital efforts could be either beneficial or problematic, see table 5.5.

Table 5.5: Themes concerning digitalisation.

General attitudes	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input checked="" type="radio"/>	Digital meetings to complement	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/>
Fast & efficient healthcare	<input checked="" type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Remote prescription renewals	<input checked="" type="radio"/> <input type="radio"/> <input checked="" type="radio"/> <input type="radio"/>
Human & accurate healthcare	<input checked="" type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Self-tests at home	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/>
Overuse of healthcare	<input type="radio"/> <input checked="" type="radio"/> <input type="radio"/> <input type="radio"/>	Unified health record system	<input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/> <input type="radio"/>
Difficulties for minorities	<input type="radio"/> <input type="radio"/> <input checked="" type="radio"/> <input type="radio"/>	Digital research & development	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>

General attitudes

The survey respondents expressed beliefs that digital healthcare would result in positive outcomes. This belief was connected to a desire that digital healthcare should provide higher care quality, be provided by the state rather than private actors, and that the healthcare system otherwise would not be able to keep up with the development of society as a whole.

Contrary to their positivity, examples of individual concerns were whether digital healthcare would be good enough, that digital-only care would nudge citizens to seek care only for very urgent conditions, and the issue of cyber security. The latter was however mentioned as a societal problem rather than an issue isolated to healthcare.

[Digital healthcare] can definitely be a good complement. But on equal terms, not as now with all online doctors who do not have to take responsibility. They just do the simplest errands and drain the healthcare system of money. / Survey respondent

Fast & efficient healthcare

The survey respondents and citizens with asthma expect digitalisation to increase efficiency within healthcare. The expectation is related to their desire for time savings for both caregivers and patients, faster care for more citizens, that waiting times would be reduced for citizens who require on-site care, and that doctors would be able to help more patients given the same amount of time. To reach this with digitalisation, however, it was believed that communication and information is needed to become more accessible.

Individual examples of these desires are that digitalisation would enable citizens to better prepare for a healthcare meeting and increase efficiency of the meeting, a decreased need for physical visits by providing different means of contact and treatment (e.g. self-monitoring, remote meetings, and at-home tests). Furthermore, one individual with asthma expressed societal benefits on how remote healthcare meetings would not require you to deprioritise work and take a day off just to attend.

I expect less frequent physical contact with healthcare. I would think that most complaints can be resolved digitally, most questions can be investigated digitally. [...] Surely healthcare has better things to do than having lots of people in the waiting room, and it takes five minutes before every appointment and after every appointment for a person to go in and out of the room and they need to disinfect everything. I guess [digital contact] is great for efficiency, even for staff and their administrative work. Plus, I don't have to leave work when I'm so busy. I don't have to run to the doctor.

/ Individual with asthma

Human & accurate healthcare

The survey respondents raised concerns that digital contact with healthcare would limit the human and personal contact they desire. The concern is related to a worry that misdiagnosis would increase and their desire that digitalisation should ease and support, but never replace on-site care and meetings if requested. Although not to the same extent, the aforementioned aspects were also expressed by the citizens with asthma.

I think it's important with our human contact and I'm afraid that the world, and therefore healthcare, is becoming too digitalised.

/ Survey respondent

Individual examples of this concern include that it is easier for some to talk face-to-face, that health workers would be more prone to misjudge or even dismiss citizens' health issues, that technical and digital solutions should be complementary to meeting health workers, and the belief that health workers risk to misdiagnose during digital healthcare meetings.

[I think] above all that you might miss things. Now it's just video calls, but a friend with rheumatism had a video call with her doctor during the pandemic. Which meant that they missed that her joints had become so swollen, because she was so used to swollen joints and they could not touch and feel. That's one such thing that you absolutely should not miss. Those kinds of things, that you miss stuff, show that the physical meeting is so important.

/ Individual with asthma

Overuse of healthcare

The survey respondents expressed mixed concerns whether healthcare would be overburdened in the future, related to the belief that digitalisation could make it "too easy" to contact healthcare. Although not to the same extent, the aforementioned aspects were also expressed by the citizens with diabetes.

Individual examples of this concern are that citizens would seek care immediately instead of realising their health condition just required some time and self-care, and that anxious or hypochondriac citizens would be nudged to seek care for the slightest problem. An opposite example expresses how anxious citizens could receive swift advice that would reduce their anxiety and in the long run lessen the time and effort required from healthcare.

It worries me that anxious people can use digital resources to a much greater extent than they would have used physical care. It becomes too easy. People who otherwise would have thought it over for one day and then felt better. Now they can reach healthcare for the slightest symptom or feeling.

/ Survey respondent

Difficulties for minorities

The survey respondents and citizens with heart failure expressed concerns that digitalisation could marginalise citizens who for various reasons may have difficulty absorbing new ways of using technology. For example, people with less technical know-how, with cognitive disabilities, or people with physical disabilities that could hinder smartphone use. The elderly was also mentioned as a marginalised group, but also with the belief that the elderly population of the future will be more accustomed to digital tools.

There are those older than me who are not that technical. This can be problematic, but I think that many older people are actually very technical today as well, so it should work. / Individual with heart failure

Digital meetings to complement

Although both the care groups and survey respondents were positive on the prospect of more efficient healthcare, they expressed mixed expectations on digital healthcare meetings. For example, that remote meetings never could replace all physical meetings, but that it is a better alternative than nothing. The overall sentiment is that digital meetings are a great complement that should not replace physical meetings if desired.

They further expressed that digital healthcare meetings would be suitable for errands with conversational or advisory nature, and without requiring physical contact, or for simple questions and well-known simple diseases. This would relieve physical resources and provide more space for healthcare where on-site attendance is an absolute must, as expressed among the citizens with diabetes. One survey respondent specified that if certain symptoms require physical examination, it should be communicated clearly (e.g. through form or chatbot) so that a physical meeting can be scheduled directly instead of wasting time on a digital meeting. Individual mentions also include lessening spread of transmittable diseases if less people have to attend physically.

I think technology is so good today, and they take my illness so seriously, that I do not think it is a problem in using Zoom. I think that such meetings can replace some others so you don't have to visit and to relieve [the staff] from visits. But not all patients can have a meeting like this. For those who are able, it is super good to have it as an alternative. / Individual with diabetes

Remote prescription renewals

The citizens with asthma and heart failure expressed positive attitudes toward digital prescription renewals, mentioning time-saving benefits and that they expect it to go faster getting your new medicines. The survey respondents expressed this sentiment as well and also that digital meetings are especially suitable for prescription renewals that do not require physical assessments and instead are more of a conversation. However, it was noted that in-person reevaluation of medical needs is sometimes a must for verification, but that simpler tests and samples would not have to be conducted by health care clinics, but instead by smaller "test offices" in shopping centres and other locations.

Imagine they had a small 'sample site', where you can give a blood sample within five minutes instead of having to wait at a primary care centre for half an hour because everything is delayed. Leave some blood, talk to the doctor and all that stuff. To exclude much of that time on your part by just doing the sampling by talking on the phone [with health workers] and then go there [to the sample site] and go back home. That is good and then you could work more.

/ Individual with asthma

Self-tests at home

All care groups expressed expectations and desires for more at-home tests and self-care at home. The citizens with milder asthma specifically expected spirometric devices for personal use and imagined how remote assessment could be enabled by new ways of measuring lung capacity (e.g. by sound volume or breathing time). The citizens with heart failure mentioned the time benefit of assumed new technology that would allow remote scanning of the heart, both during video calls with healthcare and in general to gain better self-insight. The survey respondents also expressed this expectation, in terms of both self-care and self-monitoring.

However, this expectation appears limited to less invasive body interventions. For example, even though the citizens with diabetes are measuring their blood sugar regularly, they expressed not wanting to take blood samples nor to perform surgery on themselves at home.

Our phones will only become more and more advanced and I would not be surprised if in the future I could put my phone towards my heart, which then sends an inner image to my doctor that she then can analyse. Or that I can connect myself in a way that they could see my heart. [...] I would not have to go there and lie down on a bed, which takes an hour, but instead I might sit with the phone over my heart for 10 minutes and be done then.

/ Individual with heart failure

Unified health record system

The survey respondents and citizens with asthma and diabetes expressed a desire for a more unified digital experience relating to partaking in health records (Swedish: *Sjukvårdsjournaler*), booking appointments and contacting healthcare. This combination was expected to improve continuity, follow-up and to swiftly receive and access your health results e.g. after examination.

Relating to a joint booking system, individual mentions express the ability to find time slots by competence rather than by care centre, and to spend less time navigating between different booking systems in search for available time slots. Furthermore, it could more evenly distribute bookings between primary care centres. As for health records, individual examples expressed benefits such as feeling more in control, having a better overview of your medical and healthcare history, and the belief that such a system would facilitate the work of health professionals.

Now I have separate documents. Like, I have a list of all the medications I have ever taken, when I started, when I stopped. Because otherwise a doctor will come and ask 'Have you tried this?' And then [I'll answer] 'Yes, it sounds a bit familiar but it was like 2015' and there is no chance that I remember why I did not continue using it. It may possibly be written in a journal very far away, but you will certainly not find that one.

/ Individual with asthma

Digital research & development

The survey respondents expressed expectations that healthcare could be improved with the use of AI as a complement and support to doctors. For example, automatic diagnosis for simpler wounds and diseases by means of image recognition, but also as a support for a doctor to make more informed decisions in more advanced cases. Additionally, robots as replacement for health workers were mentioned, accompanied by scepticism toward their contemporary abilities and competence but without ruling out an acceptable improvement in the future.

Expand investments in AI as a complement to and support for doctors. Start where it has proven most useful, such as diagnosis of X-ray.
/ Survey respondent

5.2.5 Data collection and sharing

This category of themes concerns expectations related to collection and sharing of health data, and the use of IoT, see table 5.6.

Table 5.6: Themes concerning health data and IoT.

Meaningful purpose		Minimalistic & automatic	
Secure data sharing		Custom & justified	
Transparent collection		Personalised & limited feedback	

Meaningful purpose

All of the care groups expect that data collection and sharing will and can be used to improve the prerequisites for diagnostics and individualised treatments. Furthermore, they had a positive attitude towards the collection of health data, in order to improve life for themselves or for others who benefit from their health data in the long run. Although not to the same extent, the survey respondents also expressed the same expectations and attitudes.

Individual survey respondents expressed a positive attitude through their belief that data collection would lead to improved self-monitoring, time-savings, more efficient follow-up meetings, and that it would be especially feasible within cardiology. It was also expressed that data collection and sharing would lead to more cost-effective healthcare and free up resources for evaluations and treatments. Additionally, an expectation was that the public would want to have better knowledge and keep track of their own health and that data collection would facilitate early discovery of serious illnesses. In contrast, concerns were also raised regarding whether technology can provide a holistic view similar to the abilities of doctors.

If it can sort of give me suggestions on how I should structure my day, or what I should eat or whether I should move around more, or things like that, then I am positive about it. But if it's just to collect data to a registry or something, without me knowing if it's going to be used for anything, then I feel a little like 'Okay, but why, just what the hell, why then?'. [However] if I only knew it would be used for research, then it's totally okay too.
– Individual with diabetes

Secure data sharing

The care groups and survey respondents expressed expectations on data security related to data collection and sharing. While leaning towards positive attitudes, their expectations were divided and conflicted, both among and within them. For example, one survey respondent expressed that data sharing would not be legal nor fulfil patient safety while also believing that citizens would not care since all kinds of data is already collected from them by the online ad-industry.

Sure, in a way, it's a little scary to post about your life online as you normally do. But still, we are monitored in society anyway. If I am to have a good life and be able to live well, I'll have to take the blow and be connected with my pump. [...] I've been thinking that it is not the kind of data with facts [about my life] either, so no, I'm likely not worried about it. / Individual with diabetes

Furthermore, some survey respondents expressed that Sweden is a secure country to share data in. They believe that data security is crucial to feel safe and have a positive experience with data collection. Individual examples of their belief are to not collect any unnecessary data, and that data is shared only with caregivers and not any third parties. Another aspect that was mentioned was that some citizens might “cheat” with the data collection and share the wrong information with healthcare.

Being arbitrarily monitored by Google, Apple, Amazon, Facebook and others is a problem for me. If I knew I was sharing relevant data of mine only with the caregiver, then that's a different matter. / Survey respondent

Transparent collection

Related to data security, citizens with asthma and diabetes expressed the importance of data collection transparency and free choice. Individual examples of this desire are that they, as users of health-data collecting products, should be able to easily find out what data is being collected and shared about them and be able to opt out. Furthermore, there was also a desire for the ability to choose what data is collected and decide when this data is shared.

Then I want to know 'Okay, but if you do this, what does it result in for me?' or that you tell me what I can use this for? / Individual with diabetes

Minimalistic & automatic

Relating to data collection tools, citizens with asthma and diabetes desired minimalism for such products so that they would be portable or comfortable to wear. Furthermore, if the technology was to be put on their body, it was desired to be put at one and the same place on your body.

There was also a desire to be able to use products already in use for other purposes, for example training equipment or your smartphone, so that they do not have to acquire additional products for data collection solely. Although not to the same extent, the citizens with heart failure also expressed the same desire in terms of incorporating new medical functionalities into the technology they are already using.

Wearing a [health device]? Bringing it with me? It should be minimalistic! As minimalistic as possible is better. / Individual with diabetes

In addition to the aspects of minimalism and multi-purpose, it was also expected that data should be collected automatically. This expectation is related to their desire of not wanting to use a measuring device and then manually having to fill in the data in a system.

It becomes this big thing, like having a burglar alarm at home. I like the idea of keeping my house safe. I do not like having to pick up and enter a code every time we go through the door, because then the benefits do not outweigh the frustration each time that I use the front door.

/ Individual with diabetes

Custom & justified

Similarly, the survey respondents expressed a desire for data collection devices to be simple, comfortable, easy to use, as well as being voluntary with personalised settings. They also showed an awareness that their current health condition may not justify collecting health data. For example, expressing aversion to attaching devices through their skin while at the same time expressing openness to use such devices in the future if they were diagnosed with a chronic disease, for example.

Since I don't have diabetes today, for example, I do not want a needle or tube into my body. That will probably change if it is an option for me that would facilitate my treatment and handling.

/ Survey respondent

Personalised & limited feedback

All care groups expressed a desire that their data collection devices should offer them personalised insights and tips if it can be offered in a scope that suits them. Their desire is related to a fear that being fed constant and unfiltered feedback would cause themselves unnecessary worry. They expressed that even small deviations would become a big deal, creating an obsession to be perfect, which in turn might affect their health more negatively than the intended benefits of the feedback.

[I think] that it can cause anxiety as well when you start to measure and register. [...] I have also observed myself that noticing things makes them also appear bigger. [...] So if you register every time that you feel bad, you will feel worse than you otherwise would.

/ Individual with asthma

This fear was also expressed by the survey respondents, in terms of feedback becoming a burden and an obsession on values. Individual examples of this fear are that people with health anxiety would have trouble interpreting feedback in a constructive way, but also that it would induce control issues in the average citizen. They believed overall that the feasibility of health feedback from data collection devices would be dependent on the individual's physical and mental health condition (e.g. having a "strong mind") and that it would be important that health data should not be analysed and interpreted in-private by the user.

I could handle this, but how do these aids affect people with health anxiety? I would have liked to avoid going to the hospital, but some need physical contact and someone who calms them down and talks to them. Health literacy is important if we are to have aids to measure at home. Managing and interpreting measured values in a healthy way needs to be checked beforehand. I'm thinking that extreme health control issues can increase.

/ Survey respondent

6 Future direction

This chapter answers to the second objective of this thesis. It begins with insights and considerations on how to address citizens' expectations, followed by scenarios that illustrate meaningful interactions between citizens, healthcare and digital services.

6.1 Influences on expectations

There are differences between what areas of expectations that were mentioned between the studied user groups, and they can mainly be seen between the care groups and the survey respondents. The care groups expressed expectations in close connection to their respective chronic disease and accumulative experiences from living with it. The survey respondents, on the other hand, expressed themselves in broad terms with less detail and more frequently about political issues than the care groups. An interpretation of this difference is that if your health condition results in more continuous contact with healthcare, you become more familiar with navigating the healthcare system, and will have more detailed expectations.

Between the care groups, the citizens with asthma expressed to a larger extent the same expectation-areas as the survey respondents while the other care groups did not. One interpretation is that the beneficial experience that citizens with diabetes and heart failure get seem to have a notable effect on their positive attitudes towards digital healthcare and health data collection. That is through a current treatment practice that includes more frequent interaction with healthcare in combination with more developed self-care strategies with successful incorporation of healthcare technologies.

In summary, the expectations between user groups appear to vary based on three main factors: self-image in relation to health condition, associated with willingness to adopt digital healthcare services; degree of interaction with healthcare, associated with how well an individual navigates within the healthcare system; and previous meaningful experience of collecting and sharing health data with healthcare, associated with willingness to use digital healthcare technology and share such data.

6.2 Addressing expectations

This study elicited a great amount of expectations on future digital healthcare services. To address them and provide actionable directions for future work, 10 overarching areas to consider are presented below related to the ambitions of SU. They relate to early discovery or prevention by improving either citizen's interaction and communication with healthcare or citizen's experience with digital healthcare technology and IoT.

6.2.1 Interaction and communication with healthcare

The areas within interaction and communication with healthcare relates to proactive healthcare, individualised healthcare, quality in remote meetings, easier ways of contact with healthcare and an improved 1177 app and web experience (figure 6.1).

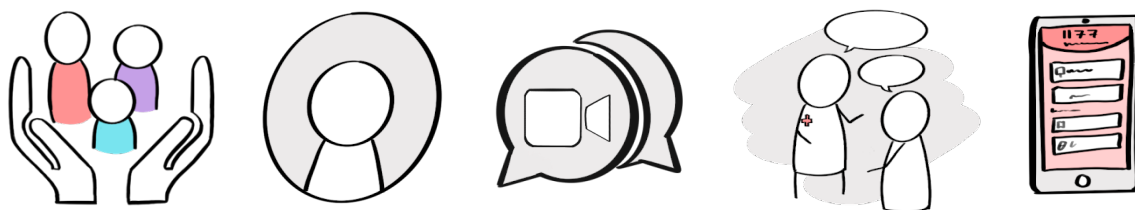


Figure 6.1: Icons representing the first five areas of considerations.

1. Transitioning to a proactive healthcare

The study indicates that citizens have a strong wish for healthcare to be more proactive in the future, primarily in terms of having a healthy lifestyle, including eating habits and exercising. Although citizens are aware of healthy habits, there seems to exist a gap between knowing and actually doing, where the underlying reasons for this gap could be many. It could relate to lack of knowledge: how to exercise in relation to your health condition, what food is healthy; lack of resources: time or affordance for gym classes and nutrient food; or a personal lack of motivation: “Changing my lifestyle wouldn’t benefit me”.

- *How could healthcare provide the correct prerequisites for citizens to engage in physical activities and healthy eating habits?*
- *How can healthcare support people to perform lifestyle changes and other proactive self-care practices by other means than just general advice?*

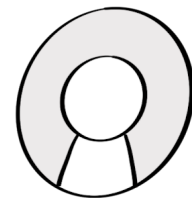


2. Transitioning to an individualised healthcare

The study suggests that citizens desire for healthcare to shift from rather standardised diagnosis-based treatment toward more focus on the individual, given their health condition and personal prerequisites. One believed way to achieve this was to have a “house doctor” or consistent healthcare contact, that could keep better track of an individual patient’s health record and care needs as a whole. This could prove especially useful for citizens with long-term conditions, such as a chronic disease.

However, meeting the same health worker is likely not desirable or necessary for all errands. Instead, there may be times when the need for quick help in occasional concerns could be considered more important.

- *Which kinds of errands would benefit from citizens meeting the same health workers over time, and why?*
- *Which kinds of errands would suffice with irregular healthcare contacts if they were supported by, for example, a more convenient and unified health record system?*



3. Assuring quality in remote healthcare meetings

Digital meetings were strongly believed by citizens to primarily function as a complement to the physical ones. An emphasised aspect was that the digital meetings could lead to impersonal and less qualitative healthcare. This indicates a need for quality assurance and a feeling of being taken care of, something that the study shows to be associated with the more personal and physical meeting.

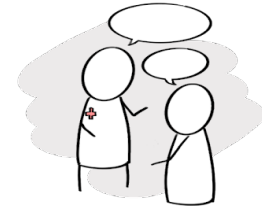
- *Under what conditions could digital meetings be perceived as personal and of high quality?*
- *What kinds of meetings are beneficial respectively problematic in a digital setting, and under what conditions?*



4. Lowering the threshold to contact healthcare

According to the study, citizens desire an increased variety of contact routes where one can use the most suitable one for the specific errand. Since not being able, by any reason, to get in contact with healthcare could hinder citizens from even getting treatment, this is an area of high relevance for early discovery of diseases.

- *How can citizens quicker be guided to the right person or place?*
- *What means of oral, written or other communication is appropriate for different kinds and complexities of errands?*



5. Improving the 1177 app and web experience

The Healthcare guide 1177, both its app and web interface, emerged in the study as non-user friendly, primarily because of poor prioritisation of what functions are presented and how, requiring too deep navigation to get to the right place and lacking consistency between web pages of different care units. This causes confusion and frustration when navigating through the site and having to click back and forth while also having to remember where to find specific information or functions.

On the other hand, the study shows that citizens desire to gather more healthcare services in the 1177 app. For example, when taking a vaccine at a specific care centre (e.g. at a private clinic or in a different region), this data should be included in the one and the same health record and not only reachable from the specific care centres' app or website.

- *What critical functions and personal data do users of the Healthcare guide 1177 want to have within convenient reach?*
- *How could systems from different actors, such as health records, be merged so that users only have one interface to interact with?*



6.2.2 Digital healthcare technology and IoT

The areas within digital healthcare technology and IoT relate to acceptance of data sharing, sensitivity of health data, convenient device design, feedback from devices and supporting the self-care of citizens (figure 6.2).

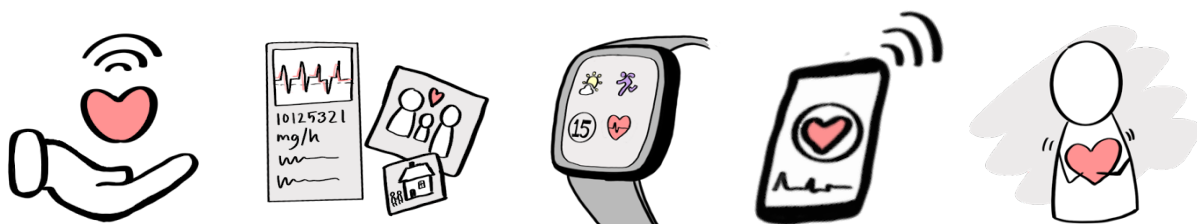


Figure 6.2: Icons representing the last five areas of considerations.

6. Making health data collection and sharing accepted

When health data is collected and shared, citizens seemingly agree that it needs to have a clear purpose and meaning to be acceptable. For the citizens with diabetes, whose daily treatment highly centres around and requires health data collection, the purpose and usefulness is clear, and it was also this group that expressed most positivity towards such practices.

Citizens with asthma and heart failure could also see a benefit from continuous health data collection, to provide healthcare more support for evaluation and improved long-term treatment, while they had less experience and expectations on how such collection would affect their daily self-care. Likewise, citizens who consider themselves healthy, and rarely are in contact with healthcare, personal benefits are not as obvious, other than providing data that in the long run could benefit R&D within healthcare.

- *What determines whether collecting and sharing health data is more or less acceptable from the perspective of citizens?*
- *What is a meaningful purpose of health data collection for seemingly healthy citizens with little healthcare contact, and how can this be conveyed to them?*



7. Mapping what health data is seen as sensitive

Citizens with chronic diseases generally tend to have a very positive attitude to share health data with healthcare, with the presumption that the benefits outweigh the possible risk of the data ending up in the wrong hands. On the other hand, it was clear that their positive attitude was associated with sharing a certain type of health data, primarily centring around measured values linked to their respective disease (i.e. blood values, heart rate or lung capacity). As such, the study indicates that expectations on health data collection and sharing is affected by the kind of data that is collected, and whether an individual considers it more or less sensitive to share.

- *Which kinds of health data, and for what purposes, are citizens okay and not okay with sharing?*
- *How do attitudes towards sharing behavioural data compare to attitudes towards sharing measurements of bodily parameters?*



8. Designing convenient devices for health data collection

The results suggest that citizens have more positive attitudes towards devices for health data collection the less body-invasive they are and if their health condition justifies it. Although implants require surgery, they were expressed as less invasive than devices attached as an “open wound” on the skin, for example, with needles or tubes.

An observed consensus was that data collection should be as automated as possible. Citizens do not want to spend their time manually filling in or interpreting their health data, as this would become a burden that may outweigh the benefits of such practices. Using already owned consumer products for data collection, both continuous and occasional, is desired by citizens, but given their wish for equal care, such devices should also be provided by healthcare if needed.

- *What health data, that today requires surgery, could be collected in new ways with non-invasive technology?*
- *What health data and self-tests could be collected and conducted by devices that consumers would already own anyway?*



9. Evaluating an adequate level of feedback from data collection

One uniform opinion among citizens concerned feedback communicated from health data collection devices. While citizens could see the benefits of getting feedback from healthcare technology to improve their health in one way or another, they were also very aware that constant feedback can lead to paranoia and anxiety if the device would show less than ideal body values.

- *What kind and level of device feedback is appropriate for each individual?*
- *Should feedback be provided by the device or a healthcare worker depending on the implications of the feedback?*



10. Supporting self-care through technology

The findings suggest that the current treatment with digital technology for citizens with diabetes and heart failure empowers them to become more independent in their self-care practice and to spend less but more meaningful time interacting with healthcare.

In contrast, citizens with severe asthma appear more reliant on having on-site access to competent staff in making sense of their complications, as they were the only care group to express expectations relative to waiting times, staff competence and working conditions. The interpretation is that with the use of digital healthcare devices, citizens with other chronic diseases, like asthma, could benefit from similar healthcare and self-care practices to better predict, prevent and treat complications.

- *How could technology enable independent self-care practices for other patient groups and citizens in general?*
- *What personal or disease-specific biometric value distinguishes each patient group, and how could it improve their self-treatment if monitored?*



6.3 Scenario on future digital healthcare

This section describes a scenario, in two parts, for how the healthcare experience, as part of a citizen's self-care practice, could be in the near future. The scenario emphasises benefits and general ideas based on the insights from previous chapters. Details on how to fulfil and deliver those benefits are left to investigate in future work. To assist such efforts, the scenario is accompanied with a list of key elements determined to be valuable components (see tables 6.3 and 6.4). The scenario describes Alva, a fictional character who recently moved from Knivsta in Region Uppsala to Lerum in Region Västra Götaland. She has no chronic diseases as far as she knows. That said, the scenario aims to improve the healthcare experience for any citizen, despite health conditions. Part one is about how to conveniently get in contact with healthcare, while part two is about how digital healthcare services enable efficient healthcare meetings.

6.3.1. Convenient contact with healthcare

Alva experiences a health concern and wants to contact healthcare. When signing in to the Healthcare guide 1177, it looks the same as she would expect it, despite having moved from another region recently: The main page has a glanceable overview of different features, from which she can select between means of contact that best suit her. Her concern is not urgent, so she selects to send a chat-message. Since Alva has self-documented her concern with pictures and comments in the 1177 app, she attaches the entries to her message before sending it. While she is tending to her daily activities, her message is examined, after which she receives a notification encouraging her to book an on-site appointment.

When clicking the encouragement, Alva can view available time slots for clinics that were determined suitable for her concern. She can filter based on desired time and meeting format, and decides to filter for afternoons in the next two weeks. A few time slots show that Michael – a health worker Alva previously has met – is available, so Alva selects one of those time slots. When booking the appointment, Alva writes a few questions in the appointment's agenda template. Ahead of the appointment, Michael is able to prepare himself by reading Alva's proposed agenda as well as her nationwide health records.



Table 6.3: Key elements to enable convenient contact with healthcare.

UNIFORM app/web experience

- Glanceable overview of appointments, prescriptions, health record
- Uniform placement of functionalities and e-services for care unit pages
- Uniform text on info-pages combined with dynamic text fields adapting to the region in Sweden
- Access to nationwide health record system
- Centralised appointment interface to reach any care unit

VARIED means of contact

- Asynchronous chat with healthcare staff, not requiring active waiting
- Screening or diagnosis by sending pictures to healthcare for analysis by person or AI
- Advice and precise referrals by answering multiple-choice questions by AI-chatbot

PERSONALISED app & webb booking

- Select preferred time slots for appointments based on e.g. date, care unit, meeting format
- Highlight appointment time slots with previous healthcare contacts
- Prompts for on-site appointment if physical examination is required
- Patient-influenced appointment agenda

INDIVIDUALISED app web functions

- Integrated self-documentation of health concerns
- Optional notifications for medication and to renew prescriptions
- Automatic and remote prescription renewals for patients with stable chronic conditions

6.3.2 Efficient healthcare meetings

It is time for the appointment that Alva scheduled with Michael. During the appointment, Alva describes her concern and how it has changed over time. After discussing the matter, including the questions that Alva added to the agenda, they agree that they would better understand her health concern if they kept track of her heart rate and sleep for a while.

Although Michael could have provided Alva with a measuring device, the smartwatch that she already owns is suitable for the intended purpose and Michael proceeds with instructing her on how to initiate continuous measuring and data sharing. However, Alva explains that she may become a bit paranoid if she pays too much attention to the measurements, so Michael helps her to restrict the ability to inspect the measurements. Alva feels relieved.



Before ending the appointment, Michael and Alva scheduled a remote follow-up appointment three weeks later since they felt it wasn't necessary to meet in person just to discuss the measurements. Michael describes that she'll have to leave a blood sample to support the assessment, and that she can do it conveniently at a local test centre. When Alva has left, Michael appends his own comments to the appointment agenda and updates Alva's health records.

Two weeks later, Alva remembers the blood sample while at work. Using the 1177 app, she finds a nearby pharmacy that acts as a test centre, where they can take the sample and forward the results to Michael. Alva enjoys that she can take a short break, and basically walk in and out of the pharmacy.

During the follow-up appointment, Alva and Michael discuss the measurements of her heart rate and sleep along with the blood values. Based on the measurements and joint discussion, the underlying problem is identified and they set out a treatment plan appropriate for Alva, given her lifestyle and preconditions.

Table 6.4: Key elements to enable efficient healthcare meetings.

MINIMALIST device design

- Ability to measure multiple biomarkers to lessen need for multiple devices
- Ability to measure biomarkers with already owned consumer products
- Possibility to borrow devices from healthcare if needed
- Leverage less body-invasive measurement methods
- Custom and limited feedback to prevent health paranoia

AUTOMATIC device interaction

- Automatic measurements as much as possible
- Ability to share data automatically from device

PURPOSEFUL device collection

- To support self-care practices of ill or seemingly healthy individuals
- Optional ability to share data for health research

ACCESSIBLE test centres

- To conduct tests not appropriate as self-test, e.g blood or urine samples
- For quick tests that does not justify long waiting times
- Provides flexibility by offering drop-in or booking at one of several locations

SUPPORTIVE test centres

- To complement digital or on-site healthcare appointments, either prior to or after
- Frees up time for discussions during healthcare appointments
- Support fast access to typical medication and treatment for chronic patients

7 Discussion

In this chapter, the thesis is discussed from two main perspectives, including recommendations for future research. The first perspective centres around the results and the second highlights ethics and sustainability concerns.

7.1 Results

This thesis is characterised by exploration and is designed to support Sahlgrenska University Hospital's ongoing discussions and upcoming work to develop digital healthcare services that could ease healthcare of the increased pressure it faces over time. In chapter 5, the thesis provides a holistic foundation for discussion on how to proceed based on citizens' own hopes, fears and ideas on future digital healthcare, and maps out areas that form the basis for future work in chapter 6. Although the scope of this thesis has been within early discovery and treatment with digital technology, the foundation in chapter 5 is expected to provide opportunities for further development within healthcare as a whole.

7.1.1 Applicability of results

Chapter 5 presents expectations on digital healthcare divided into themes, where each theme conveys the hopes, fears and ideas expressed by the study participants. The chapter includes a user profile, for citizens with asthma, diabetes, heart failure and citizens in general, that describes the average self-care practice and how they differentiate from each other.

The results in this chapter are intended to represent the voice of the participants without adding interpretations. Besides expectations related to digital healthcare services, the chapter includes themes relating to future healthcare as a whole. The reason for this was to encourage a holistic mindset, with the belief that the healthcare system first and foremost must be seen as a whole and be designed for as a whole in order for changes, for example in digital healthcare, to become improvements.

Although the themes are influenced by the scope of the thesis, the content of each theme is considered universal and useful for future work within different areas of healthcare. For example, it can be considered a pool of different opinions and thoughts on future healthcare, providing the possibility to explore themes or subthemes to investigate further. The results also reflect findings from the literature review, that citizens favour public over private healthcare and that digitally experienced citizens are more positive towards digital services.

Chapter 6 presents directions for further development of digital healthcare, with a focus on early discovery in terms of data collection and contact with healthcare. The directions are presented in terms of topics and reflective questions to consider, a scenario that presents several of these considerations in a contextual setting, and tables of key elements to include in future digital healthcare services.

Presenting the results this way was considered appropriate for two reasons: adaptability and actionability. The chapter is intended to stimulate reflection and critical thinking while presenting possible opportunities. Formulating the directions as questions allows for SU to adapt their answer to said questions depending on the context and decision level. Similarly, presenting a scenario avoids discussions from getting stuck on the feasibility of minor details. It instead allows teams at SU to use their experience, imagination and research to reach conclusions about appropriate ways to deliver the described benefits in the scenarios.

Altogether, the applicability of the results in both chapters are enforced by one another, of which the former gives insights into *the why*, and the latter gives insights into *the what*. The strength of the thesis lies in not stating specifics on "Do this", but instead asking "How can you do this?" and illustrating why the question is relevant to ask.

7.1.2 Research approach

The application of practice theory, for the purpose of the thesis, proved to be a suitable means of designing and structuring data gathering and analysis. It provided a framework of elements (i.e. images, skills, stuff) that facilitated deeper and comparative analysis on how self-care practices differ between user groups relative to their health condition and experience with healthcare. Furthermore, it provided a good foundation to analyse what aspects may influence citizens' expectations toward digital healthcare services.

The shortcomings of the framework is that it becomes less applicable with less specific practices, which "self-care practice" proved to be. Especially, the study shows that there are plenty of practices contained within self-care practices, such as practices for medication, exercise, diet and practices surrounding strategies on how to avoid complications for a specific chronic disease. What this meant for the study was that the user profiles about self-care, for example, had to be expressed on a less detailed level to not become overly complicated. However, it is clear that more nuances could have been uncovered if a specific practice would be explored in detail, although that would have impeded the holistic scope of this particular thesis. For future research and application of practice theory, it is recommended to carefully define a decent level of practice in line with the study's purpose and scope.

7.1.3 Qualitative and quantitative

The user studies resulted in large amounts of data, both qualitative from the interviews (n=15) as well as quantitative from the survey (n=100). While the questions in the interview and survey template were made to reflect one another to elicit expectations and self-care practices, the interviews resulted in more in-depth and detailed answers, centred around the participants' chronic disease and related experience with healthcare.

On the other hand, the survey respondents, who did not have a specific health condition in mind, expressed their self-care and expectations on a more abstract and political level. Naturally, and because there were more participants in the survey than in the interviews, this also resulted in a large variety of self-care practices as well as mentioned areas of expectations among the survey respondents. This complicated a direct comparison between the care groups and the survey respondents. For example, survey respondents mentioned more trivial aspects of self-care (e.g. using a toothbrush) that the care groups likely also would have mentioned if they had not focused on their disease.

Thus, it is important to be aware that even though a specific user group did not mention anything relating to a certain theme, it does not mean they do not hold opinions within that area. Instead, and given the open-ended nature of the questions, themes reflect the areas of interest most prominent to the participants. Given this and the explorative nature of the study, it was considered important to present the width of expectations in the resulting themes.

7.1.4 Sample of participants

While attempts were made to recruit participants within the intended age range 25-44, four of the five participants with heart failure were older than 44 years. This reflects the reality that the disease is uncommon at younger ages. Consequently, it makes sense that expectations related to accessibility for minorities, including elderly, were prevalent among the participants with heart failure. As assumed, the older participants also had a tendency of being less detailed in their expectations towards digital healthcare services.

While no other variation has been observed which could have affected the overall result, the study does not claim to be free of other influences, such as differences in semantics and

subtle nuances in expression between participants. At the same time, it would be complicated to discern whether such differences would be due to age or other factors, which is why such analysis is considered out of scope for this thesis. The assessment is that the influence, given that the rest of the participants are within the intended range, does not affect the study negatively.

In terms of representation, it is worth mentioning that participants with asthma showed less interest to participate in the study. Despite open requests through different channels, the interest was far less than for participants with diabetes and heart failure. Similarly, all the participants with diabetes have type 1 and not type 2 even though the study did not favour one condition over the other.

A speculative thought is that the level of interest from citizens with milder asthma and type 2 diabetes is associated with the comparatively non-severe nature of their disease that implies less urgent need for improved treatment. In other words, there is less motivation or value in participating in a study, which was also mentioned explicitly by one participant. The effect on the study, however, is considered to be negligible.

7.1.5 The term “*Digital healthcare*”

In connection with the user studies, it was evident that the findings were influenced by the respondents’ perception of *digital healthcare* and its meaning. It was noted that this perception to a high degree centred around digital healthcare *meetings* (i.e. video calls between doctor and patient), and activities related to this, such as getting in contact with healthcare, appointment bookings and prescription renewals.

The word *digital healthcare* did not spontaneously make the respondents think about physical medical products, for example an insulin pump or a pacemaker, even though the modern ones can be digitally connected to the internet. One possible reason might be the recent pandemic, during which video meetings have been a part of daily life; for work and education or as a way to socialise at a distance. Due to these experiences, the concept of video meetings in healthcare is something tangible and easy to have concrete opinions about.

Another reason might be that the word *healthcare* per se is more associated with the interaction with healthcare, rather than the treatment itself. Efforts were made during the interviews, by probing and giving examples, to widen the respondents’ perspective on digital healthcare when asked “*What are your expectations on future digital healthcare?*”, but they quickly fell back to meeting or interaction-related issues.

A third reason may be that all but one question were open-ended in nature, which was intended in order to find spontaneous hopes, fears and ideas. However, the combination of the individuals’ limited conception of digital healthcare and open-ended questions resulted in answers related to their conceptions.

This is evident as answers and expectations got more specific about data collection and sharing as part of IoT when participants were asked a specific question about that subject. Thus, it indicates that people do have expectations on digital healthcare other than meetings and interaction, but it appears difficult for them to think outside their current mental model. Utilising more specific questions could have helped. However, it is a fine line to balance between leading and exploring.

All in all, there is a risk that all of the aforementioned factors have tinted the result towards a focus on digital meetings and interaction with healthcare. In other words, more nuanced and detailed expectations regarding other areas of digital healthcare are likely to exist but have not been elicited by this study.

For future research to find out more nuanced expectations, that includes a broader perspective on digital healthcare and its possibilities, it is important to not ask general questions and to make sure that the concept of digital healthcare is explained properly. Showcasing provocative prototypes (“provotyping”), or just focusing on specific technology could be beneficial in order to elicit expectations that go outside the respondent’s current mental model of what digital healthcare is.

7.2 Ethics and sustainability

While this study suggests that digital technology can empower citizens to act on their health, the findings also emphasise healthcare as a social interaction between citizens and health workers – to be heard, seen and felt cared for – if so desirable.

Wanting social interaction with healthcare varies from person to person and is, as shown in this thesis, partially associated with the severity of their health condition. Similar to how on-site care should be a consistent option for citizens who desire it, citizens should be asked whether they want to adopt digital self-care technology that could replace meetings and treatment together with health workers, unless it is the only viable option.

Besides social reasons, the mental state of individual citizens is another reason to provide optionality on digital self-care technology. The findings clearly suggest that people in general are self-aware about existing and possible paranoia related to measuring biometric data on their own – possibly thinking too much about whether their measurements are in order. As such, the intended gains of having individuals independently measure and share biomarkers with healthcare should be weighed against the effect on their mental health. This is also why feedback from such measuring devices, at all or to a custom degree, is deemed critical to consider.

Measuring biomarkers also ties in to the fact that consumer products are increasingly able to measure biometric data. While this thesis suggests that healthcare should leverage the reality that citizens already use smart wearables in their life, future healthcare should not rely on citizens’ willingness nor ability to purchase such consumer products. If someone is recommended during consultation to use medical devices for self-care treatment, the devices should be provided by healthcare at all times to provide equal care. Furthermore, economical shortcomings should not make staff feel inclined to avoid lending such devices in favour of less viable options.

Other implications of digital healthcare services are related to environmental and economical sustainability. Digital means of self-care and healthcare contact allow development of health infrastructure that reduce citizens’ need for travel. For example, conducting self-care at home, and not necessarily having to take a day off to attend an appointment. However, if all citizens are to own digital health technology for personal use, the environmental impact would be significant. Consequently, escalating the integration and combination of healthcare technology into existing consumer products – or creating a minimalist equivalent to multipurpose smartphones – would appear more feasible.

8 Conclusion

This chapter presents conclusions based on the purpose of this master's thesis, which is to convey a better understanding of the Swedish citizens' expectations on future digital healthcare services with the aim to provide insights on how health concerns could be solved better and earlier through digital efforts.

This master's thesis conveys Swedish citizens' expectations on future digital healthcare services, and explores how their health concerns can be solved better and earlier through digital efforts that could ease healthcare from the increased pressure that an ageing population and a shortage of health workers entail.

By comparing the self-care practices and expectations of citizens, primarily aged 25-44, with asthma, diabetes, heart failure and citizens in general, the study showed that the expectations appear to vary between them based on three main factors: *self-image in relation to health condition*, associated with willingness to adopt digital healthcare services; *degree of interaction with healthcare*, associated with how well an individual navigates within the healthcare system; and *previous meaningful experience of collecting and sharing health data with healthcare and using digital devices*, associated with willingness to share such data. This has implications for how to address citizens with varying characteristics, but also that experience with digital healthcare services will become more uniform as generations grow older and bring their current experience with them.

The elicited expectations in the study constitute 34 themes and cover political context, organisational context, contact with healthcare, digitalisation, and data collection and sharing. To address the expectations, the study presents ten areas of consideration for early discovery and prevention; five for convenient healthcare contact and five for accepted health data collection and sharing. The overall implication is that no one, regardless of health conditions, wants more things to mind, carry or manage. Instead, future digital healthcare services should be uniform, minimalistic and automatic in design, as well as personalised, purposeful and supportive in order to facilitate proactive care among citizens. To illustrate these benefits, scenarios were presented.

The study points towards a future healthcare system that is easier to interact with, thanks to convenient digital healthcare services. While the convenience would nudge citizens to seek care to a larger extent in the short run, it would lay the ground for a more proactive healthcare system. In the long run, such a system would lessen the share of patients associated with complications that could have been resolved with early discovery and treatment of diseases.

To conclude, this master's thesis provides valuable insights that can support ongoing discussions and upcoming work to develop future digital healthcare services, and guide them towards solutions that will be more acceptable among citizens in Sweden.

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Appendices

- Appendix A: Interview guide
- Appendix B: Survey form
- Appendix C: Survey summary
- Appendix D: Workshop guide

Appendix A – Interview guide

This appendix contains the interview guide which was used to elicit expectations and self-care practices by citizens living with asthma, diabetes and heart failure.

Introduktion till intervju

Hejsan!

Vi är väldigt tacksamma för att du vill ställa upp på intervju. Vårt examensarbete genomförs på Chalmers i samarbete med Sahlgrenska, och som du redan vet undersöker vi vilka tankar och möjligheter som finns för att utveckla vården i framtiden, med tanke på digital vård. Med digital vård syftar vi till alla digitala hjälpmedel eller tjänster som exempelvis möjliggör att söka information, kontakta vården och genomföra vård på annat sätt. Det kan vara hemsidor, videosamtal, produkter, implantat eller appar. Intervjuerna genomförs med personer som lever med diabetes, men även med hjärtsvikt och astma, för att vi tror att ni som lever med dessa bär på värdefulla perspektiv som kompletterar varandra.

“Intervjun ljudinspelas för att kunna skrivas om manuellt till text. Vid avskrivning utelämnas sådana detaljer som annars identifierar dig som deltagare. Textmaterialet kommer sedan analyseras som del av allt intervjumaterial för att komma fram till övergripande insikter och slutsatser. När studien är färdig och administrerad, 20 september, raderas mail- och telefonkorrespondens samt individuellt intervjumaterial. Det vill säga, inga personuppgifter sparas. Examensarbetet publiceras i Chalmers databas för examensarbeten.”

Under intervjun vill vi att du i dina svar utgår från dig själv och dina erfarenheter från vården och att leva med diabetes/hjärtsvikt/astma. Vill du inte svara på någon fråga är det helt okej. Om du på någon fråga tänker att “Äh detta är en oviktig detalj”, så berätta gärna ändå eftersom det hjälper oss att förstå bättre. Vi är inte experter på ämnet, så som du är, så det är också viktigt för oss att ifall vi skulle uttrycka oss klumpigt får du gärna berätta det, så att vi kan göra om och göra bättre. Jag kommer att ställa frågor, medan Cedrik/Ellen kommer att anteckna samt flika in om något behöver förtydligas. Om du själv tycker att någon fråga är otydlig, eller om du bara vill ta en paus, är det bara att säga till.

Så, innan vi sätter i gång, har du några frågor eller annat som kan vara bra för oss att veta? [...] Då kör vi igång, och börjar vi med lite allmänna frågor.

Vad säger gruppen om sig själv

Berätta lite om dig själv!

- **Bakgrund:** Vad heter du, var kommer du ifrån och vad är du sysselsatt med? Hur gammal är du?

Då går vi mer in på din diabetes/astma/hjärtsvikt:

- **Erfarenhet:** Hur länge har du haft diabetes/astma/hjärtsvikt? När upptäckte du att du hade diabetes?
- **Tidig upptäckt:** Hur upptäckte du att du hade diabetes/astma/hjärtsvikt? (Var det du eller andra som kände på sig, uppmärksammade symtom, eller var det vid ett annat hälsobesök det framkom?)
- **Tidig upptäckt/Idé:** Om du hade haft andra hjälpmedel, hade din diabetes/astma/hjärtsvikt kunnat upptäckas tidigare?

Karaktärsdrag enligt POD – att leva IDAG

Så nu har du alltså levt med diabetes i X antal år, och då tänkte jag helt enkelt att vi går över till hur det har varit för dig och hur det är att leva med diabetes/hjärtsvikt/astma, vad det innebär för dig och din kontakt med sjukvården.

Praktik / Image: Hur är det att leva med diabetes/hjärtsvikt/astma?

- Hur tar du hand om dig själv?
- Vad gör du för att undvika komplikationer?
- Är det någon skillnad när du är hemma eller på semester?

Skill: Vad har du behövt lära dig för att kunna hantera eller bättre leva med din diabetes/hjärtsvikt/astma?

Stuff: Vad har du användning av som gör det lättare för dig att leva med diabetes/astma/hjärtsvikt?

- Vilka hjälpmedel använder du dig av för att ta hand om dig själv?
- Utöver <insulinpump osv>, har du några andra hjälpmedel?

Skill: Hur vet du att du mår bra? (t.ex. att ditt blodsocker är lågt eller högt)?

- Kan du märka att ditt tillstånd blir sämre utan hjälpmedel? Hur?

Stuff: Hur upplever du att kontakten med vården hjälper dig leva med diabetes/hjärtsvikt/astma?

- **Sensitization:** Vilken kontakt med vården har du? Vilka typer av besök?
 - Till vilka personer? Är det samma eller många olika?
 - Till vilka avdelningar? Är det samma eller många olika?
 - Hur ofta?
 - Bli du kallad till besök eller uppsöker du själv vården?
 - Vad använder du för att hålla kontakt med sjukvården?

Trend: Skulle du från din erfarenhet säga att sjukvården blivit bättre, sämre eller är oförändrad? På vilket sätt? Varför?

Historiskt: Hur var det att leva med diabetes/astma/hjärtsvikt när du var yngre?

Image: Vilka fördomar, positiva som negativa, upplever du att det finns kring att leva med diabetes/astma/hjärtsvikt? Hur ställer du dig till dem?

Förväntningar enligt ICE – att leva IMORGON

Nu tänkte vi fråga lite om dina tankar om framtidens vård.

- **Hopes:** Vilka förväntningar och förhoppningar har du på framtidens sjukvård i allmänhet och vården för diabetes/hjärtsvikt/astma i synnerhet?
 - *Probe:* Vad tänker du om framtidens digitala vård?
- **Fears:** Vilka orosmoln har du om framtidens sjukvård i allmänhet och vården för diabetes/hjärtsvikt/astma i synnerhet?
 - *Probe:* Vad tänker du om framtidens digitala vård?
- **Ideas:** Om du fick bestämma, hur skulle du förändra vården i allmänhet och vården för diabetes/hjärtsvikt/astma i synnerhet?
 - *Probe:* Vad kan vara bra att digitalisera - varför?
 - *Probe:* Vad kan vara dåligt att digitalisera - varför?
- **IoT:** Hur ställer du dig till att använda teknik som samlar in hälsodata och ger dig feedback, antingen direkt eller genom att vården tar del av dessa data?

Avslutande

Är det något mer du vill berätta, som du tycker vi borde ha frågat mer om?

Då är intervju slut. Den input du och andra har gett oss kommer vi använda för att kartlägga förväntningar som finns på framtidens digitala vård. I vårt arbete så ska vi baserat på det även komma med förbättringsförslag på framtida digital vård. Om tillräckligt många kan, så kommer vi presentera detta under en workshop om ett par veckor. Det kommer bli tre av er som intervjuats och en vårdpersonal som tillsammans får ge feedback. I vårt arbete kommer vi sluta på idéstadiet, då vi enbart ska inspirera Sahlgrenska, så om något av det som vi presenterar låter som en bra idé så får ni mer än gärna prata med andra om det.

Skulle du vara intresserad av att delta i denna workshop? [...] Med det sagt, Tack så himla mycket för ditt deltagande!

Appendix B – Survey form

This appendix contains the survey form which were used to elicit expectations and self-care practices from citizens in general.

Förväntningar på framtidens hälso- och sjukvård

Om enkäten

Tack för att du vill bidra med dina tankar kring framtidens hälso- och sjukvård!

Enkäten tar ungefär 14 minuter att genomföra och riktar sig till dig som är 25-44 år. Studien genomförs av oss, Ellen & Cedrik, som del av vårt examensarbete vid Chalmers tekniska högskola, i samarbete med Sahlgrenska Universitetssjukhuset (SU). Resultatet i sin helhet kommer SU ta med i sitt förbättringsarbete och de diskussionsforum de deltar i. Dina enkätsvar kommer analyseras som del av allt enkätmaterial för att komma fram till övergripande insikter och slutsatser. När studien är färdig och administrerad, 20 september, raderas individuella enkätsvar. Det vill säga, inga personuppgifter sparas. Examensarbetet publiceras i Chalmers databas för examensarbeten.

Genom att fylla i och skicka in denna enkät så godkänner du att dina svar behandlas enligt ovan beskrivning. Om du vill dra tillbaka ditt svar i efterhand, behöver du kunna identifiera dig själv. Du kan göra detta enklast genom att tillhandahålla en kopia av ett av dina fritextsvar, som vi kan matcha mot alla enkätsvar.

Om du har några frågor, kontakta Cedrik via cedriks@student.chalmers.se.

Med vänliga hälsningar,
Ellen och Cedrik

Bakgrund

1. Ålder *

- 25-34
- 35-44

2. Jag identifierar mig som *

- Kvinna
- Man
- Annan könsidentitet
- Vill ej uppge

3. Sysselsättning *

Du kan välja flera alternativ

- Studerande
- Arbetande
- Arbetssökande
- Sjukskriven
- Pensionär
- Annat
- Vill ej uppge

4. Lever du med en eller flera kroniska sjukdomar? *

"En kronisk sjukdom kan man oftast inte bli frisk från utan behandlingen går ut på att lindra besvären. Men sjukdomen kan vara tidvis återkommande, långvarig eller livslång" (från 1177)

- Ja
- Nej
- Vet inte
- Vill ej uppge

5. Är merparten av din kontakt med vården relaterad till din eller dina kroniska sjukdomar? *

- Ja
- Nej
- Vet ej
- Jag svarade Nej / Vet inte / Vill ej uppge på föregående fråga

Att ta hand om din hälsa

6. Hur god kännedom anser du dig ha om ditt eget hälsotillstånd? *

	Mycket god	God	Vare sig god eller dålig	Dålig	Mycket dålig
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Vad kan eller har du lärt dig för att bättre ta hand om din egen hälsa?

Ange ditt svar

8. Vad äger du eller har införskaffat för att bättre ta hand om din egen hälsa?

Ange ditt svar

9. Vilka rutiner har du eller vilka rutinförändringar har du gjort för att bättre ta hand om din hälsa?

Ange ditt svar

10. Vad signalerar för dig att det är dags att uppsöka vård?

Ange ditt svar

Din kontakt med vården

11. Hur ofta har du haft följande kontakt med vården under det senaste året? *

(Om du svarar via mobilen, klicka på varje punkt i listan så syns svarsalternativen)

	Flera gånger i veckan	Minst en gång i veckan	Minst en gång i månaden	Minst en gång i kvartalet	Någon enstaka gång om året	Aldrig
Söker hälsorelaterad information (<i>t.ex. via 1177</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ringer 1177 eller annan sjukvårdsrådgivning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Använder e-tjänster för vården (<i>t.ex. bokar tid, förnyar recept</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enstaka besök vid behov (<i>antingen på distans eller på plats</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regelbundna besök (<i>t.ex. årsbesök, på distans eller på plats</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. Hur har Covid-19-pandemin påverkat din kontakt med vården?

Ange ditt svar

Framtida vård

13. Vilka förväntningar och förhoppningar har du på framtidens vård?

Ange ditt svar

14. Vilka orosmoln har du om framtida vård?

Ange ditt svar

15. Om du fick bestämma, hur skulle du förändra vården?

Ange ditt svar

16. Vilka tankar har du om framtida digital vård?

Ange ditt svar

Digitala hjälpmedel


17. Hur ställer du dig till följande digitala hjälpmedel, i syfte att ge dig feedback om ditt hälsotillstånd för att du bättre ska kunna ta hand om dig själv? *

Med "att ta hand om dig själv" syftar vi till att förebygga eller lindra sjukdom genom att exempelvis uppsöka vård eller anpassa din vardag.

	Mycket negativ	Negativ	Varken positiv eller negativ	Positiv	Mycket positiv
Läsa på om råd och symtom på internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fylla i dina hälsovärden i app/e-tjänst (t.ex. ta kort, mäta puls)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Installera hushållsprodukt som mäter t.ex. ljudnivå, luft- och vattenkvalité i din bostad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mäta dina hälsovärden på egen hand genom produkter i hemmet, t.ex. våg, blodtrycksmätare eller smart-toalett	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Använda en produkt som mäter hälsovärden mot din hud (t.ex. smartklocka, pulsmätare)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ha en produkt fäst på kroppen som mäter hälsovärden, t.ex. genom en nål	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Använda en produkt som mäter hälsovärden via slang som kopplas in i kroppen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Operera in en produkt som mäter hälsovärden (t.ex. chip, implantat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Få hjälp av en robot hemma som tar prover på dig som vårdpersonal annars hade behövt genomföra	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. I allmänhet, hur ställer du dig till att använda teknik som samlar in hälsodata och ger dig feedback, antingen direkt eller genom att vården tar del av dessa data? *

	Mycket negativ	Negativ	Varken positiv eller negativ	Positiv	Mycket positiv
Inställning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Har du några kommentarer gällande digitala hjälpmedel? 

Ange ditt svar

Avslutande fråga

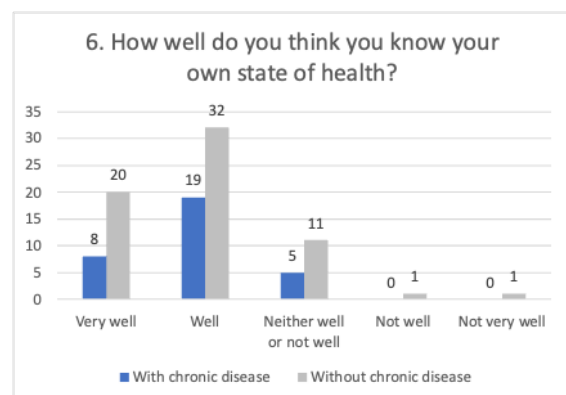
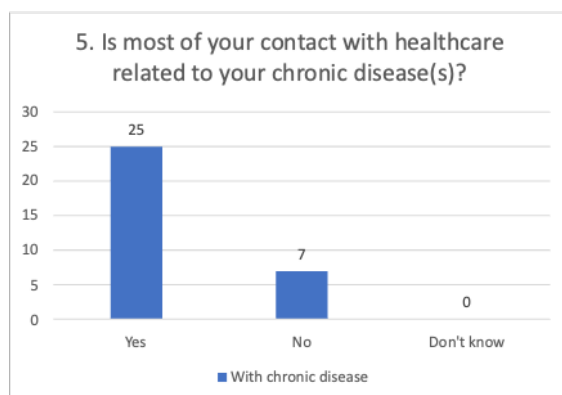
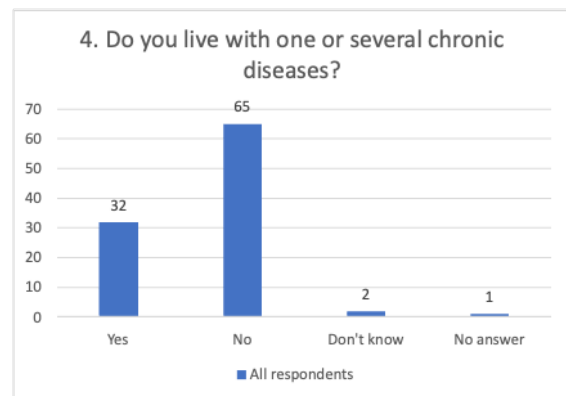
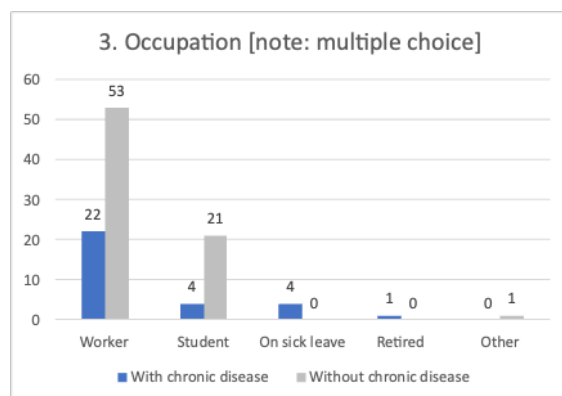
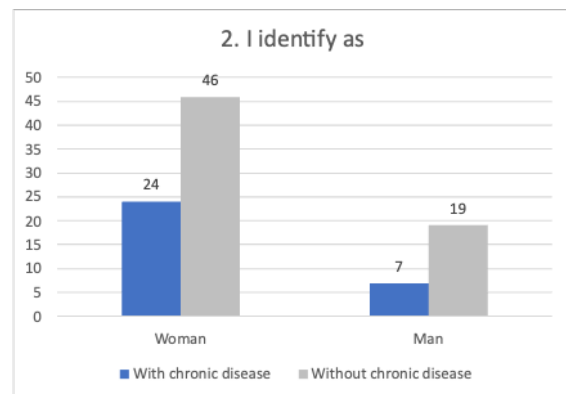
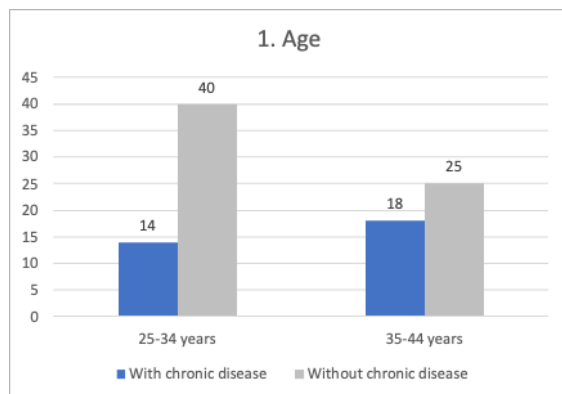
Detta är sista sidan. När du klickar "Skicka" så skickas dina svar in till oss.

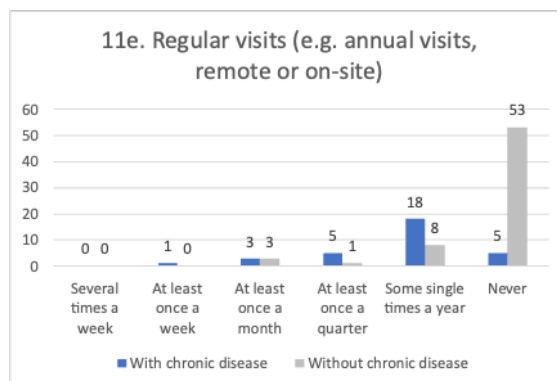
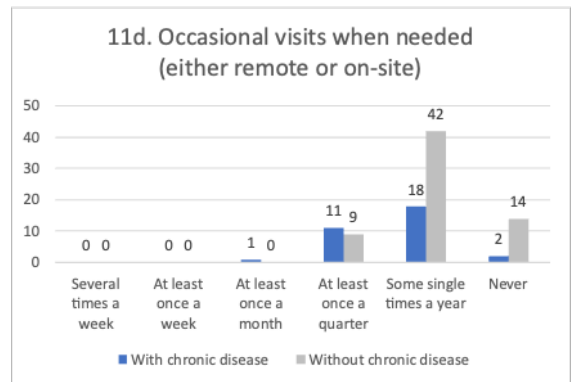
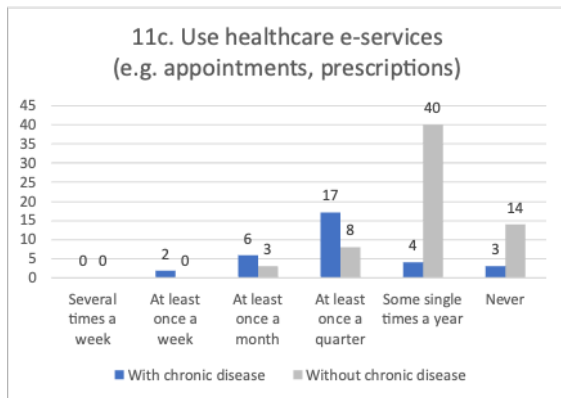
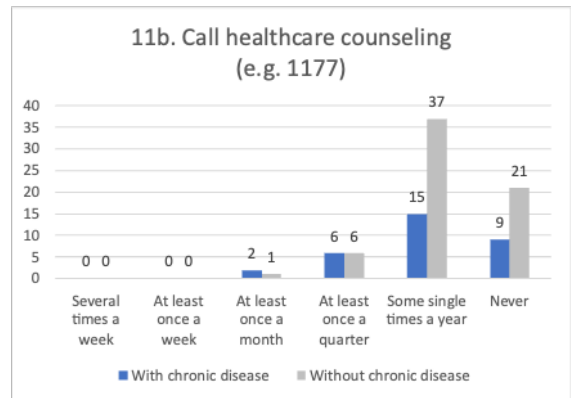
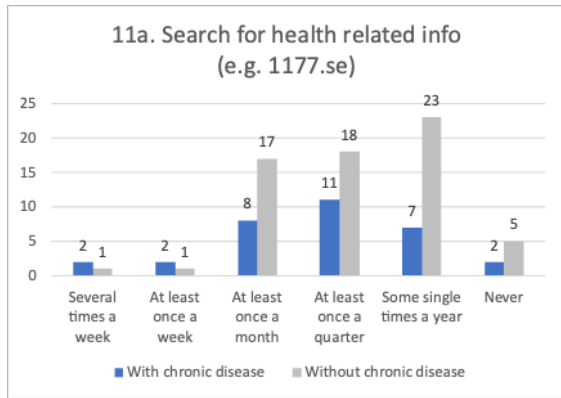
20. Har du några övriga kommentarer eller tankar du vill dela med dig av?

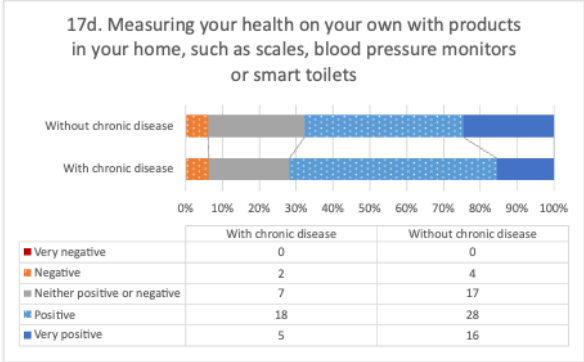
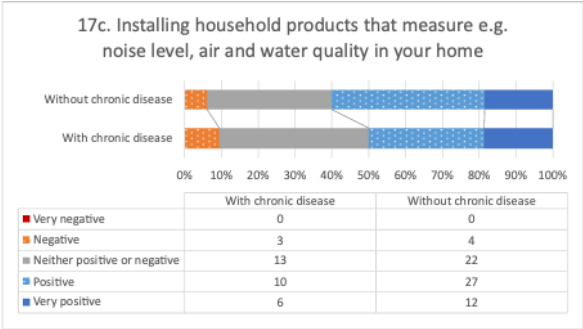
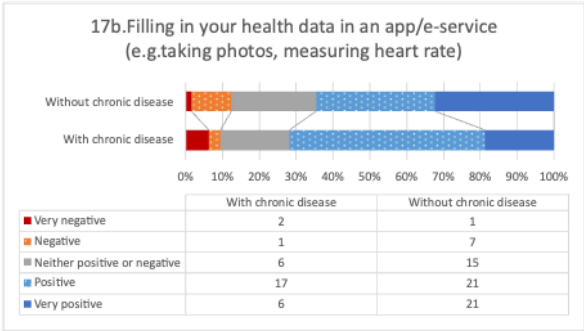
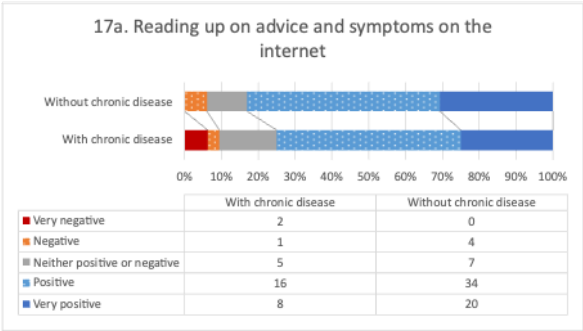
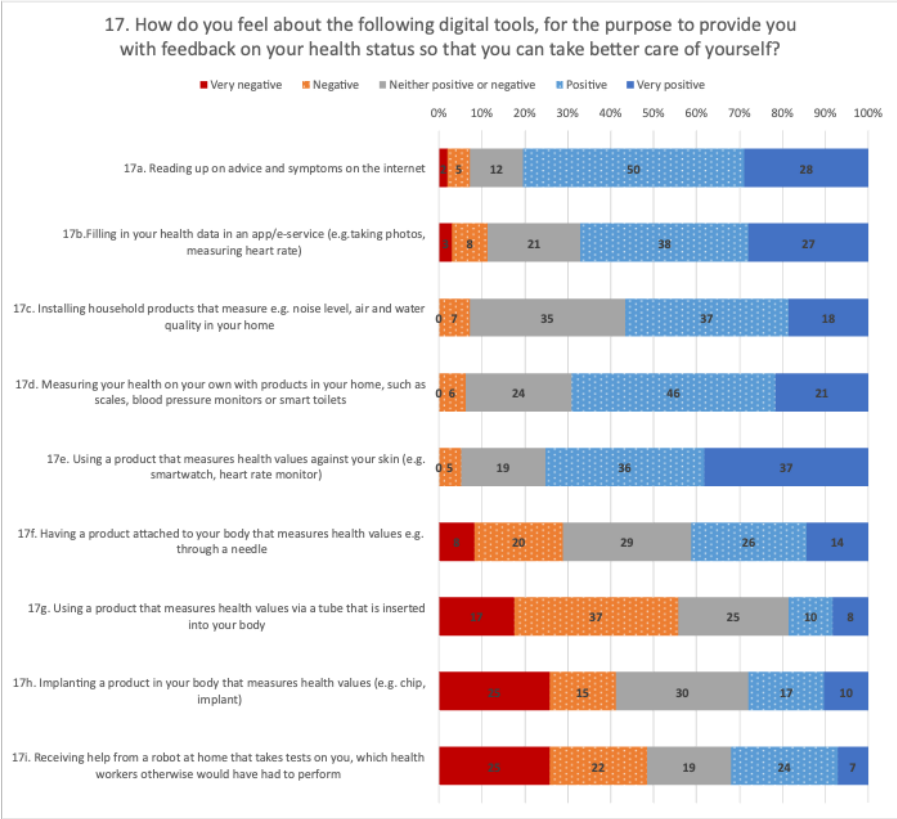
Ange ditt svar

Appendix C – Survey summary

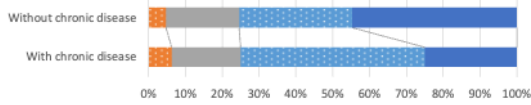
This appendix contains a quantitative summary of the survey (n=100). The qualitative answers are part of chapter 5.2 *Expectations on digital healthcare*. Note that while it was possible to distinguish between respondents with or without (unspecified) chronic diseases in the survey, this distinction is not made throughout the thesis.





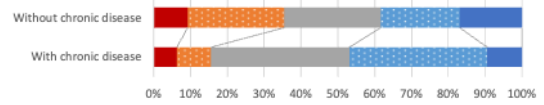


17e. Using a product that measures health values against your skin (e.g. smartwatch, heart rate monitor)



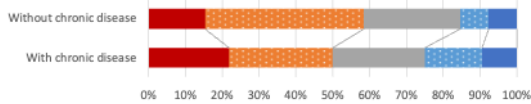
	With chronic disease	Without chronic disease
Very negative	0	0
Negative	2	3
Neither positive or negative	6	13
Positive	16	20
Very positive	8	29

17f. Having a product attached to your body that measures health values e.g. through a needle



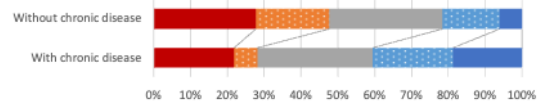
	With chronic disease	Without chronic disease
Very negative	2	6
Negative	3	17
Neither positive or negative	12	17
Positive	12	14
Very positive	3	11

17g. Using a product that measures health values via a tube that is inserted into your body



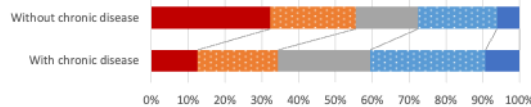
	With chronic disease	Without chronic disease
Very negative	7	10
Negative	9	28
Neither positive or negative	8	17
Positive	5	5
Very positive	3	5

17h. Implanting a product in your body that measures health values (e.g. chip, implant)



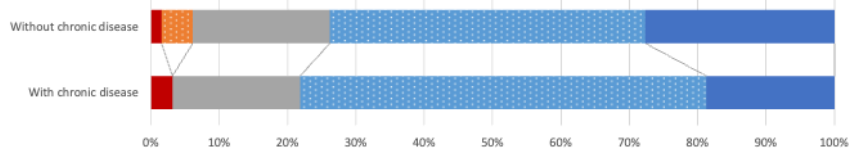
	With chronic disease	Without chronic disease
Very negative	7	18
Negative	2	13
Neither positive or negative	10	20
Positive	7	10
Very positive	6	4

17i. Receiving help from a robot at home that takes tests on you, which health workers otherwise would have had to perform



	With chronic disease	Without chronic disease
Very negative	4	21
Negative	7	15
Neither positive or negative	8	11
Positive	10	14
Very positive	3	4

18. In general, how do you feel about using technology that collects health data and gives you feedback, either directly or by having healthcare access that data?



	With chronic disease	Without chronic disease
Very negative	1	1
Negative	0	3
Neither positive or negative	6	13
Positive	19	30
Very positive	6	18

Appendix D – Workshop guide

This appendix contains the workshop slides which were used to test the assumed benefits of the proposed scenarios together with previous participants.



Examensarbete kring framtida vårdtjänster

- 15 intervjuer + 100 enkätsvar
- Teman på förväntningar:
 - Politiskt
 - Organisatoriskt
 - Vårdkontakt
 - Datainsamling
 - Digitalisering
- Riktlinjer och "smakprov" på idéer som förväntningar kan leda till

Scenarion

För vardera scenario:

- Läs igenom texten själva
- Tänk själv på vad du tycker låter bra eller dålig med scenariot
- Efter någon minut diskuterar vi gemensamt

Scenario A: Första kontakten med vården



Du har ett besvär som du vill kontakta vården om. Från förstasidan på 1177 Mina Sidor kan du skicka ett meddelande till vården om ditt besvär och kan välja att skicka med en bild. Ditt meddelande analyseras och därefter får du en notifikation med ett utlåtande om säger att ett vårdmöte behöver bokas.

När du klickar dig vidare till bokning kommer lediga tider upp för de vårdenheter som lämpar sig för att hantera just ditt besvär, där du kan filtrera utifrån tid, mötesform eller vårdenhet som passar dig.

	LEDIGA TIDER	FILTRERA >
011:00	KUNGSHÖJD	VIDEO/PLATS/TELEFON
012:30	GIBRALTAR	PLATS/TELEFON
012:45	GIBRALTAR	PLATS/VIDEO

Scenario B: Förberedelser inför vårdmöte

Inför ditt vårdmöte ombeds du fylla i din hälsodeklaration på 1177, samt förbereda dig genom att reflektera över två hälsofrågor. Inför mötet har läkaren förberett sig genom att läsa din journal, som finns tillgänglig i ett nationellt system. På vårdmötet kommer du och läkaren tillsammans överens om att hålla koll på din hjärtfrekvens och din sömn. Den smartklocka du har idag fungerar väl för syftet, och du ges instruktion på hur du ställer in så att du kan dela med dig av hälsodatan senare.

Två veckor innan nästa inplanerade möte kontaktar läkaren dig och ber dig ta ett blodprov för att kunna göra en bättre bedömning när ni väl ses. Du går förbi ditt lokala apotek, som tar blodprovet och skickar vidare resultatet till sjukvården.



Andra idéer

1. Schemalagd och anpassad träning som tillhandahålls via vården, för att enklare komma till skott med träning.
2. Fast-track inom vården för kroniker som vet vad de behöver för att må bättre, för att spendera mindre tid på att vänta och även belasta vården mindre.
3. En mätare i hemmet för tidigt upptäcka ofördelaktiga inomhusförhållanden för att undvika komplikationer (ex. ljud, vibrationer, syresättning, luftfuktighet, temperatur, radon)

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