

Exploring Needs and Possibilities of mHealth Services for Persons with Chronic Disease

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Exploring Needs and Possibilities of mHealth Services for Persons with Chronic Diseases

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Abstract

The amount of people living with chronic diseases is increasing. Chronic diseases do not only induce human suffering, it is also an economic burden on society. To ease the suffering and reduce the costs connected to chronic diseases, the usage of digital health services might be a possibility. Currently, the expectations on such services are high, but not met. To better meet the expectations, this project investigated the needs of digital health services for people with chronic disease and suggested new ways of meeting the identified needs. The project followed a user-centred design process, divided into four phases: (1) background information gathering, (2) user studies, (3) concept generation and (4) defining concepts. The first two phases provided insights regarding available digital health services and common needs of people living with chronic disease. The identified needs mostly regarded psychological challenges in accepting the disease, struggles in the communication with caregivers and authorities and difficulties in finding relevant and personalised services and treatments. Furthermore, a great willingness to use digital services to manage health and diseases was identified, along with safety concerns of such services. In the last two phases the identified needs were used for creating and detailing four different design concepts, representing four different digital health services. These included (1) a digital health account, (2) a health crowdsourcing platform, (3) a social AI health buddy and (4) a health gaming app. An assessment of the concepts showed that none of them managed to fully meet the identified needs, but by merging the concepts there are great possibilities in creating a comprehensive service.

Keywords: eHealth, mHealth, chronic disease, disease management, user-centred design

Sammanfattning

Antalet personer som lever med en kronisk sjukdom ökar, detta som en konsekvens av bland annat en snabbt ökande äldre befolkning. Kroniska sjukdomar orsakar inte bara mänskligt lidande, utan är också en ekonomisk börda för samhället. För att lindra lidandet och minska kostnaderna kopplade till kroniska sjukdomar kan användandet av digitala hälso-tjänster vara en möjlighet. För närvarande är förväntningarna på sådana tjänster höga, men inte uppfyllda. För att uppfylla förväntningarna undersöktes i detta projekt behoven av digitala hälso-tjänster hos personer med kroniska sjukdomar. Dessutom föreslogs nya sätt att möta de identifierade behoven. Projektet följde en användarcentrerad designprocess, indelad i fyra faser: (1) bakgrundsstudie, (2) användarstudier, (3) konceptgenerering och (4) definiering av koncept. De första två faserna gav insikter om tillgängliga digitala hälso-tjänster samt om gemensamma behov hos personer med kronisk sjukdom. De identifierade behoven berörde mestadels psykologiska utmaningar i accepterandet av sjukdomen, problem med kommunikationen med vårdgivare och myndigheter samt svårigheter att hitta relevanta och personanpassade tjänster och behandlingar. Dessutom identifierades en stor benägenhet att använda digitala hälso-tjänster för hälso- och sjukdomshantering, tillsammans med en viss oro över säkerhetsaspekter. I de sista två faserna användes de identifierade behoven för att skapa och specificera fyra designkoncept som representerade olika digitala hälso-tjänster. Dessa innefattade (1) ett digitalt hälsokonto, (2) en crowdsourcing-plattform för hälsofrågor, (3) en social AI-hälsokompis och (4) en spelapp med hälsoutmaningar. En utvärdering av koncepten visade att ingen av dem lyckades uppfylla de identifierade behoven fullt ut, men genom att sammanfoga koncepten finns stora möjligheter att skapa en heltäckande tjänst.

Nyckelord: e-hälsa, m-hälsa, kronisk sjukdom, sjukdomshantering, användarcentrerad design

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1 Introduction

This chapter gives a brief introduction to the problem investigated in this thesis and presents the purpose of the project and the structure of the report.

The elderly population of the world is rapidly increasing: between the years 2015 and 2030 the number of people aged over 60 years is expected to increase by 56% [1]. The reasons for this are multiple: improved standards of living, efforts to prevent accidents and unhealthy habits, and improved ability to diagnose and treat diseases [2]. An increased life expectancy is in itself a positive development, however, with it comes challenges [1]. In Sweden, for instance, the healthcare system faces a huge challenge as more than 85% of the population aged over 65 is diagnosed with at least one chronic disease [2]. Chronic diseases, i.e. long-term or incurable diseases with slow progress and gradual impairment, is the leading cause of mortality in the world [3]. Much human suffering is caused by premature illness and death connected to chronic diseases. In addition to this, the increase of chronic diseases also has a large impact on the economy. In Sweden, treatment of chronic diseases stand for over 80% of the healthcare cost and chronic diseases are the main cause behind healthcare allowances [2]. Chronic diseases do not only affect elderly: an inquiry made by Statistiska Centralbyrån during 2014 shows that almost every second Swedish citizen aged above 16 years has one or multiple chronic diseases [4]. According to WHO, the most premature deaths caused by chronic diseases could be prevented if the healthcare systems were more effectively customised to the needs of people with chronic disease [5].

There are several ongoing initiatives for managing the challenges caused by the increase of people living with chronic disease. Internationally, WHO and UN have several strategies for preventing and managing these [3] [6] [7]. During 2014, the government in Sweden developed a five year national strategy for preventing and treating chronic diseases through a more patient-centred, knowledge-based and preventive care [8].

One emerging possibility to meet these goals is eHealth, i.e. using digital tools and exchanging information digitally to maintain and improve health [9]. A subset of eHealth is mHealth, which includes using mobile computing and communications technologies in healthcare and public health [10]. There is a large potential in using mHealth for a heterogeneous and large target group while still being able to adapt to different situations with specific needs. It has been shown that mobile applications can be an effective aid for weight loss, smoking cessation and diabetes management to name a few examples [11]. Moreover, the market is rapidly increasing with new devices and new possibilities due to technology development [11]. During 2016 the Swedish government developed a national vision for eHealth, stating that by the year 2025 Sweden should be best in the world at using eHealth. Thus, making it easier for people to achieve good and equal health and for the citizens to be more independent and involved in their care [12].

However, Swedish healthcare has a long way to go in order to reach the ambitious vision. An international study from 2016 that compared the healthcare in 11 countries from the citizens point of view showed that the healthcare has not improved on these points in the last few years. Compared to other countries, chronic disease patients in Sweden are less informed and less involved in their

care [13]. According to a study initiated by Swedish Association of Local Authorities and Regions (SALAR) there is also a huge gap between expectations and existing digital services offered by healthcare. While three out of four Swedish citizens are positive towards digital services offered by public institutions, only two out of ten think that their expectations are fulfilled [14]. In a study investigating the digital contact surfaces between citizens and healthcare in western Europe 2017, made by the consultant company BearingPoint [15], it is concluded that the digital maturity among care givers is generally low. One issue that is emphasised in the study is that it is too hard for the citizens to find information regarding how to seek care and what kind of care is offered. Overall there is a need for more structured and coordinated digital communication from the caregivers [15]. Moreover, even though mHealth is considered a solution for many problems in the healthcare sector, it comes with problems of its own. One example is app overload; there are too many health apps which leads to difficulties in finding the right app. Also, it is found that health apps have limited value since they tend not to contain enough material or functions to keep the user interested [16].

It is clear that we are facing a huge problem in how to manage the increase of chronic diseases. The usage of eHealth and mHealth provides great opportunities of solving this problem. However, the healthcare system shows slow progress and the citizens, though demanding digital health services, are not satisfied with what is currently offered. Hence, there is a need of investigating what is actually requested by the citizens and finding new ways of meeting these needs.

1.1 Project purpose

The main objective of the project is to investigate the needs of digital health services of individuals diagnosed with chronic diseases. The project focuses on identifying the needs and challenges in their everyday life. Furthermore, it is investigated how these are currently managed and how they can be approached from an interaction design point of view.

1.1.1 Project limitations

The needs and challenges investigated in this project are based on Swedish citizens and the Swedish healthcare system. Since the investigation is made from an interaction design point of view, it means that focus lies on usability and functions and not on specific disease management or treatments.

The project does not present any final products, but rather focuses on understanding and describing the needs of the users. The final results are concepts describing possible ways to meet the needs, but the user evaluation and prototyping of these are left for a possible future project.

1.2 Report structure

This report starts with a presentation of the background information relevant for the project. Then the overall design process used in the project is explained. After this follows detailed declarations of the implementations, analysis and results of each step of the design process. This process is divided into four different phases, *background information gathering*, *user studies*, *concept generation* and *defining concepts*. These phases are presented in four different chapters. Finally, the execution and results of the project are discussed and evaluated and the conclusions are summarised.

2 Background

In this chapter the stakeholders of the project are introduced and theories and background information relevant to the project are then presented.

2.1 Nerve

Nerve Sweden AB is a Swedish connected health company founded in 2013. The project described in this report was partly a collaboration with Nerve. The company is developing digital self-care tools to support people with chronic conditions to improve health and quality of life. Together with patients they have created an iOS and Android app called Florence that support disease management. Florence mainly offers medication reminders, logging and tracking of mood, pain and medicine consumption and possibility to take notes. Nerve is currently investigating further technology development based on user needs to bring more value to its users.

2.2 eHälsomyndigheten

eHälsomyndigheten (the Swedish eHealth Agency) is a Swedish state agency working for better knowledge and information sharing within health and social care in Sweden. On behalf of the Swedish government they are to improve the health care by making sure that the digitalization and eHealth possibilities are used in way that benefits both individuals and the society [17].

2.2.1 Hälsa för mig

One of the services of eHälsomyndigheten is a personal health account called *Hälsa för mig* (in English *Health for me*). *Hälsa för mig* is a voluntary and free platform for personal health information storage and the users decide what information to store in their accounts. *Hälsa för mig* will allow users to collect, view and share health information through apps connected to the platform. Users will eventually also be able to subscribe to health information such as retrieved prescriptions, vaccinations, test results and information from their health records. The service is planned to be available for Swedish citizens during 2017 and users will access their account by signing in using a Swedish e-ID, such as mobile BankID [18]. Nerve and eHälsomyndigheten are currently collaborating in identifying needs for the personal health account. The project described in this report was initiated as a part of this collaboration.

2.3 Chronic disease

There is no established definition of chronic disease. Several terms can be used to describe similar states of health, such as non-communicable disease (NCD) and chronic condition. However, common for all definitions and terms are that they concern a disease (or condition) ongoing over

a period of several years [19]. In the Swedish national strategy of preventing and treating chronic diseases the Swedish government defines chronic diseases as "*diseases a person has during his lifetime or during a very long period of time*" [8]. The most common chronic diseases are heart diseases, diabetes, cancer, pulmonary diseases such as asthma or Chronic obstructive pulmonary disease, mental illnesses including dependence diseases, neurological diseases, muscle- and joint diseases as well as long term pain conditions [8].

Chronic disease affects people of all ages, regions and countries. The main causes of chronic diseases are related to lifestyle; unhealthy diets, physical inactivity, exposure to tobacco smoke or the harmful use of alcohol. Due to factors such as population ageing and widespread unhealthy lifestyles the people diagnosed with a chronic disease are growing in numbers. During 2015 as much as 70% of all deaths globally were due to a chronic disease [20]. According to WHO, enabling healthcare systems to be more effectively and equitably responsive to the needs of chronic diseased could largely prevent most of the premature deaths. By trying to counteract the risk factors of unhealthy diets, physical inactivity, tobacco use and alcohol, the premature deaths from chronic diseases could be even more largely preventable [5].

Below, the different chronic diseases of the persons interviewed in the project are presented.

2.3.1 Multiple Sclerosis

Multiple Sclerosis (MS) is the most common neurological disabling disease that affect young adults. The age of onset is normally around 30 years but it has been known to happen as early as 3 years old and up to around 70 years old. MS triggers the immune system to an auto-regressive response which attacks the myelin sheaths as well as other parts of the central nervous system (CNS) axons [21]. These inflammatory responses leaves scars, *sclerosis* in Latin, in the nerve tissue [22].

The disease normally progresses through relapses and recoveries, fully or partially [21]. The time between a relapse can vary between a few months up to years. How long the relapses last vary between days to months [22]. During a relapse, a part of the CNS is attacked. Therefore, the symptoms of MS can differ depending on which part of the CNS that is affected. Among the most common symptoms are less control over muscles, problems with balance, the sensory system and visual disturbance. Moreover, there are other general problems with fatigue, memory, concentration and depression as well as problems with the bladder [22]. Furthermore, it is quite common to have problems with speech, such as slurred words and disrupted speech pattern with long pauses [23].

2.3.2 Parkinson's Disease

In the course of Parkinson's Disease (PD) the substantia nigra, the part of the brain that produces dopamine, decays [24]. Dopamine plays a large part in body movement and the body's reward system. The symptoms of PD are commonly slowness in initiation of movements, muscular rigidity, tremors and postural instability [24]. Moreover, patients typically suffer from depression and sleep disorders [25]. Additionally, a person with PD often has problems with speech and communication which can lead to slurred, mumble or rapid speech as well as having trouble finding words and participating in fast paced conversations [26].

PD progresses slowly, however, the first stages are pre-symptomatic. The age of onset for PD is normally around 55 to 60 years and the first symptoms are usually a change in handwriting, tremor in one hand, stiffness and a reduced sense of smell [24] [25].

2.3.3 Aphasia

Aphasia is an impairment of language caused by an injury in the brain [27]. It is most common in stroke survivors but can also be a result of head trauma, tumours or dementia [28]. Moreover, the injury is often in the left hemisphere, though research shows that injury in the right hemisphere also can affect the language ability and aural comprehension [28]. The symptoms for aphasia can differ, but common for all is the difficulty of finding the right words [27]. This might, for example, be expressed through not getting any words out, repeating the same word again and again or saying the wrong word. Other symptoms are trouble with understanding what other people say, reading and writing [28] [27]. The chances of improvement are affected by where in the brain the injury is located and how large it is. Directly after a stroke or an injury the symptoms are usually worst. However, with training they can lessen over time. However, most of the affected have to learn to live and deal with aphasia [27].

2.3.4 Diabetes

Diabetes is a collection of diseases characterised by elevated levels of blood sugar [29]. There are two main types of diabetes, type 1 and 2. For diabetes type 1, typically the onset of the disease happens during childhood or adolescence [29]. In this type the ability to produce of insulin is decreased over time as the body immune system attacks the insulin producing cells in the pancreas [30]. Diabetes type 2 results from ineffective use of insulin in the body [29]. A so called insulin resistance occurs due high blood sugar levels over long time, which means that the cells need a higher dosage of insulin to absorb the sugar [30]. For all types, there are many complications that can arise from diabetes, especially when mistreated. Common complication is damage to the heart, blood vessels, eyes, kidneys and nerves which can lead to disability and premature death [29].

2.4 eHealth

eHealth is currently a very prominent field within healthcare research. There are various definitions of eHealth made by different actors at different times. For instance, during 2001 Eysenbach defined it in a broad sense [31, p. 1]:

e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology

A shorter definition is stated by the Swedish National Board of Health and Welfare who describes it as using digital tools for exchanging information digitally to achieve and maintain health [9].

2.4.1 mHealth

mHealth, or mobile health, is a branch of eHealth with various definitions. During 2011 a mHealth study conducted by the World Health Organisation described it as [32, p. 6]:

medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices

Due to the expanding spread of smartphones, as well as 3G and 4G networks, digital health-care services have been rapidly increasing. mHealth allows collection of medical, psychological, lifestyle and activity data through sensors and mobile apps. Thus, it could serve as a basis for evidence-driven care and for facilitating for patients by offering all-time access to their health information [33].

mHealth is considered by many to be an important tool for tackling the healthcare challenges related to the ageing of the population and the increase of chronic diseases. For instance, the European Commission denotes that mHealth could increase the rates of early detection of chronic diseases through self-assessment tools, remote diagnosis and sharing of data. Furthermore, mHealth supports a more active role of the patients by allowing them the use sensors and apps for tracking vitals and behaviour. This makes the patients more aware of their health condition and how to live with it [33].

However, even though mHealth is a very promising field, it comes with problems of its own. One major concern that has been raised regards the protection and security of personal health data, including the risks of unwanted sharing. This issue also covers the ownership, processing and storage of the collected data. Another big issue for mHealth is the overload of apps [33]. A study made during 2016 showed that there were around 259 000 health apps available on the global market [34]. Given this variety, it becomes difficult for the consumer to find the right app and to even know where to start looking. Moreover, the added value from one single app is often found to be limited, this since the apps do not contain enough material or functions to keep the user interested [16].

3 Design methods

This chapter gives a brief description of the overall design process used in the project. More detailed descriptions of the specific methods used in each step of the project are given in the subsequent chapters.

In this project a user-centred design process, following an interaction design method, was implemented. Interaction design can be defined as "*designing interactive products to support the way people communicate and interact in their everyday and working lives*" [35, p. 21]. The focus of interaction design is on designing the user experience, i.e. the actual behaviour and usage of the product in the real world. This includes how people feel about the product and the overall impression of the usability [35].

3.1 User-centred design

Having a user-centred approach to development is fundamental for designing systems that support rather than constrain the user, thus enhancing the human skills [35]. User-centred design is based on three principles [36]: (1) *early focus on the users and tasks*, (2) *empirical measurements* and (3) *iterative design*.

To have an *early focus on users and tasks* means understanding the user. It is the users tasks and goals that are driving the development while the technology will provide choices and options on how to meet these goals. However, it is important to not just focus on the tasks and goals. Understanding the users' behaviours and contexts is an important part of finding priorities, preferences and intentions and designing a system to support them. Moreover, designing for the characteristics of the users is important. There are certain cognitive and physical limitations that have to be taken into account, such as attention, memory and perception as well as height, mobility and strength. Some characteristics are more general but some are associated to a specific task or job. To ensure this, the users should be involved from the first to the last phase of the design process and their input is taken seriously. Moreover, all design decisions are taken with the context of the user in mind [35].

Empirical measurements includes observing, measuring and analysing the reactions and performances of the users when interacting with simulations and prototypes. Agreeing upon specific usability and goals early on in the project can be a help when choosing between designs or checking the progress of the project. Also, doing this allows for the product to be empirically evaluated during the development [35].

Iterative design means allowing feedback from user testing to refine the design. In a process where design and development are iterative, the cycle of design–test–measure–redesign is looped as often and as long as necessary [35].

To be able to successfully implement an interaction design it is important to first understand its activities and how these are related to each other. This can be visualised in an interaction design

lifecycle model. Such models exist with many different levels of complexity, but for a project with only a few members it is sufficient to use a simple model. Rogers et al. describes four main activities of interaction design: establishing requirements, designing alternatives, prototyping and evaluating [35]. Figure 3.1 shows a lifecycle model of these activities including the user-centred design principles.

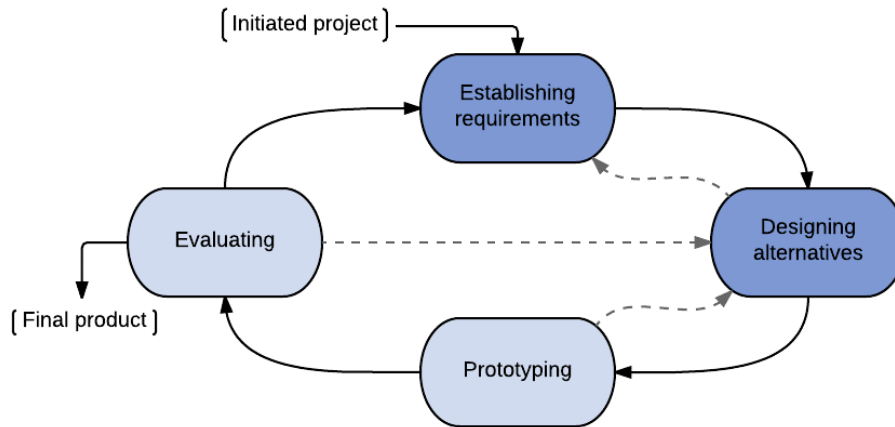


Figure 3.1: A life cycle model of interaction design, describing the activities and how they are related.

3.2 Design process

In this project the first two parts, highlighted in darker blue, of the life cycle model described in figure 3.1 were implemented. The implementation was made through following the process of a concept phase described by Arvola [37]. In addition to the steps described by Arvola, another step was added to the process: defining conceptual models. The steps of the process used in this project are described in figure 3.2.

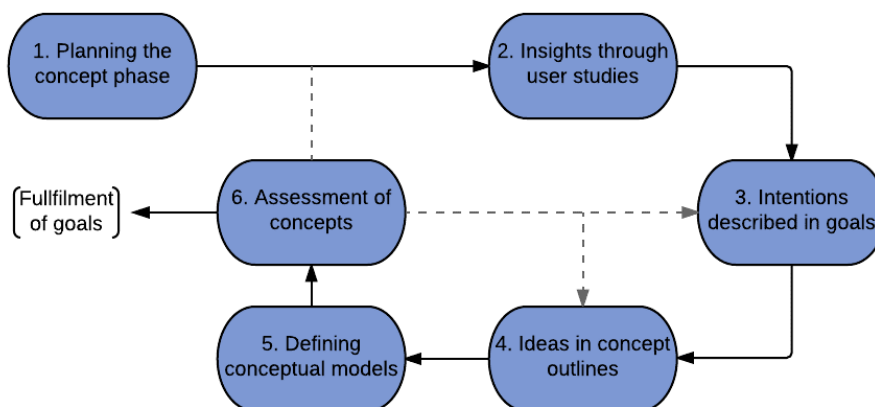


Figure 3.2: The process setup used in this project.

3.2.1 Establishing requirements

The first part of the design process included step one, two and three of the process setup described in figure 3.2. Step one, the planning of the concept phase, included background information gathering and planning the activities of the user studies. In step two, insights regarding the users were obtained in an iterative way with three different studies: (1) a workshop, (2) a survey and (3) interviews. The results from the workshop were used as input for the survey and the results from the survey were used as input for the interviews. In the third step, triangulation was performed on all the information and results obtained in the previous steps. From the triangulation, design goals were formed, thus completing the phase of establishing requirements.

3.2.2 Designing alternatives

The last part of the process included step four, five and six of the process setup in figure 3.2. In step four, brainstorming was used to generate design ideas and a diagram to visualise them was made. A few of the ideas were selected through validating the ideas against the goals. From these ideas concepts were outlined. In the fifth step the concepts were detailed through conceptual models and user scenarios. The sixth and final step included assessment of the developed concepts. It was evaluated how the concepts fulfilled each individual goal and if needed modifications were made.

4 Background information gathering

This chapter describes the implementation, analysis and results of the initial step of the project where relevant background information was gathered.

The first step of the project was to collect information regarding the area of digital health management tools, this in order to get a basic understanding of fields related to the project. The information gathering was done in two steps, first by performing a brief literature study and then by doing a benchmarking study of available mobile health applications.

4.1 Literature study

4.1.1 Implementation and analysis

The search engine LUBsearch was used to find peer reviewed articles with the purpose of gathering a basic understanding of the field of mHealth, in particular mobile health applications and how to determine the quality of these applications. A limit was set so that the search result only included articles published after 2012. Furthermore, subjects were used to make sure the search result was connected to health. Moreover, the search result was ordered by relevance. Thus, a small library of articles was created. The library was used as an information bank from which knowledge was obtained when necessary. The articles found via the search engine LUBsearch were divided into different categories for an easy overview of the different subjects they cover.

Additional literature was found through Google scholar, searching for articles related to mobile health applications and by looking through found articles' reference lists. Judging the relevance of the articles by their abstracts, a selection was made and these articles were added to the library. Lastly, literature was also found through recommendations.

4.1.2 Results

Searchwords, boolean operations, subjects as well as the number of hits, read abstracts and selected articles can be found in figure 4.1. A total of 65 articles were selected and out of those only 58 could be accessed and used for the library. In figure 4.2, the categories used for the articles found through LubSearch and the number of articles in each category can be seen.

Findings

From the articles a number of things were observed which are referred to throughout this report. The main conclusions made were: (1) There are a huge amount of articles that address the field of mHealth which makes it hard to find articles that are relevant. (2) The possibilities with eHealth and mHealth are considered to be many. (3) eHealth and mHealth have not been used for a long enough time to actually know for sure if they can have a long term impact on health and society.

	Search 1	Search 2	Search 3
Date	2017-01-26	2017-01-26	2017-01-26
Search words & booleans	Mobile AND health And app	Mobile AND health AND quality AND criteria	(Personal health record) OR (electronic health record)
Subjects	Mhealth, mobile health, health, health promotion, telemedicine, telecommunication in medicine, medical care, health behavior, ehealth, medical informatics, self-management, health self-care	mobile health, mhealth, public health, management, e-health, ehealth, health, medicine	electronic health records
Number of hits	1,715	99	15,086
Read abstracts	102	50	50
Inclusion criteria	Health management, private use, usability, UX, engagement, interaction design, demand	Assessment of health applications	Private use, usability, barriers to use PHR, PHR in society, no detirmed country
Selected articles	46	3	16

Figure 4.1: Search history.

Category	Number of articles
Challenges	2
Designing health apps	12
Electronic personal health record	13
Overview	6
Possibilities	4
Trust and safety aspects	5
Using mobile health apps	9
Validation frameworks for health apps	7

Figure 4.2: The different categories of articles.

4.2 Mobile application benchmarking study

In order to investigate the currently available mobile health apps from a user experience point of view, a mobile application benchmarking study was made. The purpose of the benchmarking study was to get a better understanding of what different kinds of health services the app market offered and how useful they were. The intention was also to use the findings as comparison and inspiration for future parts of the project.

4.2.1 Implementation

A distinction was made for what kind of apps should be included in the study. This in order for it to be manageable and comparable. The functions of the Nerve developed app Florence was used as a starting point for developing the inclusion criteria. It was concluded that the included apps should offer chronic disease management by providing medication reminders, preferably in combination with other types of functions such as vital trackers and notes. In order to achieve a broader focus the study was set to also include apps that was specifically targeting MS and Parkinson's disease patients.

The selection of apps to evaluate was made in two different steps. In the initial selection step apps were found in Google Play by searching for four different search phrases: *Medication reminder*,

Medicin påminnelse, Multiple Sclerosis and Parkinsons. Beside this the following inclusion criteria were set up for the first selection step: (1) the app should be targeting individuals (not health providers), (2) be for free (or have a free version), (3) be available in Swedish or in English, (4) contain some kind of user interaction beyond reading and (5) belong to one of the Google Play app categories: *Medical* or *Health and fitness*. In the second step, a final selection of apps was made by only including apps that had more than 1000 downloads, at least 50 reviews and above 3.8 (out of 5) stars in rating.

4.2.2 Data analysis

The criteria used for the assessment were designed using the Mobile App Rating Score (MARS) developed by Stoyanov et al [38] as a starting point. MARS was developed to be an objective tool for assessing the quality of mobile health apps and contains five different categories with in total 23 different criteria that are each evaluated on a five-point scale (where 1 is inadequate and 5 is excellent). A mean score from each category is then calculated from which a resulting total quality mean score and a subjective quality mean score are calculated [38]. Some of the criteria used in the MARS assessment were considered irrelevant for this study and were therefore excluded. A category assessing the features of the app was also added. This resulted in an assessment template containing three different dimensions; Features, Quality and Subjective quality. The feature dimension was graded according to the presence or absence of certain app functions. The Quality dimension contained three different categories: Engagement, Functionality and Aesthetics. These included 10 different criteria from MARS which were to be evaluated in an objective way. The Subjective quality dimension in this study only contained a five star scale, rating the subjective overall impression of the app. The complete assessment template used in this study can be seen in Appendix A.

4.2.3 Results

After the initial selection step 120 apps remained that met the criteria. The final selection step resulted in 21 apps remaining, 19 for medication reminders and one each for MS and PD management.

The same four apps received the highest score within all the three dimensions. These apps had in common that they all had several relevant and usable features without making the usage complicated or the layout and aesthetic cluttered. These apps also had a rather high level of customisation possibilities which made the apps possible to adjust according to the preferences of each user.

All of the apps in the study contained some relevant features, such as snoozing the medication reminder or a graphic overview of the collected data. However, about half of the apps only offered a few features, which limited their usefulness. The best apps offered a variety of features, for example, to add different health measurements, to take notes and to download the logged data into shareable formats. As a result of having several different features, these apps also became more engaging and fun to use.

Overall, the apps in the study performed the best in the Functionality category and most were considered to be easy to use and to navigate. The worst performances were among the Aesthetic category, where a lot of the apps were considered to have little or no visual appeal.

5 User studies

This chapter presents the user studies, including the implementations of methods used, the data analysis made and the results obtained.

User studies were conducted with the purpose of understanding the needs and expectations of the users. The user studies included both quantitative and qualitative data gathering. Three different methods were used in the following order: workshop, web survey and individual interviews. The results from the workshop were used as input to the survey, and the survey results were used as input to the interviews.

5.1 Workshop

As a way of facilitating the communication between designers and users and to increase their awareness, workshops can be used. A workshop is a hands-on creativity session where the participants work together. The aim of a workshop is to use the interactions between the group members to trigger new ideas [39]. In this project a workshop was held as a first step of the user studies. The purpose of the workshop was to get a basic understanding of the needs of digital health services among the end users.

5.1.1 Implementation

The workshop started off with a introduction about digital health services, where *Hälsa för mig* was presented as an example. Ten people participated; five were diagnosed with MS, one was diagnosed with Parkinson's disease and four did not have any chronic disease. After the introduction followed a brainstorming session. Brainstorming is used as a way of producing many new ideas in a short amount of time. When using brainstorming it is important that no ideas are considered as stupid and that crazy ideas are encouraged [37].

In the workshop the participants were handed post-it notes and a pen. Each person then got 10 minutes to write down as many different needs, ideas and suggestions for digital health services as possible. After the time was up each person, still individually, was to go through all their post-it notes and rank the three best suggestions. The participants were then randomly divided into three different groups and each person got to present their best suggestions to the others in their group. The group then got 10 minutes to discuss the different suggestions and come up with one final idea which they were to present to the other groups. After each group presentation a short discussion was held and the other groups gave their input to the suggested idea. The final suggestions and the rest of the post it-notes were saved for analysis.

5.1.2 Data analysis

Some of the post-it notes from the participants contained several ideas. To simplify the analysis these were divided so that each post-it only contained one idea.

In order to structure and summarise the data for analysis an affinity diagram was used. An affinity diagram is a way of categorising data into clusters according to related characteristics and common themes. The clusters can also be divided into subcategories and the relationships between the different clusters are also visualised [37, p. 52-53]. This principle was used to structure and find patterns in the post-it notes from the workshop. To do this the notes were first randomly divided into two subsets. The project members got one half of the notes each and then got to categorise their subset by themselves. This was done in order to avoid the project members from influencing each other in their way of finding patterns in the data. After the two subsets had been categorised individually the different categorisations of the subsets were compared. When the same kind of data had been structured differently in the subsets discussions were held regarding other ways of categorising it. The subsets were then merged together according to similar categorisations. Some of the notes were thereafter moved around between different categories until both project members were satisfied with the result. The ideas in each category were then arranged in different subcategories. Furthermore, the categories and subcategories were named according to their mutual attributes. Finally, the categories were sorted into four different main categories representing a broader theme that was common for some of the categories. In order to visually present this an affinity diagram was created.

5.1.3 Results

The workshop resulted in 134 post-it notes filled with the participants perceived needs and ideas for digital health services. These notes contained a total of 146 different ideas that were divided into 13 different categories and 30 different subcategories. The final categories, with the main categories in bold, were as follows:

- **Information**
 - General information
 - Personal healthcare information
- **Data**
 - Regular measurements
 - Diet
 - Health & fitness
 - Daily status
 - Habits
- **Customization**
 - Communication channels
 - Adaptation & availability
 - Personal analysis
- **Call to action**
 - Letters of healthcare appointments
 - Reminders
 - ICE

The final affinity diagram, containing all the different categories and their internal relationships, is visually shown in Figure 5.1. A complete list of categories, including the subcategories and number of mentions for each category, can be found in Appendix B.

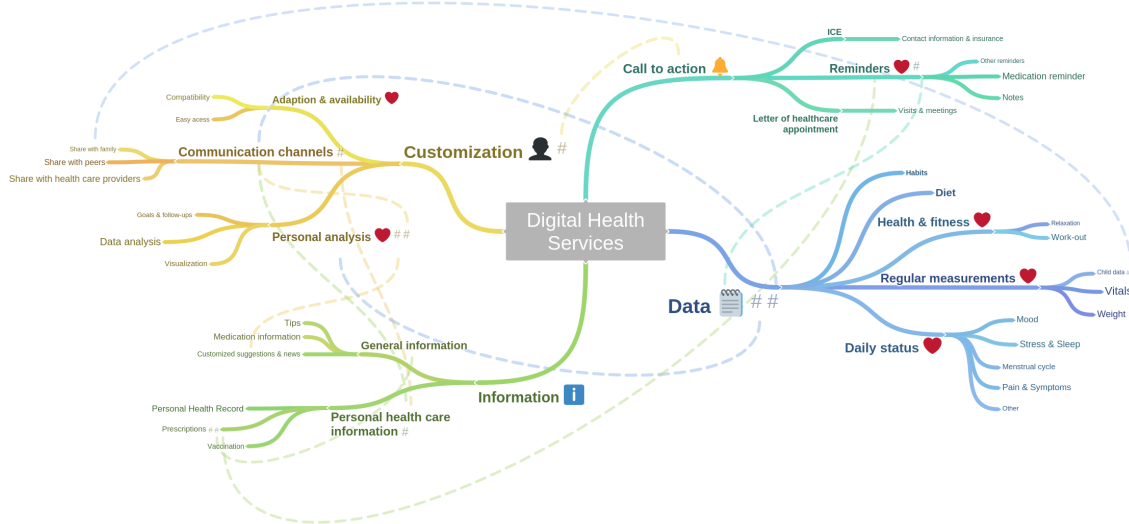


Figure 5.1: Affinity diagram showing the results from the workshop. The size of the category names corresponds to how frequent it was mentioned in the data. The dotted lines represent internal relationships between some of the categories.

5.2 Survey

Using the workshop results as a springboard, a user survey was created. The purpose of the survey was to collect quantitative data for the user study. Quantitative data means data in the form of numbers or data that can easily be transferred into numbers. In the analysis of quantitative data numerical methods are used to determine the amount or magnitude of something, for instance the attributes or opinions of the participants [35].

5.2.1 Implementation

In order to make sure that the survey results would be reliable, easy to analyse and answer the requested questions a structured creation process was used.

The first phase in the creation process was to set up clear objectives for the survey. This included answering the following questions:

- *Why are we creating this survey?*
- *What is the goal of this survey?*
- *What do we hope to accomplish?*
- *How will the collected data be used?*
- *What decisions can be impacted from the results of the survey?*

From the set objectives three different areas, that the survey was to cover, were created. These areas were *User needs and demands*, *User expectations* and *User fears and insecurities*. To be able to learn more about the users a fourth area was added: *information regarding the current state of the respondents*.

In the next phase of the process, the project members had a brainstorming session regarding what was expected to be found in each of these areas. The expectations were visualised using a mind map where some of the ideas were linked to more than one area. The expectations were then used to form questions that either would verify or deny the expectations. The categories from the workshop were also used for creating questions and to make sure that the survey covered the needs identified in the workshop. A tree structure, where logical jumps were made depending on the answers of the user, was used in order to create a more dynamic survey. A lot of time was spent on phrasing the questions correctly. This was done to ensure that they were not asked in a way that could influence the answer, but still were clear enough not to be misinterpreted by the reader. For each question it was also clarified what type of information it would bring; information regarding the current state of the respondents, the needs, expectations and demands of the respondents or the fears and concerns of the respondents.

After finishing the questions and logic the survey was sent out on a pilot study where a few peers were asked to fill out the survey and give feedback. After this pilot some smaller adjustments were made, mostly connected to how the survey looked on a smart phone screen, before it was sent out to 20 different patient associations in Sweden. An analogue, and a bit simplified, version of the survey can be found in Appendix C.

5.2.2 Data analysis

After closing the survey the collected data was downloaded into an spreadsheet where each row represented the answers of one respondent and the columns represented the questions. The data was directly anonymised and each row was instead given an ID number. Incomplete responses were identified and removed from the data collection.

The expectations used to form the questions were again used to identify what each question asked in the survey was to answer. The responses for each question were then analysed in the spreadsheet by both looking at the general result and by comparing the different distributions between different genders, ages and diagnoses. The analysis was based on the answers from the respondents diagnosed with a chronic disease, but comparisons were also made with the answers from those not diagnosed with any chronic disease.

5.2.3 Results

The survey contained around 25 questions, depending on how many logical jumps were made. The questions concerning the areas of user needs and user fears were:

- Do you currently use any health apps?
 - What do you log/manage with your health app and how often?
- What would you want to log/manage with a health app and how often?
- How beneficial would it be to be able to store your collected health information in a health account? (scale 1-5)
- How beneficial would it be with digital access to...? (scale 1-5)

- A copy of medical health record - Test results - Medical prescriptions - Doctor appointments - Vaccinations - Child health centre record
- Who would you like to share your health information with?
- Whose health information would you like to be able to access?
- Would you like to have a service that connects and performs some kind of automatic analysis based on your health measurements?
 - If yes: What would you like to see in such analysis?
 - If no: Why not?
- Where do you find healthcare information?
- What are your expectations on the future healthcare? (given 3 neutral, 4 positive and 4 negative alternatives)
- Where do you feel the most safe to store your collected health information?

In total the survey received 835 answers and after the incomplete responses had been cleared out 795 responses remained. 71% of the respondents were women and 68% of the respondents were diagnosed with a chronic or long-term disease. Out of those 44% were diagnosed with more than one disease. For an overview, see figure 5.2. In total there were around 150 different diagnoses represented in the survey.

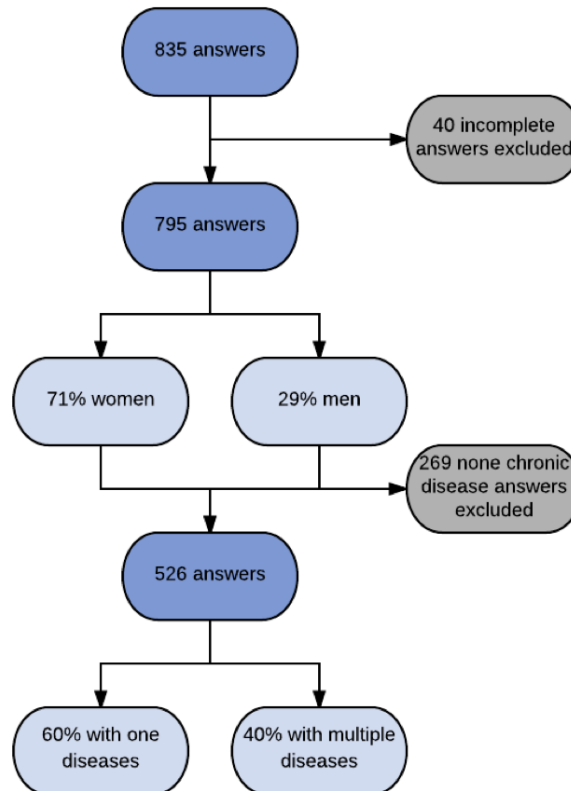


Figure 5.2: An overview of the answers in from the survey.

Unless otherwise stated the results presented below are based on the replies from the chronic or long-term diseased respondents only. Of these 77% were women and 50% were aged above 55 years. The total age distribution can be seen in Figure 5.3.

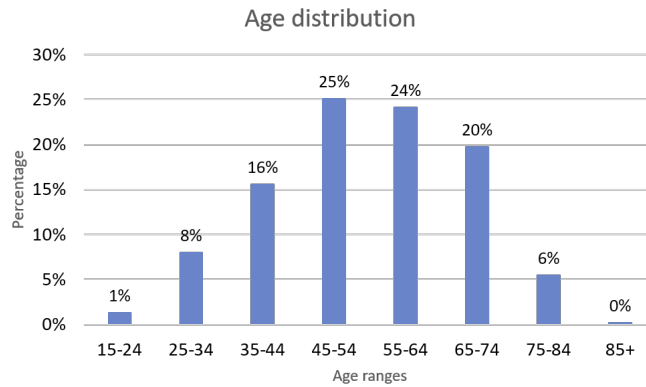


Figure 5.3: Age distribution of the respondents diagnosed with a chronic or long-term disease.

Identified needs

43% of the respondents replied that they used some kind of mobile health app today. The most common thing to log with their health apps was exercise (28%), sleep (16%), weight (12%), pulse (11%) and nutrition and diet (10%). On the question what they *wanted* to log using a mobile health app only 8% of the respondents replied that they did not want to log anything. The most common thing that the respondents wanted to log or manage was medications (53%), followed by chronic disease (45%), symptoms (43%), exercise (40%) and sleep (39%). The corresponding numbers of logging and managing these things today were significantly lower, hence a big gap could be seen between what they actually do today and what they would want to do. Figure 5.4 shows the percentages of what the respondents are currently logging and what they would desire to log using a mobile health app. The figure shows that the gap between the desire to log health and what is actually logged is large for all types of measurements.

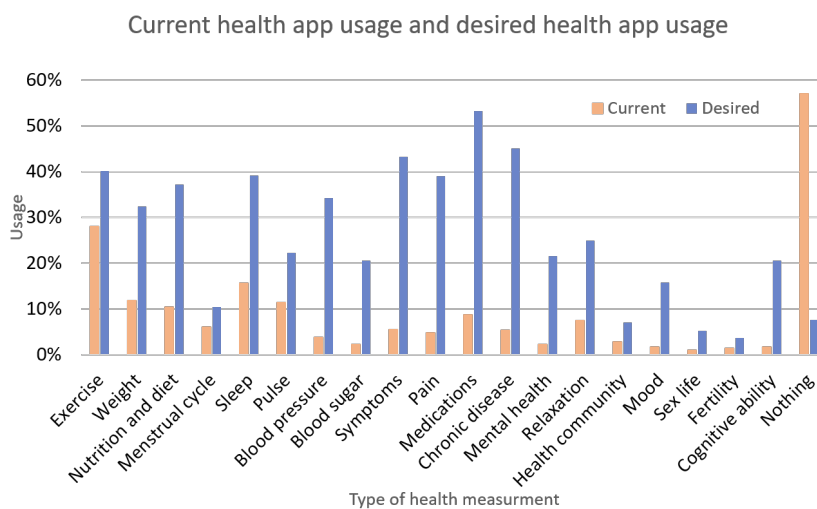


Figure 5.4: Current (orange) and desired (blue) health measurements with health apps.

Figure 5.5 shows the distribution of answers to the question how beneficial it would be to be able to store collected health information in a digital health account. The answers were given in a scale from 1 to 5 where 1 meant *no benefit* and 5 meant *great benefit*. A great majority, 75%, of the respondents felt they would have significant or great benefit from using a digital health account for their health information.

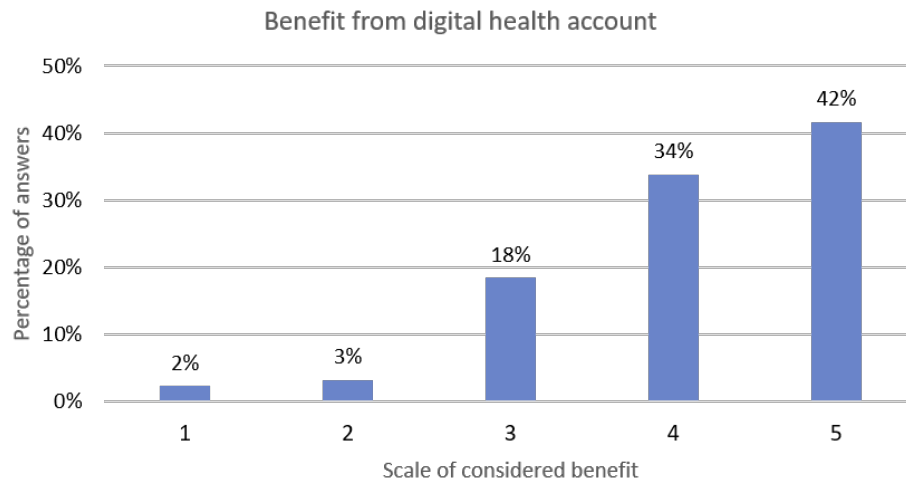


Figure 5.5: Responses of how beneficial it would be with digital health account. 1 means no benefit and 5 means great benefit.

The survey showed a great need for accessing personal health information in general. This as more than 85% of the respondents replied that they would have significant or great benefit from digital access to a copy of their medical record, their medical test results, their medical prescriptions and letters of doctor appointments. The respondents also saw great benefits with access to their vaccinations. Not as many would benefit from access to the child health centre record. Figure 5.6 shows the amount of the respondents that replied that they would have significant or great benefit from digital access to the different types of health information.

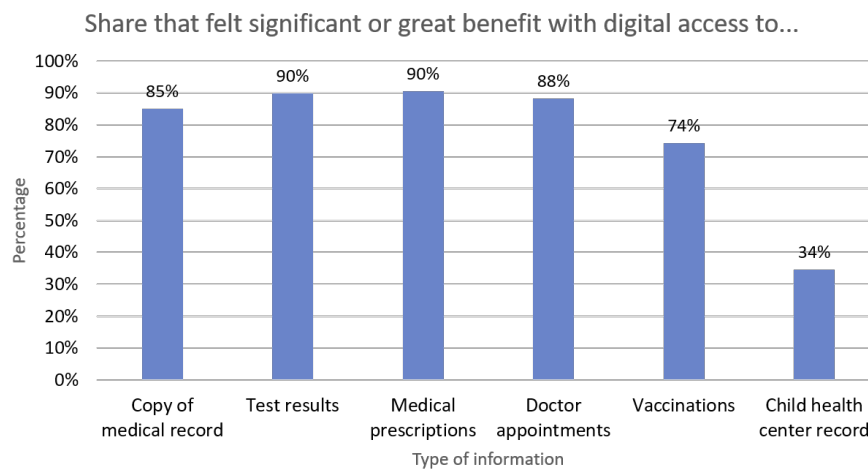


Figure 5.6: Share that would have significant or great benefit of digital access to different types of health information.

User needs were also identified from a data sharing point of view. The sharing preferences of the respondents are shown in figure 5.7. About half of the respondents, 52%, wanted to be able to share selected parts of their health information with their caregiver and 42% wanted to share it with their partner. 19% wanted to be able to share their information with their children and 8% wanted to share it with their parents. The percentage that wanted to be able to access the information of their children and parents were larger, 35% wanted to access their parent's health information and 22% wanted to access their children's health information. 27% of the respondents however did not want to share their health information with anyone and 33% of the respondent did not want to access health information from anyone.

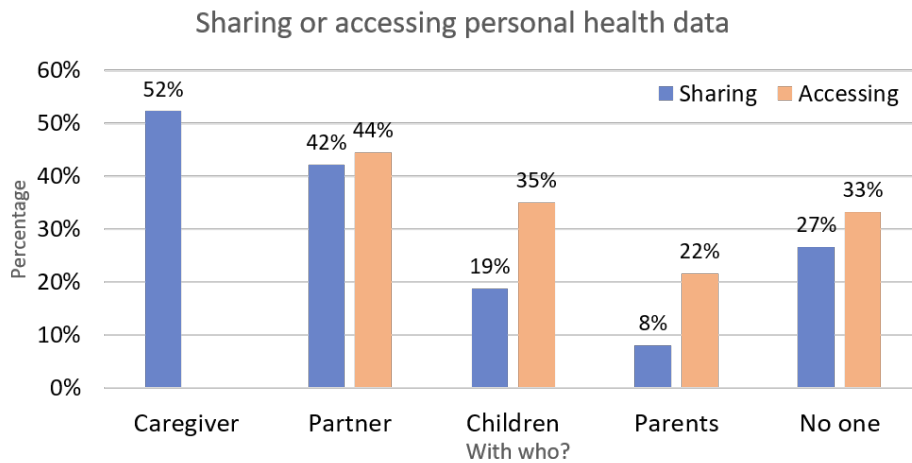


Figure 5.7: Amount of respondents that wanted to access or share health data and with whom.

A great majority of the respondents, 86%, would like to have a service that connects and performs some kind of automatic analysis based on their health measurements. The main purpose with such an analysis would be to get an overview of their own health, but a majority would also like to use it to get personal recommendations and warnings. Figure 5.8 shows how the respondents would want to use an automatic health analysis.

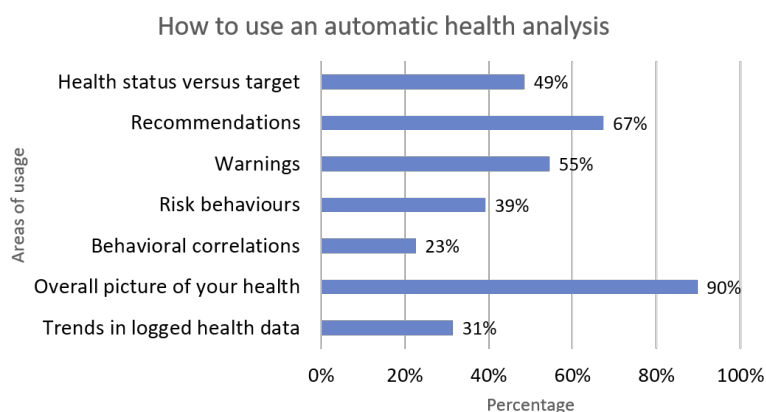


Figure 5.8: Use of automatic health analysis.

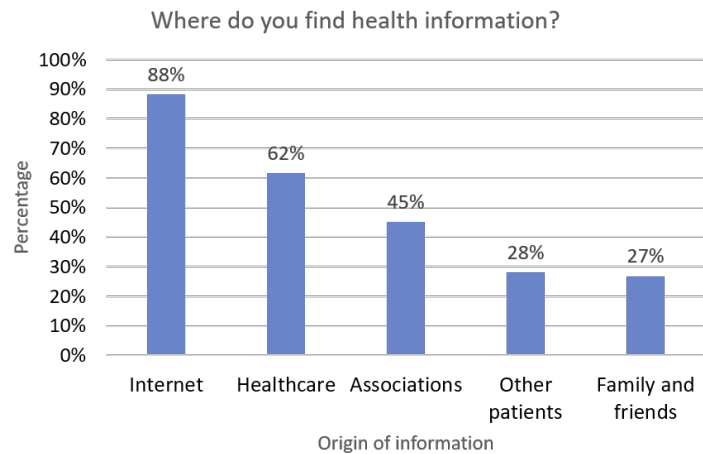


Figure 5.9: Sources used to find health related information.

The survey also showed that almost 9 out of 10, 88% of the respondents, used internet to find health related information. A majority also asked healthcare providers and 45% found information via patient associations. Figure 5.9 shows the distribution of the replies regarding where the respondents find health information.

Expectations

The expectations of the respondents on future healthcare were overall more positive than negative. Almost half of the respondents believed in increased patient involvement and in increased patient customisation. The largest concern were longer waiting times, which 40% of the respondents expected. A large majority, 74%, believed that the future healthcare contact would be digital. The distribution of the respondents' expectations on future healthcare are shown in figure 5.10.

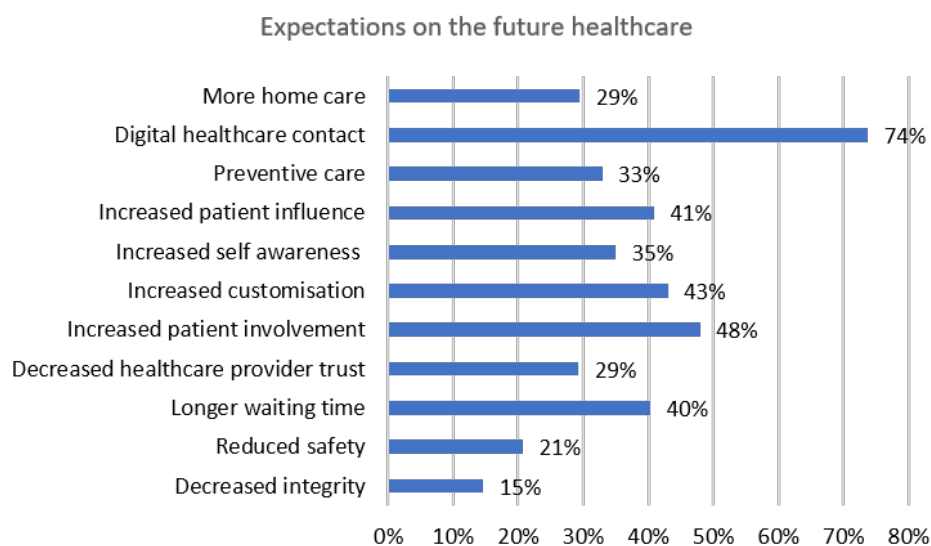


Figure 5.10: The expectations on the future healthcare.

Safety aspects

As can be seen in figure 5.11, most of the respondents felt the most safe with storing their health information within the healthcare or at their own personal storage. A few felt that a state agency would be the most safe place for storage and almost no one trusted a private company the most for storing their health information.

Some safety concerns could be seen from those who did not want to have an automatic health analysis from their logged data. On the question why they did not want it the most common answer, along with that they did not have any needs for it, was that it would be unreliable and intrusive.

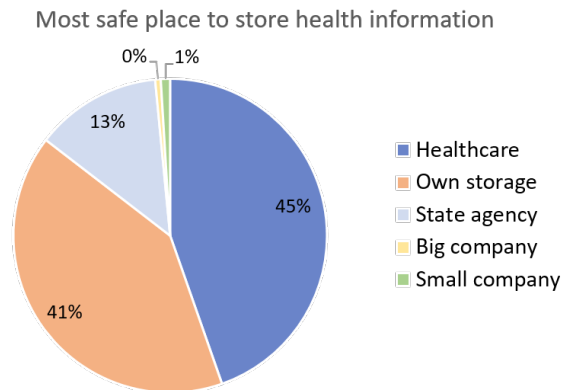


Figure 5.11: Places the respondents felt most safe to store their collected health information.

5.3 Interviews

The last step of the user study was qualitative interviews. Interviews are the most frequently used method for collecting data in qualitative studies due to their setup being perceived as natural. The aim of qualitative studies is to get an understanding of the life of the people being interviewed [40]. Such studies are used when there is a need for a complex and detailed understanding of an issue, when theoretical reading is not enough and in order to understand the contexts in which the study participants address an issue. Qualitative research can also be used for following up on and explaining quantitative research [41]. The purpose of the interviews was to get a deeper understanding of the everyday needs of a person living with a chronic disease. The interviews intended to provide insights regarding common needs and aspects crucial for usage of digital health services.

There are many different approaches for performing a qualitative study, but they all have in common that the data collection focuses on trying to understand the participants in a natural setting, and that the data analysis focuses on finding patterns or themes. One approach for conducting a qualitative study is called *phenomenology* and involves understanding the experiences of a concept or a phenomenon experienced by several individuals [41]. The purpose of a phenomenological study is to reduce individual experiences into a common essence that describes the experience. This is done by collecting data from several persons that have experienced the phenomenon. The data is collected during in-depth interviews that focus on what the participants have experienced and what context that influenced this experience. The collected data is then analysed by reducing the information to significant quotes and statements and then combining them into themes. The overall essence of the experience is then conveyed from a combination of what was experienced and how

it was experienced in terms of context [41]. Considering the motives for conducting the interviews in this study the implementation mostly followed that of a phenomenological method.

5.3.1 Implementation

There are several formats to choose from when conducting a qualitative interview. In this project semi-structured interviews were used. Semi-structured interviews seems to be the most common type and are built around a series of predetermined open-ended questions that are stated in a prepared interview guide. The semi-structured interview allows the interviewer to vary the order and formulations of questions. The interviewer can also ask additional questions to seek clarification or to explore ideas emerging during the interview. However, the interview still follows a structure that the interviewer always returns to during the interview. Semi-structured interviews encourage depth and validity and allow the researcher to find new concepts. The drawback is that the outcome might vary between the interviews and hence obstruct the analysis [40]. In this project, rich data was considered to be important for understanding the width of the phenomenon and for trustworthiness of the conclusions. Therefore, it was prioritised over an easy and smooth analysis. Hence, semi-structured interviews were chosen as method.

Interview guide

The first step in the interview phase was to create an interview guide containing the purpose, the method plan and the questions to be asked to the interviewees. The full interview guide is found in Appendix D.

The interview questions were formed in an open way, with the intention to get the participants to open up and share their situation as they perceive it, without being guided in a specific direction. The questions aimed at getting the interviewees to describe, explain and debate about the needs and demands for digital health services in their daily life. The questions in the interview guide were divided into four sections; background, needs, demands and expectations. The background section contained a few questions aiming at a basic understanding about who the participant was. The main focus of the interview, however, was on the needs section. In this section the questions focused on the everyday life of the participants and the challenges and stressors they experienced. The questions asked in the demand section focused on potential digital health services the participant currently used, had used in the past or would want to use. The last section focused on expectations of and attitude towards digital health services, with *Hälsa för mig* given as an example.

To evaluate the questions and the time consumption of the interview, the ambition was to perform a pilot study on two persons. However, due to time constraints this was not possible. Therefore only an internal evaluation was made where the project members tried to answer each question themselves and where the time consumption for the whole interview was estimated.

Participants

The interviews were held with persons diagnosed with a chronic disease or disability. Participants for the interviews were found by using the network of the company Nerve and by contacting persons within two different patient unions: Neuroförbundet and Parkinsonförbundet Stockholm.

Informed consent

In order to make sure that the participants were aware of the purpose of the study, what was expected of them, how the collected data would be used and their right to withdraw from the study, an

informed consent form was created. The form was created based on a template provided by University of California Irvine Office of Research (UCI Office of Research) [42]. Some of the headings found in the template were considered irrelevant for this study and were therefore not used in the form. The informed consent form used in this study is found in Appendix E. The form was sent out to the participants several days before the interview so that they would have the time to read it through properly. The same information was also given orally before starting the interview.

Interviews

The interviews were held where it suited the participants best, either at the location of H2 Health Hub or in the home or work place of the person being interviewed.

Before starting the interviews the participants were asked to sign the informed consent form. They were also informed about the purpose and procedure of the interview, including the roles of the project members. Both project members participated in each interview, one asked the interview questions and the other took notes of everything that was discussed. For consistency reasons the same project member had the same role during all interviews. The information given to the participants before the interviews were read word by word from the interview guide in order to make sure that all participants were given the same and all necessary information. All interviews were also audio recorded after approval from the interviewees.

During the interviews the interviewer made sure not to put any judgement into the questions or answers and always kept a neutral position. The focus was on making the interviewee feel as comfortable as possible in answering difficult and perhaps uncomfortable questions in an honest way. To get a deeper understanding of the situations described by the interviewees supplementary questions such as "*Could you develop that further?*", "*How did that make you feel?*" and "*How did you cope with that?*", not included in the interview guide, were asked depending on the answers given.

Directly after the interviews the notes were read through and unclear parts were re-written according to the recordings. Particularly interesting and relevant segments were marked and commented on. The most important impressions from the interview were also written down while still remembered clearly.

5.3.2 Data analysis

Analysis of the interviews were done following a qualitative content analysis method described by Graneheim and Lundman [43].

The notes from each interview were thoroughly read through individually by the project members. Important and relevant segments with related content, so-called meaning units [43], were marked. To make sure to not miss any relevant information and that the notes were interpreted correctly the audio recordings from these segments were listened to and, if necessary, transcribed. In the next step the project members, still individually, condensed the meaning units into fewer words, while still making sure to preserve the core of the meaning unit. The project members' chosen meaning units and condensed meaning units were then compared and merged. In general both team members had marked more or less the same meaning units and where differences were found a discussion whether it was relevant or not was held. If the condensed meaning units for the same meaning unit differed the recorded segment was listened to once again and the interpretation of the actual core of the segment was discussed. Each condensed meaning unit was then labelled with a code, describing the condensed meaning unit in an abstracted way. When setting the codes, the whole context of the condensed meaning unit was considered. Labelling the condensed meaning

units with codes is used as a way of allowing the data to be thought of in new ways [43]. An example of how this was done for the interviews conducted can be seen in figure 5.12.

The next step after coding all of the condensed meaning units was to group all of the codes associated with the same content area together. Content areas are parts of the text dealing with specific issues or topics from the interview [43]. Five different content areas were used: possibilities, challenges, security, scepticism and UX aspects. The different codes within each content area were then compared and sorted into different categories and subcategories based on similarities and differences. The categorisation of codes was done in an iterative process where codes were moved around until both of the project member felt satisfied with the results. Finally, common themes within the categories were highlighted and put into words.

5.3.3 Results

In total twelve interviews were held with eight women and four men, aged between 26 and 66 years. Six of the interviewees were diagnosed with MS, three of the interviewees were diagnosed with Parkinson's, two of the interviewees had aphasia and one of the interviewees had diabetes type 1.

Figure 5.12 below shows two examples of meaning units from each category as well as how these were condensed and coded. These are in Swedish since the interviews were held in that language.

Meaning unit	Condensed meaning unit	Code
Man har ingen aning idag om vilken hjälp man faktiskt kan få Det finns kanske saker som kan hjälpa mig men vet kanske inte om dem	Svårt att veta vilken hjälp som finns Saknar kunskap om vilka hjälpmedel som finns	Saknar kunskap om befintlig hjälp Kunskapsbrist om tillgängliga hjälpmedel
Vill kunna få tips om saker som passar mig. Personanpassa. Ge tips om vad man kan äta och göra Jag skulle vilja ha försäkringar och tips. Vem ska man vända sig till för att kolla upp saker, ex pension	Vill få hjälp med att hitta tips och appar som är anpassade Vill ha tips om vem man ska vända sig till om pension och försäkringar	Individanpassade tips och rekommendationer Tips om försäkringar och pension
Datan kommer överleva mig Jag är inte så rädd för att lagra data digitalt	Data har långlivslängd Inte rädd för digital datalagring	Data lever kvar Trygg med digital datalagring
Spontant undrar jag hur mycket det kommer att användas. Delar finns ju nu, receipt, journal, även om alla är i spridda system Tidigare har jag haft en stegräknare för koll på 10 000 steg. Om man känner att nu går jag inte så bra är det inte så kul	Tror inte det kommer användas eftersom delar redan går att få tag på Slutade logga steg pga tråkigt att se försämring	Skeptisk till användning Omotiverad att logga pga försämring
Saknar anpassat gränssnitt. Jag blir jättestressad av att jag skakar och skatrycka på telefonen Hade definitivt använt det om det var automatiskt	Gränssnitt på appar ej anpassat, svårt att trycka med skakningar Använt det om automatiskt	Appgränssnitt ej anpassat Automatik ökar användande

Figure 5.12: Examples of meaning units, condensed meaning units and codes from the categories in the following order: challenges, opportunities, security, scepticism and UX aspects.

The categories and findings from the five content areas are presented below. Among the challenge content area the symptom related challenges are not included since these were considered to be individual and related to disease or impairment. However, among the interviewees the common threads were cognitive difficulties, walking and balance difficulties and being more influenced by external circumstances.

Challenges

The identified challenges can be divided into five categories. These are presented below.

- *Psychological challenges* - The psychological challenges in coping with and accepting the disease:
 - Stress and anxiety connected to being forced to a restricted life style and to economical factors.
 - Frustration from being sick and not improving.
 - Trouble accepting the diagnosis and continuously denying of symptoms.
- *Changed circumstances* - Practical consequences due to disease:
 - Being forced to give up interests due to decreased abilities.
 - Decreased ability to work or not being able to work at all.
 - Lost friends and family members due to their fear or own lack of energy.
- *Lack of knowledge* - Limited knowledge regarding available aids connected to the disease such as apps, treatments and insurances.
- *Treatment* - Challenges connected to diagnosis and treatment:
 - Difficulties in getting the correct diagnosis, which is often a drawn-out process.
 - Difficulties in identifying other diseases or symptoms due to chronic disease.
 - Side effects from or long acclimatisation time for medications.
- *Contact with healthcare* - Challenges connected to the interactions with healthcare and authorities:
 - Caregivers do not see the big picture: They only focus on treating the physical symptoms and forget about the human.
 - The healthcare communication channels are slow and mismatched. The digital channels 1177 and Mina Vårdkontakter are outdated and not user friendly.
 - Difficulties in getting certificates in time for sick-leave.
 - Problems with the insurance fund (Försäkringskassan): poor treatment, time consuming and poorly trained officers.

Possibilities

The identified possibilities of digital health services can be divided into the seven categories presented below.

- *Overview* - To see one's own, and family members, health status:
 - A way of getting better control and understanding of ones health.
 - Easy access to one's health information such as health records, test sample responses, prescriptions and vaccines.
 - Possibility to have all health related information in one place. Thus a creating the possibility of an easier and better coordination of one's health care.

- Better understanding of certain health aspects, such as pulse, blood pressure, sedentary, sleep and mood, through data logging.
- *Personalised information* - Easy accessibility to relevant information and recommendations:
 - Personalised recommendations relevant to one's situations, ranging from tips about health and pain management to training and insurances.
 - Information relating to diagnosis, for example about aids and treatments. In addition to increasing the knowledge of available aids the general knowledge of the disease will also increase.
 - Allowing for an easier way to exchange personal experiences with peers.
- *Reminders* - A help to keep track of practical things in every day life and creating good habits:
 - Create continuity in logging through reminders to obtain good and reliable health data.
 - Improve health with reminders of everything ranging from when to exercise and rest, to when to update prescriptions and vaccines.
 - A way to relieve the memory.
- *Sharing data* - Sharing data with care givers and allowing data to be shared between care givers:
 - Sharing logged health data allows the care giver to see a more representative overview of one's health status.
 - Sharing data between care givers to allow access to the same information.
- *Easily accessible treatment* - Digital treatment with exercises and follow-ups. Also allowing contact with curator, physiotherapist, etc at a distance.
- *Correlations analysis* - Logging data about, for example, medication intake, pain and mood as well as activities and events will allow for way to see consequences and patterns in habits and health.

Security

The identified concerns about security and trust connected to storing health data digitally are summarised below. Regarding this content area it was not possible to find any commonalities for all interviewees. However, by dividing the codes into two subgroups common themes were identified.

- *Data storage* - There are divided feelings, those who feel worried and those who feel comfortable, about storing health data digitally:
 - The worries about storing data digitally are that data will outlive us all, the wrong people may get there hand on the data and abuse it. Moreover, questions about if it is possible to reach high enough security are raised.
 - Most of the interviewees felt secure about storing data digitally reasoning that data is already stored digitally today. Hence, they were sure that no one is interested in individual data and believing in technology. Mobile BankID is considered a safe way of protecting ones data.
- *Trust* - The trust in the state is very high while trust in private companies is not:

- Most are trusting of the state since they believe that the state have no commercial interest in their health data. Moreover, they feel that the state is a secure institution that will not go bankrupt, close down or be purchased.
- Those questioning the state do this on the grounds that ownership may change and because of a fear of "Big Brother".
- Few trust in private companies with their health data because of the commercial interest in it. Also, private companies may try to influence one's opinions and access to information according to their own interests.

Scepticism

The identified scepticism against digital health services substantially concerned five categories. These are presented below. Just as for the security aspect, the codes needed to be divided into subgroups to find common themes among scepticism.

- *Unwillingness to log* - Restrained usage due to resistance towards logging of data:
 - In the long run people will forget to log.
 - Continuous logging is a stressful reminder of constant health decline, both in comparison with others and with oneself.
 - The usage of health apps consumes too much battery.
 - Only willing to log on the advice of a doctor and for a short period of time.
- *No personal benefit* - No personal gain is seen in the usage of digital health services:
 - No interest for the quantitative.
 - Nothing to prove for oneself or others.
- *Negative impact* - Concerns over negative impact on the individual from access to information:
 - Access to health information can have negative impact on the mind.
 - Access to health information can lead to too much individual responsibility.
 - Sharing possibilities risk decreasing personal integrity.
- *System scepticism* - Suspicion against the healthcare's ability to run IT projects:
 - New systems will be as useless as existing systems.
 - A new system would only be one in the crowd of systems.

UX aspects

The identified usability requirements can be categorised into four different categories which are presented below.

- *Simple interaction* - The interaction with services must be simple:
 - Few main functions
 - Few steps to get where you want
 - Easy to understand

- Easy to start using
- *Easy access* - Easy to access services at all times and smooth sign-in process.
- *User customised* - The services need to be able to accommodate possible disability. For example, by making sure that the interface is uncluttered, the text is readable and voice control is possible even with unclear speech.
- *Automatic* - It is important to make the usage as automatic as possible since time consuming logging with manual input will discourage usage.

6 Concept generation

This chapter describes the different steps in the implementation, analysis and results of generating concepts based on the findings in the previous phases of the project.

The third step of the concept phase was to put the insights from the user studies into action by generating ideas and concepts that would satisfy the users. This was done in several steps. First the insights regarding the users were summarised into different personas. These were then used to generate goals and requirements. Lastly, the goals and requirements were used as a foundation for generating several concepts.

6.1 Personas

A persona is a concrete representation of a hypothetical type of user, based on the collected user data. Personas are synthesised from the observations of several people and are made alive by creating personal portraits including names, pictures, personalities and goals. A persona provides a concrete picture of who the design is for which increases the empathy of the designer. Since personas portray the needs and goals of the users they become a concrete way of discussing, understanding and remembering the end goal of the design process [37]. Furthermore, it can be useful to include attitudes, skills, tasks and environment as well as hobbies and other things that help the designer to see the persona as a real user [35].

In this project personas were created as a concrete way to discuss the different user groups and problematise their context. Moreover, they were also intended to be used as a validation basis in future phases of the process.

6.1.1 Implementation

The data from the interviews was used to create the personas. Different variables from each interviewee were summarised, such as age, attitude, motivations and frustrations. Using these variables the interviewees were divided into different categories, though they could belong to several categories at the same time. From these categories the personas were formed. Each persona had clearly stated backgrounds, motivations, frustrations and user goals as well as a profile describing attitudes, fears and difficulties in life.

6.1.2 Results

The categories, that the interviewees were divided into, were age, attitude towards storing data digitally, disease and ability to work. From these, four personas were created: two men aged 28 and 58 and two women aged 47 and 62. All had different attitudes towards storing data digitally as well as individual motivations and frustrations in life. The full portrait of each persona is found in Appendix F.

6.2 Concept goals

As a way of concretise the intentions and aims of the users, and consequently the project, goals were formulated. This was done using the findings from the previous phases of the project. Though there are different kind of goals that can be used, in this project effect goals and UX attributes were considered the most suited. Effect goals are supposed to answer to *why* the project is being implemented. This kind of goals should point out the needs or challenges that constitute the basis of the project and what the project should accomplish in the long term. UX attributes are a particular type of effect goals which describes the qualities intended to be experienced by the users while interacting with the system or product. The UX attributes are descriptive keywords that should target the user experience to strive for [37].

6.2.1 Implementation and analysis

To set the final goals, a creativity session was held, trying to find the core of the needs identified in the user studies. A technique called *Why – why – why?* described by Löwgren and Stolterman was used as inspiration [44]. The challenges identified in the background information gathering, the survey and in the interviews were put together and for each challenge the question *Why is this a problem?* was asked. This was discussed by the project members and when a conclusion was reached it was written down as a statement. The same question was then applied on the statement and the same procedure followed resulting in a new statement that was written down. The question of why was then asked a third time on this statement, and was discussed until a final conclusion was reached. During this procedure several ideas were generated and written down. An example of this, concerning contact with healthcare, is displayed below.

Challenge: It is difficult that the caregivers do not see the whole picture, instead they focus on the physical symptoms.

– *Why is this a problem?*

Statement 1: The caregivers do not prioritise the psychological problems.

– *Why is this a problem?*

Statement 2: An important part of the care needed is not given.

– *Why is this a problem?*

Statement 3: Lack of psychological support makes everything else more difficult to deal with.

After applying this technique on the most critical challenges all of the final conclusions were summarised in a list. These were then used as basis when forming the effect goals. It was made sure that each effect goal was helpful for at least one of the challenges and that all challenges were covered by at least one of the effect goals. Each goal was discussed and re-written until both of the project members were satisfied. After this, UX attributes were created, using findings from the background information gathering and interviews. Foremost the findings regarding UX aspects from the interviews were used in forming the UX attributes.

Finally, a discussion was held regarding the match between each effect goal and the personal goals of each persona. This in order to evaluate the effect goals in a more realistic context to see if they were reasonable and comprehensive.

6.2.2 Results

In total, seven effect goals and eleven UX attributes were formulated.

Effect goals

The effect goals are presented below, together with a summation of the underlying challenges and facts as motivation:

Goal 1: Provide easy-to-understand and personalised information

Motivation: One of the key findings from the interviews was that the users found it very challenging to find and verify available and customised aids, services and treatments and thereby missing out on necessary help. One of the reasons for this was that there was no intuitive place where this kind of information could be found. Moreover, when looking for available services, it was considered a problem to identify and verify which ones were suitable and safe to use. This insight is further validated by looking at the literature, where the problem with mobile health app overload has been recognised [16]. Another finding from the interviews was that the websites offered by the healthcare, possibly containing this kind of information, were considered not user friendly and cumbersome. This is further validated in the study conducted by BearingPoint, where it was concluded that the websites provided by Swedish caregivers contain limited interactive elements explaining how to find different caregivers. In the same study it is also concluded that the channels provided by healthcare where patients can search for information are very limited. Furthermore, the Swedish caregivers fail in providing digital contact surfaces through mobile channels as they do not offer any apps or have particularly mobile adjusted websites with prioritised content [15].

According to the survey sent out in this project, 88% of those with a chronic disease, used the internet to find health information. Hence, there is a gap to be filled as the users want to use the internet to find health information and services, but due to above mentioned reasons it is often difficult. However, this could be facilitated by offering a service in which clear and customised information for specific types of conditions can be easily accessed.

Goal 2: Enable smooth communication with healthcare

Motivation: Deficient communication with caregivers, with limited channels for getting in touch with a caregiver on own initiative, was considered a big issue among all of the interviewees. From the interviews it was concluded that the need for flexible communication with caregivers is not only connected to treatment, but also essential to get certificates needed to access sick pay from the insurance fund. The recurring issues connected to getting sick pay certificates in time were considered very time consuming and caused both stress and frustration among the interviewees. At the same time, three out of four of the survey respondents thought that the future healthcare would include digital contact with caregivers. Moreover, half of the respondents would like to be able to digitally share their health information with caregivers. Hence, there are both big needs and expectations on efficient ways to communicate digitally with caregivers.

Goal 3: Provide a tool for better mental health

Motivation: Psychological challenges were described by all of the interviewees. Many expressed that the psychological issues overshadowed everything else. Furthermore, the interview analysis clearly stated that being diagnosed with a chronic disease can

mean a lot of life adjustments. In several cases the interviewees had been forced to give up on hobbies and work and lost friends and context. Moreover, their ability of performing as others and doing things they had dreamt of were sometimes lost. Due to decreased abilities, an increased risk of facing economical insecurity was also identified. All of this, along with possible symptoms of the disease, contributes to a huge psychological burden which is often hard to handle. In order to manage this, all but one of the interviewees used support from other patients by engaging in patient associations. Some also regularly visited a psychologist on their own initiative. Almost all interviewees expressed concerns about the absence of physiological help connected to the diagnosis. Furthermore, frustration about the healthcare only focusing on the physical symptoms and forgetting the mental health, was expressed. Thus, a simple tool for helping patients with psychological challenges would make a great difference.

Goal 4: Provide a safe platform for sensitive information

Motivation: Personal health information is very sensitive information, which in the wrong hands can be misused. This is something most interviewees addressed. Hence, the demands on security when storing health data are high. According to the survey almost every second respondent feel most safe in storing their health information themselves. Only a very small number of people feel most trust for private companies. This was further confirmed by the interviews, where all but one interviewee expressed concerns regarding the safety aspects of digital storage of private health data. These interviewees would not want to store health information in a private company and felt a greater trust for the state. At the same time, half of the interviewees expressed some kind of reflection of the risks of sharing too much information with the state, one example being that state owned agencies not always remain that way (i.e. become private companies). Considering these concerns it is of utmost importance that health services, which in almost all cases are required to store some kind of personal health information, are safe.

Goal 5: Provide a tool for easy contact with the insurance fund

Motivation: Ten of the twelve interviewees were partly or fully on sick-leave. As mentioned, meeting the requirements from the insurance fund for accessing sick-pay or sickness compensation were among these considered time consuming and linked to a lot of frustration and stress. Much alike the caregivers, the communication channels to the insurance fund were considered to be very restricted. Moreover, several of the interviewees felt that the insurance fund officers were treating them badly due to poor knowledge about their condition. Not being able to work full-time is overall very common among people with chronic diseases, and during 2016 these stood for 86% of the sickness compensation and 40% of the sick-pay [2]. Hence a better and easier way of communicating with the insurance fund is very much required for people with chronic diseases.

Goal 6: Provide effortless storage of collected personal health information

Motivation: Most of the interviewees, ten out of twelve, expressed a frustration regarding not having any smooth way of accessing their health related information. Some had been able to get their medical journal printed on paper, but this was not possible in all hospitals. According to the survey, a similar share of about 85% replied that they would have a significant or great benefit of accessing their medical information digitally. Furthermore, three out of four of the survey respondents with a chronic dis-

ease found it to be very beneficial to be able to store their collected health information digitally. As mentioned, several of the interviewees expressed frustration towards the websites offering digital access to health information today, which were considered not user friendly and difficult to navigate.

The survey showed that almost all of the respondents diagnosed with a chronic disease, 92%, wanted to regularly log some kind of health information. Almost as many, 86%, also wanted to be able to perform automatic analysis on their logged data. For this to be possible it is very important that the logging and storage of this information is effortless and simple. This was enhanced in both the workshop and the interviews, which addressed effortlessness and simplicity as a requirement for continuous usage.

A further motivation for this effect goal is that patients, when able to effortlessly access and store health information, would become more involved in their own health. Research shows that patient engagement increases health status and quality of life [45].

Goal 7: Enable communication and exchange with peers

Motivation: 73% of the participants in the survey wanted to be able to share selected part of their health data with others. Furthermore, all except one of the interviewees said that they were a part of a patient community, where patients exchange experience. As mentioned before, the exchange with others in similar situations is an important part in handling the psychological pressure of having a chronic disease. A majority of the interviewees mentioned meeting other patients as a fundamental part of accepting their disease and feeling better. Therefore, it is important to enable easy communication with peers.

UX attributes

The UX attributes are shown below. The motivations behind these attributes are found both in the results from the interviews and in the motivations of the effect goals.

<i>UX 1:</i>	Simple interaction
<i>UX 2:</i>	Easy to understand
<i>UX 3:</i>	Easy to start using
<i>UX 4:</i>	Few steps
<i>UX 5:</i>	Easy access
<i>UX 6:</i>	Minimised number of main functions
<i>UX 7:</i>	Easy to overview
<i>UX 8:</i>	User customised
<i>UX 9:</i>	Entertaining to use
<i>UX 10:</i>	Automatic usage
<i>UX 11:</i>	Safe

Relationships between effect goals and personas

From the evaluation of the effect goals it was concluded that they were applicable. However, the original wording of Goal 6 was considered to be too broad and not pinpointing the essence of the goal. Therefore, the word *effortless* was added. In appendix G the meaning of the effect goals for each persona can be seen.

6.2.3 Generating concepts

After formulating the goals of the project, the next step included using these goals to create design concepts. A design concept is a way of communicating the core of a product or a service. Furthermore, it is a working hypothesis regarding the knowledge, actions and feelings related to the product or service. According to Arvola, the design concept can be defined by three things: (1) *what* - a description of what is about to be designed, (2) *why* - a motivation describing the purpose of why something needs to be done and (3) *overall how* - what kind of service it is and concrete principles and qualities to follow and aim at. Answering these questions can result in several different concepts. By refining the differences between the generated concepts a further divergence between the concepts can be achieved [37].

In this project concepts were generated as a way of expressing diversified possible solutions to the identified needs at a high level.

Implementation and data analysis

Ideas for the concepts were generated in a brainstorming session with the two project members. During this session the project members spent 15 minutes of individually brainstorming ideas and writing down keywords on post-it notes. As an inspiration the effect goals and the overall findings from the user studies were used. After the individual idea generation each project member presented their ideas. These were then categorised according to similar characteristics and types of interfaces. During this phase some new ideas emerged and were added to the others. The categories and their related ideas were then summarised in an affinity diagram. Some of the categories, that were considered rather vague, were put together to create a more distinct suggestion.

Each of the final categories was set to symbolise a concept. These concepts were then further explored by discussing different possibilities. The concepts were also further detailed by defining the what, why (as in the purpose of the concept) and overall how. Furthermore, each concept was given a name.

Results

The 15 minute brainstorming resulted in 20 ideas regarding different digital services for easing the everyday challenges of chronic diseased. The subsequent categorisation of the ideas finally resulted in four concepts. In the further detailing of the concepts some of the concepts were modified as they were considered too similar to the others.

The final four concepts were:

- **MyHealth** - A personal, digital health account
- **HealthSharing** - A health crowdsourcing platform
- **S.A.M.** (Social Artificial intelligence Mate) - A social AI buddy for disease management
- **GoHealth** - A gaming app for health challenges

The purpose and overall how of these concepts are presented in figure 6.1 below.

MyHealth

A digital health account

What?
An interactive digital health account for collecting, storing and overviewing health related information and data.

Why?
Helping chronic diseased to take control of their disease management and accessing all relevant information in one place.

How?
A personal account customised according to the interests of the user. For instance the user can access personal information from healthcare. Furthermore, by adding information about condition and by logging data, personalised recommendations and compilations of useful links can be provided. The account should be compatible with health apps and wearables for automatic logging and be easy accessible from smartphone and computer. Logged data should be safe and easily overviewed and sharing data with healthcare, authorities and others should be smooth.

(a) MyHealth

HealthSharing

A health crowdsourcing platform

What?
A platform for finding solutions to health related challenges by using the knowledge of the crowd.

Why?
Helping chronic diseased, relatives, caregivers, other healthcare related officials and students with health related challenges by sharing knowledge and experiences.

How?
A platform where anyone can create an anonymous account and add challenges or cases related to chronic diseases. The challenges are created by choosing a category, such as “disease acceptance”, “insurances” or “physical pain”, and adding information to a standard form customized to the category. Further relevant information, such as logged data, can easily be attached to the form. All the other users can then add solutions or comments for everyone to see. The solutions of each challenge are prioritised and summarised using AI and the clicks and votes of the users. Trending threads and popular profiles within the user’s regular search fields are shown in an interactive compilation.

(b) HealthSharing

Figure 6.1: Concepts

<h2 style="margin: 0;">S.A.M.</h2> <h3 style="margin: 0;">A social robot for health management</h3>
<p>What? An intelligent and social robot created to be a friendly help with everyday disease management.</p> <p>Why? Supporting patients with chronic diseases with everyday disease management, motivation and support by creating a personal relationship.</p> <p>How? A robot with built in AI that is both a social support that converses, listens and remembers, and also an aid that helps with care administration and reminders. The interfaces of the robot can be customised according to needs, from being voice, chat or touchscreens. The amount of interactions initiated by the robot can also be customised according to preference. Health information can easily be uploaded and stored to be used for better support, reminders and analysis. The robot can inform about new research or treatments if desired, and can alert caregivers or relatives in case of not being answered.</p>

(c) S.A.M.

<h2 style="margin: 0;">GoHealth</h2> <h3 style="margin: 0;">A mobile app game for better health</h3>
<p>What? An app using gamification and challenges for creating incentives for better disease management.</p> <p>Why? Supporting and motivating a sustainable everyday chronic disease management by making it entertaining.</p> <p>How? An app where the users enters medical conditions and overall ability level with regards to mobility, energy and similar. The user can also do diagnostic tests to set ability levels. The app sends out challenges to be achieved, related to physical and brain exercise, meditation and relaxation, healthy diets and learning about disease. The user can add own challenges and goals to be supported by the app. The severity of each challenge is set according to the ability of the user and is automatically adjusted according to previous performance. For each completed challenge the user receives points that can be used for donating money to research. It is also possible to connect to groups where one can compete together. The app can be extended with wearables or other types of technology.</p>

(d) GoHealth

Figure 6.1: Concepts

7 Defining concepts

In this chapter the design concepts developed in chapter 6 are further elaborated by defining conceptual models and writing scenarios.

In the last step of the concept phase the generated concepts were further elaborated by defining conceptual models and scenarios for each concept. The results were then evaluated and compared against a number of criteria.

7.1 Conceptual models

When using, reading or talking about an interactive system, the users construct a mental model of how the system works. This mental model allows the users to predict the behaviour of the system and generalise what they learn to new situations. When designing a system interface, the designer should strive towards helping the users to quickly create a mental model that corresponds to the designer's intention. A good way to do this is by defining a *conceptual model* of a system before designing its user interface [46]. A conceptual model is a way of describing a proposed system and its user experience [35]. Conceptual models help the designer to communicate the underlying intention of the design. Johnson and Henderson describe a conceptual model as "a high-level description of how a system is organised and operates" [46, pp. 26]. This means illustrating, on an abstract level, what the user is able to do with the product and what concepts are needed to understand it [35]. This is done by specifying and describing four core components [46]: (1) the major design metaphors or analogies, (2) the concepts that the user is exposed to when using the system, (3) the relationships between these concepts and (4) the mappings between the concepts and the task-domain.

Metaphors are used to make people understand what the product is for and how to use it. The usage of a known metaphor allows for a direct understanding through familiarity [35]. The concepts of the conceptual model includes the objects that the user creates and manipulates, their attributes, and the operations performed on them [46]. These types of concepts, however, are not to be mistaken for the design concepts generated in the previous chapter. An important component of the conceptual model is the object/action analysis. In this the concepts, i.e. the user-understood objects, including their attributes and operations, exposed to the user are summarised [46].

When creating a conceptual model the goal is to keep it as simple and as focused on the task-domain as possible. By designing a conceptual model the final product is more likely to be more coherent, less arbitrary and less complex [46]. In this project conceptual models were produced for the four design concepts. This was done as a way of further detailing the overall how and describing the suggested solutions on a system level.

7.1.1 Implementation

The first step of creating the conceptual models was to discuss the actual purposes of the systems. These had been defined as the "Why?" in the design concepts. In the next step relevant metaphors to use were specified, this through a discussion between the project members.

The object/action analysis was performed in several steps. Firstly the tasks that the users could perform using the systems were identified. This was done using the descriptions of the concepts. The chronological executions of these tasks were then detailed in a schematic description. By using the schematic descriptions of the tasks the different objects and their related attributes and operations were identified. During this implementation it was constantly taken into account that the conceptual model should be as simple as possible and thus, having a minimum number of objects.

To visualise the relationships between the concepts, flow charts were created. In these arrows and disposition of the objects were used to symbolise their inter-relationships.

7.1.2 Results

An example of how the schematic descriptions of the tasks were done is shown in figure 7.1. The direction of the arrows show the order in which the steps are preformed.

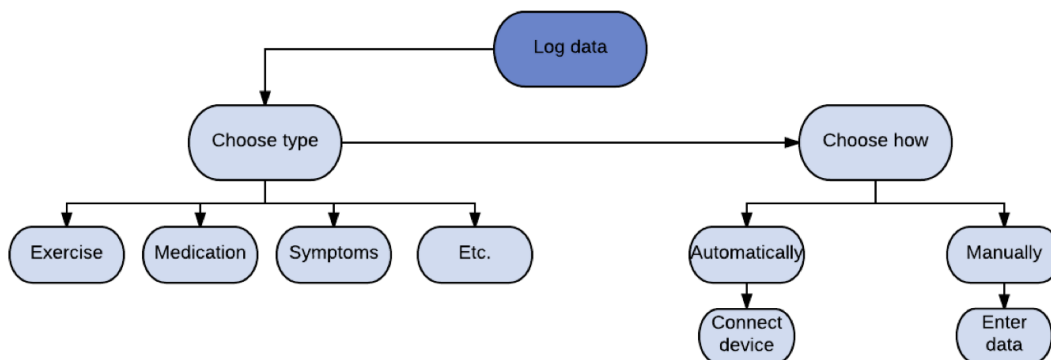


Figure 7.1: A schematic description of how to log data in the health account MyHealth

The conceptual models of each design concept are described below. Figures 7.2-7.5 show the flow charts describing the objects, attributes and actions and their relationships. As mentioned, the relationships between the concepts are described through arrows and disposition of the objects. The direction of the arrow shows the direction of the information flow, i.e. information in the object that the arrow originates from can be added to the object the arrow points at. The disposition of the objects represents the hierarchy of them, meaning that objects below are dependent on one or several of the objects above.

MyHealth

The major metaphor that this conceptual model is based on is that of an account. Having many accounts already, it is natural to assume that a user directly is capable to understand the concept and what can be done with it. In this case, instead of money, as in a bank account, the account will be filled with health information. And rather than money, it will be information flowing in and out of the account.

As can be seen in figure 7.2, the user is exposed to eight different objects. The user Account is at the top of this conceptual model and contains basic information about the owner (user). To the Account three other objects are directly connected: User data, Healthcare information and Calendar. User data can be of different categories (such as exercise, medication, pain etc.) and is added manually by the user or automatically by a connected device. Healthcare information can also be of different categories (such as health record, prescriptions, test results etc.) and is requested by the user and added automatically from caregivers. The Calendar object, which can be chosen to show a daily, weekly or monthly focus, contains Event objects. These can either be manually created from the calendar or automatically created from the healthcare information object. The Notification objects, including Reminders as a subtype, can be related to either User data (e.g. reminder to log data), Events (e.g. reminder to attend appointment) or Healthcare information (e.g. notification that new information has been added). The Recommendation objects collect information from the User data and the Healthcare information and from this propose customised recommendations to the user.

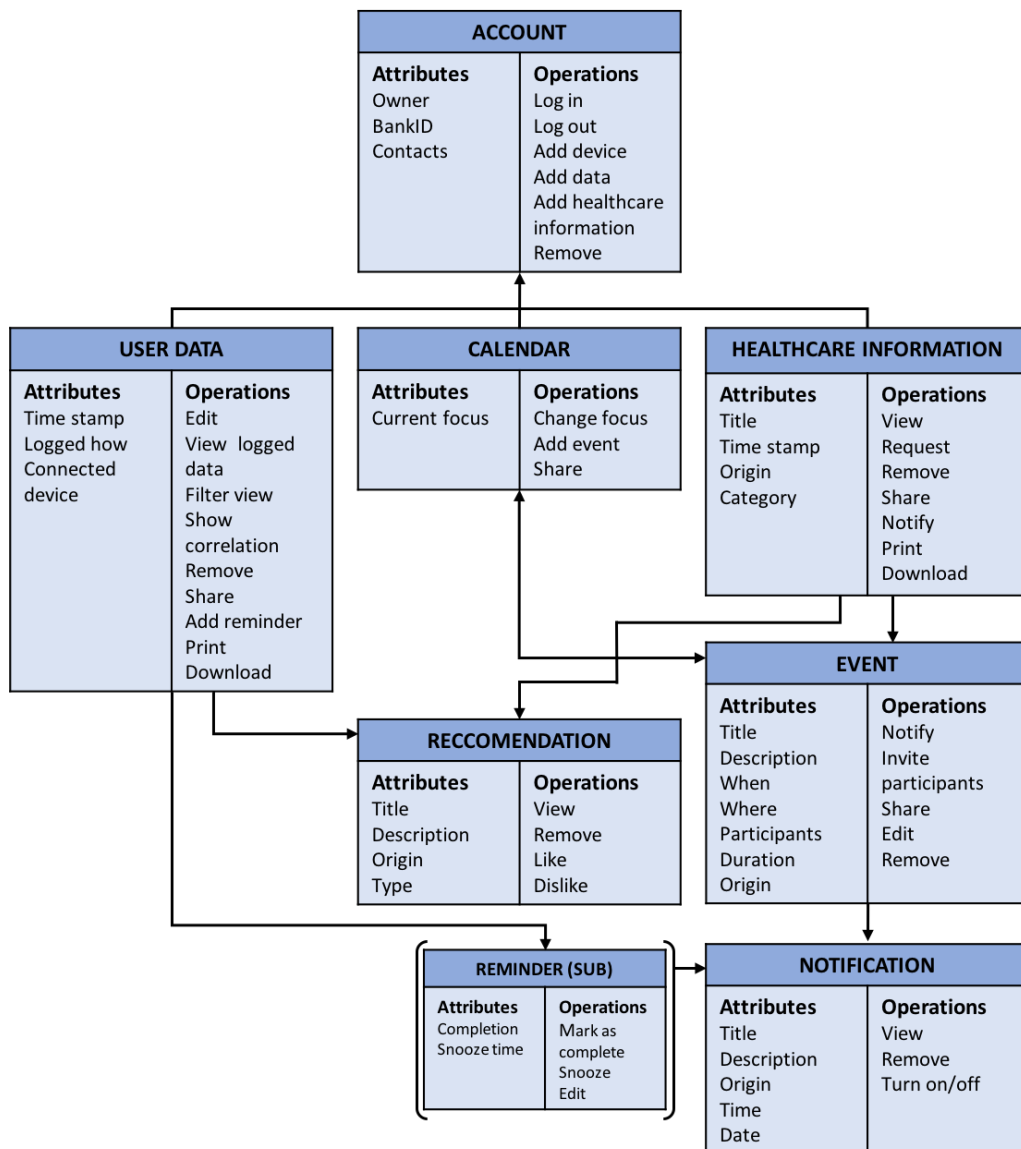


Figure 7.2: Flowchart of MyHealth including objects, attributes and operations.

HealthSharing

Using the knowledge of the social networks used today, the main metaphor in this model is based on a social feed. In this feed the challenges, the other users and overall content are presented as cards. Cards have a familiar form factor and an intuitive way of organising limited content. Just like on Facebook or Twitter, the users are able to comment or follow content directly on the card. In addition to this, the users can also add a solution which will present itself to the user as another card attached to the challenge card.

The platform is built on five different objects: Account, Feed, Other profile, Challenge and Solution. These can be seen in figure 7.3. The Account, where the owner is the user, is connected to the Feed which shows automatically prioritised content from the followed profiles and challenges. Hence, the Feed is connected to and contain information about Other profiles and Challenges. Other profile objects contain information about the other users and the user can interact with these by following them. Challenge objects are of different categories (such as disease acceptance, pain management, authorities etc.) and are created by users. A created Challenge enables users to create Solution objects. Each Solution is connected to a Challenge object which contains all suggested solutions created by the other users.

S.A.M.

The conceptual model of this system is built on the metaphor of human interaction. The system is able to converse with the user, both through speech and text, and to express concerns, thus mimicking human relationships.

The system is built on five objects which are visualised in figure 7.4. The top object is the Owner of the system, i.e. the user. Connected to the Owner are Conversation objects and a Calendar object. Conversation objects include communication with S.A.M. through calls or chat which are either initiated by the user or by S.A.M. The Calendar contains Event objects. The Events, which can be added manually by the user in the Calendar or by S.A.M. after a conversation, can either be Future events or Memories. Future events are connected to Reminders which can be set by the user or by S.A.M.

GoHealth

One metaphor for this conceptual model is a timeline. Having a timeline is a simple way of representing passed event, using the linearity of time and the familiar longitude representation. Moreover, the conceptual model includes a data library with challenges. In this the users can see all available challenges. In this library it is possible to find and search for challenges that are completed and not completed, just as it is possible to find and search for read and unread books in a real one.

The gaming app concepts and their relationships are visualised in figure 7.5. On the top is the Account object which contains profile information and user settings. Connected to the Account are a Timeline object and a Library object. The Timeline can be filtered and shows all of the user's accepted challenges over time. The Library, which can also be filtered, contains all available Challenges. The Challenge objects are connected to the Library and can be of different subtypes (such as physical, learning, relaxation etc.). The Challenges are found in the Library and can be accepted and completed. Challenges are also linked to different types of Notification objects with the purpose to encourage, remind or inform the user.

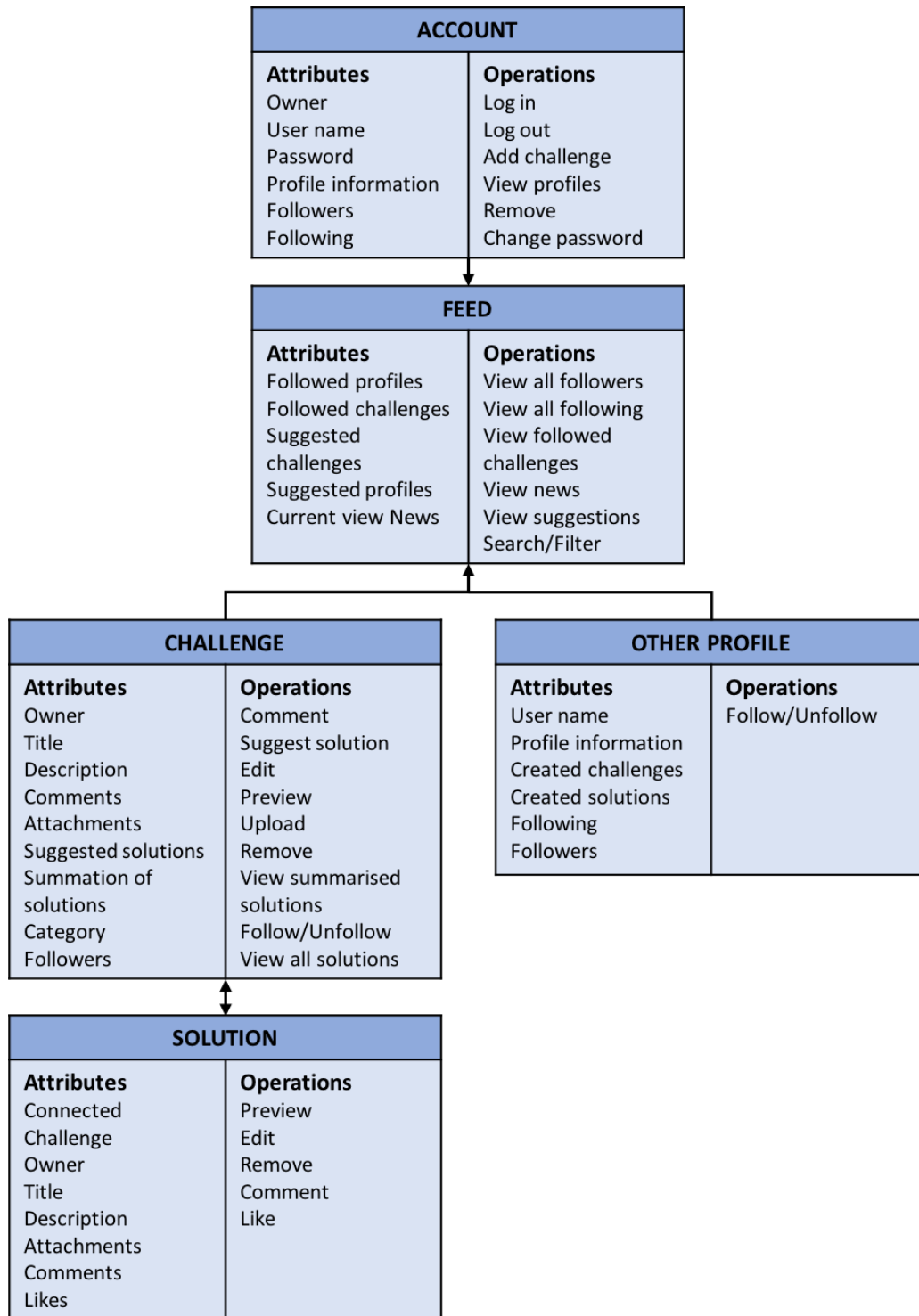


Figure 7.3: Flowchart of HealthSharing including objects, attributes and operations.

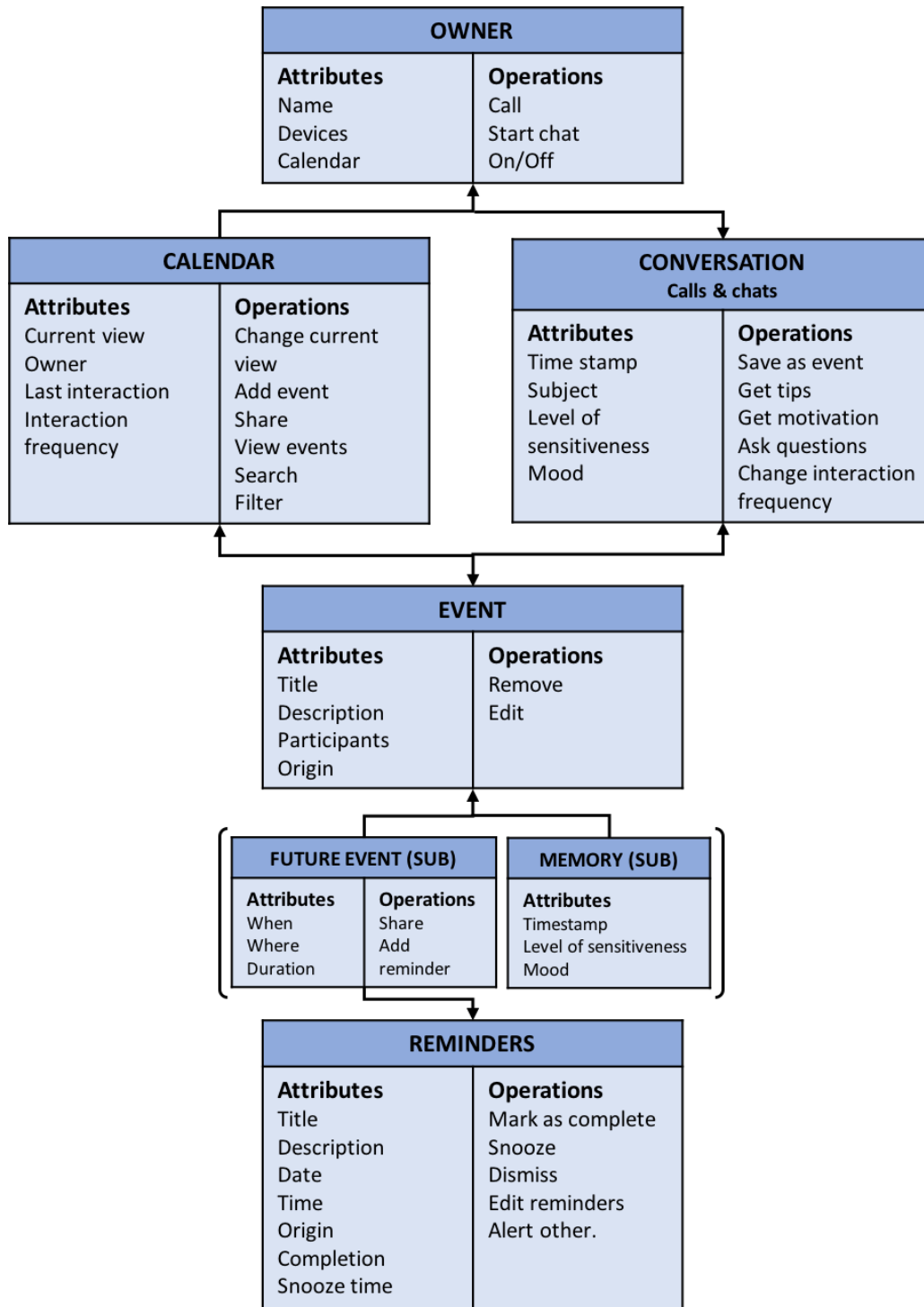


Figure 7.4: Flowchart of S.A.M. including objects, attributes and operations

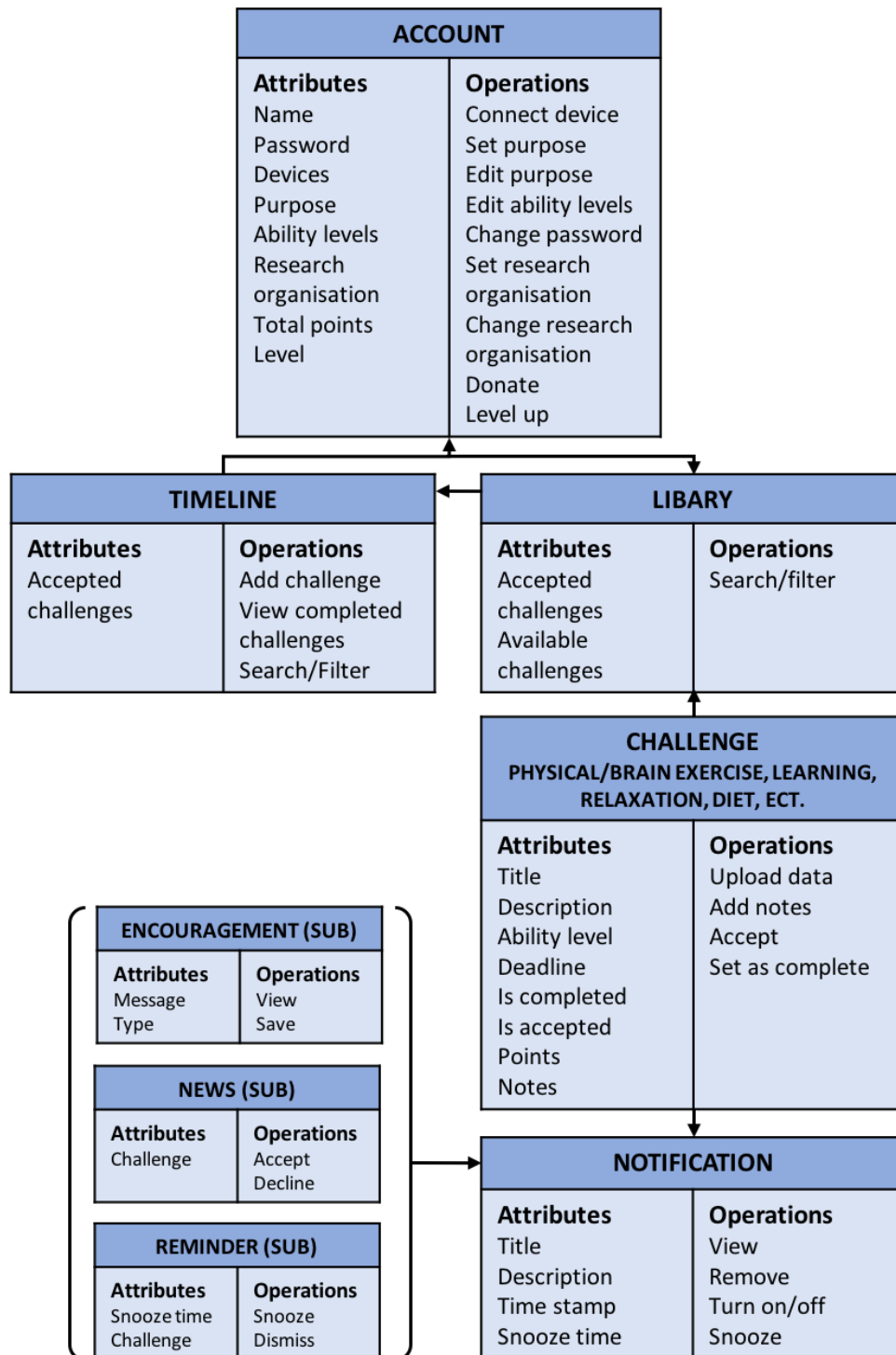


Figure 7.5: Flowchart of GoHealth including objects, attributes and operations.

7.2 Scenarios

A scenario is a narrative that describes interactions and behaviours of a persona in a given context [35]. The scenario describes when, where and how a series of events occur from the perspective of the persona [47]. Scenarios are created to better understand the current behaviour of the users and to explore their constraints, irritations, contexts and facilitators [35].

In this project, scenarios were created in order to better understand the behaviour of the users in the different design concepts and as a way of testing and describing the conceptual models.

7.2.1 Implementation

The personal goals of the personas, and their relations to the effect goals were used as a basis for formulating scenarios for each concept and person. Trying to describe as much of the design concepts and conceptual models as possible through them, the scenarios were chosen to be diverse while still suiting the situations and goals of the personas.

7.2.2 Results

Four different scenarios were created for each design concept. The below sections contain the scenarios for each user and concepts.

MyHealth

The scenarios below describes a health account called MyHealth and how the users interact with it.

Dennis

Dennis has been noticing that his mood the last few months has been very varied in a way he has never experienced before. To keep track of his mood swings his therapist asked him to log his mood twice a day. This he has done for the last two months using the MyHealth app. He has tried to find a reason for the mood variations, and the only thing that he can think of that has changed is that he has modified his training schedule to include more cardio training after he got a cardiometer for his birthday.

To investigate the potential influence from the cardio training on his mood, Dennis brings up his phone and opens the MyHealth app. In the app his account is pre-set and to log in he presses the log in button. This opens his BankID app where he enter his BankID code which brings him back to the app. In the app he chooses to view his logged data. Since he only wants to see the cardiometer values and mood logs he filters out all other measures he has saved in his account. Doing this shows him a time plot of his logged cardio values and mood. The plot shows that the morning after training cardio his mood is often better than than other mornings. To be sure this is an actual trend, Dennis presses show correlation which shows him the statistical correlation between this cardio training and mood variations. From the text and plots presented on his screen he can see that his suspicion, indeed, was right.

Lena

After a doctors appointment regarding a new medical certificate for her continued sickness compensation, Lena needs to directly send in the forms to the insurance fund. Since she was not able to book a doctors appointment until last minute she wants to

make sure that her allowances applications are on track. Opening up her iPad, she logs into the MyHealth app using her mobile BankID. After logging in, she sees she has one new notification as that the notification icon displays a 1. By clicking this icon a menu drops down showing her that she has received a new medical certificate. She clicks "view" and the certificate is shown. However, she wants to check if the date she received the previous certificate matches what this certificate states. Therefore, she clicks on Health information in the menu and chooses to see her medical certificates. These are shown in a list displaying receive date and title and are currently sorted so that the most recent is on top. Lena clicks on the second certificate, sees that the received information is correct and then clicks the left arrow to go back to the list. She then opens the new certificate and clicks the share icon. Clicking this provides a menu from which she can choose to share her medical certificate with her officer at the insurance fund. Said and done, Lena now has completed her application for continued health allowance. She receives a confirmation notification that her certificate has successfully been sent.

Eric

Eric is concerned what he has written down the wrong date for his next doctors appointment. Though he does not like to use his health account much, he has found that the calendar can be of help since his appointments with caregivers are automatically updated in it. Eric wants to check when his next appointment is and add a reminder to it so he does not miss it. Therefore he logs in to his MyHealth account, which according to his preference, directly shows his calendar. The calendar sheet displays the current month and there he can see that he has an appointment next week with his speech therapist. He clicks on this appointment and a card pops up showing detailed information about the appointment. This also contains a menu from which he chooses to set a reminder of this appointment that will notify him on the morning of the appointment. In the card of the speech therapist appointment Eric also reads the notes from what they discussed the last time he was at the speech therapist. This reminds him that he has forgot to do the speech exercises he was given why he directly starts to practise these.

Ruth

Tomorrow, Ruth has an appointment with a new doctor. She suspects that she will be asked the usual questions regarding what medications she takes. Since Ruth always forgets the name of some of her medications and doses she wants to print out a list of her prescriptions to show her new doctor. Therefore she opens her computer and logs in to her health account. In the menu she clicks on her health information and then chooses her prescriptions. These are presented as cards in a list, where each card contains information such as dosage and prescriptions date about one medication. In the right upper corner of the view there is a printer icon which Ruth presses to print out a copy of her prescriptions. Now, she feels ready for her doctors appointment tomorrow morning.

HealthSharing

The scenarios below describes a crowdsourcing platform called HealthSharing and how to interact with it.

Dennis

HealthSharing has helped Dennis a lot in accepting his disease. Though not an active member regarding posting his own challenges, Dennis has for some time now followed a few profiles with psychological challenges similar to his own. Reading the suggested solutions and comments on these challenges has given him new tools to handle anxiety and the pressure he has on himself. After a long working day he is curious about what has been posted regarding a challenge HealthSharing suggested him the same morning which he started following. The challenge, created by a man in his own age, regarded difficulties in letting new people into his life and sharing his feeling with others. This is something that Dennis can very much relate to. When logging into HealthSharing his feed is shown where this challenge directly shows up at a card at the top of the page. The notification icon also shows that updates regarding challenges and profiles he follows has been updated. He clicks on view solutions on challenge card which pops up and shows the solutions sorted after highest ranking. He reads the first one and finds it really interesting. To find out more about the author he clicks his name to go to his profile. There Dennis reads that he is a professor in psychology, specialised on issues of young people diagnosed with a chronic disease. Dennis instantly presses the follow button.

Lena

Lena is having problems with the insurance fund since they do not want to accept she cannot not work full time. When talking to her officer she is met with lack of understanding and little knowledge of the cognitive impairments related to Parkinsons Disease. Therefore, she decides to add a challenge on the HealthSharing to see if somebody else has tips or solution to this problem. When she clicks on the add a challenge a card pops up asking here to choose from a list which category this particular challenge belongs to. Choosing contact with authorities, she then comes to a form customised for these kind of challenges where she answers the questions to describe the problems she has. When this is done she selects to attach the medical certificate from her doctor, which is automatically anonymised, to the form. After previewing the challenge to see that everything is in order, Lena posts her challenge. A day later, Lena, who has turned off mobile notifications from the app in order not to be stressed by it, logs into her account. There she sees that she has received several comments and followers on her challenge. Her problem is more common than she thought. Moreover, she has received some suggested solutions to her problem. She chooses to see an automatically created summation of the solutions, which gives her a good idea of how to proceed when dealing with the insurance fund.

Eric

Eric does not use HealthSharing to create challenges of his own. However, he likes the fact that this is an anonymous forum and finds it very stimulating to follow a few profiles who often post very interesting scientific solutions related to stroke rehabilitation. One of these profiles, a neurologist, regularly posts solutions which are based on the most recent and up to date medical research. Eric loves to read these. Eric has been abroad for a couple of days and has not had any internet connection. On the airplane he read

in a scientific magazine about a new aphasia treatment study and he is now interested to see if this neurologist has posted anything new related to this. He therefore logs in to his account and in his feed he chooses to see his followed profiles. A list of cards containing Eric's followed profiles shows up, displaying the neurologists at the top. He presses the see recent activity button linked to the neurologist and a summation of his recent posts shows up. There he directly finds a challenge regarding which benefits to come from the recent study which the neurologist added a long solution to. Eric first reads the challenge and then leans back as he starts reading the neurologists very interesting reflections on the subject.

Ruth

While not having added any challenges herself, Ruth is quite active on HealthSharing. Through her engagement within her patient association and her many years of living with the disease she has gained many insights and experiences. These she likes to share with others. In her account she has chosen to filter her feed so that she can see only her favourite categories. These are exercises for the brain, symptom management and contact with authorities. After being out on a short walk she has an hour to spend before meeting her oldest daughter for dinner. She therefore logs in to her HealthSharing account to see if anything new has happened. In her feed she finds suggestions for several new challenges. One she finds particularly interesting is about wanting to find a way to exercise her cognitive abilities. Since Ruth has recently tried out a new app called GoHealth, which makes a game out of all kinds of exercises, she directly clicks on the challenge and chooses to add a solution to it. A form pops up in which she describes the app and where to find it. She then previews her answer, making sure not to have made any spelling mistakes, and then presses post. Ruth goes back to her feed and sees that a profile which she follows has posted a new challenge about having problem with her contact at the insurance fund. Ruth does not have any concrete tips or solutions but nonetheless she wants to show her support. Therefore, she comments on the challenge, wishing her fellow patient good luck.

S.A.M.

The scenarios below describes how a user may interact with the social AI, S.A.M., in different ways.

Dennis

Dennis has used his S.A.M. for some time now and has connected his fitness tracker to it. A month ago he got a task from his psychologist to make notes of his mood three times a day to see if he can notice patterns. As Dennis has already much on his plate, instead of taking notes and trying to find patterns himself he leaves that to S.A.M. Each day Dennis sends S.A.M. a text regarding his mood in the morning, during lunchtime and in the evening. If he forgets, he gets a text from S.A.M. to remind him. The last couple of days Dennis has been feeling rather down and inadequate. This is of course something S.A.M. has noticed. As Dennis has previously indicated that he prefers written communication he gets a text from S.A.M. saying Hi there pal, seeing you've not had the best week. Care to talk about it? You know you can call me at any time.. Dennis, who just got home from work and really need some motivation before going to his work-out session presses the call-up button in the text message. During a ten minutes talk, he gets both motivation and answers from S.A.M. who has seen patterns in his mood and activities. After the talk Dennis feels encouraged and has reached the

conclusion that he should go back to the evening exercise class he took before, an hour earlier. This as he has been sleeping uneasily and hence been feeling worse since he changed.

Lena

For Lena, S.A.M. is a stress relief. Since starting using S.A.M. Lena has talked to it every day about everything and nothing. She has shared her calendar with it and now feels confident about not missing any appointments or deadlines as S.A.M. always reminds her. Lena has just been to her quarterly visit at her neurologist. From previous neurologist appointments S.A.M. has learnt that afterwards Lena usually books an appointment with her insurance fund officer. Therefore, by itself, it looks if there are any available times on the website and suggest which one Lena should book. The suggestion is based on her scheduled activities and which hours a day she usually have the most energy. Lena gets a text from S.A.M. saying "Hi Lena! How was the neurologist appointment? Do you want to book an appointment with Sara at the insurance fund on Monday at 11 a.m.?" . Lena texts back: "Yes, Monday at 11 a.m. works great! Ill call you later about the neurologist.". She gets a link to the website where she just needs to confirm the appointment booking using her BankID and it is then automatically saved in her calendar.

Eric

Eric likes to stay up to date with new research and treatments within stroke and aphasia. However, there are a lot of research being published within these areas and he sometimes struggles in concentrating when reading. Though he does not want S.A.M. to contact him by itself, Eric gladly asks it regarding new research. Eric has also realised that talking to S.A.M. is a good way of practising speech without being judged. Eric has just been to his speech therapist and got some new speech exercises. Therefore he opens his S.A.M. app and presses the Call button. S.A.M. greets him and asks him if he has anything particular on his mind. Eric tells it about the new exercises and S.A.M. then acts like a mentor, correcting Eric gently when wrong and praising him when right, while he does the exercise. After doing the exercise Eric asks about the most recent research. S.A.M. has two new articles on aphasia that it, based on previous interests, thought might be of interest. Eric asks S.A.M. if it can read a summation of them for him to see if he wants to hear the whole article or not.

Ruth

Ruth has not initiated any contact with S.A.M. for a while, something she usually does frequently. Therefore, S.A.M. calls her to see if everything is alright. When answering, Ruth admits that she simply forgot to call, something S.A.M. has noted that she has been doing more and more often lately. S.A.M. then asks her if she would like to set a more narrow timespan between contact so that she can feel safe knowing that she will have someone who checks up on her regularly. Ruth says that she is fine but it can ask her again in a few months and maybe she will have changed her mind. Leaving that, S.A.M. then asks her if she has been out walking today. She answers that she has, and that she managed to walk longer than last week. S.A.M. then praises her for her drive for improvement, and reminds her that since she changed medication she has improved her walking a lot.

GoHealth

The scenarios below describes a gaming app called GoHealth and how the users interact with it.

Dennis

Dennis really likes to take on new challenges. Since starting using GoHealth Dennis has done at least three challenges a day. He gets a thrill from knowing he can manage to do these while having a chronic disease. Today he has completed all of his suggested challenges and feels like trying out something new, going out of his comfort zone a little bit. He opens his GoHealth app and goes to the challenge library. There he can see all active challenges and sort them according to relevance to him. Among the challenge categories he finds mindfulness which to him sounds interesting. He filters the challenges in the library on that subject. This shows him all mindfulness challenges, showing the ones best matching his abilities and experience first. He chooses to read more about one that span over several days and after this clicks on Accept challenge. He can now see this challenge on his timeline. During the next few days, Dennis gets notifications from GoHealth to remind him to complete the challenge and motivating him do the necessary exercises.

Lena

For Lena the greatest motivation for using GoHealth is to collect as many points, and consequently money to research, as possible. Lena has chosen to donate her money to Parkinsons Disease research in hope that it will lead to new discoveries and treatments. Though she tires easily and needs to be careful not to exhaust herself, Lena has found that she can manage to do several challenges every day as long as they are not all of the same type. Her suggested challenges from her GoHealth app have been adjusted according to this. Today, after completing her meditation challenge her phone buzzes. The GoHealth notification is telling her that there is an exercise challenge that might interest her. She reads about it and feels tempted to accept it and to go directly out running, but as she has not eaten her lunch yet she decides to snooze it. Instead she makes a salad for lunch and eats a fruit for dessert, and then goes into her app and marks the fruit and vegetable challenge as completed. After lunch Lena gets a new notification reminding her about the snoozed challenge. She decides to accept it and puts on her training clothes.

Eric

Since Eric likes to to read research articles and learn more about aphasia. Above all, he really enjoys the quizzes offered by GoHealth. He likes to go into the app regularly and play a quiz or two. Eric has also found that he can exercise his speech through GoHealth, and finds the points received after each completed challenge as a fun motivation. After visiting his speech therapist he wants to add his new speech exercises as a challenge. He opens the GoHealth app and and goes to his timeline where he can see all his accepted and and completed challenges. He feels a bit proud as he sees how many quizzes he has finished. He can also see that he makes progress since these challenges get more advanced. To add a new challenge he presses the plus button and a form pops up where he adds information about and deadline for the speech exercise. He then chooses to add a notification to the challenge in order to be reminded to do the exercise. After saving as an accepted challenge he sees that the new challenge has been added to his timeline.

Ruth

Ruth has found that through exercising her cognitive abilities she gets better at finding the right words which allow her to take a more active part in conversations. GoHealth helps her with this through finding challenges and making a game out of exercises these abilities. Twice a day she gets a new challenge, a gamelike exercise where she trains her multitasking skills, memory and vocabulary. Today she has already finished her cognitive exercises, but after dinner she feels like doing some more challenges. She knows that she is close to reaching a new level which will give her access to even more challenges and to collect more money to donate. Ruth opens the GoHealth app on her tablet and goes to the library to see all active challenges. She is prepared to filter for a brain exercise challenge, but at the top she finds a 15 minutes walking challenge that seems to suit her ability. She sees that the points are just enough for reaching the new level, and as it is a beautiful spring evening and she has been inside all day she feels motivated to take a walk. She therefore accepts the challenge. After putting on her walking shoes she presses the Start walking button connected to the challenge which will notify her when completing the challenge.

7.3 Concept assessment

The final step of the project included comparing the different concepts, and evaluating their respective advantages and disadvantages. In order to do this in an objective and systematic way a Pugh matrix was created. A Pugh matrix, also known as a decision matrix, is a way of systematically evaluating and choosing the best solution of several possible solutions. The rows of the matrix contain a couple of criteria for assessing the possible solutions and the columns of the matrix represent the different concepts. The effect goals and UX attributes are used for creating the criteria, but other relevant criteria can also be added. When performing the evaluation one of the solutions are used as baseline, receiving 0 points at all criteria. The other solutions are then compared to the baseline, receiving a plus if performing better or a minus if performing worse than baseline on the respective criteria [37].

7.3.1 Implementation and analysis

The criteria used in the evaluation was set using the effect goals and UX attributes of the project as a basis. Some of these were considered hard to assess from only using the design concepts and conceptual models and were therefore excluded from the criteria. The project members made sure that the criteria used covered the most important aspects with respect to the collected data and that they were not too vaguely nor too strictly formulated.

After both project members were satisfied with the criteria, the baseline concept was chosen. Each of the criteria was then used for assessing the concepts, comparing them to the baseline. The relevant aspects by which the concepts satisfied or did not satisfy the criteria were written down. After having gone through all the criteria the points of each concept were summarised and compared.

7.3.2 Results

A total of 13 criteria was set, representing the applicable effect goals and UX attributes. The goals excluded from the assessment were effect goal 4 (Providing a safe platform or sensitive information), UX4 (Few steps), UX7 (Easy to overview), UX10 (Automatic usage) and UX11 (Safe). The

Health account concept, MyHealth, was chosen as baseline. This as it was considered to cover the most of the effect goals, and as it was a concept well known to the project members by its similarities with *Hälsa för mig*.

Figure 7.6 shows the Pugh matrix created, including the criteria used (and its related goal) and the scores of the concept assessment. As can be seen in the matrix the S.A.M. concept received the highest points, followed by HealthSharing. MyHealth and GoHealth received the same amount of points. However, one can also see that when only looking at the first six criteria, being the effect goals, MyHealth received the same amount of points as S.A.M. and HealthSharing. When only looking at the effect goals it is also clear that GoHealth performs much worse, with a lot of minuses. Moreover, when only looking at the UX attribute criteria S.A.M. and GoHealth performs the best, and MyHealth the worst.

Goal #	Criteria	MyHealth	Health-Sharing	S.A.M.	GoHealth
EG 1	Provide easy-to-understand and personalised information	0	0	0	-
EG 2	Enable smooth communication with healthcare	0	-	0	-
EG 3	Provide a tool for better mental health	0	+	+	0
EG 5	Provide a tool for easy contact with the insurance fund	0	0	0	-
EG 6	collected personal health information	0	-	0	-
EG 7	Enable communication and exchange with peers	0	+	-	+
UX 1	Simple interaction	0	+	+	+
UX 2	Easy to understand	0	+	0	0
UX 3	Easy to start using	0	0	-	0
UX 5	Easy access	0	0	+	0
UX 6	Few main functions	0	0	+	+
UX 8	User customised	0	0	+	0
UX 9	Fun/entertaining to use	0	+	+	+
	Total +	0	5	6	4
	Total -	0	2	2	4
	Total	0	3	4	0

Figure 7.6: Pugh matrix including the criteria and result of the concept assessment.

8 Discussion

In this chapter the methods used and the results obtained in the project are discussed. Furthermore, a reflection is done regarding ethical aspects of the project.

In this project a user centred design process has been implemented. This process is discussed in section 8.1. During the project the main focus has been on collecting data, foremost on performing user studies. The data collection methods are discussed further in section 8.2. As a result of the findings from the user studies goals were set up from which design concepts were developed and elaborated. The possibilities and obstacles as well as the future prospects of these concepts are discussed in section 8.3. The restrictions of the project are considered in section 8.4 and the ethical aspects of the project are then discussed in section 8.5.

8.1 Overall design process

A user-centred design process suited this project well. The methods used in the different phases of the project are only a selection of methods that could be used. Hence, the project could have been executed in many different ways. The methods chosen were established and already familiar to project members. Overall the methods could be said to work well and resulting in both trustworthy and insightful conclusions.

The choice not to implement the last two activities (*Prototyping* and *Evaluation*) of the model for user-centred design, shown in figure 3.1, was made mostly due to shortage of time. Instead, a step (*Defining conceptual models*) was added between *Ideas in concept outlines* and *Assessment of concepts* in the concept phase process. The reason for this was that it was judged that conceptual models were needed to visualise the concepts. The fact that no prototypes were made, made it harder to assess how well these concepts meet the goals and UX attributes. Even though scenarios were made, it is hard to determine how the concepts would stand in a real context.

8.2 Data collection

The data collection was by far the major phase of this project. This was made in several steps in order to collect data from many different sources. Consequently, the sheer amount of data was a challenge to handle and time consuming to analyse. However, this also contributed to make the conclusions trustworthy.

8.2.1 Background information gathering

Initiating the project by performing a literature study and a health application benchmarking study was a good way of getting valuable background information and insights regarding the area of interests. However, it was also connected to some difficulties.

Since eHealth is currently a very prominent field for many decision makers and scientists, a lot of decisions and research have been made in this area during the most recent years. Hence, there are a lot of available articles written about eHealth and mHealth. At the same time fast paced development might cause literature to be irrelevant after only a short amount of time. Furthermore, it is still a rather new research field. This means that a lot of the literature is based on short-term studies. The huge amount of articles written during the last few years made the screening of relevant and up-to-date literature a great challenge.

As mentioned in earlier chapters there are a huge variety of available mobile health apps. To make the benchmarking study reasonable and not too time consuming strict inclusion criteria were set. As this study was made early in the project the focus areas and limitations were not yet clear. Thus, the search words chosen to find the applications were based on the application of Nerve, a medication reminder developed in cooperation with MS and Parkinson's patients. In retrospect, the search words could have been chosen differently to better match the rest of the project. However, the study mostly focused on the user experience of health apps and thus still can be considered relevant. The criteria used in the final selection step were not set according to any scientific guidelines, but rather what seemed to be reasonable numbers for assuming a certain level of quality. This might have caused exclusion of relevant apps, but was not considered to have any major affect on the result. Another issue of the benchmarking study was assessing the apps in a consistent way, this as the assessment criteria, even though being designed to be objective, in some aspect required a rather subjective opinion. To achieve a high level of consistency the evaluation of all apps were made by the same project member. If any uncertainties arose the assessment was verified by the other project member.

In the benchmarking study Google Play was chosen for finding apps, this because detailed information could be gathered regarding number of downloads, reviews and ratings from Google Play. Google Play was also considered to contain most of the apps available in App Store. Hence, the risk of excluding relevant apps was considered to be low.

8.2.2 User studies

Both the qualitative and the quantitative user studies suggested that there is a great need and demand of digital health services among people with chronic diseases. The survey clearly confirmed what the workshop indicated, i.e. that collecting and storing personal health information would be of great benefit to many. It also showed that most of the respondents would like to log health related data and to be able to receive automatic analysis based on this. This was also confirmed by the interviewees, who expressed several possibilities with digital health services. These correlations are also good examples of how different data sources were used to perform data triangulation. However, one thing that was only expressed in the interviews, and not the other user studies, was concerns and scepticism regarding the safety and integrity aspects of digital health services.

In the survey, around 150 different diagnoses were represented, making it hard to draw any conclusions for a specific group, more so because of many with multiple illness. However, the survey and the interviews both suggest that even though having different diagnoses most patients are battling similar wars. For instance, many are having problems with the communication with healthcare and the insurance fund. Moreover, the psychological issues of dealing with a chronic disease are not limited to one diagnosis.

Since over half of the interviewees had a neurological disease or condition, they can not be seen as representative for a larger, more heterogeneous group. This makes it difficult to draw any general conclusions for all patients with chronic diseases from the data gathered. However, with regards to

the survey, our findings suggest the general needs are the same, regardless of diagnosis.

In both the survey and the interviews a majority of the participants were women. This can partially be explained by the fact that more women than men have a chronic disease, however, not to that extent that it can explain the higher percentage of participating women in the survey. The predominant proportion of women among the participants might introduce bias towards women in developing the concepts. This introduces an interesting new phenomenon, since in general in present research the male is the norm [48]. Also, many of the diagnoses represented here are generally considered low prioritised and low status diseases, such as fibromyalgia and joint pain [48]. In this survey they are among the largest represented groups, showing the importance of addressing the issue of unequal care.

Participants

Due to the limited time and resources of the project, the user studies were based on people available within the network of the project members and the company and within patient associations. Hence, a lot of the input came from people diagnosed with Multiple sclerosis and Parkinson's disease. Thus, although the project is based on chronic diseases in general, it is mostly specified towards neurological diseases. Moreover, as not all patients are involved in patient associations it cannot be said that the basis for the user studies is representative for all chronic disease patients. However, the method used for finding participants was considered to be the best possible way of reaching the target group. One can also question if there might be a slight bias in the results since the people with interest in digital health are most willing to contribute. However, with the number of respondents to the survey and interviewees, the results are still relevant for a large population.

8.3 Evaluation of concepts

The design concepts and related conceptual models created and elaborated in this project are not to be considered as finished. They are rather suggestions for possible ways of meeting the needs and facilitating the challenges identified in the user studies. A discussion regarding the most obvious advantages and disadvantages of the suggested concepts is presented below. In order to proceed in making final products out of the concepts, a deeper evaluation would be needed, where the concepts would be evaluated against the actual users.

8.3.1 MyHealth

From the survey, it is clear that being able to store collected health information in a health account would be a significant benefit for many. As shown by the assessment made in chapter 7.3, the health account concept performs very good compared to the others when it comes to the effect goals. It provides most of the requested features associated with the practical everyday disease management, such as collected data, personalised information and tools for communicating with caregivers and authorities. In these aspects the health account concept is better than the other concepts.

However, looking at the "softer" criteria, such as the psychological and the UX aspects, it performs worse than the others. It does not cover the goals related to psychological challenges and only fulfils a few of the UX requirements. Especially when it comes to the UX attribute of simple interaction it performs worse than all of the other concepts. In the app benchmarking study made in chapter 4.2 it was concluded that the apps receiving the highest score succeeded in having several features without making the usage complicated. Looking at the flow chart representing the conceptual model of MyHealth it is clear that it is a bit unorganised. Compared to the conceptual models

of the other design concepts this one has a higher number of objects and actions exposed to the user. While the many different objects and possible actions help covering most of the identified challenges it also results in many things for the users to keep track of.

8.3.2 HealthSharing

The concept of a crowdsourcing media for health related challenges performed well in the assessment. It provides great opportunities for exchanging experiences and tips with peers and experts. This were needs clearly requested in both the workshop and the interviews. Since this concept is built on a simple and familiar model of a social media network, with a limited amount of objects exposed to the user, the interaction is understandable for the user. This provided that the user has used other types of social media platforms. The similarities with other platforms would also suggest that it would be entertaining to use, and thus encourage continuous usage.

However, this concept fails in providing effortless storage of collected health information. It also fails in easing the communication with caregivers. These are both effect goals based on clearly expressed needs from the user studies. However, one can argue that HealthSharing would provide a smooth way of anonymously communicating with healthcare experts. By doing this, it might also ease the needs of smoothly communicating with healthcare related employees.

One big disadvantage of this concept is that it, being driven by the users, would require a lot of recurrent users to be successful and valuable. Another issue with such a system is the risk of commercial companies, such as pharmaceuticals, using it for commercial purposes. This by, for instance, suggesting, following and upvoting solutions which are beneficial to them. This would decrease the credibility and in order to prevent this an algorithm discovering such activities would be needed.

The fact that the user accounts would be anonymous would mean that safety risks and integrity violation would be lower than for the other concepts. It would probably also increase the willingness among users to share challenges which they might otherwise not do. A downside with the anonymity is that it may attract untrustworthy and deceptive users proposing unreliable solutions. However, by using clicks, votes and follows for automatic prioritising of content, these would quickly disappear, provided that there are a lot of serious users.

8.3.3 S.A.M.

In the assessment, the concept of the social AI buddy received the highest score. Compared to the other concepts, this concept succeeded as good or better in meeting most of the effect goals. Since the conceptual model is built on the metaphor of human voice or chat communication the interaction would be very simple to figure out. Moreover, the learning algorithm of the AI would allow the usage to be effortless and extremely user customised.

However, the customisation would require some time of active usage. Furthermore, the usage of such a system might feel unnatural to start with. This is since robots are still mostly associated with science fiction. Hence, initiating a trusting relationship with a robot could feel apprehensive. Another issue of this concept is related to the ethical aspects of building trusting relationships between humans and machines. For instance, for the user the relationship might feel as that of a close friend. However, in reality the robot only mimics human behaviour. Furthermore, data from the trusted conversations are stored digitally which might be an issue. The risks of digital storage of data is further discussed in section 8.5.

8.3.4 GoHealth

One of the advantages of using gamification is that it provides the emotional support often needed for maintaining motivation to improve and maintain health. Hence, the GoHealth concept could provide a way of motivating people to better disease management. Looking at the UX related assessment criteria this concept performs well. It succeeds in being customised according to user ability, having a simple and easy-to-understand interaction and being entertaining for the user. Thus, a recurring and continuous usage could be expected.

However, this concept fails to fully meet several of the effect goals. For instance, it does not provide tools for smooth communication with either healthcare or the insurance fund. Furthermore, it only offers storage of personal health information related to the accepted challenges. For some of the effect goals this concept was difficult to assess. The purpose of this concept is helping persons with chronic disease to find ways and to be motivated to improve health related aspects of life. These aspects might be mental health or learning about the disease through a simple quiz. Hence, the app might be a tool for better mental health and to get easy-to-understand and personalised information, but it is not as clear as for the other concepts.

8.3.5 Future prospects

With more time, the next step of the project would have been to choose a single concept to continue with. Considering that none of the concepts fully covers all of the goals set up for the project a good idea would be to investigate the possibilities of merging some of the concepts. This could be done by choosing one of the concepts as basis and then merging it with aspects from some of the others. Before moving on with a concept, one should do a proper evaluation of similar systems already available on the market and then, an analysis of what differentiates the new concepts from the available and enhance this.

After choosing a final concept to continue with this would have needed to be further defined and brought to life in prototypes. The prototypes would need to be evaluated against the actual users before continuing the iterative process of creating updated prototypes.

8.4 Restrictions

A consequence of the limited selection of participants in the user studies was that all but one interviewee lived in Stockholm. Therefore, the project members felt that they could only portray persons living in urban areas. Hence, the personas created were all based in Stockholm. It is hard to tell how this has influenced the effect goals and resulting concepts. Therefore, if continuing the project, studies with users living in rural areas would be needed.

Throughout this project, the digital health account *Hälsa för mig* created by the Swedish eHealth Agency, has been referred to. One reason for this is that the company Nerve, with whom the project was performed, collaborated with the eHealth Agency on developing *Hälsa för mig*. By referring to *Hälsa för mig* during the user studies, bias towards a solution in shape of a health account might have been introduced. By using it as an example, it is possible that the participants in the user studies were locked in a certain way of thinking about digital health services. Furthermore, there is also a risk that the project members themselves have been unintentionally biased when generating and developing the concepts. Thus, it is possible that they were hindered in exploring other, possible, solutions widely different from *Hälsa för mig*.

It was reasoned that having legitimate source, such as the Swedish eHealth Agency to refer to gave this study credibility. Moreover, having a concrete digital health service as an example was

a good way of concertising what a digital health service might include. Hence, it was assured that all information given to the participants was consistent. Thus, the advantages of using *Hälsa för mig* as an example were considered to out-weigh the disadvantages. Being aware of the risks, the project members have throughout the project actively questioned possible bias in every design choice.

8.5 Ethical aspects

8.5.1 User studies

In this project, a lot of sensitive information has been gathered. This is not an uncomplicated issue since the majority of those answering the survey and all the interviewees had a chronic disease or condition. Therefore, it was very important to make sure that the user studies were made in an ethical way.

For the survey, the questions of consent, integrity and storage of the data were raised before distributing it. To address these issues several measures were taken. In the introduction to the survey it was underlined that participating was voluntary and that no questions were obligatory. When analysed, the data was anonymised, minimising the risk of connecting an answer to a person. Lastly, the data was stored in an internal server at Nerve. The questions of consent and integrity were discussed yet again when preparing for the interviews. An informed consent form was sent to all participants beforehand and repeated orally before the actual interview started. This was to make sure that every participant knew that they were under no obligation to answer a question if they did not want to and that they could withdraw their participation at anytime. Moreover, to preserve the integrity of the participants, each interviewee was given a code name by which they were referred to in every documentation of the data. While developing the interview guide the formulation and sensitiveness of the questions were considered. It was important that the questions did not feel judgmental in any way. Also, it was an active choice not to ask questions about the future and the progress of their disease. For the purpose of this project the measures taken regarding confidentiality and safety were considered enough.

8.5.2 Storage of health data

There are so many possibilities with health data, such as better healthcare and personalised treatment, that it is easy to forget the more negative aspects. Storing health data digitally is considered by many to be a risk. Firstly, it is hard to ensure security and privacy of the information. If storing it in the cloud, one no longer has complete control over the data and it may be exposed or lost. Secondly, making the data available raises the question of whom to share it with. While protected by the healthcare, it is hard for potential employers or insurance companies to demand access to individuals health data. However, this may change if it is the individual who owns the data. Lastly, many of the digital health services available today are owned by companies. Most of them collect and save data about the user. This data can be used to improve the service but it can also be sold to a third party and/or be used for commercial purposes. Not saying that this always is the case, it introduces complicated ethical questions. For example, using knowledge of patients to promote medications or treatments is something that can be beneficial for the patients, provided that it is something new that can help them. However, using patients' desire to be cured or live a descent life is to wander into an ethical grey zone of wright and wrong.

At the same time, the process of sensitive data, for example health data, is well regulated in EU and Sweden. However, some people see these regulations as an inhibitor of innovation. Hence, there

is a fine balance between protecting citizens health data and creating new possibilities for a better life.

8.5.3 Usage of eHealth

In a way eHealth is still a new subject. The long term consequences of usage has not been determined which make some unprepared to invest in it. Moreover, there are, as mentioned before, risks that come with digitally storing data and also with increased pressure on patients. As mentioned before, eHealth is considered to be a tool for increasing patient involvement. Though generally considered something that has a positive influence on health, patient involvement is not without challenges. There is a fine balance between empowerment and laying too much responsibility on the patient. This is something that must be considered when designing digital health services.

Still, the possibilities of eHealth are many. Already today, it can ensure care and treatment for patients that otherwise would have gone without. It can also provide a tool for monitoring or following up patients outside the hospital and thus, making sure that patients are not left alone without guidance when leaving the healthcare system. Though not disregarding the risks and challenges of eHealth, it seems unethical not to use these tools to improve lives.

9 Conclusions

This chapter summarises the main conclusions made along the project.

The purpose of this project was to, from an interaction design point of view, investigate the needs of digital health services for people with chronic diseases. Furthermore, the project aimed at suggesting new ways of meeting the identified needs. Several conclusions were made during the process of the project and the most important ones are summarised below.

9.1 User studies

The survey, built on the results from the workshop, received over 500 responses from people diagnosed with a variety of chronic diseases. The following points were the main conclusions from the analysis of the survey:

- Most people would like to continuously log some kind of health related data.
- People diagnosed with chronic diseases would mostly like to log medications, chronic disease, symptoms, exercise and sleep.
- People diagnosed with chronic diseases would find it very beneficial to be able to collect and digitally access their health related information.
- A lot of people would like to be able to share their personal health information with their caregiver.
- There are overall differing opinions regarding sharing personal health information.
- Most people would like to receive automatic health analyses based on their logged health data.
- More people use the internet than the healthcare system to find health related information.
- Own storage or healthcare storage are considered being most safe for health information.
- Very few trusts private companies the most for storage of health information.

The collection of qualitative data through interviews resulted in a lot of insights regarding the needs of people with chronic diseases. These included their everyday challenges, the possibilities of digital health services seen from their perspective, their security concerns and scepticism related to digital health services and the most important UX aspects from their point of view.

From the user studies it was concluded that digital health services are requested by people with chronic diseases, but there are several challenges connected to the design and implementation of these.

9.2 Design concepts

The conclusions from the user studies were used to formulate effect goals and UX attributes. The effect goals of the project were formulated as follows:

1. Provide easy-to-understand and personalised information
2. Enable smooth communication with healthcare
3. Provide a tool for better mental health
4. Provide a safe platform for sensitive information
5. Provide a tool for easy contact with the insurance fund
6. Provide effortless storage of collected personal health information
7. Enable communication and exchange with peers

The goals set up were used for generating concepts aiming at fulfilling the goals, hence meeting the identified needs of the users. This resulted in four different concepts:

- **MyHealth** - A personal, digital health account
- **HealthSharing** - A health crowdsourcing platform
- **S.A.M.** (Social Artificial intelligence Mate) - A social AI buddy for disease management
- **GoHealth** - A gaming app for health challenges

The assessment of the concepts, using a Pugh matrix, resulted in the conclusion that none of the concepts managed to fulfil all of the goals. However, they all had several promising aspects and met most of the goals. By merging the concepts it might be possible to design a digital health service that meets and eases the needs and everyday challenges of people with chronic diseases. For this though, further development is required. This would include defining a final concept, evaluating it with the users and benchmarking it towards what is available on the market. Furthermore, prototyping an continuous evaluated would also be needed before resulting in a final product.

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Appendices

A Mobile health app assessment template

HEALTH APP ASSESSMENT TEMPLATE

THIS TEMPLATE ASSESSES APP QUALITY ON FIVE DIMENSIONS. THE FIRST DIMENSION RATES THE APPS BASED ON ITS AVAILABLE FUNCTIONS. IN THE OTHER DIMENSIONS ALL ITEMS ARE RATED ON A 5-POINT SCALE FROM "1.INADEQUATE" TO "5.EXCELLENT".

SECTION A – FEATURES

1. Does the app contain any of the following features/functions?

Feature	Points
Onboarding (5 p)	
Reminders (5 p)	
Snooze option (5 p)	
Graphical overview (5p)	
Relevant functionalities other than reminders (2/5 p)	
Client server (5 p)	
All functionality available for free (5 p)	
Free from adds (5 p)	
FAQ (5p)	
Relevant/interesting content (5 p)	

FEATURE MEAN SCORE : _____

SECTION B – ENGAGEMENT

2. Entertainment: Is the app fun/entertaining to use? Does it use any strategies to increase engagement through entertainment (e.g. through gamification)?

1. Dull, not fun or entertaining at all
2. Mostly boring
3. OK, fun enough to entertain user for a brief time (< 5 minutes)
4. Moderately fun and entertaining, would entertain user for some time (5-10 minutes total)
5. Highly entertaining and fun, would stimulate repeat use

3. Customisation: Does it provide/retain all necessary settings/preferences for apps features (e.g. sound, content, notifications, etc.)?

1. Does not allow any customisation or requires setting to be input every time
2. Allows insufficient customisation limiting functions
3. Allows basic customisation to function adequately
4. Allows numerous options for customisation
5. Allows complete tailoring to the individual's characteristics/preferences, retains all settings

4. Interactivity: Does it allow user input, provide feedback, contain prompts (reminders, sharing options, notifications, etc.)? Note: these functions need to be customisable and not overwhelming in order to be perfect.

1. No interactive features and/or no response to user interaction
2. Insufficient interactivity, or feedback, or user input options, limiting functions
3. Basic interactive features to function adequately
4. Offers a variety of interactive features/feedback/user input options
5. Very high level of responsiveness through interactive features/feedback/user input options

5. Target group: Is the app content (visual information, language, design) appropriate for your target audience?

1. Completely inappropriate/unclear/confusing
2. Mostly inappropriate/unclear/confusing
3. Acceptable but not targeted. May be inappropriate/unclear/confusing
4. Well-targeted, with negligible issues
5. Perfectly targeted, no issues found

ENGAGEMENT MEAN SCORE: _____

SECTION C - FUNCTIONALITY

6. Ease of use: How easy is it to learn how to use the app; how clear are the menu labels/icons and instructions?

1. No/limited instructions; menu labels/icons are confusing; complicated
2. Useable after a lot of time/effort
3. Useable after some time/effort
4. Easy to learn how to use the app (or has clear instructions)
5. Able to use app immediately; intuitive; simple

7. Navigation: Is moving between screens logical/accurate/appropriate/ uninterrupted; are all necessary screen links present?

1. Different sections within the app seem logically disconnected and random/confusing/navigation is difficult
2. Usable after a lot of time/effort
3. Usable after some time/effort
4. Easy to use or missing a negligible link
5. Perfectly logical, easy, clear and intuitive screen flow throughout, or offers shortcuts

7. Gestural design: Are interactions (taps/swipes/pinches/scrolls) consistent and intuitive across all components/screens?

1. Completely inconsistent/confusing
2. Often inconsistent/confusing
3. OK with some inconsistencies/confusing elements
4. Mostly consistent/intuitive with negligible problems
5. Perfectly consistent and intuitive

FUNCTIONALITY MEAN SCORE: _____

FUNCTIONALITY MEAN SCORE: _____

SECTION D - AESTHETICS

8. Layout: Is arrangement and size of buttons/icons/menus/content on the screen appropriate or zoomable if needed?

1. Very bad design, cluttered, some options impossible to select/locate/see/read device display not optimised
2. Bad design, random, unclear, some options difficult to select/locate/see/read
3. Satisfactory, few problems with selecting/locating/seeing/reading items or with minor screensize problems
4. Mostly clear, able to select/locate/see/read items
5. Professional, simple, clear, orderly, logically organised, device display optimised. Every design component has a purpose

9. Visual appeal: How good does the app look?

1. No visual appeal, unpleasant to look at, poorly designed, clashing/mismatched colours
2. Little visual appeal – poorly designed, bad use of colour, visually boring
3. Some visual appeal – average, neither pleasant, nor unpleasant
4. High level of visual appeal – seamless graphics – consistent and professionally designed
5. As above + very attractive, memorable, stands out; use of colour enhances app features/menus

AESTHETICS MEAN SCORE: _____

SECTION E – SUBJECTIVE QUALITY

10. What is your overall star rating of the app?

1. * One of the worst apps I've used
2. **
3. *** Average
4. ****
5. ***** One of the best apps I've used

SCORING

A: Feature Mean Score = _____
B: Engagement Mean Score = _____
C: Functionality Mean Score = _____
D: Aesthetics Mean Score = _____
E: Subjective quality Score = _____
Total quality mean Score = _____

B Workshop categorisation

Main category	Category	Subcategory
Information (27)	General information (10)	Customized suggestions and news (2)
		Medication information (4)
		Tips (4)
	Personal healthcare information (17)	Prescriptions (5)
		Personal Health Records (9)
		Vaccinations (2)
Data (64)	Regular measurements (15)	Vitals (8)
		Weight (6)
		Child data (1)
	Diet (10)	Meals and nutrition (10)
	Health & fitness (17)	Work-out (12)
		Relaxation (5)
	Daily status (18)	Mood (4)
		Stress and sleep (6)
		Pain and symptoms (4)
		Menstrual cycle (2)
		Others (2)
	Habits (4)	Routines and behaviours (4)
Customization (40)	Communication channels (16)	Share with family (3)
		Share with healthcare providers (8)
		Share with peers (5)
	Adaptation & availability (9)	Easy access (4)
		Compatibility (5)
	Personal analysis (15)	Goals & follow-ups (3)
		Data analysis (9)
		Visualisation (3)
Call to action (16)	ICE (3)	Contact information & insurance (3)
	Reminders (10)	Medication reminders (5)
		Notes (3)
		Other reminders (2)
	Letter of healthcare appointments (3)	Visits and meetings (3)

Figure B.1: Overview of the results from the workshop categorisation with the number of post-it mentions within brackets.

C Survey

ENKÄT

ENKÄT OM DIGITALA HÄLSOTJÄNSTER

eHälsomyndigheten i samarbete med Nerve genomför en undersökning för att få djupare förståelse kring behoven av digitala hälsotjänster. Deltagandet är frivilligt och inga frågor är obligatoriska. Enkäten tar ca 10 minuter att fylla i.

DEL 1 AV 4

Vi börjar med några frågor angående hälsorelaterade mobilapplikationer (hälsoappar).

FRÅGA 1. ANVÄNDER DU I DAGSLÄGET NÅGON HÄLSOAPP?

Exempelvis appar för träning, sömn, medicinering, kost etc.

- A) JA
- B) NEJ (→ FRÅGA 4)

FRÅGA 2. VAD LOGGAR/HANTERAR DU MED HJÄLP AV DINA HÄLSOAPPAR?

- | | | |
|------------------|--------------------|---------------------|
| A) TRÄNING | H) BLODSOCKER | O) HÄLSOCOMMUNITY |
| B) VIKT | I) SYMPTOM | P) HUMÖR |
| C) KOST OCH DIET | J) SMÄRTA | Q) SEXLIV |
| D) MENSTRUATION | K) MEDICINER | R) FERTILITET |
| E) SÖMN | L) KRONISK SJUKDOM | S) KOGNITIV FÖRMÅGA |
| F) PULS | M) PSYKISK HÄLSA | T) ANNAT: _____ |
| G) BLODTRYCK | N) AVSLAPPNING | |

FRÅGA 3. HUR OFTA LOGGAR DU OVAN NÄMNDA SAKER MED DINA HÄLSOAPPAR?

- A) MINDRE ÄN EN GÅNG/MÅNAD
- B) 1-3 GÅNGER/MÅNAD
- C) 1-3 GÅNGER/VECKA
- D) 4-6 GÅNGER/VECKA
- E) DAGLIGEN

FRÅGA 4. VAD SKULLE DU VILJA LOGGA/HANTERA MED HJÄLP AV HÄLSOAPPAR?

- | | | |
|------------------|--------------------|---------------------------|
| A) TRÄNING | H) BLODSOCKER | O) HÄLSOCOMMUNITY |
| B) VIKT | I) SYMPTOM | P) HUMÖR |
| C) KOST OCH DIET | J) SMÄRTA | Q) SEXLIV |
| D) MENSTRUATION | K) MEDICINER | R) FERTILITET |
| E) SÖMN | L) KRONISK SJUKDOM | S) KOGNITIV FÖRMÅGA |
| F) PULS | M) PSYKISK HÄLSA | T) ANNAT: _____ |
| G) BLODTRYCK | N) AVSLAPPNING | U: INGET ALLS (→ FRÅGA 6) |

FRÅGA 5. HUR OFTA SKULLE DU VILJA LOGGA OVAN NÄMNDNA SAKER MED DINA HÄLSOAPPAR?

- A) MINDRE ÄN EN GÅNG/MÅNAD
- B) 1-3 GÅNGER/MÅNAD
- C) 1-3 GÅNGER/VECKA
- D) 4-6 GÅNGER/VECKA
- E) DAGLIGEN

FRÅGA 6. SKULLE DU VILJA/HANTERA HÄLSODATA NÅGON ANNANSTANS ÄN I EN APP?

- A) JA
- B) NEJ (→ FRÅGA 8)

FRÅGA 7. VAR?

ANGE SVAR: _____

DEL 2 AV 4

Detta avsnitt handlar om hälsorelaterad vårdinformation samt om delning och lagring av information och data.

FRÅGA 8. VAR SKULLE DU KÄNNA DIG MEST TRYGG ATT LAGRA DIN SAMLADE HÄLSODATA?

- A) SJUKVÅRDEN
- B) STATLIG MYNDIGHET
- C) EGEN FÖRVARING
- D) STÖRRE FÖRETAG
- E) MINDRE FÖRETAG
- F) ANNAT: _____

FRÅGA 9. HUR STOR NYTTA SKULLE DU HA AV ATT KUNNA SAMLA ALL DIN HÄLSODATA I ETT DIGITALT HÄLSOKONTO?

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

FRÅGA 10. HUR STOR NYTTA SKULLE DU HA AV DIGITAL ÅTKOMST TILL...**A) ... EN KOPIA AV DIN JOURNAL?**

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

B) ... DINA PROVSVAR?

Exempelvis från blodprov, urinprov etc.

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

C) ... DINA LÄKEMEDELSRECEPT?

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

D) ... DINA KALLELSER TILL VÅRDEN?

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

E) ... DINA VACCINATIONER?

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

F) ... DIN INFORMATION FRÅN BARNAVÅRDSCENTRALEN (BVC-JOURNAL)?

1	2	3	4	5
---	---	---	---	---

Ingen nytta alls

Väldigt stor nytta

FRÅGA 11. FINNS DET NÅGON ANNAN TYP AV HÄLSOINFORMATION DU SKULLE VILJA HA DIGITAL ÅTKOMST TILL?

Exempelvis från optiker, sjukgymnast, kiropraktor etc.

- A) JA
- B) NEJ (→ FRÅGA 13)

FRÅGA 12. VILKEN TYP AV INFORMATION SKULLE DET VARA?

ANGE SVAR: _____

FRÅGA 13. HUR HITTAR DU HÄLSOINFORMATION I DAGSLÄGET?

- A) VIA FAMILJ/VÄNNER
- B) VIA ANDRA PATIENTER
- C) VIA FÖRENINGAR
- D) VIA INTERNET
- E) VIA SJUKVÅRDEN
- F) ANNAT: _____

FRÅGA 14. VEM/VILKA SKULLE DU VILJA HA MÖJLIGHET ATT DELA DIN HÄLSODATA MED?

Exempelvis din träningsdata, dina provsvar eller andra utvalda delar av din hälsodata.

- A) PARTNER
- B) MYNDIGHETER
- C) SYSKON
- D) FÖRÄLDRAR
- E) VÅRDGIVARE
- F) BARN
- G) ARBETSGIVARE
- H) COMMUNITY FÖR LIKAR
- I) ANNAN: _____
- J) VILL INTE DELA ALLS

FRÅGA 15. VEM/VILKA SKULLE DU VILJA HA MÖJLIGHET ATT TA DEL AV HÄLSODATA FRÅN?

Exempelvis träningsdata, provsvar eller annan typ av hälsodata.

- | | | |
|--------------|------------------------|--------------------------|
| A) PARTNER | D) BARN | G) VILL INTE TA DEL ALLS |
| B) SYSKON | E) COMMUNITY FÖR LIKAR | |
| C) FÖRÄLDRAR | F) ANNAT: _____ | |

DEL 3 AV 4

Detta avsnitt handlar om intelligent dataanalys, digitala hälsomätare och framtidens sjukvård.

FRÅGA 16. SKULLE DU VILJA HA EN TJÄNST SOM KOPPLAR SAMMAN DINA HÄLSOMÄTNINGAR OCH UTFÖR NÅGON FORM AV AUTOMATISK ANALYS PÅ DEM?

- A) JA
- B) NEJ (→ FRÅGA 18)

FRÅGA 17. VAD SKULLE DU VILJA FÅ FRAM I EN SÅDAN ANALYS? (→ FRÅGA 19)

- | | |
|-------------------------------|-------------------------|
| A) TRENDER I LOGGAD HÄLSODATA | E) VARNINGAR |
| B) SAMLAD BILD AV DIN HÄLSA | F) REKOMMENDATIONER |
| C) BETEENDEKORRELATIONER | G) HÄLSOLÄGE KONTRA MÅL |
| D) RISKBETEENDEN | H) ANNAT: _____ |

FRÅGA 18. VARFÖR INTE?

ANGE SVAR: _____

FRÅGA 19. ANVÄNDER DU NÅGON TYP AV DIGITAL HÄLSOMÄTARE?

Exempelvis aktivitetsarmband, smart våg, blodtrycksmätare etc.

- A) JA
- B) NEJ (→ FRÅGA 21)

FRÅGA 20. VAD MÄTER DU MED DIN/DINA DIGITALA HÄLSOMÄTARE?

- | | | |
|--------------|---------------------|-----------------|
| A) SÖMN | D) KROPPSTEMPERATUR | G) BLODSOCKER |
| B) STEG | E) PULS | H) VIKT |
| C) KONDITION | F) BLODTRYCK | I) ANNAT: _____ |

FRÅGA 21. HUR TROR DU ATT FRAMTIDENS SJUKVÅRD KOMMER ATT SE UT?

- | | |
|------------------------------|--------------------------------|
| A) ÖKAD PATIENTDELAKTIGHET | G) ÖKAD SJÄLVKÄNNEDOM |
| B) MINSKAD PATIENTINTEGRITET | H) MINSKAT VÅRDGIVARFÖRTROENDE |
| C) STÖRRE INDIVIDANPASSNING | I) ÖKAT PATIENTINFLYTANDE |
| D) FÖRSÄMRAD SÄKERHET | J) DIGITAL SJUKVÅRDSKONTAKT |
| E) MER PREVENTIV VÅRD | K) MER HEMSJUKVÅRD |
| F) LÄNGRE KÖTIDER | L) ANNAT: _____ |

DEL 4 AV 4

Nästan klar! Vi avslutar med några frågor om dig.

FRÅGA 22. HUR HÄLSOSAM ANSER DU ATT DIN LIVSSTIL ÄR?

1	2	3	4	5
---	---	---	---	---

Väldigt ohälsosam

Väldigt hälsosam

FRÅGA 23. ÄR DU DIAGNOSTISERAD MED EN KRONISK ELLER LÅNGVARIG Sjukdom?

- A) JA
- B) NEJ
- C) VILL INTE SVARA

FRÅGA 24. HUR GAMMAL ÄR DU?

- A) 15-24 ÅR
- B) 25-34 ÅR
- C) 35-44 ÅR
- D) 45-54 ÅR
- E) 55-64 ÅR
- F) 65-74 ÅR
- G) 75-84 ÅR
- H) 85- ÅR

FRÅGA 25. VILKET KÖN IDENTIFIERAR DU DIG MED?

- A) KVINNA
- B) MAN
- C) ANNAT

FRÅGA 26. FINNS DET NÅGOT MER DU VILL TILLÄGGA?

ANGE SVAR: _____

SKICKA

STORT TACK FÖR HJÄLPEN!

Har du några frågor om enkäten kontakta hello@nervelabs.se.

D Interview guide

INTERVJUGUIDE

SYFTE MED INTERVJUERNA

Syftet med intervjuerna är att få en fördjupad förståelse för digitala behov och efterfrågan hos MS (och Parkinson)-diagnostiserade medborgare. Intervjuerna syftar också till att ge insikter i vad som avgör om och vilka digitala hälsotjänster som faktiskt används och vad som avgör vilka tjänster som inte blir använda.

Intervjumaterialet kommer användas till jämförelse med enkätresultat samt för att förstå användaren bättre. Detta ger en grund för hur ett användbart hälsokonto kan byggas. Resultatet kan också vara intressant för potentiella utvecklare för att dessa ska förstå vilka tjänster de ska satsa på att bygga.

METODPLAN

Semistrukturerade intervjuer med svenska medborgare kommer genomföras. Intervjupersonen ska utifrån frågorna och sig själv beskriva, förklara och resonera kring behov och efterfrågan av hälsotjänster i vardagen.

Intervjupersonerna är framförallt medborgare diagnostiserade med den kroniska sjukdomen MS. Urvalet bör vara sådant att det finns en spridning mellan hur långt gången sjukdomen är hos intervjupersonerna.

För att utvärdera intervjumetoden ska det göras en pilotstudie på en till två personer. På dessa personer ställer vi inga krav på diagnos.

INTRODUKTION

DEN KURSIVA TEXTEN NEDAN LÄSES UPP ORDAGRANT INFÖR VARJE INTERVJU.

Syftet med den här intervjun är att få en fördjupad förståelse för behov och efterfrågan av hälsotjänster hos MS- och Parkinson-diagnostiserade medborgare. Genom intervjun vill vi också få insikter i vad som avgör om och vilka hälsotjänster svenska medborgare faktiskt använder sig av. Vi gör dessa intervjuer som en del av vårt examensarbete som kommer resultera i en rapport, denna får du gärna ta del av när vi är klara i juni.

Intervjun kommer ta mellan 40 och 50 minuter. Ställer vi en fråga du inte vill svara på är det bara att du säger till och du har när som helst rätt att avbryta intervjun. Allt som sägs i intervjun kommer hanteras anonymt och konfidentiellt och inget i resultatet kommer kunna kopplas till dig.

För att vi i efterhand ska kunna säkerställa att vi återger en korrekt tolkning av intervjun skulle vi vilja spela in den. Är detta okej för dig?

Har du några frågor innan vi sätter igång?

INTERVJUFRÅGOR

FRÅGOR TILL INTERVJUPERSONEN STÅR I KURSIV TEXT. DE VIKTIGASTE ORDEN I VARJE FRÅGA, DET VILL SÄGA DET SOM FRÅGAN SYFTAR TILL ATT FÅ BESVARAT ÄR FETMARKERAT.

BAKGRUND

1. Starta inspelning.

2. Vilket kön har intervjupersonen?
3. Börja med att berätta lite om dig själv.
 - a. Hur gammal är du?
 - b. Hur ser din familjesituation ut?
 - c. Har du barn?
 - d. Vad har du för yrkesroll? (anpassa beroende på situation)
 - e. Har du jobbat med något annat innan?

BEHOV

1. Vill du beskriva **steg för steg** hur en vanlig dag ser ut för dig?
2. Kan du berätta om dina **hobbies och intressen**?
 - a. Vad är **syftet med dessa aktiviteter**? Roligt, förebyggande etc?
 - b. Vid **vilka tillfällen** sysslar du med detta?
 - c. Fler relevanta följdfrågor utifrån svar
3. Kan du beskriva hur du använder dig av **teknik i din vardag**?
4. Kan du berätta om några **utmaningar i din vardag**?
 - a. Finns det något du kan komma på som skulle kunna **underlätta dessa utmaningar**?
 - b. Vad har du för **hjälpmedel idag** som du tycker fungerar bra?
5. Skulle du kunna berätta lite om din sjukdom?
6. Skulle du kunna beskriva hur din **diagnos/diagnoser påverkar dig** i din vardag?
 - a. Vad gör du för att **handskas med detta**?
7. Finns det något **moment med din behandling/sjukdomshantering** som du **upplever som stressigt**?
 - a. Vad tror du hade kunnat **minska den stressen**?
8. Kan du beskriva ett **tillfälle då du känner att du saknar någon form av hjälpmedel**?
 - a. Kan du komma på något som skulle kunna **hjälpa dig vid dessa tillfällen**?

EFTERFRÅGAN

1. Använder du i **dagsläget** någon form av **hälsotjänster**?
 - a. Ja: Kan du berätta om **vilka**?
 - i. Kan du beskriva i **vilket syfte** du använder dig av tjänsten/tjänsterna?
 - ii. Vad är det med just denna tjänsten/tjänsterna du **tycker om**?
 - iii. I vilka **situationer** använder du dig av tjänsten/tjänsterna?
 - iv. **På vilket sätt** använder du dig av tjänsterna?
 1. Finns det något i detta som du tycker är **svårt**?
 - v. Hur **kom du i kontakt** med tjänsten/tjänsterna?
 - b. Nej: Kan du berätta **varför**?
 - i. Skulle du vilja använda dig av denna typ av tjänster?
 1. **Varför/varför inte**?
2. Har du **testat någon typ av hälsotjänst** som du **slutat använda**?
 - a. Ja: Vad fick dig att sluta du använda den?
3. Finns det någon typ av tjänst du **skulle vilja ha** som du **inte använder dig av** i dagsläget?
 - a. Hur skulle denna tjänst **se ut**?
 - b. I vilket **syfte** skulle du använda denna tjänst?
 - c. Vid vilka **tillfällen** skulle du vilja använda denna tjänst?
 - d. Hur har du **gått tillväga för att undersöka** om denna **tjänsten redan finns**?

FÖRVÄNTNINGAR

Statliga E-hälsomyndigheten arbetar just nu på uppdrag av regeringen med att ta fram en digital hälsoplattform för svenska medborgare som heter Hälsa för mig. Hälsa för mig är ett personligt hälsokonto som ska hjälpa dig att hålla koll på din hälsa genom att samla, överblicka och dela din hälsoinformation. Det kommer vara möjligt att själv samla hälsoinformation med hjälp av olika applikationer, sk appar, som är anslutna till Hälsa för mig och att prenumerera på hälsoinformation som uthämtade läkemedel och vaccinationer. Tanken är också att det i framtiden ska vara möjligt att prenumerera på ytterligare information från hälso-och sjukvården, till exempel labbsvar och uppgifter ur kontoinnehavarens journal.

1. Beskriv dina **tankar** kring ett **digitalt personligt hälsokonto** som Hälsa för mig?
 - a. Hur känner du för att **lagra** din hälsodata **digitalt**?
2. Hur ser du på att ha ett **statligt** hälsokonto?
 - a. Hur skulle din reaktion varit om hälsokontot kom från den **privata sektorn**?
3. Vad anser du skulle vara ditt **huvudsyfte** med att använda ett digitalt hälsokonto?
 - a. På vilket sätt vill du att ett digitalt hälsokonto ska **hjälpa dig**?
 - b. Vilka **hinder** ser du som kan försvåra att detta syfte uppnås?
4. Skulle du kunna tänka dig att **betala för vissa tjänster**?
 - a. **Varför?**
 - b. **Vad skulle krävas** för att du skulle betala för en tjänst?

AVSLUTNING

1. Är det något du skulle vilja tillägga innan vi avslutar intervjun?
2. Har du några frågor kring studien?
3. Är det okej om vi kontaktar dig om vi har några ytterligare frågor eller vill få något förtydligat?
4. Stäng av inspelningen.

E Informed consent form

Syftet med studien

Studien ingår i ett examensarbete vid Lunds Tekniska Högskola som görs i samarbete med företaget Nerve. Syftet med intervjuerna är att få en inblick i kronisk sjuka, framför allt MS- och Parkinsonsdiagnostiserade, medborgares vardagliga problem samt att skapa en fördjupad förståelse för deras behov av digitala tjänster. Intervjuerna syftar också till att ge insikter i vad som avgör om och vilka digitala hälsotjänster som faktiskt används.

Proceduren

Intervjun, som beräknas ta ca 50-60 minuter, kommer vara ett friare samtal kring dina upplevda problem och behov i vardagen. Om du vid intervjutillfället samtycker kommer intervjun att spelas in för att vi i efterhand ska kunna säkerställa att vi återger en korrekt tolkning.

Avhopp från studien

Du kan när som helst under studien välja att, utan att ange någon anledning, avsluta din medverkan. Eventuellt insamlat material från dig kommer då att tas bort från studien.

Sekretess

Allt material från intervjun kan komma att användas i studien (om du inte väljer av avsluta din medverkan). Intervjumaterialet kommer hanteras konfidentiellt och endast ansvariga för studien kommer att ha tillgång till det. Du kommer vara helt anonym och inget i resultatet kommer kunna kopplas till dig.

Kontaktinformation

Om du har frågor eller funderingar är du välkommen att kontakta oss via e-mail:

Elin Magnusson: elin@nervelabs.se

Elisabeth Vajta Engström: elisabeth@nervelabs.se

Frivilligt deltagande

Jag intygar härmed att jag frivilligt ställer upp på en intervju enligt ovan beskrivning.

Datum, ort: _____

Signatur: _____ Namnförtydligade: _____

F Personas

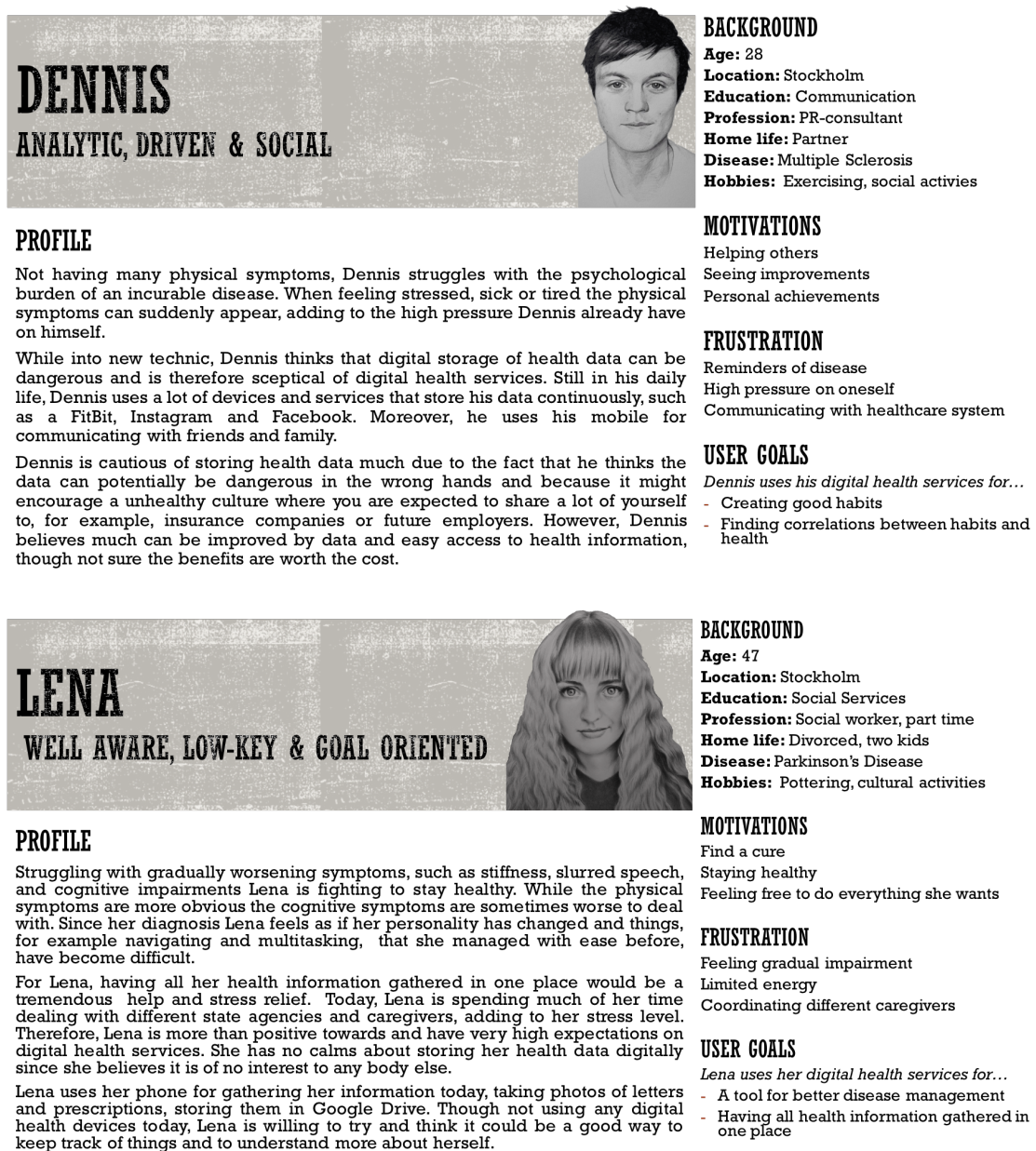


Figure F.1: Personas

ERIC

CAUTIOUS, SUBDUED & NICE



BACKGROUND

Age: 58
Location: Stockholm
Education: Teacher
Profession: Sick-leave
Home life: Lives alone, brother, nieces
Disease: Stroke survivor, aphasia, partially paralysed
Hobbies: Painting, engagement within patient association

PROFILE

Eric's sudden stroke left him with long period of recovery. Though he has come a long way he is still not back to the way he was before the stroke happened. Directly after the stroke Eric's right side was paralysed and he could not say more than a few words. Now he walks and is able to speak, even though he does it slowly and sometimes with difficulty. For Eric, being an old teacher, it is immensely frustrating not being able to express himself clearly even though he is completely clear in his head and know what it is he wants to say.

Eric thinks that digital health services are a bad substitute for real doctors. Eric believes this new wave of digital healthcare put too much pressure on the individual while giving doctors to much leeway. He also thinks that knowing to much about yourself can be dangerous; placebo is a strong force and without it people will feel sicker.

If the digital health services were offered by the state, Eric thinks that the fear of Big Brother would be a hindrance. However, if the digital health services instead were owned by private companies, the data will be misused and people in vulnerable positions, like patients, will be the first to be hurt by it.

MOTIVATIONS

- Manage on his own
- Having routines
- Experience improvement

FRUSTRATION

- Not being able to fully express himself
- Being patronized due to speech difficulty
- Not understandable interfaces

USER GOALS

- Eric uses his digital health services for...*
- As little as possible
 - Reading about new research

RUTH

PLEASANT, ENGAGED & OPTIMISTIC



BACKGROUND

Age: 62
Location: Stockholm
Education: Engineer
Profession: On disability pension
Home life: Partner, three kids
Disease: Multiple Sclerosis
Hobbies: Gardening, engagement within patient association

PROFILE

Ruth has always been a very active person, though over the last few years less so due her more prominent symptoms. Loving to take long walks, it is a grief for her not to be able to do that anymore. For Ruth, who always has been well articulate, it is a great annoyance when she can't find the words or loses the thread in conversations. However, Ruth is more inclined to think of what she can still do instead of what she can't do as she is an eternal optimist.

Though not believing a digital health services can improve much in her life, Ruth thinks it could be nice to have help with prescriptions and maybe, out of curiosity see her health record. However, Ruth is a firm believer in human connection and doesn't think it can be replaced by a computer.

Ruth thinks the healthcare system works fine today and more help would be unnecessary. Moreover, Ruth thinks that for her it would not be of any benefit to see have more information of her personal health, applying the saying about "what you don't know can't hurt you".

MOTIVATIONS

- Not getting worse
- Staying active
- Focusing on possibilities

FRUSTRATION

- Feeling gradual impairment
- Limited energy
- Not being able to walk long distances

USER GOALS

- Ruth uses her digital health services for...*
- Seeing medical record
 - Keeping track of prescriptions

Figure F.1: Personas

G Evaluation of the effect goals for each persona

Goal	Dennis
1. Provide easy-to-understand and personalised information	(a) Wants access to new research and new treatments of MS for young people (b) Wants to hear about meetings and network for young people with MS
2. Enable smooth communication with healthcare	(a) Wants to be able send emails to doctor (b) Wants to avoid telephone queues and inconvenient appointments
3. Provide a tool for better mental health	(a) Digital contact with therapist between appointments (b) Reminders to do exercises he got from his therapist (c) Receive suggestions of exercises, such as mindfulness exercises and brain exercises
3. Provide a safe platform for sensitive information	(a) Encrypted (b) BankID (c) Guarantee no one but him can access the information
4. Provide a tool for easy contact with the insurance fund	(a) Works full time and does not need to have contact with the insurance fund
5. Provide effortless storage of collected personal health information	(a) Wants to have digital access to health record for greater freedom and flexibility when, for example, moving places (b) Wants to set personal health goals and follow the development (c) Wants to see correlations between habits and mood
6. Enable communication and exchange with peers	(a) Wants to be able to share his experience to help persons, especially young, newly diagnosed with MS

Dennis' personal goals for using health services

Goal	Lena
1. Provide easy-to-understand and personalised information	(a) Wants access to new research concerning cure for PD (b) Wants information about future studies and available treatments (c) Receive easily understandable information about requirements from the insurance fund (d) Wants to find information about relevant insurances (e) Wants to find information about relevant compensations and allowances she can apply for (f) Wants to find relevant information of available aids and services (g) Wants to find health apps that would suit her
2. Enable smooth communication with healthcare	(a) Being able to more easily book an appointment (b) Being able to book doctor's appointments in time for sending in certificat to the insurance fund (c) Being able to contact caregivers on her own initiative
3. Provide a tool for better mental health	(a) It will relieve her biggest stressor through enabling easier contact and being a tool for coordinating her care (b) Being able to not worry about if she will receive her money from the insurance fund
3. Provide a safe platform for sensitive information	(a) BankID will make it safe (b) Is neither worried or interested in safety aspects
4. Provide a tool for easy contact with the insurance fund	(a) Minimise time spent on the insurance fund (b) Provide better contact with her insurance officer (c) Increased transparency of the process and her place in it
5. Provide effortless storage of collected personal health information	(a) To have all health related information in one place (avoid keeping track on several systems) (b) A better understanding for her health status (c) Follow her own development in relation to her goals (d) Easy access to prescriptions (e) See her doctor's appointments
6. Enable communication and exchange with peers	(a) Wants tips and recommendations from other that can help her (b) Find training buddies

Lena's personal goals for using health services

Goal	Eric
1. Provide easy-to-understand and personalised information	(a) Hear about new research within the fields of stroke and aphasia (b) Find exercises to improve his right side's strength (c) Find aphasia and speech related courses (d) Keep track of events and activities arranged by patient association
2. Enable smooth communication with healthcare	(a) Easily book doctor's appointments (b) Access notes from meetings (c) Be able to not feel patronised in contact with caregivers
3. Provide a tool for better mental health	(a) Believes that digital health services can have opposite effect
3. Provide a safe platform for sensitive information	(a) Not to store anything in health services make them safe
4. Provide a tool for easy contact with the insurance fund	(a) Be able to not feel patronised in contact with the insurance fund (b) Being able to more easily express questions
5. Provide effortless storage of collected personal health information	(a) Does not see any benefit with digital access to personal health information (b) Already has his health record in a paper copy, feels this is enough (c) Wants to measure and follow his development (d) See doctor's appointments
6. Enable communication and exchange with peers	(a) Find persons in close proximity with experience of aphasia

Eric's personal goals for using health services

Goal	Ruth
1. Provide easy-to-understand and personalised information	(a) Wants to know what kind of brain exercises she can do (b) Keep track of events and activities arranged by patient association (c) Get tips about aids to increase her wellbeing
2. Enable smooth communication with healthcare	(a) Collect phone numbers to caregivers (b) Access notes from meetings (c) See appointments (d) Important to preserve the personal contact
3. Provide a tool for better mental health	(a) Believes that with a positive mindset mot will be good (b) What you do not know cannot hurt you
3. Provide a safe platform for sensitive information	(a) Has not thought much about potential safety risks associated to digital storage
4. Provide a tool for easy contact with the insurance fund	(a) Has no problems with her contact currently (b) Important to preserve the personal contact
5. Provide effortless storage of collected personal health information	(a) Wants to see her health record (b) Keep track of her prescriptions
6. Enable communication and exchange with peers	(a) Connect with persons she can recruit to the patient association (b) Keep contact with others living far away which she met on Neuroförbundets yearly meeting

Ruth's personal goals for using health services