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Project HOME

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Abstract

Chronic diseases are an increasing problem in society. This is both due to a change in demographics, with an increasing older population, as well as lifestyle related diseases affecting younger generations.

SmartCare is a European project with the purpose to develop integrated care services delivered with help of information and communication technologies. The goal of the HOME project is to explore SmartCare from a holistic view on request of Uppsala County Council. This is achieved through an international collaboration between students at Uppsala University and Rose-Hulman Institute of Technology.

When exploring the possibilities for a new system it is important to include the user perspective. In the HOME project that has been done through interviews with potential private and professional users as well as field studies with the purpose of understanding how usability can be achieved when integrating technology in medical care. These studies resulted in four *personas*, which can be used to visualize the system.

The result found was that motivation matters far more than expected. When integrating technology in medical care, it is not enough to make a system user-friendly, focus also has to lie on usability. The results show that a system has to make work easier for medical professionals in order to motivate usage. The behavioral and motivational studies done in the HOME project also show that technology itself will not make the private user change his or her lifestyle. Therefore technology has to support greater sources of motivation such as a close dialogue with medical personnel, setting up goals for improving lifestyle and getting feedback for improved results.

These results were found through studies made locally in the Uppsala municipality. In order to give more general recommendations applicable to the whole EU, a broader study must be made. However, the conclusions regarding motivation and user involvement in the development process is not uniquely representative for Uppsala or Sweden and could serve as guidelines for the whole SmartCare project.

Contents

1 Introduction

"*The world's population, now estimated at 7.2 billion, could reach 8.1 billion by 2025 and up to 9.6 billion by 2050*[41]" The population of the earth is constantly increasing. Scientific and medical breakthroughs during the last 100 years, such as penicillin and vaccines, have treated an increasing number of diseases. Effects of that, together with an increasing human welfare, result in an older population but also in new lifestyle related diseases that affect younger people.

Two such chronic diseases related to lifestyle (Section 2) which are increasing rapidly, are type 2 diabetes (Section 2.1) and chronic obstructive pulmonary disease, also known as COPD (Section 2.2)[32][35]. Today, medical personnel have been overextended in treating these diseases and are now looking for a solution in both maintaining and reducing the risks of lifestyle related diseases.

The next stage of medical innovation is continued integration of technology into personal healthcare. This both gives the patient a central role (Section 4.3.1) and alleviates some of the work performed by the medical personnel. Patients will be able to record their results at home and maintain their own health so that they do not have to go to the hospital as often as many of them do now.

A central question that emerged during the work of this project was how to motivate individuals to maintain their own personal medical information. A technological solution with a high functionality and usability that is both reliable and secure would be effective in motivating many types of people.

1.1 HOME Project - a Branch of SmartCare

HOME Project stands for Healthcare Optimization through Motivational Equipment. It is a student-led branch of the SmartCare Project (Appendix E) which is run by Uppsala County Council. HOME has assisted SmartCare in investigating and evaluating different possibilities and implications of implementing a system for self-tests in a home environment, secure data transfer, efficient data representation and motivational feedback tools.

Studies made in HOME were focused on remote self-care of type 2 diabetes and COPD. SmartCare will also focus on the third chronic medical condition heart failure[34]. This delimitation is made due to the time limit of the HOME project while SmartCare is estimated to run from 2013 to 2016, HOME only lasts 4 months.

1.2 The Authors of this Report

This report has been created by eight students that took part in the course *"IT in Society"* at Uppsala University, Sweden and four students participating in the course *"Computing in a Global Society"* at Rose-Hulman Institute of Technology, USA in autumn 2013. There have been collaborations between these courses for the past nine years. In order to improve the collaboration between the Rose-Hulman and Uppsala students, the American students and

their Professor Cary Laxer, resided in Uppsala for a week in September and a week in December for initialization and finalization of the work for the HOME project. The names and contact information of all authors can be found in Appendix A.

1.3 Goal

The goal of Project HOME is to create a holistic understanding of the SmartCare Project. This includes exploring the SmartCare Project from a professional as well as a private user's point of view, researching how technology can motivate these users and enhance patient-centered care and also evaluating ethical, legal and social implications of SmartCare. In order to easier understand the needs of the users and the potential of a system a prototype was created and used through the exploration process.

1.4 Methodology

Throughout the project, different methods were used for collecting, analyzing and evaluating data and results. The main research was made through user interviews and data was analyzed in a qualitative way in order to create representative personas. An initial literature research was performed and material was collected through databases such as SCOPUS, INSPEC and IEEE Xplore (Appendix B), articles found in contemporary newspapers and scientific journals as well as patient associations' web sites.

1.4.1 User Interviews

The greatest source of information has been interviews with potential users. Due to limit in time and experience fewer people than desired were interviewed. Four persons with diabetes were interviewed, one with COPD. All informants were from Uppsala. As for medical personnel, two medical doctors, one in Uppsala and one in the US, and one nurse in Uppsala were interviewed.

The interviews were performed with a semi-structured approach. Questions written in advance (Appendix D) were used as context from which a dialogue evolved. This method was chosen to encourage interviewees to share their thoughts and experiences unimpededly. This resulted in interviews providing a lot of material despite limited number of paticipants.

1.4.2 Field Studies

In addition to interviews, field studies were performed in order to get more general knowledge about the diseases, medical work environment and previous studies in the area.

These included visits to

- **Uppsala Diabetes Association's annual meeting** where type 1 and type 2 diabetics as well as medical personnel and companies manufacturing glucose meters were present
- **Blå rummet**, a Library at Uppsala University Hospital where patients and relatives can seek information in literature as well as talk to a nurse
- **Medicinsk teknik, sjukhusfysik och it** at Uppsala University Hospital, talking to researchers involved in *Dreaming*, a previous study of telemedicine in Uppsala County.
- **A primary care center**, studying the current work environment from a doctors perspective

1.4.3 Application Prototype

A smartphone application prototype was created using Blend for Visual Studio 2013[44] with a student license through Microsoft DreamSpark[46]. It was completed over a series of weeks taking approximately 30 hours to develop. The prototype was created through an iterational process where each version was briefly evaluated by the whole project group and modified to meet new requirements that arose as the project evolved.

The purpose for creating the prototype was to give a visual representation of ideas developed by the HOME project for a smartphone application, using motivational guidelines (Section 3). A central goal of the application was for it to be functional and usable to the everyday user.

The prototype was used during the presentation of HOME to Uppsala County Council to explain how HOME envisioned a possible solution for a smartphone application. Screenshots of the application are found in Appendix G.

1.4.4 Personas and Scenarios

For this project, the personas are created from interviews performed with both patients living with different chronic diseases and doctors. A persona is a fictional character based on studies from the target population when developing a system and its design[62]. The patients, *Eva* (type 2 diabetes) and *Lars* (COPD) have different characteristics and needs that have to be considered in the system design. Similarly, representing the healthcare, there are one Swedish doctor named *Anna* and one American doctor named *John*. All personas can be found in Appendix C.

1.4.5 Methods for User Experience Evaluation

There are several methods to evaluate user experience and usability. One such method is AttrakDiff™[2], which is an evaluation method to measure the attractiveness of an interactive product. By providing users with a questionnaire consisting of opposite words (e.g., good - bad) and a point scale in between, they will grade the experienced appeal of the system design. When users have

answered the questionnaire, the results are calculated to provide an average score for each pair of words. AttrakDiff™measures all the four user experience dimensions of the product, pragmatic quality, hedonic quality stimulation, hedonic quality identity and attractivness.

Another method of measuring usability is heuristic evaluation, one of the more widely used is Nielsen's heuristic evaluation[53]. It consists of ten *heuristics* (Appendix F) or so called *rules of thumb*. A number of evaluators examine the product and judge it in relation to the heuristics. In a short amount of time, a rather extended evaluation can be produced and show a number of errors with only a few participants. A heuristic evaluation in combination with other evaluation methods is likely to provide sufficient material to improve upon.

By using AttrakDiff™as support material and Nielsen's heuristic evaluation, a set of recommendations have been developed by the group members. First, two different heuristic evaluations were done, one by a group of three members with prior knowledge of the prototype and the other one by a group member in the US who also had very good prior knowledge about the prototype. Secondly, an AttrakDiff™evaluation was done with the group members to see how dimensions of user experience would result. Since the sample of people all had the same background (University students in the IT field, 20 years of age) the evaluation was not very useful. However, it could be used as supporting material to develop recommendations for future design process.

2 Chronic Diseases

As mentioned in Section 1, the SmartCare project has been investigating three chronic diseases, heart failure, type 2 diabetes and COPD. The HOME project has focused on the two latter.

In an email correspondance with Heléne Eriksson, Project Leader SmartCare Sweden, it was explained that the EU chose chronic diseases for the study because they cost society a lot of money. "*We must follow the restrictions provided by the EU. They want us to select patients with chronic diseases. These diseases affect the lifestyle and cost society a lot of money. It is about giving patients a better understanding of their illness and reduce the need for emergency care.*"

Both type 2 diabetes and COPD are chronic diseases (i.e., cannot be cured), with symptoms that often are directly affected by lifestyle choices. This makes these diseases good targets for project HOME regarding motivation.

2.1 Diabetes Mellitus

Diabetes mellitus is a disease that has several types, all of which have symptoms of increased blood-glucose levels. Insulin is a hormone, produced in the pancreas, that has a central role in the human metabolism. A person with diabetes has little to no insulin production and can therefore not absorb the glucose in

the blood[10]. This study is focused on type 2 diabetes, where the pancreas still produces a small amount of insulin.

Diabetes cannot yet be cured, but with the right lifestyle changes, a person can live a full life despite the disease. Exercising and eating the right food, avoiding substances (i.e., carbohydrates) that increase the glucose levels in the blood, will in most cases make the existing amount of insulin sufficient[11]. Self-monitoring (e.g., factors such as weight and blood-glucose) is an important tool for motivating lifestyle changes and tracking results thereof.

Blood Glucose Meter Diabetes mellitus is a disease that has several levels of severity. All of these levels have the symptom of increased blood-glucose levels. Patients with type 1 diabetes usually measure their levels around three to ten times per day, while a patient with type 2 diabetes only measures it at most once a day.

Development of glucose meters have in the last years focused on usability, mobility and connectivity[8]. For example, in older meters users often had to program the meter themselves for the specific test strip that was used. This had to be done because test strips may vary from batch to batch. Programming the meter with the wrong strip code could cause misreadings. Most of today's meters do not require this manual coding, therefore risk of miscoding is reduced.

A standard meter is about the size of the palm of a hand, often equipped with a large display and just a few buttons. There are of course a wide spectrum of different devices ranging from the simplest ones which show just the current measurement to more sophisticated ones with color-displays and ability to show detailed statistics and history. The latter ones often have the possibility to export data to a computer via a cable or wirelessly (in most cases via Bluetooth). With software from the manufacturer installed on the patient's computer, it is possible to save all tests in a electronic "logbook". This has shown to be associated with reduced HbA1c[1] values in a controlled trial, compared to paper log[24].

2.2 Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is a lung disease defined by a reduced ability to breathe. COPD is the fifth most common cause of death today and is predicted to become the third most common by 2020[36]. COPD is said to be a smoking-induced disease, and as many as 80-95% of the people suffering are or have been smokers[36]. Quitting smoking is the most important step when beginning treatment for COPD. In Sweden, all patients are offered free consulting to encourage them to quit smoking.

Breathing provides the body with oxygen as well as transporting carbon dioxide out of the body. For a healthy person, exhalation is a passive process. However, for a person suffering from COPD both the inhalation and the exhalation are active. That person has to suck in, and push out air in every breath[36]. Due to

[1] Measured to determine the glucose concentration in the blood plasma over a longer period of time.

shortness of breath, it can be difficult to do every-day tasks, such as walking up stairs or moving around. Despite this, people suffering from COPD are strongly encouraged to exercise. Shortness of breath is not dangerous and even though lung capacity cannot be recovered, a better physical shape will increase oxygen uptake and reduce breathing problems[27].

Spirometer To measure the severity of COPD, a device called a spirometer is used. A spirometer measures the volume of air inspired and expired by the lungs and can be used to monitor several different lung diseases and not just COPD. As opposed to diabetes patients, COPD patients do not have to measure their metrics on a daily basis. It is measured periodically after the doctors recommendation to track the lungs functionality. The basic procedure for a test is that the patient has to take a deep breath and then exhale as hard as possible through the spirometer turbine.

Two parameters are used for measuring the severity of COPD. The first one is forced vital capacity, that is the maximal volume of air exhaled after a maximal inhalation. The other one is forced expiratory volume in 1 second that measures the first second of forced vital capacity. A motivation of doing spirometry more often is to detect exacerbations, worsenings at an earlier stage.

Oximeter A pulse oximeter can be used to provide additional information about a patient with COPD. This device allows users to monitor quickly and easily their blood oxygen saturation. Blood oxygen saturation refers to concentration of oxygen in the blood. Since a human body needs a precise balance of oxygen in the blood it is very important to assess that value, especially for patients with chronic disease such as COPD. For a healthy person, the saturation level is situated between 95 and 100%. Oxygen saturation levels for patients with COPD are usually lower[68]. A too low level could compromise the function of organs, such as brain and heart. To avoid that, oximetry can be used to rapidly detect changes or inadequate levels in oxygen saturation and provide an early warning.

For this kind of test, the procedure is usually non-invasive, simple and user friendly. The patient puts a sensor on a part of the body that is relatively translucent and which has good arterial pulsed blood such as a fingertip or an earlobe. The sensor will use a light of two wavelengths to measure the oxygen saturation[42].

3 Motivational and Behavior Research

Even with a lot of efforts being focused on making technology easy to access and use, it is far from enough to be successful in regards of reaching goals to affect users in the intended way. Because of this, it is important that this solution is accompanied by support from sources which are external to this technological setting. In order to make effective use of this solution, the users have to be motivated. Some users will show a tendency of being motivated by the technology in itself, but this is far from generalizable. It is important to

remember that each individual is different, and thus, it is not possible to affect and motivate each individual in the same way.

As the HOME project is a part of a bigger plan, which is to ease for and affect individuals into living a more healthy lifestyle, plans of how to change their behavior has to be considered and thought through. These plans will have to deal with the fact that different individuals have a different perceived view of what motivates them and what does not. The following topic concerns these factors, which are highly related to motivation and behavioral change.

3.1 Motivational Theories

"*Motivation is the driving force within individuals that impels them to action. This driving force is produced by a state of tension, which exist as the result of an unfilled need.*"[26]. Motivation can be viewed as a psychological basis that can lead a person to act toward desired states. In this project, motivation can be used to create desired goals for people which will arouse awareness of health habits and thus convince potential users to use the HOME system.

3.1.1 Self-efficacy

Self-efficacy is a concept defined as "*the conviction that one can successfully execute the behavior required to produce the outcome.*"[4] In other words, the belief a person holds regarding her power to affect situations and how it influences the choices the person is likely to make. Self-efficacy is found in every aspect of the humankind's thoughts and very apparent with regard to behaviors affecting health in relation to the Health Belief Model[4].

A person with a higher self-efficacy is more likely to not avoid a requiring or advanced task. It is likely that the motivation given by high self-efficacy leads to completion of tasks and longer and more active efforts in doing so. However, low self-efficacy sometimes leads to incentives to learn more about unfamiliar subjects[58].

In regards to health effects, self-efficacy is very apparent and a key factor in the choices people make. First of all it determines if a behavior change will be initiated, how much effort will be put into it and how long the duration will be in face of obstacles and failures. It also influences how high people set their goals. Within the focus group, the necessity to improve self-efficacy can play a role for an extended use of the system in connection with the other theories.

3.1.2 Need Theories

Needs can be defined as "*gaps between the desired and the current states*"[60]. In this project, building the desired state for people, in addition to form *needs* for people, is wanted. Triggering potential users to react towards and diminish gaps between their perceived current and desired states created by the HOME system is one goal the system can accomplish. Since individuals usually over-perceive

their current state, it is also important to make individuals aware of their actual current state and motivate them to take necessary action in advance.

For example, *Eva* (Appendix C Persona 3) overperceive the current state and experiences the gap between the current and desired states is smaller than it is. That could be explained by the fact that she does not feel ill and does not have enough knowledge about her disease. If *Eva* were to use the system, she would be well informed about her disease and the state of it.

3.1.3 Intrinsic and Extrinsic Motivation

"*Intrinsic motivation refers to doing something because it is inherently interesting or enjoyable, and extrinsic motivation refers to doing something because it leads to a separable outcome*"[9]. Briefly, intrinsic motivations are those motivations driven by a task itself and mainly within people themselves. Extrinsic motivations on the other hand are related to achieving certain outcomes or to receive certain rewards outside actors themselves such as a bonus, promotion or receiving awards. Intrinsic motivation is a much stronger motivational source than extrinsic motivation, which is why it is beneficial to try to convert an individuals extrinsic motivation to intrinsic.

For example, *Eva* wishes to gain more knowledge about her disease (intrinsic motivation). However, she only takes her medication to make the doctor happy (extrinsic motivation). If she was to gain more knowledge through the HOME system, possibly understanding the severity of the disease could lead to her taking medication for her own sake.

3.1.4 Incentive Theory

An incentive is reward obtained from external resources. In this theory, individuals can be motivated by the incentive that they will receive a reward after specific behaviors occurred. That is, individuals can get rewarded extrinsically by others because of their behaviors. A reward can be intangible or tangible such as attention or monetary reward. The reward received can continuously motivate certain behaviors to happen again. After repeating the combination of behavior-reward and with the help of continued reinforcement, the bond between behavior and reward becomes stronger and thus, an individual can build habits over time.

For example, *Lars* (Appendix C Persona 4) does not have a gym pass, therefore he could be motivated with the reward of getting a free gym pass if he continuously used the HOME system.

3.1.5 Goal-setting Theory

"*Goal-setting theory purports a direct link between setting achievable, specific, realistic, challenging, and measurable goals and increased performance among those participating, as noted by Edwin Locke and Judith Bryan in 1968*"[3]. The goal-setting theory argues that an individual, group or organization will

perform better when these type of goals are set in relation to the performance without goals. If the set goal is realistic, it is more likely that an individual has self-efficacy enough to work all the way toward that goal. On the other hand, if it is not realistic, if it is too far ahead in some distance measurement, it is not as likely that an individual feel that they can attain this goal. "*Goal setting derives its motivational force through six fundamental motivators: participating, rewarding, supporting, clarifying, communicating, and challenging, as noted by Locke and colleagues in 1988*"[3].

To make use of goal-setting motivation in making plans and strategies for lifestyle changes, it is important to plan for and consider these six fundamental motivators. An individual feels more motivated when he or she has participated in the goal-setting process. Incentives can be given which will motivate individuals to reach goals. Helping the individual to work towards and hopefully reach certain goals would be helpful first for the individual and also to this project. Support can keep up and rise the individual's self confidence which is a motivating factor. The individual's role should be clear and good communication is of importance. This is to avoid confusion and conflict, which would demotivate him or her. This would also get the individual more involved and committed[3].

For example, *Lars* and *Eva* were not introduced to any kind of health promoting programme with realistic goals. If they were to participate in such a programme they could be more motivated to reach the ending goal and continuously use the system. The HOME system would assist *Lars* and *Eva* to set realistic goals, plan for action and evaluate the outcome (Section 3.3.2 and 3.3.3).

3.1.6 Attribution Theory

"*The process of assigning causes is called making attributions*"[60]. This theory is based on individuals' desire to find and assign causes to events and behavior. This includes finding and assigning causes to individuals' own behaviors. One way of splitting up and specifying attributions is by internal and external attribution. Internal attributions assign causes to personal factors and external attributions assign causes to environmental and situational factors, which at the moment of the event or behavior were not controllable by the individual. External attributions can, for example, be used by individuals to explain why they behaved in a certain way in order to put the blame on the environment and not on themselves which they will use to justify their actions[60].

Understanding attribution theory should give an understanding how people find causes to something. When developing self-regimen programmes, it is necessary to shine light on the actual causes of a follower. For example, when *Eva* has a conversation with a nurse she states she has no time to regularly exercise. *Eva* is newly retired and the truth is that she does not want to exercise and then put the blame on not having enough time. It is necessary to find actual causes when individualizing programmes.

3.2 Perceived Barriers, Benefits and Severity

Perceived barriers, benefits and severity are three dimensions of the Health Belief Model. The Health Belief Model is a psychosocial model which describes aspects of why people take action to health promoting behavior. Two of those aspects are perceived barriers and benefits[52].

One of the main motivational barrier perceived by diabetes patients is a global lack of knowledge and understanding. This lack of information will affect patient motivation and adherence because they will not be likely to follow a program they do not understand. For example, studies showed that many participants were not satisfied with their healthcare providers because they felt like they did not have sufficient information about the program, a diet plan or their disease. If the people are convinced by the gravity of their disease, what should be done and that they understand that lifetime changes will be effective for their health, they will be more likely to respect a program.

The second perceived barrier identified by studies is lack of individualized care. Patients felt that plans to follow were too general, not enough individualized but also uncoordinated between care providers. This barrier was emphasized by the fact that participants of group education sessions perceived classes as having limited personal significance.

For a long run treatment like for type 2 diabetes, the barrier can also be situated in the fact that patients can lose motivation over time. In that case, motivation is usually related to the fact that goals defined are too difficult to reach. Patients stated that they could feel frustration and helplessness by the lack of results despite adherence to the self-care program. This lack of result could also lead to a lack of motivation and discouragement regarding the program.

For different reasons, patients stated that it was sometimes difficult for them to obtain recommended resources such as medicines, equipment, laboratory tests or provider services. As a consequence, it creates a barrier for patients who want to follow a self-management program. The fact that resources could be difficult to access could be justified, once again, by lack of information about access to resources, limited incomes or insurance coverage[51].

One of the main motivational benefit perceived by diabetes patients is exercise[23]. That means that diabetics have a belief that exercising will lead to a better lifestyle. However, the benefit is not enough by itself to trigger health promoting behavior. Additional benefits need to be perceived by the diabetic and the benefits should outweigh the barriers[52].

Interviews in this study show that diabetics perceive the severity of their disease as lower than it is. Only a minority of diabetics (7%) comply to the self-regimen actions considered necessary for control of their disease[23]. Studies have also shown that compliant groups of diabetics perceived their diabetes as more severe. These patients might be more realistic about consequences of the disease, and therefore more motivated to take action[52]. Therefore, it could be stressed that diabetics should gain more knowledge about their disease to realise how severe the disease is.

3.3 Behavior Change Strategies

With knowledge about motivational factors and barriers, different types of plans should be consider in order to overcome these barriers and make use of motivational factors. Following are a few suggestions that have proven to be effective and supportive in changing individual behavior.

3.3.1 Motivational Interviewing

Motivational interviewing is an effective approach of talking to people about change. Decision making is a natural part of everyday life and does often contain some sort of change including shift in career, family, dealing with unhealthy habits etc. When people experience difficulties in making a change it is often because of *ambivalence*, an uncomfortable feeling of anxiety when wanting incompatible things simultaneously. In turn, ambivalence does often result in procrastination to avoid the feeling of being anxious. Hence, motivational interviews can be applied in order to resolve ambivalence and evoke people's own motivation to perform a change[15].

3.3.2 Plan actions

One of the good practice to achieve a goal is to plan needed actions to reach that specified goal. Each patient needs to think of when, where and how they have to realize an action. With that reflection, patients will be able to identify the best situations and opportunities to act. As a consequence, patients in that specific situation are supposed to initiate action in an nearly automatic way. The action should be initiated quickly and without effort. This could be explained by the fact that action is started unconsciously. For the end user, it allows him or her to avoid distractions and to abandon because of faced difficulties.

From a psychological point a view, the goal of planification is to integrate new behavior on a daily basis with limited needs of self-efficacy. Since self efficacy is a limited resource needed for realize an action, it is important to preserve it as much as possible in particular for patient with low self-efficiency.

Nevertheless, planification can be limited during period of stress, life transition or changement transitoire such as holidays. In theses cases, patients are likely to break with their routine. One of the solutions is to consider these potential barriers and once again, plan the actions to overcome these barriers[50].

3.3.3 Evaluate Changes

The main objective of behavior changes is to reach a goal. These changes need to be continuously evaluated to assess progress of patients but also potential barriers and needed efforts. This evaluation can be done by a mechanism of feedbacks which can reduce the gap between hopes and actual state, provoke motivation but also reinforce patients actions persistence in the pursuit of their goal. In case of positive feedbacks, users will be aware that they are going in

the right direction and they will be motivated and more likely to persevere. On the other hand, in case of negative results, feedbacks are supposed to stimulate patient perseverance and encourage him to redoubling efforts. However, it can also lead to discouragement and motivation drop when the gap between hopes and results tends not to be reduced. Feedback is important in handling the aspects related to the pursuit of a goal and to adapt patient strategy[50].

3.4 Conclusion

In order to make effective use of a solution such as the HOME Project, users have to be motivated to both use the system itself and also when performing a change in their lifestyle. Some users will show a tendency of being motivated by the technology in itself (i.e.,*Lars*), but this is far from generalizable. It is important to remember that each individual is different and thus it is not possible to affect and motivate each individual in the same way.

By identifying barriers and motivational factors on an individual level, followed by making use of these while forming behavioral change plans will, with support of this technological solution, assist and support individuals into changing their lifestyles into a healthier way of living. This will both be beneficial, in terms of financial and health, to members within societies and to societies seen as a as a unit.

4 Importance of Knowing the User

To successfully implement a new system of any kind, it is very important to know *for whom the system is made*. Many existing systems, both in medical care and in society as a whole, were created without any input from the actual users[28]. In the HOME project, a lot of resources are focused on answering the questions *Who are the users?* and *What can HOME provide to assist them in their professional and personal life?*.

4.1 The Users

The potential users of the HOME system include the entire populations of every country implementing the HOME System. At this time and in the scope of this project, the users are a bit more limited. As of this time the users can be split into three groups, patients, doctors and caregivers.

Patients are people who suffer from illnesses that require long term care but do not require constant hospital visits. Focus lies on type 2 diabetes and COPD sufferers. The age of these patients has a very large range but primarily they will be older than 40. They will be the ones who provide data to the HOME system.

Doctors are specifically the medical doctors responsible for treatment of the patient group. They will, together with specialized nurses, be receiving data from the patient. A majority of these doctors will be specialized in treating the particular illness associated with their patient or are general care providers. Many of these doctors opposed the current patient access system, and it is probable that this group may oppose the HOME system as well if they are not included in the design and implementation process.

Caregivers are those people who are helping to take care of the patients (note that these are not doctors). They can be the family of the patient in question or they may be hired to help them out with their daily activities or on a need to need basis.

All of the people from these groups will have access and familiarity with variable ranges of technology. They will be from a variety of ages, except for a tendency of the patients to be middle age and older. Due to the scope of this project, the focus lies mainly on people living in Sweden though some focus is also on Americans. Location of the users is also a variable. In the HOME project as well as in the initial state of the SmartCare project, users are likely to be concentrated in cities as opposed to the country.

4.2 Introducing the HOME System to Private Users

The people who will be using HOME devices will come from different backgrounds and have different purposes for using it (Section 4.1). The private user (i.e., the patient) is just as important to include in the developing process as the professional user (i.e., medical personnel). Private users (Section 4.1) are mostly elderly people, therefore it is important that devices are very user friendly, taking things like font size and unfamiliarity with technology in consideration. Furthermore, it is necessary to consider aspects of motivation (as presented in Section 3) to support the patient to make use of and profit from the system.

No matter how good the graphical user interface (GUI) of the HOME application and other devices will be, if the introduction of the product is not made with consideration to users abilities and needs, the user will have less or no motivation to use the product. Therefore, it is important to adapt the way a product is presented in a way suitable for the customer. People who are unfamiliar with technology, for example *Eva* (Appendix C Persona 3), will probably be less receptive to large quantities of information and might need step-by-step instructions and repeated guidance. A person with great technological experience, like *Lars* (Appendix C Persona 4), who are capable of using more advanced functions will probably have a better understanding of the underlying system and could be more receptive to abstract information such as authentication and data security.

4.2.1 How Much Information is Too Much

Once the private users are categorized, a central question needs to be answerd: *What is sufficient and necessary information when presenting a system like HOME to the private user?*

Is it for example enough to tell *Eva* that the system is developed by the County Council without going into security details? Will patients like *Eva*, who in an initial state learn that they need to provide personal data through Internet using an unfamiliar device be more or less positive towards the system than those who do not get as much technical details thrown upon them? It must be taken into consideration how to inform people like *Eva* about aspects of the system such as security, so that they can make an informed decision on how to use the system, thereby not being unfoundedly cautious or afraid.

4.2.2 Results from User Interviews

In order to explore users' expectations of such a system, during the interviews (see questions, Appendix D) the users were asked about how they would like to be introduced to the system and how they would prefer to receive information about security, usability and infrastructure of the system.

Even though the answers varied, there was a pattern leaning towards *Lars* wanting the device introduced during a doctor's appointment and written instructions to read. When it comes to security, he would like a rough sketch showing how data is transferred, but he does not care about more detailed security information. While *Eva* would prefer an introductory group lecture, followed by a personal home visit where the device, as well as a written manual would be handed over. *Eva* is not bothered by security issues and thinks BankID feels secure enough. Knowing that her doctor and the County Council is behind the system also increases her trust in a HOME device. "*The important thing is that its presented in a professional way and that the product feels familliar, that I can trust it*" says one interviewee that Eva is based on.

4.2.3 Information Overload

Information overload is a common problem these days, often caused by the massive data-flow generated by social media. However, the phenomenon existed before technology was used by "everyone" in common life. The following quote is from 1977.

" *Information* over*load refers to the fact that there are finite limits to the ability of human beings to assimilate and process information during any given unit of time. Once these limits are surpassed, the system is said to be 'overloaded' and human performance (including decision making) becomes confused, less accurate, and less effective.*"[19]

If detailed security and technical information will cause information overload in the elderly patients, focus on such information needs to be toned down. It

is important to provide patients with accurate amount and type of information. However, this is not always easy: " *If provision should be limited for the consumer's welfare, just which information should be provided?*[19]"

4.2.4 Conclusion

The interviews show that different patients requires different information in order to embrace a new product. Results indicate that patients used to technology could be more recipient to security and technology information. However, the interviews also show that patients in general are not very interested and concerned with security details as long as the system is recommended by their doctor.

Studies done in this area point out some of the essential, but difficult questions: "*How much information produces overload?"* and *"How does this vary across market segments (e.g., for the elderly, the disadvantaged, etc.)?*"[19]

A more thorough research among the patients in the target group could generate results that, if used to adapt the introduction process to suit the patient, would make the implementation of the system more efficient. Resources could then be used efficiently, focusing correct guidance, tutoring, and support where needed. If users who learn best by reading the manual are allowed to do so, money saved can be spent on those who have a higher threshold that they need help to overcome.

4.3 Medical Work Environment

A pleasant work environment is crucial in order to provide fully functional care and keep appealing to the young population with interest in medicine. A stressful schedule along with badly designed systems will most likely have a negative effect in the long run for medical personnel which, in turn, also affects patients[40]. By performing interviews with professionals in medical care along with field studies in order to properly understand the needs in their daily work, it is possible to gain insights into: *How a system like HOME would affect the work environment of the medical staff, considering requirements, amount of work and experienced stress.*

4.3.1 Patient-centeredness

Patients with chronic diseases are often scheduled to visit their personal doctor regularly which might be tedious for the patients. To make an appointment today, the patient has to contact the hospital to be given a time slot. When entering the hospital at the reserved hour, the patient has to wait for an available nurse to begin basic measurements which will be handed over to the doctor by the time he or she is accessible and ready to begin the actual appointment[64]. Once the actual appointment begins, the doctor typically spends a lot of the reserved time doing administrative work including booking and waiting for test results. A doctor that the persona *Anna* (Appendix C Persona 2) is based on

estimates that "*clinical doctors spend about half their time doing patient related work, where about 50 % is spent in front of the computer. The other half consist of administrative tasks that require a computer and meetings with other medical personnel. Thus, about 65 % of a clinical doctors time is spent in front of the computer.*"

Patient-centeredness of healthcare is an expression that is widely used today and might have different meanings. For this project it can be described as *vision to increase quality of care within each doctor's appointment*. One way to obtain this would be to let patients take some of their tests at home and send directly to their health account. By doing this, doctors would have more time to talk with the patient, which would lead to an increase of patient-centeredness.

4.3.2 Results from User Interviews

During the interviews with professionals in medical care, one important topic discussed has been how medical personnel would like submitted data from patients to be presented. It turns out the majority, including *Anna*, would like to experience it through graphs and trend curves in order to easily see in what direction a patient under treatment is heading.

Another important aspect to consider is how to handle incoming measurements. Since an expanded use of the system would lead to a massive amount of sample readings, it should be handled in a way that will not have a bad effect on the concerned user's (i.e., medical personnel's) work environment. Based on results from the interviews, the most suitable way to avoid such a problem would be to only notify the medical personnel if the result of a measurement is crucial, or the trend curve is starting to approach a critical level.

4.3.3 Effect on the Quality of Care

With the electronic healthcare solution of the HOME project, patients have the possibility to take their routine measurements in the comfort of their home. In addition, medical personnel will have the opportunity of viewing the results in an efficient and satisfying way using graphs and trend curves. Thus, there will be more time during appointments dedicated actually talking with the patient, improving the quality of care. *Anna* also thinks that the vision of performing measurements at home would be helpful in order to observe diseases at an earlier stage.

4.4 Importance of User Experience

User Experience (UX) is a very important aspect of designing attractive systems for a user. It is defined as following " *UX is what users experience and feel before, during and after interacting with an interface. It also affects and is affected by surrounding aspects such as brand experience. UX is broader than usability, and thus encompasses usability. It also extends this with focus on users stimulations and motivations, and what users perceive as good or bad.*

This also means that UX focuses on both Do-goals (pragmatic) and Be-goals (hedonic), which means for example, both being able to find information and feel that the use is interesting and engaging. UX is dependent of the context of use and the user's internal state. UX is about designing for positive emotions and experiences."[20]

Generally four dimensions of user experience are described, pragmatic quality, hedonic quality stimulation and identity and attractiveness. Pragmatic quality describes the usability of the product and how successful the user is to reaching her goal. Hedonic quality stimulation describes the way in which the product encourage the user's personal growth through interesting and novel functions and content. Hedonic quality identity describes to what extent the user can identify herself with the product. Attractiveness describes the quality of the product based on perception of the user, for example if the typography is good looking or not[2].

4.4.1 Evaluating User Experience

Evaluating user experience can give a good idea how improvements in pragmatic and hedonic qualities can be improved as well as the general attractiveness of the system. However, with the aforementioned complexity, simple evaluations in one of the dimensions will not be sufficient enough to provide enough broadness to measure the full aspect of user experience. Other evaluations have to be done to measure emotions or experiences of the user, and how they feel about the product[56]. Therefore, it is important to follow several methods of evaluating user experience. These evaluations are often done with the help of a protype, whether it be a prototype developed in a programming language or paper. Very often, several iterations of evaluation are done, to ensure that the finished developed product or system, is as user experience friendly as it should be.

By observing the user in a field study and through a questionnaire or recall session, it is also possible to retrieve more opinions of the product in regards to how the user feels and experiences it. By providing a questionnaire before the evaluation to measure user expectations, and another questionnaire to measure the user experience afterwards; a systematic difference between the expectations and user experience will be shown. The hedonic and pragmatic expectations are much higher than the user experience[25].

4.4.2 Integrated Technology

Integrated technology in medical care (as well as any kind of business) exists for the purpose of unburdening the human performing its everyday tasks. If the usability within a system design is bad and results in poor user experience, it will have a negative effect on the user's vitality and could lead to devastating errors. In this case, errors could consist of incorrect prescriptions or difficulties reaching essential information in critical situations. However, some of the basic principles of a useful system can be summarized as lucidly, easy to learn, and navigate as well as making the user feel in control of the system.

It is clear that the usability of integrated systems in medical care is extremely important in order to make sure that the patient's health and information stay secure. This can be obtained by letting professionals constantly evaluate and optimize the system to fit its specific environment and users (i.e., medical staff and patients). It is also important to make the users feel satisfied regarding reliability and to make them trust a steady use without interruption especially among caregivers who might be on the road and need to reach necessary data quickly. The information should be presented in an efficient and well-structured way[57].

During the design process of a system, there are several questions or aspects, that should be revisited in order to cover the fundamental purposes, including: who will use it, and in which situations; what kind of tasks should be solved; in what context should the system be implemented and what are the specific needs.

4.4.3 Conclusion

Taking into account all the information at hand, regarding psychological aspects (Section 3), work environment, patient-centering and user experience, the design of the project HOME application should be created with consideration to all of the aspects. This should be done to ensure an optimal experience for the user. If that is done, the pragmatic and hedonic quality should be high and should ensure a prolonged use of the application and system. With this information, a prototype was developed and a set of guidelines or recommendations created (Section 7.4.3). However, it is necessary that further research is done in the fields of user experience.

5 Personal Health Record Systems

There are several technologies that can be used for telemedicine, both from a users perspective and from a providers perspective.

5.1 Microsoft HealthVault

Microsoft HealthVault is a service developed by Microsoft. It is described by Microsoft as a safe place to gather, store, use and share medical information online. It offers several applications for different platforms. The supported mobile platforms are Windows, Windows Phone, iOS and Android. As an official Microsoft product, the most applications are found for Windows Phone.

5.1.1 How it Works

Microsoft HealthVault offers storage space where all medical information about a patient can be accessed online. The user can track several different pieces of information regarding everything from complex health issues to lifestyle choices.

Medications, allergies, blood pressure, lab results, conditions, illnesses and x-rays are some of the data that can be stored. It also enables the user to access data from wherever an Internet connection is available. All information can be shared to trusted people in case guidance is needed or when someone is managing another person's health. HealthVault offers services which enable emergency situations to be handled more smoothly by making the most important information available to emergency responders. It also enables the user to sort and keep all data up-to-date and ready to be shared with caregivers and doctors. The user can also track his or her measurements to help monitor chronic diseases such as COPD and type 2 diabetes, by using devices which are connected for easy upload to HealthVault. When the user has done a few readings it is possible for caregivers, doctors and the user to see trends and patterns. These trends can be used to analyse and flag potential health issues[47].

5.1.2 Devices

Microsoft HealthVault offers a total of 224 different devices in Sweden and the US. All devices manufactured by third-party companies are connected to HealthVault for easy upload of information. They are also screened to be certified by Microsoft HealthVault. Most devices can be connected to applications on mobile devices, for the users to bring HealthVault with them wherever they go. There are often several different versions of devices offered, however with little difference in hardware or usage. Not all of them are available for purchase without contacting the provider[43].

List of devices offered:

- Blood Glucose Monitor
- Blood Pressure Monitor
- ECG Device
- Heart Rate Monitor
- Peak Flow Meter
- Pulse Oximeter
- Weight Scale
- And many others ...

5.1.3 Privacy

There are issues regarding the privacy statement and usage agreement for the free version of Microsoft HealthVault which is a drawback with using Microsoft HealthVault as a foundation for a new system[37, 38].

- Microsoft does not claim ownership of any data.
- The user controls who may access the data, along with any custodian and invited users. If the user shares the content, the user agrees that any of the invited may use that content. If the user shares content which infringes others rights, the user breach the contract.

- Microsoft considers the user's use to be private. That means that the user can upload, share and use their data without interference from Microsoft. However, Microsoft may access, disclose, or preserve information associated with the users use of the service, including (without limitation) the users personal information and content, or information that Microsoft acquires about the user through the usage of the Service when they feel the necessity. These situations are a) to comply with applicable law or to respond to a legal process from competent authorities; or b) to enforce this contract or protect the rights or property of Microsoft or their customers.
- Microsoft might gather data about the user's usage of the Service, its performance and the users machine.
- Microsoft might change the contract, and will notify the user by posting new terms. If the user continues to use the Service, they agree to them. Otherwise, the user will have to terminate his or her account.
- HealthVault is located on a private computer network that Microsoft operates for the benefit of itself and their customers.
- The service is intended for personal healthcare, not healthcare providers.
- The user is responsible for backing up the data.

5.2 Google Health

Google Health was another web service like Microsoft HealthVault, developed and maintained by Google. Launched in 2008, Google took their own approach from other domains into healthcare, hoping to make a big impact. However, the expected impact never occurred and thus Google Health shut down January 1st, 2012. It was possible to download the data the user had kept on Google Health, as well as transferring it to other e-health services for a while.

Google Health managed to reach two user groups and not *the everyday user*. The two user groups however were very small (tech-savvy patients and doctors and fitness people) but sufficient enough to have the service running for five years[7].

5.3 Conclusion

The main purpose of Microsoft HealthVault and the now shut down Google Health is to store health data and provide that data during doctor's appointments, as well as to give feedback on progress in order to encourage a better lifestyle. Microsoft HealthVault as it is, is a good solution, but the main problem in the HOME Project's perspective is that data will be stored and secured on Microsoft's servers and on their terms. Microsoft HealthVault Service Agreement states that the data will be processed and that the service comes with no warranty. Other aspects such as data security and possible data leakage also has to be considered when using a commercial product. Many of the problems faced can be avoided when finding a possible solution. For example, information that each user stores in commercial systems is not medical data and should not be treated as such. A new system which is non-commercial and provided by the government opens more possibilities regarding data becoming medical data,

as well as making users feel more secure. Another possibility is the integration aspect, giving the user the ability to import their previously stored data from other services to a new system. The need of a newly developed non-commercial government provided system is high, and could provide a much better foundation for future development than a commercial system could.

6 Current Devices and Hardware Solutions

Currently there are thousands of medical devices and hardware solutions. Hardware is ever evolving and the solutions to choose from are many, but not all are applicable to the HOME project.

6.1 Stand-alone Devices

There are devices that could be used completely stand-alone. That means that the devices are independent, and does not rely on other devices or hardware. These devices have a built-in GSM-module that allows the device to directly upload test data to a server. Stand-alone devices could be used by users who are not interested in having more than one device as well as users who are not interested in their data.

6.1.1 Blood Glucose Meter

In 2012, the company Telcare released an interesting glucose meter[49], the Telcare BGM®. What was unique with this meter was that it was the *"World's first wireless enabled meter"* according to Telcare themselves. With its built in GSM-module, users can directly upload their test data from the meter to an electronic logbook on Telcares servers. Telcare provides a SIM-card and data plan for a fixed price all included in the listing price, there is no additional cost for data traffic. Through a web portal or a mobile application, the users can access their log book for detailed statistics. A user has the possibility to allow other users (e.g., family members or caregivers and doctors) to access their data. Another available feature is the possibility to automatically send the data to Microsoft HealthVault. All prices are without any insurance coverage.

HOME Project Applicability Due to the limitations of configuration of the meter, its possible use in the HOME project is questionable. Even if a solution with Microsoft HealthVault would be chosen, the data would still have to go through Telcares servers.

6.1.2 Spirometer

Spirotel®from Medical International Research (MIR)[39] is one of the latest spirometers on the market for Telemedicine. It has award winning design[55]

and an intuitive touch screen display and easily changeable turbine for sanitizing. An Oximeter can be connected to it as well and with the built in accelerometer MIR has developed an intelligent 3D Oximeter for combining these two. The Spirotel® comes in a variety of different connectivity configurations. From simple wired USB-connection to Bluetooth, Wi-Fi and GSM. The data is either e-mailed or uploaded to an FTP-server through a secure connection, but can also be completely customized because of its support of multiple internet protocols like TCP/IP, HTTP etc.

HOME Project For the HOME project, the Spirotel® would definitely be of interest because of its configurable interfaces and connectivity. This would make it easy to set up for the pilot study to have it securely transmit data. In the scenario of *Lars'* doctor appointment (Lars), this particular device could be used.

6.2 Smartphone

A smartphone is probably one of the most commonly used hand-held technological devices today. Due to its increasing acceptance in society, it could be an entry gate to the rest of the HOME system. *Lars*, who already is a smartphone user would prefer to interact with the HOME system using his phone whereas *Eva*, as in her user scenario (Eva, might need to learn how to use and operate such a device before using it for this purpose.

iOS With iOS 7, data in both iOS itself and the third-party applications installed are encrypted by default. Apple has built-in encryption into the hardware and firmware of its devices[6]. Building encryption and hashing into the physical architecture makes it faster to encrypt all data stored. Moreover, the level of encryption is set by default and does not permit it to be disabled[59].

In addition to the encryption, Apple uses a technology called Data Protection[31] to further protect data stored in flash memory on the device. Data Protection allows a device to respond to events such as incoming phone calls without decrypting sensitive data and downloading new information while locked. To enable this functionality, iOS users must simply enable passcodes on their device.

Another security feature available in iOS devices is VPN (Virtual Private Network). It allows the iPhone to create a secure connection and encrypt the traffic to prevent it from being intercepted or compromised as it travels across the Internet. Also, the VPN tunnel is specific to this application, thus only the data related to the specific application will transit over the tunnel.

Another advantage of Apple's security policy is the App Store. Apple effectively controls the submitted applications before they are marketed on App Store to avoid security breaches. For example, applications must be designed to use the Data Protection API (Application Programming Interface) to ensure that data is protected. This control is possible because iOS is a relatively *"closed"* platform which allows more control over the system and quality of it.

Android On Android devices, data encryption is possible but not enabled by default. Users can choose if they want their data to be encrypted or not. Nevertheless, there exists an API which allows developers to create applications which use encryption algorithms. All data related to that application will be encrypted before storage[29].

Android also uses a password protection to prevent unauthorized use of the device. This password protects the cryptographic key for full file system encryption. It also provides a VPN functionality to upload and download data securely[18].

Unlike Apple, the Android application market, Google Play, is more open. This market accepts almost all applications, such as those from third party sources and also applications which have been developed in countries known for malware development. This is due to the fact that Android is an open platform which give lots of freedom for developers and users alike[48].

Windows Phone Windows Phone delivers hardware-assisted encryption of the entire phone, including the operating system and data files. Like iOS and Android, Windows Phones use an AES encryption feature called BitLocker[45]. It is enabled by default on each device.

Regarding VPN functionality, it is available only for Windows Phone 8.

Alike Apple, the market proposed by Microsoft is *"closed"*. It only allows secure components validated by Microsoft. It ensures the integrity of the platform and helps to protect against the latest malware.

7 HOME Application Overview

Since an already existing application could not be found that fitted the needs of HOME, the following section proposes a simplistic overview of how such an application could be designed and implemented. The description of the application is independent of the platform it is on, whether iOS, Windows Phone or Android. The data is uploaded to a server where it is analysed and stored. Based on the research done in HOME, an Android based prototype is recommended to reduce costs in a pilot project. The only prerequisite is Bluetooth, which is almost a standard in modern smartphones. For a better understanding of the application's different steps and features, see *Eva's* and *Lars'* user scenarios (Section 7.5).

7.1 Security

The system will handle personal and medical data. That makes security to one of the most important aspects. The data will be stored encrypted and sent via HTTPS to the server. To authenticate the patient, Mobile BankID[33] will be used when uploading data. The user should be able to specify different security levels in the settings of the application. An example would be that the user can

protect the application with a PIN-code to prevent other people from opening it. A PIN-code, or another offline verification method would be necessary here due to the fact that Mobile BankID cannot be used if the smartphone is offline. User interviews have shown that private users are very willing to use Mobile BankID as authentication. The common opinion among the interviewees is that BankID is secure. An example of this type of authentication can be viewed in *Eva's* user scenario (Eva).

7.2 Devices

External devices are connected to the smartphone via Bluetooth. The devices should ideally use the Bluetooth Health Device Profile[67] to help facilitate transmission of medical data. A key feature here is that the patient should easily be able to pair (connect) a device with the smartphone under the application settings.

7.3 Data Collection

The application should automatically notify and encourage the user when it is time to do new measurement. How often this occurs is dependent upon the individual and could be determined by the physician or automatically by the system depending on previous readings. A patient should not be limited or forced to only do the tests at these points, he or she should feel encouraged to do it at any time.

The test data is stored locally in the device for certain time frame. This is to reduce the traffic between the application and server but also to work as a buffer if the application would fail to connect to the server. The data will automatically be uploaded after user confirmation when a connection can be established.

7.4 Modules

The application should be modularized which means that it would only be one application for several different diseases/health conditions that the patient would like to monitor. The different tests are modules that can be activated in the application depending on the user. For example *Lars* (Appendix C Persona 4) would only have the COPD module activated while a person with both COPD and diabetes would have both modules activated.

7.4.1 COPD

The COPD module would include a couple of tests that are designed to detect exacerbations (worsening) of COPD. Previous work in telemedicine for COPD monitoring[66] suggests that in addition to physical measurements a set of questions in form of a questionnaire is recommended to detect exacerbations. Combining the questionnaire and measurement outcome in statistical models

can be used to help detecting abnormalities. This statistical analysis should be done on the server but as well on the smartphone to allow the application to still fully function without any connection to the server.

Detecting Exacerbations A COPD Assessment Test[22] was developed in 2009 to provide a simple but accurate questionnaire to measure symptom and functional state of COPD patients. Several studies have validated it[12, 21] with successful results.

Performing a Test When it is time for a patient to perform a new test, he or she starts the application either directly from the notification or manually. First the questionnaire will show up for the user to fill in. After that, the patient will be asked to perform the spirometry and the pulse oximetry. The patients gets notified that the readings was successfully transferred to the application and an overview of the whole performed test is shown. At this step, the patient can choose to redo a measurement or change the answer to a question. With the Mobile BankID the patient now signs the test and it is stored locally and uploaded to the server. The patient receives instant feedback (Section 3.1.4) on the results and advice depending on it, e.g. recommendation to contact his or her physician.

Overview The overview gives the patient the possibility to view previous test results both parameter specific over a period of time and also unique tests.

7.4.2 Type 2 Diabetes

The diabetes module has the basic functionality as a normal glucose meter. The patient performs a normal test with the paired glucose meter, the data is transferred to the application where the patient can verify and store the measurement. The patient has the possibility to attach additional parameters to the test (e.g., Test performed after a meal). After the test the patient gets instant feedback on the result and statistics (Figure 1) e.g., informing the patients that he or she has kept the blood sugar at a good level for the last five days.

Overview The overview gives the patient the possibility to view previous test results and should give the patient a good overview of its health.

Other Modules Other modules for the application could for example be weight tracking, ECG-monitoring and general health questionnaires.

7.4.3 Recommendations Regarding User Experience

With the given information in Section 3 and 4, as well as the performed usability and user experience evaluations described in Section 1.4.5, a set of guidelines was created in order to give recommendation for a future design process.

General

- The language of the application should be available in several translations, and customisable.
- Date, time and measurement units should be customisable.
- No system-oriented terms should be visible to the user.
- Information should always be shown in the right context, and follow a logical order.
- An advanced view should be available to experienced users, as well as the option to tailor the application to some extent.
- Feedback should be available in reasonable time after an action has been committed.
- The user should not have to recall information from previous steps in a dialogue.
- All objects, actions and options should be visible to the user.
- When the user is introduced to the system, he/she should receive some kind of introductory tutoring.

Design

- The application should make good use of design metaphors, placing it in a real-world setting and context(Appendix B).
- The design should be minimalistic and simple.
- The typeface should be easy to read and the font-size customisable.
- The design should focus on the content.

User Control

- There should always be a button which leads to the Home view, and it should always bring the user back to it (Home button).
- There should always be a button which brings you back one step in the dialogue (Back button).

Errors, Help and Documentation

- There should be no erroneous states. If they were to happen; no intricate error codes should be shown to the user. Instead simple error messages with suggestions to solutions should be shown.
- Documentation about the application and system should be available in and outside the system (a manual).
- A support group should be available to help the user, in case they need it. Support could be given over email or telephone.

7.5 User Scenarios

A user scenario is a fictional narrative description which describes the interaction of actors and the technical system. The actor has a goal and the scenario describes one way which the system is imagined to be used in the context of the activity performed.

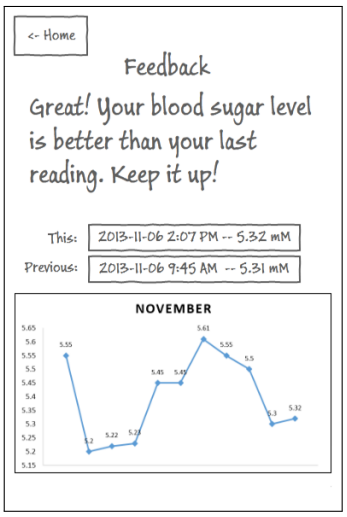

Figure 1: Instant feedback

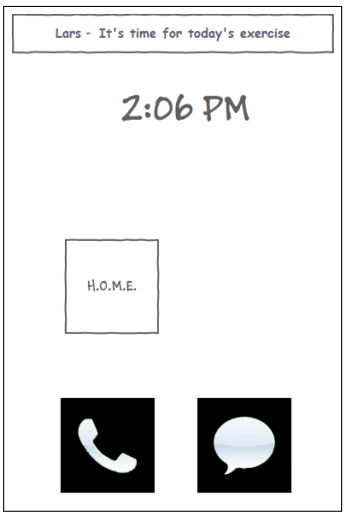

Figure 2: Notifications

7.5.1 Eva

After a full group lecture at the hospital, Eva booked an appointment for a more personal introduction to the system in her home. During the visit, Eva was given a simple smartphone provided by Uppsala County Council with the HOME application installed. To be able to transmit glucose readings to her personal health account, she was also given a glucose measuring device.

Eva starts up the HOME application and chooses her name in the user's menu (Figure 3) followed by signing in using BankID (Figure 4). Once logged in, she sees the main screen for her diabetes (Figure 5) and picks up her glucose device for today's sample.

To submit her measurement, Eva's phone automatically detects the glucose device (Figure 6) and displays the values, which she notice to be a bit better than the latest sample. By pressing the "Next" button (Figure 7), she have the opportunity to provide additional information related to the current measurement. Since Eva just had dinner, she chooses to include this data (Figure 8) and proceeds to upload the sample (Figure 9).

Eva is in a good mood as she recently has started to exercise more regularly with help from a personal trainer. As expected, today's glucose level were an improvement since the latest reading, which her phone recognizes (Figure 1). Apart from displaying visual statistics over the latest measurements, her phone

tells her to keep up with the good work in order to continue improving her health.

7.5.2 Lars

Lars was introduced to the system during a doctor's appointment. Since Lars is open to new technology, he installed the HOME application on his smartphone himself. Due to the few occasions he need to perform spirometry tests, these will only be done at the hospital.

Apart from walking the dog, Lars has not worked out in a few days. During the evening while watching TV, he receives a notification from the application telling him it is time to exercise (Figure 2). Knowing he have a spirometry test booked for tomorrow at the hospital, he have recently felt an urge to perform well, hence, motivating him to exercise regularly.

During the spirometry test, out of curiosity, Lars asks his doctor if it is possible to use the application for this measurement. Once the test has been performed and Lars has signed in using BankID, there seems to be an error when connecting his phone to the spirometer (Figure 10). After a few retries and no success, they head over to the troubleshooting guide by pressing the "Help" button to check for errors. In step one (Figure 11), the application make sure both devices are placed close together, which they certainly are. Step two (Figure 12) instructs them to ensure that the spirometer device is turned on, which it is. The last step (Figure 13) suggests that Lars' phone and the hospital's spirometer might be unpaired and hence should be reconnected.

Conclusion Taking in account what individual needs users have along with identifying what factors that motivates people to behavioral change is crucial. Assisting users in increasing their intrinsic motivation and setting individual goals are some of the important aspects that has to be considered. By developing the application with these aspects in mind, it could really help people towards a healthier lifestyle.

8 Ethical, Legal and Social Implications

The implementation of an electronic healthcare system where patients can take measurements at the comfort of their home provides advantages for all the users as already discussed in section four. However, the use of electronic medical records, the transfer of personal data through Internet and the access to such information, rises up concerns regarding the collection of data, its storage and access.

8.1 Data Collection

The way information is stored has changed throughout time. From hammering on rock tablets to the contemporary age where some of the data started

to be written using polarization of grouped atoms as a binary system[17]. The innovation is unquestionable and technology have made it easier to store and share information. However, along with technologies which are storing increasing amounts of information, comes concerns about who has access to collections of private information and how the data might be misused if breached and/or applied to a different context than the one where the data was collected.

The importance of considering these aspects in the design of technological solutions such as integrated health care, has increased and gained space due to, among other reasons, many digital incidents where sensitive and private data breached from the original databases and, in some cases, became available unrestrictedly to the public domain. Databases which contained descriptions of one's geographical location[61], financial transactions[69], medical historic[61] and even registers of one's internet activity[63], has breached due to flaws in security. Furthermore, besides security issues regarding the safety of information, the denounce of surveillance practices[16] using digital data, has also raised awareness of citizens around the world[5].

8.1.1 Privacy is a Human Right

In article 12 of the Universal Declaration of Human rights is stated:

> *"No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks."*[65]

This means that the system for electronic healthcare and the technologies used to transfer private data through the internet, in order to comply with this and other European laws[13], must have an architecture that ensures that the private data of the patients is protected and handled safe in a way where this basic principle of human right is not violated in any circumstance.

8.1.2 Previous Incidents and Current World Scenario

The website informationisbeautiful.net[14] has gathered a compilation of the 300 biggest incidents in the past ten years where data leaked with more than 30.000 records. Some of these leakages have alone more than 160 million registers of private information, and among these 300, one finds that in 2006, twenty million search requests made through the Internet provider AOL, together with the information that could track the person behind the request, became publicly available. This resulted in lawsuits against the company and in one of the biggest leakages of data by that time[63]. On October 2011, a computer with unencrypted data was reported stolen from the facilities of Sutter Medical Foundation in California. The stolen data included personal information of around four million patients, Including descriptions and diagnoses written by the doctors[61]. During summer 2013, the name Edward Snowden became widely known when the 29 year old who was working as a system analyst for the National Security Agency (NSA) disclosed that the government of the United

States was working with a global surveillance program capable of accessing private information of, in practice, any person around the globe, including civilians, corporations, Chief Executives, politicians and public administrators. According to Snowden, using the NSA's network he could easily get access to large amount of personal information, simply by knowing a person's email address[16]. Further, he reveals that some technological companies were working closely with the agency. According to The Guardian, the American companies Google, Microsoft, Facebook and Yahoo were some of the companies who received millions of dollars from NSA to cover costs resulted from the collaboration between the companies and the agency[30]. The government of the U.S., chasing the young analyst, took measurements that resulted in the shut down of an American based webmail company due to the fact that Snowden was one of the 350.000 costumers who had a webmail account at lavabit.com[1]. Reading the apologies written by Ladar Levison, the owner of lavabit.com, where he explains why he decided to shut down lavabit, one finds in his testimonial:

> *"This experience has taught me one very important lesson: without congressional action or strong judicial precedent, I would strongly recommend against anyone trusting their private data to a company with physical ties to the United States."(Ladar Levisson)*[1]

If the physical and legal ties of some companies bring danger to the patient's privacy, the best position is to avoid such companies in order to ensure that the data of European citizens is secured and free from abusive purpose in the future.

8.1.3 Privacy as Contextual Integrity

As presented in section one and discussed in section 4.2.2, *Eva* is a fictional character who does not have too much knowledge about technical and security aspects of a system. When asked about concerns regarding security and privacy, *Eva*'s answer was that "Knowing that her doctor and the County Council is behind the system, it increases her trust". Due to *Eva*'s limited knowledge, she assumes that the people responsible for building and maintaining the system have ensured that it is free from all the security issues that she herself does not have a clue.

When *Eva* visits her doctor or uses telemedicine, she has one goal: The good condition of her health. In order to ensure that *Eva* is or becomes healthy, she needs to provide her doctor with information about herself. *Eva* agrees on describing her condition or taking measurements because she believes that providing this information will lead to better results concerning her good health. However, if *Eva* knew that someone else, other than her doctor, would use the same information in another context, she might decide against providing information about herself. Imagine the system would include information about her emotional and psychological condition. For example, her psychological and emotional condition has one value to her psychologist and a very different value to her future employer.

According to Helen Nisenbaum[54], human behavior is bounded to social norms that are different in different contexts. It is ok to hug a stranger in a religious

ceremony but the same does not apply in a grocery store. Information is also bounded to a context and its content can represent treats and bring harm if used in different contexts than the one primarily intended. The same talk a Professor has with his friend about his sexual orientation has an impact on a Friday night at a gay club in Amsterdam and a very different impact on a Monday morning during the meeting at the conservative institution where he works in Rome. Consciously or unconsciously, all people only share information about themselves because they relate the information to a given context where they believe to know what and with whom they are sharing their information. When information leaves its original context, what happens, is, according to Nisenbaum, the violation of contextual integrity.

Since the Electronic Medical Records can be stored for a very long time, the risks of having the health care context violated increases and so does the chances of undesirable results if the information is accessed with different purposes than the health care one. Nevertheless, the risk of having the information leaving the hospital and ending up somewhere else in a different context, diminishes with the use of encryption, policies and practices that try to avoid the leakage of data as well as unauthorized access to the patient's private information.

9 Conclusion

Throughout this four-month project, many aspects were studied to provide a holistic understanding of the SmartCare Project. The starting idea was to develop a solution which could fulfill the objectives of having a cost-effective mobile health care system. The first part of the project was focused on the technical aspect of the solution, discussed in Sections 5, 6 and 7. The possibility of commercial solutions such as Microsoft HealthVault (Section 5.1) was studied and it was found that these products could work as foundation for this project. However, it might also contain significant breaches which could put the patients' private data at risk and violate the contextual integrity of the health care context. As a consequence, it was recommended that SmartCare should develop its own system in order to ensure security and acceptance of its users. Three complementary solutions were identified to be adapted to preferences and capabilities of patients. Important issues such as security, data integrity and ethics were covered to secure the private information of patients as well as regulating the access to sensitive medical diagnoses.

Patients interviews and motivational research showed that it is crucial to offer products which will enhance patient's motivation to engage themselves in the development of their health condition by following a self-care program. To do so, one of the main notions to take in consideration is that each patient is different and have individual needs. Therefore, it is really important to know future users of the system to meet these needs. For example, patients will have different technological backgrounds and this will impact the way information should be provided (Section 4.2). From a motivational point of view, each patient will face different barriers and have different motivational factors according the goal they want to reach (Section 3). Personas were developed to represent several individuals (Appendix C). Personas were a way to identify needs and link this

motivational background to future patient behaviors. By individualizing self-care programs and supporting these programs with adapted technology, patients will be more likely to change their lifestyles into a healthier way of living. A recommendation to SmartCare is therefore to use these personas in future work, as well as to do further research on the users' needs based on findings in this report.

A prototype for a smartphone application was designed to offer a guideline to future developments of SmartCare. Scenarios that exemplify usage of the prototype is found in Section 7.5, and screen shots are found in Appendix G. The goal of the prototype was to show features that could be implemented to enhance and maintain patients' motivation to change their lifestyles. It was used to give recommendations for designing a usable and attractive product which will offer a good user experience and could be adopted by a large amount of users.

To conclude, the purpose of this system is not simply to transfer information from patient to medical personnel but above all motivate people to take change in their lifestyle.

10 Discussion

Since integrated technology certainly is part of the future, it will be even more used in society than today. A wider usage of technical devices would make a framework like the HOME Project a natural feature of health care.

In order to fully involve the users in the system design, more research is necessary. Even though the majority of interviewees within the HOME Project felt comfortable regarding security and privacy, it would be recommended to perform a more general investigation about these aspects.

The personas presented reflect results found in the HOME Project but a wider study with more medical personnel and patients represented is needed to get results that are of benefit for all potential users. Continued studies with personas and the prototype as a basis, performed in collaboration with medical personnel and patients, has the potential of creating a system that drastically can change the way medical care is handled. It would allow patients to take more control of their treatment and giving more time for actual conversation between patient and doctor.

Future work also includes more detailed research regarding how data should be stored to be as efficient and secure as possible. Continuous development of the prototype as more knowledge evolves is also important so that it continuously is a usable tool. And most important, all potential user groups need to be included when evaluating the system and implementing the pilot project.

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Appendix A

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Appendix B

Glossary

Android An operating system for mobile devices based on the Linux kernel

AOL America Online, a multinational mass media corporation

API Application Programming Interface. Specifies how some software components should interact with each other.

App Store Application store provided by Apple

ATT Attractiveness. Describes the quality of the product based on perception of the user.

AttrakDiff™ Web application that provides anonymous usability evaluation

BankID A Swedish system for online identification

Bluetooth A short-distance wireless technology standard for transferring data

Bluetooth Health Device Profile A profile designed to facilitate transmission and reception of medical device data.

Caregiver People who are helping to take care of the patients (not doctors)

Cybercrime A crime involving a computer and a network

Design metaphor A metaphor is a way to give a user the understanding of an interface by taking already aquired knowledge and applying it to design.

ELSI Ethical Legal Social Implications

Extrinsic motivation When a person is doing something because it leads to a separable outcome.

FTP File Transfer Protocol. Standard network protocol used to transfer files from one host to another host over a TCP-based network, such as the Internet.

Google Play Digital media store for Android devices provided by Google

GSM-module Global System for Mobile Communications

GUI Graphical user interface, the visual representation of a system.

HTTP Hypertext Transfer Protocol. Standard for Web browsers and servers to communicate and format contents.

HTTPS HTTP Secure. HTTP placed on top of a security protocol.

Information overload The difficulty a person can have understanding an issue and making decisions that can be caused by the presence of too much information

IEEE Xplore A full-text database containing litterature in computer science, among other areas

INSPEC The leading English-language bibliographic information service providing access to the world's scientific and technical literature

Intrinsic motivation When a person is doing something because it is inherently interesting or enjoyable

iOS An operating system for mobile devices developed by Apple

Malware Malicious software, used to disrupt computer operation, gather sensitive information, or gain access to private computer systems.

Medical personnel General term for a person involved in medicine

NSA National Security Agency. Main producer and manager of signals intelligence for the United States.

Persona An fictional character used to represent the target population in system design

PQ Pragmatic quality. Usefulness and usability of the system.

Push-notifications A notification that is sent to the device from the central network or server

REST Representational state transfer. Architectural style consisting of a coordinated set of constraints applied to components, connectors, and data elements, within a distributed hypermedia system.

SCOPUS A comprehensive scientific, medical, technical and social science database containing all relevant literature.

Server A system that responds to requests across a network

Smartphone A telephone with an advanced operating system

Stand-alone Something that is not dependent on anything else

TCP/IP Internet protocol suite, commonly known as Transmission Control Protocol/Internet Protocol

Telemedicine The use of telecommunication and information technologies to provide health care at a distance.

Third party A party which is not the consumer or the provider

Usability The effectiveness, efficiency and satisfaction with which specified users achieve specified goals in particular environments.

UX User Experience. Involves a person's behaviour and emotions when using a product.

VPN Virtual Private Network, a private network across a public network

Web portal A page at a website which brings together information in a uniform way

Windows Phone An operating system for mobile devices developed by Microsoft

Appendix C

Persona 1

Name: John

Age: 45

Profession:
Doctor, sports medicine

Characteristics:
John is 45 year old male working for a regional hospital in the state of Indiana in the United States of America. He works primarily with long term patients but occasionally has some patients requiring only short term care.

Technical interest
John is not excessively technically proficient but he knows his way around everyday applications. He is frequently required to use various computer applications during his job and in his free time.

Need:
John often has difficulty ensuring that his patients are actually doing the tests and exercises he wishes them to do. As such he wants patient data submitted through a possible Smart Care application to be verifiable by him and not to just be taking the patient's word for the success or progress of various tests. He is also frustrated with the US Medical records systems which have no centralized records and each hospital keeps its own records making it difficult for him to easily get his patients' information.

Persona 2

Name: Anna

Age: 35

Profession:
General practitioner at a primary healthcare centre

Characteristics:
Anna became director of department at the primary healthcare centre a couple of years ago. She has been using different medical records systems over the years. The latest were introduced by a nurse and a couple of IT-professionals from the County Council. Anna experiences that system to be wide in the sense that medical records from the whole County Council can be reached, which is an improvement in relation to older systems. However, she also experiences it to not be synoptically enough and that it has a long learning time for new users. She does not think it is a patient-centered tool meaning one has to wear different "suits" when navigating inside the system.

Need:
Anna shows a great interest in the HOME and SmartCare project and thinks that patients being able to read their medical record online has obvious advantages and is part of the future. She also thinks that the vision of performing measurements at home would be really helpful in order to observe diseases at an earlier stage. She feels that the ideal method to present received data would be showing it in the form of graphs and curves to be able to easily see in what direction the values of interest are heading.

Persona 3

Name: Eva

Age: 65

Characteristics:
Eva is newly retired and lives in a terraced house in Uppsala with her husband. They have children and grandchildren. Eva got her diagnosis four years ago during an annual health check-up. She takes medicine (pills) to keep her glucose levels under control. She tries to think about what she eats and she enjoys going for walks but mostly she lives like she always has. Eva does not not feel that the diagnosis has affected her life and she hardly experiences any symptoms nor does she see herself as an ill person. Eva does not monitor her glucose levels regularly, due to new recommendations from her diabetes nurse.

Technical interest
Eva is not very open to new technology. She does not own a smartphone and she rarely uses the family's computer. She believes she has an e-mail address but she does not remember what it is. Eva does not feel comfortable using e-mail as a communication tool. Eva would prefer the system presented in an introductory group lecture, followed by a personal home visit where the device, as well as a written manual would be handed over. She is not botherd by security issues and thinks BankID feels secure enough.

Need: Eva says that she wishes she had more knowledge about her disease and that she thinks she should show more interest for her health if she had. When she meet her nurse for an annual check-up, she would like the focus lie on creating a dialogue around the disease. She thinks it is difficult find questions to ask and she would like her nurse to explain more about the disease. Eva thinks that more knowledge would lead to a greater interest in her disease, and a greater interest would affect her motivation to change her lifestyle.

Persona 4

Name: Lars

Age: 70

Characteristics:
Lars has been retired for eight years and is currently living with his wife in an apartment close to Uppsala. As a long-time smoker, Lars was beginning to feel a slow decrease in his fitness and shape at the age of 50 and measurements started to show a remarkable impact on his lung capacity. Still being on the "non-sick" side, he didn't stop smoking. About ten years later, he got the diagnose COPD and with sixty percent lung capacity left, decide to quit smoking. Today he uses inhalation drugs such as airway expanding and cortisone a couple of times/day and have to book spirometry tests himself, which he does within three year intervals. He rarely sees his doctor for checkups and has never been introduced to associations involving other people with COPD or been given special exercises for breathing with his disease.

Technical interest
Lars is open to new technology and uses different devices daily. He currently owns a smartphone in which he uses e-mail, mostly for reading, and apps such as data usage and song identifiers. Lars says that he wants the device introduced during a doctor's appointment and written instructions to read. When it comes to security, he would like a rough sketch showing how data is transferred, but he does not care about more detailed security information.

Need: Lars would not feel home equipment for spirometry measurements to be necessary due to the few occasions he needs to perform it. However, Lars understands that he plays the most important role in how the disease will progress. He knows that physical exercise is the key to keeping the symptoms under control but he has a hard time finding the motivation. Lars requests the possibility to use a motivational application for reminders and feedback, both automatic and directly from his doctor/nurse. He can also see the benefit with having access to free workout at a gym and he thinks that would increase his motivation to exercise radically.

Appendix D

Patient interview questions

Background information

1. Disease?
2. How old are you?
3. How long have you had diabetes/COPD?
4. How did the disease affect your everyday life within your family?
5. Have you changed your diet, exercise habits?
   Have you changed your diet, exercise habits?
   Has the disease prevented you from doing something you enjoy?
   Has the disease had any positive effect on your life? (New friends, improved fitness, etc.)

Technical interest/knowledge

6. Do you have a computer in your home?
   How often do you use it?
   What do you use it for?
   What are your feelings towards email?
   On a scale 1-5 where 5 = confident, everyday user maybe even use phone to sync and 1 = never uses/don't have an email address
7. Do you have a (broadband) Internet connection? What about 3G, 4G phone connections?
8. Do you have a smartphone?
   Did you chose/buy it yourself?
   What do you use it for?
   What is the latest app you installed?
   Which three apps do you use every day?
   Do you have any apps specialized for your disease?
   Do you use any kind of applications (e.g. Runkeeper) do you use to monitor your exercise, diet, other health aspects?
9. What is the best way to contact you?
   Ordinary mail
   Home phone
   Mobile phone
   E-mail
   SMS
   Other
10. Have you ever bought something/signed an agreement on the internet?
    Did you read the terms of agreement?

Health aspects

11. How often do you see a healthcare professional?
    How many different persons have you meet that are related to you disease?
    Do you know the name of "your" doctor/nurse?
12. How much of the health information that you receive from healthcare professionals during face-to-face visits do you understand?
    Do you feel that the healthcare professionals you meet "knows" you as a patient?
    What do you feel is most important when seeing your doctor;
    A thorough examination and tests taken in a medical environment
    A chance to talk through your thoughts and concerns, asking questions and getting instant feedback and a more personal contact with your doctor.

13. How much of the life-style-related advice you receive from health care professionals do you follow?
14. Do you take any tests at home? If so, what kind and how often? What do you do with the data?

    How often do you check your general health when you are feeling alright?

    Did you have to pay for your home measuring device?

    How much would you be willing to pay for a spirometer or Glucose meter? (Given a price interval)
15. If you were to create your own glucose meter/spirometer, what features would it have?
16. Would you feel a regular check up service (explain that service) at home to be useful/an advantage? Why/why not?
17. Would you feel confident if you had the opportunity to share selected information in your medical record with neighbours/relatives/caregivers, to help them give you the best possible care?
18. Have you ever had electronic contact with the health care?

    Using email to communicate with a special doctor/nurse or healthcare in general?

    Asking a question at "Mina vårdkontakter" or similar

    Booking/rescheduling an appointment

    Renewing a prescription

    Viewing medical record

    Other/Why not?

Online and data privacy

19. Do you use internet banking? Do you have BankID/Mobile BankID

    Do you use BankID for anything other than internet banking?
20. Do you have any online accounts? (Facebook, Google, Blocket etc)

    What concerns do you have about you data and personal information being stored online?
21. Do you know that you can view your medical record online? Have you ever done that?
22. How often do you want access to your medical records? Do you feel that access to your medical records is helpful? How is it helpful to you?
23. Do you receive information about how your medical data is stored, used and protected?
24. Have you ever considered the risk of all your medical records becoming public if someone ill intentioned get access to your medical records? Which medical department concerns you most regarding information that could become public?
25. How important is it for you that your medical records are safe from unauthorized people accessing them?
26. Do you know that you can block access to your medical data for certain staff or units of the hospital?
27. Would you feel better if more public investments were done to ensure the security of your data? What if this leads to raised taxes, is it worth it?
28. What are your suggestions or thoughts about how you think your medical data should be treated?

System specific information

29. How would you like to be introduced to the system and devices?

    Group lectures at the hospital

    Personal visits in your home by a medical professional

    Individual introductions during a doctors appointment

    Written instructions

    Other/A combination several alternatives
30. Do you feel that it is important to have a person of the county council, responsible, present when introducing the system?

31. How much security information would you like to receive?
32. How would you like technical (and common) support to work?
    Phone number to a "helpdesk"
    Regular (group) meetings with a person responsible
    Email communication with "your" doctor/nurse
    Other
33. Would you feel comfortable changing batteries and calibrating the devices?
    If not, what kind of support would you want?
34. Would you like to have a family member/friend present during the introductions?
35. What do you want to know about the future system?
    If we cannot answer right now, we will get back to you.

Doctors

Background information

1. In what department do you work?
2. For how long have you been working at this care centre, and why did you choose it over a "big" hospital?
3. Do you work in a "team" along with "your" nurses (how many?) or do you collaborate with everyone at the care center?
4. How do you feel about technology in general?
   What kind of technology do you use in your everyday work?
   How much time do you spend in front of a computer each day?
   What introduction did you get to the current system (some system you use for, e.g. medical records or other)

The Dreamer Project

5. What made you decide to participate in the dreamer project?
6. Can you tell us about your experiences from the project?
7. Did you help in introducing that system to the patients?
   How was the general reaction?
   What difficulties did you experience with the "introduction"?
   Do you know how the patients were selected?
8. Do you know anything about the result of the project?
9. Why do you think people (patients, doctors) are less willing to participate in this (our) study?

Disease specific questions and the current/future system

10. What are your experience with diabetes/COPD?
    What is the difference between diabetes type 1 and 2?
11. What is the youngest patient with COPD?
12. What kind of tests is necessary/possible to do at home? (For both diabetes and COPD)
13. If you were to receive patient data from a home measured online service, what would be the benefits/drawbacks?
    How would you like the data to be presented? (e.g Graphs or plain text)
14. How many readings are needed to see a trend (gain or loss of weight, ability to breath, glucose level)?
15. What are the most important changes a diabetes/COPD-patient can make to their lifestyle? (And as a follow up question; What kind of feedback can motivate a patient to do that?)

16. Who are the COPD patients?
17. Who are the diabetes patients?
18. What measure of error rate are you able to accept (might be personal or praxis)?
19. Would you be willing to be presented medical data by the patient, and/or accept it?
20. (Med. students) Based on your current knowledge about diabetes/COPD, do you think it would be helpful to receive measurements from patients via a web service?

Security and computer systems

21. How do you feel about patients having the opportunity to access their medical record online? What are the benefits/drawbacks?
22. Have you accessed medical records of a person that was not under treatment?
    Why did it happen?
    Did it lead to any advertence?
    Do you know the legal implications of accessing medical records of a patient you are not treating?
    Did you receive information about this?
    Do you know that all the accesses are logged for investigation?
23. How is security handled when storing patient information?
    Do the patients get any info about this?
    Can a patient choose to not have their info saved?
24. Do you perceive that you have received enough training to use the current system?
    Did you get information about the ethics implications of using electronic health records(EHR) system?
    What are your suggestions for improving the system to ensure that the EHR of people are not accessed inappropriately?
    When does the data become medical data? When should the data be written into the medical record?

Work environment

25. What are your general opinions regarding your work environment today?
26. Does the current system(s) ease the amount of work?
    Do you experience any issues?
    What problems/tasks/requirements are not covered by the current system(s)?
27. Do you think the current system(s) are developed from a proper perspective?
    By people understanding your work and your needs?
    How was it introduced?
28. Do you feel the system(s) to be secure enough?
29. What improvements would you like (need) to have in the system to get a better work environment?
30. Do you ever use ”Mina vårdkontakter”?
    What do you think about doctor-patient contact through that service?
    Do you have electronic contact with patients in some other way? (email etc.)

Other

31. Experience of patients using any self testing device?
    For which purpose did they use it?
    What did it measure?
    How did it function?
    How frequent were they meant to use it?
    How frequently did they use it?
    For how long did they use it?
    What feedback did it give them?

Where did they use the device or devices? Environment (home, outdoors, workplace)?

What is the type of person that did use the self testing device (lifestyle, age, medical background/health status etc)?

32. Do you feel a positive or negative attitude from patients using self testing devices?

    What do you think is the benefit of selftesting?

    How would you like them to be functioning, how do you think they would like them to be functioning?

    How would you like to see them use them? How do you think they would use them?

    Frequency

    Feedback

    Way of usage

    How often do you think it is acceptable for them to use selftesting devices?

    For how long time do you think they can consider to be using the devices?

    How long time per each usage do you think is acceptable?

    Where would you consider it to be okay for them to perform the usage (measurement)?

33. Will you feel confident about the data measured if the user/patient have measured it themselves using a selftesting device?

    If yes, why do you feel confident?

    If no, why don't you feel confident about it and how can it be adjusted to make you feel confident?

Appendix E

12 2nd wave pilot site #5 – Uppsala (CCD)

12.1 Point of departure: The current service landscape

The Swedish healthcare system today is in many aspects a fragmented system. There are two major care deliverers, the County Council (including both hospitals and Primary Care) and the municipalities. Each has their own organization and IT systems. For patients with a chronic disease or patients, with many contacts in both sectors, this means that they experience a somewhat non coordinated treatment. Even though the Swedish healthcare system has a well-established system of electronic messages, each actor typically has their own IT- system and can only in a limited way share and see relevant patient data. Especially different municipalities are organizations with difficulties in communicating across departments even though they share the same patients.

The electronic communication today consists mainly of the secure Swedish National Patient Overview (NPÖ), where standardized electronic basic information of Health Care services delivered to the patient are stored. The NPÖ stores for example the following information items:

- Health and care recipients
- Diagnosis
- Health and social care contact
- Medicines ordination
- Medicines prescription
- Received drugs
- Observation signal
- Examination results
- Care and related documents unstructured
- Padl disabilities
- Health and social care services
- Demand for care
- Health and social care plan unstructured

In Uppsala County there is a messaging system called “Prator” between the Health Care and Municipalities for exchanging data between organizations. Presently there are some national initiatives such as the Swedish National Patient Overview (NPÖ), where the patients’ basic data is kept updated and shared among the actors, in order to make sure that common medical information is available to the actors.

The patients living in Uppsala today have access to their Medical Record through the public portal “Mina Vårdkontakter” , where they can see appointments, test results and more or less their medical record.

The purpose of the SmartCare service in the County of Uppsala is to gather and store remote monitoring data as well as all other relevant information in one overview, Hälsokontot (Personal health record). In this manner the Hälsokonto and NPÖ are supplements to the existing systems.

Appendix E

12.2 Initial use case scenario for the SmartCare pilot service

The focus will be on people with chronic diseases and aged over 20 who are suitable for remote monitoring of physical parameters at home, especially on those who are in need of both health and social care elements on a long term basis. When the patient is ready to be discharged from a hospital stay the responsible nurse fills out a discharge report in the hospitals IT-system (called "Prator"), which then is to be sent to the homecare department in the municipality. In this report is included information such as:

- General information on the patient and their relatives contact information
- Information on the cause of the admittance and the treatment delivered while in the hospital
- The patients current need for further care.
- An evaluation of the patients level of functions and a description of which social care elements that need to be put in place in the patients home

Hence, the hospital staff decides which care the patient needs when discharged from the hospital. They also send an electronic report to the Primary Care with relevant information on the patient's needs. These messages are all automatically sent to the specific IT-systems in the different sectors.

So in this sense it is the hospital that takes the lead in assessing the patient's needs for care services, both health care and some social care. The latter is planned in cooperation with the municipally staff in a discharge conference. In this discharge procedure it should be decided who is enrolled to the SmartCare service.

Social care professionals, the GP or the hospital staff select the patients to be entered enter into their system. GPs and the primary care as well as the hospitals already share their data in a common medical records system. All relevant data can be reached through the NPÖ. The Remote monitoring data can be reached for the professionals if the patients give their consent.

The hospital sends a plan for physical rehabilitation to the municipality through the system called Prator, where they describe the patient's need for support and training.

The patients also attend and receive relevant social and health care services with the involved caregivers being able to access the SmartCare platform to see and enter relevant information to be shared.

The nurse also evaluates the patient's ability to perform home monitoring and if they are judged to be able they are given the opportunity to get home monitoring equipment. This is then ordered from the municipalities depending what equipment (in some cases the Health Care must be consulted), where employees set up the devices at the patient's home and at the same time introducing the patient to its use.

Care professionals from the different relevant clinics in the hospitals as well as staff in the general practitioners offices and selected staff from the municipalities will be able to share data from their individual systems, use the SmartCare portal to support their workflow across sectors and to view data from the different caregivers. Information shared from the hospitals and GPs could be lab-results, measurements, notes, symptoms, diagnosis. They will also be able to see the information provided by the different actors such as patients and municipalities. Social carers will be able to see relevant information about the patient's disease and self care ability. They will also be able to see the information provided by the different actors, such as patients, hospitals and GPs.

In general the patient is called in for a check-up at their chosen general practitioner after the responsibility is transferred from the hospital to the primary Care. This varies among different cases

as well as different diagnoses. Depending on the level of functionality and self-care ability home care may be reduced and the hospital passes the responsibility of check-ups and monitoring measurements made from home to the GP. When a patient needs acute medical treatment he or she is admitted to the hospital where he or she receives the necessary treatment. The patients will remain in the long term care pathway until they are deceased or no longer willing to participate.

12.3 Envisaged implementation requirements

A set of implementation requirements have been identified so far deserving particular attention in the given local context.

End user requirements:

- In several projects concerning the barriers for a coordinated treatment there has been collected information on the patients' needs and experiences. Those experiences represent the initial knowledge base for our vision about the end user requirements. These will be further consolidated

Organisational, staff and business related requirements

- There will need to be made specific analysis of the end-users current workflow and the changes that will be made to that when implementing the NPÖ, Prator and the EHR.
- How technology and it's use on everyday basis of the staff, especially on the field, needs to be further analyzed.
- One common requirement is that those information sources must be integrated in the systems the staff is using in their daily work. E.g. it shouldn't be necessary to log in different system to get a full overview.

Legal / regulatory / contractual requirements

- In Sweden there are some regulations to have in mind.
- The most important legislation is the Personal Data Act, Patient Data Act and the Social Services Act,

Other requirements

- The system will need to accommodate existing national standards.

Appendix F

Nielsen's 10 Heuristics for User Interface Design

1. **Visibility of System Status** The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.
2. **Match Between System and the Real World**
   The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.
3. **User Control and Freedom**
   Users often choose system functions by mistake and will need a clearly marked "emergency exit" to leave the unwanted state without having to go through an extended dialogue. Support undo and redo.
4. **Consistency and standards**
   Users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions.
5. **Error Prevention**
   Even better than good error messages is a careful design which prevents a problem from occurring in the first place. Either eliminate error-prone conditions or check for them and present users with a confirmation option before they commit to the action.
6. **Recognition Rather Than Recall**
   Minimize the user's memory load by making objects, actions, and options visible. The user should not have to remember information from one part of the dialogue to another. Instructions for use of the system should be visible or easily retrievable whenever appropriate.
7. **Flexibility and Efficiency of Use**
   Accelerators – unseen by the novice user – may often speed up the interaction for the expert user such that the system can cater to both inexperienced and experienced users. Allow users to tailor frequent actions.
8. **Aesthetic and Minimalist Design**
   Dialogues should not contain information which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility.
9. **Help Users Recognize, Diagnose, and Recover From Errors**
   Error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.
10. **Help and Documentation**
    Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large.

Appendix G

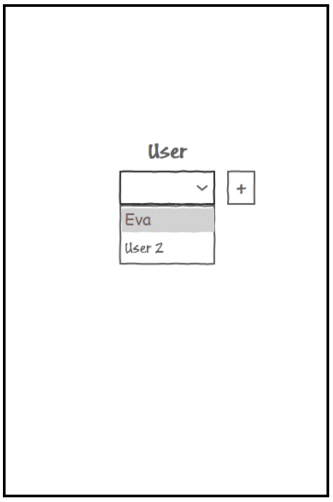

Figure 3: Login

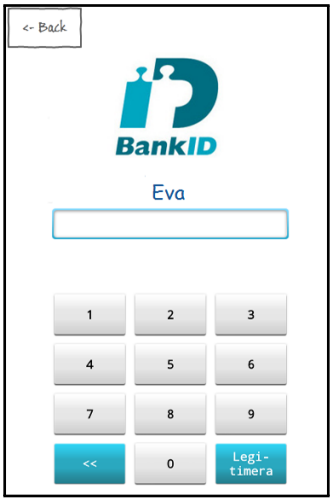

Figure 4: BankID

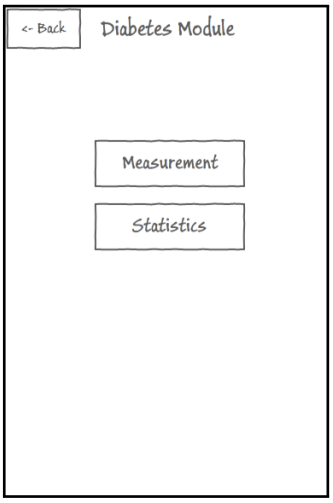

Figure 5: Diabetes module

Figure 6: Device reading

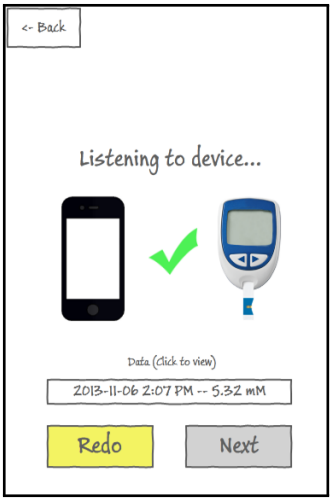

Figure 7: Test done

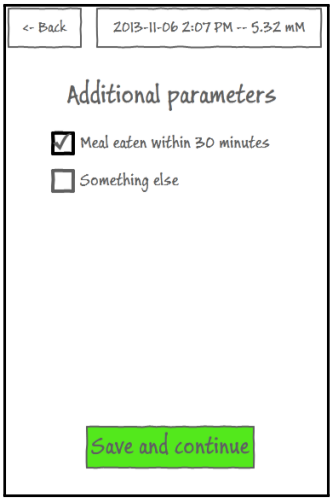

Figure 8: Test parameters

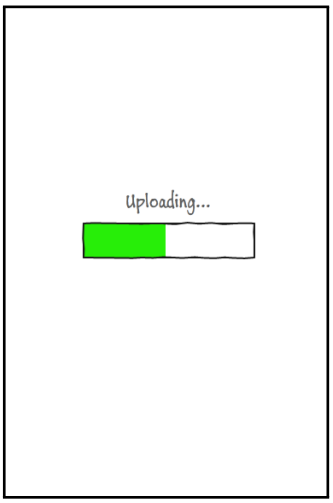

Figure 9: Uploading data

Figure 10: Error connecting

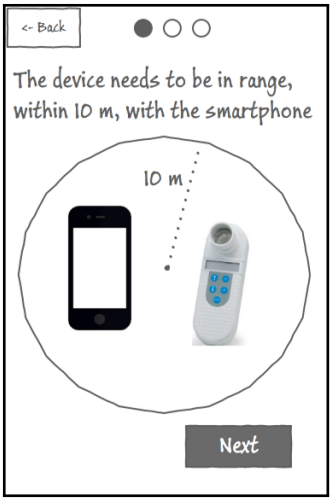

Figure 11: Help tips 1

Figure 12: Help tips 2

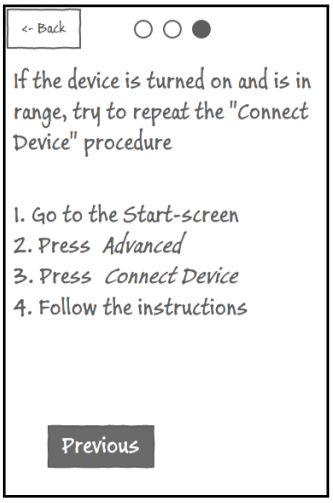

Figure 13: Help tips 3