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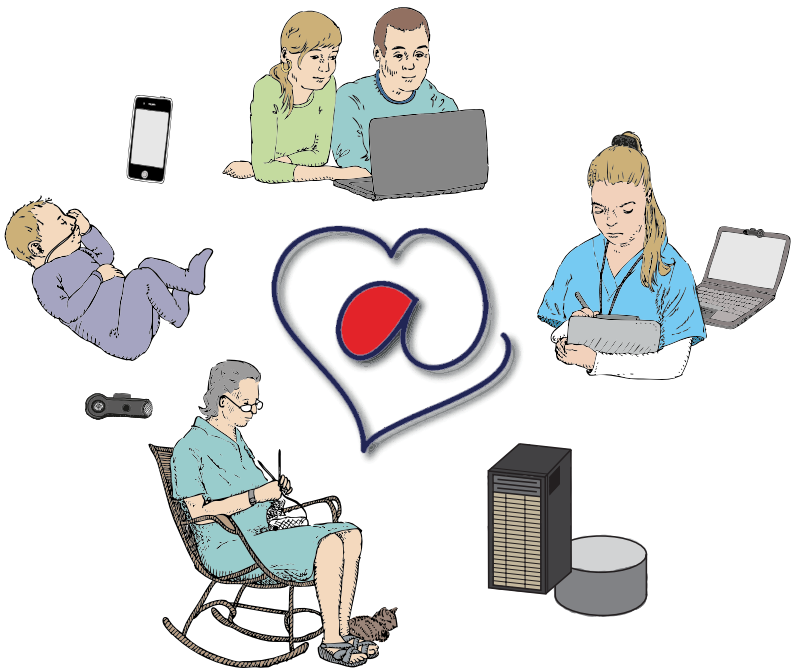

On the Design and Evaluation of an eHealth System for Management of Patients in Out-of-Hospital Care

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Department of Signals and Systems
CHALMERS UNIVERSITY OF TECHNOLOGY
Gothenburg, Sweden 2011

Thesis for the degree of Doctor of Philosophy

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by

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Time is an illusion.
Lunchtime doubly so.

–Douglas Adams

To my Anders

Abstract

This thesis covers the design and evaluation of a generic web-based eHealth system into real clinical settings. Moreover, the use of an off-the-shelf video communication system for out-of-hospital care is tested and evaluated. A large part of the thesis will cover the design process of the web-based system (WBS) for out-of- hospital long term disease management. The systems were implemented in two very different settings: heart failure care and neonatal home healthcare.

The methods of evaluation are questionnaires, including both patients and nurses. Also, data extracted from a blood pressure monitor, and data extracted from the prototype system database are used in the evaluation.

The first study, performed in 2008, indicated that the prototype developed was applicable in the patient group (heart failure). However, several issues concerning the system were found, resulting in the development of a new prototype system. The two subsequent studies, heart failure care and neonatal home healthcare, were performed using the new system. Results from these two studies indicate that the WBS is usable for two very different applications.

In heart failure care compliance with the system is very good, however in neonatal care the results are ambiguous. The neonatal evaluations show that even though the patients may be positive towards eHealth systems, the necessity of care personnel participation is vital. If there is no feedback, the patients loose interest and find the system useless.

A questionnaire survey studying attitudes towards information and communication technology (ICT) as a tool in health care, and also studying the attitudes towards home follow up, was also performed. The target group was healthcare personnel in heart care, and the questionnaire was sent out to 84 cardiology and medicine clinics in Sweden. All 21 counties and regions in Sweden were included in the dispatch, and of these responses were collected from 17. The results indicate a large interest and confidence in healthcare ICT, and well as in home follow-up and monitoring of patients. A comparison between nurses and physicians indicate a slight difference where nurses in general are more positive than physicians.

Keywords: eHealth, health informatics, telemedicine, out-of-hospital care, home monitoring, disease management, personalized care, chronic diseases, heart failure, neonatal home healthcare, internet, web-based, attitudes.

Contents

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When I first wrote my acknowledgement it consisted of one sentence: ”I thank everyone”. This is still true. There are far too many people who have helped me through these 6 magical, horrible, wonderful years during which I have done my PhD studies at Chalmers to mention by name in this text. I still would like to mention a few special people.

First of all, my supervisors Bengt Arne Sjöqvist and Kaj Lindecrantz; the instigators of this project. Your help in this thesis work has been invaluable.

Bo Håkansson, Bosse, you have helped me through some really rough times, and gave me the strength to finish my work. For this I am ever grateful. Sabine Reinfeldt who has always been a good friend in a rather stressful and confused working environment. Lars Börjesson, who is always there when you need help with all the technical stuff. Oskar Talcoth, we haven't found the time to see each other as much as I would have liked. Two floors up is apparently too far away! Of course, everyone else at S2. You're the best work mates ever!

My thanks also goes out to all my partners at Östra and Mölndal Hospital! This work could not have happened without you guys! I look forward to continue my work with you.

I do have a life outside of Chalmers as well (although some might not believe that). Peter Holdfeltd, I think it is wonderful that we can stay in touch even though we don't work together anymore. My girls! Angelica Hardenklo, Charlotte Skyfall, Johanna Rappe and non the least Ulrica Prahl. What would I do without you? Dr Hallberg, your sense of decency makes sure I don't drift into a sinful life. Or not. Johan Dufberg, although we live far apart, we will always be close in spirit. Mikael Gustavsson, you will always be near to my heart, that will never end. All you other cool guys! You know I luv ya!

Last but absolutely not least: my family! Mom and dad, I can always feel safe when I have your support. Världens bästa mormor! Jag hinner inte träffa dig så mycket som jag hade velat, men jag hoppas att du vet hur mycket du betyder för mig!

Anders, I look forward to spending my life with you. You mean everything to me, and I would never have been able to do this work without you.

Thank you!

Abbreviations and Acronyms

ACE	Angiotensin-Converting Enzyme
AMI	Acute Myocardial Infarction ("heart attack")
BNP	B-type Natriuretic Peptide
BPD	Bronchopulmonary Dysplasia
CHF	Chronic (or Congestive) Heart Failure
COPD	Chronic Obstructive Pulmonary Disease
CPAP	Continuous Positive Airway Pressure
CTG	Cardiotocography
CVD	Cardiovascular Disease
ECG	Electrocardiogram
EDV	End Diastolic Volume
EHR	Electronic Health Record
ELBW	Extremely Low Birth Weight
ePrescription	Electronic Prescription
ESC	European Society of Cardiology
GA	Gestational Age
gTalk	Google Talk
Hb	Hemoglobin
HD	High Definition
HTA	Hierarchical Task Analysis
ICD	Implantable Cardioverter Defibrillator
ICT	Information and Communication Technology
ITU	International Telecommunication Union
LBW	Low Birth Weight
LGA	Large for Gestational Age
MD5	Message-Digest algorithm 5
MDD	Medical Devices Directive
MSN	Microsoft Messenger
NIBP	Non Invasive Blood Pressure
NPÖ	Nationell Patientöversikt (National Patient Summary)
NYHA	New York Heart Association
ONC	Office of the National Coordinator for Health Information Technology

PC	Personal Computer
PDA	Patient Data Act
PDF	Portable Document Format
RDS	Respiratory Distress Syndrome
SD	Standard Deviation
SGA	Small for Gestational Age
SpO2	Pulse Oximetry
SSL	Secure Sockets Layer
SQL	Structured Query Language
TLS	Transport Layer Security
VLBW	Very Low Birth Weight
VPN	Virtual Private Network
WBS	Web-based System
WHO	World Health Organization
VINNOVA	Verket för Innovationssystem (Swedish Governmental Agency for Innovation Systems)

Included Papers

I *Design Evaluation of a Home-Based Telecare System for Chronic Heart Failure Patients*, A. Gund, I. Ekman, K. Lindecrantz, B. A. Sjöqvist, E. L. Staaf and N. Thornesköld, Engineering in Medicine and Biology Society, 30th Annual International Conference of the IEEE (EMBC), August 20-24, 2008, Vancouver, Canada.

II *Design and Development of a Generic Internet Based eHealth System for Long Term out of Hospital Care*, A. Gund, K. Lindecrantz, B. A. Sjöqvist, Submitted to BMC Medical Informatics and Decision Making in September 2011.

III *Using eHealth in the Care of Premature Infants at Home*, A. Gund, B. A. Sjöqvist, E. Pedersen, E. Hentz, K. Lindecrantz, K. Bry, Submitted to BMC Medical Informatics and Decision Making in November 2011.

IV *Evaluation of a Web-Based eHealth System for Out-of-Hospital Care of Chronic Heart Failure Patients – Preliminary Results*, A. Gund, B. A. Sjöqvist, M. Schaufelberger, K. Lindecrantz, H. Patel, In manuscript.

V *Caregiver Attitudes towards ICT and Home Follow-up in Heart Failure Care*, A. Gund, M. Schaufelberger, K. Lindecrantz, H. Patel, B. A. Sjöqvist, Submitted to BMC Medical Informatics and Decision Making in November 2011.

Conference Appearances

The work presented in this thesis has been presented by the author at the following conferences. Conference abstracts have been published for all conferences, except EMBC 2008 where a full conference paper is available (also included as a paper in this thesis).

Medicinteknikdagarna, 11-12 October 2011, Linköping, Sweden. *Using eHealth as a Tool in Neonatal Care at Home*, A. Gund, B.A. Sjöqvist, K. Lindecrantz, K. Bry, E. Hentz, E. Pedersen.

Medicinteknikdagarna, 11-12 October 2011, Linköping, Sweden. *Internet-based system for chronic heart failure follow-up at home*, A. Gund, B.A. Sjöqvist, K. Lindecrantz, M. Schaufelberger, H. Patel.

Medicinteknikdagarna, 6-7 October 2010, Umeå, Sweden. *System för insamling av medicinsk data i hemmet hos kroniskt sjuka*, A. Gund, B. A. Sjöqvist, K. Lindecrantz.

Japan-Sweden Conference on 'Challenges and Opportunities in Aging Society', 7-9 October 2009, Tokyo, Japan. *Management of Patients with Chronic Diseases - a Web Based Solution*, A. Gund, B. A. Sjöqvist, K. Lindecrantz.

Medicinteknikdagarna, 28-29 September 2009, Västerås, Sweden. *System för uppföljning av kroniskt sjuka i hemmet*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, Ants Silberberg, I. Ekman.

Medicinteknikdagarna, 14-15 October 2008, Gothenburg, Sweden. *Utvärdering av system för uppföljning av hjärtsviktspatienter i hemmet*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Engineering in Medicine and Biology Society, 30th Annual International Conference of the IEEE (EMBC), August 20-24, 2008, Vancouver, Canada. *Design Evaluation of a Home-Based Telecare System for Chronic Heart Failure Patients*, A. Gund, I. Ekman, K. Lindecrantz, B. A. Sjöqvist, E. L. Staaf and N. Thornesköld.

Tromsø Telemedicine and eHealth Conference, 9-11 June, 2008, Tromsø, Norway. *Evaluation of a Disease Management System for Chronic Heart Failure Patients*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Medicinteknikdagarna, 2-3 October 2007, Örebro, Sweden. *Care@Distance - Disease Management för hjärtsviktspatienter i hemmet*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Tromsø Telemedicine and eHealth Conference, 11-13 June, 2007, Tromsø, Norway. *Care@Distance - Home Monitoring System for CHF Patients*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Svenska Läkaresällskapets Riksstämman, 29 November - 1 December, 2006, Gothenburg, Sweden. *Care@Distance - IT-baserad hemvård av hjärtsviktspatienter*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Medicinteknikdagarna, 3-4 October 2006, Uppsala, Sweden. *Care@Distance, Home Monitoring System for Patients with Congestive Heart Failure*, A. Gund, B. A. Sjöqvist, K. Lindecrantz, I. Ekman.

Chapter 1

Introduction

1.1 Introduction

It is a generally accepted idea that eHealth, the use of information and communication technology (ICT) in healthcare [1,2], is likely to play an important role in the future delivery of healthcare [3–5]. In Sweden, electronic health records (EHR) and electronic prescriptions (ePrescriptions) are examples of applications that are already in widespread use [6,7]. Another area with great expected future potential is out-of-hospital eHealth support for chronically ill people, particularly elderly. Studies have shown the feasibility of home monitoring of patients with chronic diseases and the advantages for the individual patient have been demonstrated [8–14]. However, to demonstrate the advantages and values for the healthcare supply system, and for the society as a whole, requires the full implementation of a system targeting all relevant patients in a community, or at least a larger part of a community. Patients with different diseases and with multiple diseases will also have to be included. Especially the latter group is expected to increase significantly in the years to come [15, 16]. A large scale implementation pilot of this type would unravel organizational issues, within healthcare organizations as well as between different health care actors. But also the involvement of the social system and the interaction between social care and healthcare, and not the least, issues related to business models. All of these are issues that probably explain the limited progress in the field so far [17, 18].

With the ambitious aim of setting up such a large scale implementation pilot, the project Care@Distance was initiated. Care@Distance will investigate and provide knowledge on how to design, introduce and implement eHealth applications in real clinical healthcare settings. Furthermore, the project aims to show how to gain acceptance to out-of-hospital eHealth applications among all relevant stakeholder. More specifically, the objectives of Care@Distance are to:

- Improve treatment compliance, i.e. to support patients to follow their treatment plans.

- Improve the possibilities for an active dialogue between patient and healthcare provider.
- Improve disease management.
- Support healthcare personnel to make informed decisions on individualized care.
- Individualize care, and alert about deteriorating health.
- Promote a person centered care, and an informed patient.
- Identify crucial factors limiting a wider penetration of out-of-hospital eHealth systems.
- Suggest applicable business models.

However, the launch of this ultimate out-of-hospital eHealth project requires that many components are in place. There must be hardware and software tools designed not only to perform the required functions but also to be accepted by the users, patients as well as healthcare staff. A good knowledge on how to motivate healthcare personal and patients to wholeheartedly engage in the development of future healthcare services is required. The aim of the thesis work presented here was to put some of these initial stepping stones on the route towards a large scale implementation of an out-of-hospital eHealth pilot in place.

1.2 Objectives of Thesis

The steps taken within the scope of this theses work involve the design and evaluation of an information exchange system and to verify its functionality. The specific objectives of this thesis work were the following:

- Design a generic web-based eHealth system (WBS) for out-of-hospital care.
- Configure and customize the generic solution, WBS, to specific out-of-hospital applications.
- Evaluate the applications in real clinical settings.
- Evaluate the value of video communication as future additional option to the WBS.
- Investigate the attitudes towards healthcare ICT and out-of-hospital monitoring and follow-up among healthcare professionals

1.3 Method – How to Address the Objectives

The design of the WBS was based on the experience from previous studies, described in Paper I [19] and the licentiate thesis previously published by the author of this thesis [20], as well as interaction with intended users (Paper II). During the design of the user interface of the WBS, we have been influenced by methods and terms within the usability domain. *Usability* was defined in 1993 by Jakob Nielsen as five attributes [21]:

- Learnability - how easy the system is to learn.
- Efficiency - the level of productivity of the user after the learning period.
- Memorability - how easy it is remember how to use the system.
- Errors - number of errors made by users.
- Satisfaction - how well the users like the system.

Nielsen also mentions usability in context with the larger term *acceptability* which is described as whether the users will in fact approve of (or accept) using the system. A third term used is *utility* which concerns if the functionalities follow requirements of the system.

There are several usability "tools" which can be applied to a design process. Examples of these are *participatory design*, *prototyping* and *iterative design* [21]. All these were in some way used in this thesis work. More specifically, tools such as hierarchal task analysis [22] and paper prototyping [23] were used. However, although the philosophy of usability engineering was considered in the design process, it was not within the scope of this thesis work to directly apply usability- and evaluation techniques. The design of the WBS is described in more detail in chapter 4, and the evaluations are described in chapter 6.

In order to clinically evaluate the WBS, two patient groups were chosen. These two patient groups represent two very different types of users, and were chosen for test of generality of the WBS. Moreover, there is a strong potential for eHealth solutions in both groups. The first group is families with prematurely born infants in home healthcare, and the other is patients with chronic heart failure (CHF). Healthcare background of these two groups can be found in chapter 3. The system was configured, customized and evaluated for the two applications neonatal home healthcare, named NeoReg, and CHF care, named HeartReg respectively (Paper II, III, IV and V). In the neonatal home healthcare scenario video communication was also tested.

Finally, the attitudes of a targeted group of healthcare personnel, those working at cardiology clinics in Swedish hospitals, were surveyed by the use of a questionnaire (Paper V). The survey addressed healthcare ICT and out-of-hospital monitoring and follow-up.

1.4 Security and Integrity

Security and integrity aspects are very important when working with sensitive healthcare related information. There are laws, rules and directives which regulate this market, both nationally and internationally [24–26]. In this thesis

work these aspects are considered, however, as they are not a part of the thesis objectives the regulations are not applied fully. Information on these laws and rules can be found in chapter 2. Chapter 4 contains information on the security and integrity measures we have taken in this thesis work, and chapter 7 discusses our future plans regarding these issues.

1.5 Ethical Approvals

All clinical studies presented in this thesis are covered by ethical approvals from the Ethical Review Board in Gothenburg, reference numbers 533-10 and 775-10. The preparations of these approvals were part of the thesis work.

Chapter 2

Background

> "eHealth is the single-most important revolution in healthcare since the advent of modern medicine, vaccines, or even public health measures like sanitation and clean water."
>
> -Denise Silber

2.1 What is eHealth?

The statement above was given by Denise Silber at the European Commission's first high-level conference on eHealth in 2003 [27]. This is a very strong, and in a way provocative, statement which illustrates the importance and possibilities that are attributed to eHealth. In general, eHealth is a term referring to a combination of different areas and disciplines, including medical informatics and telehealth [2]. Several different definitions exist, where one of the most well cited is by Gunther Eysenbach, published in the Journal of Medical Internet Research in 2001. There Eysenbach states that:

> "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology." [1]

Another definition of eHealth is given by the European Commission who defines the area as:

> "eHealth means Information and Communication Technologies tools and services for health. Whether eHealth tools are used behind the scenes by healthcare professionals, or directly by patients, they play a significant role in improving the health of European citizens." [2]

In short, one could define eHealth as the use of ICT in health care; as an umbrella term covering several different areas (see figure 2.1). This very broad definition partly explains why this area attracts so much attention. Included are applications and services such as electronic health records (EHR), electronic prescriptions (ePrescriptions), remote monitoring of patients, systems for health care organization, medical education, imaging systems, robotic surgery, smart homes, etc. [1, 2, 27].

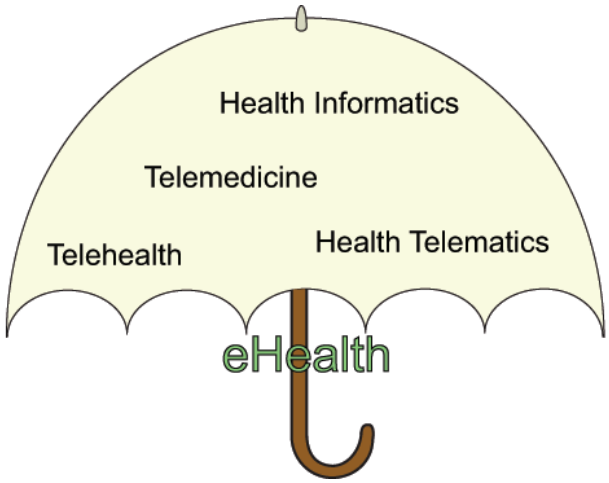

Figure 2.1: Description of the term eHealth, which can be seen as umbrella term for several different terms.

2.2 eHealth in Sweden and Internationally

All around the world, eHealth is being recognized as an important area. Therefore, many countries, regions and organizations have initiated strategies for eHealth. Below are some examples of ongoing eHealth strategies.

The Swedish Strategy for eHealth [28] was initiated in 2005 (changed name from "national IT-strategy" to "national strategy for eHealth" in 2006) after the adoption of the 2004 European Commission Action Plan on eHealth [29]. This national strategy contains a plan for the implementation of nationwide eHealth. As an example, the national patient summary (NPÖ) was introduced in order to increase patient mobility by making sure all hospitals in Sweden has a summary of the patient's EHR [30].

In England a national strategy, named Connecting for Health, commenced implementation in 2004, with a very ambitions scope including EHR, ePrescriptions, etc. [31]. This has become a huge project which is both over budget and behind schedule, and is now being dismantled or heavily restructured on request of the government [32]. Initially the budget of the program was £6.2 billion, but now the estimated cost amounts to £11.4 billion [32].

Many other European countries have also initiated eHealth programs and/or

systems [33]. Both Germany and France have introduced electronic health cards (Elektronische Gesundheitskarte [34] and Sesam Vitale) [35]. In Denmark, eHealth was a part of a larger strategy initiated in 2007 to digitalize the country by e.g. introducing the web-based service Sundhed.dk [36]. Norway has a number of eHealth projects running, as well as national strategies for ICT in which eHealth is mentioned [37].

Since 2008 Australia has a national strategy for eHealth [38]. In North America, Canada has introduced the term "health infostructure" to describe their work in eHealth [39], and in the USA the Office of the National Coordinator for Health Information Technology (ONC) has been created to handle these issues [40]. Moreover, since 2006 Japan also has strategies for ICT which includes the healthcare sector [41].

In the developing regions, such as parts of Africa, eHealth strategies are being managed by larger organizations such as the World Health Organization (WHO) [42] and the International Telecommunication Union (ITU) [43], both United Nations (UN) agencies.

2.3 eHealth Drivers

2.3.1 The Aging Population

A term which is often heard in relation to eHealth is "the aging population". So what does this mean? If we look back in time, people did not live as long as they do today. The life expectancy in Sweden around the 1900's was approximately 55 years, compared to over 80 years of age today [44]. People tend to live longer, which of course is a good thing. However, from an economical point of view these demographical changes become a problem. If the ratio of elderly, non-working, citizens becomes too high the young, working part of the population will not be able to support the growing group of elderly [16]. As a consequence there is now an ongoing discussion in society about raising the retirement age [45].

Not only has the life expectancy increased, new achievement in medicine have also turned diseases that used to be lethal into chronic diseases where lifelong medication and control can yield many years of good quality life for the individual [16]. However, for the healthcare system this is a real challenge. New tools and/or working methods are needed in order to handle the rising demand and declining resources.

2.3.2 Chronic Diseases

One of the major challenges for the healthcare system is chronic diseases [15]. Chronic diseases[1] account for approximately 60 % of all deaths, worldwide [46]. Among them the largest groups are cardiovascular diseases (CVD, 30 % of all deaths), cancer (13 %), chronic respiratory diseases (7 %), and diabetes (2 %). Ischemic heart disease (reduced oxygen supply to the heart) is the most common cause of death in the world, and it alone causes as many deaths as all types of

[1] As defined by the World Health Organization (WHO); includes all cardiovascular diseases, e.g. stroke, ischemic heart disease, heart failure, etc. [46]

cancer together [47]. Since only 20 % of all deaths due to chronic diseases occur in high income countries [46], it can be interesting to take a deeper look at these numbers in the western world. Taking the European region as an example, chronic diseases account for approximately 86 % of all deaths; CVD 51 %, cancer 19 %, respiratory diseases 4 %, and diabetes 1 % [47]. In the USA and Canada the numbers are similar with about 88 % of all deaths being due to chronic diseases; CVD 38 %, cancer 23 %, respiratory diseases 8 %, and diabetes 3 % [47]. In fact, this pattern can be seen in most regions of the world, except in very low income regions where the group "communicable diseases, maternal and perinatal conditions, and nutritional deficiencies" is the major cause of death [46].

Although chronic diseases not only affect elderly people, elderly are highly over represented as about 77 % of all deaths due to chronic diseases, worldwide, occur in the age group 60 year of age and older [46]. Multiple chronic diseases are also a large issue in elderly [15, 16]. For example, in the USA it is approximated that over 80 % of the population over 65 years of age suffer from one or more chronic diseases [48], and more than 60 % has two or more [49]. In Sweden 17.5 % of the population is 65 years of age or more and, as in the rest of the world, the amount of elderly is increasing [50]. Considering that the demographics of the world are changing rapidly, age related disorders will become a large problem in the near future. The baby-boom generation of the 40's and 50's will soon reach retirement age, putting higher demands on the health care for the elderly [16].

In the USA about 80 % of the health care costs are due to chronic diseases [49, 51], and people with chronic diseases represents five times higher costs than those without [51]. The total cost for CVD alone was in 2005 approximately $394 billion (including production lost due to morbidity and mortality) [51]. For cancer the cost in 2005 was $210 billion, and in 2002 the cost for diabetes was $132 billion [51]. For comparison, in 2003 the total cost for CVD in the EU was about €169 (€105 billion in health care costs, the rest production loss due to morbidity and mortality, and informal care), with Germany and the UK in the top with €54 billion and €37 billion respectively [52]. Sweden spent an estimated €5 billion in total costs on CVD, of which almost €3 billion were health care costs, representing 11.6 % of the total health care expenditures [52].

2.3.3 Internet and Technology Use

The population is rapidly becoming more technologically advanced. Both computer and internet knowledge is increasing, especially in the older age groups. For example, statistics from Statistics Sweden (Statistiska Centralbyrån) show that more than half of the population aged 65-74 used internet regularly in 2010 [53], which can be compared to less than 40 % in 2007 [54]. In the younger age groups these numbers are today close to 100 % [53]. It can also be assumed that the future elderly will be even more knowledgeable in internet usage. However, one must keep in mind that technology does not cease to develop, and it is not certain that the future elderly will be able to handle future technology in a better way or to a higher extent than today [55].

2.3.4 Healthcare Motivation

There are several healthcare driven reasons for the introduction of eHealth solutions. Person centered care is a care model where the *person* rather than the *patient* is in the center of the care planing process [56]. Self-reported information by the patient, health related as well as social, is considered a very important complement to objective physiological data. Actively involving the patients in the care process, an empowering them, is also a vital part of this model. Moreover, research indicate the benefits of individualized (or personalized) care, which is care customized, or tailored, for the individual patient [57,58]. eHealth systems focusing on personalized and/or person centered care, and an active dialogue between patient and healthcare provider, can promote this care model [13, 17].

Early discharge, or possibility to stay home in longer intervals, is another benefit which eHealth might bring by the possibility of remote follow-up [17]. Many people also prefer the comfort of their home, where they feel more secure and comfortable. Moreover, at hospitals diseases thrive [59], and the risk of becoming infected is larger there than at home. This is especially true for neonatal departments where the patients (prematurely born infants) are highly susceptible to diseases [60–62].

2.3.5 Resources and Costs

Financing, cost and personal resources are also a large driver in the development of new eHealth systems. By introducing new working methods where eHealth applications are utilized, resources can be allocated to where they are better needed, and thereby improving the care [9, 17, 63]. It is possible that costs can be reduced, but it is more likely that cost will stay the same while quality of care increases.

2.4 Considerations on Design and Clinical Introduction

One of the major challenges when developing medical applications is not the technology itself, but rather the introduction and the acceptance among the users [17]. If a new medical method or application is to be successful, cooperation with the future users, i.e. nurses, physicians, administrators, etc., is crucial. One has to remember for whom the solution is being designed, and what problems it is addressing. As an engineer it is easy to get "lost" in new and advanced technology, but it is not always the most technologically advanced solutions that give the best overall results. Cooperation with clinical staff is a necessity; to perform tests in clinical environments, to get access to test patients, to get constructive feedback during the development process, and to get clinical assistance in introducing the finished product in the clinic.

Another key factor is evidence-based practice, i.e. showing that the new system and/or method is beneficial to e.g. the quality of life for the patients, the economy, and/or the work load for the staff [64]. For this, testing and

validation is necessary. During the development phase, several prototypes may be needed in order to show the benefits of the new solution. These prototypes do not have to be finished products [21]; it is often better to keep it simple at start and then add more advanced features, stepwise governed by acceptance and clinical needs. A less advanced solution may be accepted more easily by the users. It will also be easier to change the design concept if it proves to be non-beneficial. Once the simple prototype has been tested and accepted, new features and ideas from e.g. users can be added to improve the functionality of the product. Within the scope of this thesis work the intention is therefore not to create a technologically advanced medical solution. It is rather to design a system which can be accepted in the daily routines, by care personnel as well as patients. With help from these users the system can then be developed further.

As for the users who are patients, it is important to reflect on which patients are to be considered during the design of a new system. Sometimes, designers of medical technology systems tend to focus on making their product usable for all patients in a certain patient group. The result may be quite complicated products where a great deal of time has been put into making sure everyone can use it. In the Care@Distance project the idea is instead to design a system which works on the large majority of the patients and, at least in the beginning, disregard the special cases. All these issues have been taken into consideration during the project described in this thesis.

2.5 Patient Safety, Information Security and Integrity

Information security and integrity are important issues when developing new products and solutions within healthcare. Sensitive information is being stored and communicated, and it is crucial to prevent this information from becoming available to unauthorized individuals. The healthcare market is therefore regulated by substantial laws, rules and regulations, both nationally and internationally [24–26].

Handling and storing of patient related information is in Sweden regulated by the Patient Data Act (Patientdatalagen) [24]. This act, updated in January 2011, involves personal information in healthcare, and contains rules on e.g. how to handle this information, the obligation to keep patient records, confidentiality and access to information, and transfer of patient information. As this project deals with a prototype system only intended for limited research, no effort has been put into implementing this act so far. Instead, to ensure patient integrity, no personal data such as name or personal number is stored or communicated in the system. Each patient is instead identified using a code.

Apart from the issues related to the handling of information, there is also always an issue on patient safety when designing medical applications as well as devices. Each product has to be certified for its intended use; and this is valid for hardware as well as software [65]. In March 2010 the Swedish Medical Products Agency (Läkemedelsverket) updated the Swedish Medical Devices Act [25]. The background for this was an update in the European Union's Medical Devices Directive (MDD) from 2007 which discusses the use of software in healthcare.

Figure 2.2: The start of Care@distance in 2001.

Medical devices, including software such as clinical information systems (CIS) and eHealth applications, are divided into four groups (I, IIa, IIb and III) depending on the risk they expose to the patient. A product based on WBS in this thesis work would be classified into the lowest risk group, group I. However the WBS used in the studies in this thesis work is not classified.

2.6 The Care@Distance Project

The project Care@Distance, of which this thesis work is a part, started in 2001 as a Master of Science thesis in design at Umeå University [66]. In this design thesis, a concept of a system for disease management of CHF patients in their homes was developed, including a non-functioning prototype, as seen in figure 2.2. The main instigators of the project Care@Distance are Professor Bengt Arne Sjöqvist and Professor Kaj Lindecrantz, who are also the main supervisors of the author of this thesis.

In 2005 the project had evolved into its current form. As part of a Master in Technology thesis at Chalmers University of Technology, a functioning prototype system for monitoring of health related data in the home was developed [67]. After this the project transformed into a doctoral project at Chalmers with the purpose to develop the prototype further, as well as to evaluate and introduce it in various clinical settings. The project resulted in a Licentiate of Technology thesis in 2008 where an internet-based prototype system for monitoring and follow-up of patients in the home was evaluated [20].

The project has been partly financed by VINNOVA (Swedish Governmental Agency for Innovation Systems) and Ortivus AB.

2.7 Related Work

2.7.1 eHealth in Neonatal Care

eHealth in the area of neonatal care in the home is a somewhat unexplored area. In 1994 an early project addressing the neonatal area was Neonatel. This project primarily targeted prematurely born infants in need of additional oxygen also after having left the hospital. By using Neonatel the infants could potentially be discharged from hospital earlier since there was a real-time remote monitoring facility as well as alert functionality, as shown in figure 2.3. The project was a collaboration involving Chalmers and Sahlgrenska University Hospital/Östra Hospital [68].

Figure 2.3: Neonatel in 1994; home unit and hospital unit.

A research study in Luleå, Sweden, has used video conferencing to support parents in early discharge [69]. In the USA the project Baby CareLink combined the use of video conferencing with information through a web site [70], and NICU-2-HOME is a project which deals with making the transition from hospital to home easier for the parents using a mobile application [71].

2.7.2 eHealth in CHF Care

In contrast to neonatal out-of-hospital care, eHealth in CHF home healthcare is more common. The MyHeart project, funded by the European Union 6th framework program, is one example where 10 European countries and 33 different partners collaborated in management and monitoring of chronic CVD [72]. The system Zertiva from the German company SHL also aims at using eHealth for monitoring of CHF patients [73]. This system can be connected to a blood pressure monitor and weight scale.

Robert Bosch Healthcare (previously Health Hero Network) has developed Health Buddy through which patients can be followed in their homes using a

small device placed in their homes and an application on the healthcare personnel's computer [74]. This system covers more than 30 different diseases, and has built in decision support. A similar system is available from the UK based company Docobo [75]. Their doc@HOME solution gives health care providers a tool for monitoring chronically ill patients in their homes using either a combination of web-based solutions together with medical equipment and patients' personal mobile phones, or Docobo's own tool HealthHUB. Both Health Buddy and Docobo combines the use of objective and subjective information.

At Tromsø Telemedicine Center, the project MyHealthService [76] deals with managing chronically ill patients by use of low cost components. Depending on the patient, different home solutions can be used, e.g. the patient's own TV or mobile phone, or a touch sensitive device created from an all-in-one PC. Another system which utilizes the patient's own TV is designed by the Swedish company Ippi, through which patients can use their TV for communication with healthcare and relatives [77]. Hälsodagboken (the health diary) is a project at Linköping University, Santa Anna IT Research Institute, Catrel and Linköping University Hospital where a digital pen is used for home follow-up of CHF patients in late stages of the disease (NYHA III and IV) [78].

Chapter 3

Healthcare Background

3.1 Neonatal Care

Neonatology is defined by The American Heritage Medical Dictionary [79] as:

> "The branch of pediatrics that deals with the diseases and care of newborns. Also called neonatal medicine."

This section will begin by describing the pregnancy and then move on to describing the prematurely born infant, and complications regarding a preterm birth. All information in this section is obtained from the Swedish book "Neonatologi" (Eng: Neonatology) [80] and discussions with professor in pediatrics Krisina Bry [81], unless otherwise cited.

3.1.1 The Pregnancy

A normal pregnancy (full term) is 37-42 weeks long. The age of the fetus during the pregnancy is called the gestational age (GA), and it is this age that determines the development of the child. Calculating the GA is not always easy. Most commonly, the self-reported last date of the woman's menstrual period is used to assess the GA. The GA is later adjusted using ultrasound measurements of bodily parameters of the fetus, such as the biparietal diameter (head diameter), crown-rump length (length from top of head to buttocks) and length of femur (thigh-bone).

The pregnancy is divided in three parts:

- 1^{st} trimester, <14 weeks GA
- 2^{nd} trimester, 14-28 weeks GA
- 3^{rd} trimester, >28 weeks GA

Before 10 weeks GA the child is called an embryo, and after 10 weeks it is called a fetus. The 1^{st} trimester covers everything from conception to the embryonic development which is when all organs form.

In the 2^{nd} and 3^{rd} trimester the fetus grows and the organs of the body mature. When reaching the 3^{rd} trimester the fetus is mature enough to survive outside the mother, although certain organs may be rather underdeveloped. The time from approximately 21 weeks until the birth is sometimes referred to as the prenatal period, the time surrounding the birth is the perinatal period, and the age after birth is the postnatal period.

3.1.2 Born too Soon

A child born before GA week 37 is defined as prematurely born. If born before week 28, i.e. not having a 3^{rd} trimester, the child is called extreme premature. In 2003, 6.2 % of the children in Sweden were prematurely born (approximately 1 % before 32 weeks GA, and 4.3 % weighing under 2500 g).

In about two thirds of the cases, the premature labors are spontaneous. The reasons for spontaneous premature labor are not completely understood. However, in a majority of the cases the preterm birth is associated with infections in the membranes surrounding the fetus, so called chorioamnionitis. In the other third of the cases are iatrogenic (the physician is involved), either by inducing the labor or by performing a cesarean. Reasons for inducing preterm labor could be illness in the mother, such as extreme hypertension (high blood pressure) and proteinuria (protein in the urine), poor fetal growth or malfunctioning placenta.

Often, spontaneous premature contractions stop by themselves and do not result in preterm labor. However, once the labor has begun there is nothing that can be done to stop it. By pharmacological treatment the process can be delayed, but only 48-72 hours. Instead, focus shifts to accelerating the lung development process, which can be done by inducing the mother with steroids. During the labor the health status of the fetus can be monitored using cardiotocography (CTG), i.e. registering heartbeat of fetus and contractions of mother, and ultrasound.

Type of delivery differs depending on the position of the fetus in the womb, the reason for delivery, and the GA. Vaginal delivery is preferred, and also most common. If in breech position, buttocks or feet first, a caesarean is often performed. Place of delivery is also very important, as experienced personnel and the right material resources improves the outcome of the delivery.

The size of the newborn child can be either small for gestational age (SGA) which is 2 standard deviations (SD) below average, normal, or large for gestational age (LGA) which is 2 SD above average, as shown in figure 3.1. This should not be confused with the actual birth weight of the child which is divided into normal weight, low birth weight (LBW), very low birth weight (VLBW) and extremely low birth weight (ELBW). These definitions apply to all children, meaning that a premature infant can still be LGA, and a full term can be SGA. However, most premature infants are LBW, VLBW or even ELBW while the majority of full term children are normal weight.

3.1.3 Hospital Care of Premature Infants

Although being prematurely born is not a disease (despite the ICD-10 classification O60.1), prematurely born children often suffer from a large number of

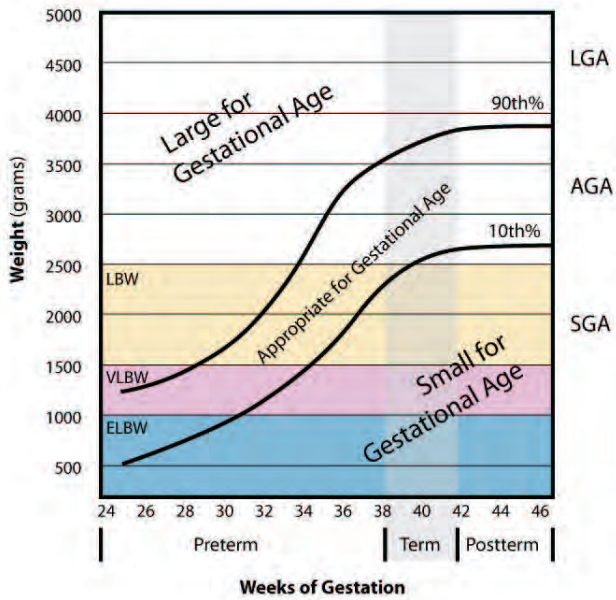

Figure 3.1: Graph showing the weight of the child as a function of the birth week. Also showing the definition for SGA, LGA, and birth weight.

diseases resulting from their immaturity. These diseases often lead to hospitalizations for a prolonged period of time, especially for the extremely premature. Many of the children have complications, and are susceptible to infections.

Among the more common afflictions in premature infants, especially in those born before GA 32 weeks, is respiratory problems. Since the lungs are often immature, the child can suffer from a condition called respiratory distress syndrome (RDS), which is caused by a lack of pulmonary surfactant. Surfactant is a substance covering the inside surface of the alveoli (the small vesicles in the lungs where gas exchange occurs) lowering compliance by changing the surface tension. This substance is vital to prevent the alveoli from collapsing at the end of expiration. These children are in need of supplementary oxygen therapy, and often require nasal continuous positive airway pressure (CPAP), as seen in figure 3.2, or intubation. Moreover surfactant administration and respirator therapy can be necessary. In some cases where the infant is in need of prolonged oxygen therapy, a chronic lung condition called bronchopulmonary dysplasia (BPD) can be developed.

Due to a reduced amount of subcutaneous fat and brown adipose tissue, as well as a large surface area compared to volume, keeping warm is often difficult for the premature infants. Moreover, because of thin skin, fluid evaporation from the skin is relatively high. Therefore, prematurely born children are treated in incubators (see figure 3.3), where both temperature and air humidity can be regulated.

Nutrition is a major concern among prematurely born children, especially

Figure 3.2: Premature child in incubator with CPAP. Public domain picture.

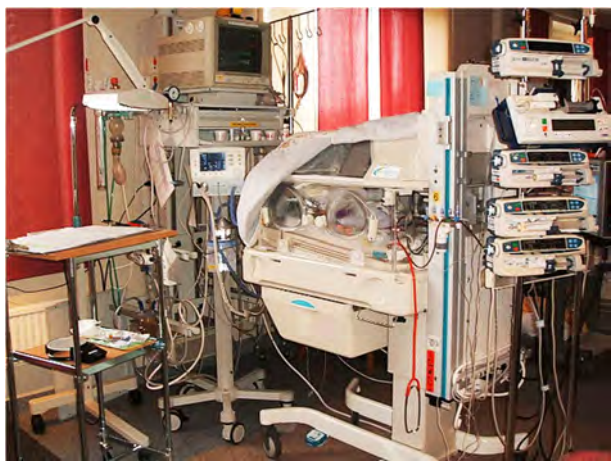

Figure 3.3: Incubator set-up at Östra Hosptal neonatal unit.

the most immature. Although breast milk is introduced as soon as possible, glucose, protein and fat is initially administered intravenously to increase the amount of nutrition given. In addition to breast milk, these children are in need of supplementary nutrition until they reach an age corresponding to at least 35 weeks GA.

Prior to a GA equivalent to 34-35 weeks, premature infants often have difficulties breastfeeding fully. Therefore, these children are partially given their meals using a nasogastric tube (nasal feeding tube). Tube feeding is gradually reduced in favor of breast feeding as the child increases in maturity.

3.1.4 Coming Home; the Transition

Coming home is something many parents long for. Hospitalization is not only difficult for the child, but also for the parents who cannot continue their daily life. Many hospitals do not have family rooms, meaning that the parents are often separated from their child during the hospitalization. Even more issues occur when the family already has another child. The older child is often not allowed to visit the neonatal department due to risk of infection, and the family is therefore divided.

However, once the time has come to return home, the family may feel anxiety about taking care of their new child at home [82–84]. Being on your own with a child who has previously been cared for 24 hours a day by professional health care personnel can be frightening. By aiding the parents in this first time at home, for example by regular home visits by a nurse, the parents' feelings of safety can be increased. Also, having and effective home health care system might make it possible to discharge some infants earlier [85], thereby reducing the risks of hospital infections and giving the family the comfort of their own home [60–62, 85].

3.1.5 Out of Hospital Care of Premature Infants

At Mölndal Hospital at Sahlgrenska University Hospital, the parents of prematurely born children are offered neonatal home healthcare. This service started in 2008, and involves more than 200 families per year. To be eligible to this service the infant needs to be physiologically stable, weigh more than 1 500 g and have reached an age corresponding to of 34 weeks GA. Moreover, at least the mother needs to understand instructions in Swedish.

When discharged into neonatal home healthcare, the infant will be visited approximately 2-3 times per week a neonatal nurse. The nurse travels to the family to support them in the care, and can during the visit e.g. examine and weigh the child, measure head circumference, and check the nasogastric tube. Moreover, the family can ask questions and get advice on the care of the child. Daily contact with nurses is provided by phone. Usually, the family needs home visits for about three weeks. At the end of this period the family has a consultation with a neonatologist.

Although the infants are stable when leaving the hospital, some nursing care is still required. The mother may need help with breastfeeding, and supplementary nutrition can be provided through a nasogastric tube. Skin-to-skin care, or Kangaroo care, i.e. holding the child directly against the skin of the parent, is encouraged.

Home healthcare allows the parents to spend more time with their infant child than would have been possible at the hospital. The comfort of home and family reduces stress levels. Decreased stress may result in better breast feeding by the mother, hence reducing the need of tube feeding. Removing the child from the hospital environment also means a reduced risk of serious infections.

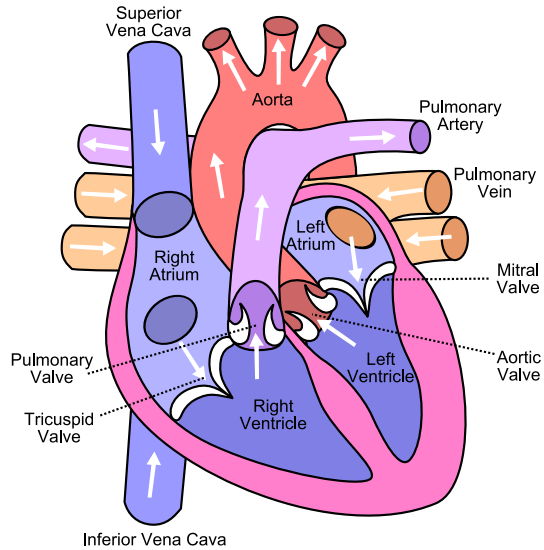

Figure 3.4: Cross section sketch of the human heart.

3.2 Heart Failure

Cardiovascular diseases (CVD) is, according to the World Health Organization (WHO), the number one cause of death in the world. Chronic heart failure (CHF), also called congestive heart failure or simply heart failure, is a condition which belongs to this category. It is estimated that approximately 2-3 % of the western population suffer from CHF, and looking at people aged 70 or more the prevalence is 10-20 % [86]. In the USA an estimated 5 million people (∼2.3 % of the population) [87], and in Sweden about 250 000 people (∼2.7 % of the population) [88], are afflicted by this condition. Studies have shown that treatment compliance is low in this group of patients [86, 89, 90], which opens up the possibility to improve the care given to them by disease management.

3.2.1 Physiology and Pathology of CHF

Information in this section is retrieved from "Vander's Human Physiology" [91], unless otherwise cited.

The heart is, together with the circulatory system, responsible for distributing blood throughout the body. Figure 3.4 shows a cross section of a heart. Deoxygenized blood enters the right atrium through the superior vena cava, and then flows into the right ventricle. As the right ventricle contracts the blood is pushed through the pulmonary artery into the lungs where oxygen is once again collected. From the lungs the oxygenized blood runs through the pulmonary veins into the left atrium, and then into the left ventricle. The left ventricle, which is the strongest part of the heart, pushes the blood out into the body.

CHF is not a disease but rather a condition, described by a series of signs and symptoms, resulting from a reduced function of the heart [91]. The European

Society of Cardiology (ESC) defines heart failure according to three criteria, seen in table 3.1. A common cause of CHF is acute myocardial infarction (AMI), or "heart attack" in common speech. This is one of the ischemic heart diseases which, as previously mentioned in chapter 2, is one of the largest causes of death in the world [47].

I	Symptoms typical of heart failure
	and
II	Signs typical of heart failure
	and
III	Objective evidence of a structural or functional abnormality of the heart at rest

Table 3.1: Definition of Heart Failure according to European Society of Cardiology. Quoted from "ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2008" [86].

There are two different types of CHF: diastolic and systolic dysfunction. In diastolic dysfunction the compliance of the ventricles of the heart is decreased, leading to a lowered end-diastolic volume (EDV[1]). A lowered EDV results in less blood being pumped out into the body at each heart beat (stroke volume). In systolic dysfunction the contractibility of the heart is instead reduced, due to damage of the cells of the heart. Here the heart is unable to eject all blood from the ventricle, resulting in a lowered stroke volume.

Both conditions result in the same thing: reduced stroke volume. The body tries to compensate for this, by e.g. increasing the heart rate, leading to increased blood pressure and increased interstitial fluid, so called edema. Depending on if the right or the left side of the heart is affected, the edema can be situated in the peripheral system (right side of the heart), or in the pulmonary system (left side of the heart). Edema in the peripheral system usually leads to swelling of limbs, e.g. legs and feet, while edema in the pulmonary system leads to water accumulation in the lungs. Decreased stroke volume also results in an increased blood pressure, forcing the heart to work harder. This in turn leads to a worsening of the condition, and finally a complete loss of cardiac function.

The severity of CHF has been divided into four different classes by the New York Heart Association (NYHA) [92], as seen in table 3.2. NYHA I is the least severe case where there are hardly any signs or symptoms, and NYHA IV is the most severe.

Symptoms of CHF varies between patients, but some of the most common are dyspnea (shortness of breath), edema, increased weight, fatigue (tiredness), high blood pressure and increased heart rate. Worsening of symptoms could be a sign of deteriorating health, thus important indicators for adjustment of treatment.

3.2.2 Treatment of CHF

The information in this section is attained from guidelines by the ESC from 2008 [86], unless cited otherwise.

[1]EDV is the volume of blood a ventricle right before ventricular contraction

Class	Symptoms
I	No limitation of physical activity. No undue fatigue, palpitation, dyspnea or anginal pain during ordinary physical activities.
II	Slight limitation of physical activity. Comfortable at rest, but experience fatigue, palpitation, dyspnea or anginal pain during ordinary physical activity.
III	Marked limitation of physical activity. Comfortable at rest, but experience fatigue, palpitation, dyspnea or anginal pain during less than ordinary activity.
IV	Inability to perform any physical activity without discomfort. Symptoms of heart failure or anginal syndrome may be present even at rest, and discomfort increases during physical activities.

Table 3.2: Classification of heart failure according to New York Heart Association. Obtained from American Heart Association (AHA) web site. [92]

CHF is to a large extent defined by present symptoms, and the reasons behind the condition can be many. Therefore, a first step in treating CHF is to treat the underlying causes. Since symptoms are not closely related to the severity of the cardiac dysfunction, it is important to titrate (adjust to) the patients so that the individual patient receives the correct dosage.

When it comes to pharmacological treatments there are several drugs commonly used to treat CHF. Among them are diuretics, angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers, beta-blockers, aldosterone antagonists and cardiac glycosides. It is important to monitor the patient signs and symptoms when administrating new drugs or changing doses, since the response to the treatment is individual, and also depends on combination of the drugs. To customize the optimal treatment for the individual patient is a sophisticated balancing act.

Common clinical tests of CHF include electrocardiography (ECG), chest x-ray, echocardiography (heart ultrasound), and laboratory tests. Among the laboratory tests are B-type natriuretic peptide (BNP), creatine, blood count, electrolytes (natrium, potassium) and glucose.

Furthermore, self-care management is highly recommended. Daily monitoring of weight at home can discover quick weight changes due to water retention. If a weight increase of more than 2 kg in 3 days is registered, the patient needs to contact the hospital and/or increase the diuretic dosage. An unintentional decrease in weight can mean a reduction in total body fat and lean body mass due to insufficient nutrition. Moreover, it is important to educate the patients in

how to handle their condition and recognize signs of deteriorating health. Diet and exercise are important to consider, as is reduction in alcohol intake and smoking.

One reason behind worsening symptoms in CHF is low treatment compliance [86, 89, 90]. Patients with CHF tend to not follow the treatment they are prescribed, pharmacological and/or non-pharmacological. Regardless of reason behind deteriorating health, monitoring of signs and symptoms is crucial in order to correct treatment plan, or encourage compliance with the treatment. Using eHealth-solutions is one possible method of managing CHF on a regular basis, allowing for a fast detection of worsening conditions.

In some cases surgical measures can be motivated. This includes mitral valve surgery, and implantable devices such as pacemakers and defibrillators (ICD). As a last measure, heart transplantation could be considered. However, this should only be contemplated when the patient is at the end stage of CHF. Even though heart replacement surgery can increase quality of life greatly, there are major risks with the procedure, including organ rejection and infection. The lack of donor hearts is also a major issue.

Chapter 4

The Web-Based System

During the years, the prototype system used in the project Care@Distance has gone through several transformations. The first two systems were in need of software installation and special hardware which caused some issues for both the project and the patients, as described in Paper I [19]. In the latest prototype system a completely web-based system (WBS) was developed. By "web-based" we refer to a system that does not require installation of any special software at the users, the client computer only requires a web browser. The information in this chapter is also available in Paper II.

4.1 Previous Systems

In 2008 Care@Distance resulted in a Licentiate of Technology thesis [20] describing the prototype systems which thus far had been developed. These prototype systems, first version shown in figure 4.1, were both internet-based; however both specialized hardware (true touch screen tablet PC) and installed dedicated software were required.

Although these first versions of the prototype system were very user friendly and most likely easy to use for a large part of the CHF patients, it soon became apparent that this way of designing eHealth-solutions for out-of-hospital patient management was not optimal. The design caused several issues concerning mobility, flexibility, robustness, support, maintenance and cost if to be used at a larger scale than in a small test-project.

Considering these issues and the rising amount of computer and internet users the decision was to redesign the system and go for a completely web-based design, i.e. a system based on modern standard technology like web servers, databases and web browsers.

Figure 4.1: Previous version of the prototype system used in the project Care@Distance.

4.2 Benefits with Web-Based Systems

The benefits with using web-based solutions are several. As such solutions do not require dedicated equipment they become mobile and accessible. The web-based application can be accessed from most modern communication platforms, e.g. computers or smart-phones, which have access to internet. Moreover, they become easy to maintain and support since they do not require on-location support. Installation of software is reduced to the minimum as the only software needed is a web browser, e.g. Microsoft Internet Explorer, and this also ensures portability since the applications basically become platform independent. Web-based systems are also robust as they are not dependent on specific technical equipment. Costs are kept at a minimum as there is no need for special hardware, and support is easily handled remotely.

4.3 Choices and Limitations

4.3.1 Healthcare Aspects

When dealing with chronic diseases such as CHF, the patients self-reported symptoms are often as important as measured values such as blood pressure [93–95]. It was therefore decided early in the design process that both subjective and objective data should be used. This requires patient interaction with the system, something which also could lead to increased patient awareness. Compared to applications where the entire process is automated, here the patients need to be

aware of their condition in order to answer the questions. This in turn could lead to improved treatment compliance and increased self-care.

Which questions and measurements to be used is very disease dependent. For example, in heart failure care body weight and blood pressure is interesting to follow, while with diabetes patients blood glucose is instead more interesting. The same goes for the subjective questions. Therefore the WBS was designed so that it would be easy to add and change which information should be included. This can be done by the healthcare personnel and does not need special support by technical staff. For the studies reported in this thesis, however, a set of predetermined questions and measurements was compiled together with healthcare staff before the studies in order to simplify the start-up of the studies.

Regular reporting of health data is important. Certain parameters, such as weight, can change quickly, and it is important to catch these changes early. To simplify the procedure, daily measurements were recommended to the patients in order to create a habit. It is much easier to remember to do something every morning rather than e.g. 3 times per week.

As gradual changes are of outmost importance when studying the progress of a long term condition, it was decided to represent all data in graphs; objective as well as subjective. If data were to be represented in numeric form only, e.g. tables or filled in forms, it would be more difficult to see steady changes and trends in the values. Graphs simplify this, and the caregiver can quickly see if something is out of the ordinary, something which has been noted in related work [96].

Finally, one function which was stressed by the nurses to include was the possibility of free text comments and written contact. Patients' reports are in some instances very important in the care decision process. Therefore, a messaging function was included in the application, enabling the patient to send information not included in the set of questions and measurements. Moreover, this function allows for two-way communication between the healthcare provider and the patient as the provider can answer questions and send comments to the patient through the application.

4.3.2 Technical Choices

The choice was made to use Microsoft Server 2008 and Microsoft SQL Server database in this project. The server is a virtual server hosted in a server center with failover functionality etc. This increases security as a failure of one machine does not lead to a complete system shut down or loss of information. Also, management and support of the hardware is outsourced to the managers of the server center, in this case at Chalmers University of Technology.

PHP was the language of choice in programming the web application due to the ease of use for the programmer. It is also free to use, and there are several development platforms free of charge. No scripts or add-ons were included in order to further increase mobility and portability. The prototype application was tested in the most common web browsers, e.g. Microsoft Internet Explorer, Google Chrome and Safari.

Although security and integrity aspects were not stressed in these early stages of the project, certain security measures were still implemented. A secure login

using Message-Digest algorithm 5 (MD5) was used. Moreover no personal information, such as name or personal number (social security number) was stored in the database. Instead, all patients received a unique code which could only be decoded using a paper key securely stored at the hospital.

4.4 System Design Process

System design is an iterative process which involves several stages, and several trips back to the drawing board [21, 22]. Figure 4.2 shows a flowchart of the design process used in this project to develop the WBS.

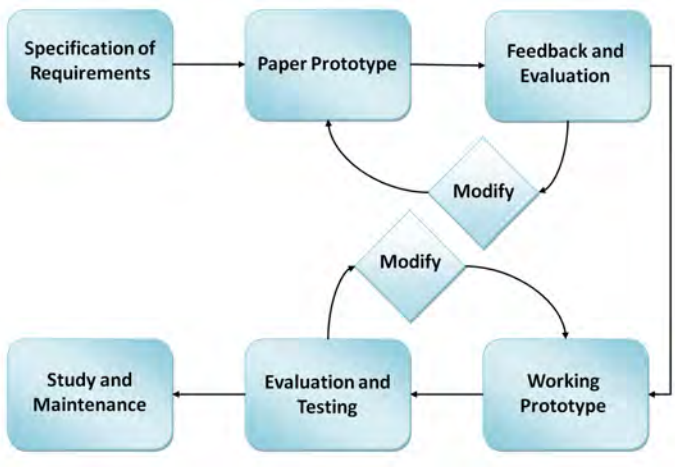

Figure 4.2: The design process of the WBS. User participation is of outmost importance in the design of new systems. Inspired by [22].

In this project healthcare personnel have been involved during the entire process. One specialized nurse, one physician and one professor in neonatal care/pediatrics, and one specialized nurse in heart failure care were involved. Moreover, comments and results from previous work [19], both from healthcare personnel and patients, have also been taken into consideration.

When introducing new tools in a work environment, familiarity of the system and user interface is very helpful. If the users recognize the ways of performing tasks, the learning process will be facilitated. Therefore, care was taken to mimic other user interfaces commonly seen in web-based systems today.

Experiences from the previous applications and the healthcare personnel involved played important roles in the design. Paper prototyping [23] was a technique used when developing and designing the new system user interfaces and functionalities. By having something to look at and discuss around, it is easier for the user to picture what the final design will look like compared to only writing specifications down. The paper prototypes in this project, of which samples are shown in figure 4.3, were created in Adobe LifeCycle Designer, resulting in a partly functioning PDF (Portable Document Format) mock-up. The technique

used when developing the paper prototype was HTA (Hierarchal Task Analysis) in which tasks are decomposed into subtasks and analyzed in order to improve functionality [22].

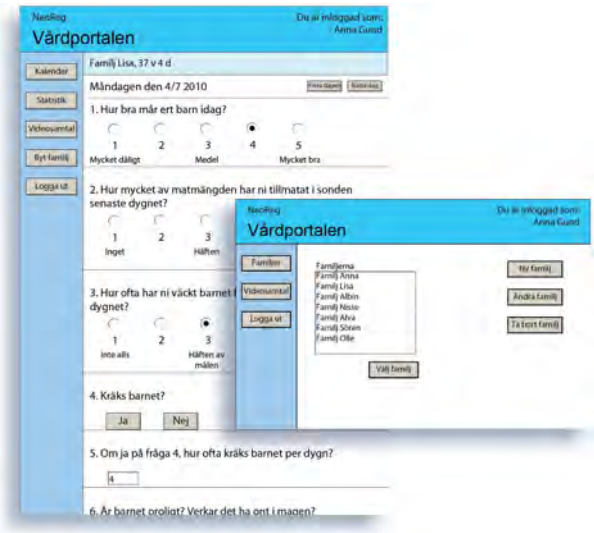

Figure 4.3: Paper prototype used in the design process of the WBS.

Testing of the applications NeoReg and HeartReg, as mentioned in chapter 1, was performed by non-users. One family and nurses in neonatal home care used the NeoReg application before the start of the study in order to test it in a real setting. This last test resulted in some changes which improved the final application greatly.

4.5 System Architecture

The final WBS architecture can be seen in the schematic figure 4.4. The architecture is very generic, and can be used to describe basically any web-based solutions, both in- and out of healthcare.

As can be seen in figure 4.4 the patients, and possibly also the relatives of the patient, enter information either gathered from medical equipment or in forms of subjective questions. The data is then sent through internet to the database located adjacent to the web server. Once stored in the database healthcare personnel as well as patients and relatives can access the information. Restrictions on which data is accessible by different users is implemented using roles, e.g "administrator", "staff", "patient", "relative". The system also allows for the healthcare personnel to send feedback and other information to the patient and relatives, which makes the communication two-way.

Examples of screenshots from the HeartReg application can be seen in figure 4.5, and more images are found in appendix E.

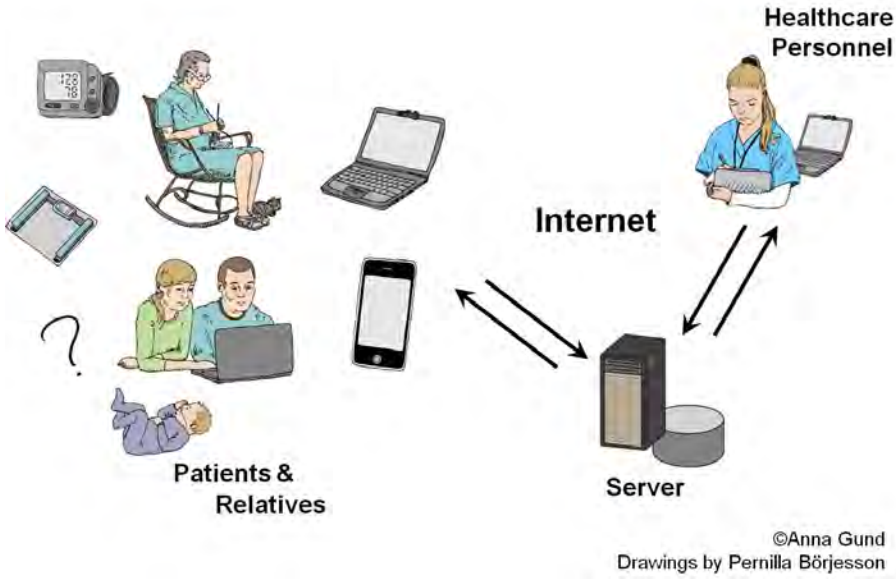

Figure 4.4: The design process of the third prototype system.

Figure 4.5: Screenshots from the CHF specific version of the third prototype application.

4.6 Conclusion

Our goals in Paper II were to describe the development process and final set-up of a generic WBS. Both previous experience from Paper I, and new interaction

with healthcare providers as future users were considered in the iterative design process. HTA and paper prototyping were the techniques of choice during design phase. Once a working prototype had been created, one family in neonatal home healthcare along with the participating nurse tested the system in a real clinical setting in order to validate the technical implementation. The result is a generic WBS platform suitable for future studies in various clinical environments.

Chapter 5

Off-the-Shelf Video Communication in Out-of-Hospital Care

5.1 Why Video Communication in Healthcare?

Communication between healthcare providers and patients in out-of-hospital care is usually done by phone or through home visits. However, new technology enables for another type of communication: web-based video calls or web conferencing. In this type of communication a web camera connected to a computer, or a specialized all-in-one product, is used for both video and speech communication between two or more users.

For healthcare purposes, the possibility for patients and healthcare personnel to see each other have several advantages before traditional phone calls. Facial expressions and body language can lead to an improved communication and stronger feeling of closeness. In e.g. rehabilitation the healthcare personnel can show movements to the patients thereby making the instructions easier to understand [97]. In the same way, the patients can show e.g. rashes or wounds to healthcare personnel.

Compared to a care model with traditional home visits, video communication can be a complement and reduce the number of necessary visits, or include patients in home care models who otherwise would not be able to have this service due to e.g. long distances. This in turn opens up possibilities to reallocate resources and allow healthcare staff to handle more patients instead of spending their time on traveling. As another consequence costs can be reduced and positive effects on the environment achieved.

In Sweden, the availability of broadband internet access is high [53]. This gives an opportunity to introduce these type of services to a large part of the population. Moreover, numbers from Statistics Sweden (SCB) show that many people in Sweden, especially the younger ones, already utilize web conferencing

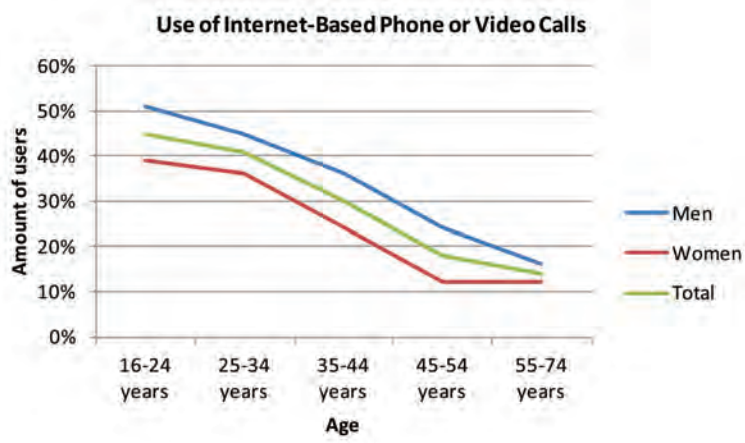

Figure 5.1: The usage of internet-based phone calls or video conferencing in Sweden, depending on age [98].

as can be seen in figure 5.1 [98].

One example of healthcare applications with video conferencing is the ACTION project which uses video communication as support to dependents caring for dementia patients [99]. Both communication between the dependent and the hospital, as well as communication between different dependents is used. Another example is the Ippi-project, mentioned in chapter 2, which uses the TV of patients for communication with the healthcare and relatives [77]. At Luleå University of Technology a dedicated system for communication between the neonatal department at the hospital and parents of newborn children at home is used [69]. In comparison to the video communication implementation evaluated as part of this thesis, a dedicated all-in-one product is utilized.

5.2 Our Choices and Set-up

In the scope of Care@Distance, video communication is used to improve communication between parents of premature infants and nurses in home healthcare. By using off the shelf products cost could be kept down. This allows for more families to be included and would make a future wider introduction into healthcare practice easier. The chosen communication software was Skype, due to its simplicity to use and being free of cost. In UK, a Skype based service have been launched by the company Patients Know Best [100]. Through this service Clinicians hold consultations with patients from their own homes using a Skype based application which also include an online patient record accessible by both parties [101].

A high-definition (HD) web-camera (Logitech QuickCam Pro9000 for Microsoft Windows users and Logitech QuickCam Vision Pro for Macintosh users) and speakers (Ace G35) were provided to the families for use with their own computer in our study. At the hospital side, the personnel were equipped with a

Figure 5.2: The Skype set-up at the hospital.

laptop computer (Asus K72DR-TY030V) with HD web-camera (Logitech QuickCam Pro9000) and speakers (Logitech X-140) or headset (Logitech Headset Premium). Figure 5.2 shows one of the nurses involved in the project starting up a video call to a family.

Chapter 6 discusses the trial and results of the video communication facility, as do paper III.

5.2.1 About Skype

Skype is a free off-the-shelf program for video communication over the internet. The user can call other Skype users with voice or video calls through a contact list. Hardware requirements are a computer, PC (Personal Computer) with Windows or Macintosh computer, and internet access [102]. For video calls, a web-camera, a microphone and speakers, or a headset are also necessary. Table 5.1 shows the achievable video quality using Skype, table 5.2 shows the hardware requirements, and table 5.3 shows the requirements on internet speed [103]. The tables show that already at modest internet speed, video calls with reasonable good quality can be achieved.

Video quality	Image resolution (pixels)	Frames per second
Standard	320x240	15
HQ	640x480	30
HD	1280x720	30

Table 5.1: Achievable image quality for video calls using Skype [102].

Hardware	Required	Recommended
CPU	1 GHz	>1.8 GHz
Graphics card	32 MB	>64 MB
Memory	256 MB	>512 MB

Table 5.2: Required and recommended hardware for using Skype [102].

Call type	Required speed (down/up)	Recommended speed (down/up)
Voice call	30kbps/30kbps	100kbps/100kbps
Video call	128kbps/128kbps	300kbps/300kbps
HQ video call	400kbps/400kbps	500kbps/500kbps
HD video call	1.2Mbps/1.2Mbps	1.5Mbps/1.5Mbps

Table 5.3: Required and recommended internet speeds for using Skype [103].

5.2.2 Other Video Conferencing Services

Other commercially available systems for video conferencing are for instance Cisco (previously Tandberg) [104] and Polycom [105]. Both can provide different solutions; all-in-one solutions where the camera is built into the screen, as well as software similar to Skype for use on any computer with a web-camera. Adobe Connect is another video conferencing application used for online web meetings. Moreover, both the instant messaging software Microsoft Messenger (MSN) [106] and Google Talk (gTalk) [107] have built in possibilities for video communication.

Chapter 6

Evaluations and Trials

This chapter will summarize the results from the studies and evaluations described in Paper III-V. These papers cover three different studies of which two of them involve the internet based prototype system (WBS) described in chapter 4 and one is a questionnaire survey. The healthcare background to these studies can be found in chapter 3.

6.1 Neonatal Out-of-Hospital Care

In neonatal home healthcare, as described in section 3.1, the child is cared for in the home instead of at the hospital. The family is visited by a neonatal nurse 2-3 times per week, and in between visits contact is possible by phone. In order to improve the feelings of safety for the family, and provide the personnel with more information about the family situation in between visits, a study was started in 2010. The study involves two different methods for communication between the home and the hospital. One method is using the WBS configured and customized for the neonatal application NeoReg. The other is using the computer software Skype, as described in chapter 4, for video communication.

6.1.1 Objectives

In this study the objectives were to evaluate:

- Whether the WBS is customizable and configurable for use in neonatal home healthcare.
- User acceptance of NeoReg and Skype.
- How NeoReg and Skype are utilized and introduced in the home healthcare and how the functionalities are applied.
- If Skype is a potential appropriate complement to NeoReg in neonatal home healthcare.

Group	# Families	# Responses
Group 1	13	12
Group 2	12	12
Group 3	9	8
Total	34	32
Not included	17	-

Table 6.1: Number of families included in the three groups 6 months into the study.

6.1.2 Method and Material for the Neonatal Study

Families of prematurely born children admitted to neonatal care in the home at Mölndal Hospital at Sahlgrenska University Hospital in Gothenburg, Sweden, were included in the study. The inclusion criteria were that they had access to computers with internet at home, and ability to understand Swedish instructions. After being informed about the study the families were enquired about participation in the study. If accepting and signing a patient consent, they were randomized into one of three groups.

All three groups received the same care as the families that did not take part of the study, but families in group 2 were asked to use the NeoReg application and families in group 3 were assigned Skype. Table 6.1 shows the number of families that were included in the study 6 months into the trial. It is these families that are included in the results of this thesis, as well as in Paper III.

When discharged from the care at home, after approximately three weeks, they were asked to fill in a questionnaire with questions on their opinions on the care given. The questionnaires, originally written in Swedish, can be seen in a translated version in appendix B. Since this thesis concentrates on the user acceptance, experiences and technical aspects, this will also be reflected in the result analysis. Therefore, healthcare aspects will not be the focus.

On the healthcare side, 6 nurses were part of the study. These were the nurses assigned to the home healthcare service at Mölndal Hospital. One of these nurses is also a co-author of the work, and her opinions were therefore not included in the study. Moreover, one nurse did not answer the questionnaire. Her opinions are therefore also not included in the results.

Group 1 - Control

The control group received the same care as families not participating in the study. Nothing was added or removed from the standard care. The difference was that when discharged they were asked to fill in a questionnaire about their view on the care in the home. Results from this group will later on be compared to group 2 and 3 in order to see if the internet prototype system or video communication through Skype can improve the quality of care. However, in this thesis these results will not be analyzed.

Group 2 - Internet Based Prototype System

Group 2 were given the same care as group 1, with the addition of use of the NeoReg application. The families in this group were given written instructions on how to use NeoReg, and were asked to use their home computer for this.

The parents were instructed to each day report their child's health status and other information through NeoReg, and were also encouraged to write free text messages to the neonatal nurse. After home visits, the nurse entered the results from the weight and head circumference measurements into NeoReg. Through NeoReg both nurse and parents could observe the infants's progress. Among the other functions in the system were to view message dialog between themselves and the nurse, and see information about premature children (provided by the hospital). At the end of the care at home the parents were asked to fill out a questionnaire. It is the analysis of the answers from this questionnaire that is the results from this group. Since the number of families in the group is so small, no statistical analysis is performed.

Group 3 - Video Communication through Skype

As with group 2, group 3 received the same care as group 1 but complemented with Skype for video communication with the hospital. The video communication replaced the ordinary phone calls. The families were given a bag containing a high definition web camera (Logitech QuickCam Pro9000 for PC users and Logitech QuickCam Vision Pro for Mac users), speakers (Ace G35), a CD with the Skype software (version 5.3), and written instructions on how to use Skype for communication with the hospital. This group was also asked to fill out a questionnaire when discharged from the care at home.

6.1.3 Results from Neonatal Study

In this study, the WBS was successfully configured and customized to the application NeoReg for use in neonatal home healthcare. Patient (family) opinions on NeoReg were positive, and they found it easy to use. Furthermore, several improvements were suggested by the families. The possibility to view the child's data was appreciated by most. Half of the families felt that NeoReg helped them feel more secure in the care of their child, and a third thought that the number of visits could be reduced as a result of using NeoReg.

However, as many as a quarter of the families claim to have received no feedback from the nurses on the information entered into NeoReg. Moreover, in one case the nurse did not enter information about the child's progress as intended. This resulted in negative feelings towards NeoReg.

Skype was very much appreciated by the families, and was considered easy to use. Most families found video communication to be better than ordinary phone contact. All families thought the use of Skype had made them feel more secure when caring for their child at home, and half of the families thought the stress could be reduced before home visits by using video communication. As many as 5 out the 8 families who responded to the questionnaire felt that the number of home visits could be reduced when using video communication, and one family even claimed the home visits could be replaced by Skype calls.

The number of patients recruited by each of the four nurses who answered the questionnaire differed much. Moreover, as two of the nurses participating in the home healthcare did not answer the questionnaire (one due to bias), the results from the nurses are based on rather few patients compared to the number of patients in the study.

All four nurses used NeoReg during the study. Basically, all nurses were positive to both the study and the application. Although the number of functions in NeoReg was considered appropriate, only a small part of the total amount of functions was actually utilized. Only one of the nurses used Skype during the study, indicating that most of the families in group 3 were actually assigned to one of the nurses who did not participate in the evaluation. This nurse was neutral to most parts of the video communication, something which did not reflect the very positive responses from the families.

6.2 Out-of-Hospital Management of Chronic Heart Failure Patients

Chronic heart failure (CHF) is, as described in chapter 3, a common chronic disorder which needs regular monitoring. By using the WBS application HeartReg the patients can transmit self-reported health related data to the hospital staff. This data can then be used to help make depictions on the patient's care plan among other things. In March 2011 a study was started in collaboration with Östra Hospital to investigate if usage of HeartReg would improve the care of CHF patients. The study is two-parted with the first part being a pilot, followed by a second larger trial. It is the first three months of the pilot study which are presented in this thesis and in paper IV.

6.2.1 Objectives

In this study the objectives were to evaluate:

- Whether the WBS is customizable and configurable for use in CHF care.
- User acceptance of HeartReg.
- How HeartReg is utilized and introduced in CHF care.
- If manual entry of objective data is a potential source of errors.

6.2.2 Method and Material for the CHF Study

The intervention group in this study consisted of patients at Östra Hospital diagnosed with CHF. Inclusion criteria were that they had access to computer with internet in their home and understood Swedish instructions. All patients signed a written consent after receiving both written and spoken information about the study. After this they were instructed on how to use the system. They could at any time chose to leave the study. A research nurse handled all contacts with the patients, except for the instructions on the systems which were

handled by the author of this thesis. Follow-up visits were planned at 1, 3 and 6 months, after which the trial was ended for that patient. Results were compiled after the 3 month follow-up.

In total, 14 patients were asked to participate in the study. One declined, and one chose to resign from the study after one month. Out of the 14 patients, 13 were male and 1 was female. The patient who resigned was female, meaning that all of the patients who completed the study were male. During the study one patient passed away. Each included patient were handed a wrist non-invasive blood pressure monitor (NIBP), Omron R7, with memory and USB connection allowing for data extraction up to 90 measurements.

The patients were instructed to bring the monitor for each revisit to the research nurse who extracted the data from the NIBP monitor into a computer file. If the patients did not already have a digital personal weight scale at home they were also given one of these. The accuracy of the scale was not considered a priority for this particular study. Rather it was the trend of gaining or losing weight which was important.

Besides extracting data from the NIBP at the revisits, the patients were asked to fill out a questionnaire consisting of several different parts. The parts of the questionnaire covered in this work contained questions on the functionalities, experiences and acceptance of HeartReg. This part of the questionnaire can be seen in a translated version in appendix C. For future studies there were also parts in the questionnaire covering e.g. health changes, economy and self-care. Besides analyzing the questionnaires, data from both the memory of the blood pressure monitor as well as the system database was used in the results.

6.2.3 Results from the CHF Study

The WBS was successfully configured and customized into the application called HeartReg. HeartReg was highly accepted by the patients in the study, and compliance with the system (i.e. how often it was used) was high. However, utilization of HeartReg differed between individual patients. For example, one patient did not send any messages to the nurse, while others used this function much more frequently. Satisfaction with HeartReg was high at both 1- and 3-month follow-ups, however less so at the 3-month follow-up.

As for manual entry of objective data received from the weight scale and NIBP, our results, based on the NIBP measurements, show that this is not a major source for concern. Although all patients had at some instance entered incorrect values, the number of errors compared to the total number of measurements was few. Moreover, these errors were quite small, and did not show an indication to deceive the healthcare provider.

6.3 Survey: ICT as a Tool in Healthcare

Introduction and implementation of new healthcare ICT is, as mentioned in the introduction, often a problem. One of the reasons for this could be resistance from healthcare personnel. Therefore it was of interest to study their attitudes on ICT as a tool in healthcare. Furthermore it would be of interest to also get

opinions on home follow-up and monitoring as well as to investigate whether the parameters we had chosen to follow-up through the WBS application HeartReg in the CHF study were considered relevant also outside the clinic at Östra Hospital. Therefore a questionnaire was sent out to all medical clinics at Swedish hospitals working with heart patients. This section covers the results from this questionnaire, which can also be found in paper V.

6.3.1 Objectives

In this study the objectives were to, in a selected group of healthcare providers investigate:

- General attitudes towards healthcare ICT today and in the future.
- Confidence in healthcare ICT.
- Attitudes towards home follow-up and distance monitoring.
- Whether CHF patients are appropriate for home follow-up and distance monitoring.
- Which methods of follow-up are most appropriate.
- If there is any difference in opinions between selected sub-groups.
- Which parameters are best suited for CHF follow-up at home (not included in Paper V).

6.3.2 Method and Material for the Survey

In the best of worlds the questionnaire, which can be found in a translated version in appendix D, would have been sent out to every person working with CHF patients in Sweden. Unfortunately, no such register exists today, and we were therefore obliged to find other methods of dispatching the questionnaire. Eventually it was decided to send 5 questionnaires to the head of department at each medicine, cardiology or heart clinic at Swedish hospitals. The heads of departments were asked to distribute the questionnaires to their staff. Each questionnaire included a self-addressed envelope, and the responders could also chose to answer through an electronic, internet-based form.

In total 425 questionnaires were dispatched, and 139 were collected. The number of collected questionnaires varied between different counties and regions in Sweden, however, geographical spread was large. 73 % of the responders were female, which is not surprising considering that more than 80 % of Swedish healthcare professionals are female [108]. 66 % were nurses and 30 % were physicians (4 % other).

No statistical analysis was done on the material for two reasons. First, the aim of this study was not to perform a hypothesis test, but rather to investigate the area and general attitudes. Moreover, due to the uncertainties in the methods of dispatch, it would be difficult to draw any conclusions on the opinions from the entire population from our results.

6.3.3 Results from the Survey

The opinions on healthcare ICT among healthcare professionals working in cardiology were surprisingly positive. Attitudes toward healthcare ICT today as well as in the future were high, and so was the confidence in these tools. As for home follow-up and distance monitoring, a majority were positive. Some were neutral to these methods, and a very small part was negative. The results indicate that the opinions of these methods are that they can increase patient commitment and allow for a better care. Moreover, CHF patients were considered appropriate for home follow-up and distance monitoring, and the most popular methods among the healthcare providers were home visits by nurse and phone contact. Some small differences could be noted between nurses and physicians, as physicians tended to be more critical. Also, nurses showed a greater belief in phone contact with patients than did physicians.

Opinions on Choice of Parameters to Monitor

One part of the survey was not included in Paper V. It is instead described in this section. This part regarded the healthcare providers' opinions on which parameters are preferred to register in hospital care, and which parameters would be suitable for home monitoring and follow-up.

At the clinic all suggested parameters, i.e. weight, blood pressure, pulse, oxygen saturation (SpO2), brain natriuretic peptide (BNP, also B-type natriuretic peptide) and hemoglobin (Hb), were suggested by a large majority of the healthcare providers, both physicians and nurses. Although extremely small, differences could be seen among groups as nurses valued weight and BNP more than physicians. Physicians on the other hand have a slightly larger interest in blood pressure, pulse, SpO2 and Hb than nurses. Other parameters healthcare providers measure at the clinic, not mentioned as alternatives in the questionnaire, are electrocardiography (ECG), electrolytes (e.g. potassium and creatine), waist measurement, auscultation "cor et pulm" (listening to heart and lungs), body temperature, blood glucose, echocardiography (ultrasound of heart), ejection fraction (amount of blood pumped out of the heart at each heartbeat) and spirometry (test of lung function).

When it comes to symptoms, dyspnea, tiredness and swollenness are most asked about at the clinic. Nurses show a larger interest in dizziness and diarrhea and cough than physicians do, while physicians are slightly more interested in dyspnea than nurses are. As for lifestyle choices, compliance to medication and physical activity are considered more important than diet. Here there is also a quite large difference between physicians and nurses as only half the physicians and almost all the nurses ask about diet at the clinic. Other symptoms and life styles choices mentioned, not included as alternatives in the questionnaire, were pain, sleeping patterns, urination, smoking, alcohol and drugs, quality of life, allergies, psychological wellbeing, appetite, and how informed the patient is.

According to a majority of the healthcare providers, dyspnea is the parameter which best mirrors the health status of the CHF patient, followed by tiredness and physical activity. The objective physiological measurements are not considered to be of as great importance. This goes for both physicians and nurses,

however there are some differences between the groups which can be seen in figure 6.1.

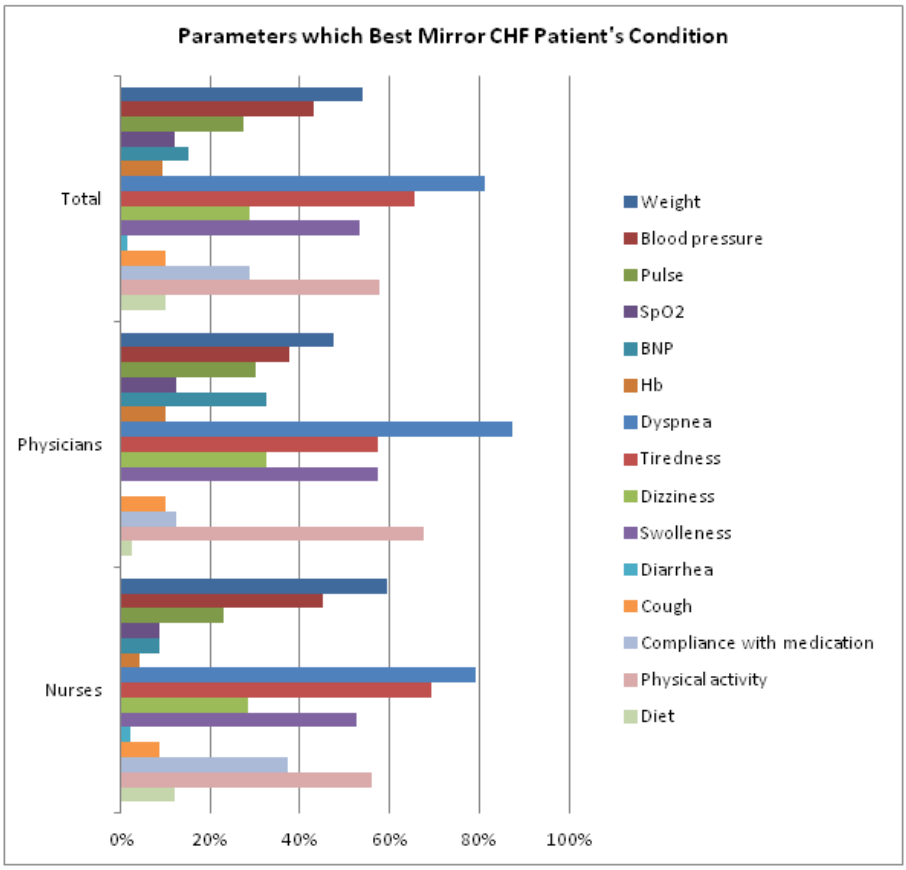

Figure 6.1: Comparing physicians' and nurses' opinions on which parameters that best mirrors the CHF patient's condition, along with total opinions.

Although the responders believe that dyspnea best mirrors severity of CHF, the parameter they think is best suited to follow-up in the home is weight, as shown in figure 6.2. Dyspnea comes in second place, followed by blood pressure, swollenness and pulse. There is a small difference between physicians and nurses as the physicians tend to think that objective physical measurements are more suited for follow-up and nurses believe more in subjective symptoms and lifestyle choices.

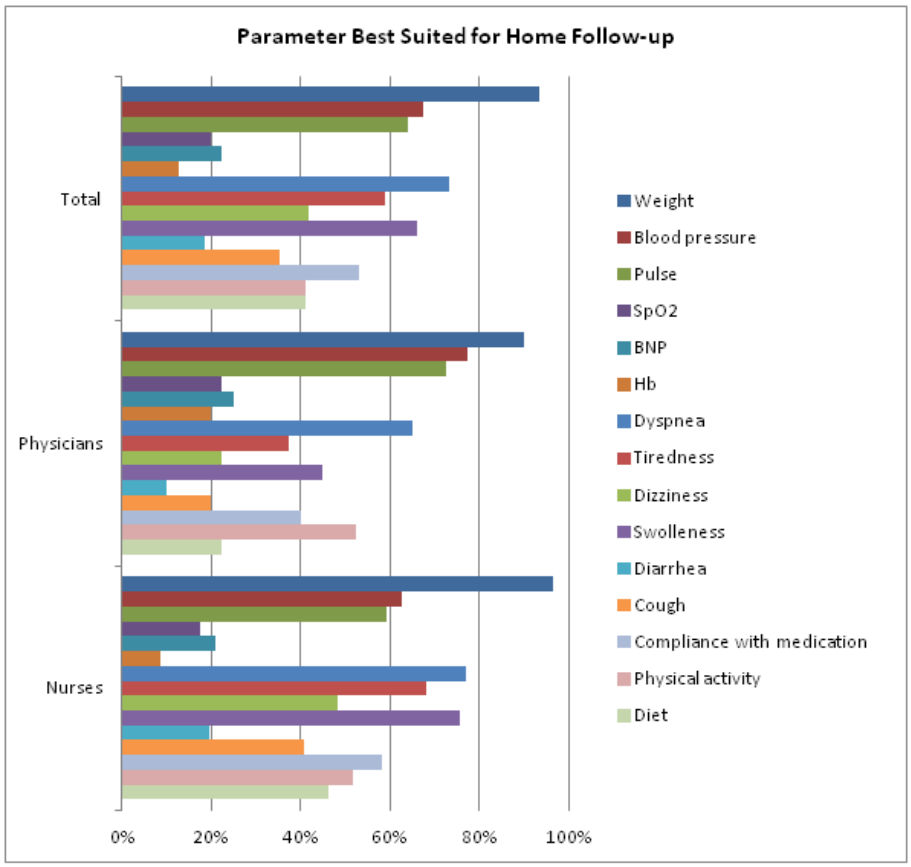

Figure 6.2: Comparing physicians' and nurses' opinions on which parameters are best suited for home follow-up, along with total opinions.

Chapter 7

Discussion

In the thesis work the design, clinical introduction, evaluation and user acceptance of a generic web-based eHealth prototype system (WBS) for follow-up of patients in out-of-hospital care has been studied. Moreover, an off-the-shelf video communication system, Skype, was used to investigate whether communication between caregivers and patients could be improved by utilizing video communication. Finally a survey on attitudes among healthcare providers towards ICT in healthcare and home follow-up/monitoring was carried out.

7.1 Thesis Work Objectives

As part of this thesis work we have designed and created a generic WBS for follow-up of patients in out-of-hospital care. An iterative process that started with a system based on dedicated hardware in Paper I, followed by incorporation of opinions from users along with tools such as paper prototyping [23] and HTA [22], described in Paper II, turned out to be a successful method.

Through evaluations and tests in two very different user groups, prematurely born infants in home healthcare and patients with CHF, we have verified that the system can be configured and customized to suit different user groups and needs. This means that we now have a well-functioning platform, based on off-the-shelf products, on which we can base future studies and applications. Moreover, the WBS meets the requirements on mobility, portability, support and maintenance, robustness and cost as put forward in chapter 4. These requirements are, in our opinion, necessary to fulfill in order to allow for a wider penetration of out-of-hospital applications in general. To build the applications on dedicated hardware and software, such as Docobo and others [74, 75], is likely to increase costs, lock in users to one vendor, and limit a wider adaption.

The results from the survey on healthcare provider opinions on healthcare ICT and home follow-up/monitoring show that the choices made together with healthcare personnel to include subjective information as an indication of health status is appropriate. The majority of the responders believe that dyspnea and tiredness are the two parameters which best mirror the patient's condition, and

these are also questions which we have included in HeartReg. Other studies have shown the importance of subjective information such as symptoms in CHF care [93–95].

Weight and blood pressure are the two most important objective measurements to evaluate in CHF patients, followed by pulse, and these three are also included. Looking at other CHF home care applications weight is also almost always included in these [8, 14, 109–115]. Moreover, the European Society of Cardiology (ESC) recommends daily weight measurements by the patients at home [86]. However, if the opinions of a specific healthcare provider should differ, or if a specific individual patient should be in need of a different care plan, these parameters can easily be modified trough the WBS without having to reconfigure the system. This also opens up the possibility to include other parameters such as lifestyle choices.

The studies and evaluations performed in clinical settings with two different patient groups, presented in Paper III and IV, have given us much insight. Most of the results gained on usage, user interface, functionalities etc. have been through patient opinions and to a smaller degree comments from nurses involved in the studies. During the studies both positive and negative results have been noted, the most positive being the acceptance by patients which we consider to be high. Although the WBS is used in very different ways, not only by the different patient groups but also between individuals within the groups, in general patients respond positively to using it. This is also in agreement with other studies [110, 114, 116].

Very few of the functions in NeoReg were used by the healthcare staff. "Everyday tasks" such as looking at answers from the parents and sending messages were frequently used, but the more administrative functions such as adding or editing questions or adding new personnel were basically not used at all. The reason for this is partly that during the relatively short period of time for the evaluation study very few changes were needed in the questions since the patient group was fairly homogenous and there were no need of personalization. Moreover, at the start of the study a pre-determined question-bank was set up in collaboration with staff at the neonatal department. Therefore, the existing questions were already well thought through.

One interesting fact is that all patients in the CHF study were male. This was not intentional, but since many of the patients were recruited after participating in other studies (often pharmaceutical trials) we were bound to the socio-demographic characteristics of these patient groups. As it turns out, according to the research nurse, more men than women volunteer to participate in those studies [89]. Future studies with the HeartReg application are planned to take place in more "ordinary" healthcare settings (e.g. a CHF clinic) and is therefore likely to cover a more representative group of patients.

In both the CHF and the neonatal studies the participation of healthcare staff was shown to play an important role. This was most obvious in the use of NeoReg. Several families claimed to have little or no feedback on their use of the application, which greatly affected their view on the value of the application. If no one is "on the other side" examining the data entered, and no one replies to messages, then the application becomes useless, and may even impair the parents' feelings of security. We have concluded that great measures have to be

taken to make the healthcare staff involved in the use of the application and also be convinced that it is a way to provide better healthcare service to their patients. Furthermore, the large number of patients declining participation in the study could be caused by poorly motivated staff. Making sure that the staff is aware of their importance in the study, and the usefulness of the applications as such, is therefore a vital part of the ongoing and future work.

The value of video communication as a future addition to WBS was studied in the neonatal study by replacing ordinary phone contacts between the parents and hospital with Skype. We showed that it was possible to use off-the-shelf products for video communication in neonatal home healthcare, and that it was received very well by the parents. These results are supported by other studies in the area [69, 117].

As compared to ordinary phone calls, video communication was considered better by the parents. Although we have not tested the use of Skype together with NeoReg, we believe that the results indicate that combining NeoReg and video communication will improve the total service provided to the parents. Moreover, as NeoReg and Skype are separate solutions, a service suiting the individual family could be assembled by "picking and choosing" the parts that are most appropriate.

In this thesis work, we have shown that healthcare providers' motivation to use eHealth applications could influence the values of the applications, and one may therefore wonder if it is their reluctance to use healthcare ICT in general that is the issue. In Paper V we discussed a survey performed on healthcare providers working in cardiology where we asked them about their attitudes toward healthcare ICT and home follow-up/monitoring of patients. We expected to get results indicating that the opinions regarding, and confidence in, current healthcare ICT were poor, and that there was little hope for the future, as indicated in related work [118]. This belief was also underpinned by discussions in media on e.g. EHR applications.

Healthcare providers were very positive to both healthcare ICT and home follow-up/monitoring of patients. And CHF seems to be a suitable patient group for home follow-up, something which is supported by the large number of other studies and systems targeting this group [8, 14, 109–115]. No large differences between nurses and physicians could be seen, however there was a trend that physicians were less positive than nurses, which could be explained by e.g. difference in working methods. Darr et. al. supports our finding as their research show that nurses were more positive than physicians [119]. They also found differences between junior and senior physicians. However, their work is based on the opinions on EHR and not on ICT in general.

Not included in Paper V, but mentioned in chapter 6, are opinions on the choice of parameters to follow-up at home and at the clinic. Surprisingly, while subjective information such as dyspnea and tiredness are regarded to best mirror the patient's condition, it is weight measurements which are considered most appropriate for home follow-up. This might have to do with the difficulties in conceiving how follow-up on subjective information would be done and presented in an attractive way. Maybe also the word "monitoring" in home monitoring is misleading; it is too much related to measurements. Furthermore most existing or studied applications dealing with CHF uses weight as one of the main

parameters to follow [8, 14, 109–115].

7.2 Care@Distance

7.2.1 Care@Distance objectives

The work presented in this thesis also forms part of the wider Care@Distance project. Consequently it is of interest to discuss how the results presented in the thesis relate to the objectives and aims of this project.

One of the objectives of Care@Distance is to improve patient treatment compliance, also known as "adherence" in literature [89]. As an example the recommendations for patients with CHF are to track their weight daily in order to quickly capture any sudden changes. A gain of more than 2 kg in 3 days is an indication of fluid retention [86]. CHF patients have documented low treatment compliance [86, 89, 90], and therefore one might expect that these recommendations would not be followed. However, the results from the heart failure study in this thesis (Paper IV) show that patients enter information about blood pressure and weight daily to a large extent. Data retrieved from the blood pressure monitor even shows that the days where the patients did not enter information into HeartReg, they still measured their blood pressures. If this good compliance is due to the HeartReg application or the fact that the patients are part of a study is difficult to judge, but it has been found previously that if patient are regularly in contact with the healthcare provider, for instance via telemonitoring, the treatment compliance increase significantly [8, 120, 121].

According to results from the survey, presented in chapter 6 of the thesis and also discussed above, weight is considered to be one of, if not the, most important parameters to monitor in CHF. Unfortunately the body weight scales that were used did not store the measurements in a similar way as the NIBP monitor did, so there is no traces of weight measurements when data was not keyed into HeartReg. But if the same compliance could be achieved with scales as with NIBP it would be beneficial for the treatment; given that the data collected are used in the right way to follow trends over time by the care provider. Still, the observation indicates that an application such as HeartReg could improve treatment compliance by changing and maintaining good routines among the patients.

As mentioned before, several studies have shown the benefits of telemonitoring systems in CHF care. However, Chaudhry et. al. recently published a study which in contrast does not support telemonitoring [109]. It seems that using telemonitoring might not by itself have impact on care outcomes. However, in combination with e.g. patient education and increased two-way-communication between patient and healthcare provider it might be more effective. This is an issue for future investigation.

In the neonatal study many questions in NeoReg were designed not for direct use in the care of the baby, but rather to remind the parents of certain things. Examples of this are the questions on interaction with the child, and skin-to-skin contact. This could also be seen as a way of helping the parents to follow their baby's treatment plans. Within the neonatal project, treatment plans for home

care targeting the parents have not been much discussed yet. But by utilizing an application like NeoReg it would be simpler to introduce such plans and to do follow-ups, than it is today. Since treatment and care plans in general are "hot topics" today in healthcare, such plans may not be too far away in the future. In summary, the results from the thesis work support the overall Care@Distance objective of providing means for improving treatment compliance.

Another objective for Care@Distance is to improve the possibilities for an active dialog between patient and healthcare provider. This is something which has shown to have increasing importance for patients [13]. As a result of the end-user interaction before the evaluation phase of NeoReg, described in chapter 4 and paper II, a messaging service was introduced into the NeoReg application as well as in the generic WBS. Even without this service WBS promotes an active dialog between patient and healthcare provider. For instance the information gathered in between visits can be used as input to discussions on treatment, medications, disease progress etc. A simple way to have this discussion is to print out the long-term trends of both subjective and objective data and use these as dialog input at follow-up visits. It is also possible for the healthcare provider to introduce unique patient specific questions in the WBS, which also can support a more individual dialog.

In the neonatal project a video communication facility was evaluated. The result of the evaluation were positive; the possibility to see each other added extra value to the home care service [69]. This outcome may result in adding this function to the general Care@Distance WBS platform in the future.

Disease management is a term used to describe a way of managing patient treatment based on a long term plan for how the particular disease is best handled for the specific individual. An objective in Care@Distance is to support patient treatment according to this principle. Again the possibilities to study data over longer periods and individualize measurements, questions and report intervals is a good enabler for an active disease management process from the responsible healthcare provider.

Very closely related to the disease management objective is the objective to support healthcare personnel in making informed decisions on individualized care. Once again the data stored in the database is the key. By analyzing and studying the data, and also individualize the data to be gathered, the healthcare provider get access to information that enables a more informed decision making than without this information. The concept becomes more important if the patient suffers from multiple diseases, and the treatment therefore has to be more individualized and dynamic.

Every person is different, and therefore the care should be customized for the individual patient's needs. This is often referred to as individualized care [57, 58]. Promoting individualized care is another objective with the wider Care@Distance project. Multiple diseases, common in both patients with chronic diseases and prematurely born children, differences in sensitivity to certain drugs or combination of drugs, etc. are drivers for this. By using the same platform, WBS, for applications for both neonatal home care (NeoReg) and CHF patient care (HeartReg), we have shown that such a system can be highly adaptable and can be used to promote individualized care.

Seeing, hearing, and feeling the patient is of course irreplaceable when making

good treatment decisions. But what about the time in between visits? CHF patients can have several months between follow-up appointments at the clinic, and during that time the healthcare personnel receives no information about the patient. This could result in unnecessary hospitalizations if the patient's health declines between visits; something which could be prevented by more frequent monitoring [13]. Moreover, at the follow-up visit it will be difficult to assess the patient's health since the last visit since it can be very difficult for them to remember what has happened. Each visit becomes a "snap-shot" in time. Also, a slow and steady decline might not even be noticed by the patients themselves. A system for regular patient follow-up can catch these changes automatically and alert the healthcare provider about deteriorating health. At this stage this functionality is not yet implemented in WBS, but still a future objective for Care@Distance.

Person centered care [122] and "the informed patient" [123] are expressions used within modern healthcare and in some cases eHealth. Both expressions are among the objectives for Care@Distance, and the main principle behind both is that if the patient takes a more active role in treatment and knows more about the disease, the outcome will be better. The WBS and the NeoReg and HeartReg applications can support this. As an example NeoReg is not only capable of presenting the registered data to the parents, it can also present written information related to the relevant diseases or on how to handle the baby in certain situations. The same option is possible in HeartReg but nothing similar has yet been introduced for the CHF patients. In the project ACTION [99] as an example the patient and the relatives can obtain disease relevant information directly through their application. In NeoReg and HeartReg selected relatives can also have access to the data if the application is configured for this. This option may enhance the patient's active participation in his own care which has been found to be very positive [56].

An important objective within the Care@Distance project is to identify crucial factors limiting a wider penetration of out-of-hospital eHealth systems. Results and experiences from the thesis work have contributed to this. From the survey in Paper V we have learnt that attitudes towards ICT and home follow-up/monitoring among the healthcare providers participating are not a major obstacle. On the contrary, they are surprisingly positive. Consequently the problem, or the problems, is to be found elsewhere. Maybe the experiences from the clinical evaluations (Paper III and IV) give some hints. In these studies we noticed that it sometimes was difficult to have people changing their traditional way of working or carrying out tasks. Other studies discuss the importance of adaption in working processes when introducing new systems; a culture change [96,124]. As in the neonatal project this may result in less number of patients being recruited to the study or that no feedback was given to the parents via NeoReg as expected. This observation may be described as:

> "It's not progress we oppose; it's change."
>
> -Unknown

In the end, no eHealth application will gain ground without a successful business model. How to do this in the case of home monitoring/follow-up is

not obvious, as several issues arise regarding e.g. payment and support of the applications [13, 17, 18]. Also the simple question "who is the customer" lacks a clear answer, although some applications have been rolled out commercially in US, UK and Germany [73–75]. Reasons for this may be differences in healthcare financing and structure in comparison to for instance Sweden. Moreover, in UK a roll out have been promoted by funding from NHS [125,126]. Our design choice for WBS and the active choice to keep the applications fairly "simple", as well as using off-the-shelf products at low cost, increases the possibilities to reach out to larger volumes of customers once a suitable business model has been found. Apart from this not much information was revealed as part of the thesis work to support the business related Care@Distance objective

As with many eHealth or telemedicine/telecare applications there is always an environmental dimension. Since the applications promote remote and distributed working models there is a potential to reduce for instance traveling. Also the applications NeoReg and HeartReg fit in to this model. In the case of neonatal care at home, both NeoReg and especially the video communication application can be used to reduce the number of home visits. This was also suggested by the participants in the study. Today, some visits are done unnecessarily, and those resources could instead be placed on families with greater needs or to increase the number of patients in home healthcare. This has also been noticed in other projects like [69].

Also HeartReg have this potential built in, but to a less extent since the service provided in this case is not depending on traveling nurses. Still traveling may be reduced since some follow-up visits by patient to healthcare facilities may be canceled. What we can hope to also avoid are some of the ambulance journeys to the casualties departments just because deteriorating conditions are not captured until they become acute.

7.2.2 Care@Distance Aims

The Care@Distance project has also some high-level aims presented in chapter 1. One of these is to investigate and gain knowledge on how to design, introduce and implement eHealth-solutions in real clinical healthcare settings.

The thesis work has added some knowledge to this specific aim. We have learnt about eHealth system design and introduction into clinical settings for two applications, NeoReg and HeartReg. But we have not learnt about wide-scale implementation. Our clinical projects and studies still represent small projects and not routine care. In the end, however, the question still remains as for why eHealth services for out-of-hospital care tend to fail. Our results indicate that it is not the user, neither patients nor healthcare staffs, resistance to the new technology which is the main concern. Change in working routines might be an issue, something which is implied in the neonatal nurses' reluctance to accept new working methods. Change management is often referred to as a crucial point [96].

Moreover, the resistance to implementation of new systems might be found higher up in the decision chain. Maybe the people responsible of purchasing new systems do not see the advantages since many benefits are not directly or immediately translated into economic terms. It can also be that the benefits are

not necessarily seen where the investment take place, but somewhere else in the large healthcare domain.

In both the neonatal application NeoReg and the heart failure application HeartReg the patients and families were positive towards the application. Although these two user groups differ in both age and technical knowledge, the system was accepted and used. This tells us that a generic system such as WBS developed within this thesis work is applicable to a large variety of users. Moreover, the success of these studies shows that it is possible to customize the application to suit the different need that different illnesses have.

Skype as a mean for video communication between nurses and families in neonatal care also turned out well. The families were very positive towards video communication. This communication technique opens up the possibility to include families who previously could not participate, due to e.g. long distances to the hospital, just by adding low-cost off-the-shelf technology to a computer they already have. This can also reduce the number of home visits as some contact could be had through video calls instead.

Another lesson learned is that finding acceptance among patients does not seem to be a major issue as long as the application is customized to the requirements of the care. If the patient sees the value and need of the application, it will most likely be accepted. However, if the value is not obvious, as in the case where the families in the neonatal study did not receive any feedback from the nurse, willingness to use the application will quickly diminish and could even result in increased stress.

Acceptance among care personnel for ICT based applications in healthcare also seems to be rather high, as indicated by the survey study presented in this thesis. However, it might not be the actual ICT tool which is the issue, but the need to change working routines. The neonatal study shows that introducing a new application into already working routines might not be so easy. Even though no loud protests are heard, a more passive aggressive approach might take place, where the negative feelings of the nurses are transferred onto the patients. This could for example be done by not using the application as instructed, or informing the patients in a way which brings the study into bad light.

The second aim of Care@Distance is to show how to gain acceptance to out-of-hospital eHealth applications among all relevant stakeholders. The thesis work has contributed and will contribute to this aim in various ways. Conferences, papers and various presentations is part of this. Also the clinical projects and the impact they make on all becoming aware of them is important.

Most important however is probably to be able to expand the projects in the direction presented in chapter 1, i.e. into larger installations. This will help to gather the evidence needed, clinical and economical, necessary to gain acceptance among all relevant stakeholders long term.

7.3 Future Work

7.3.1 Security and integrity considerations

An important issue when working with medical solutions and applications is patient security and integrity [30]. As mentioned in chapter 2, this area is regulated by laws, rules and regulations. The question on how to handle patient data according to the Patient Data Act (PDA) [24] has not been the focus of this work. This is mainly due to the fact that the aim of the project is not to create a commercial medical product; the intention is to attain new knowledge, it is not product development.

However, when the Care@Distance project is stepped up to include larger groups of patients or enter routine care the security issue will have to be reviewed again. As with all systems connected to the internet, there is a great risk of security breaches. When combining web-based applications with patient specific medical data, the demands on security becomes even greater. In the WBS used in this project, no patient related information, such as name or personal number, is currently stored on the database. Instead, each patient is identified using an identification key, and a list connecting each patient to its identification key is securely kept aside. Also, the WBS is password protected using MD5 cryptography. Unfortunately, securing web portal using passwords reduces the usability of the system since the users have to remember their passwords.

There are several possibilities to increase the security in future prototype systems or commercial solutions. Virtual private networks (VPN) where a link, or "tunnel", is created between two points on a network is one possible way to increase security. Another possibility is using transport layer security (TLS, successor to the SSL, secure sockets layer), which is a protocol for creating encrypted links over the network. This is a very common security solution for internet applications today. Also, data security can be further increased by encrypting data stored on the server. Furthermore strong authentication through e.g. using electronic identification cards, such as SITHS [30], will be necessary.

7.3.2 Information Overflow

Creating a system for monitoring chronically ill patients might very well be a good way of improving quality of life for the patients, and reducing the costs on society. However, information overflow is something that has to be considered for all disease management systems. The WBS and the applications developed for this project may work for small groups of patients, but what happens when the number of patients increases? Even if examining the data of one or two patients is feasible, this will not be the case when the nurse has many patients to watch over.

Displaying data in graphs was a design choice to give a swift overview of the condition of the patient, but one can hardly expect nurses to look at the data of every patient on a regular basis like everyday. Therefore, a kind of automatic decision support system needs to be added. If the patients could be categorized into high or low risk on a daily basis for instance, depending on

individual criteria, it would be easier for the nurse to see which patient is in need of further attention. How this should be done is subject to further research, but a suggestion would be to use some type of classification or prediction, where individual data is weighted and compared to base-line data for the patient. Cooperation with specialists in treatment of CHF, and other chronic diseases, will be necessary to get accurate thresholds. As larger amounts of data from patients with different and multiple diseases is accumulated it can be foreseen that decision support system combining different features of the data into alerts or warnings, will be developed. Some related systems, such as the Bosch Health Buddy, have already implemented such decision support [74] and it would be of interest to study their algorithms for alert categorization.

7.3.3 Other Applications

Although we have focused on neonatal home healthcare and CHF care, the WBS is designed to be applicable to basically any patient group with a physiological or mental need of out-of-hospital follow-up. The WBS is easily configurable to contain other questions and measurements. Therefore, more studies are to be performed on other groups. Examples of such groups could be patients with hypertension (high blood pressure), diabetes, chronic obstructive pulmonary disease (COPD), cancer, depression and rehabilitation needs. We will also investigate other usages within neonatal care, such as communication between different neonatal care units.

Summary of Papers

Paper I

Engineering in Medicine and Biology Society, 30th Annual International Conference of the IEEE (EMBC), August 20-24, 2008, Vancouver, Canada. *Design Evaluation of a Home-Based Telecare System for Chronic Heart Failure Patients*, A. Gund, I. Ekman, K. Lindecrantz, B. A. Sjöqvist, E. L. Staaf and N. Thornesköld.

This paper describes the design of the first prototype system for follow up of heart failure patients in their home. The system is an installed software program on a Tablet PC with a true touch sensitive screen, making the system very user friendly considering the elderly user group. User aspects have been important during the development of the system, as well as close collaboration with the health care staff in heart failure care. The paper also includes a small scale questionnaire survey and a case study on two patients. Both the answers in the questionnaire as well as the interviews with the case study patients indicate that it is possible to use the prototype system for out of hospital care in this patient group.

Main contributions of the author

The main contributions of the author was to design the software in the system together with master thesis student L. Ivarsson, to handle purchases of hardware and install software on computers, to handle and manage the server and database, to design the survey and case study together with co-authors E. L. Staaf and N. Thornesköld, to perform the survey and interviews with the case study patients, to handle installation, support and maintenance, to perform analysis of the data, and lastly to be the primary author the paper. All work was done in close collaboration with supervisors B.A. Sjöqvist and K. Lindecrantz.

Paper II

***Design and Development of a Generic Internet Based eHealth System for Long Term out of Hospital Care*, A. Gund, K. Lindecrantz, B. A. Sjöqvist**

In this paper the design and set-up of a generic web-based prototype system (WBS) is described. The WBS can be applied to several patient groups. In this study the system is configured and customized to heart failure patients and to families with prematurely born children. The paper includes design choices and specifications, as well as a small pre-trial case study on one family.

Main contributions of the author
The main contributions of the author was to design the software in the system aided by personnel at Östra Hospital in Gothenburg. Construction of the system was done together with student M. Sjöqvist who also aided in design choices. Moreover, the author handled contacts with provider of server, and also managed the database and server. The pre-trial was planned together with staff at Sahlgrenska University Hospital, and the analysis was performed by the author. Lastly the author was the primary author of the paper. All work was done in close collaboration with supervisors B.A. Sjöqvist and K. Lindecrantz.

Paper III

***Using eHealth in the Care of Premature Infants at Home*, A. Gund, B. A. Sjöqvist, E. Pedersen, E. Hentz, K. Lindecrantz, K. Bry**

The third paper describes the results of a study at the home healthcare unit of the neonatal department at Sahlgrenska Universioty Hospital, Mölndal Hospital. In the study the WBS described in Paper II was customized and configured for this purpose, and named NeoReg. Families with prematurely born children in home healthcare were included, and randomized into three groups: control, NeoReg or Skype. The control group received traditional care in the home, the NeoReg group complemented the traditional care with NeoReg, and the third group complemented with using Skype for video calls with the nurse. Results in this paper were collected 6 months into the trial and includes 34 patients. The results indicate that both Skype and NeoReg can be used in neonatal home healthcare. Also, the results indicate that the families in the Skype group are very positive to the use of Skype. Moreover, results highlight the importance of having the health care staff included and participating in the communication.

Main contributions of the author
In this paper the author planned the study together with the co-authors, wrote parts of the questionnaire to the patients, designed the questionnaire to the nurses, and took part in the writing of the ethical approvement application. The author handled purchases and support of technical equipment. Analysis of data, both questionnaires and information collected from database, was primarily done by the author. Finally, the author was the primary author of the paper. All work was done in close collaboration with supervisors B.A. Sjöqvist and K.

Lindecrantz.

Paper IV

***Evaluation of a Web-Based eHealth System for Out-of-Hospital Care of Chronic Heart Failure Patients – Preliminary Results*, A. Gund, B. A. Sjöqvist, M. Schaufelberger, K. Lindecrantz, H. Patel**

This paper includes the preliminary results of a study with heart failure patients at Sahlgrenska Universioty Hospital, Östra Hospital. In the study the WBS from Paper II was customized and configured for this purpose, and named HeartReg. Moreover, data stored in the patients' non-invasive blood pressure monitors (NIBP) was compared with data entered into NeoReg. In the study involves 13 patients using the internet based system described in Paper II during 6 months of the trial, and this paper covers the first 3 months. Results show that compliance to HeartReg among the patients was high, however patients used the application differently in e.g. using the messaging function. Satisfaction with NeoReg was also high. Moreover, the results show that manual insertion of blood pressure data is not a major concern as coherence with stored data from the NIBP was high.

Main contributions of the author
In this paper the author took large part in the planning of the study. Also, the author compiled the parts of the patient questionnaire relating to the web based system. The author instructed all included patients about the web based system at inclusion meetings, handled technical support, and was responsible for purchases of technical equipment. Analysis of data was performed by the author. Lastly, the author was the main author of the paper. All work was done in close collaboration with supervisors B.A. Sjöqvist, K. Lindecrantz and H. Patel.

Paper V

***Caregiver Attitudes Towards ICT and Home Follow-up in Heart Failure Care*, A. Gund, M. Schaufelberger, K. Lindecrantz, H. Patel, B. A. Sjöqvist**

In this paper a survey of the attitudes towards the use of ICT in health care among health care staff working in cardiology is studied. Questions about general attitudes and of patient follow-up at home was asked in a questionnaire sent out to 84 cardiology or medicine clinics in Sweden. The results indicate a general positive attitude toward ICT in health care, as well as to home follow-up of patients. One can see slight differences in attitudes between nurses and physicians, where nurses tend to be more positive than men.

Main contributions of the author
The author was in this study responsible of locating the clinics, and sending out the questionnaire. Also, the author compiled the questionnaire together with the co-authors K. Lindecrantz, M. Schaufelberger and B. A. Sjöqvist. Analysis

of the data was done by the author, and finally the author was the main author of the paper. All work was done in close collaboration with supervisors B.A. Sjöqvist and K. Lindecrantz.

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Appendix A

First Prototype

This appendix contains non-translated versions of the forms and interview protocol used in Paper I.

A.1 Patient Survey Questionnaire

The questionnaire begins on the next page.

Care @ Distance

Tack för att Du medverkar i denna undersökning!
V.g. fyll i formuläret nedan enligt instruktioner. Beräknat tid att fylla i är 5 minuter.

Bakgrund

V.g. fyll i det alternativ som passar bäst in med Dig:

1. Kön ☐ Man ☐ Kvinna

2. Ålder ☐

3. Vilken tidigare datorvana har du?

☐ Ingen ☐ Liten ☐ Medel ☐ Stor ☐ Mycket stor

Användning av datorprogrammet

Fråga: Hur enkelt tyckte du det var att:

(1=mycket svårt, 2=lite svårt, 3=medel, 4=enkelt, 5=mycket enkelt)

	1	2	3	4	5
4. Skriva in blodtrycket?	◯	◯	◯	◯	◯
5. Skriva in vikten?	◯	◯	◯	◯	◯
6. Svara på frågorna om trötthet och andfåddhet?	◯	◯	◯	◯	◯
7. Förstå instruktionerna ?	◯	◯	◯	◯	◯
8. Se knapparna på bildskärmen?	◯	◯	◯	◯	◯
9. Förstå vad knapparna på bildskärmen gjorde?	◯	◯	◯	◯	◯
10. Trycka på knapparna på bildskärmen?	◯	◯	◯	◯	◯
11. Läsa texten på knapparna på bildskärmen?	◯	◯	◯	◯	◯

Var god vänd -->

Utseendet på datorprogrammet

Fråga: Vad tyckte du om:

12. Storleken på texten? ☐ Bra ☐ Dålig ☐ Vet ej

13. Storleken på knapparna på bildskärmen? ☐ Bra ☐ Dålig ☐ Vet ej

Fråga: Tyckte Du att:

(1=inte alls, 2=lite, 3=mellan, 4=väl, 5=mycket väl)

	1	2	3	4	5
14. Formen på knapparna på bildskärmen ökade förståelsen av deras funktion?	○	○	○	○	○
15. Färgen på knapparna på bildskärmen var behaglig att titta på?	○	○	○	○	○
16. Färgen på knapparna på bildskärmen var tydlig?	○	○	○	○	○
17. Färgen på bakgrunden var behaglig att titta på?	○	○	○	○	○
18. Färgen på bakgrunden var tydlig?	○	○	○	○	○
19. Kombinationen av knappfärg och bakgrundsfärg var behaglig att titta på?	○	○	○	○	○
20. Kombinationen av knappfärg och bakgrundsfärg gjorde knapparna tydliga?	○	○	○	○	○

Var god vänd -->

Mätutrustningen

Fråga: Hur lätt tyckte Du det var att:

(1=mycket svårt, 2=lite svårt, 3=medel, 4=enkelt, 5=mycket enkelt)

	1	2	3	4	5
21. Använda vågen?	◯	◯	◯	◯	◯
22. Läsa av värdena på vågen?	◯	◯	◯	◯	◯
23. Använda blodtrycksmätaren?	◯	◯	◯	◯	◯
24. Läsa av värdena på blodtrycksmätaren?	◯	◯	◯	◯	◯
25. Använda nummerknapparna (tangentbordet)?	◯	◯	◯	◯	◯

26. Skulle Du kunna tänka Dig att använda detta system dagligen. ☐ Ja ☐ Nej ☐ Vet ej

Övriga kommentarer

27. Är det något övrigt Du vill tillägga?

Återigen, tack för Din medverkan! Dina åsikter kommer vara till stor nytta vid utvecklingen av detta system!

MVH,

Anna, Eva Lina och Niklas

Care@Distance-projektet

Sida 3 av 3

A.2 Nurse Survey Interview Template

I Bara kort, vad var ditt allmänna intryck av hemsidan?

a. svårighetsgrad?

b. utseende?

II Vi skippar inloggningssidan, utan går direkt till Patient-sidan.

a. Fanns det något sätt du tyckte kändes intuitivt rätt för att välja patient?

b. Efter att jag visat andra metoder, var det någon du tyckte verkade lättare?

c. Vad tycker du om att få upp detaljer i ett "pop-up" fönster? Hade det varit bättre att se all information på patient-sidan?

d. Är det något du saknar, tycker är överflödigt, eller vill ändra på i denna sida?

III Vidare till "värde"-sidan. Denna är mest omarbetad av de tre sidorna.

a. Vi börjar med metoden att välja värden, vad tyckte du om den?

b. Var det bra att kunna välja flera värden, och tyckte du det var ett bra sätt att göra det på?

c. Var det bra värden som fanns representerade? Är $\triangle$vikt en bra idé? Något annat du vill se?

d. Om vi nu istället tittar på grafen, är det bra att få en stor graf som fyller nästan hela fönstret? Alternativet är att kanske ha fler funktioner.

e. Exempel på andra sätt att visa värderna är i tabellform. Hade du föredragit detta framför att se numeriska värden som "cursor" i grafen?

f. Vad tyckte du om att ha två axlar, en för stora värden (blodtryck och puls) och en för små värden (frågor, $\triangle$vikt)? Kan du tänka ut en bättre representation?

g. Är det något du saknar, tycker är onödigt, eller vill ändra på?

IV Bara en kort diskussion om schema-sidan, vilken jag inte arbetat så mycket med.

a. Vad tyckte du var svårt/lätt med funktionerna på denna sida?

b. Är det något du saknar, tycker är onödligt, eller vill ändra på?

V Slutligen, är det några andra saker du saknar, tycker är onödiga, eller vill ändra på? Någon sida du "saknar"?

VI Är detta något du skulle använda i ditt arbete?

A.3 Field Trial Interview Template

Inledning

Tack så mycket för att jag får komma hit och göra denna intervju. Om det är ok med dig så kommer jag att spela in samtalet för att sedan kunna använda dina svar i min forskning. Du kommer givetvis att vara anonym, dvs. ditt namn kommer inte att finnas med någonstans. Många av de frågor jag ställer har vi redan pratat om, men jag kommer att ställa dem ändå för att få med dina svar i protokollet.

Jag kommer att börja med några frågor om din bakgrund. Sedan ställer jag lite frågor om det tekniska, och till sist lite om designen. Du får när som helst välja att inte svara på en fråga.

Har du några frågor eller funderingar innan jag sätter på bandspelaren? (Paus för frågor och reflektioner från patienten) Då börjar vi! Jag slår på bandspelaren nu.

Bakgrund

Först tänkte jag ställa lite frågor om dig och din hälsa.

I Hur gammal är du?

II Vilken är din högsta utbildning? (Realen, studenten, universitet)

III Vad är din sysselsättning nu? (Pensionär)

IV Vad arbetade du med tidigare?

V Har du någon erfarenhet av datorer innan detta?

a. Hemma?

b. På jobbet?

VI Har du någon hemma/i familjen/i närheten som kan hjälpa dig?

VII Hur ofta träffar du läkare?

VIII Har du några andra sjukdomar förutom hjärtsvikt?

Funktioner/teknik

Nu tänkte jag fråga lite om datorn och mätutrustningen du haft hemma i drygt en månad.

I Hur ofta har du gjort dina mätningar? (Två gånger, en gång om dagen, då och då)

II Har du gjort blodtrycks-/viktmätningar varje gång? Om nej, varför inte?

III Har du svarat på formulären varje gång? Om nej, varför inte?

IV Har du använt extramätningsfunktionen? Om ja, varför?

V Vad tyckte du om:

a. Pekskärmen? (lätt/svårt att trycka)

b. Tangentbordet? (små/lagom knappar, svårt/lätt att träffa rätt, förståelse)

c. Blodtrycksmätaren?

d. Vågen?

VI Stötte du på några problem under försökets gång?

a. Vad för problem? (Datorn, mätutrustningen, Internetuppkopplingen)

b. Hur löste du dem? (Ringde Anna, löste själv, fick hjälp på annat håll)

VII Vad tyckte du var svårast med systemet?

VIII Hade du velat ändra något? Vad?

IX Hade du velat lägga till något? Vad?

Design

I Vad tyckte du om färgerna? (Behagliga, otrevliga, otydliga, kontrast bra/dålig)

II Vad tyckte du om teckenstorlek/färg?

III Vad tyckte du om storleken på knappar, fönster och bilder?

IV Vad tyckte du om formen på knapparna?

Annat

I Har du varit på undersökning på sjukhuset under försökets gång?

a. Tittade sköterskorna på dina värden i datorn då?

b. Om nej, varför inte?

c. Om ja, vad tyckte du om det och vad tror du de tyckte om det?

Avslut

Då var jag klar med alla mina frågor! Jag stänger nu av bandspelaren. Denna intervju kommer att användas som bakgrund till ett större försök vi ska ta ut i vår med fler patienter. Den kommer ev. också att finnas med i konferensartiklar och i min licentiatuppsats som kommer ut nästa höst om allt går väl.

Om du vill får du gärna behålla systemet hemma. Jag skulle uppskatta det eftersom vi kan upptäcka fler brister då, och kan göra bättre förbättringar till nästa version.

Är det något du undrar över, eller vill tillägga? (Paus för patienten att reflektera) Då tackar jag för mig!

Appendix B

Neonatal Study

This appendix contains translated versions of the forms given to patients in the neonatal study. Moreover, the translated nurse questionnaire is also included.

B.1 Neonatal patient questionnaire

B.1.1 Questions for parents who participated in neonatal home healthcare / Study group 2

I. General questions about home healthcare

1. How satisfied were you in general with neonatal home healthcare?
Very satisfied
Fairly satisfied
Neither satisfied or dissatisfied
Somewhat dissatisfied
Very dissatisfied

1b. What are the specific things you were satisfied respectively dissatisfied with?

2. Were well prepared when the baby was transferred from hospital to home healthcare?
Very well prepared
Fairly well prepared
Neither well or poorly prepared
Very poorly prepared
Very poorly prepared

2b. If you were poorly prepared, what did you need to be better prepared?

3. Have you felt secure in the care of the child at home?
Very secure
Fairly secure

Neither secure or not
Fairly unsecure
Very unsecure

4. How satisfied were you with nursing home visits?
Very satisfied
Fairly satisfied
Neither satisfied or dissatisfied
Fairly satisfied
Very satisfied

5. Have you had to change daily routines before home visits?
Yes
No

5b. If 'Yes', tell us how the home visits have affected your day?

6. Have you felt that the home visits have been stressful for your family?
Yes
No

6b. If 'Yes', tell us how the home visit felt stressful.

7. Have you had the right number of home visits?
Yes, just right
No, would have needed more
No, had too many

8. Have home visits been long enough?
Yes
No, sometimes unnecessarily long
No, often unnecessarily long
No, sometimes too short
No, often too short

9. Have the instructions that yo got from the nurses during home visits been easier to understand?
Yes
No

10. Have you made contact with home healthcare nurses or doctor at neonatal department of home care?
Yes
No

10b. If 'Yes', how often and for what reasons?

II. Questions on communication with the nurse by telephone

11. How satisfied are you with phone calls with the nurse?
Very satisfied
Fairly satisfied
Neither satisfied or dissatisfied
Somewhat dissatisfied
Very dissatisfied

11b. If you feel unhappy, tell you why. How could one improve talks?

12. Have telephone conversations with the nurse helped you feel comfortable with the care of your child at home?
Yes
No

13. How important have telephone conversations with home healthcare nurse felt for you?
Very important
Fairly important
Neither important or unimportant
Somewhat unimportant
Very unimportant

13b. Tell us, in what ways the talks were important or not important.

14. Has it been easy to communicate with the nurse over the phone?
Very easy
Fairly easy
Neither easy or difficult
Somewhat difficult
Very difficult

15. Have you received answers to the questions you asked the nurse about over the phone?
Yes
No

16. Have the instructions that got from the nurse during telephone conversations been easy to understand?
Yes, always easy
Yes, almost always easy
Neither easy or difficult
No, not always easy
No, often not easy
No, almost never easy

17. Have the answers or instructions you received by phone been useful to

you?
Yes, very useful
Yes, quite useful
Neither useful or not
No, not particularly useful No, not at all useful

18. Was there anything you have missed in communicating over the phone?
Yes
No

18b. If 'Yes', tell us how you think telephone communication had been made better.

III. Questions about using the computer system / website.

19. How much computer experience do you have?
Very large
Fairly large
Neither large or small
Fairly small
Very small

20. In what situations do you use computers? Several options are possible.
In the home
At work
In school
Other

20b. In "Other", please specify.

21. What is your general impression of the web site?
Very good
Good
Neither good or bad
Poor
Very poor

21b. Comments:

22. How easy did you think it was to use the web site?
Very easy
Fairly easy
Neither easy or difficult
Somewhat difficult
Very difficult

22b. If "Somewhat difficult" or "very difficult", tell us how it has felt hard.

23. Have you missed anything on the web site?
Yes
No

23b. If 'Yes', tell us what you have missed

24. Had anything on the web site have been done better?
Yes
No

24b. If 'Yes', tell us what you / you think could have done better.

25. Did you get any answers to questions by information on the web site (The green booklet)?
Yes, many questions
Yes, some questions
Yes, no question
No, no question

25b. Was there any question you missed answers for?

26. Did you get any feedback from home healthcare nurse for what you entered on the web site?
Yes, very much
Yes, some
Yes, very little
No

26b. If 'Yes', what was the feedback on?

26c. If 'Yes', how was this feedback?
At home visits
Through the site's messaging
By telephone
Other

26. If other, please specify.

27. How often did you view your child's data?
Several times a day
Daily
Several times a week
Weekly
At some point during the experiment
Never

28. Do you believe that it was good to see your child's data on the web site?
Yes

No
Never looked at the data

28b. Comments:

29. Has the use of the site helped you to feel secure in the care of your child at home?
Yes
No

30. Do you feel that use of the site reduces the need for home visits?
Yes, the web site can completely replace home visits
Yes, the web site reduces the need for home visits (eg, their number or length), but can not completely replace home visits
No

31. Do you feel that the web site decreased stress before home visits and / or telephone contact?
Yes, the web site led to much less stress
Yes, the web site led to somewhat less stressl
The web site did not affect the level of stress
No, the web site led to more stress
No, the web site led to much more stress

IV. Other

32. Do you have any other comments?

B.1.2 Questions for parents who participated in neonatal home healthcare / Study group 3

I. General questions about home healthcare

There questions are identical to the general questions about home healthcare for Group 2, in section B.1.1.

II. On communication with the nurse with video calls

11. Has the system with Skype and webcam been easy to use?
Very easy
Fairly easy
Neither easy or difficult
Fairly difficult
Very difficult

11b. If you think it has been difficult, please tells us why.

12. How satisfied are you with video calls with the nurse?
Very satisfied

Fairly satisfied
Neither satisfied or dissatisfied
Somewhat dissatisfied
Very dissatisfied

12b. If you were dissatisfied, please tell us why. How could one improve the video calls?

13. Have video conversations with the nurse helped you to feel secure with in care of your child at home?
Yes
No

14. How important have the video calls with the home healthcare nurse felt for you?
Very important
Fairly important
Neither important or unimportant
Somewhat unimportant
Very unimportant

14b. Please tell us, in what ways the video calls were important or not important.

15. Has it been easy to communicate with the nurse through video calls?
Very easy
Fairly easy
Neither easy or difficult
Somewhat difficult
Very difficult

16. Have you received answers to the questions that you asked the nurse in the video call?
Yes
No

17. Have instructions that you received by the nurse during video calls been easy to understand?
Yes, always easy
Yes, almost always easy
Neither easy or difficult
No, not always easy
No, often not easy
No, almost never easy

18. Have the answers or instructions you got through the video talks been useful for you?
Yes, very useful

Yes, quite useful
Neither useful or not
No, not particularly useful
No, not at all useful

19. Do you believe that the possibility to see each other by video has made communication with the home healthcare nurse better than a regular phone contact would have been?
Yes
No, a phone contact had been as good
No, a phone contact would have been better

19b. If 'Yes', tell us why you think that web phone calls are better than ordinary telephone calls.

19c. If "No", explain why you think that web phone calls are as good or worse than regular phone calls.

20. Have you used the opportunity to show the baby to nurse on video?
Yes, several times
Yes, a few times
Almost not at all
Never

20b. If "Yes", do you think that the web camera has made it easier to explain to nurse the child is feeling or what problems he / she has?
Yes
No

21. Do you think video calls decreased stress before home visits?
Yes, video calls led to much less stress
Yes, video calls led to somewhat less stress
Video call does not affect the level of stress
No, video calls led to somewhat more stress
No, video calls led to much more stress

22. Do you know / you that the use of video calls reduces the need for home visits?
Yes, video calls can completely replace home visits
Yes, video calls, reducing the need for home visits (eg, their number or length), but can not completely replace home visits
No

23. Do you feel that communication by video calls means less stress for the family than house calls?
Yes, communication with the web cam is much less stressful than house calls
Yes, communication with the web cam is slightly less stressful than house calls
Communication with the web cam does just as much stress as home visits

No, communication with the web cam is slightly more stressful than house calls
No, communication with the web cam is much more stressful than house calls

24. Was there something you missed in communication with the video call?
Yes
No

24b. If 'Yes', please tell us how you think the communication could have done better.

III. Questions on communication with the nurse by telephone

There questions are identical to the questions on communication with the nurse by telephone for Group 2, in section B.1.1.

IV. Other

33. Do you have any other comments?

B.2 Neonatal nurse questionnaire

Background

1. When were you born?
Year of birth

2. What are your computer skills?
None
Small
Average
Large
Very large

3. If you use the internet private?
Never
Rarely
Weekly
Daily
Several times a day

4. Are you using Skype for video calls in private?
Never
Rarely
Monthly
Weekly
Daily

The study

5. How many families have you asked so far about participation in the study, roughly?
Number of families (each)

6. What proportion of these families accepted roughly (0-100%)?
Percentage of families (%)

7. What proportion of the families who accepted ended up in each group is roughly (total 100%)?
Homepage
Skype
Control

8. Do you think the families are interested in participation in the study after information?
No opinion
Very interested
Interested
A little interested
Uninterested
Very uninterested

9. In what way had parental information could be done better?

10. What is your opinion about the study?
No opinion
Very good
Good
Average
Poor
Very poor

11. Comments

Homepage - NeoReg

12. Did you use the web site NeoReg in the study?
Yes
No
If "No" to question 12, skip to question 34.

13. What is your general impression of the site?
No opinion
Very good
Good
Average

Poor
Very poor

14. How easy / difficult was it to learn how to use the web site?
No opinion
Very easy
Easy
Average
Severe
Very difficult

15. How easy / difficult was the material on the web site to understand?
No opinion
Very easy
Easy
Average
Severe
Very difficult

16. Was it the right amount of features on the web site?
No opinion
Too few features
Just in time
For many functions

17. What did you think was unnecessary, and / or what was missing on the web site?

18. Did you think the web site added something to the care for your patients?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

19. Was your sense of security as a healthcare provider affected positively because of the web site?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

20. What do you think of the site's value relative to time?
No opinion
Very good

Good
Average
Poor
Very poor

21. Have your patients used the home as instructed?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

22. Have your patients appreciated the web site?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

23. Did the patients who used the web site feel more secure than those who did not?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

24. How did you like the look of the web site? (Chose from the following options: No opinion, very good, good, average, poor, very poor)
General design
Sidebar
Main window
Top graphics (page name, etc.)
Message page colors
Size of the text
Text fonts
Size of text boxes
The size of buttons
General diagrams
General Forms
General dialogue
Login page

25. How often did you use the various functions in the main menu when you had patients enrolled on the web site? (Chose from the following options: Had not,

several times / day, daily, 2-3 times / week, about 1 time / week, less often)
Selecting a patient
Patient Archive
Adding new question without supplementary
Adding new question with follow-up question
Modify existing query
Adding new measurement
Change the existing measurement
Add new patient
Adding new staff
Change own data
See / read new messages
See / read old messages
Send New Message

26. How often did you use the various functions of patient menu (after selecting the patient) when you had patients enrolled on the web site? (Chose from the following options: Had not, several times / day, daily, 2-3 times / week, about 1 time / week, less often)
See a chart
Zoom in the chart with the buttons below
Zoom on the graph with the mouse
select / deselect curves in the graph
See full details on a particular point on the graph by clicking on the
See the form for a particular point on the graph
Examining the data in an old form
Selecting an ancient form from the drop-down
Reading the messages in the dialogue
Send a message of dialogue
Selecting issues for the patient
Selecting the measurements for the patient
Registered measurement of patient
Change the child's name
Change the password
Change of age

27. What did you think of the difficulty in using the various functions in the main menu? (Chose from the following options: Had not, very light, light, medium, hard, very hard.)
Show patients
Selecting a patient
Archive patient
Adding new question without supplementary
Adding new question with follow-up question
Modify existing query
Adding new measurement
Change the existing measurement
Add new patient

Adding new staff
Change own data
See / read new messages
See / read old messages
Send New Message

28. What did you think of the difficulty in using the various functions of patient menu (after selecting the patient)? (Chose from the following options: Did not use, very easy, easy, medium, hard, and very difficult)
See a chart
Zoom in the chart with the buttons below
Zoom on the graph with the mouse
Select / deselect curves in the graph
See full details on a particular point on the graph by clicking on the
See the form for a particular point on the graph
Examining the data in an old form
Selecting an ancient form from the drop-down
Reading the messages in the dialogue
Send a message of dialogue
Selecting issues for the patient
Selecting the measurements for the patient
Registered measurement of patient
Change the child's name
Change the password
Change of age

29th Have you had any technical problems with the web site?
No opinion
Yes many
Yes some
No.

30. If yes to question 29, what kind of problems?

31. Had you wanted to use the site outside the study?
Yes
No
Maybe

32. If no or maybe to question 31, why not? If so, why?

33. Other comments on NeoReg homepage.

Skype

34th Did you use Skype to communicate with patients in the study?
Yes
No

If "No" to question 34, skip to questions 52.
35. What is your general impression of Skype?
No opinion
Very good
Good
Average
Poor
Very poor

36. How easy / difficult was it to learn how to use Skype?
No opinion
Very easy
Easy
Average
Severe
Very difficult

37. How easy / difficult was it to use Skype?
No opinion
Very easy
Easy
Average
Severe
Very difficult

38. Did you call via Skype brought something to the care of your patients?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

39. If yes to question 38, do you have one / some examples of what?

40. Was your feelings of security as health care provider affected by Skype?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

41. What do you think about value in relation to time?
No opinion
Very good
Good
Average

Poor
Very poor

42. Hav your patients been using Skype as instructed?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

43. Have your patients appreciated the calls via Skype?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

44. Do the patients who use Skype feel more secure than those who do not?
No opinion
Yes to a large extent
Yes, to some extent
Average
No, not directly
Not at all

45. What did you like the sound quality of your calls?
No opinion
Very good
Good
Average
Poor
Very poor

46. What did you like the picture quality of your calls?
No opinion
Very good
Good
Average
Poor
Very poor

47. Have you had any technical problems with Skype?
No opinion
Yes many
Yes no
No

48. If yes to question 47, what kind of problems?

49. Had you wanted to use Skype for calls to patients outside the study?
Yes
No.
Maybe

50. If no or maybe, why not?

51. Other comments on Skype

Other

52. Is there anything you would add?

Appendix C

Heart Failure Study

C.1 Heart failure patient questionnaire

C.1.1 Baseline

Socio-demographic questions

1. Gender:
Male
Female

2. Your age: years

3. Marital status:
Single
Married
Divorced / separated
Widow / widower
Cohabitation (living with partner)

4. Do you live with someone else at the moment?
No
Yes

5. Do you have home health care (nurse)?
No
Yes a number of hours / month
I've had in the past but not now

6. Do you get the help of home care?
No
Yes a number of hours / month
I've had in the past but not now

7. What is your highest level of education (graduation)?
Junior high school or less
Hight school
Studies on college / university
Two-year college education
University graduate (BA).
Master degree
Doctorate

8. Employment / Recruitment:
Full- or part-time work outside the home
Voluntary unemployment or housewife / house husband
Sick or impaired function
Retired due to heart failure
Retired, not because of heart failure
Other, specify:

9. How well can manage on your household income? Do you think that household finances are:
Good - more than is needed for it to make ends meet
Have enough for it to make ends meet
Have too little money for it to make ends meet

10. Do you consider your health in general is:
Excellent
Very good
Good
Fairly good
Poor

11. LVEF: UCG: Date:

12. NYHA class:

13. When were you diagnosed with heart failure? Year: Month: Do not know

14. Goes to heart failure clinic for:
Medicine titration
Medicine adjustment
Controls

System Usage

1. Have you recently started going in heart failure clinic at Eastern hospital or have not been there?
Yes: Go to question 10
No, I go there now

No, I have been visiting the hearth failure clinic earlier but not any longer

2. What is your general impression of the heart failure clinic?
Very good
Good
Neither good nor bad
Poor
Very poor

3. How often do you see a nurse at the heart failure clinic?
Once a week or more
A couple times a month
Once a month
Every two to three months
Every six months
More rarely
Never

4. How often do you see a nurse outside the heart failure clinic?
Once a week or more
A couple times a month
Once a month
Every two to three months
Every six months
More rarely
Never

5. How often do you see a doctor for your heart?
Once a week or more
A couple times a month
Once a month
Every two to three months
Every six months
More rarely
Never

6. How often do you see some other type of health care providers, such as dietician, for your heart?
Once a week or more
A couple times a month
Once a month
Every two to three months
Every six months
More rarely
Never

7. How often do / did you have contact with a nurse in the heart failure clinic by phone?

Once a week or more
A couple times a month
Once a month
Every two to three months
Every six months
More rarely
Never

8. How do you think communication is / was between you and the nurses at the heart failure clinic?
Very good
Good
Neither good nor bad
Poor
Very poor

9. Would you have liked more contact with nurses in heart failure clinic?
Yes, much more
Yes, a little more
No, same as now
No, a little less
No, much less

10. Do you have someone who helps you at home with your everyday life? (Multiple choice possible)
Yes, a husband / wife / partner
Yes, other family / friends
Yes, home health care
Yes, other

11. Do you often feel alone in your everyday life?
Yes, always
Yes, often
Yes, sometimes
No, rarely
No, never

12. Do you feel safe in your everyday life?
Yes, always
Yes, often
Yes, sometimes
No, rarely
No, never

13.Do you worry a lot about your heart failure?
Yes, always
Yes, often
Yes, sometimes

No, rarely
No, never

14. What are your computer skills?
Very high
High
Average
Low
Very low

15. Do you use computers?
Yes
No: Go to question 20

16. Where do you use computers? (Several options are possible)
At home
at work
At the library
Nowhere
Other

17. How often do you use computer?
Rarely
A couple times a month
A couple times a week
Daily
Several times a day

18. Do you use internet on my computer?
Yes
No: Go to question 20

19. How often do you use internet on my computer?
Rarely
A couple times a month
A couple times a week
Daily
Several times a day

20. Do you use a mobile phone?
Yes
No: Go to question 23

21. Do you use the internet on your mobile phone?
Yes
No: Go to question 23

22. How often do you use internet on your mobile phone?

Rarely
A couple times a month
A couple times a week
Daily
Several times a day

23. Is there someone in your neighborhood that can help you with technical problems and / or questions? (Several options are possible)
Yes, a husband / wife / partner
Yes, other family / friends
Yes, other
No

24. Do you have any other comments?

C.1.2 1- and 3-month Follow-up

Socio-demographic questions

1. Do you have home healthcare (nurse)?
No
Yes: hours / month
Use to in the past but not now

2. Do you get the help of home care?
No
Yes: hours / month
Used to in the past but not now

3. Do you consider your health in general is:
Excellent
Very good
Good
Fairly good
Poor

4. NYHA Class:

5. Goes to heart failure clinic for:
Medicine titration
Medicine adjustment
Controls

System usage

1. Has your lifestyle (housing, relationship, etc) changed during the experiment?
Yes
No: Go to question 3

2. How has your lifestyle changed?

3. Do you feel alone in your everyday life?

Yes, always
Yes, often
Yes, sometimes
No, rarely
No, never

4. Do you feel secure in your everyday life?
Yes, always
Yes, often
Yes, sometimes
No, rarely
No, never

5. Do you worry a lot about your heart failure?
Yes, always
Yes, often
Yes, sometimes
No, rarely
No, never
No

6. What is your general impression of the web site?
Very good
Good
Neither good nor bad
Poor
Very poor

7. How easy do you think it is to use the web site?
Very easy
Easy
Neither easy or difficult
Difficult
Very difficult

8. What is most difficult with the web site?

9. Have you had any problems with the web site?
Yes, many problems
Yes, one / some problems
No: Go to question 11

10. What were your problems with the web site?

11. How easy is your blood pressure monitor to use?
Very easy
Easy
Neither easy or difficult
Difficult
Very difficult

12. Have you had any problems with blood pressure monitor?
Yes, many problems
Yes, one / some problems
No: Go to question 14

13. What kind of problems did you have with the blood pressure monitor?

14. Did you receive technical support from Chalmers?
Yes, many times
Yes, sometime / some times
No: Go to question 18

15. How did you get in contact with Chalmers?
E-Mail
Telephone
Other

16. Was the support good enough?
Yes: Go to question 18
No

17. What did you miss in the help?

18. Have you been helped by someone else with the technology?
Yes
No: Go to question 20

19. Who helped you?
Husband / wife / partner
Other family / friends
Other

20. Have you entered data on the web site every day?
Always: Go to question 22
Usually: Go to question 22
Sometimes
Rarely
Never

21. What was the reason why you did not enter data on the web site?

22. Have you wanted to change or add something on the web site?
Yes
No: Go to question 24

23. What had you wanted to change or add?

24. Have you been to visit with a nurse in the heart failure clinic for your heart failure during the experiment?
Yes
No: Go to question 27

25. Did the nurse examine the data you entered on the web site then?
Yes
No: Go to question 27

26. Did you discuss your data?
Yes
No

27. Has the research nurse, Kim, contacted you during the course of the experiment?
Yes
No: Go to question 30

28. Why did she contact you?
29. Did you know that it was good that she contacted you?
Yes
No

30. Do you think it is a burden to enter your values on the web site?
Yes, very much
Yes, a little
No

31. Do you think that the method is to use the web site for the benefit of your treatment?
Yes, large
Yes, a little
No

32. Do you have any other comments?

Appendix D

Survey

D.1 Survey questionnaire

Hello,

As part of Project Care @ Distance wish we explore attitudes towards IT as a tool in health care and special applications involving health care and monitoring of heart failure patients in the home. As caregivers are Your opinions are very important, and we would therefore appreciate it if you could spare 10-15 minutes to answer this questionnaire. All questions are of course optional to answer.

If you prefer to answer the questionnaire on the Internet so you can go to the following address:
Address not disclosed in the appendix

The aim of the project include to increase safety and adherence to treatment, improve treatment outcome and the individual decision-making data, and increase the individual's insight and knowledge about their disease. This without increasing the total cost picture or the workload of those involved. This survey is a step towards achieving these goals.

Care @ Distance started as a project in its present form in 2005 with the vision to include improve treatment of heart failure patients with the help of information and telecommunications technology, known as eHealth. A Internet-based prototype system was developed to gather and take part of the patient signs and symptoms. The patient logs into the system via a computer or phone, and health professionals can administer the system and see the information curves or individual forms via a web- interface. The system is cheap, robust, easy to administer, dynamic and mobile, thanks to the internet.

Responsible for the project are:
Contact information not disclosed in the appendix

Please return the filled in a questionnaire in the enclosed postage-paid return envelope, if you do not choose to respond to the Internet. Thank you for your participation!

Best regards, Anna Gund
Contact information not disclosed in the appendix

Attitudes to ICT to support the care of heart failure patients at home

Background

1. When were you born?
-1919
1920-29
1930-39
1940-49
1950-59
1960-69
1970-79
1980-89
1990 -

2. Are you male or female?
Male
Female

3. What is your main function / title?
Head of department
Specialists physician, cardiology
Specialists physician, other
General practitioner
Specialist nurse, heart
Specialist nurse, other
Registered nurse
Assistant nurse
Other

4. In which county/ies do you work now?
Blekinge County
Dalarna County
Gävleborg County
Halland County
Jämtland County
Jönköping County
Kalmar County
Kronoberg County

Norrbotten County
Skåne County
Stockholm County
Södermanland County
Uppsala County
Värmland County
Västerbotten County
Västernorrland County
Västmanland County
Västra Götaland County
Örebro County
Östergötland County

5. How much do you use computer at work?
Never / rarely
Weekly
Daily
Several times a day
Most of the working day

6. For what do you use computer at work? (Several options are possible.)
EHR
Prescription systems
Finding medical information
Finding non-medical information
Social networks (eg Facebook)
Contact with patients via e-mail
Contact with other healthcare providers via e-mail
Other contact by e-mail
Chat (eg MSN)
Video telephony (eg Skype)
Writing documents
Other

7. How often do you use a computer at home?
Never
Rarely
Weekly
Daily
Several times a day

8. For what use the computer at home? (Several options are possible.)
Search for information
E-commerce
e-mail
Social networks (eg Facebook)
Reading the news
See video and / or TV programs

Chat (eg MSN)
Video telephony (eg Skype)
Download movies, series, music, etc.
Listen to music (eg Spotify)
Writing documents
Play games
Other

Attitudes to ICT tools in health care

9. What do you think about IT (information technology) as a tool in health care today?
Very bad
Bad
Neither good nor bad
Good
Very good

10. What do you think about the possibilities of IT as a tool in health care in the future?
Very bad
Bad
Neither good nor bad
Good
Very good

11. What do you think of the possibility of remote monitoring / follow-up of patients via eg Internet?
Very bad
Bad
Neither good nor bad
Very good
Good

12. Do you have any experience with remote monitoring of patients via eg Internet?
Yes
No

13. Do you believe that remote monitoring can lead to increased patient involvement?
No, not at all
Unlikely
Neutral
Possibly
Yes, very likely

14. Do you believe that remote monitoring can improve your ability to com-

municate better care?
No, not at all
Unlikely
Neutral
Possibly
Yes, very likely

15. How do you see the possibility that with the help of IT tools influence the health care cost in a positive direction?
Worsen
A little worse
Same as now
A little better
Improved

16. How do you see the possibility in the future with the help of IT tools influence medical time-saving aspects of positive direction?
Worsen
A little worse
Same as now
A little better
Improved

17. What is your confidence in IT as a tool in health care?
Very low
Low
Neutral
Large
Very large

Opinions about monitoring in the home

18. What physiological parameters, indications, do you measure in the clinic? (Several options are possible.)
Weight
Blood Pressure
Pulse
SpO2
BNP
Hb

19. Other physiological parameters, please specify.

20. What do you ask the patient about at the clinic? (Several options are possible.)
Dyspnea
Fatigue
Dizziness

Cough
Compliance with medication
Physical activity
Diet
Swelling
Diarrhea

21. Other, please specify.

22. Please specify the 5 parameters that you think best reflects your patients' well-being.
Weight
Blood Pressure
Pulse
SpO2
BNP
Hb
Swelling
Dyspnea
Fatigue
Dizziness
Cough
Diarrhea
Compliance with medication
Physical activity
Diet

23. Other parameters, please specify.
24. Do you think your patient groups are suitable for monitoring in the home?
Yes, to a large extent
Yes, to some extent
No

25. If no, why not?

26. Which of the following do you think is appropriate to follow up at home? (Several options possible.)
Weight
Blood Pressure
Pulse
SpO2
BNP
Hb
Swelling
Dyspnea
Fatigue
Dizziness
Cough

Diarrhea
Compliance with medication
Physical activity
Diet

27. Other parameters, please specify.

28. Which patients would benefit most from being followed up at home? (Several options are possible.)
The sickest (eg NYHA IV)
They pretty sick (eg, NYHA III)
The healthier (eg, NYHA II)
The healthiest (eg, NYHA I)
No patients

29. Other patients, please specify.

30. What are the best ways to monitor patients at home? (Several options are possible.)
Through home visits by nurse
Through home visits by other staff
By phone
By video phone
By e-mail
By internet forms

31. Other methods, please specify.

Other

32. Do you have any comments, thoughts, ideas or experiences in this area?

33. Would you like to be contacted for an in-depth discussion of the subject and / or participate in a study for follow up at home with an IT-based system? If so, enter your contact information below and we will contact you.
This data will be used for direct contact between us and you. They will not be stored together with your answers, and not used for other purposes.

Thank you for your participation in the study! We value your opinions.

Appendix E

System Screenshots

In this appendix, a selection of screenshots from the web-based system applications NeoReg and HeartReg are presented.

E.1 NeoReg


NeoReg
Care@Distance
Familj
Inga olästa meddelanden.
Logga ut
Svara på formulär
Diagram
Gamla formulär
Information
Meddelanden
Dialog
Min information
Instruktioner
Hem
Information
-Det gröna häftet
Denna sida innehåller allmän information och svar på vanliga frågor som du som förälder kan ha om ditt barn. Det är i stort sett samma information som står i det gröna häftet som du fick på sjukhuset.
Innehåll
Ålder
Infektionskänslighet
Transport
Temperatur
Utomhus
Badning
Läge
Matning
Barnets allmäntillstånd
Telefonnummer
Andningsproblem
Ålder
Det för tidigt födda barnet har två åldrar:
Den faktiska åldern - räknat efter barnets födelsedag.
Den korrigerade åldern - räknat efter när barnet egentligen skulle ha fötts.

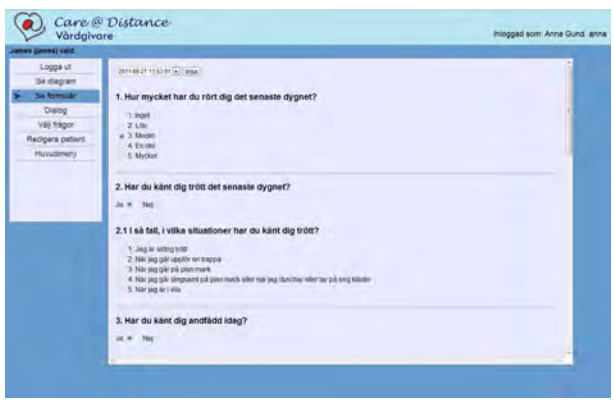

NeoReg
Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
Inga olästa meddelanden.
Logga ut
Visa patienter
Rimligera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelanden
Namn
Användarnamn
Ålder
Födelse-vecka
Registrerings-datum
Senaste mätning
Arkivera
visa
Alice
famAlice
75 veckor 3 dagar
33
2010-10-28
2010-11-12
Arkivera
visa
fb.iseland
famiseland
39 veckor 2 dagar
34
2011-07-12
2011-08-05
Arkivera
visa
Izabella
famahlström
37 veckor 3 dagar
33
2011-07-22
Arkivera


NeoReg
Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
Alice: 75 veckor 3 dagar
Logga ut
Diagram
Gamla formulär
Dialog
Välj frågor
Redigera mätningar
Redigera patient
Huvudmeny
Vikt
g
Huvudomfång
cm
Datum:
Augusti
2011
Spara

E.2 HeartReg

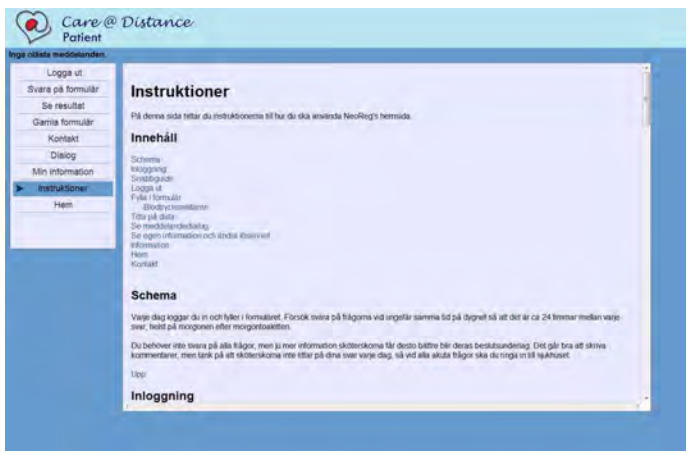

Care@Distance
Patient
Logga ut
Svara på formulär
Se resultat
Gamla formulär
Kontakt
Dialog
Min information
Instruktioner
Hem
Välkommen James!
För att fylla i dagens formulär, klicka här: Dagens formulär
Om du mår dåligt och/eller vill ha snabb kontakt med sjukhuset, kontakta DAGA på 031-343 55 81.


Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
Logga ut
Se diagram
Se formulär
Dialog
Välj frågor
Redigera patient
Huvudmeny
Meddelandedialog
Formulär | Från: James | Till: Anna Gund | 2011-04-30 09:13:07
Sv: Formulär | Från: Anna Gund | Till: James | 2011-04-09 11:06:52
Formulär | Från: James | Till: Anna Gund | 2011-04-09 08:31:01
Sv: Formulär | Från: Anna Gund | Till: James | 2011-04-05 09:58:17

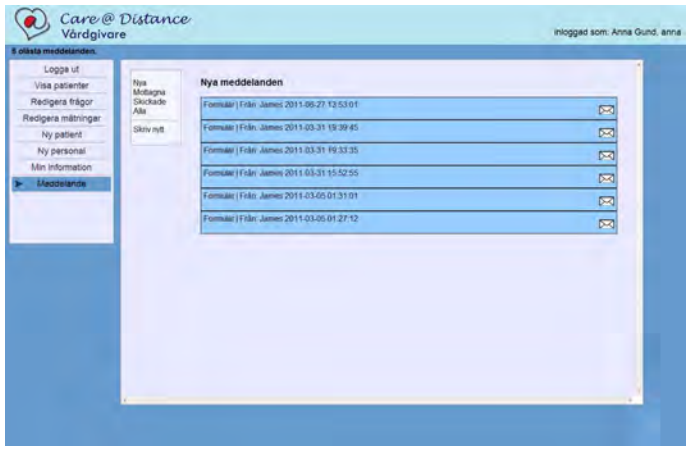

Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
Logga ut
Se diagram
Se formulär
Dialog
Välj frågor
Redigera patient
Huvudmeny
1. Hur mycket har du rört dig det senaste dygnet?
2. Har du känt dig trött det senaste dygnet?
2.1 I så fall, i vilka situationer har du känt dig trött?
3. Har du känt dig andfådd idag?

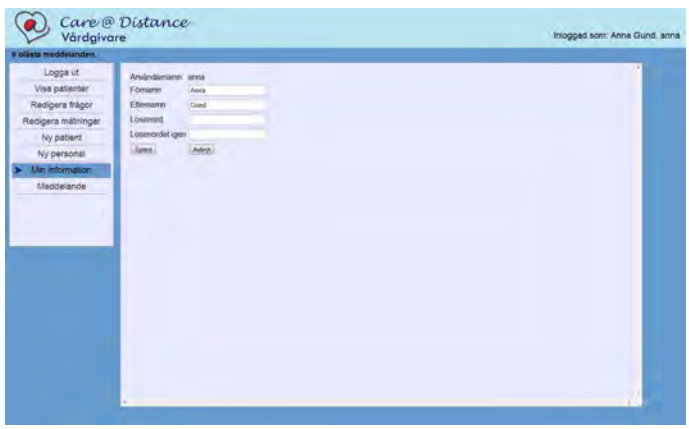

Care @ Distance
Vårdgivare
Inloggad som: Anna Gund, anna
James (James) vald.
Logga ut
Se diagram
Se formulär
Dialog
Välj frågor
Redigera patient
Huvudmeny
Frågor
Aktivitet
Trötthet
Andning
Hosta
Illamående
Yrsel
Diarré
Spara
Mätningar
Vikt
Övre blodtryck, SYS
Undre blodtryck, DIA
Puls
Spara

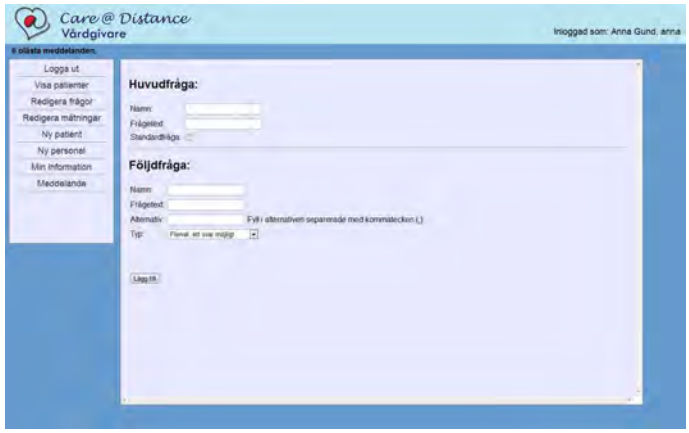

Care @ Distance
Vårdgivare
Inloggad som: Anna Gund, anna
CAD001 (CAD001) vald.
Logga ut
Se diagram
Se formulär
Dialog
Välj frågor
Redigera patient
Huvudmeny
Frågor
Datum
2011-07-29 8:2:55
Illamående
0
Trötthet, följdfråga
2
Aktivitet
3
Andning
1
Trötthet
1
Andning, följdfråga
2
Illamående, följdfråga
Ej svarat
Hosta
0
Diarré
0
Yrsel
0
Visa formulär
Alla
Senaste veckan
Senaste månaden
Dölj alla
Senaste 3 månaderna
Senaste 6 månaderna


Care @ Distance
Patient
Inga olästa meddelanden.
Logga ut
Svara på formulär
Se resultat
Gamla formulär
Kontakt
Dialog
Min information
Instruktioner
Hem
Instruktioner
På denna sida hittar du instruktionerna till hur där ska använda NeoReg's hemsida.
Innehåll
Schema
Inloggning
Snabbguide
Logga ut
Fylla i formulär
Blodtrycksmätaren
Titta på data
Se meddelandedialog
Se egen information och ändra dessa vid
information
Hem
Kontakt
Schema
Varje dag loggar du in och fyller i formuläret. Försök svara på frågorna vid ungefär samma tid på dygnet så att det är ca 24 timmar mellan varje
svar, helst på morgonen efter morgonbadet/tet.
Du behöver inte svara på alla frågor, men ju mer information sköterskorna får desto bättre blir deras beslutsunderlag. Det går bra att skriva
kommentarer, men tänk på att sköterskorna inte tittar på dina svar varje dag, så vid alla akuta frågor ska du ringa in till sjukhuset.
Upp
Inloggning


Care@Distance
Patient
Inga olästa meddelanden.
Logga ut
Svara på formulär
Se resultat
Gamla formulär
Kontakt
Dialog
Min information
Instruktioner
Hem
Kontaktinformation
DAGA, hjärtsviktsmottagningen
Telefon: 031-343 55 81
Forskningssjuksköterskan
Kim Fahlén
Telefon: 031-343 59 28
Fax: 031-19 14 16
Teknisk support
Anna Gund
E-post: anna.gund@chalmers.se
Telefon: 031-772 17 83
Mobil: 070-718 59 11


Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
8 olästa meddelanden.
Logga ut
Visa patienter
Redigera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelande
Nya
Mottagna
Skickade
Alla
Skriv nytt
Nya meddelanden
Formulär | Från: James 2011-06-27 12:53:01
Formulär | Från: James 2011-03-31 19:39:45
Formulär | Från: James 2011-03-31 19:33:35
Formulär | Från: James 2011-03-31 15:52:55
Formulär | Från: James 2011-03-05 01:31:01
Formulär | Från: James 2011-03-05 01:27:12


Care@Distance
Vårdgivare
Inloggad som: Anna Gund, anna
8 olästa meddelanden.
Logga ut
Visa patienter
Redigera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelande
Användarnamn: anna
Förnamn
Efternamn
Lösenord
Lösenordet igen
Spara
Avbryt


Care @ Distance
Vårdgivare
Inloggad som: Anna Gund, anna
6 olästa meddelanden.
Logga ut
Visa patienter
Redigera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelande
Huvudfråga:
Namn:
Frågetext:
Standardfråga:
Följdfråga:
Namn:
Frågetext:
Alternativ:
Fyll i alternativen separerade med kommatecken (,)
Typ:
Flerval, ett svar möjligt
Lägg till


Care @ Distance
Vårdgivare
Inloggad som: Anna Gund, anna
6 olästa meddelanden.
Logga ut
Visa patienter
Redigera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelande
Användarnamn:
För- eller smeknamn:
Lägg till
Lösenordet kommer att bli samma som användarnamnet. V.g. be patienten att byta sitt lösenord vid första inloggningen.


Care @ Distance
Vårdgivare
Inloggad som: Anna Gund, anna
6 olästa meddelanden.
Logga ut
Visa patienter
Redigera frågor
Redigera mätningar
Ny patient
Ny personal
Min information
Meddelande
Användarnamn:
Förnamn:
Efternamn:
Lägg till
Lösenordet kommer att bli samma som användarnamnet. V.g. be användaren att byta sitt lösenord vid första inloggningen.