

Telemedicine for Lung Cancer Patients

MILLA OLSSON
and CAROLINE ROSELL



**KTH Computer Science
and Communication**

Telemedicine for Lung Cancer Patients

MILLA OLSSON
and CAROLINE ROSELL

DM129X, Bachelor's Thesis in Media Technology (15 ECTS credits)
Degree Progr. in Media Technology and Engineering 300 credits
Royal Institute of Technology year 2013
Supervisors at CSC were Anders G. Askenfelt and Anders Friberg
Examiner was Daniel Pargman

URL: www.csc.kth.se/utbildning/kandidatexjobb/medieteknik/2013/olsson_milla_OCH_rosell_caroline_K13023.pdf

Kungliga tekniska högskolan
Skolan för datavetenskap och kommunikation

KTH CSC
100 44 Stockholm

URL: www.kth.se/csc

Telemedicin för lungcancerpatienter

Sammanfattning

Den svenska sjukvården står idag för ett antal utmaningar om den skall fortsatt kunna erbjuda god service som vårdgivare och vara attraktiv som arbetsgivare. Bland annat diskuteras frågor som förvärrad platsbrist, läkarbrist samt avstånd till specialistsjukvård. På Karolinska Universitetssjukhuset i Solna ligger Radiumhemmet och där behandlas bland annat lungcancerpatienter. Där diskuteras huruvida telemedicin kan vara en möjlig väg för att lösa ovanstående problem. Denna uppsats utreder på vilket sätt telemedicin kan användas på Radiumhemmet för lungcancerpatienter.

För att kunna utreda en telemedicinsk lösnings möjligheter på Radiumhemmet genomfördes intervjuer och fokusgrupper med personalen. Externa experter från sjukvården och industri intervjuades och ett besök gjordes på barnsjukhuset Childrens Healthcare of Atlanta, USA, där man har kommit långt i användningen av telemedicin.

Det finns delar av verksamheten på Radiumhemmet där telemedicin skulle kunna bidra till att skapa möjligheter till en tätare kontakt mellan patient och vårdpersonal. Detta i syfte att lugna oroliga patienter och hjälpa till med lättare symptombedömningar och på så sätt minska väntetiderna. Genom de undersökningar som utfördes upptäcktes dock även svagheter i en telemedicinsk lösning avsedd för lungcancerpatienter. Patientgruppen ofta är äldre med liten erfarenhet av datorer och sjukdomen är allvarlig. Det krävs personlig kontakt och fysiska undersökningar, men i vilken utsträckning är individuellt.

Telemedicin kanske inte kan ses som en absolut lösning för de problem som råder i sjukvården idag när det kommer till lungcancerpatienter, men väl som ett komplement. Om lungcancerpatienter är den optimala målgruppen är ifrågasättbart men att telemedicin kan underlätta i den svenska sjukvården står klart.

Telemedicine for Lung Cancer Patients

Abstract

Nowadays the health care system in Sweden is faced with several challenges like shortage of space, physicians and long distances to specialized health care.

A possible solution for this being discussed at the lung cancer department of Karolinska University

Hospital is the use of telemedicine. If implemented it would be part of the follow-up treatment. The objective of our research is to find out if this technology can help improve the health care.

In order to investigate the opportunity for a telemedicine solution, we collected qualitative data from multiple different sources. This included two doctors specialized in lung cancer, and a focus group with nurses from Radiumhemmet. We also conducted interviews with relevant individuals outside the hospital including Nirav Desai who is the Founder and CEO of Hands On Telehealth; furthermore, we visited the Children's Healthcare of Atlanta based in Atlanta, Georgia where telemedicine is used on a daily basis.

Thanks to the carried out research, we have discovered that telemedicine could be used in certain scenarios and contribute towards a more frequent contact between the patient and the medical professionals. Thus, this new technique could help nurses execute lighter symptoms assessment remotely and reduce waiting times. We also discovered some inconveniences in a telemedicine solution designed for lung cancer patients. We personally do not think they are the best target group for such a solution since the patients are mostly the elderly with little computer experience. Also the disease is severe and requires physical examinations where the telemedicine existing today would not improve the care giving.

To all intents and purposes, telemedicine might not be the only and ultimate solution for the problems identified within healthcare for lung cancer patients at Radiumhemmet, but it can work well as a supplement.

Table of Contents

1. Introduction	6
1.1 Introduction.....	6
1.2 Problem Formulation.....	7
2. Background	8
2.1 Medical Background.....	8
2.1.1 Lung Cancer.....	8
2.1.2 Treatment.....	8
2.1.3 Side Effects from Treatment.....	9
2.2 Radiumhemmet in Solna.....	9
2.3 Human Computer Interaction (HCI).....	10
2.3.1 Usability.....	10
2.3.2 User Centered Design (UCD).....	10
2.4 Telemedicine.....	11
2.4.1 What is Telemedicine?.....	11
2.4.2 Different Types of Telemedicine.....	12
2.4.3 Existing Telemedicine Solutions.....	12
2.4.4 Human Computer Interaction and Telemedicine.....	14
3. Methodology	15
3.1 Interviews.....	15
3.2 Focus Groups.....	15
3.3 Shadowing at Radiumhemmet.....	16
4. Results	17
4.1 Shadowing at Radiumhemmet.....	17
4.2 Interviews with Doctors.....	17
4.2.1 Doctor 1, MD, Department of Oncology-Pathology at Karolinska University Hospital.....	17
4.2.2 Doctor 2, MD, PhD, Consultant Clinical Oncologist, Department of Oncology at Karolinska University Hospital.....	18
4.3 Interviews with Users and Developers of Telemedicine.....	18
4.3.1 The Service TeleQ.....	18
4.3.2 Head Manager at a Health Centre in Sweden.....	19
4.3.3 The Children’s Healthcare of Atlanta.....	20
4.3.4 CEO of Hands on Telehealth.....	21
4.4 Result Focus Groups.....	21
4.4.1 Focus Group Nurses.....	21

4.5 Summary of Interviews and Focus Groups.....	24
4.5.1 Doctors.....	24
4.5.2 Developers and Experts.....	26
4.5.3 Focus Group Nurses.....	26
5. Discussion and Analysis.....	27
5.1 Possibilities and Challenges of Telemedicine for Lung Cancer Patients.....	27
5.2 How to Approach Developing a Useful Telemedicine System for Lung Cancer Patients.....	28
5.3 The Greater Picture.....	30
5.4 Discussion of Methodology.....	31
5.4.1 Interviews.....	31
5.4.2 Focus Groups.....	31
5.4.3 Shadowing at Radiumhemmet.....	31
6. Conclusion.....	32
7. Recommendations.....	33
8. Acknowledgement.....	34
9. References.....	35
9.1 Bibliography.....	35
9.2 Internet Sources.....	35

1. Introduction

1.1 Introduction

In today's society, cancer patients are a steadily growing group who require advanced healthcare. Due to today's fast growing population, the incidence as well as the prevalence are increasing at an alarming rate. (Bergman, Hont & Johansson, 2009) The fast growing population in Sweden can be connected to the increasing amount of immigrants, which also leads to additional demands in areas such as language and culture. (Statistiska centralbyrån 2012, February 20) The reason for the higher number of cancer patients in the last two decades is also related to the fact that the population is getting older, and improved methods of diagnosing cancer. (Cancerfonden 2012, March 12) The increasing number of patients brings new challenges and demands on the capacity within health care.

In 2016, the New Karolinska in Solna will open its doors; this medical center is going to include the oncology¹ clinic, which already exists at the Karolinska University Hospital. The patient capacity at the new oncology clinic is going to be lower than what it is today. This will, amongst other things potentially lead to a shortage of space, and a possible solution for this upcoming problem is the use of telemedicine.

Telemedicine is a generic term for applications within health care where telecommunication is used as a tool for transferring information between two sources (Nationalencyklopedin 2013, February 14). The implementation of telemedicine could be a possible solution when it comes to handling the fast growing population. It could enable a more efficient and more available health care, and ease the situation for both patients and health care personnel.

The use of telemedicine at Radiumhemmet, the oncology clinic of Karolinska University Hospital, would have most impact when it comes to the follow-up of the patients. The follow-ups include continuously periodic control after the cancer patient has finished the primary treatment. If implemented, the telemedicine-based solution at the oncology clinic at Karolinska would be used as part of the follow-ups of lung cancer patients.

¹ The privity of tumor diseases

1.2 Problem Formulation

The purpose of this study is to analyze if a telemedicine solution can empower the efficiency of today's follow-ups of lung cancer patients at Radiumhemmet, in Solna. The line of argument in this report is the following problem formulation:

Can a telemedicine system enhance the follow-ups of lung cancer patients at Karolinska University Hospital?

The following sub-questions will be studied throughout the process to enhance the problem formulation:

- *Compared to today's solution, which advantages and disadvantages does telemedicine have as a means of communication between healthcare providers and patients at Radiumhemmet?*
- *What are the users', in our case healthcare providers and patients, attitude towards using a telemedicine system?*
- *How do you approach designing a user-friendly telemedicine system for the intended target group?*

2. Background

2.1 Medical Background

2.1.1 Lung Cancer

In today's society, lung cancer is a global problem and the incidence all over the world is increasing. The carcinogen in tobacco smoke is unquestionably the major cause for lung cancer, not to mention air pollution, radon exposure and viruses. (Hansen, H., 2008) Among the lung cancer patients, 85-90 % are smokers and every fourth of those who do not smoke is diseased from being exposed to secondhand smoke. (Bergman, Hont & Johansson, 2009)

In Sweden, every fifth of those who has been diagnosed with cancer has lung cancer. It is the one type of cancer with the worst prognosis. On a five-year basis the survival is 12 % amongst men and 15 % amongst women. The number of new cases related to lung cancer in 2007 was 3203; of which 1627 were men and 1576 were women. It is mostly common amongst people who have turned 70 years old; whereas only a hundred are diagnosed before their 50th every year. (Bergman, Hont & Johansson, 2009)

The two major types of lung cancer are small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). Out of those who get diagnosed, the majority gets diagnosed with NSCLC. After the patient has been diagnosed with lung cancer the average time of survival is six months. However, if the diagnose is SCLC it can be much shorter. Depending on which type of lung cancer, the treatment looks different. Since cancer is a very aggressive and unpredictable disease there is no assurance that the patient can ever get rid of the cancer. Despite this the patient is declared healthy if they have not had a relapse within a five-year period. (National Cancer Institute n.d., March 20)

2.1.2 Treatment

There are several different kinds of treatments for lung cancer, which one is the most suitable depends on the type and stage of the cancer. Also the patient's well being needs to be taken into consideration. (National Cancer Institute n.d., March 20) The possible treatments include:

- Surgery
- Radiotherapy
- Chemotherapy

Surgery is the treatment that saves most lives. Approximately one third of newly diagnosed patients are recommended surgery. Of this third the diagnosis of NSCLC is almost exclusionary, and the lung cancer is in an early stage. Within a five-year period, the total survival is approximately 50 %. (Cancerfonden 2013, March 23)

Radiotherapy is often combined with surgery. If the surgery is not expected to treat the patient, they will be given radiotherapy afterwards. It can also be used if it is not possible to perform surgery. Then radiotherapy will be given in high doses for a curatively purpose. In these cases, the total survival percentage is 10-15 within a five-year period. This applies to those with high health status, and a small tumor since the treatment is exhausting for the patient. There are also situations where radiotherapy is given for a palliative purpose. (Bergman B., 2010)

In the later stages chemotherapy can result in remission and is often given together with radiotherapy. This procedure is successful amongst 20-30 % of the treated patients with NSCLC. This leads to an increasing median survival of 2-4 months, and increases the one-year survival with 10 %, according to Bergman.

2.1.3 Side Effects from Treatment

After the patients have been treated with radiotherapy there are several side effects. The most common ones are oesophagitis², pneumonia, fever, cough and tiredness. The chemotherapy treatment results in similar side effects as radiotherapy. These include feeling tired and nauseous. Further it can have an effect on the bone marrow and cause hair loss. If the treatments are combined the side effects usually become more intense. Weight loss is also a common side effect from the disease and the treatment. (Bergman B., 2010)

2.2 Radiumhemmet in Solna

The research was conducted at Karolinska University Hospital in Stockholm. The oncology clinic at Karolinska University hospital is the largest oncology division in Sweden. Today it has 600 employees, and is divided into three different departments; one at Danderyds Hospital, one at Stockholm South General Hospital and the third one at Radiumhemmet in Solna. Together they have 220 000 patient visits a year within non-institutional care, and 4200 occasions within enrolled care. These patients have already been diagnosed with cancer, often defined by the house doctor. At Radiumhemmet they only treat patients diagnosed with cancer they believe to be curable. Palliative care³ is given at other departments at Karolinska University Hospital. As from the first visit at Radiumhemmet, every patient gets their own contact-nurse that follows them throughout the course of their treatment. (Karolinska 2013, April 15)

² State of inflammation in the throat

³ The care that is given when it is not possible to cure the disease

Today the average time for analyzing a lung cancer patient in Stockholm is 30 days; if it is an early stage of lung cancer the average time is 49 days. However, the oncology department has an ambition to decrease the investigation to 28 days for 80% of the patients. Out of those who are diagnosed with cancer in the Stockholm area every year, 1200-1300 has lung cancer, a number that is consistently increasing. (Karolinska 2013, April 15)

After treatment at Radiumhemmet, the follow-ups occur throughout a five-year period. Usually it contains six visits the first year, and from there on the follow-ups is reduced gradually. Each patient's follow-up is different. They usually include a dialogue with the doctor, blood sampling and X-ray image examination. As from the first visit at Radiumhemmet, every patient gets their own contact-nurse that follows them until they are remitted from Radiumhemmet. (Karolinska 2013, April 15)

2.3 Human Computer Interaction (HCI)

2.3.1 Usability

The term *usability* refers to a system that is usable by the intended target group. A product is usable when there is no hindrance, hesitation or questions experienced from the users. There are several categories a usable product should fall under; these include being useful, efficient, effective, satisfying, learnable and accessible. (Rubin, J., & Chisnell, D., 2008) In order for a system to be usable it does not have to be tested for all of these categories. The three most important to focus on are efficiency, effectiveness, and satisfaction. Effectiveness and learnability refers to how well the product behaves towards the users' expectations, and how well the user is able to learn how to operate it. Efficiency has to do with how fast a user can reach his goal accurately and completely, where a short amount of time is usually strived for. Lastly satisfaction includes the comfort level of the end-user including perceptions, feelings and opinions towards the system. (CCPS, 1995)

According to the ISO 9241 standard covering ergonomics of human computer interaction, there is certain information that is needed in order to measure and specify usability. This includes a clear picture of the intended goal, detailed information of users, tasks, equipment and the environment of usage, and lastly measured data of the effectiveness, efficiency, and satisfaction. (CCPS, 1995) Making a product as usable as possible for the end-users is part of a larger field of User-Centered Design (USD). (Rubin, J., & Chisnell, D., 2008)

2.3.2 User Centered Design (UCD)

According to the ISO standard 13407, User Centered Design can be described as “Characterized by: the active involvement of users and a clear understanding of user and task requirements; an appropriate allocation of function between users and technology; the iteration of design solutions; multidisciplinary design.”(Rubin, J., & Chisnell, D., 2008) The standard applies to both the software and hardware

designing process where multidisciplinary teams further develop products based on the feedback from users. This standard provides usable techniques on which way to move forward for project managers who have the intention of design and implement a system for a specified user group. It puts the users in center and it focuses on the importance of the end-users. (Demiris et al., 2010)

Human factors and ergonomics are two interchangeable words that are part of the human centered design. There are many definitions of the two but the International Ergonomics Association and the Human Factors and Ergonomics Society shows a consistency in their definition of the words and can be described as followed, “The scientific discipline concerned with the understanding of interactions among humans and other elements of a system, and the profession that applies theory, principles, data, and other methods to design in order to optimize human well-being and overall system performance”. (Demiris et al., 2010)

When designing a new system, factors like what technology to use to building it and what the use of the system will play a big role. But in order to put the system in use, the users' experience especially must be taken into consideration throughout the entire designing process. (Rubin, J., & Chisnell, D., 2008) It is required for the designer to have knowledge, skills and a vast variety of information about the end-user and what the product is going to be used for. (Rubin, J., & Chisnell, D., 2008)

2.4 Telemedicine

2.4.1 What is Telemedicine?

Telemedicine can be defined as using information and communication technology such as telephones and/or computers to deliver healthcare services. The major advantage of telemedicine is that it provides consultation between caregiver and patient, and vice versa beyond any geographic boundary. It enables the transportation of a vast variety of information such as voice, sound, video, still picture and text using communication technologies such as telephone lines, satellite, wireless, cable and Internet. The most common user interfaces when it comes to using telemedicine include desktop and laptop computers, fax machines, regular and mobile telephones, video cameras and a variety of standalone systems. (Miller, 2010)

Telemedicine opens up the opportunity of teamwork between doctors and nurses that have never worked together before. It can, if applied correctly, provide more efficient health care. It creates new ways of working within healthcare, and many times involves determining the right treatment for patients without seeing them face-to-face. In today's society many concerns about safety and integrity are raised when the system is used. A system like telemedicine also includes expenses on technology, training, and other functional support. (Desai, 2011)

2.4.2 Different Types of Telemedicine

There are three major types of telemedicine services that are being used around the world today. These include:

- Remote monitoring
- Interactive telemedicine services
- Store-and-forward telemedicine

Remote monitoring refers to a system that enables the doctors and nurses to check up upon patients from distance. This communication service does not occur live, and does not always require both parts to be connected at the same time. It includes patients doing self-monitoring, and recording it on a web-based system. (Innovateus 2011, April 23) This type of telemedicine service requires both parts to have access to hardware and software that enables this kind of communication. An example of this service is *WebChoice* described in the next chapter. Interactive telemedicine services involve real-time communication between patients and doctors. Some examples of this technology include phone conversations, online chatting and video consultations. (Innovateus 2011, April 23) The hardware and software used for this service varies between users. The connection, operating system, sound, image quality, context of use etc. determine what the interactive service is going to look like. (Global Media 2010, April 23) If bluetooth equipment is available, some medical examinations could be done using this service. For example, bluetooth stethoscope can be used to monitor heart and lung sounds. It works just like a normal stethoscope, the only difference is that with the touch of a button, two devices can be connected. This result in having both the heart and lung sounds monitored from many miles away. (Georgia Partnership for TeleHealth 2012, April 23) The last type, store-and-forward telemedicine, refers to the transfer of images, medical information and bio-signals between healthcare professionals and patients. (Innovateus 2011, April 23) For all these services, the two parties are linked together with high-speed telephone lines, cables or satellites for a secure connection. (TTUHSC 2013, April 23)

2.4.3 Existing Telemedicine Solutions

In 2012 an empirical study was conducted to evaluate patients' experiences when using the Interactive Health Communication Application (IHCA) *WebChoice*. *WebChoice* is an online application designed for people with breast and prostate cancer. The goal of the application is to provide support and comfort when the patients are at home, between treatments or during rehabilitation. To begin with, *WebChoice* provides the patient with information about symptoms and cancer-related consequences and effects. They could monitor their symptoms and problems associated with their illness. The patient to provider communication was made more effective through this application by enabling the patients to email questions and thoughts to nurses specialized in cancer treatment. They could also communicate with other patients in E-forums.

There were both positive and negative reactions from the patients concerning this system. The level of their satisfaction with the usage of the system could be connected to how frequently WebChoice was used. One of the high frequency users said *“I feel that WebChoice gives me what I need ... [It is] one of the first things I check every day, and at night, when I can't go to sleep, I'm in there looking as well.”* Overall, the high frequency users gave WebChoice a central role in their private life. On the other hand, the patients who did not use the system very often looked at WebChoice more as a complement to ordinary health services. They especially emphasized the need of human contact, and to look someone in the eyes when being provided health care. However, the patients highly valued the ability to email a proficient nurse. They also valued the ability to take the time needed to write and edit the email being sent to a nurse. Also the ability to write in the moment of a thought, and from the safety and comfort of their own homes was highly appreciated. (Grimsbø, Engelsrud, Ruland, & Finset, 2012)

Another study took place at the Townsville Cancer Centre in North Queensland, Australia. It was a video consultation system tested on a very limited target group of Indigenous patients, and took place between 2007 and 2011. The goal of this study was to determine the level of satisfaction and receive feedback from the Indigenous patients, their families and health workers on a telemedicine video consultation system. The health care professionals using this system received proper training in order to provide telemedicine care for the specified patients. It was also important that the communication between the specialists was effective and that they were well informed of the consent procedures. The satisfaction level from Indigenous patients, their relatives and the health specialists was overall high, and they would be interested in using more systems like this in the future. Interviews were conducted with the users and they all preferred video consultation when it was available instead of seeing their doctors face to face in order to minimize waiting time, cost, the inconvenience of travel and being separated from support groups. It was concluded from the study that in order to increase satisfaction of the patients using a telemedicine system, it is important to have efficient integration between clinics, user friendly and functioning equipment for the video consultations and internet connection and lastly sufficient and helpful support for the health professionals at locations far away. In other words, the healthcare received from the video consultation is more effective and satisfying than the one at the closest clinic. (Mooi, Whop, Valery, & Sabesan, 2012)

Susan Royer writes in her article *Telemedicine in Cancer Management* about several telemedicine projects and their outcome. Below follows a few examples from her article.

In Indiana, The United States, telecare is used to help patients with cancer within the area of pain and depression management. In July 2010, a research was done to evaluate the outcome. The results were positive and by documenting the pain and depression of the patients, major reductions of these health related problems were made. Another conclusion from the research was that telecare can be used in management of other conditions than cancer too. (Royer, 2011)

There have been several other telemedicine system researches done in the United States, where the focus has been on quality, safety and economical benefits for patients living in outreached areas. Throughout their treatment, the patients visited the health professionals on their first

appointment and half of the following appointments. The rest were done through telemedicine. It could be concluded, based on patient satisfaction and economical savings, that telemedicine can be considered a “promising” technical solution. (Royer, 2011)

In Australia, women with hereditary breast and/or ovarian cancer, living in rural areas, were given video consultation by a genetic clinician. The result was reduced travelling and cost for the patients, which were highly appreciated by the participants. Despite the non-physical contact in the telemedicine consultations, the patients felt a “social presence”. (Royer, 2011)

From this review of different telemedicine systems, it was concluded that in general telemedicine benefit patients. It can improve clinical outcomes, and increase quality of life. It can be beneficial to all kinds of patients, not only those living in rural areas. It was also concluded that the type of cancer the patients have determines what type of telemedicine system should be developed and implemented. (Royer, 2011)

2.4.4 Human Computer Interaction and Telemedicine

When designing a system used in healthcare it is important that the user can use the technology without having to learn how to operate a computer. The computer serves as a tool, and will only be accepted if it provides more efficient, effective and satisfying healthcare for the patient. This leads to the importance of not only making the computer a usable tool, but also designing the user interface in a way that it optimizes the health care service. (Borälv, E., 2005)

When it comes to telemedicine, the definition of human factors can be defined as the study of how the users experience the product, and the strive to enhance the positive elements of the system’s design, implementation and usage. (Demiris et al., 2010) It is especially important to take human factors into consideration when designing telehealth systems to make sure that the systems are effective, efficient and usable by many different people with a wide range of physiologic and psychological disabilities. (Demiris et al., 2010) When designing a telemedicine system that is going to be doctor-patient used, it is important to take age-related questions into consideration, not only for the patients, but also for the healthcare professionals and the family members. The patients in many cases are above the median age, and the others are usually around the median, which in 2008 was 40 years old. This age difference in the user groups can cause some complications in the designing process. (Demiris et al., 2010)

3. Methodology

3.1 Interviews

In order to meet stakeholders and users needs, it is important for the designers to learn about the situation, context and the users. An easy and efficient way to do this is to arrange interviews (Preece Jenny, Rogers Yvonne, 2002.) This research project consisted of interviews with two different target groups. One being doctors and nurses at the lung cancer department at Karolinska University Hospital, and the other being any person that have developed and/or used a telemedicine system. To get the most out of our target groups we used semi-structured interviews. There was a basic script that was followed in order to make the interviews more concise. It included both open and closed questions. This was also to make sure that the same major topics would be covered for every person in each target group. We asked the first topic question, and then the interviewee was encouraged to talk until they went outside the topic. We made sure to add probes like, "Do you want to tell me anything else?" to give the person being interviewed a chance to add their own ideas to the semi-structured interview. (Preece Jenny, Rogers Yvonne, 2002)

As part of one of the interviews with experts within the telemedicine field a visit to the Childrens Healthcare of Atlanta was made. This was done in order to pertain a better understanding of what telemedicine is, and how it can be used. Located in the state of Georgia in USA it is a hospital that have been using telemedicine for several years. They mainly use interactive telemedicine to connect with smaller health care centers in Georgia to provide them with live video consultations, evaluations and training. While visiting the hospital Jill Davis, the Telemedicine Program Manager at the Children's Healthcare of Atlanta, was interviewed regarding their system.

3.2 Focus Groups

Focus group research is an adequate way to evaluate preliminary concepts with representative users (Rubin, J., & Chisnell, D., 2008) . In an early stage of a project it is important to identify and discuss matters such as "how acceptable the concepts are, in what ways they are unacceptable or unsatisfactory, and how they might be made more acceptable and useful", according to Chisnell and Rubin. One of the main advantages of focus groups as a research method is that it "encourages contact between developers and users". (Preece Jenny, Rogers Yvonne, 2002.)

To keep focus in the discussion and redirect if necessary a facilitator was required, in our focus groups one of the authors was the facilitator. (Preece Jenny, Rogers Yvonne, 2002.)

Focus groups are useful exercise to carry out to gain an insight on how the end-users are responding to a

device or a system is to create a simulation, according to the author of *The Role of Human Factors in Telehealth*. (Demiris et al., 2010)

From the results of the interviews we collected enough information to create a simulation of a video consultation. This video was then used as part of the discussion in the focus groups. This way the potential users of the system acquired a feel of how telemedicine could be used.(Demiris et al., 2010) This is an adequate method to use for explaining a scenario that a lung cancer patient might have, and explain a solution telemedicine could bring. (Demiris et al., 2010)

A focus group was conducted with nurses working at Radiumhemmet. Three scenarios were presented during the focus group. For the first scenario a short simulation of what a video consultation could look like was developed. The participants in the video were doctor 2 and one of the authors of this paper. It was filmed from both the doctor's and the patient's perspective and was presented to the focus group. From this a semi-structured discussion around reactions and reflections followed.

Our plan was to conduct the same type of focus group with lung cancer patients as we did with the nurses. We tried to get contact with patients through Stödet, which is a society where lung cancer patients can receive support after treatment of their cancer. Our contact person placed a "shout out" in the magazine they receive in their mailbox. He explained to us that email contact with the patients would be hard due to the fact that many of them do not have a computer. Additionally we placed information sheets at several different locations at Radiumhemmet. These sheets had a short description of the project, and our phone numbers. Unfortunately we received no call back. From shadowing a doctor at Radiumhemmet we learned that lung cancer patients are a very sensitive group of people which might be the reason no contact was acquired.

3.3 Shadowing at Radiumhemmet

When doing a user centered design it is important to not just name and categorize the target groups, it is strongly recommended to have a one-to-one contact with them. This is not only in the beginning; it applies for the entire development cycle. (Rubin, J., & Chisnell, D., 2008) Since our intention was to design a usable telemedicine system for both doctors and patients at the lung cancer department at Karolinska University Hospital we decided to acquire a direct contact with both groups. To do this we did what is called shadowing of a doctor, which implicates us being allowed to be part of several doctor-patients consultations at the lung cancer department. During these consultations notes were taken, and after the patient left we stated some general questions to the doctor concerning the consultation.

4. Result

4.1 Shadowing at Radiumhemmet

Shadowing at Radiumhemmet gave us a good understanding of how the interaction between the doctors and patients is functioning today. It also made us feel closer to the target groups and we received a general picture of the entire department. From the questions stated we learned how the doctors work at Radiumhemmet today, and what a visit could look like. The doctors we met believed telemedicine could work during the follow-up period of lung cancer patients, but they pointed out how important it is for them to see the patient. We asked more about this in the following interviews.

4.2 Interviews with Doctors

Two doctors from Karolinska University Hospital were interviewed. They are both lung cancer specialists, and work part-time at the Radiumhemmet treating cancer patients. Questions about the side effects, treatment, and complications of lung cancer were asked. We also asked questions regarding how the lung cancer department operates today to acquire an overview of it.

4.2.1 Doctor 1, MD, Department of Oncology-Pathology at Karolinska University Hospital

The interview took place at a facility at the Karolinska University Hospital. The interview was recorded and later transcribed. The answers that were relevant to this research paper are summarized below.

According to Doctor 1, dyspnoea⁴ and tiredness are the two most common side effects of radiation treatment. The tiredness is mostly an effect of the treatment of lung cancer. Dyspnoea on the other hand is often caused by the tumor itself, but also the radiation. He argue that the possibility to look at the patient instead of just having a conversation over the telephone is better in every case. There are always patients with special needs who need to see a doctor in person every time. He also claimed that it is important that the two first follow-ups after the radiation treatment are done at the hospital. These visits include physical examinations. This early stage after completed treatment can be very critical since the majority of relapse occurs in the first few months.

The follow-ups are almost always connected to newly taken X-ray photographs that need to be discussed with the patient in person. If these X-rays do not show anything unwanted no further clinical observations will be done, given that the patient do not have other complications. The follow-ups continues in a five year

⁴ breathlessness

period, and according to Doctor 1 the visits can be considered unnecessary if the X-rays have shown positive pictures all along. In these cases the patient only have to visit the hospital when a summon is received from the hospital. The patient may have to take a day off work to make it to the hospital. In a scenario like this Doctor 1 believes that telemedicine would work just as well as meeting the doctor in person.

When talking about Radiumhemmet and business Doctor 1 has a strong feeling that telemedicine could help them grow and develop. He thinks it will be much more time efficient, and improve the contact and evaluation of the follow-up patient. Today if the patient is feeling sick as a side effect of the cancer, they telephone Radiumhemmet. If the nurse/doctor judge that the follow-up patient's state is an emergency they have to go to the emergency room, otherwise if they could wait a day or two they will get an appointment at Radiumhemmet.

4.2.2 Doctor 2, MD, PhD, Consultant Clinical Oncologist, Department of Oncology at Karolinska University Hospital

When the interview was done with Doctor 2, specialist in lung cancer, he also mentioned the most common complaints due to lung cancer and the pertained treatment. He talked a lot about the diminished immune defense and the high risk of infections such as pneumonia and urinary infection. Other ailments also included fever, nausea, tissue-inflammations and of course stress and anxiety. It is important to understand that after the treatment the patient is feeling sick no longer because of the cancer, but on the basis of the treatment and the infections that comes along with it.

When asking if any follow-up visits can be considered unnecessary, Doctor 2 describes a scenario where the patient is feeling anxious and wants to talk to the doctor. Maybe it takes an hour to make it to the hospital, after that a 3-hours waiting time for a ten minutes session with the doctor. This is a typical case where at the end, just having a conversation with the patient is necessary. According to Doctor 2 another very typical scenario is that the patient often have many follow-up questions that are not brought up during the visit to the hospital. This is because many times questions are coming to the patient gradually after their visit. Due to this matter Doctor 2 feels that with some patients it would be good to have more steady and frequent follow-ups. Since only having a calm and steady conversation with the patient is a part of this, telemedicine could be a solution.

4.3 Interviews with Users and Developers of Telemedicine

4.3.1 The Service TeleQ

The patients treated at Radiumhemmet have the possibility to call the nurses with questions at any time

and every day of the week. The calls involve the patients leaving a message for the nurses and then waiting for a response. The nurses are able to call the patients back with answers and advice during a scheduled time. This service is being used today and is called TeleQ. An interview was conducted with the head nurse at Radiumhemmet, where she explained how the service is being used. At Radiumhemmet patients have their own contact-nurse. There are always one or two nurse's scheduled at the TeleQ-service between 7.30-16.30, but all of the nurses have to be ready to call back the patients who ask for their contact nurse. On a regular day there are 80-100 patients' calls to TeleQ. This number can however sometimes vary; it usually increases before holidays.

She explains that there are no statistics on what questions are most frequently asked, but it is very common that patients are calling because they just want to talk about their disease and are suffering from anxiety. Common questions include talking about the side effect and different treatments of their cancer. It is also very common that they receive questions where they lack competence. If so, they always contact a doctor before returning an answer to the patient. When talking about the difficulties and how the TeleQ-service could be improved she mentioned that it would be a lot easier if they were able to see the patient on a screen. When they are calling today and the patient has swellings, dyspnoea, inflammations and so on the nurses have to rely on the patient's descriptions.

4.3.2 Head Manager at a Health Centre in Sweden

A telephone interview was conducted with the head manager at a health center based in Sweden. He is also a district doctor and the head of an applied research in video consultation. From here on out he is going to be referred to as Person 1. Before the system was implemented the attitudes from both caregivers and patients were positive. The expected outcome was a more efficient healthcare. He was very positive to using a telemedicine system to make the health care better, more flexible and more available, but many in his staff were not after the pilot test. They experienced the system difficult to use, and too time consuming. According to Person 1 these reactions were due to how the system was designed and structured, not the functions of it. And since there was no marketing of the telemedicine system, the patients desire to use and approach the system depended on the encouragement of the doctors and nurses at the clinic. This, says Person 1, is why the system never was successful. Since the nurses were not excited to use the system, it discouraged other users as well.

Regarding security and integrity of the patient they argued that if the patient is at home she is responsible of others who might be in the room for example, the doctors and nurses answer for their rooms at the hospital. There were no economical benefits for the clinic; the visits were cheaper with telemedicine for the patient since the patient fee was diminished.

After the pilot test was concluded it was found that the most suitable patients groups are well known patients, follow-ups and sick-listening says Person 1. It is important to never use the system for new patient visits.

4.3.3 The Children's Healthcare of Atlanta

At the visit to The Children's Healthcare of Atlanta Jill Davis was interviewed with questions concerning a telemedicine system that is being used at the hospital today. This was done in order to gain a greater understanding on how to develop and implement a useful telemedicine system, and to gain a general idea of how it could work.

The interviewee put a lot of emphasis on what she believed to be the four most important components in a successful telemedicine system. These include the technology, buy-in, marketing, and support. It was explained that the technology used was easy to operate, and in order to minimize usage problems for the doctors and nurses proper training was given by Georgia Partnership for Telehealth. When it comes to satisfaction and comfortableness in using the system Jill gave a further explanation on what kind of equipment and technology was being used, and what the users thought of it. The stethoscope was connected via a Bluetooth connection, which enabled the doctor to listen to the heartbeat of a patient at a different facility. The medical equipment used to examine the patient's throat, ears and mouth had all a camera built into them. Jill explained that all doctors using this equipment believed that these high definition images transferred to them through a video consultation gave a much more detailed view than what they would receive in real life. The wall behind the doctor was painted in a special blue color to give the patient and the nurse, watching the doctor on the screen, a clearer picture of the doctor.

This system mostly saves time for the patient since they do not have to drive as far. The doctors do not save a big amount of time because there is a lot of paperwork required. Papers had to be faxed back and forth and filled out at the time of the consultation. Jill explained that the mission at the Children's Healthcare of Atlanta is not to make money, their only goal is to acquire better healthcare for the patients.

In order for the patients to feel safe and comfortable with the use no Internet connection was being used, instead they were powered by a dedicated cable managed by Georgia Partnership for Telehealth. This gave a trustworthy connection.

Jill also explained that the doctors at the hospital get paid the same amount they would if they were to see the patient in person, the clinics or presenting cites get paid \$ 25 dollars per session.

According to Jill marketing is a very important component of encouraging target groups to use the system. They have a marketing team that travel around in Georgia presenting the system to users. This not only helps when selling the system to stakeholders, it also helps the team to acquire knowledge, skills and other information about the end-users and to see in what environments the systems are going to be used.

4.3.4 CEO of Hands on Telehealth

A telephone interview was conducted with Nirav Desai. He is the CEO of Hands on Telehealth, which is a media and consultant company that helps providers and telehealth companies succeed with telemedicine. He is also the author of the book *10 Secrets of Telehealth Success*, and additionally he has written many articles about how to succeed when it comes to developing and implementation of telemedicine system.

What Nirav put the most emphasis on was the importance of getting to know the users and exactly what the users are in need of. He said “Don’t push telemedicine”, he strongly believed that it was important get to know the users before starting the development, and then throughout the whole designing process keep the users in mind. When it comes to telemedicine, according to Nirav, it is important to start researching questions like “At what time does the patient need extra care?” “When is the care giving delayed?”, “What issues are there today that need to be fixed?”, “What information do we need to know about the patient to give them care?”. Once questions like these are researched it is possible to zero in on what type of solution would be most useful for the target-group, and acquire the best user experience.

Nirav explained that concerns patients might have, like integrity and security, could keep them from using a system like this, and have to be taken into consideration. His words were, “There are a lot of systems specifically designed for Telehealth and these systems are secure for patients”. He also said that Skype and other Internet based systems would not be safe to use.

Other than getting to know the users well Nirav gave the advice to always start small when developing, designing and implementing a useful telemedicine system. This is to acquire an early win and make the users think “Yeah telemedicine works”. To make the users comfortable with the system it is important to minimize new things like technology, interfaces, and systems. Instead start small and add things on as time passes by. It is important for the end-users to “trust” the system.

4.4 Result Focus Groups

4.4.1 Focus Group Nurses

The focus group with nurses took place at Radiumhemmet with five nurses participating. The simulation of the video consultation was showed in the beginning, and after a discussion regarding the three scenarios followed. Below are the written scenarios followed by the nurses reactions and reflections of them.

Scenario 1:

A simulation of a video consultation was made for this scenario.

Patient A finished her radiation treatment six months ago. A week ago she came for a follow-up visit at Radiumhemmet to discuss her new X-ray images and her current health conditions. The X-ray images were positive even though there was something “unknown” that appeared in them. But according to the doctor this was nothing she had to worry about since the change was not significant and since she was healthy otherwise. A few days have passed since she had the meeting and she has been able to think about how she has been feeling lately and realized that she has been coughing frequently and is now feeling a bit tender in her throat. She has been searching online about complications after lung cancer treatment. The “unknown” in the X-rays, her cough and complications, and the research done online has made her extra worried and she wants to be in contact with her doctor as soon as possible.

Discussion questions:

- What do you think about this video consultation meeting? First reactions?
- Are there any “important” parts that are left out because of the telemedicine meeting with the doctor? (In other words, since the doctor is not able to see the patient in person)

The nurses had seen similar solutions, and their reaction was negative towards telemedicine systems. They could however see a telemedicine system with video consultation as a complement to TeleQ. Today the nurses confirm and follow up questions of the side effects and symptoms of the patients using TeleQ. They all agreed that telemedicine would ease these tasks since you would be able to see the patient. But they were negative to doctors not seeing their patient in person. They spoke of the importance of the ability to touch the patient and for example listen to the heartbeat and the breathing. Another topic they discussed was if the workload would be much higher with these consultations. Something else that the nurses brought up in the discussion was that almost none of their patients use the system *Mina vårdkontakter* (<http://www.minavardkontakter.se/>) to send messages or questions. Which is an eHealth-service used in Sweden where individuals can contact their health center to schedule, reschedule, or cancel a visit. Services such as renewing prescriptions and ask questions are also available. They thought this was an question of age and how comfortable you are in using a computer. The nurses believed the elderly patients prefer telephone contact before sending a message. Also the nurses prefer telephone conversations since there is almost in every case follow-up questions. One nurse expressed the difficulty to describe how one feels with written words in comparison with a telephone conversation, she said “You can hear pain through a telephone”.

Scenario 2:

Patient A went on a follow-up meeting to take his X-ray images some time ago. The images are positive and the doctor is going to call the patient up using a video consultation system to give the patient these news. The images have been sent to the patient with the help of the telemedicine system to give him a clearer picture of what his lungs look like. The patient has many questions

concerning the images that the doctor is answering.

Discussion questions:

- What do you think about this scenario? First reactions?
- What are the pros and cons in giving news like these through telemedicine?

One of the nurses opened the discussion with, “This would be very suitable!”. Another answered with the question what this would contribute with comparing to a telephone call. She continued, “I don’t really understand the thing with telemedicine. Possibly the patient can save travel time but I can’t see what we are gaining from it”. But they all agreed that giving someone positive news would be no problem and could work perfectly with telemedicine. The issue is how the patient reacts. It is impossible to predict one’s reaction, whether it is good or bad news. If you are not seeing the patient in person when the news are presented, what do you do if the patient gets upset? “If it is concerning bad news I could never use telemedicine” one of the nurses said. The other agreed, but one nurse added that it does not have to be a bad thing to give bad news with telemedicine; maybe it depends on the patient. As a nurse, patients sometimes tell you about their experiences and what they are going through with the disease. Often you hear about stories how they receive the news concerning the sickness, one of the nurses said. She ended with explaining the importance of the location of the patient when the news are received especially bad news, because of the possibility of a strong reaction. They should definitely not be alone when this happens.

Scenario 3:

It is year 2020 and Patient A has to take new blood samples for her next checkup. He lives far away from the Karolinska Sjukhuset and had therefore chosen to take the samples at home. During the sampling the doctor is present through telemedicine and later the tests are sent to the lab. The doctor is also able to do an overall evaluation of patient and is able to listen to the heartbeat and measure blood pressure through a Bluetooth system. Next time they meet, through telemedicine, is when the samplings have been processed. The patient is able to contact their nurse any time until then. The samplings are sent through a safe system; how this will be enabled the future will tell.

Discussion questions:

- Does this sound like a reasonable scenario? Do you think the patients would feel safe doing this?
- What are the pros and cons of moving the care away from the hospital?

Many nurses were sceptical towards the idea of patients taking their own blood samples. They were asking questions about integrity, and one nurse expressed "Why would you want to take your own blood sample if this could be done at your closest clinic". However, they believed that having a bluetooth stethoscope could work very well. When asked about moving the healthcare out of the hospital in the

future one nurse said “We are already there”. They believe it makes the healthcare more effective but only when it comes to minor cases. One nurse expressed, “Chlamydia tests are a good example of a minor case, the patients can take the test at home and if they receive the wrong treatment it would not be a big problem”. They believed that with cancer it is a completely different story. For these patients it is important to visit the hospital, since cancer is such a sensitive subject and the treatment has to be carefully managed. The nurses believed that if a patient were to take blood samples and tests at home they need to be healthy and very active in their own care giving.

4.5 Summary of Interviews and Focus Groups

4.5.1 Doctors

From the interviews with the doctors, and the responsible head nurse at Radiumhemmet it was clear that the biggest concern after treatment is the side effects and the risk of relapse. The most common types of side effects include infections, inflammations (most common within thorax), fever, anxiety and of course stress. Lung and heart monitoring are two common types of examinations during a follow-up-meeting, and with today’s technologies it can be done by using a Bluetooth stethoscope. However, X-rays and blood sample that also are parts of the follow-up cannot be done with today’s telemedicine technologies. After the conducted interviews we understand that it is important for the doctors to meet the patient face to face to. This is to be able to create an overall picture of the patient’s health status. From the interviews with doctors and nurses we were able to establish what can and cannot be done when it come to using telemedicine in medical examinations of lung cancer patients. This is summarized in Table 1 below.

Today there are around a hundred calls to TeleQ in one day, and many are made by anxious patients with a lot of questions. If telemedicine could provide a more frequent and steady follow-up of the lung cancer patients it would help the patients with their worries. It could also save some of the patients travelling time if questions could be answered by telemedicine. Video consultation would also help the work in TeleQ, the possibility to see the patient would make it easier to establish what symptoms that troubles the patient and how serious they are. In the interviews we also discussed when it was most important to see a doctor in person, and it was concluded that this would be the first months after treatment. “This early stage after completed treatment can be very critical since the majority of relapse occurs in the first few months.” says Doctor 1. However, the doctors thought telemedicine could make Radiumhemmet more time efficient and provide help with a more frequent follow-up of their patients. Telemedicine could also decrease the tension at the ER. In table 2 we present which patient concerns that can and can not be handled in a proper way using telemedicine.

Table 1. This table shows the most common medical examinations done on patients during the follow-up period .*
Both the patient and the health care professionals need the required equipment

	Telemedicine	Face to Face
Medical examination		
Blood sample		X
X-Ray		X
Lung and heart monitoring	X*	X
Overall health inspection		X

Table 2. This table shows the most common concerns lung cancer patients have after treatment.

	Telemedicine	Face to Face
Patients concerns		
Pain in chest		X
Fever		X
Anxious	X	
Strong cough		X
Questions concerning the disease	X	X
Questions concerning the X-rays	X	X

4.5.2 Developers and Experts

From the developers and users of telemedicine it can be concluded that it is important to know the users, and understand where the system would have the greatest impact. All of them agreed that the system should mainly benefit the patients; they had no economic benefit in mind. The major reason why the system was not successful at the health care center in Sweden was because none of the users were encouraged or eager to use it, and they did not see the benefits it would bring. Both Jill and Nirav talked about the importance of making the users feel comfortable with the system, and in order to do this it is important to start small and move forward from there.

4.5.3 Focus Group Nurses

Overall the nurses from the focus group were skeptical towards the use of telemedicine for lung cancer patients at Radiumhemmet. Their concern was how it would contribute to a better quality of the service for the patients and a better workplace for the medical staff. However, they thought it could be useful as a complement for nurses when discussing symptoms and side effects with the patients using TeleQ. They expressed the importance for a patient to meet a doctor in person since it is such a severe disease. Additionally, they believed telemedicine would work better for less serious diseases, but for lung cancer it is not suitable.

5. Discussion and Analysis

The fact that we were not able to conduct the focus group with lung cancer patients influenced our results. However, we believe that we acquired enough information from the interviews and the focus group with nurses to proceed with the discussion, and come to a general conclusion from our results.

In our discussion, we analyzed our results and answered our sub-questions to the best of our ability. The following sub-questions were researched:

Compared to today's solution, which advantages and disadvantages does telemedicine have as a means of communication between healthcare providers and patients at Radiumhemmet?

What are the users', in our case healthcare providers and patients, attitude towards using a telemedicine system?

How do you approach designing a user-friendly telemedicine system?

5.1 Possibilities and Challenges of Telemedicine for Lung Cancer Patients

New technology is an important part of taking a public service or business further, and making it successful and competitive. Within health care, telemedicine is gaining ground and adding new opportunities for medical treatments in countries around the world.

The goal of our research was to investigate the possibilities of using a telemedicine system at Radiumhemmet during the follow-up period of lung cancer patients. When talking to doctors and nurses working with lung cancer patients at Radiumhemmet some positive aspects and some challenges of telemedicine were brought up.

After being at Radiumhemmet for a few months, we experienced that the nurses have close contact with the patients, especially due to the contact via TeleQ. Therefore we believed it was important to listen to their thoughts and feelings regarding telemedicine. From the focus group it was clear that they were

worried about telemedicine decreasing the personal contact between patients and doctors. Since lung cancer is a very deadly disease and only 10% survives, it is important that the patients visit a doctor when they are feeling sick. Even if the patient has a meeting with their doctor through telemedicine, this would most likely result in a visit to the hospital. As Doctor 1 said, the first months after treatment are very critical since there is a high risk of relapse. During the early visits, new blood samples often have to be taken, and sometimes even new X-ray images. The doctors also expressed that they usually examine the patient physically when seeing them face to face. They look at the way they breathe, talk and move to gain a general picture of their overall health status. Both nurses and doctors mention the importance of being able to “touch and feel” the patient. Taking this information into consideration, we believe that telemedicine could not replace the visits in the early stage of the follow-up period. It is evident that the patient needs physical contact at the beginning. The high risk of relapse shows how important it is for the patients to make physical visits to the clinic. However, if they later during their follow-up period show positive X-rays, like Doctor 1 mentioned, their visits to the clinic could be eliminated with the help of telemedicine. Furthermore, this could help with the lack of patient space at the department.

The most common side effect of the treatment includes oesophagitis and coughing. Therefore, it is important for the doctors to be able to monitor the heart and lungs of the patients. This would not be possible by only using a video consultation. This concerned the nurses during the focus group meeting. However, there is a possibility to use stethoscopes with bluetooth-functions, this would enable the doctor to listen to the patient’s heart and lungs. If the patient could get a medical examination through telemedicine using bluetooth equipment at home, we believe the patient could avoid travelling and possibly save waiting time. It would go faster to ease the patient’s worries or establish if new tests are needed. If such technology and instruments can be used, we think new opportunities can open up, and telemedicine could have a greater use. Without this equipment, telemedicine can not assist in the treatment of the patients; instead, we believe it would have the most impact as an improvement of the TeleQ service. If the patients could have a video conference with a nurse or a doctor, we think the system could help treat side effects such as anxiety and worries.

5.2 How to Approach Developing a Useful Telemedicine System for Lung Cancer Patients

From the literature study carried out and from the interview done with Jill and Nirav, it can be concluded that telemedicine has a great impact on health care all over the world. If the developers are well informed about the end-users and both the hardware and software is user friendly, telemedicine can bring great benefits. These benefits, however, should mostly focus on the patients. When the focus group was conducted with the nurses we believe that they were too concerned with what benefits telemedicine would bring to them. As one nurse expressed, “I don’t really understand the thing with telemedicine. Possibly the patient can save travel time but I can’t see what we are gaining from it”. They were not able to see the greater picture of telemedicine. It was concluded from the interviews with the developers and users that in order to have a successful system, it is important to put main focus on improving patient health care

instead of focusing on the benefits for the nurses and doctors.

If the main focus would be on lung cancer patients when developing and implementing a telemedicine system, it would create some challenges. The disease is mostly common amongst people who are 70 years or older. In Sweden, it is also one of the deadliest cancers, and many patients do not survive longer than a 5-year period. From the focus group with the nurses it was said that many patients prefer to call Radiumhemmet rather than email questions using *Mina Vårdkontakter*. The nurses expressed that they believed this was a question of generation, and how comfortable the patients feel when using a computer. When we contacted Stödet to get in touch with treated lung cancer patients, the head person of the society explained to us that the easiest way to reach them would be by writing a “shout out” in their weekly newspaper, and then wait for them to call. He said that the contact with patients would mostly be done through the phone since many of them do not have a computer. Having this information about lung cancer patients, we believe that it could be difficult for patients to have the energy, will and knowledge to learn how to manage and use the technology that comes with telemedicine. This conclusion can of course not be made for every patient. There are lung cancer patients that have had successful treatments and are living a healthy life today. For these patients, a system where they could monitor their progress and contact their doctor through a video consultation system could be useful and bring great benefits. The big question is if the positive cases outnumber the negative.

From the focus group with the nurses, it is concluded that they accept the technology, but not the intended use of it. They do not think it will be successful for the intended target group, or meet the objectives in terms of benefits for patients and medical staff. Despite these opinions, if a system like this was developed to be used at the lung cancer department at Karolinska University Hospital we believe that the system and interface would have to be carefully designed. Also it would be important to take the current clinical processes into consideration. Either the system has to be adjusted to the routines of the department and the users behaviour, or the clinical processes have to be remodeled after the telemedicine solution. As mentioned many times in this report, in order for the system to be usable by the intended target group the system has to be modeled after the users, and not vice versa. Like Nirav claimed it would be important to start small, maybe even start with a small group of people who can test the system for some time. Once the users are accepting and trusting the system they most possibly will encourage other people to use it. We believe that it is important to follow ISO standard 13407 of a user centered design, which provides usable techniques on how to proceed when designing and implementing a system for a specified target group. This standard puts the users in the center.

The importance of marketing was expressed by Jill. We learned that in order to get to know the users of the telemedicine system they have a marketing team that travels to different sites in Georgia. This way they can see what environments the systems are going to be used in. The failure at Björknas health care center shows the importance of marketing. Since there was no marketing used at the health care center in Sweden the desire to use the system solely depended on the encouragement of the doctors and nurses. This technique of promoting the system was a failure since the nurses were not eager to use the system, which discouraged the patients to use it too. The nurses at Karolinska University hospital were skeptical to

the use of the system, therefore we believe that only relying on them and the doctors to sell the system would not bring success. It is important to have people that are engaged and have knowledge about telemedicine to promote the system to the end users.

5.3 The Greater Picture

In this paper we have only studied if telemedicine could bring opportunities for lung cancer patients and healthcare professionals at Karolinska University Hospital. Even though this research only included a limited target group we have realized that a system like this can be used in many different departments and businesses both within and outside health care.

In our study we looked at patient to doctor consultation using telemedicine. If the system was to be used, like it was at The Childrens Healthcare of Atlanta, between clinics and larger hospitals it could bring great opportunities for health care. Many elderly would not have to travel long distances since they could go to a local clinic that has a “connection” to a larger hospital, and they would probably feel more comfortable if they did not have to control the technology themselves.

Another benefit telemedicine could bring, is helping the patients receive the right care depending on their symptom. When it comes to cancer patients, the side effects are many and sometimes the oncologist might not be the right person to visit. The patients could be examined by using a video consultation system, and from this be told what type of health professional to visit. This would make the process of treating patients more effective, and proper care could be given right away.

We also think that telemedicine could be a compliment to already existing eHealth-solutions in Sweden. We think for instance video consultation could work perfect as a plug-in module in such systems. For example could *Mina Vårdkontakter* easily be made more useful if more functions were available. If it could be used as a self monitoring system and have a video function it would be a whole different tool for both patients and doctors, and bring new possibilities.

By looking at the even greater picture, it is evident that telemedicine could be used in other business fields. For example video consultation is suitable for educational purposes. It can help to provide lectures and tutoring despite any geographic boundary, and also be solution when there is a shortage of teachers. Also different banks in Sweden today are cutting down office space to save money. Video consultation could replace face-to-face meetings with the personal bank official to help solve the shortage of office space and available time.

"Making a product usable for people with disabilities—or who are in special contexts, or both—almost always benefits people who do not have disabilities" (Rubin, J., & Chisnell, D., 2008)

5.4 Discussion of Methodology

5.4.1 Interviews

The way the interviews were carried out differed from one another. One interview with a doctor was conducted at a location where recording was not possible. The other doctor interview was recorded and transcribed. This also happened with the interviews carried out with the developers and experts. From the interviews that were not recorded we fear that we could have missed out on minor details from what was said. This could have had a small effect on the results of the interviews.

5.4.2 Focus Groups

To be able to come to more a complete result a focus group including patients would have been needed. We believe that we did as much as we could during this limited time period to include them in our research. When it comes to the focus group of the nurses we believe that five different nurses were enough to get the discussion going, however some nurses talked more than others. We think that we could have directed the conversation a little better to get each nurse's opinion heard. We could have moved a little bit faster on the other discussion points, when the focus group was over we had some questions that we didn't have time to ask

5.4.3 Shadowing at Radiumhemmet

Even though a lot of time was spent at Radiumhemmet we were only able to participate in two doctor-patient meetings, both meetings being with the same doctor. If time would have allowed we believe that experiencing more meetings like this would have been beneficial to our research. Also shadowing different lung cancer doctors could have given us a better understanding of the department. However, we believe that the shadowing we were able to accomplish played a big role in our research. The area of telemedicine was completely new to us, as well as the hospital environment, and this was a great opportunity for us to get to know the potential users of the system.

6. Conclusion

Problem formulation:

Can a telemedicine system enhance follow-ups of lung cancer patients?

From our research, it can be concluded that telemedicine can enhance the follow-up of lung cancer patients to a certain extent. We believe that the service TeleQ could be improved with telemedicine. If the patients were able to have a video consultation with the nurse, it would make it easier for the health care professional to give the right advice, and ease worries concerning the disease. It would also make it easier for the nurse to establish how bad the patient's health status is, and therefore direct them in a more effective way to the right health care department. If a telemedicine system was to be used for the health check-ups during the follow-up period, technologies such as Bluetooth equipment would be needed.

In our research, the health care professionals have expressed the importance of seeing the patients face-to-face; also, the nurses were especially concerned over the fact that telemedicine could eliminate patient's visits to the hospital. However, the doctors believed that telemedicine could serve as a usable tool at the late stage of the follow-up period. Therefore, we think that telemedicine could not replace the follow-up meetings but instead serve as a complement to the clinical process.

Designing a telemedicine system for the intended target group will bring some challenges. The main focus needs to be on the patients, and a good idea would be to follow ISO standard 13407 which focuses on the end users of the system. The patient's computer skills and age have to be taken into serious consideration. The majority of the patients are diagnosed at an older age creating problems with the usability of the system. This does not include all lung cancer patients, some are younger and more technically advanced. However, since lung cancer is such a serious disease, we believe that the first named case outnumbers the second.

7. Recommendations

Telemedicine is a hot topic within healthcare, and the use of this technology is growing and evolving fast globally. Within a few years, we believe it will be more used in Sweden compared to today. Therefore, further research in the field of telemedicine is recommended. Areas of research that we believe are important include getting deeper understanding of patients' needs, studying the required infrastructure in more details, looking into the possibility of using telemedicine in use-cases and lastly researching the ability to use telemedicine between clinics and specialized hospitals.

A further research that could be done concerning the lung cancer patients at Karolinska University Hospital is specifying the user-scenarios that would benefit from telemedicine. This includes economical, patient and clinical benefits.

We recommend to follow Nirav Desai's advice to start developing and implementing telemedicine at a smaller scale. We do not believe that lung cancer patients would be the right target group to start with, instead a less seriously diseased group of patients should be a better option. If this group of users are accepting the system, they can encourage more departments to use it; thus, the system could grow to a great success.

Since marketing the system has shown to be an essential part of the development and implementation of telemedicine, we suggest that further studies be done. Our research has shown the importance of reaching acceptance among the users of a new technical system, and in a simple way shown the benefits of it.

8. Acknowledgement

This Bachelor thesis is a part of the unique investment made by the Clinical Innovation Fellowships (CIF), which is operated by the Center of Technology in Medicine and Health (CTMH) and is a collaboration between The Royal Institute of Technology, Karolinska Institutet and Stockholms Läns Landsting. CIF 2012-2013 cooperates with the oncology clinic at Karolinska. The Bachelor thesis is being supervised by two clinical mentors from Radiumhemmet; Rolf Lewensohn, MD within oncology and Michele Masucci, M.Sc. Information and Communication Technology. There was also additional supervision assigned by the multidisciplinary team of four individuals who are included in the project carried out at Radiumhemmet at Karolinska; Rui Chen, M.Sc. Mechatronics & B.Sc. Business Administration, Andreas Rundström M.Sc. Engineering Physics, Louise Warne, M.D. and Annika Österdahl, M.Sc. Economics & M.Sc. Biomedicine. The leader in the telemedicine project is Andreas Rundström.

To all intents and purposes, we would like to express our special thanks to Andreas Rundström who has supported us with great help and enthusiasm. We would like to thank our academic supervisors Anders G. Askenfelt and Anders Friberg, as well as our clinical supervisors Rolf Lewensohn and Michele Masucci for all the guidance throughout the process. We would also like to thank all the employees at Radiumhemmet for being helpful and accepting our presence at the department. Last but not least, we would like to thank the individuals who participated in the interviews and focus group.

9. References

9.1 Bibliography

- Demiris, G., Charness, N., Krupinski, E., Ben-Arieh, D., Washington, K., Wu, J., & Farberow, B. (2010). The role of human factors in telehealth. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association*, vol.16, no.4, pp. 446–53.
- Desai, N. (2011). *The 10 Secrets of Telehealth Success*, Hands on Telehealth, LLC, Marietta, GA.
- Center for Chemical Process Safety (CCPS) (1995) Human Factors. *Guidelines for Process Safety Documentation*, In: American Institute of Chemical Engineers, New York, NY, pp. 153-175
- Grimsbø, G. H., Engelsrud, G. H., Ruland, C. M., & Finset, A. (2012). Cancer patients' experiences of using an Interactive Health Communication Application (IHCA). *International journal of qualitative studies on health and well-being*, vol. 7, pp. 1–14.
- Mooi, J. K., Whop, L. J., Valery, P. C., & Sabesan, S. S. (2012). Teleoncology for indigenous patients: the responses of patients and health workers. *The Australian journal of rural health*, vol. 20, no.5 ,pp. 265–9.
- Preece, J., Rogers, Y., & Sharp, H. (2002). *Interaction design: Beyond Human-computer Interaction*, J. Wiley & Sons, New York, NY.
- Miller, E.A., (2010). *Telemedicine and the Provider-Patient Relationship : What We Know So Far*, Ph.D., M.P.A, Department of Gerontology University of Massachusetts Boston
- Royer, S. (2011). The King ' s Fund - Ideas that change health care Telemedicine in cancer management, 4–7.
- Rubin, J., & Chisnell, D. (2008). *Handbook of Usability Testing: How to Plan, Design, and Conduct Effective Tests*, Wiley Publishing, Indianapolis, IN.
- Borälv, E. (2005). *Design in Telemedicine. Development and Implementation of Usable Computer systems*, Ph. D, Uppsala University.

9.2 Internet Sources

- Bergman, O., Hont, G., Johansson, E. (2009) *Cancer i siffror 2009*. Cancerfonden och Socialstyrelsen. Retrieved March 12, 2013:
http://www.cancerfonden.se/Global/Dokument/omcancer/cancer_i_siffror/Cancer_i_siffror_2009_ny.pdf
- Bergman, B. (2010) Läkemedelsboken. *Lungcancer*. Retrieved March 23, 2013 from Web site:

<http://www.lakemedelsverket.se/upload/om-lakemedelsverket/publikationer/lakemedelsboken/lakemedelsboken-hyperlinked-h-adj/LB%202009-2010/J4-LUN-BB-HR.pdf>

Cancerfonden (2013) *Lungcancer*. Retrieved March 12, 2013 from Web site:

<http://www.cancerfonden.se/sv/cancer/Cancersjukdomar/Lungcancer/>

Cancerfonden (2012). *Cancer i Sverige*. Retrieved March 12, 2013 from Web site:

http://www.cancerfonden.se/Documents/CF-rapporten%202012/cfrapport2012_statistik_ny.pdf

Georgia Partnership for TeleHealth (2012) *Vital to Rural Georgia Future*. Retrieved April 23, 2013 from Web site:

<http://www.gatelehealth.org/index.php/2012/12/telemedicine-vital-to-rural-georgia-future/>

Global Media (2010) *How to get Started in Telemedicine*. Retrieved April 23, 2013 from Web site:

<http://www.globalmed.com/public/manuals/getting-started.pdf>

Hansen, H. (2008). *Textbook of Lung Cancer* (2nd ed.). United Kingdom: Informa Healthcare (accessed 2013-03-20 as e-book via Karolinska University Library at

<http://informahealthcare.com/action/showBook?doi=10.3109%2F9781439802014>)

Innovateus (2011) *What are the types of Telemedicine?* Retrieved April 23, 2013 from Web site:

<http://www.innovateus.net/health/what-are-types-telemedicine>

Karolinska (2013) *Onkologiska klinikens visioner och uppdrag*. Retrieved April 15, 2013 from Web site:

http://www.karolinska.se/Verksamheternas/Kliniker--enheter/Om-Cancer---Onkologiska-kliniken_20101104_1020/Onkologiska-klinikens-uppdrag-och-vision_20110606_1657/

Karolinska (2013) *Tematisk vård ska rädda fler liv*. Retrieved April 15, 2013 from Web site:

<http://www.karolinska.se/OM/Om-sjukhuset/Strategiskt-utvecklingsarbete/Berattelser-om-vart-flo-desarbete/Tematisk-var-d-ska-radda-fler-liv/>

Karolinska (2013) *Bra att veta för dig som är patient eller besöker oss*. Retrieved April 15, 2013

from Web site:

http://www.karolinska.se/Verksamheternas/Kliniker--enheter/Om-Cancer---Onkologiska-kliniken_20101104_1020/Kom-i-kontakt-med-onkologiska-kliniken_20110310_0945/Bra-att-veta-nar-du-kontaktar-eller-besoker-oss/

Lungcancerförbundet Stödet (n.d). *Indelning i stadier*. Retrieved March 23, 2013 from Web site:

http://www.stodet.se/?id_site=1&id_item=101&iPage=4

Nationalencyklopedin (2013) *Telemedicin*. Retrieved February 14, 2013 from Web site:

<http://www.ne.se/telemedicin>

National Cancer Institute (n.d). *Cancer Cells*. Retrieved March 20, 2013 from Web site:

<http://www.cancer.gov/cancertopics/wyntk/lung/page3>

Statistiska centralbyrån. (2012) *Befolkningsutveckling; födda, döda, in- och utvandring, gifta, skilda 1749 – 2011*. (Elektronisk) Rapport. Stockholm, Statistiska centralbyrån. Retrieved

February 2, 2013 from Web site: http://www.scb.se/Pages/TableAndChart____26046.aspx

TTUHSC (2013) *Telemedicine*. Retrieved April 23, 2013 from Web site:

<http://www.ttuhscc.edu/telemedicine/faqs.aspx>

