# Design and Acceptability Testing of a Medical Data Collection System Using Smart Technologies

Master's thesis in Software Engineering

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# Summary

The purpose of this thesis is to identify key criteria that maximizes the acceptability of a data collection and visualization system using smart devices for cancer surviving patients and their nurses. It focuses on oncology nurses and their respective pelvic region cancer surviving patients. The thesis makes use of participatory research and participatory design. Specifically, a case study on nurses and patients of Sahlgrenska universities oncology department was conducted. It was done in collaboration with EfterCancern, a collaboratory research group within Sahlgrenska's oncology department.

The data was gathered by a series of interviews and workshops with the nurses as well as a one month usability study with a patient. In addition, parts of design science research was used by creating prototypes and evaluating them with the participatory parties. The developed software includes a server backend, a web portal, and a mobile application. Smart devices including Flic buttons and FitBit armbands were used. The devices communicate with various parts of the system. The results were taken from a thematic analysis of the collected data and the associated usage data from the devices and software.

The nurses major acceptability factor for the smart devices was purely in the data gathered by the said devices. In regards to the software they would be interacting with, the biggest criteria is that they must believe that the software is helping them and/or the patients. A more measurable criteria is that the software must easily supplement their work practices and be easy to learn. It also came apparent that the similarity to the nurses previously used systems largely affects the learnability and understandability. On the other hand, the patients acceptability of the collection system and smart devices mostly regarded their motivation for using the said technologies and the autonomy of the devices.

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# 1
# **Introduction**

"Alla vill att det ska vara som vanligt, men för mig kommer det aldrig att bli det" [2]. This translates roughly to... "Everyone wants things to be normal, but for me, it never will be."

## 1.1 The Problem

The above situation is the situation that pelvic region cancer surviving patients (PRCSP) face. Software systems such as Patient Communicator [3], Equilibrio [4], and Avado [5] have attempted to help increase patients life quality by doing various things such as communicating directly with physicians, creating health and wellness plans, and managing patient relationships. However, although these software systems being developed can potentially help the patients' life quality, they are not always accepted and used. There are various reasons these systems fail and are not accepted. One reason is the lack of a specific focus [5]. Software may be trying to solve too many things at the same time within the same system. There is also the problem of motivation. Expecting the users to enter too much information can have a discouraging effect on them, in turn they may lose confidence in the system [5].

It can be argued that software systems can solve the problem of population aging and the shortage of medical professionals. It is estimated that 1 in every 8 people will be over 65 in the year 2030 [1]. With more elderly, it can be assumed that there will be more patients. This phenomenon increases the demand of medical professionals, medical centers, and medical resources. It is estimated that today, the world is short 7.2 million healthcare professionals, and by 2035, that number will be 12.9 million. [6] One possible scenario is that eHealth solutions would help following, assisting, and diagnosing patients from the comfort of their homes. This could potentially drastically reduce the number of medical professionals needed and provide patients that previously could not get care to receive medical treatment. However, usability and acceptability are big challenges for all eHealth solutions.

At Sahlgrenska University Hospital, a medical data collection and visualization system to improve the lives of cancer surviving patients is under development. This system is collecting data by using smart devices: a FitBit armband, Flic button, and smart phone. Like other eHealth solutions, the development of this system is also facing the challenges of usability and acceptability.

## 1.2 The Purpose

This thesis aims to identify key criteria that maximize acceptability of a data collection and visualization system for cancer surviving patients. In the same way system usability by healthcare professionals should as well be maximized. The scope is specifically confined to pelvic region cancer surviving patients and a special focus is given to smart wearable devices. This study also looks at the feasibility and usefulness of using new smart devices to supplement data collection in healthcare. This study will look at the acceptability of these specific smart devices to find general criteria in which a smart device is accepted or not.

This study is not just meaningful from a research perspective, but also from a practical perspective for the patients participating. This research may allow the patients to receive better individualized treatment that may help them recover faster as well as it may help to reduce the risk of misdiagnoses and incorrect treatment.

## 1.3 The Structure

This thesis opens with the background, providing a theoretical framework in order to explain the concepts needed to understand the thesis. The background introduces the case used by this study as well as key terms, the research questions, a literature overview, assumptions, and the variables of analysis. It is then followed by the methodology used, which is geared towards a participant centered research approach. The results follow the methods, which include the main findings of this study including the discovered acceptability criteria. Naturally, the discussion of the study follows the results. The discussion includes limitations of the study, potential variables that may have affected the study, and, a more qualitative and discussion based approach of analysis. Finally, the conclusion will wrap up this thesis, which combines all of the important main points of the study.

# 2
# Background

This section provides a theoretical framework for this study. It begins with common important key terms throughout this study and is then followed by the main case. After a background understanding is set, the research questions are brought out and, of course, the background for why this study has those research questions follows. Wrapping things up, the variables that will be looked at and this study's assumptions are presented.

## 2.1  Key Terms

**Data accuracy** How close a measured data value is to the real value. For example, a patient saying the afternoon is less accurate than saying 12:30.

**Data precision** How specific a data value is. For example, the data type "time" with a value of 13:55 is more precise than a value of 'In the afternoon'.

**Feasibility** In this specific study, because the word acceptability is used in many cases, the definition of feasibility is slightly skewed. This study refers to the feasibility of a system as whether or not the nurses and patients would accept a system such as the developed system on a general level. Whereas the acceptability of the system is the specific acceptance of a system meeting certain acceptability criteria.

**UX(User Experience)** "UX is about technology that fulfils more than just instrumental needs in a way that acknowledges its use as a subjective, situated, complex and dynamic encounter. UX is a consequence of a user's internal state (predispositions,expectations, needs, motivation, mood, etc.), the characteristics of the designed system (e.g. complexity, purpose, usability, functionality, etc.) and the context (or the environment) within which the interaction occurs (e.g. organisational/social setting, meaningfulness of the activity, voluntariness of use, etc.)"[7].

**Wearable** Electronic technologies or computers that are incorporated into items of clothing and accessories which can comfortably be worn on the body. [8]. For example, a FitBit armband.

**Semi-automatic Data Collection** is data collection that partially collects data automatically but still requires the manual user input of specific data factors that are not collected automatically. The system in this study involving an event driven system is semi-automatic.

**Pelvic Floor Exercises** The pelvic floor muscles support the bladder and bowel. Pelvic floor exercises are activities that can be done to strengthen those muscles.

**FitBit armband** The FitBit armband is an activity tracker, which is a wireless-

enabled wearable technology device that measures data such as the number of steps walked, heart rate, quality of sleep, steps climbed, and other personal metrics. [9] The FitBit armband can be seen in Figure 2.1.



**Figure 2.1:** The FitBit armband

**Flic button** "Flic is a small wireless button that you can stick anywhere. It connects to your iOS or Android device and works right from the start." [?] The Flic button can be seen in Figure 2.2.



**Figure 2.2:** The Flic Button

## 2.2 EfterCancern

EfterCancern (EC), a collaboration between Gothenburg University and Sahlgrenska Hospital, believes that technology, digitizing medical knowledge, and artificial

intelligence is key to the future of the medical field [2]. The project aims to improve the lives of cancer surviving patients. One way they plan to do this is by developing an intelligent system for PRCSP that will analyse the patients' data and offer individualized treatment plans. However, such a system may or may not be accepted. Motivation and many more factors become a role when collecting data from the patients as well as when the patients are asked to test and use the system as a whole.

In order to continuously collect data from the patients in a self collecting system with manual components, the data collection method must be enticing enough to keep the patient interested. To minimize the amount of work needed by the patient to collect their own data, EC aims to automate as much of the data collection as possible. This study analyzes the possibility of making use of user friendly smart devices to help EC collect this data. Some devices are semi-automatic and require minimal user interaction(Smartphone app, Flic button), while other devices are fully automatic, such as the FitBit armband. Although the projects' scope is PRCSP, EC expects their research can be built upon and used to help revolutionize the medical field as a whole.

## 2.3 Research Questions

One focus of this thesis is based around the feasibility, usability, and acceptability of using smart technologies in a data collection software system along with the patient and nurse acceptability criteria of such a system. The driving research question is specifically "what are the patient and nurse acceptance criteria for a data collection and visualization system using smart technologies?" (RQ1).

### 2.3.1 Software Engineering Sub Questions

RQ2 Is it feasible to develop a data collection system using smart technologies to gather the patient data?

RQ3 Does using smart technologies in a data collection system, assist in improving the accuracy and precision of data?

RQ4 Does the increase in data collection smart technologies decrease the usability of the software system as a whole?

### 2.3.2 Medical Sub Questions

RQ5 Do patients believe they are more motivated to participate in fully autonomous, semi autonomous, or fully manual data collection projects?

RQ6 Do the nurses believe the data gathered by this system allows them to provide, in their opinion, better individualized treatment plans for PRCSP?

RQ7 What is the perception of nurses and patients when introducing a new technological system to compliment already existing practices?

RQ8 Can a semi-automatic data collection system elicit data faster than traditional methods and in turn shorten the necessary patient meeting time?

## 2.4 Literature Review

This literature review starts by going over the current state of mobile health to get a general overview of what can be done with current technology. In the next section, acceptability of technology in general is reviewed. Both the health care sector as well as acceptance of wearables and mobile technology, both from a health care professional and patient perspective.

### 2.4.1 The Study's Importance

Interdisciplinary work between multiple fields such as medical professionals, engineers, and psychologists is necessary for the success of wearable devices and applications [10]. This is why nurses, patients, researchers, and engineers must all be a part of creating acceptable and usable software. Likewise, the development of an integrated architecture of intelligent home services using wearable systems and devices for health and wellness are considered one of the key solutions for moving research and development forward [11].

Despite the potential benefits of these devices and their data, there are many challenges that the device manufacturers, software developers, researchers, medical professionals, and more face. One major challenge is motivation and the user's drive to use these devices for a prolonged period of time. In order to obtain a potentially useful and accurate analysis of the data, the users must wear the devices for a prolonged period of time and must collect accurate and complete information. Studies have shown multiple ways of retaining user participation and reducing tracking fatigue and failure [13]. Automatic collection with the minimization of patient interference is needed. Also, showing a user a lot of numbers and information is not effective in retaining user participation. One way around this is to use of gamification techniques and metaphorical representations in the applications using the data, such as [14]. In order to support long term engagement with wearables, personalization and the patients' feeling that the data and interfaces are unique to them are key [15]. Another thing that keeps motivation is the ability to support self efficacy needs, which can be solved by introducing goals that can be met based on the wearable devices [16, 17].

Another challenge faced is informational privacy. It is connected with the confidentiality of patient data. That means that informational privacy is going to take on increasing importance in the future with the on-going growth of data processing [18]. It is very important to address ethical and privacy concerns related to this data and inform the users exactly how their data will be used and the process the data takes from collection, to analysis, and back to the users. The main areas of privacy concern in the delivery of health care are related to the protection of data and prevention of inaccuracies of information, which could have an effect on people's confidence in the system [18]. Wireless networking is another barrier to the deployment of such technology. Not only because of privacy concerns but also because of availability. In France for example, high-speed internet is not available

everywhere. Therefore, accessing services online is not always possible [19].

Despite complete availability of high-speed internet, the usage of mobile phones to access medical data is increasing exponentially and the number of wearable technology units are expected to grow from 9.7 million units in 2014 to 135m in 2018 [20]. These figures show that wearables are just starting to grow. This may suggest that wearables and research on wearables in the medical field will also explode and grow as well. This is one of the driving points behind why this research on acceptability criteria for software, specifically regarding wearables, has been undergone.

A common technology applied within mHealth is wearables. The term mHealth was coined by Robert Istepanian as the usage of "emerging mobile communications and network technologies for healthcare" [21]. Wearables are considered the predecessors of wellness and mHealth applications. Some of these trackers collect data about the user's physical activity from various sensors, for example for measuring steps taken and time periods between standing and sitting [22]. Due to the exponential growth of wearable devices expected in the coming years [20], it is to be expected that the market of applications making use of this technology will become increasingly competitive. Thus it is important to research the acceptability criteria of both the devices themselves and the associated applications as the number of devices and software grows exponentially in an increasingly competitive market.

Data without context is not very useful [23], which is the reason for the need to consult health care professionals to interpret the medical data collected. A problem arises when the need is to separate irrelevant patient data for their nurses from the critical and useful patient data for the nurses. By focusing on patients, mHealth contributes to the reformation of health care by changing it from a push system to a pull system where the patient pulls only necessary resources [24]. It places tools for monitoring and health diagnosis in the hands of consumers along with online services to monitor their data [25]. In the future mHealth apps and services have the potential to provide actionable information, coaching and alerts at the fraction of the cost of conventional health care [22]. EC plans on making use of this technology to both lower workload on oncology nurses and provide better treatment for cancer surviving patients [2]. With the increase in wearables and the increase in active patients in a pull system, the need for usable software in order to accommodate these patients increases.

### 2.4.2 Technology acceptability in the healthcare sector

Research on medical technology has been mostly based on technical, medical and economic disciplines [26]. However, aspects of technological acceptance as well as the detailed study and understanding of using motives and barriers tend to be disregarded within technical development [26]. Medical technology, especially when it comes to home-care and rehabilitation, cannot achieve its full

potential unless acceptance issues of medical applications are well considered and implemented into design [26]. User perception and acceptance is important [27]. For acceptance of devices and technologies, system efficiency, reliability, and unobtrusiveness are essential [28].

### 2.4.2.1  Acceptance of mobile and wearable technology

Elderly users(the most common group needing medical assistance) perceive independence and autonomy as crucial for their everyday life, so that any systems or technology that can prolong that independence tends to be highly considered [27]. This is supported in an Australian research study. Authors of the study claim that any system or technology that can prolong independence tends to be highly accepted[29]. However, there can be tension between assistance and autonomy, or privacy and independence that forms the judgement of individuals when using mobile health technology [30]. In [29]'s study, researchers found that 93% of patients in a geriatric care facility accepted a wearable system. The reason for that was because it was minimally invasive and did not interfere with their normal daily life.

The acceptability of certain systems was reduced when patients confidence in the devices decreased, with a key confidence factor being the correct use of the equipment. When patients were not sure about correct usage, it had a negative effect on data output, compliance and confidence levels in the system. [31]. This shows the importance of understandability of such medical systems involving wearables.

In a study made in 2010 on technical acceptability of health care technology, they found that age had the most significant effect on peoples' technical confidence [26]. Not surprisingly, the higher the age of the respondents, the lower technical experience they had. Gender also played a large role in the amount of experience. It was found that women had a lower technical self-confidence in technology than men.

Surprisingly when it came to positive attitudes towards medical technology, age seemed to have no effect. Also surprising was that despite women having less technical experience and confidence, they seem to have more positive attitude towards medical technology. When it came to negative attitudes towards medical technology, age had a significant effect, where negative attitudes increased with age. Gender had no effect on the negative attitudes. It is apparent from this study that despite the older generation having the most need for medical technology, they still have lower acceptance than the younger generation [26]. This shows the importance of involving the older generation in design approaches of medical technologies because they are the ones in the most need of assistance, as health deteriorates with age [26]. Based on these results it may seem to be essential to take elderly patients, especially women in consideration when discovering the software acceptability factors.

## 2.5 Variables of Analysis

This study will focus on the acceptability criteria of software systems for PRCSPs. Specifically, the variables of analysis are the usability of each of the smart devices along with specific quality attributes of interest. The quality attributes of interest include privacy, security, usability, adaptability, accuracy and operability. In addition, from a medical standpoint this study will look at the accuracy and precision of patient defecation data gathered from the developed intelligent data collection system using smart technologies and evaluate the time of each defecation, the number of defecations a day, and richness of information about the defecation with what the patients normally say about these factors of their defecations during a nurse's patient meeting. This study will also look at the following variables to further elaborate on the sub-research questions: the experience of the patients using the system, usage statistics of the system, and the nurses' final evaluation of the usability of the system as a whole.

## 2.6 Assumptions

We assume that smart technologies and semi-automatic data collection systems increase the time efficiency of data collection. We assume this because automatic data collection requires no user interaction except for setting up the device, on the other hand, manual data collection requires the documentation of every bit of information being collected. For example, the FitBit armband only requires the user to connect it to their phone and wear it instead of manually checking and documenting it on their own. This vastly reduces the amount of time needed to collect data factors such as a users heart rate and the number of steps taken in a day. The Flic button is also assumed to increase efficiency because rather than a user taking out their phone, unlocking it, going into the application, and logging a defecation; a user only has to take out the Flic button and press it twice to signify they just had a defecation.

The understandability of the data regarding the smart technologies is assumed to be similar to the results of other projects surrounding data collection. It is assumed that the data will be understandable when the user is not flooded with options and factors. Also it is assumed to be understandable when the data is relevant and the user can easily see the reason behind being shown the data. It is assumed that when more factors are added, the understandability will decrease. It is also assumed that when more data factors are visualized, if the system is used, many of the factors will be ignored and just cause unnecessary added confusion. The visualizations of the data assumptions were assumed because of chats in EC and also because of previous development experience.

# 2. Background

# 3

# **Methods**

This thesis followed a design research methodology focusing particularly on using participatory design practices [32] [33] [34] in order to improve the software engineering design process when developing for pelvic region cancer surviving patients. This study is also conducted using an qualitative case study. To begin, in order to start answering RQ1 a literature review was conducted to gather knowledge from previous experiences and to find a basis for the important general acceptability factors of consideration. Regarding a majority of the remaining research questions, participatory research was used and data was elicited through various types of meetings. Specifically, the case study involving workshops, interviews, and surveys was used to answer all of the research questions.

This section begins by looking at why participatory research was chosen for this project. Following, the beginning of the study and how the study was approached is addressed. Finally, methods specific to eliciting the data from EC are discussed. This study's case of EC was broken up into many small chunks, each for a reason to elicit specific requirements and software engineering knowledge. Everything regarding the case was done in a participant based approach so that knowledge was gathered from every participatory party.

## 3.1   Participatory Research

Participatory research and participatory design specifically were chosen because user involvement can be argued as crucial for the success of any medical innovation. A similar methodology, design-science research [35] would have been a valid option, but because of the goals focus on finding acceptability criteria and focusing on the design and the design process, participatory research was chosen. [36] argues that users that take part of the design process will have an easier time using the product and an easier time supporting their work with it. Participatory design was also chosen because [36] states that in a hospital, medical experts hold most of the power and control, while the patient and researcher are in low control. In retrospect, in a home setting, the patient holds most of the control and the medical expert and researchers are in low control again. This is why both the patients and nurses were chosen as main participants. Our system is to be used both from the patients' homes, and at the nurses offices. These reasons are exactly why we chose to do a participatory research case with a prototype and review based approach.

Certain participatory research methods were chosen over others because of the proposed benefits and challenges of each method. Sittings with the nurses were held because it was important for the nurses to have an understanding of the technical possibilities and the developers to have a better understanding of the nurses work practices to ensure a usable system was built [37]. Workshops with the patients were chosen because workshops have been shown to keep user engagement, which is important for continuous data collection. Also, workshops are claimed to produce new concepts and artifacts which can potentially find areas where different technologies can collect data, or where new UX practices can reduce time taken to gather certain data factors, or where it is too hard for patients to fill in so a new way to gather that data factor must be found. However, participatory research has it's limitations and challenges. [37] says that "you can't just add users and stir". Most users don't understand the possibilities and limitations of the technologies being used like the developers and designers do. This is precisely why it's important to prioritize the requirements that are elicited with participatory research and it's very important to take a stand and speak up when something can't be done or is too costly to be done. Finally, because there were actual patients involved, data privacy and security was taken very seriously. More about this can be read in appendix A.

## 3.2 Requirements Elicitation

To elicit the initial requirements, a literature review of previous work in the fields of quantified self data, wearables, patient acceptability, IT in a medical setting, and UX design was completed. The literature review was to elicit a starting point for not only the research study, but also the design of the systems being developed. Because participatory design was a main focus, throughout the study several interviews, semi-structured, were held in order to gain nurse and patient input in both the design and content of the application.

## 3.3 Workshops and Surveys

In order to answer a majority of the research questions, a qualitative study involving workshops, interviews, and a survey was conducted. These workshops were semi structured and involved the showing and evaluation of a back-end prototype as well as thoughts of the nurses work practices and how to meet the software to their needs. The survey was sent to patients in order to get their thoughts on the application and smart devices that were used and discover why the patients were or were not using it. These workshops and interviews would be analyzed and coded looking specifically at what made the software acceptable or not acceptable and then analyzing the principles behind why the specific criteria made for acceptable or unacceptable software. It is important to note that the survey was analyzed a bit differently because the surveys were not qualitative transcribed meetings. Instead, the survey was analyzed on a question to question bases where the direct written response of the patient was the analysis answering the

specific questions about the software. The survey given to the patients after their system trial is located in Appendix F.

## 3.4 Usage Statistics

Addressing acceptability can be a difficult task. In order to identify if our solutions were acceptable, usage statistics were gathered regarding the nurse usage of the back-end system and the patient usage of the application and smart devices. Based on if the applications were used and how often, as well as the qualitative study with the nurses and patients, this thesis can assume if our application was actually accepted or not, beyond what the participants just say.

## 3.5 Analysis

It can be argued because of the main research question itself, that a thematic analysis [38] is the best way to detect the acceptability criteria of the nurses. A thematic analysis was used because if a theme is identified, then that theme may very well be an acceptability criteria. In addition, because the patients talk about their usage of the system and their personal experiences with it, a narrative analysis [39] fits for eliciting patient requirements. The idea behind these two methods is to find patterns in what would make the users not use the system, in turn, generating acceptability criteria.
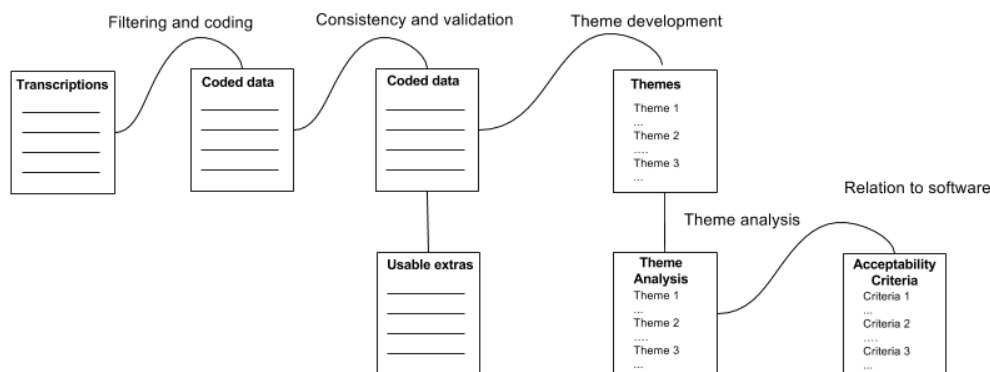


**Figure 3.1:** Methodology overview - Thematic Analysis

Figure 3.1 shows the steps taken in regards to the thematic analysis used in this study. It is important to note that some steps were modified because of limitations for this study. The steps cited next do not relate to the steps listed in this thesis, instead they relate to the steps in [38]. Step 1 in the process of reading and re-reading the data was skipped because of the time constraints. Step four was also skipped because there were no preconceived interpretations

or expected results. The following sections describe the steps used in this thesis for the thematic analysis of this study's data.

### 3.5.1 Thematic Analysis - First Pass

After the transcription of each workshop and interview, the first pass of the text was meant to generate the initial codes and to eliminate text not related to the software. The result of this pass on each text was another shorter, but still very long, text where each section or idea was labelled with a code. Below is an example of a transcription before any passes are complete.

*"D1: So we are first trying to figure out exactly what is known. We already know from the website that they can have a diet for the gas and probiotics and em the different tablets and toilet gyms, the training, but we were wondering... we were also measuring things such as the type of defecation that they have and the frequency. How often can they not control it and stuff, things such as that. So we are going to be building an application where you fill out forms... [nurse short question] hopefully. [nurse short question] button. We were basically wondering... Is there anything you ask the patients for, certain questions that maybe are not specifically here on the website so you ask the patients and maybe they might not give you the exact correct answer but you need it."*

During the first step, text not related to the software was removed. The previous text was removed and changed to say just "unrelated" in the output of the step. This signifies that something did exist at that location, but it does not relate to the software. Leaving a marker potentially helps with the analysis when looking at the context of resulting themes.

Below is another example of the first pass of the thematic analysis and how it was coded.

*"D2: Okay and then when you finish it should be really happy. It should feel good to finish.*
*S2: När man är färdigt då får du torta, it looks great.*
*D1: When you finish and you try to log in again and you have no surveys it would be like, yay you did it.*
*D2: Hopefully some animated balloons.*
*S2: Good yes."*

The code of the previous transcription is "Nurse's thoughts on patient's perspective". This transcription was mapped to this code because the nurses were talking about the application and what they thought should be in the application because their patients think a certain way. The text was kept the same and only the code was added.

### 3.5.2 Thematic Analysis - Second Pass

The second pass of the text created a second text. It was meant to validate the codes and recode the remaining text from after the first pass to ensure consistency and accuracy after the unrelated text was removed and all the initial codes were completed. An example of this is a pass on the data requirement for Inolaxol. The nurses spoke about Inolaxol and the initial code was "Inolaxol". After the second pass and realizing that this data does not relate to software criteria, the "Inolaxol" code was changed to "Data". Like this, the codes were made more relevant to software if they weren't previously. the result of this was another text that looked very similar to the result of the first pass.

### 3.5.3 Thematic Analysis - Themes

The third step taken was to group the codes into themes. For example, all data codes were grouped into the theme of "talking about data". Additionally, all the questions and trouble they had while navigating with the codes of "Video Chat Confusion", "Homepage Navigation Confusion", and more were grouped as the theme of "UX confusion". The result of this step was a list of themes for the text, similar to a keyword list.

### 3.5.4 Thematic Analysis - Why

The fourth step in the analysis was discovering why each theme emerged. The data was reread by first looking at the theme, then looking at all of the codes that made up that theme, and finally reading all of the text that was labelled with those themes in order to discover why that theme may have emerged. The result was a text similar to the results section that had a theme and then a description of why the theme may have emerged.

### 3.5.5 Thematic Analysis - Acceptability Criteria

The final step was to take the themes and the reasoning behind the themes and relate them to software acceptability criteria. The theme and reasoning was analyzed to look at what that meant in relation to software. The results of this is a text that looked similar to the results of the thematic analysis but modified and worded in a software acceptability way. This resulting text was moved to the results section in this thesis and elaborated on and structured in a point to point way as can be seen in section 4, "Results".

### 3.5.6 Analyzed and Usable Extras

In addition to the thematic analysis, some results were taken from the codes themselves and analyzed if the codes related directly to the software. An example of this is the code of "relating to other software". This was not a major theme, however, when walking through the system and finding out why they could or could not use it, comments regarding the system in relation to other systems

came up as a way or trying to use the developed system. The comments were specific to the learnability of the system and thus it was judged as a notable software criterion and brought to the results.

## 3.6   Case Study - EfterCancern

Working with EfterCancern allowed direct nurse and patient involvement in order to do a more qualitative study discussing and discovering which parts of software are more important than others and which things software engineers should not do in order to keep both patient and nurse acceptability. Because the nurses are the main actors using the back-end system, the majority of the study continuously involved them in order to contribute to the understandability of the system as well as the usability of data being gathered.

### 3.6.1   First Nurse Interview

The first interview was unstructured and was held in order to elicit the data collection and data visualization components' requirements. This interview also was to help in understanding the work flow of nurses, how they communicate with the patients, the technologies they currently use, and the disagreements the nurses have amongst themselves. Knowing this helped to begin understanding what it took for software to be accepted by the patients.

### 3.6.2   Second Nurse Interview

After the schema, structure, and design were developed, another nurse interview was held. During this interview, the schema, structure, and design were rated and validated in order to analyse which parts implemented were the most important and what were some factors in our design that made the product unacceptable and which factors the nurses liked and made it usable.

### 3.6.3   First Nurse Workshop

The first nurse workshop was held after a prototype of the back-end system of a video chat, nurse portal, and patient portal was developed. This was held in order to estimate the acceptability of the prototype as well as find factors in the prototype that may lead to low and high product acceptability from the nurses perspective.

### 3.6.4   Second Nurse Workshop

Similar to the first nurse workshop, this was held after modifications were made to the web portal to improve the acceptability of the nurses based on the input of the first workshop. At this point, the patient application was also developed and tested with the nurses to ensure that it could be delivered to the patients and the data being collected was usable to the nurses. Again, this was held in order to further

analyse the acceptability of the product and discover the factors in which made it acceptable or not by the nurses. During this workshop, the nurses were asked to do specific tasks regarding the software. These tasks were logging in, calling a patient, hanging up, viewing a patients data, and sending an announcement.

### 3.6.5 Patient Usability Study

Following the second nurse workshop, a patient study took place. During this study, the patient was introduced to the application, FitBit bracelet, and Flic button and asked to utilize the three items for one month. This usability study would provide insights about the acceptability of the application, FitBit bracelet, and Flic button. For example, the usage statistics would show how long they spent on the app, how long they spent on each survey portion, as well as the number of days and times they took the surveys.

### 3.6.6 Third Nurse Workshop

The third nurse workshop was held during the time the patients were using the application. The workshop was there go over the usability and acceptability of the visualizations of the patient data. Also during this workshop, a short interview was held to go over their thoughts on the preliminary results of the acceptability standards derived from the previous studies and there thoughts on the importance of those standards versus what was observed as the importance level of those standards.

### 3.6.7 Patient Survey

At the end of the study, the patient would complete a usability survey regarding what she thought about the application, the FitBit, and the Flic button as well as talk about experiences using the three and where she saw room for improvement and why she had motivation to use one or all of them. This would ideally elicit why the patient thought each method was or was not acceptable.

# 3. Methods

# 4

# Results

This section covers the themes that emerged and the findings related to the data analysis. This is specifically a qualitative evaluation of the implemented eHealth solution to gain some insight from a few participants. The different pieces of the system can be seen in appendices C, D, and E. As mentioned in the methods section, the results from the patient's perspective were gathered from a survey and not analyzed in the same way as as the thematic analysis. Additionally, there are many irrelevant usage statistics that were gathered. Because of which, usage statistics are only mentioned when they are relevant to a result.

## 4.1 Themes

While coding and analyzing, several themes appeared. When talking about major and minor themes, a theme was classified as major if it was coded more than twice and if it related directly to software acceptability. Initially, the first and only major theme was comments about the data being gathered. During the nurse workshop where the nurses were on their own to walk through the system, new themes emerged. The two major themes during this workshop were: relating the software to previously used software and questions about navigation. These three themes, mainly data comments, account for over 90% of the transcriptions, when irrelevant chat and comments are excluded, after step 2 of the thematic analysis. Additionally, there were many minor themes and usable extras relating to software acceptability that were found when analyzing the text. These minor themes and extras are brought up throughout the results in the form of quotes from the transcriptions and analysis of the quotes to infer a result.

## 4.2 The Nurses' Perspectives on Smart Devices

From the first requirements elicitation, the nurses perspective on the Flic button and FitBit armband was clear. A major theme regarding the data output kept recurring. When explicitly asked about the usability of the FitBit and Flic button and what their thoughts were on these two devices and if the patients would find them usable, the nurses replied only with concerns and questions about which data was being gathered. Hence one of the major themes being "data". One nurse responded with "what does it mean if they press the Flic button?". After replying with the instructions that one press means the patient urinated, two presses means they defecated, and a press and hold means they started or stopped pelvic floor

training, the followup question was, "can we see when they do these actions?". The meetings regarding the smart devices all centered around the data being gathered. A vast majority of the questions asked about the smart devices during each of the workshops and interviews that were held before the first release, on or off topic, resulted in comments and questions about the data gathered. Thus, because of the major "Data" theme, it can be derived that when using smart technologies in this study's context, the nurses focus mainly on if the data being gathered is usable for them to assist in the diagnosis and treatment of their patients.

In regards to research question 3, the nurses focusing only on the data can potentially be seen as a large positive. From the interviews and workshops, the nurses believe that the data gathered by the smart devices is "much better than what [the nurses] [get] now" and much more accurate because "[the nurses] don't have to rely on the patients memory". Also, when asked if they thought the data would be more efficient and rich, the nurses unanimously said yes, they thought it would be. This is because one problem they have is knowing the consistency of each of their patients' defecations, which to them is very important for diagnosing the patient. Currently, they have no way to accurately gather the consistency data except for having the patients manually track those factors, which they believe is unreliable and demotivating for the patients. This again points to the data focus, as well as it may begin to point towards the feasibility and acceptability of the smart devices.

## Survey Question - Imodium: Requirement Evolution

1

**Initial Elicitation**

How much Imodium they took (numerical scale)

Expected

2

**First Requirements Group Interview**

How much Imodium they took (0 - 10, inc by .5)

Unexpected

3

**Workshop 1 - First Walkthrough**

How much Imodium they took (0-20, inc by .5)

Unexpected

4

**Workshop 1 - Recap**

How much Imodium they took (0-20, inc by .25)

Unexpected

5

**Workshop 2**

How much Imodium/Dimor they took (0-20, inc by .25)

**Figure 4.1:** The evolution of a survey question regarding Imodium.

Regarding Figure 4.1, The initial elicitation and the group interview were meant to fully elicit this requirement. However, during subsequent workshops focusing on other matters, the data requirements, this being a specific example, were in focus. Minor requirement modifications and the corresponding elicitation techniques can be seen. It must be noted that the elicitation techniques for the data requirements were only in step one and two. Step three to five were not meant to elicit any data requirements. The complete list of what was gathered can be seen in Appendix B.

## 4.3 The Nurses' Perspectives on Software

During workshop 1 the nurses were walked through the entire nurse portal. The nurses were walked through searching for patients and seeing their profiles and data, as well as calling the patients and using the video chat service. While walking them through using the system, they made some comments like, "wow, this looks great" and "I like that we can ask you anything and it will show up". Their comments were mostly positive, showing that the development was on track, and there were just a few questions such as "can the patients call us?" This question was asked because of the video chat component where nurses call the patients when they have a meeting set up, but the patients are unable to call the nurses.

However, during workshop 2, the nurses were tasked with walking through the system on their own. This system was almost exactly the same with very minor and insignificant changes. They had no assistance and they were given a task to search for and call a test patient. They could not remember how to do it, and although in the visible menu there was a item that said call patient, it confused them and it took three minutes in order for them to have the confidence to click the menu item "call patient". Following, when there was one patient online, they typed his name into the search box and waited. They did not realize that they had to click on the patient and then select call patient, despite the text directly above the search box saying "click on the patient you wish to call". Once the call was taking place, they were tasked with sending a message. There exists a box that says, "type your message here", and a button that says, "send". However, they did not type in that box and instead tried clicking in another box and hitting back space. This showed that text and labels aren't as easily understandable as some software engineers may think.

During this exercise, they were saying things to each other such as; "do you think we click here?", "in the website you're supposed to click the buttons that look like this", and "in Skype you click in a box like this". This brought out the recurring theme of this workshop, navigation confusion. Based on the exercise and the comments, the nurses were not confident in using the software and always over-thought their actions. They interacted and spoke about the system in such a way that they related it to past systems they used. New requirements were elicited from this exercise that all regarded making our system look similar to systems they are familiar with, such as Skype. The nurses gravitated to what they believed was most like previous systems, rather than evaluating the new system as a whole and reading the texts and instructions. It can be assumed that based on this, software engineers should elicit which systems the nurses are already familiar with and build their system's user experience similar to the systems they are familiar with.

In addition, based on these actions, the nurses will not explore to discover the system as a whole, but rather work in the system trying to accomplish their task while at the same time being afraid to make mistakes and click the wrong things.

This makes for a very slow learning period if they are not assisted. When the nurses were assisted, like in workshop one and three, everything appeared to be clear and they had no questions. When asked about how easy it was to use after being shown, one nurse had said that "yeah, it seems very simple". This shows that walking a nurse through a system and having them learn the exact same system has two completely different usability, learnability, and understandability dimensions. This should be taken into account for software engineers building medical systems involving nurses in the future, they should consider having the participants learn the system without expert interference to elicit learnability and understandability requirements.

Also, when building software for nurses, the seamless flow into their everyday work is an essential acceptability factor. The nurses have repeated phrases similar to "I already write that in a different system". They seemed, based on their language and expressions, that they do not want to do any double work. It seems as though the developed system must fall perfectly in line with their work practices, otherwise they potentially may see it as too much of a hassle or too much work to be worth it. The nurses currently have six or seven other systems that they must work with and adding another one shouldn't just be duplicating their work and making their work more difficult. Because of this, it can be argued that it is important to sit in and observe the nurses, non-participatory, in order to understand their daily practice so that a developer can build a system that fits with everything else they do.

However, there is an exception to this. During workshop number three, the nurses were asked explicitly, "If our software let you see all the patient's data you needed to see before a meeting, but in order to do that, you had to enter all of the data into two systems, do you think you would still use our software?". Their responses to this question were partially unexpected, they all said yes because it still saves a lot of time having to ask the patients for the particular data that is gathered and the accuracy and precision is very important for some patients more than others. Specifically, one nurse stated "yes, I would but only for patients with serious problems that I really needed the accurate data for, which is maybe 5 in a year." All of the nurses quickly agreed with this and said that because of the "much better data", they possibly would "transition over time by getting it into the routine for all patients rather than just the ones with serious problems". Although they say they only have 5 patients a year with very serious problems, it can be derived that as long as the system is important enough to improve diagnoses of patients, the nurses may use it. Of course, a developer must take into account that all of the nurses had a lot to say when it came to seamless integration into their workplace, even so that one of the nurses listed it as the utmost importance.

Finally, the nurses were asked to prioritize the following in regards to the importance to them from a usability perspective: the ability to see the patient's data, the video chat, the easy and natural integration into their everyday work practice, and the accessibility of the system from phones and tablets wherever they happen to

meet with the patients. Two of the nurses ranked them, from most important to least important: the ability to see the patient's data, the video chat, the easy and natural integration into their everyday work practice, and the accessibility of the system as last. The third nurse put the easy and natural integration as the first priority for usability while the rest of the ordering was the same as the previous two nurses.

It is also worth closing on a note that when asked about if they use all the systems they were supposed to, they all said no. They gave a specific example of a system called MedControl that they are supposed to report problems in but never use. They said because "it's not in [their] work practice and [they] don't have it in their routine" that they don't use it. Another reason they don't use it is that it takes too long to fill out and submit a problem. The time constraints along with their perception of the system and the fact that it's not in their routine makes the system unusable for them. This can be seen to verify the points that simplicity and seamless flow into their work practice are two very important acceptability criteria for the nurses.

## 4.4 The Collection System's Feasibility and Acceptability

Building a patient monitoring system using smart devices is feasible based on the patients perceptions of the system. When asked the question, "what is your reason for participating in this study?", the patient responded that they are participating simply "to make things better for me and others in my situation." This goes hand in hand with what the nurses said when they stated that "we think most patients will participate because they all want to help others going through the same problem". This suggests that patients are will to participate, which means that since these types of systems would be used, that they are feasible. Additionally, the patient, despite having a very limited technical background, also responded that she "really liked the study". Which may also mean that she liked the collection system because the collection system was the only part of the study that the patient interacted with apart from the final survey.

In regards to the smart devices, the patient responded that she "loved [the FitBit]". She said that she liked that it "didn't interupt [her] daily life and it tracked so many useful things" about her. The usage statistics show that she wore the band every day and nearly all day for the entire one month of the patient study. Since the patient was so accepting of using the FitBit in [her] daily life, this patient's perception of the device suggests that the device itself is feasible. In regards to the Flic button, she had issues with her phone and was unable to test it for the month and did things manually using the touch screen. She did however get to see, feel, and use the Flic button for a short period of time to test it. When asked, "Do you think you would have input defecations and urinations more if you were to have the Flic button to press instead of opening up your phone all the

time?" She said yes, she believed that she would have reported more urinations and defecations if she had the button. She also said that she did not complete all of the surveys that were given and she didn't always track the urinations and defecations. The usage statistics also back up her claim because they show many gaps in the reporting days for urinations and defecations. Throughout the study only 5 urinations were tracked in the one month. Because she believed the Flic button would be easier to use for reporting defecations and urinations, it is possible to believe that the Flic button is feasible since she believed that it would have helped her track herself better and she believed she would have used it more.

## 4.5   Feasibility of a Medical System for the Nurses

Based on the analysis and the responses of the nurses, new medical systems for nurses are feasible despite many potential barriers. One factor that supports that in the case of the nurses at EfterCancern, is that they are using 8-10 systems already but none of them are similar to this developed system that is patient centered. The nurses believe in the newly developed system, which as previously mentioned, was discovered to be the main acceptability criteria for these types of systems. In the nurses' work, they have many non-digitalized practices that have the potential be digitalized to speed up their work and shorten their patient meetings. In the case of this study's developed system, the nurses believe they are getting data faster and more accurately from the patients. The nurses are open to new technology if it helps their practice and, even more importantly, their ability to help their patients. Since the nurses have accepted the developed system and since the nurses have stated, before even viewing the system, that they believe it is a good system because they can help the patients better, it can be derived that a medical system for the nurses, in this context, is feasible if they believe it will help them. Again, the system is believed to be feasible because of the willingness of the nurses to use and accept the system.

When it comes to the feasibility of the video chat between nurses and patients, the nurses have said that in their case "many of [their patients] have problems coming to the hospital and many come from far away, around two hours drive or sometimes more, to get here and [the video chat] could make it so they only have to take an hour out of their day instead of including all the driving time." They all agreed and were thinking and talking in terms of what benefits and helps the patients the most, which is additionally shown by the nurses motivation and acceptance for the system because they "believe [it] can help patients". The constant theme of helping patients can show that if the software system helps patients in any way, nurses will use it strictly for the patients' benefit. The nurses have also said that they "rarely feel the patients". They were referring to physically touching the patients. Additionally they said that they "can get all of the information [they] need by talking to them". This can suggest that in most cases, a video chat can suffice for providing all the data the nurses need to give as good of treatment to their patients than a physical meeting. Because of the potential benefits and the

willingness of the nurses to use the system, it can be assumed that the video chat system is feasible.

## 4.6 Answering the Research Questions

This section organizes and recaps the main results in relation to the research questions set out to be answered. This section is a summary of the previous results sections in relation to this specific setting, pelvic region cancer surviving patients and their associated oncology nurses.

### 4.6.1 Acceptability Factors - RQ1

*What are the patient and nurse acceptance criteria for a data collection and visualization system using smart technologies?* There were many acceptability factors derived from this study, the following factors are in no particular order. First, the system should be easily learnable and understandable, potentially by looking and interacting similar to other systems. The requirement of learnability can potentially be met by the software engineers hosting workshops letting the participants learn the systems on their own. Secondly, the system should provide important and usable data to the nurses. From the nurses perspective, the data given is by far the most important. It is very important that a software developer ensures all of the content in the system matches the needs of the users.

Furthermore, the system should compliment the users' work practices and fit in to their current workflow. The software engineer should observe the nurses' workflow and create a system that integrates with their practices. Fourthly, in relation to the patients, the collection systems should be as automatic and easy to use as possible. A software engineer should try to find devices that require the least intervention from the user. Lastly, the motivation and the perception of the perceived benefits plays a large role in the acceptability. It is important to ensure that both the nurses and patients understand how the system helps them and/or others in their situation.

### 4.6.2 Feasability - RQ2

*Is it feasible to develop a data collection system using smart technologies to gather the patient data?* Data collection systems using smart devices are feasible from both a nurses and patients perspectives. For the nurses it is feasible as long as it fits into their work practice, doesn't interfere with their daily routines and is easily learnable. For patients it is feasible especially if autonomy is maximized. Devices with minimal interference to their lives increases feasibility. As long as the patient can collect data with minimal effort, such data collection systems are feasible. The feasibility of this system is measured based on two factors; first is the acceptance of the developed system and second is the perceptions of the nurses and patients. The nurses and patients accepted the developed system, specifically because of the fact that they are using it in practice and that

they explicitly said multiple times in many ways that they liked it. Additionally, because both the nurses and patients perceived this system as being able to help the patients with their problems and the nurses in their diagnosis of their patients' problems, it can be argued that the nurses and patients are willing to use this type of solution. In both cases, the system is desired, and hence, the solution feasible.

### 4.6.3 Data Accuracy and Precision - RQ3

*Does using smart technologies in a data collection system, assist in improving the accuracy and precision of data?* Using smart technology for data collection, reduces the need for memory and manual logging, which can result in accuracy errors of the data. The nurses believe the data collected automatically using the smart devices presented is more accurate than using previous methods. One reason for the increase in precision is because these devices catch events when they occur, which again reduces the need for human recollection. Thus, data accuracy and precision can increase by using smart technologies.

### 4.6.4 Multiple Smart Devices Usability - RQ4

*Does the increase in data collection smart technologies decrease the usability of the software system as a whole?* This question can unfortunately not be answered by this study's interpretation of the data. Further research needs to be done by experimenting with a varying number of different smart devices to see if adding on more smart devices means a decrease in usability and possibly acceptability. One idea is that there is a limit to the number of devices that can be added to keep acceptability and feasibility and the usability is affected when the devices are significantly different and the users understand that.

### 4.6.5 Patient Motivation - RQ5

*Do patients believe they are more motivated to participate in fully autonomous, semi autonomous, or fully manual data collection projects?* This question can also unfortunately not be entirely answered by this thesis. However, it is worth noting that when asking the question "Theoretically, if there was a camera in the toilet that took a picture of your defecation and sent it to the nurses, and you didn't have to do anything, would you be comfortable with that?" the answer was yes, she would use it and be comfortable with it as well. In addition, when asked "What if you had to take the picture yourself and send it instead of filling out a survey?" the answer was "yes, it would be the same thing". These may hint at autonomous systems being usable, but there is no comparison to manual data collection systems, which is why this question can't be answered.

### 4.6.6 Nurses Opinion - RQ6

*Do the nurses believe the data gathered by this system allows them to provide, in their opinion, better individualized treatment plans for PRCSP?* The nurses believed that the data gathered from this systems is better and more accurate.

They said that the differences in what a patient tells them or the uncertainty of the patients, for example "a patient [saying] 10 to maybe 25 defecations a day", hinders their ability to make a proper diagnoses. Thus, the nurses believe that the data gathered by the developed system will help them provide better treatment to their patients.

### 4.6.7   Change of Flow - RQ7

*What is the perception of nurses and patients when introducing a new technological system to compliment already existing practices?* The perception this study received from the patients is purely positive. The patients were eager to help themselves, the nurses, and others like them and they couldn't wait to participate. Of course, only one patient was included in the study, as discussed later in the discussion. The nurses, like the patients, were very positive and receptive to the system and have already started test usage in practice. The nurses do have a few criteria though, such that the system must not disturb or hinder their other work practices and also the system needs to be meaningful for them. They must see the point in the system and believe it is worth using.

### 4.6.8   Speed of Elicitation - RQ8

*Can a semi-automatic data collection system elicit data faster than traditional methods and in turn shorten the necessary patient meeting time?* The patient meeting time is able to be shortened based on elicitation using the smart devices because the nurses have the data before they even meet the patients and can prepare in advance. The starting questions eliciting this data can be removed from the physical meeting altogether. However, in this specific case, the data gathered is much richer than the data that would be gathered normally during their patient meeting. The accuracy, precision, and richness of the data that is collected from the developed system is obtained by partial patient interaction. Thus, the patients much actually spend more time to convey the data to the nurses which slows down the elicitation time from a patients perspective. However, the patient said that it did not feel like it took too much time, but automating the process even more with less manual intervention could be even better.

# 5

# Discussion

The discussion aims to reflect on the results interpretations, the strengths and limitations of the study, and potential future work.

## 5.1 Results Reflection

This section is dedicated towards discussions around specific results and the results in general. Specifically it discusses the limitations, the potential analysis bias, and other research with similar or conflicting results.

### 5.1.1 The Nurses Data Interest

The nurses seemed to only have interest in the data collected. During their appointments with the patients they try to give their best diagnosis and more accurate data can certainly help. The nurses did seem to be not very sure of what data should be collected though, and sometimes could not give much of a reasoning for why that particular data should be collected. The only data factor they could give reasoning for was the number and consistency of defecations. The rest of the data gathered by the system are factors they prioritized as important or very important, but the importance might have been overstated for some of them. Their interest on only the data collected, and not how it is collected might also cause problems, as the accuracy is closely related to how the data is collected such as the devices used by the patients.

### 5.1.2 Data Accuracy

In a study made in 2009, 74% of the participants felt that before meeting the nurses, filling in their symptoms on an e-tablet system helped them remember the symptoms they experienced better. 34% of the participants reported that the system encouraged them to discuss medical issues that they may have otherwise forgotten [40]. A study like this alone, shows that patients do have issues with remembering the symptoms they experience between their nurse meetings, and an eHealth system can assist with not only memorization but also potentially tracking of their symptoms. This supports our results saying that using smart systems, such as the developed application, improves the accuracy of data from patients. The application both helps patients describe their symptoms more accurately and soon after the symptoms occur and also the previous study suggests

that they may memorize their symptoms better because they had to think about them and enter them into the developed system.

### 5.1.3 Similarity to Similar Systems

One study argues that learnability is affected by a user's past knowledge and experience with similar systems because there may be a knowledge transfer from the previous systems use [41]. It also says that similarity to previous systems can benefit new users just like teachers use their transfer of knowledge when teaching. This goes hand it hand with the discovery from the workshops, which found that similarity to previous software was important for the learnability of medical systems.

Although similarity to previous software can improve the initial learnability, in the long term it can potentially lead to the overlooking of new ways to perform the tasks needed. Thus, software designers should beware of sacrificing certain qualities for improved learnability. New technology is constantly emerging. For example, the recent development and market trends of touch screen devices such as tablets and smart phones. It can be assumed that smart phones had a steep learning curve when they first were released to the market, but look at how people now-a-days use their smart phone. Smart phones don't just allow users to call one another for instant communication, but they also allow for access to social networks, emails, calendars, and so on. These are all tasks that previously may have been much less efficient and possibly disorganized. Now, because people have learned how to use smart phones despite a potential steep learning curve, it has increased the efficiency in completing many tasks.

However, these are all trade-offs. During the second nurse workshop, letting the nurses walk through the system and learn it on their own did not work and they were extremely confused. The learnability can potentially not be an issue at all if the nurses were taught to use the system as opposed to letting them learn the system on their own. Depending on the system that is being built and if there is a direct connection to users or not, learnability needs to be addressed at different importance levels.

### 5.1.4 Motivation

The nurses and patients in this study are all motivated to use the developed system, however these nurses and patient were already interested in participating the EC project and intentionally joined this project. This must be taken into account because it can be seen as a limitation to the feasibility study. The feasibility of the nurse's side and the patients side could have been affected and biased in the positive direction because the participants actively sought to help and advance their situations and their fields. If the study was done on a random sample of nurses and patients matching similar criteria, regardless of if they want to participate or not, the feasibility of the systems may be different. If nurses were happy

with their current workflow and didn't want any change but were forced to use a new system, they may not enjoy it at all and potentially may refuse to use it. Further research on this is needed to develop the feasibility and acceptability factors further In addition, outside of an academic perspective, motivation might differ as there might be conflicting interests and varying goals.

Future research is needed on motivation, even though it can't be fully measured or accurately generalized. However, since the patient was so willing to replace the manual logging of defecations with an autonomous system like an automatic camera may suggest that these types of patients are willing to increase autonomy, possibly because of convenience. This goes hand in hand with the study discussed in the background that autonomy is the key to wearables acceptability. On the flip side, it is also possible that the patient's motivation and the reasons they participate in the study are a bigger factor than the specifics of the system developed.

### 5.1.5 Participatory Feedback Development

Also one finding, not entirely related to this study, based on the nurse observations and workshops is that the activeness and level of feedback using participatory design changes based on the presentation of the requirements, design, and system as well as with the time the nurses have spent in a participatory design setting. In the beginning the nurses agreed a lot with whatever was said and said it all sounded amazing to them, they never had a say before in the technology they would use. They only offered their feedback on the actual medical information that was presented. If a new factor was brought up, they either said "yeah we didn't think about that, that could be useful, lets track it" or "no we don't need to see that". However, throughout the project, the nurses started having more input on the software itself. They tried to see the system from the patients perspective as well as their own. They thought certain things might be confusing or difficult for the patients and that helped eliciting requirements. They also thought that patients may not be motivated to do certain things relating to smart devices and the related software. They were much more engaged as they became more comfortable with the technology and also as they developed their understanding of what was possible. It was useful to bring many suggestions and ask them to evaluate them rather than asking them to think about what they may need. It is very important to have the developer and the one that knows technologies drive the meetings in a semi structured way rather than letting the nurses run wild, because when the meetings were unstructured, the nurses had nothing to say.

### 5.1.6 Disagreements Between Nurses

During the initial requirements elicitation, a list of data requirements was developed that the nurses believed was useful to know about the patients. It was slightly problematic because the nurses disagreed with each other, despite all having a background in oncology. Each nurse has a unique approach for their patient communication and treatment plans all roughly based on the same knowl-

edge bank of oncology. Their unique approach caused differences in which data factors they thought were important. It was discovered that certain treatments are different based on individual patient and also the approach of the nurse. The nurses adapt pieces of different treatments to treat a single patient because of their past experiences. In a qualitative study such as this study, when such a small sample size disagrees and then comes to a consensus, the consensus may not be completely true even within the specific setting. When the participants disagree, there can be multiple interpretations of data within the same setting which can cause for problems in the strength of the research and data in particular.

## 5.2 Strengths

Participatory design allows elicitation and verification of the research because the information is not just gathered once, but rather it is gathered, implemented, verified, and repeat if needed. Participatory design may have also biased motivation in favor of the developed software because of the participants feeling of inclusion with the development of the software. Another strength is the real world application of this research. The research did not take place in a lab or test environment, instead it used real nurses and real patients. Likewise, the full-stack development is in place and research can continue or be built upon using the developed software.

## 5.3 Limitations

Obviously, a major limitation in this thesis is the sample size. There were 3 oncology nurses involved and only one patient. Initially, there were 5 patients to be involved in this study. However, due to their health and persistent problems they are dealing with, meeting with the patients was very difficult and always postponed. Because of this, only one patient went through the study completely. Another limitation to this study is the mixture of languages. Being in Sweden, the patients and nurses often communicated their thoughts in Swedish, mostly when talk to each other or to native Swedish speakers, and it was up to the English speaking researchers to translate. It may have been possible that information was missed or misunderstood during the interviews and workshops.

## 5.4 Why the Chosen Smart Technologies?

The FitBit arm band was chosen because of the ability to detect exercise based on the wearer's heart rate, the available access to getting these events from the API, and the FitBit's were already being tested in the EC project. The Flic button was chosen because the research heads in EfterCancern believed that when a patient is using the restroom, they do not want to use their smart phone to fill out a survey or signify saying they defecated or urinated. Also the patients may use the restroom multiple times in a row, one after another, and each time must be tracked

because data about each defecation is believe to be very useful by the nurses. The smart survey and intelligent interaction techniques were used to speed up the process of data collection to see if that had an effect on the experience of the patient and the overall usability of the application. After these collection techniques were described, an automated collection schema and structure was developed for all of the questions along with a design for the application.

## 5.5 Future Work

One way this study can be built upon is by verifying the discovered criteria. The themes can be taken into other, much larger, scenarios and have them tested for validity using quantitative methods. Another way this study can be built upon is by looking at patients using other similar smart devices and seeing which criteria emerges and if the studies are able to validate or contradict each other. Because qualitative research is very domain and setting specific, taking any part of the study into another setting will help validate and provide a better general acceptability criteria list.

From a different perspective, wearables and the data gathered can be seen as objects geared towards encouraging behavioral change, such that a patient can obtain their goals of happiness, healthiness, etc [10]. However, when meeting patient acceptability criteria, do the patients still achieve their behavioral change goals or do the patients' own perceptions and criteria on usable technology prevent them from ever reaching the true behavior change they wish to achieve? This is a question that requires further research. It's entirely possible to develop an extremely useful system that can change a patient's life for the better, however the patient does not use it even with the potential benefits.

This study, specifically the situation studied, does not need to be built upon just from a medical and software engineering perspective. It is also possible to look at this from a social science perspective. Looking at nurses and patients preconceptions of software to see if it has an affect on the usability and acceptability criteria is another potential research study. This research is just the tip of the iceberg regarding the new and ever growing field smart technologies and there are many different ways in which they can be studied.

# 5. Discussion

# 6

# Conclusion

In conclusion, the main aim of this thesis was to discover specific acceptability criteria for nurses and patients in relation to a semi-automatic data collection system. The first main finding is that nurses main criteria surrounds the perceived impact of the system. On a more implementable note, the most important implementable factor for the nurses is that the information gathered and visualized in the system must be useful to their practice and diagnostics. The nurses liked the developed system because they believed that it would assist in improving the lives of the patients. Similar to this, the major criteria the nurses had was that it shouldn't be complicated to learn and also it should fit into their daily practice easily. In addition, it is incredibly important to include the users of the system when designing and building the system so that it can match the nurses' and patients' daily practices.

Regarding the sub-research questions, developing a data collection system using smart devices is feasible and the data gathered will be more accurate and precise because of human cognition errors. The nurses believe that the data gathered by the smart devices will improve the way in which they can diagnose their patients as well as improve the time needed to make a proper diagnoses. Feasibility may have also been affected because the patients and nurses were incredibly motivated, not because of the system itself, but because of the underlying purpose. The participants joined this study because they believed that they could help their patients, themselves, or others in their condition.

The smart devices used in this study are feasible from a patients perspective because they speed up the process of the patients tracking themselves. This also may be affected by the motivation of the patients when entering the study rather than the devices actually being feasible on their own. However the patient and nurses involved did like the devices. Specifically, they liked the FitBit because it is as simple as wearing a watch and they find the data very interesting. They liked the Flic button because it's an easy way to track anything countable from anywhere just by the press of a simple button. On the flip side, the FitBit was not useful for the nurses because they believe that the data gathered by the FitBit is not useful in any way to help improve the diagnoses of their patients. However, because the Flic button is so versatile, the nurses thought it was very usable and useful. The data being gathered in this specific case: the number of defecations, the number of urinations, and time spent on pelvic floor exercises is thought to be incredibly useful in accurately diagnosing and assisting their patients.

## 6. Conclusion

This research can help software engineers build more acceptable and usable systems by showing them that the nurses and patients are motivated and want to help build the software that they use so that it fits their work and daily lives. This research can help researchers by giving underlying themes and categories that can be then taken to a broader study that includes more participants. This study can also be built upon by doing similar studies with nurses and patients in other settings and comparing the results which could suggest that the results can be applied in a general setting or that the results are specific to this case.

Because there are many limitations to this study, mainly involving the limited participants and the time available, there is a lot that can be built upon. Not only can future researchers build upon the acceptability factors, but also the results of the sub-research questions from both a software engineering perspective and a medical perspective. This interdisciplinary field can affect work and research in all fields surrounding technology in healthcare. Further research can be done from the medical field regarding the medical benefits of this or similar systems. Likewise, the social science field can also potentially benefit by researching preconceptions of such systems before and after they are implemented to see if a person's background and/or experience affects the feasability, usability, and acceptability of them. Obviously, this is one small step into this field of study, but there are many interesting ways in which others in all different fields can build upon this research and the developed system.

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Bibliography

# A

# Data Security and Privacy

Real patients and nurses were involved in this study. This meant that data security and privacy were major concerns. Throughout the thesis, until the patient study took place, the back-end and front-end of the application were being developed with strict privacy concerns in mind. In order to enforce privacy, a large Swedish university hosted a virtual server. This server was highly secured and all data transmitted to and from the system was encrypted using the latest standards. In addition, [10] argues that "it is essential to inform patients on exactly how their data is going to be handled and give them an understanding of the exact role they are playing in the research along with the mechanisms involved." Because of this, a privacy section was added to the patient presentation regarding how their data would be handled and secured as well as who had access to this data.

A. Data Security and Privacy

II

# B
# Gathered Data

The data gathered by the developed EfterCancern application is as follows. It is important to note that these data factors are gathered via a smart survey that changes based on events and based on the users personal profile.

- In regards to each instance of pain...
    The time the pain first occurred
    The duration of the pain in minutes and seconds
    The type of pain
    The intensity of the pain on a scale of 1-10
    If they took medication before the pain
    If they ate before taking the pain
    If the pain was before a defecation
    If the pain was during a defecation
- In relation to a majority of the time, could feel their gas was gas
- Was there any leakage during gas today
- Could they hold their gas today
- Did the gas smell bad today
- How many Minifom capsules they took during different times of the day
- How much Inolaxol they took during different times of the day
- How much Imodium/Dimor they took during different times of the day
- If they drank anything after 18:00
- In regards to each defecation...
    The consistency in relation to the bristol scale
    If the defecation was oily
    If the defecation was painful
    If the defecation contained blood
    If the defecation contained mucus
    If they did toiletgym before the defecation
    If the defecation was hard to flush
    If the defecation floated
- In regards to each urination...
    If they did toiletgym before the defecation
- In regards to each time they did backenbottenträning..
    When they started doing it
    How long they did it for

B. Gathered Data

IV

# C

# Software Architecture

The developed system consists of 4 main components:
- An Android phone application
- An online web portal
- An HTTP REST API
- A MySQL Database
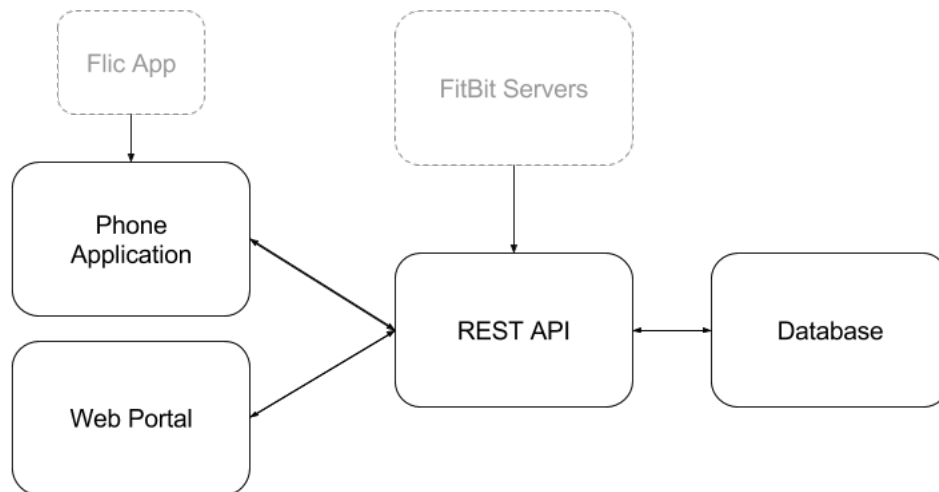


**Figure C.1:** A general diagram of the developed software's architecture.

External components are grayed out. The Flic app handles all communications with the Flic button and triggers events in the application.

The FitBit armband only communicates with servers owned by Fitbit, which do the analysis of the user's data. When receiving new data from the armbands owned by EfterCancern, the FitBit servers send the analyzed data to our servers using the REST API.

Both the phone application and the web portal retrieve and store data using the REST API which handles authentication and communication with the database. All communication to and from the API is encrypted using the latest standards (TLS). The API and database are both running on a secure virtual server only accessible by the people in the EfterCancern project.

The Android application is native, written in Java, while the web portal is a Javascript based browser application. Both the phone application and the web portal communicate directly with the REST API using HTTPS and JSON. The REST API was

built using the Django REST Framework which maps data to and from a MySQL database.

# D
# **Web Portal**

The developed web portal contained multiple features such as a video chat system, patient goal and stepping system, and a visualization system. The nurses and patients have different roles and different interfaces in the system. It is very important to note that these images are of the final version in relation to when this study took place.

## D.1 Nurse Portal

This section, by a series of images, walks through the developed web portal after a nurse logs in. It also shows and highlights key points that are discussed in the text. The images are shown enlarged in a page to page manner so that the images are clear to see the details, especially in relation to the data and the results derived from the images in the results section.
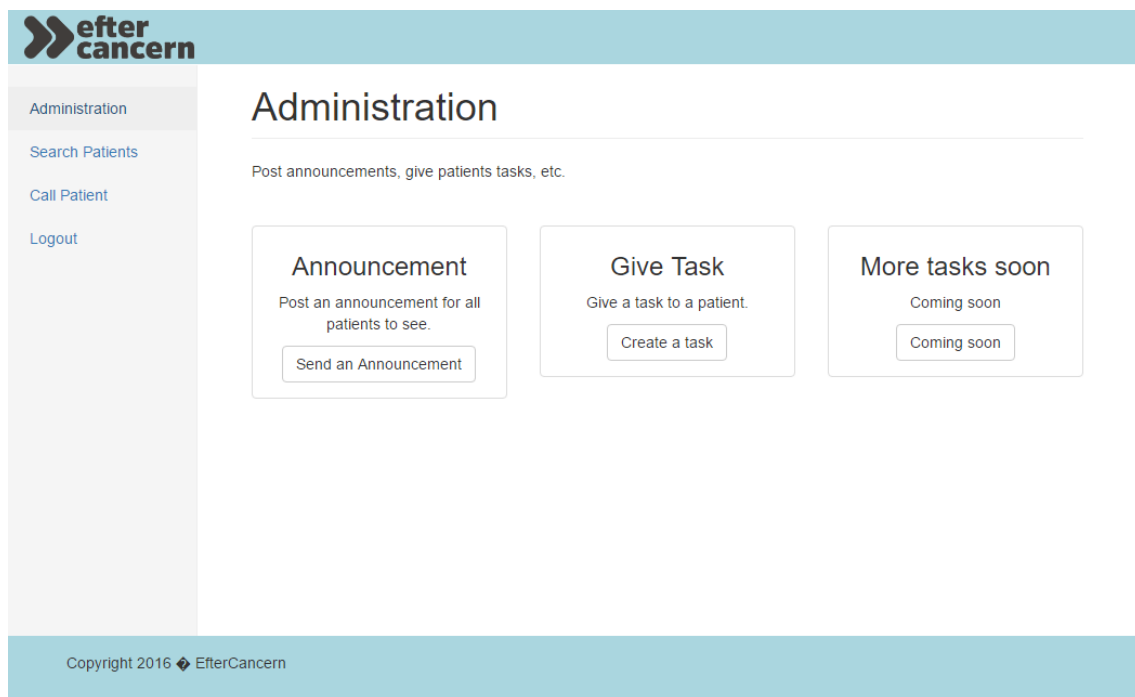
**Figure D.1:** Web Portal - Nurse Landing Page

This figure shows the page which cause the most confusion for the nurses. It took a very long time to figure out how to call a patient. They first click on the create a task button and then on the coming soon button. They discussed a lot regarding what they should click each time and finally they managed to gather the courage to click call patient after five to six minutes and much debate. This shows the importance of understandability or possibly just someone that can teach them the system.
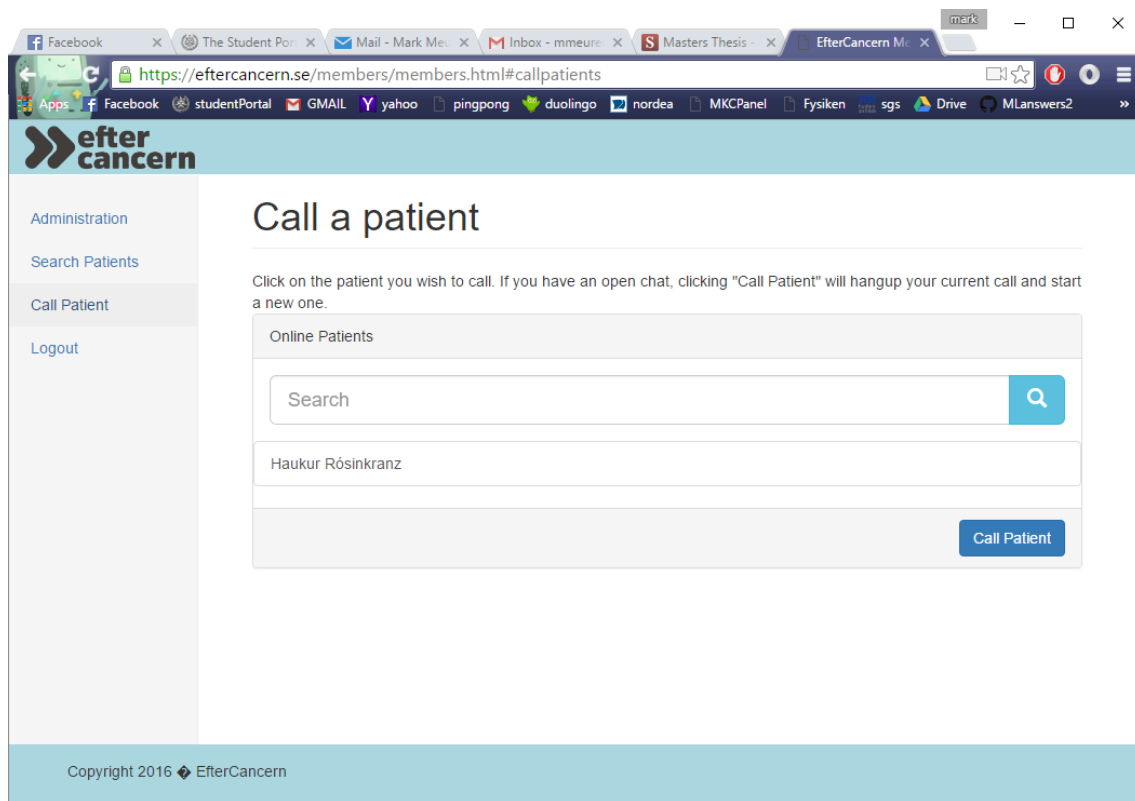
**Figure D.2:** Web Portal - Nurse Calling Page

This figure shows how a nurse would call a patient. The idea is that the box labelled online patients will show all patients that are currently online. The nurse then must click on the patient they wish to call which will highlight their name, and then they should click the button that says Call Patient. This was also difficult to figure out, despite the text under Call a patient that describes the process. It outlines the need for very clear navigation. In this case, the search bar confused them as well and they started typing names there of patients that were not online and then when trying to call they clicked the search button to try and call the patients.

X
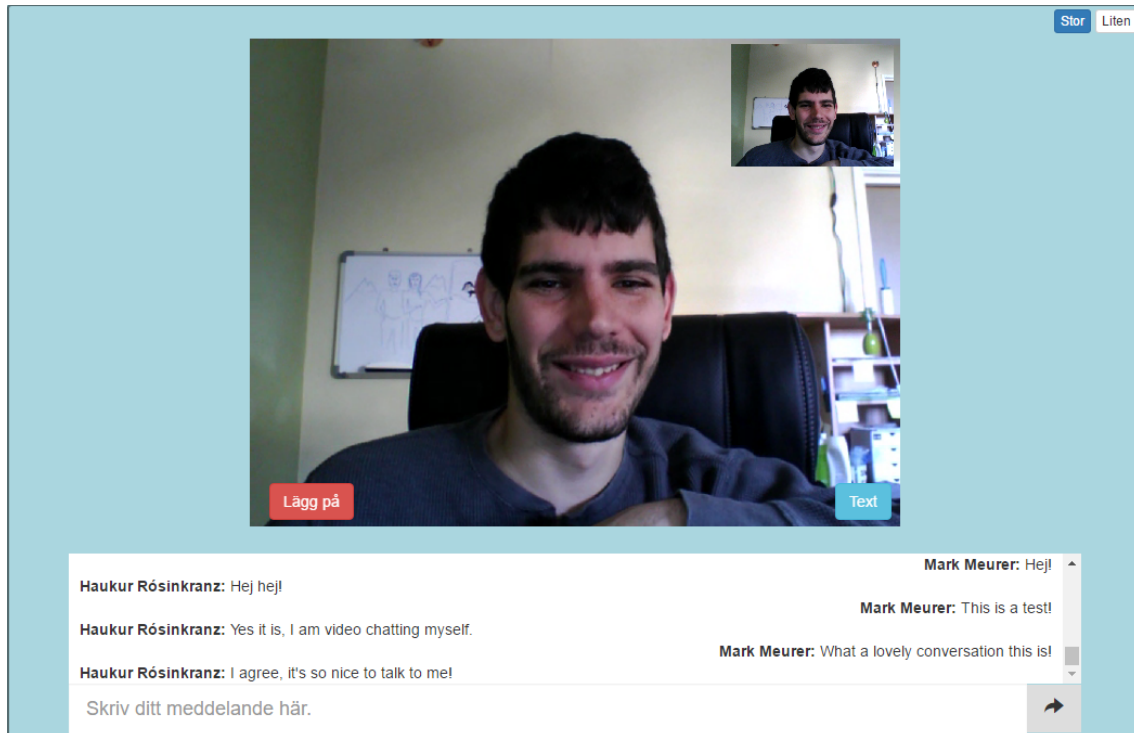


**Figure D.3:** Web Portal - Video Chat

This figure shows the video chat when it is enlarged. A nurse and patient can send links and images through the messaging system. It is possible to click the button in the top right "Liten" to make the video chat small enough to continue navigating through the portal and discuss tasks or data for example. This section has undergone the most changes throughout the process and is important to note that this is the "final" version as of when this study was completed.

X

**Figure D.4:** Web Portal - Nurse Viewing Patient Profile

This figure shows how the nurses can view a patients information, tasks, and activities. It also shows the video chat running so a patient and nurse can go over the content of this page together. A nurse can also modify the patients goal.
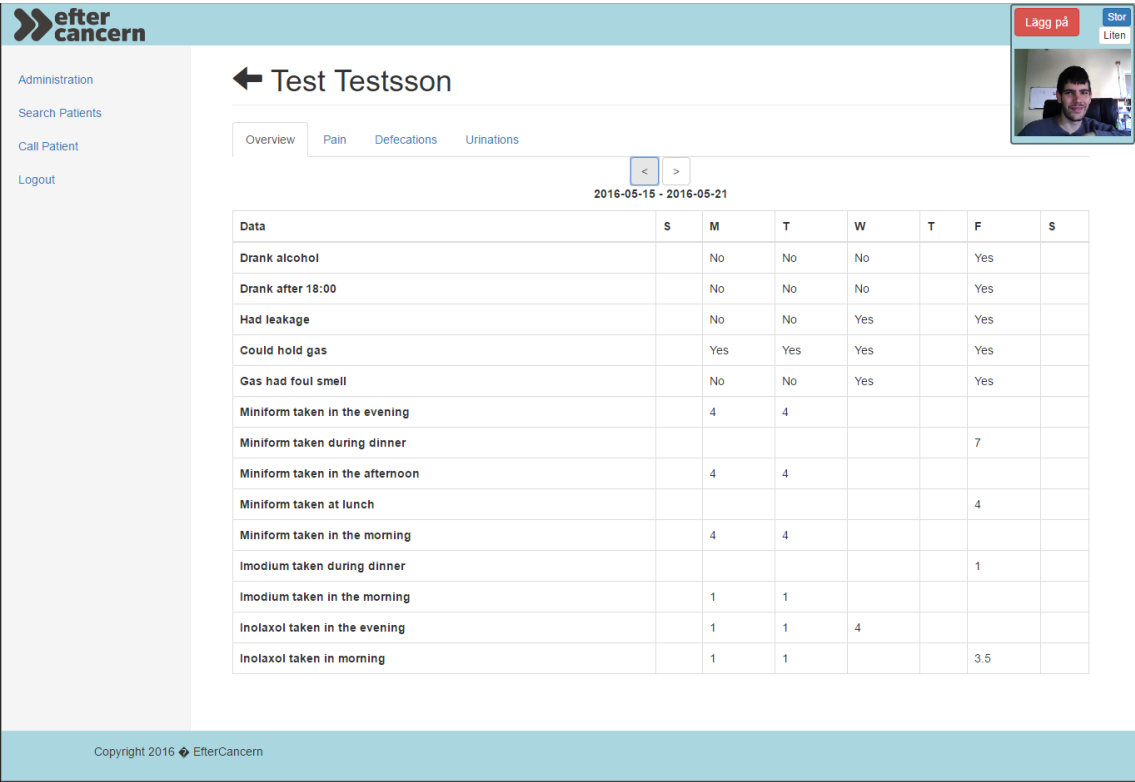
**Figure D.5:** Web Portal - Nurse Viewing Patient Data

This figure shows the screen in which a nurse would get to after clicking the "View Their Data" button in the previous image. Again, the nurse and patient can go over this data together while on the video chat. It is important to note that this data section is incomplete and just a rudimentary visualization of the patient's data. In this case specifically, the data shown is all randomly created test data.

## D.2 Patient Portal

This section walks through the system after a patient logs in.



**Figure D.6:** Web Portal - Patient Home Page

This figure shows the main screen after a patient logs in. Patients can see the latest announcements from the nurses, see their current tasks, and also their recent activities.
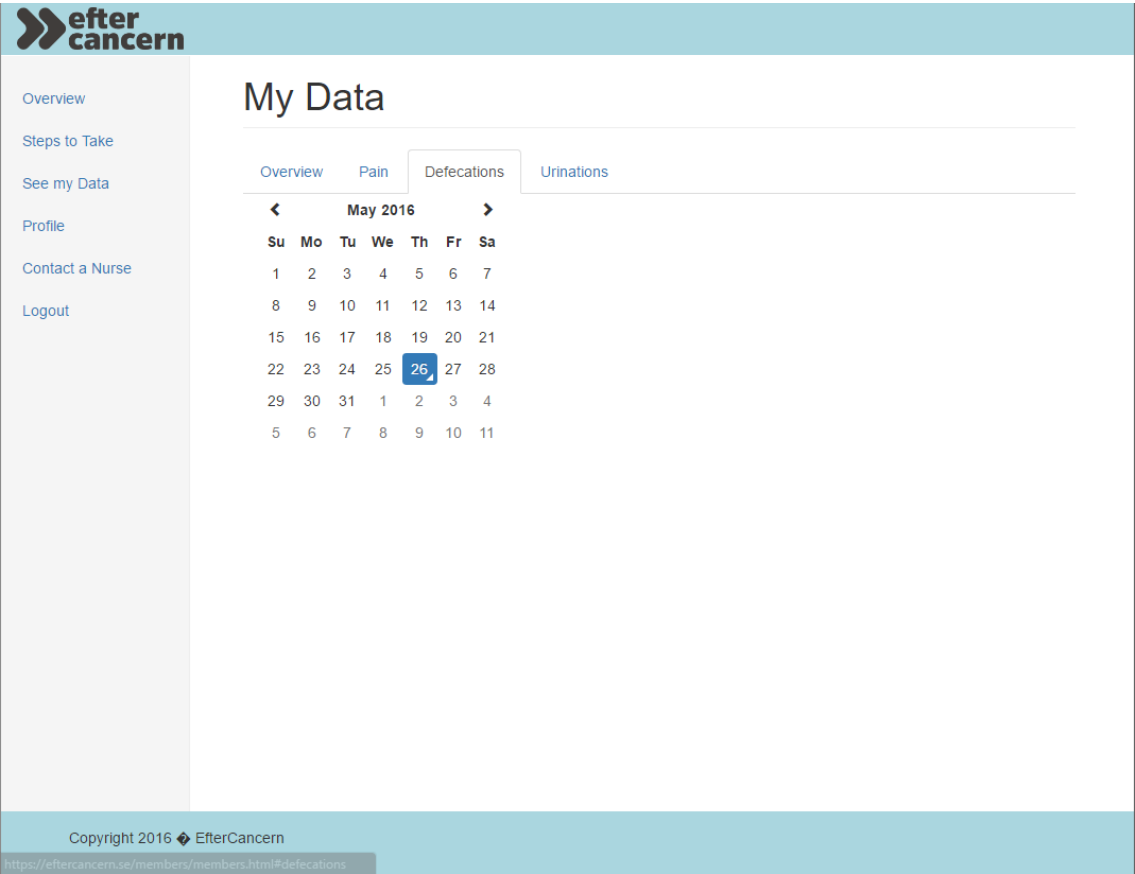
**Figure D.7:** Web Portal - Patient Data

This figure shows the screen in which a patient would get to after clicking the "See my Data" button on the navigation bar. The nurse and patient can go over this data together while on a video chat. It is important to note that this data section is incomplete and just a rudimentary visualization of the patient's data. In this case specifically, the data shown is all randomly created test data.

**Figure D.8:** Web Portal - Patient Profile

This figure shows the patients profile. The patient can update their information from this page. The nurses are able to see all of the data that is on this page.
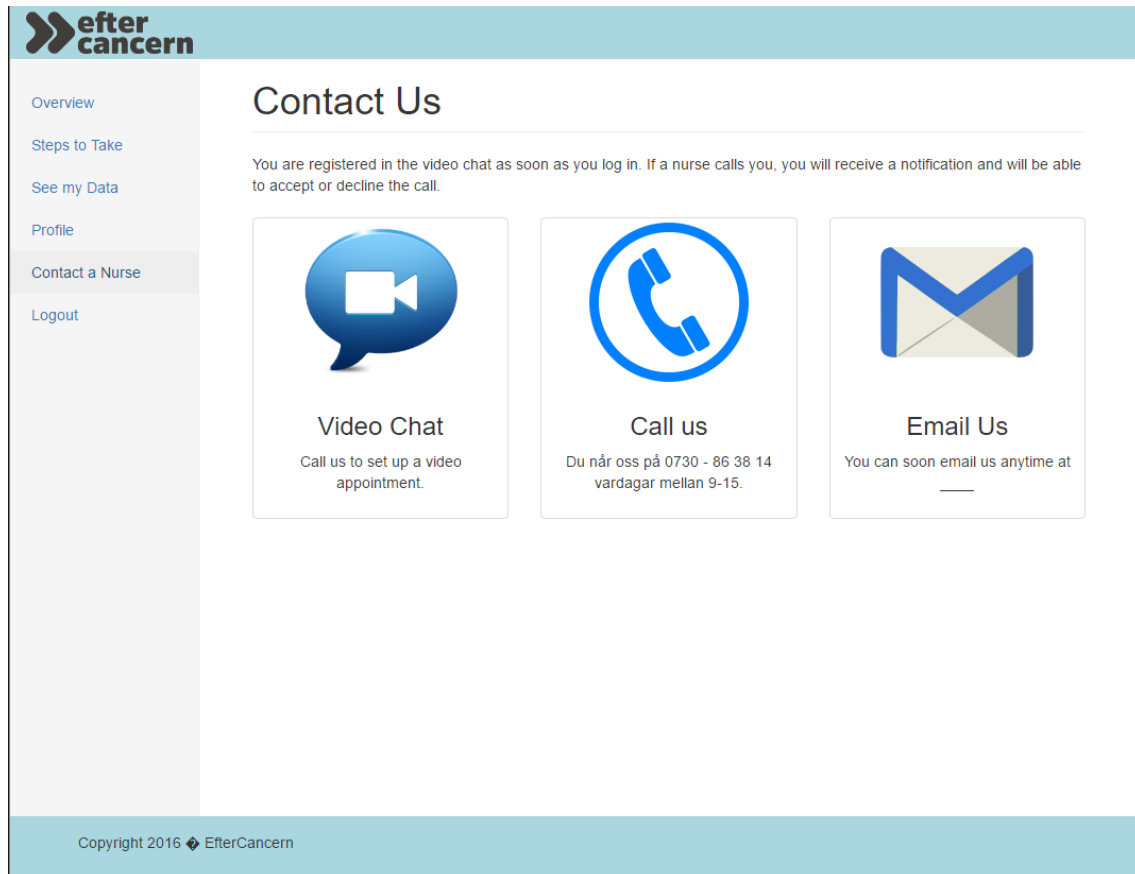
**Figure D.9:** Web Portal - Patient Contact Page

This figure shows how the patients can contact their respective nurses. It also has text that says that if they have a video chat meeting planned, the nurse will call them and they will receive a pop up notification. Without an appointment, the patients can also call the nurses or email them at anytime.

# E

# Android Application

The developed android app is a patient data collection system that acts as a survey system that can be trigger by the Flic button. The user received phone notifications to take a survey after they clicked the Flic button once for a urination, twice for a defecation, and held to start/stop the pelvic floor exercise timer. In addition, the user received a notification at their selected notification time to take the daily survey. Below are two screen shots of the user interface.



**Figure E.1:** Application Home Screen
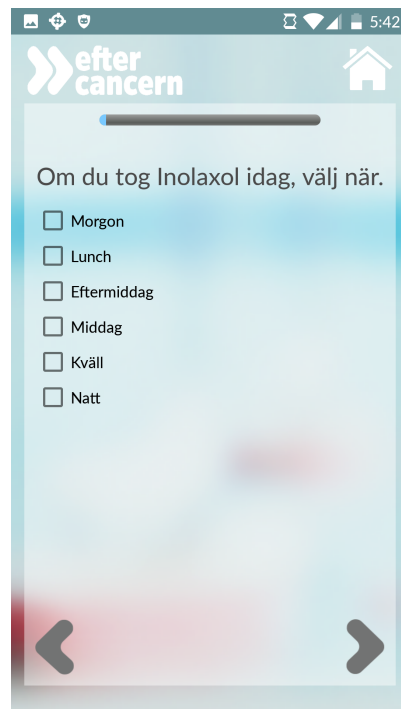


**Figure E.2:** Application Question

E. Android Application

# F
# **Patient Survey**

The next page contains the survey that the patient took after four weeks use of the developed application and smart devices. This survey was answered online via a link provided to the patient.

# Patient Survey

This is a survey regarding the study you took part of the past 4 weeks.

1. **What is your reason for participating in this study?**

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2. **In the past 4 weeks, how many days did you wear the FitBit armband?**
   *Mark only one oval.*

   ( ) Never

   ( ) Less than one week

   ( ) Less than two weeks

   ( ) Less than three weeks

   ( ) Less than four weeks

   ( ) The entire study

3. **When and why did you take off the FitBit armband?**

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4. **Regarding the mobile application, did you feel comfortable opening it and answering questions in public? (If you never did this, would you feel comfortable doing that?)**
   *Mark only one oval.*

   ( ) Yes

   ( ) No

5. **Why would you or would you not feel comfortable? Would you feel uncomfortable if someone was looking over your shoulder at what you were entering? Why?**

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6. **Regarding the mobile application, was it difficult to understand and use?**
   *Mark only one oval.*

   ⬭ Yes

   ⬭ No

7. **Why was it or was it not difficult?**

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8. **Regarding the mobile application, did you feel like it took too much time?**
   *Mark only one oval.*

   ⬭ Yes

   ⬭ No

9. **Why did you feel that way? For example, were the surveys too long or were there too many surveys?**

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10. **Do you think you would have input defecations and urinations more if you were to have the Flic button to press instead of opening up your phone all the time?**
    *Mark only one oval.*

    ⬭ Yes

    ⬭ No

11. **What are your thoughts on opening your phone and answering a survey after every time you use the restroom? And what are your thoughts about if the Flic button would make things better or worse?**

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12. **Theoretically, if there was a camera in the toilet that took a picture of your defecation and sent it to the nurses, and you didn't have to do anything, would you be comfortable with that?**
*Mark only one oval.*

◯ Yes

◯ No

13. **What are your thoughts on this? What if you had to take the picture yourself and send it instead of filling out a survey?**

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14. **In general, what are your thoughts on collecting data about yourself and giving it to the nurses?**

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15. **What are your general thoughts on the FitBit armband?**

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16. **What are your general thoughts about the mobile application?**

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17. **What are your general thoughts about this study? Why did you or did you not like it? What was the problems and benefits with it?**

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18. **If you have any last comments, suggestions or problems, please tell us here! All of your thoughts are very useful for us.**

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Powered by

Google Forms