

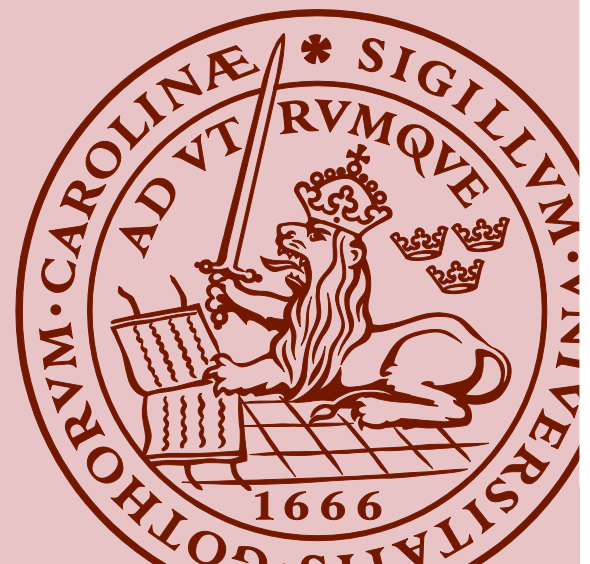
Connected Health for Patients Diagnosed with Prostate Cancer

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MASTER THESIS

EXINI



Connected Health for Patients Diagnosed with Prostate Cancer.

A technical solution to follow disease changes.

Emmy Sandwall



LUND
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Abstract

Prostate cancer is one of the most commonly diagnosed diseases among men, both in Sweden and the US. It is a consuming disease that tears on both the patient and his relatives. The different stages of disease are many, as are the different treatment options and drugs. New diagnostic techniques are constantly being developed and more imaging methods become available. As new digital techniques evolve, so does the possibilities to involve the patients in their health care. Providing the patients with a tool that could help follow disease changes over time could be an important part towards recovery. What this tool and technical solution could contain is something that is researched in this report. A high-fidelity prototype for such a solution was created using established methods of human-centered design. The prototype contains design for some of the features discussed throughout the report, such as; viewing and comparing of diagnostic images, mood tracking, comparing test results and sharing updates with family and friends. The prototype was evaluated with a heuristic evaluation and a SUS score. This evaluation provided useful feedback on how to make this a functional product in the future, with a positive result to the prototype.

keywords: diagnostic images, connected health, e-health, digitalisation, prostate cancer, interaction design

Sammanfattning

Prostatacancer är en av de mest diagnostiserade sjukdomarna bland män, både i Sverige och i USA. Det är en påfrestande sjukdom som tär på både patienten och hans anhöriga. Det finns många olika stadier av prostatacancer och många behandlingar och läkemedel. Nya diagnostiska metoder utvecklas konstant och fler och fler tekniker för bilddiagnostik blir hela tiden tillgängliga. I takt med att nya digitala tekniker utvecklas, utvecklas också möjligheten att involvera patienten i sin vård. Att förse patienten med ett verktyg som gör det lättare att följa sjukdomsutvecklingen över tid skulle kunna vara en viktig pusselbit på vägen mot tillfrisknad. Hur detta verktyg och teknisk lösning skulle kunna se ut är något som undersöks i denna rapport. En hifi-prototyp för en sådan lösning skapades genom att använda väletablerade metoder för användarcentrerad design. Prototypen innehåller design för några av de funktioner som diskuteras i rapporten, så som; visa och jämföra diagnostiska bilder, humörsuppföljning, jämföra testresultat och att dela uppdateringar med familj och vänner. Prototypen utvärderades med en heuristisk utvärdering och ett SUS-värde. Denna utvärdering gav användbar feedback för hur detta skulle kunna göras till en användbar prototyp i framtiden, med ett positivt resultat för prototypen.

nyckelord: diagnostiska bilder, uppkopplad hälsa, e-hälsa, digitalisering, prostatacancer, interaktionsdesign

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Lund, May 2018
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List of Acronyms and Abbreviations

HCI - human-computer interface

hi-fi - high-fidelity

HIPAA - Health Insurance Portability and Accountability Act

lo-fi - low-fidelity

PSA - prostate-specific antigen

SUS - System Usability Scale

TPM - template prostate mapping biopsy

TRUS - transrectal ultrasound-guided prostate biopsy

UI - user interface

UX - user experience

1

Introduction

This introductory chapter contains background information about the goals of the project and the motivation for the project scope. The tools used within the project are shortly described. Project limitations and report structure are presented.

1.1 Goals and Research Questions

The goal of this master thesis is to examine the need for technical solutions to help men diagnosed with prostate cancer in their journey towards recovery, and to come up with a design that meets those needs. The technical solution should provide the patient with tools that make the tracking of changes in disease progress easier. To reach these goals the following questions were asked:

- What is the patients missing in today's health care in terms of technical solutions?
- Is there an interest among patients to access medical images at home?
- How could such a solution be designed to facilitate the whole age span of prostate cancer patients?

1.1.1 Background and Motivation

The first step when suspecting prostate cancer is often a PSA-test. PSA stands for prostate-specific antigen, a protein that is produced by the prostate. Even healthy men might have low levels of this protein in the bloodstream. A blood sample with an increased PSA-value could indicate prostate cancer. However, even benign prostate enlargement and prostate infections (i.e. not prostate cancer) might result in an increased PSA-value. Since PSA-test do not always indicate prostate cancer further examination is always necessary [1]. One of the biggest disadvantages of PSA-tests is that a lot of men are diagnosed with prostate cancer and receive treatment even though the cancer would never have evolved into a serious disease without the treatment. This means that a lot of men live their lives with lasting unnecessary side effects [2]. The PSA-test is followed by a palpation where a doctor feels the prostate with a finger to examine if its shape is abnormal. Later, after a biopsy, the cancer is scored

according to cell shape which is then used to determine a suitable treatment [1]. Doing a biopsy is not without risks. The most common complications include different infections and bleeding [3]. Since not every single part of the prostate is examined there is also a risk of missing the tumor. In a study from 2017 it was found that the standard TRUS-biopsy (transrectal ultrasound-guided prostate biopsy) had a sensitivity of 48% when controlling the results of clinically significant cancer with a more advanced TPM-biopsy (template prostate mapping biopsy). Among the 452 men that were primary diagnosed with no cancer or non-significant cancer the later control showed that 119 men actually had clinically significant cancer [4].

From this it is not hard to imagine that new methods and better diagnostic tools constantly are being developed and studied. Fusion techniques that combine different imaging modalities can be seen at conferences like *The International Symposium on Focal Therapy and Imaging in Prostate and Kidney Cancer* held in Noordwijk February 11-13, 2018. There are also articles describing these techniques which combine functional and anatomical imaging [5]. As the techniques become more complex the possibilities of doing more with the images increases. Under the HIPAA (Health Insurance Portability and Accountability Act) the patient has right to a copy of his or her medical records and data [6]. At the same time this is often described as a hard and time consuming process, especially when it comes to accessing medical images. This gave rise to a question about the possibility to involve the patients through a technical solution, making it easier to access data such as medical images.

1.1.1.1 Previous Work

There are a lot of applications available for patients today, both specific for patients diagnosed with prostate cancer and more general apps. Many of these have the functionality of tracking patient progress or connecting the patient to relatives and close ones.

The *chemoWave* app offers patient support through chemo therapy, it is available in the US for cancer patients (i.e. not specifically prostate cancer) receiving chemo. It allows the user to track their care, symptoms, and side effects [7]. In the Swedish market there is a similar support system especially designed for prostate cancer patients where medical test results and examinations are stored and presented to the user. *Patientöversikt prostatacancer (PPC)* is of use both to the patient and the treating doctor who can follow how the treatments are affecting the patient in different graphs [8]. PPC is today used in Swedish prostate cancer health care. It is used as a tool for the doctors at different departments who are treating patients with advanced cancer. To improve the workflow the doctors update the PPC with drugs, side effects and test results at every visit. This makes it easier for the next doctor to get a quick overview of patient status [9].

Different apps for family support are the *LivingWith* and *MyLifeLine* apps. They are not specific for prostate cancer patient and available only in the US. They let the patient create a support system of family and friends to help manage different complications that comes with living with cancer. They also let the members of the support system follow changes that the patient reports. This could either be asking for help with driving to the hospital for an appointment or just sharing and keeping up with changes in how the patient is doing with

treatment [10, 11].

When it comes to cloud based systems and mobile platforms that allow doctors to easily share images between different specialists and clinical teams there are the *Lify* and *MIM* systems on the US market. Both are available for many types of medical images and are not specific to cancer or prostate cancer. They have systems that allow the patient to view their own medical images [12, 13]. For *VueMe™*, that is a part of the MIM system, the app is a non-diagnostic medical imaging app that is specifically designed for the patient. Besides letting the patient see the images is also allows the user to share images with medical specialists and loved ones [14].

From what the research shows, no applications combining all above mentioned functions exists. It is unclear how many patients actually use applications like these and to what extent they use them. Examining the use and need for different technical solutions among prostate cancer patients in order to provide them with the best fitted application could have an impact on helping the patients through the journey of disease and towards recovery.

1.1.2 Project Limitations

Since EXINI Diagnostics works on image analysis within prostate cancer this project is limited to patients diagnosed with prostate cancer. The project should be seen as pre-research for a potential future product and no product is developed in the scope of this project. The project is limited to studies among Swedish patients and health care due to geographical limitations. Research for background information has been made on both the Swedish and the American market.

1.2 Tools

1.2.1 Artecture

The Artecture app for Android by Samsung R&D Institute Bangladesh is an application for sketching digitally [15]. Throughout the project it has been used to draw handmade sketches. The app allows sketches to be created in vector format. It consists of features such as layers, unlimited undo/redo, and a large set of brushes and pencils for free.

1.2.2 InVision

The InVision prototyping tool by InVision is a web application for producing interactive prototypes [16]. In this project it has been used to create the interactive prototype in chapter 5. It makes it possible to create a prototype that lets the user navigate just like in a real product.

1.2.3 Inkscape

Inkscape is an open source software for editing scalable vector graphics (SVG-files) [17]. In this project it has been used to produce the images that were used in InVision to create the interactive prototype. It was also used to create png-files of diagrams and workflow charts.

1.3 Report Structure

The structure of this report is following the workflow of the project, beginning with background information and then presenting the work process. The project has been done in four main parts, establishing requirements, designing alternatives, prototyping, and evaluation based on the design cycle for interactive design. Each of these main parts are described in separate chapters with associated captions. Since the design cycle is an iterative process each of the chapters contains influences from the other parts as well. In each chapter the main focus has been to present the workflow against reaching the goal described by each chapter caption. This means that each chapter contains methods, results, and evaluation. Each of these chapters end with a summary of the key learnings. The report ends with final results, and conclusions about the work done with suggestions on how this research could be used to develop a product in the future.

2

Theory

In this chapter, theory about prostate cancer and different design methods are presented. It contains information that is of importance for the methods and techniques used in the rest of the project.

2.1 Prostate Cancer

Prostate cancer is a tumorous disease that originates from the prostate. Every year about 10000 men in Sweden are diagnosed with the disease. These numbers make it the most common form of cancer in Sweden [18]. In the US it is the second most common form of cancer among men [19]. The average age for diagnosis is 70 and among men under 50 it is mostly uncommon [18]. The survival rate for prostate cancer patients is dependent on type and stage of the cancer. The five-year survival rate (i.e. patients alive after five years) for low risk cases is almost 100%. This rate drops over the years, and 96% are alive for at least 15 years. For prostate cancer that has spread to other parts outside the prostate, so called high risk cases, the five-year survival rate is 29% [19].

2.1.1 Stages and Grading

Based on the results from medical tests and scans the physicians can use the TNM-system to determine the stage of the cancer. This is a way of describing where the cancer is located, if or where it has spread and whether it is affecting other parts of the body. The TNM-system is based on the following questions:

- Tumor (T) - How large is the primary tumor? Where is it located?
- Node (N) - Has the tumor spread to the lymph nodes? If so, where and how many?
- Metastasis (M) - Has the cancer metastasized to other parts of the body? If so, where and how much?

Depending on the answers this is translated into five stages, stage 0 and stages I to IV [20]. To determine the stage physicians use biopsies, different imaging techniques and sometimes even lymph nodes excision (removing lymph nodes close to the prostate). In early stages the tumor is slow-growing and only

located in the prostate. In the later stages the tumor grows outside the prostate and might spread to lymph nodes and skeleton [21].

The cancer is also given a score. A so called Gleason score is the most commonly used grading system. This is based on the look of the biopsied cells. A pathologist looks at how the cells in the prostate are arranged and assigns them a score of 1 to 5. Different scores are given for the most common and second most common morphology. These two scores are then added together to create a final number between 2 and 10. Lower scores are assigned to cancer cells that look similar to healthy cells since these are less aggressive. Higher scores are assigned to the ones looking less like healthy cells suggesting a more aggressive tumor [20].

2.1.2 Treatments

The treatment options are many. The decided treatment should be an agreement between patient and physician and the different side effects have to be considered. The stage of the cancer is important in determining what options that are suitable [21]. Since early stage prostate cancer is slow-growing there is a risk that treating the cancer would cause more discomfort than the disease itself. The recommended treatment could then be to wait and actively monitor the progression of the tumor. If a patient develops symptoms and the cancer becomes more aggressive or spreading, the patient starts receiving other treatments. Other treatments can be both local treatments like surgery or radiation therapy or be systemic treatments like hormone treatments or chemotherapy [22].

2.2 Design

In human-centered design it is the user and their goals that are the driving forces in development. By having this in mind when designing, the result will be a product that supports rather than constrains the user and that will be directly relevant to the task at hand. To achieve this it is important to have early focus on the users and tasks, which means understanding who the user will be and how they will use the product. To do this the users have to be involved early on in the design process. It is also important to observe and measure the reactions and performance of the intended users when confronted with tasks and manuals. In later stages the same observations have to be done when the intended users are faced with interactive prototypes and simulations of the product. The design cycle should cover the steps of design-test-measure-redesign repeatedly as often as necessary [23, pp. 327-328]. Norman [24] describes human-centered design as a design philosophy and as the process that ensures that the design match the needs and capabilities of the intended users. This means adding deep consideration and study of human needs to the design process. The different steps of the human-centered design cycle can be described in four terms, namely establishing requirements, designing alternatives, prototyping and evaluating. Working in these phases should be an iterative process as seen in Figure 2.1 [23, pp. 332]. In the following sections it will be described how different methods can be used to accomplish these different steps.

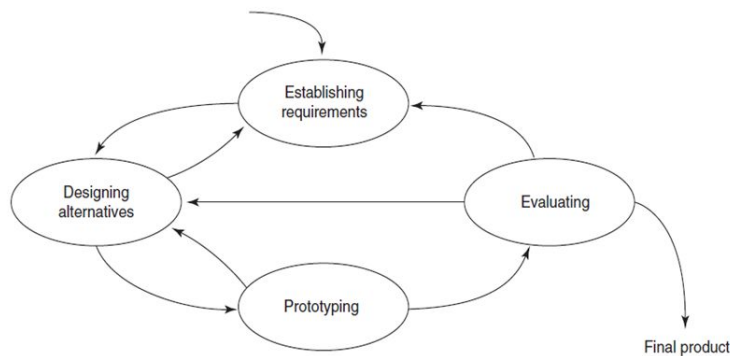


Figure 2.1: Iterative cycle of the interaction design phases [23, p. 332].

2.2.1 Establishing Requirements

When establishing requirements it is important to find out whom the users are, get to know their needs, and find out what the product could offer in terms of support of those needs. The user needs and the gap in existing technology forms the basis of product requirements. The goals for the product are set through analyzing the result from data gathering sessions [23, p. 19].

2.2.1.1 Data Gathering

Data gathering in form of establishing requirements has the purpose to collect sufficient, accurate and relevant data so that the requirements for the product can be established correctly. Data gathering is often done by interviews, questionnaires and/or observations. The first step is setting goals clarifying how the data should be used and what it should be used for. The participants (called population) have to be identified. This is done according to the goals. The population could either be random or not random. How many persons the population should contain of is dependant on the type of data that is to be gathered. It is important that the relationship with the participants is professional and getting the participant's consent is crucial. In large studies it might be a good idea to perform pilot studies prior to the real study. This is so that annoying and confusing questions can be avoided, and to see that all instructions and questions are easily understood [23, pp. 227-230].

2.2.1.1.1 Interviews

When conducting an interview it is important that the participants know their rights regarding the interview. They should have given their consent to participate and should always be offered the right to end the interview at any given time, and informed that no gathered data from an ended session is kept. The participant should be informed what the answers are going to be used for and offered to take part of the results. If any participant is a minor the consent must come from the guardian. The participant should in advance know how much time the interview is supposed to take. An interview should be kept under 1.5 hours [25, p. 42-44]. To get the most out of interviews it is a good idea to know

something about the participants in advance and act accordingly. The following five steps should be covered in the given order at any interview [23, p. 242]:

1. An introduction presenting the interviewer and the reason for the interview. If the interview is to be recorded, permission needs to be asked in the beginning. The introduction should be the same for all participants.
2. A warm up session covering the most basic and easy questions.
3. A main session where the questions are asked in a logical sequence with the most probing ones at the end.
4. A cool-off period with easier questions to ease possible tension.
5. A closing session with thanks to the participant. This part should signal that the interview is over by switching off the recorder and putting away the notebook.

Interviews can be performed in different ways. Since it can be viewed as a conversation with a purpose the best way of performing the interview is depending on that purpose. Following four types of interviews are the most common [23, pp. 233-238]:

Unstructured Interviews

Unstructured interviews contains open questions with no clear answer and is a lot like a conversation about a specific topic. Both the interviewer and the interviewee can steer the interview in any direction. The interviewer should however have a set of questions prepared that contain the key topics to discuss. Follow up questions and probing (e.g. "can you tell me a bit more") generates rich data. Since this does not generate any correlations between the interviews these answers will be very time consuming to analyze.

Structured Interviews

Structured interviews contain only closed questions where the predefined set of answers are presented to the interviewee. The questions should be phrased exactly the same for all interviews and each participant, and they should be asked in the same order. Structured interviews closely assemble questionnaires.

Semi-structured Interviews

Semi-structured interviews contain a combination of closed and open questions and combines the structure of unstructured and structured interviews. The closed questions should come early in the interview and the more probing ones later on. The structure of the interview should be set in advance and the probing questions should make sure that everything important is covered.

Focus Group Interviews

Focus group interviews are interviews performed in groups of normally 3-10 participants in each group. This is especially good when trying to understand community issues and less good for personal experiences. The key is to get the group to open up and start discussing. The discussions should be led by a

trained facilitator. These interviews are very flexible and the benefit is that this might allow new issues to arise that would be missed in single subject interviews.

2.2.1.1.2 Different Tools

When gathering data, by for instance an interview, different tools can be used to help driving the conversation forward. Prototypes, images and work artifacts are all tools that could be of great help enriching the interview experience. The main reason to bring props is that they can provide a context for the questions making it easier to understand the questions since the data is grounded in something real [23, p. 243].

In order for the interviewer to collect as much data as possible it is important that the data is recorded. This can be done with notes, audio, video, photographs or any combinations thereof. What kind of recording techniques that should be used depends on the setting, the type of data that should be gathered and how much details that has to be collected from the data. Video recordings can be considered to be very intrusive, and if it is not especially important to collect the visuals of the data recording audio can be an useful alternative. Both audio and video has the benefit of allowing the interviewer to be fully focused on the conversation, not having to worry about getting it all into notes [23, pp. 231-232].

2.2.2 Designing Alternatives

When the design requirements are established, the next step is to generate potential solutions. Creativity is critical and some kind of brainstorming process is often used. It is important not to fixate on one or two ideas and to embrace every possible idea in this phase. Even the craziest ideas should not be criticized in the beginning, since they might be the key to some great solution later on [24, p. 225]. Great design should produce pleasurable experiences for the user. When interacting with a product the user needs to figure out how to work it, meaning figure out what it does, how it works and and what actions are possible, i.e. discoverability. To design a product with high discoverability the designer has to consider the application of the five fundamental psychological concepts that is affordances, signifiers, constraints, mappings, and feedback [24, p. 9]. When designing alternatives the key is to design multiple solutions meeting the needs in different ways. The designs should suggest ideas on how to meet the requirements [23].

2.2.2.1 Usability and UX Goals

In terms of setting usability and user experience (UX) goals it is important to focus on how the product can be developed to be easy to learn, easy to use and enjoyable to the user [23]. Usability is defined in the ISO standard ISO:9241-11(1998) as *"the extent to which a product can be used by the specified user to achieve special goals with effectiveness, efficiency and satisfaction in a specified context"* [26]. To break this down usability can be described by the following goals [23, pp. 19 ff.]:

- Effectiveness: The product should be effective, meaning that it should do what it is supposed to without the user having to use workarounds and

perform complicated tasks.

- **Efficiency:** The product should be efficient to use, meaning that it should help the user to carry out tasks with a high level of productivity, i.e. quickly and organized.
- **Safety:** The product should be safe to use and protect the user from unsafe use, dangerous conditions and possible errors.
- **Utility:** The product should have good utility and have the appropriate set of functions and right functionality so that the user can do what is intended.
- **Learnability:** The product should be easy to learn how to use and the time spent learning the functionality of the product should be as short as possible.
- **Memorability:** The product should be easy to remember how to use once learned. This is especially important for products with infrequent use.

The UX goals are a set of goals that defines how the product should feel when used. Emotions can be divided in desired aspects, (e.g. satisfying, enjoyable, challenging, surprising, rewarding or entertaining), and undesirable aspects (e.g. boring, frustrating, annoying or making one feel stupid). What determines whether a product feature rises undesirable or desirable emotions may depend on the setting and context in which it is used. This is important to keep in mind when designing interactive products [23, p. 22].

2.2.2.2 Mental and Conceptual Models

The conceptual model is something that highly simplified should describe how something works and should provide the true understanding of the product. The model may come from the product itself, from manuals or from one person telling another. Most of the model is constructed by experience. The model made up in the users mind becomes the mental model. This model may differ from person to person depending on their relations and experience with the product. If the mental model is erroneous and there is a gap between the designers conceptual model and the users mental model this can lead to faulty or difficult usage of the product. A good conceptual model should allow the user to predict the effects of the user actions and hence create a correct mental model [24].

2.2.2.3 Design Principles

In the book *Designing with the mind in mind*, Jeff Johnson describes simple guides on how to design products with a high usability. The guides include, among other things, how to use gestalt principles and other theories to make it as easy as possible for the user to interact with the design. The gestalt principles described include the principal of proximity, similarity, continuity, closure, symmetry, figure/ground, and common fate. They are all described as ways of grouping items together in different ways. The grouping of menus, buttons and dialogues should be done so that they match the way the human mind sees and

perceive structures. The principles hence provide a useful basis for graphic and user interface (UI) design. Johnson also describes how the capability of reading works and how that can limit the user in taking in information provided in an interface. For instance, text should always be left-aligned since that helps the reader place the eyes in the right place between each row of information. How the information is presented is also important. Using colors that are non-distinctive or pairing colors that color-blind people cannot distinguish makes the interface harder to perceive. Humans also miss a lot of information that appears in the periphery, or that do not match the goal of action. Johnson also points out that the design always should be consistent in a system since that makes the system easier to learn [27].

2.2.3 Prototyping

Prototypes can be used in many different ways and take many different forms. Everything from simple sketches to advanced molded 3D-models can be considered prototypes. Prototypes can also be software, pictures and simulations. Prototypes are a useful tool when discussing and evaluating ideas and concepts. Also, just creating the prototype encourages the designer to reflect on the design which is useful in the design process. The prototype can for instance be further used in choosing among alternatives, test technical features and clarify requirements. Which kind of prototype that is made is based on what kind of properties that is to be tested and what the purpose of the prototype is. Depending on the level of functionality and resemblance to the real product, prototypes can be described as low-fidelity (lo-fi) or high-fidelity (hi-fi) prototypes [23, pp. 386 ff.]. Studies have shown that the use of lo- or hi-fi prototypes makes little difference when it comes to testing the UX and therefore lo-fi prototypes are a suitable option in order to both save time and money in early stages of development [28].

2.2.3.1 Lo-fi Prototypes

A lo-fi prototype does not resemble the final product in means of look and functionality. It is often made of paper, cardboard or other materials far away from the final product. The functions can either be partially integrated or only represent the functions without providing the functionality. Lo-fi prototypes are not meant to be kept and developed into final products, they are temporary prototypes. The main advantages of a lo-fi prototype are that they are cheap, easy to make and do not take long to provide. This also means that they are highly modifiable, which is great when exploring alternatives and changes to design and concepts. Flexible prototypes encourage modifications. In the early stages of development modifications are important to drive the concept forward. Storyboarding, sketching, index cards and Wizard of Oz are common types of lo-fi-prototyping [25, pp. 12-15][23, pp. 389-391].

2.2.3.2 Hi-fi Prototypes

A hi-fi prototype resembles the final product a lot more than a lo-fi prototype, both in functionality and appearance. Hi-fi prototypes are especially good for selling ideas and testing technical problems and issues [23, pp. 391-392]. In many cases the hi-fi prototype is developed into the final product and can be

seen as a first version. This is called an evolutionary prototype where the parts of the final concept are added gradually [25, p. 15].

2.2.4 Evaluating

The evaluation of a design takes place at different times along the design cycle. At an early stage in the design process the evaluation can be used to find out if the initial design (often simple sketches) meets the established requirements. Later on in the process evaluation is used to test more advanced prototypes. The result from the evaluation is supposed to help modify the design and develop new prototypes that can be further evaluated. Normally, evaluation can be made in one of the following three ways:

- *Controlled settings involving users*: The evaluation takes place in a controlled environment (i.e. labs) and the user activities are controlled in order to test hypothesis. Usability testing and experiments are the main methods used. This approach has been especially successful when wanting to evaluate software applications. The evaluation can then be based on a predefined set of tasks that the participants perform under surveillance.
- *Natural settings involving users*: The evaluation takes place in the natural environment where the product is supposed to be used. This is often used for field studies. The advantage is that the evaluation shows how the product would work in the real world and the disadvantage is that there is no control over the user activities.
- *Any setting not involving users*: The evaluation is made by a group that is not the intended user and is used to find the most obvious problems with a product.

When deciding what kind of evaluation that is suitable the most important is to decide what kind of control that is needed to find out how the product and design is used [23, p. 456].

2.2.4.1 Heuristic Evaluation

Heuristic evaluation is an evaluation method used for finding usability problems. A set of heuristics (e.i. usability principles) are used to guide the evaluation of different aspects of the interface. The most used heuristics are the ones developed by Jacob Nielsen [23, p. 501]. His heuristics consists of ten tested principles for a good human-computer interface (HCI) [29]. These heuristics were developed and revised in the 1990's, which means that they are no longer directly applicable to new systems since technology has evolved since then. It is therefore encouraged that designers evaluate against their own heuristics. In order to generate these, it is a good idea to combine principles from different perspectives. For example one could use both Nielsen's original heuristics, general design guidelines and Ben Shneiderman's 8 golden rules as a basis for coming up with principles fitting to a specific system. For a heuristic evaluation the evaluators should not be the end user. The evaluators should be good at usability and have knowledge about the field in which the product should work. Three to five evaluators are enough to find the most basic problems. However,

if the evaluators have different background and different expertise, having more people could help finding problems in different areas [30].

2.2.4.2 The System Usability Scale (SUS)

For getting a measure of usability the System Usability Scale (SUS) can be used. SUS was first released in 1986 by John Brooke [31]. SUS is a questionnaire with ten questions that the test users answer on a scale of 1 (strongly disagree) to 5 (strongly agree). The questions focus on how the user experiences the system. A full list of the questions is found in Appendix A. The answers are scored based on a scoring system that weights differently on odd and even questions. The SUS adds up to a number between 0-100. A number of 68 or higher is considered to be above average [32]. Over the years since its release, many researchers has proven the reliability of SUS [33].

3

Establishing Requirements

In this chapter, the user requirements will be established. First the process will be presented with methods used and thoughts about these. Then the requirements from different perspectives will be presented. The chapter ends with a summary of the concluded requirements and key learnings.

3.1 Design Process

The workflow of establishing requirements is described in Figure 3.1. The first step (section 3.2) was to get to know the user in order to later be able to find out their needs. Since the intended user is a male patient diagnosed with prostate cancer it was important to get to know more about what it is to have cancer and how that could affect the final design. The data about the user was gathered by conducting an interview. Since the interview was about background information and experience the questions were designed in an unstructured manner with open questions and discussions about the answers. The interview was sound recorded and took about 45 minutes. The discussions resulted in a rich background that also contained information about the tools used in Swedish health care today. Since the goal of the interview was mostly about getting a first insight, the personal experience of the interviewee was more important than statistical relevance. It was therefore determined that one interview was enough for gathering the right data. The insights that were gained about prostate cancer, the patients diagnosed with this disease and the tools used were of great help in order to start the project and to move on and design questions for actual patients.

With support from those insights and the scope of the master thesis, a new set of questions were constructed. It was discussed how many patients that needed to answer these questions and in what form the questions should be asked. It was concluded that a low amount of face-to-face interviews were to be conducted so that more time could be spent on presenting detailed ideas to more participants later on. Contact was made with two patients and individual interviews were set up (section 3.3). The men were of different age and therefore supposed to represent different target groups. They were presented with questions in a semi-structured way. The interviews were sound recorded and took roughly 45-60 minutes each. The reason for having these interviews was to

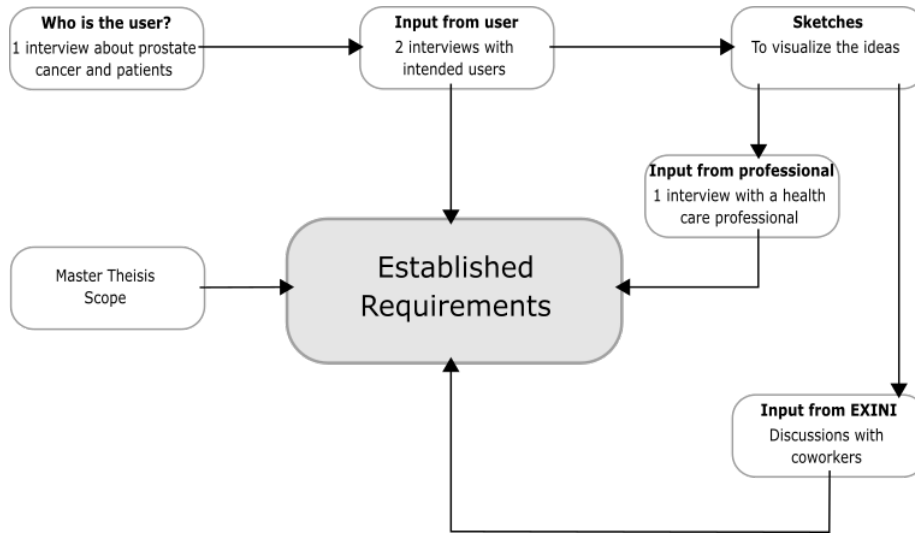


Figure 3.1: The design process for establishing requirements.

gain input from the intended users on their thoughts about different concepts. The conclusions from these interviews were divided into different feature categories. Having these conclusions helped create sketches of the platform and conclude what seemed to be missing in Swedish health care when it comes to digital technology. The interviews worked as a sounding board for the ideas already existing at EXINI and those that arose during the first interview, rising new ideas and new problems.

For a professional take on the ideas and the possibilities for a technical solution from a health care perspective, a small interview of 30 minutes was conducted with semi-structured questions about the ideas from the previous interviews (section 3.4). Also this interview was sound recorded to ease the compilation of answers. To make this interview easier, sketches to accompany some of the questions were created. The sketches were created based on the features discussed in the previous interviews. Having a sketch helped supply a mental model for the interviewee that made it easier to discuss the questions and features more specifically. As described in section 2.2.2.2 it is important to supply the user with a mental model that corresponds to the conceptual model, so that the right understanding for the product is made.

In the interviews the participants were presented with an information sheet containing information on the thesis work and the study (Appendix C) and asked to sign an informed consent form about their participation (Appendix D). This was followed by a short presentation of the thesis work, general thoughts, and goals of the interview. All interviews were constructed as to follow the steps in section 2.2.1.1.1 which gave a good structure to the interviews that was easy to follow.

In order to decide what kind of features that were actually interesting and doable from a company perspective a meeting with the EXINI coworkers was set up (section 3.5). This gave the opportunity to really discuss the ideas from different perspectives.

After each interview evaluation on the content was made and the key parts

were conducted into the requirements found in section 3.6.

3.2 The User

In order to get to know the user, i.e. male patients diagnosed with prostate cancer and their close relatives, an interview was conducted with one of the research nurses at the department of Urology at *Skåne University Hospital* in Malmö. The questions were aiming at finding out who the patients are and in what kind of situation they meet the health care system. Both questions and answers are compiled in Appendix B. In a discipline where there is a huge range in patient age and background it is hard to generalize and describe a typical patient. Based on this interview the most interesting insights were that:

- There is no good way of generalizing the patient and their relatives to describe the user as one, even though most patients are older men.
- All patients react differently depending on age, background and personal experiences.
- The tools used to help patients today are mostly analogue.
- Patients search for a lot of information on their own and often talk to other men in the same situation. This is something that is described as a good thing.
- Most patients wants to know their PSA-value at every appointment.
- Most patients are very open about their cancer and easy to talk to.

3.3 Input: Intended User

The next step in finding out the user needs was to set up two individual interviews with men diagnosed with prostate cancer. The goal of these interviews was to discuss possible features of the patient platform such as image viewing, information, mood changes and the need for relatives and close ones, and to find out the general attitude towards different solutions in terms of a patient platform. The questions discussed are presented in appendix E. The features presented in these questions origins from discussions with the EXINI coworkers and the scope of the master thesis. Another goal was to find out how the answers would differ between the large age gap. The general conclusions that were drawn from this were:

- Different cases of prostate cancer differs a lot. Both when it comes to health care and personal experience.
- Personal background seems to have a huge effect on the attitude about cancer.
- It will be important that any technical solution works both on computer and smart phone in order to not exclude any users.

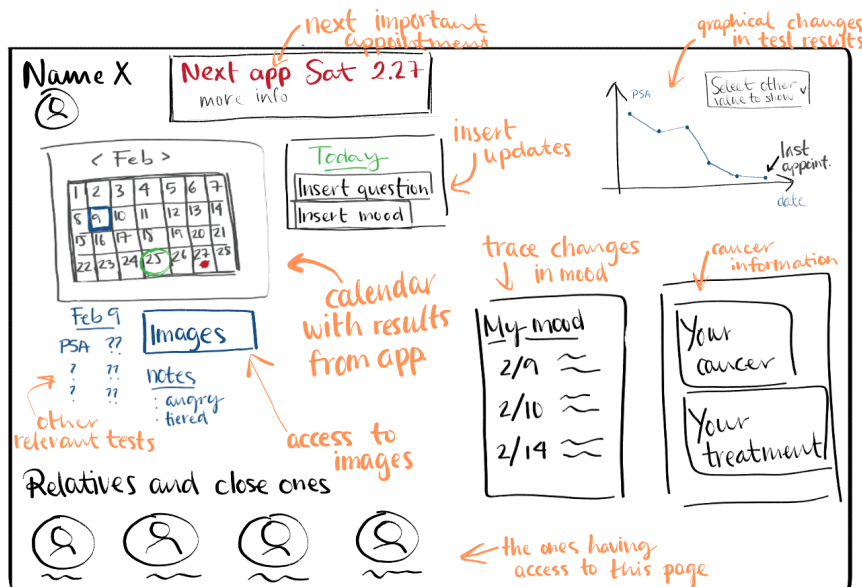


Figure 3.2: Sketch containing initial requirements.

- The term *technical solution* was hard to mediate and the different concepts were sometimes hard for the participants to grasp.

In the following sections conclusions about the different features discussed during the interviews are presented. In order to make it comprehensible and divisible the interviewees are presented as person A and person B. Person B has presented experience from both his one diagnosis and his work in *Prostata-cancerförbundet*. These conclusions resulted in the sketches found in Figures 3.2 and 3.3, and contributed to the requirements stated in section 3.6.

3.3.1 Images

The benefit of being able to access and see images from examinations at home does not seem very clear to the participants. For person A images were never relevant since these never showed any tumors. Person B has actually asked for images at one point but that was because of professional curiosity more than patient concern. From another case person B recognizes that the transfer of images between hospitals does not happen easily and this is something that could be improved on. Images are hard to read and it is concluded that there is a concern from both participants that the information they provide must be controlled. The access to images at home should not replace or precede the doctor's appointment. There should also be a question about whether the patient wants the images or not.

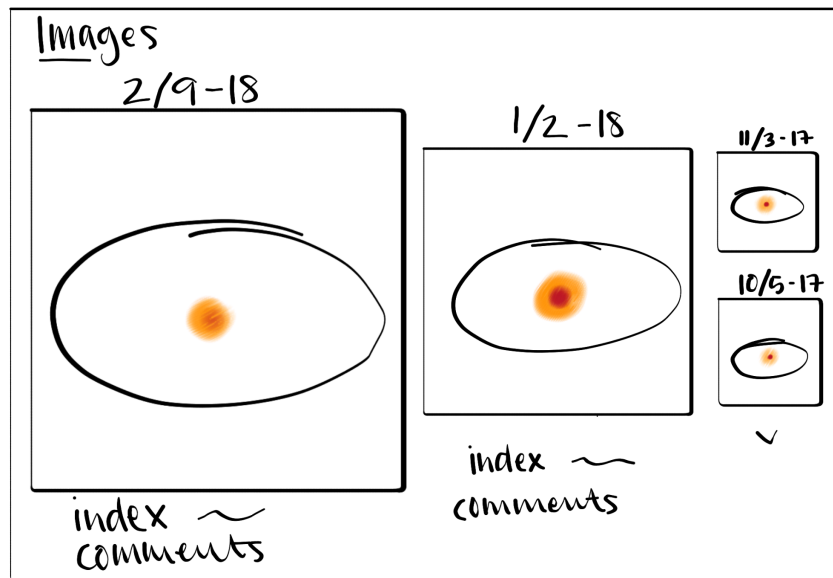


Figure 3.3: Sketch containing the idea of comparing different imaging results from different appointments.

3.3.2 Information

Person A was told by doctors not to search for information online since most of it did not apply to his case. The health care provided him with sufficient information and he did never feel the need to search elsewhere. The experience person B has with different cases and patients tells that there are a lot of men searching for information online and from other resources outside the hospital. From these results there is no way of concluding what the preferred way of showing information is. It seems relevant to think that some kind of information is important and that some patients could benefit from a case where the information is specialized according to patient, cancer type, and stage.

3.3.3 Data and Test Results

It seems that if the data could be automatically inserted in some kind of technical solution it would be beneficial to store and present this information in some kind of collected way. For person B it is especially important that this is not something that he has to do himself manually.

3.3.4 Inserting Mood Changes

For both participants it seems relevant to have a feature that allows the user to insert their mood into the technical solution. This is both useful for the patient himself in order to follow up on how treatments affect the body but also useful in the conversation with the health care provider. For person A this would be especially important during the time of after care when the appointments are fewer. This could maybe be a tool for the patients to communicate worries

about their status to some kind of health care provider that could very quickly see if something seems off or if everything is as expected.

3.3.5 Communities

The usage for communities with the ability to contact and talk with other men in the same situation seems very age dependant. If this is something that should be part of a technical solution or the interested finds these in other forms (like live chats at meetings) is not to be concluded from these interviews.

3.3.6 Relatives and Close Ones

The role of relatives and close ones seems to differ between the participants depending on their background and experience. Person A recons that the ability to have relatives be able to follow the updates in a technical solutions would be good. He also thinks that the amount of information that one is comfortable sharing with others depends on the type of person you are and maybe also how much the cancer affects the body functions. It seems that relatives search for alternate treatments and information on the patient's behalf. Giving them access to the same information and updates as the patient could therefore be beneficial.

3.3.7 Other Thoughts

The technical solution should be some kind of connection between patient and different health care providers. It is especially important during the time of after care. It would also be good if the technical solution could collect all health care information such as appointment times and results that today are provided by mail. It would also be useful if there was some way of communicating and asking questions through the technical solution. In that case the health care provider receiving this should have easy access to all the information stored there. Both participants imagine that it would be important that the use of a technical solution is initiated by a health care professional in order to make it feel reliable and useful.

3.4 Input: Health Care

An interview with a professor in urology was set up at the department of Urology at *Skåne University Hospital* in Malmoe in order to establish a more professional take on the initial thoughts about the technical solution. The interviewee works close to patients and is involved in everything from initial examination to treatment decisions and possible surgery. The interview was focused on the findings from section 3.3. The sketches in Figure 3.2 and Figure 3.3 were brought to this interview in order to more easily communicate about the concept. The most dominant part of the interview contained questions about the image part of the solution. In appendix F all questions are stated. Among health care providers it is already common that they to some extent show images to patients to emphasize on different findings. This is something that is considered helpful and the interviewee was positive to a situation where he could provide such a feature

to the patients, both as an informational tool and as something for the patients to bring home. The findings from this interview were:

- At the initial appointment the patient is provided with as much information about the clinical findings as possible. This includes, among other things size of tumor, aggressiveness, and possible spreading of the cancer.
- Images are already an important tool that the physicians use.
- If patients get access to images at home they need to come with good explanations.
- Applications for surveillance and tracking of side effects are today used by physicians only for patients with advanced prostate cancer.
- The input of information should be automatic.

These findings added to the requirements found in section 3.6.

3.5 Input: EXINI

A meeting with the EXINI coworkers was held to discuss the findings from the two previous sections. It was agreed that the feedback from the previous interviews was really good and that all parts are parts that can be further examined. The relative role in the platform was discussed as whether they should be passive bystanders or able to interact with the platform, asking questions and reacting to updates. It was also discussed that the users should be able to restrict what content to share with the relatives, maybe there should be an alternative to share the fact of an update without sharing the content of said update. It was concluded that in the current state, as in Figure 3.2, the platform can be divided into two parts, one clinical and one personal. These parts could represent the clinical journey with test results and diagnostic images and the personal journey with relatives, personal information and mood updates. It was also discussed to add a feature that allowed the user to scan and save documents that are received from the health care by mail. This could help the user collect everything in the same place if some information is not sent digitally.

These discussions added to the requirements in section 3.6.

3.6 Key Learnings

3.6.1 Features and Requirements

The technical solution should:

- be initiated by a health care provider
- contain a feature where images with good explanations might be seen upon request
- contain information about latest test results
- be available to selected relatives

- contain information about prostate cancer
- provide the user with the ability to follow mood changes
- let the user share updates and questions with a health care provider
- be accessible through both computer and smart phone
- import data and test results automatically

3.6.2 Further Evaluation

Requirements to further evaluate:

- The need to access raw image data that can be transferred to another hospital.
- In what form the information should be presented.
- The usage of communities.
- The communication between health care and patient.
- What kind of test results that are relevant to the patient to access at home.
- The ability for the user to show different content to different relatives.
- If relatives should be bystanders or participate actively in the platform.

4

Designing Alternatives

In this chapter, sketches for a lo-fi prototype will be presented. It is also described how these sketches were used in a questionnaire to evaluate the features and requirements found in the previous chapter. For each sketch and feature, the result of the evaluation is presented. The chapter begins with a summary of the design process and ends with the key learnings being stated.

4.1 Design Process

In Figure 4.1 the design process is shown. From the requirements in section 3.6 sketches were created to illustrate the ideas and different concepts in a lo-fi prototype. The sketches were made by hand digitally in the Arctecture app for Android [15]. This made the prototype easy to change, alternate and further develop. The prototype was supposed to work as a model illustrating the project progress, and to make it easier for the participants evaluating the features to understand the concept. Sketches were made for the different features previously discussed. For some features alternative sketches were made, this was so that different ideas could be separated. For other features only a single sketch was made. For these it was enough to add comments on the side to illustrate the ideas. A lot of time was spent creating the alternative home screens (section 4.2). It was important to include all the features in an intuitive way. Even though these sketches only are first mock-ups, thought was given to design principles described in section 2.2.2.3 when trying to divide the features into feature groups helping the user understand the platform. Where it was possible menus were created to better organize the view for the user. In each sketch, buttons and menus have been separated to create groups that fit the gestalt principles making the right parts belong together and fit the human perception (section 2.2.2.3).

In order to evaluate the features and platform ideas the sketches were used to create an online questionnaire. The questionnaire was sent out to 12 men diagnosed with prostate cancer. Out of these, all 12 completed the form. This allowed for a larger scale evaluation of the ideas originating from the initial interviews and to find out which features that should be kept to later stages of the project. The questions in the questionnaire were designed to help the participants understand the idea and concept behind each feature. The answers were given in free text, scales and multiple choices. The scales were set to be

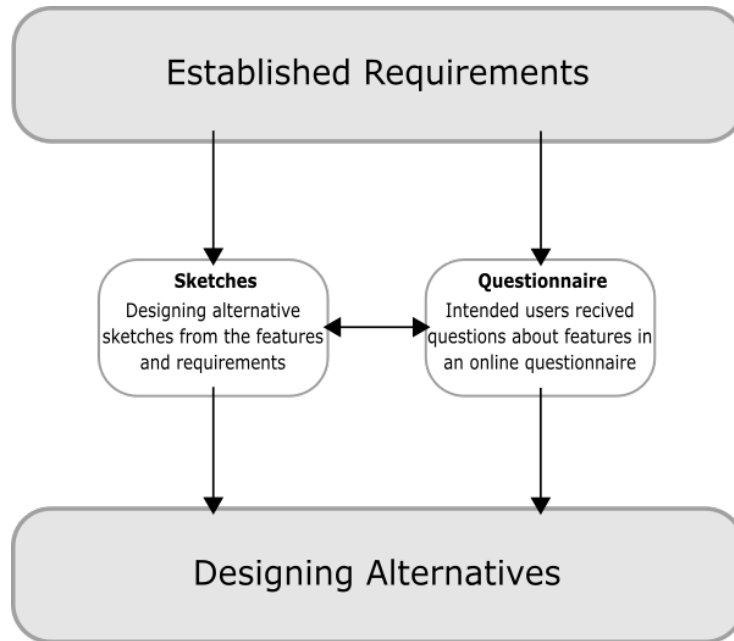


Figure 4.1: The design process for designing alternatives.

between 1 (negative) and 4 (positive) in order to make the participants reflect and either choose a negative or a positive response. The questions with multiple choices was by choice designed with positive alternatives in order to get the participants to think in new ways. Since it previously had been shown that it was hard for the patients to grasp the concept of new features the choices were designed to present possible opportunities that the feature could present. This means that the answers were leading to the participants. The idea with this approach was to reduce the risk of participants discarding features because of lack of understanding. If the participant wanted to discard the feature anyway the option to choose "Other:" and to comment why, was available. For each feature it was also possible for the participants to add their own comments. The main focus in the questions was on the features and what they could provide in terms of possible benefits. At this point no consideration was taken to the design of the features. Since the features were presented with sketches that are far from finished, the design aspect was deemed unnecessary to ask about. The whole questionnaire is available in Appendix G. The age distribution among the questionnaire participants is shown in Figure 4.2. Almost all participants (91.6 %) reported that they have access to, and regularly use a tablet, and a smart phone. All participants reported that they have access to a computer.

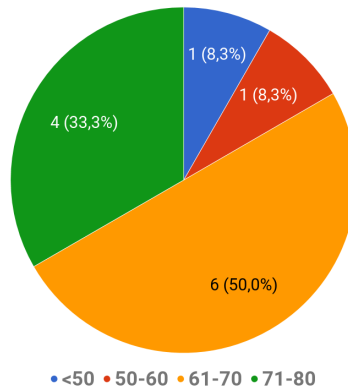


Figure 4.2: Age distribution among the men who answered the questionnaire.

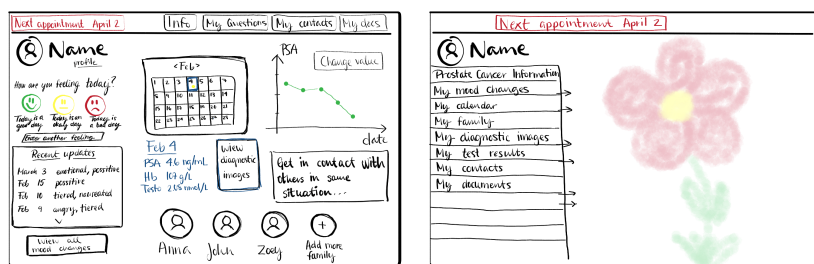
In the following sections, the idea behind the sketches and the evaluation of each feature will be presented. The sketches are also presented in Appendix G, where they can be viewed in larger detail together with the questions for each sketch.

4.2 Home Screen

4.2.1 Sketches

Two versions of the home screen was created. The first sketch, seen in Figure 4.3a, contains all features easily accessible from the same screen. The features have been divided into groups that represent different parts of the platform. The point is to make it easy for the user to see all the different features and get a quick understanding of the different functions and possibilities.

In the second sketch, all features have been moved to a sliding menu which can be seen in Figure 4.3b. The thought is that when the user clicks on a feature in the menu only that specific feature will show up on the screen.



(a) Everything presented at the same screen. (b) The features hidden in a sliding menu.

Figure 4.3: Alternatives for the home screen with two different presentations.

4.2.2 Evaluation

The alternative home screens were evaluated based on how much the user felt he got an overview of the different features and how much understanding the design helped generate in terms of what actions that were possible. In the questionnaire the participants were asked which design they liked the most.

For the first alternative with all the features on the home screen, Figure 4.3a, the responses varied a lot. Over 50 % of the participants thought that the design gave little to no understanding of how the platform could be used. Only 8.3 % (1 participant) thought that this alternative looked the easiest to use. For the second alternative with the features in a menu, Figure 4.3b, there were a lot more positive responses, both regarding the overview and the understanding. 75 % of the participants thought the second alternative looked the easiest to use. The distribution over what alternative the participants figured the most easy to use is shown in Figure 4.4.

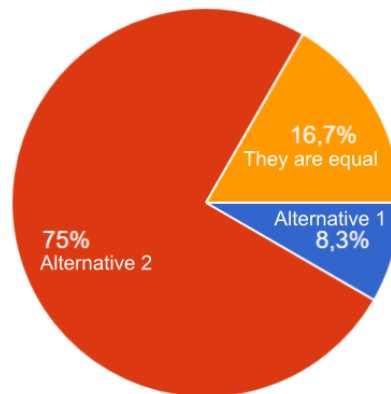
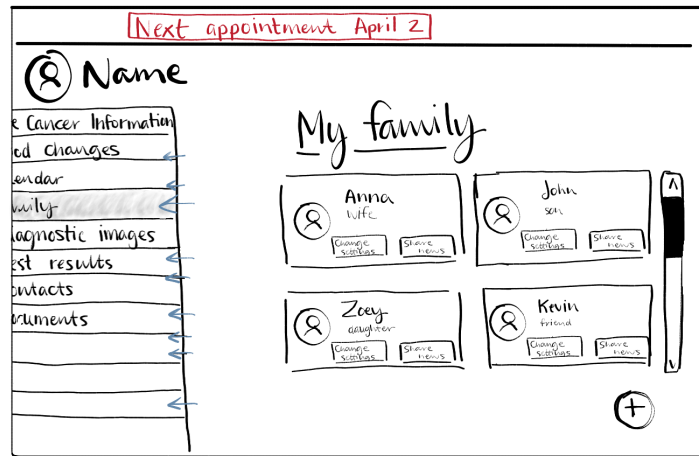


Figure 4.4: According to the participants, the alternative with a menu was preferred.

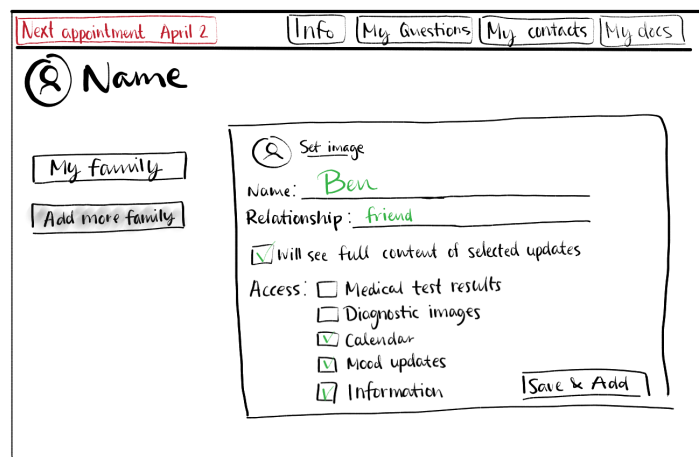
4.3 Relatives and Close Ones

4.3.1 Sketches

In Figure 4.5a it can be seen how the sketch for viewing added family members looks like. The thought was to make the view easy to browse and make it easy for the user to see who has been added to the platform. In this view it should also be possible to click on a person to change settings for that person. Like shown in Figure 4.5b, the thought is that the user should be able to set restrictions so that not everyone gains instant access to all personal information. That means that the user should be able to decide what an added person will get updates about and what those updates contains. Since this might change over time depending on personal relationships and medical conditions it seems important to make these settings easy to change.



(a) Overview of added family and possibility to add more.



(b) The possibility to add more close ones. The user can set limitations to the shown content by ticking the boxes.

Figure 4.5: The sketches for the feature *Relatives and Close Ones*.

4.3.2 Evaluation

This feature was evaluated based on how the participants felt that they were in need of relatives and close ones having access to updates about their condition and how they felt about the opportunity to restrict certain people’s access. Questions about the gain with such a feature was also asked.

Regarding the use of involving family the responses were mixed among the participants with both positive and negative answers, Figure 4.6. The evaluation showed that it is important for all participants that they should be able to control the amount of shared content. The benefits seen by the participants were:

- Easier communication with family.
- Quick way to update news to family.
- Less worry for family.

How much use would you have for the feature to add family members that could follow your journey?

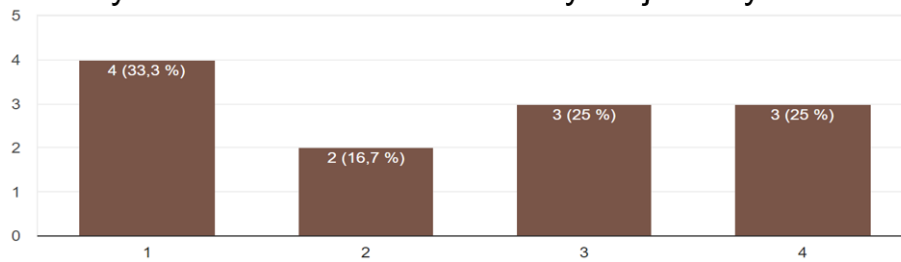


Figure 4.6: Both negative (1-2) and positive (3-4) responses on the feature for involving family.

4.4 Diagnostic Images

4.4.1 Sketches

Images that could be used as a diagnostic tool could be accessible for the patient at home. In Figure 4.7 the sketch for such a solution is shown. The thought is that it should be easy for the user to compare results from different appointments and to see how the tumor activity changes over time. The latest study is therefore shown as a larger image than the others, then this could be compared to the previous two studies. By clicking on one of the images or one of the dates in the left menu the user should see details about that specific study, preferably together with a statement from the treating doctor about the contents of the image.

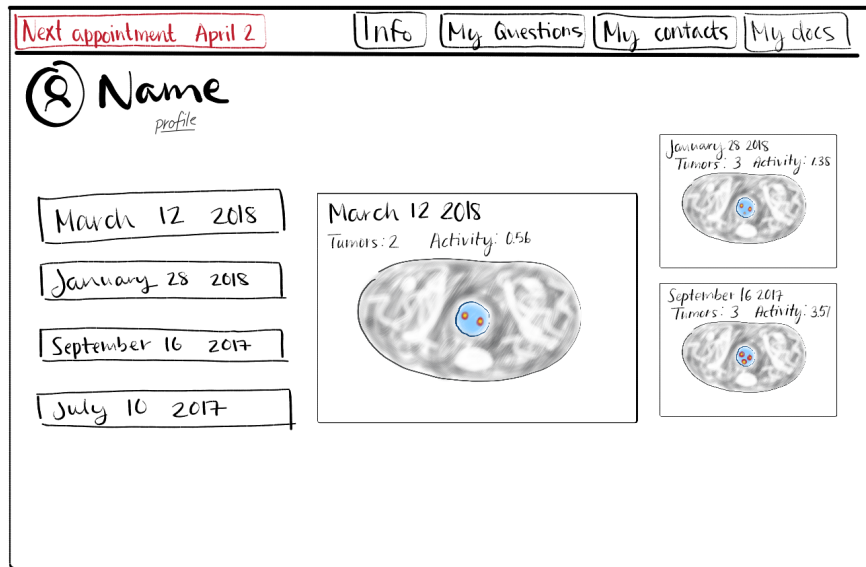


Figure 4.7: Feature of seeing diagnostic images at home.

4.4.2 Evaluation

The feature of accessing diagnostic images at home was evaluated based on the users perceived gain with the feature and how much use the participants thought they would find for such a feature. The participants were also asked how important it would be with a professional opinion accompanying each image.

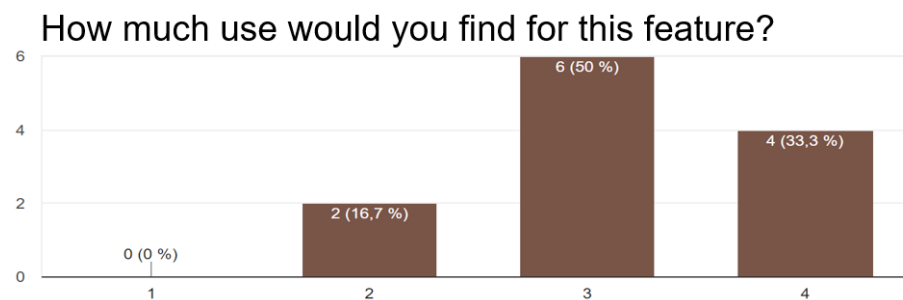


Figure 4.8: Mostly positive responses (3-4) on the feature of accessing diagnostic images at home.

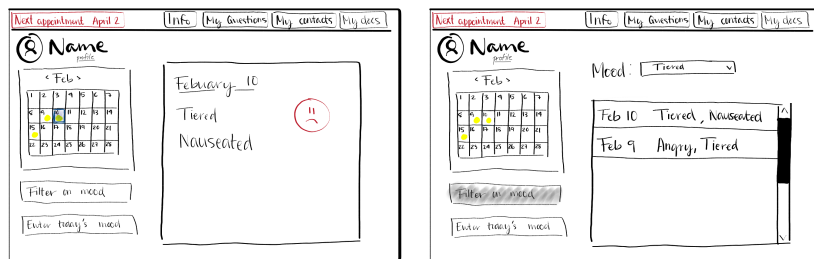
Overall the responses were positive, Figure 4.8. It was important to the participant that the images would come with a professional opinion. The benefits found with this feature were:

- Getting an overview of changes.
- Reminder of doctor's opinion.
- Showing family.

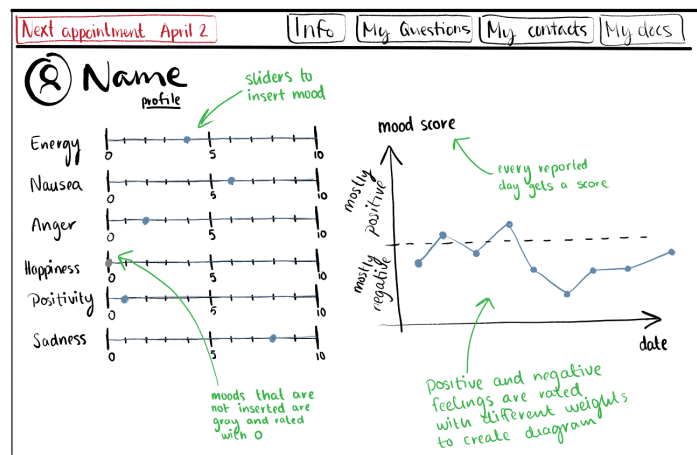
4.5 Mood Tracking

4.5.1 Sketches

The first alternative is based on a key word system where the user enter moods and feelings on the home screen (section 4.2). The moods can either be positive, negative or neutral with different colours to match. Like in Figure 4.9 the moods could either be viewed day by day as in Figure 4.9a or be filter to show all days containing a certain mood as in Figure 4.9b. The second alternative is shown in Figure 4.9c. In order to make it a bit easier to follow up on mood changes and how they alter over time this alternative contains a grading system so that the user has the possibility to add a value to each feeling and mood. This value could then be used to create a plot on the overall well being. The grading is done by moving a point between zero and ten for the relevant moods.



(a) Calendar to see every mood on a reported day. (b) Filter for a certain mood and show all days that mood has been reported.



(c) An alternative way of displaying mood changes. Instead of just inserting a mood or feeling there is also a possibility to rate the feelings.

Figure 4.9: Different parts of the feature for *Mood Tracking*.

4.5.2 Evaluation

Evaluation has been made based on the necessity of the feature and how important the participants think it is to be able to follow up on how their mood changes over time. The benefits of the feature were also evaluated. Only the sketches in Figure 4.9a and Figure 4.9b were a part of the questionnaire. Figure 4.9c was designed later as a result to the first participants answering the questionnaire. The participants thought it important to be able to follow up on how their mood changes, Figure 4.10. The benefits found were:

- Easier communication with health care provider.
- Better personal overview.
- Keeping relatives updated.

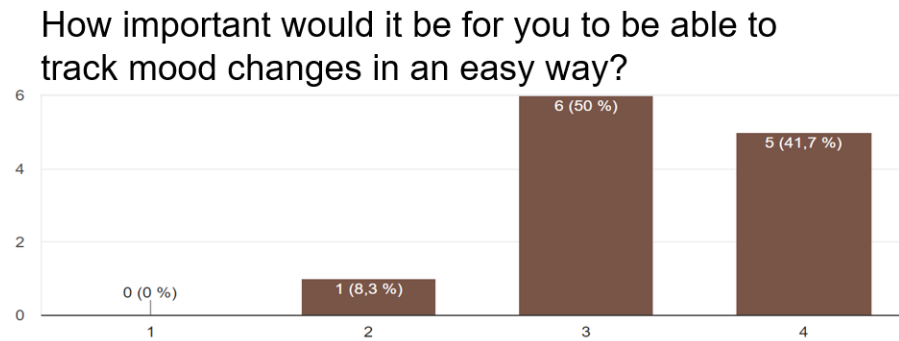


Figure 4.10: Almost every participant thought it important to easily follow up on mood changes.

4.6 Calendar

4.6.1 Sketches

The thought of this feature is that the user could get a quick overview on the details of the next appointment. The appointment cards that can be seen in Figure 4.11 could contain information about time, doctor, address and appointment reason. The address could be accompanied by a link to a map that could provide directions. The feature should also provide a way to view all entries that have been made in the platform.

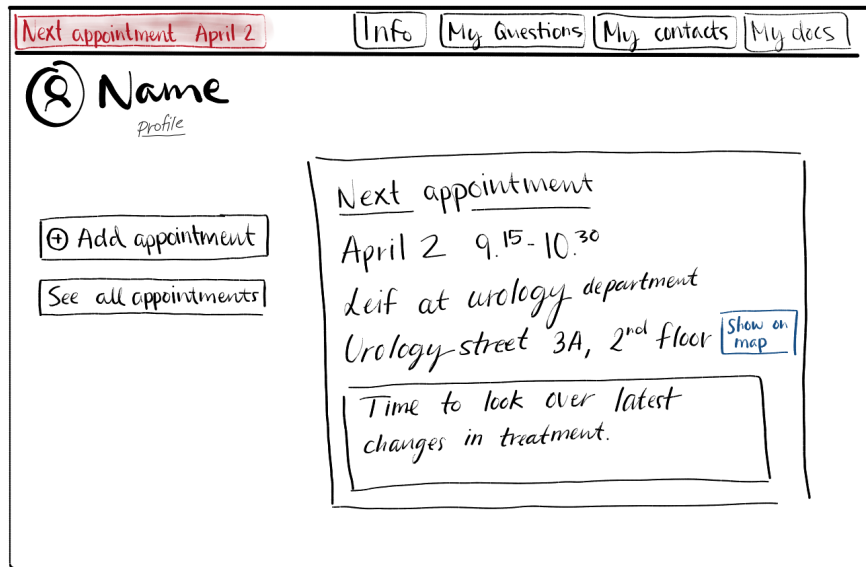


Figure 4.11: Showing an appointment from the home screen calendar.

4.6.2 Evaluation

The participants have been asked how important it is that the appointments get into the platform automatically, provided from the health care or if it would still be a beneficial feature if the user has to add appointments manually. Many participants thought this to be a useful feature, Figure 4.12. When it comes to whether or not the appointments should be added manually or automatically, the answers were spread over both the *important* and the *not important* part of the scale. It was figured that these responses were depending on age, but no such correlation could be found in the answers. The only thing that could be concluded was that the participants who found this feature the most useful also thought it was most important that the appointments would be added automatically.

How much use would you find for adding appointments to a calendar?

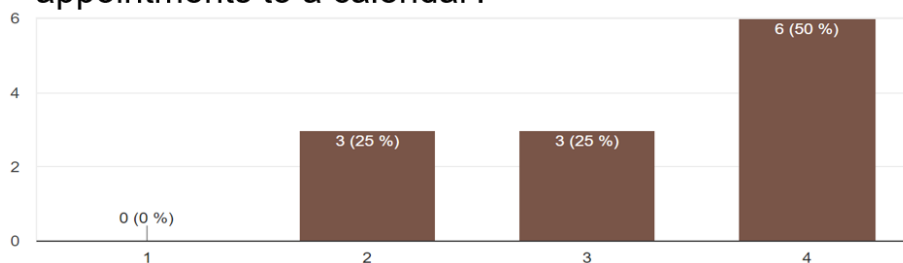


Figure 4.12: 75 % of the participants were positive (3-4) to a calendar feature.

4.7 Information

4.7.1 Sketches

The amount of information a patient can get hold of by just searching the internet is huge. The sorting of information has to be done manually by the patient, trying to find information relevant to his particular case. The information feature is supposed to make it easier for the patient to find the right information. Based on the staging and grading of cancer and decided treatments only that particular information will be available in the platform. In Figure 4.13 an alternative for the information cards can be seen. The card contains customized information about Stage 3 cancer.

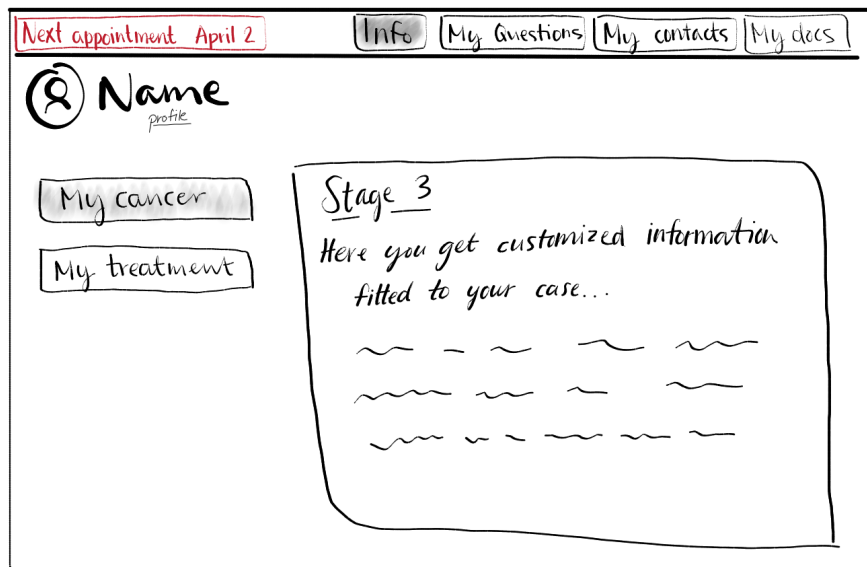


Figure 4.13: Showing only information customized to patient diagnosis and treatment.

4.7.2 Evaluation

In the evaluation consideration has been taken to the participants thoughts on the benefits of presenting only relevant information and what they consider to be relevant information. As can be seen in Figure 4.14, all participants answered positively on the possibility of accessing customized information about their specific case of cancer in the platform. The participants thought that the most important pieces of information that should be presented were:

- Cancer information.
- Treatment information.
- Drug information.

Would it be good to access more customized information?

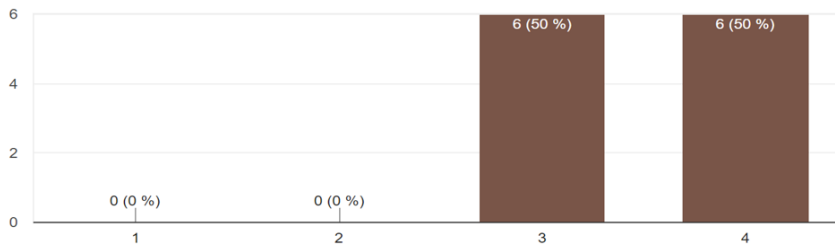


Figure 4.14: Only positive responses on presenting customized information in the platform.

4.8 Contacts

4.8.1 Sketches

The contacts feature should provide the user with a place to gather information about all relevant health care providers and how to contact them. In the sketch in Figure 4.15 there is also an alternative with a section containing contact information to the added relatives and close ones (section 4.3). Here the thought was to provide the user with a quick way to scroll through the contacts and to easily see what their position is and how to contact them. Depending on how many health care providers an average patient actually has, sub-menus and filtering on different categories might be a good idea.

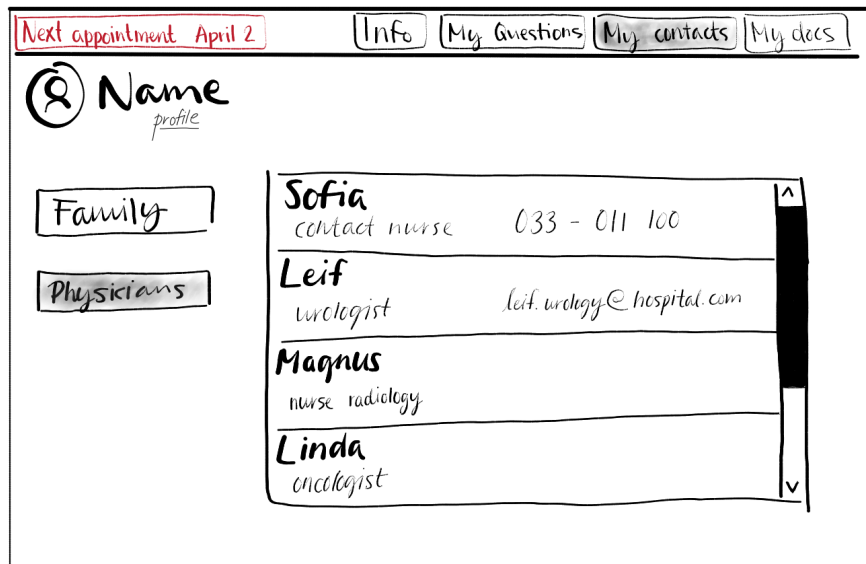


Figure 4.15: View for showing contact information to health care providers.

4.8.2 Evaluation

In the questionnaire the participants have been asked if they think it is a good idea to gather all health care providers like this and if they would also be interested in adding contact information to relatives and close ones. They were also asked if it would be important that the contacts were added directly from the health care system or if it would be okay to add contacts manually. Among the participants there were only positive responses on gathering contact information about health care providers in the platform, Figure 4.16. 83.3 % of the participants found it important that the contacts were added automatically from the health care. No conclusions could be drawn about also adding contact information for relatives and close ones since the responses varied too much among the participants.

How much use would you have for the feature to add family members that could follow your journey?

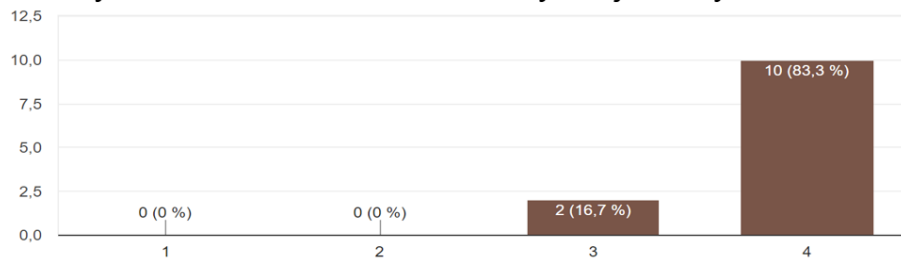


Figure 4.16: Collecting contacts for health care providers in the platform seems to be a useful feature for the participants.

4.9 Questions

4.9.1 Sketches

The main thought about the feature in Figure 4.17 is that the user could ask question to his health care providers. One alternative is that these questions could be sent directly to someone answering them in the platform. Another alternative is that the questions could be stored in the platform for the user to take out at the next appointment. The sketch also contains a button for adding notes. These could be a compliment to separate notes about things that the user just wants to keep track of and notes with actual questions. The user also has the opportunity to view all asked questions and stored notes.

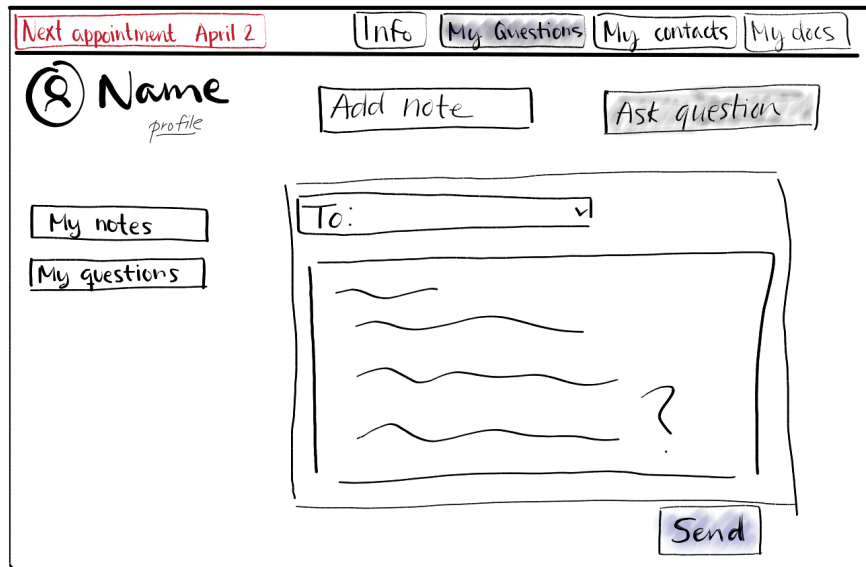


Figure 4.17: Sketch for asking questions to health care provider or adding a personal note.

4.9.2 Evaluation

Evaluation has been made on this feature in terms of sending questions directly to the health care system and getting an answer back or just storing everything to discuss later. Since all persons previously talked to were in agreement on that as a patient questions come up constantly, no questions were asked in the questionnaire about the benefit of such feature. For the majority of participants it was important that the questions were sent directly to a health care provider with the opportunity to receive an answer, Figure 4.18. One person left a comment saying that the most useful would really be to just have a place to store all questions that later could be brought to a doctor's appointment.

Would it be important that the questions were sent directly to health care providers?

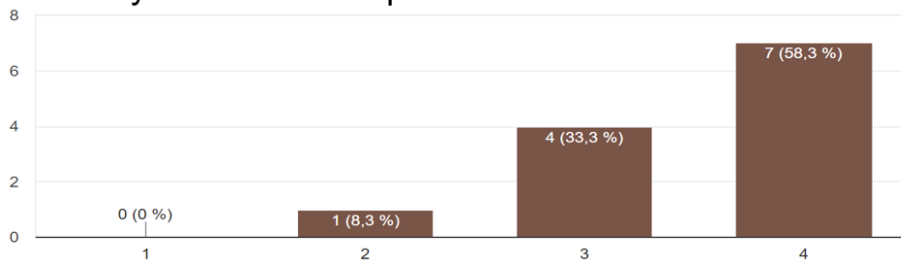


Figure 4.18: Only one participant thought it not important that the questions were sent directly to a health care provider.

4.10 Community

4.10.1 Sketches

This feature is supposed to contain a community with access to other men using the platform with a feed that allows the users to share updates, thoughts, questions and other interesting items. The feed could be a place to talk to others in the same situation, sharing experiences and news with each other. The user could also interact with the shared items by responding, commenting and sharing. In Figure 4.19 the sketch for the community feature is shown. Here it is easy to scroll through the latest updates. An additional feature that could be interesting is the option to filter out certain events, persons or geographic locations to customize the feed depending on user interests.

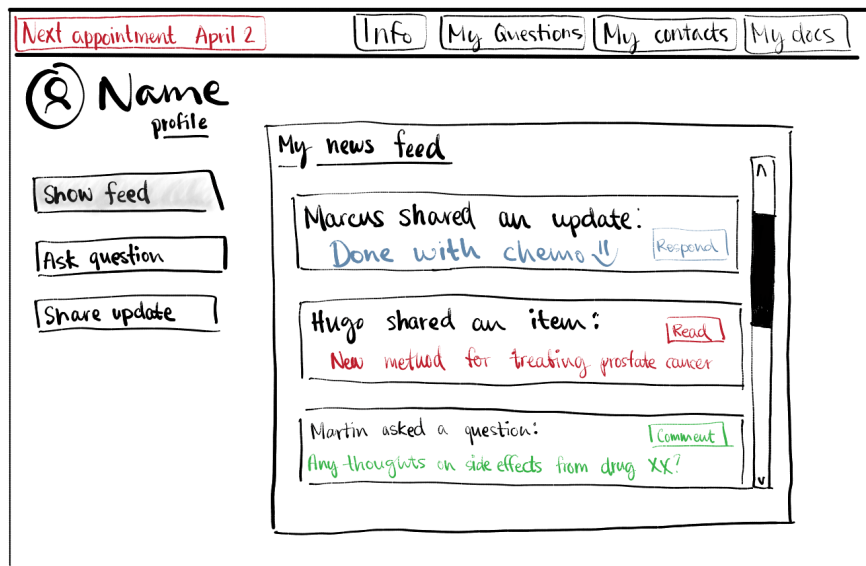


Figure 4.19: News feed with access to a platform community.

4.10.2 Evaluation

When evaluating this feature it has been compared to the ability to meet people face-to-face. The participants gave their view on whether it would be beneficial or not to access such a community online and why it would possibly be better than live communication. Among the participants there were mostly negative reactions to the community feed feature. The need for getting in contact with others in the same situation was not great, Figure 4.20, and 50 % of the participants reported that they would not see any benefits if this contact would be through a digital platform. The only benefit that was reported from multiple participants (33.3 %) was that it could be a compliment to meeting persons face-to-face.

How large is your need to get in contact with other men in the same situation?

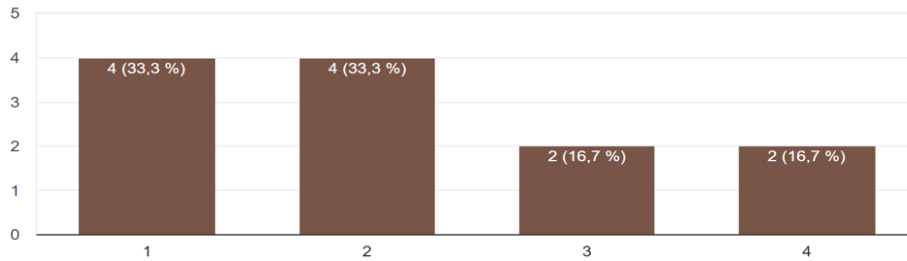


Figure 4.20: The need for getting in contact with other men in the same situation was not great among the participants.

4.11 Key Learnings

In the questionnaire the participants were asked to state which feature they thought was the best and which feature they thought was the worst among all the presented features. The results are shown in Figure 4.21. The feature of accessing diagnostic images at home was the most liked feature and the community feed was the least liked one. Mood tracking was also one of the reported worst features. As previously stated (section 4.5) the participants reported it important to be able to follow up on mood changes in an easy way. From this the conclusion was drawn that the feature is important, but the way it was presented in the questionnaire was not a likable option. From the evaluation it was also concluded that the community feed feature should not be part of the future features for the platform. Since the participant did not see any big advantages on having this sort of communication in a digital platform and it was reported to be the worst feature it should not be in the platform. This also corresponds to the findings from the previous chapter. Among the findings, no correspondence was found between the answers and how old the participants were. Since almost all participants reported that they regularly use technology there was no diversity on how experience with technology affected the answers.

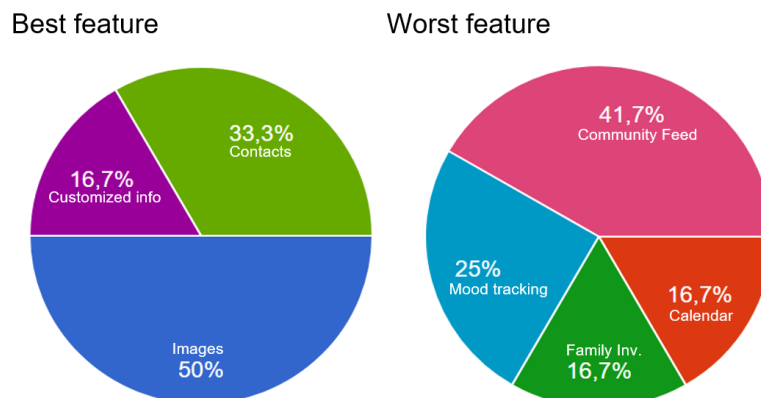


Figure 4.21: The best and worst features, reported by the questionnaire participants.

4.11.1 Features and Requirements

Features that are kept to later stages in the design process:

- Home screen designed with a menu
- Relatives and Close Ones
- Diagnostic Images
- Mood Tracking
- Calendar
- Contacts
- Questions

Features that are discarded:

- Home screen designed with all features on the same screen
- Community Feed

4.11.2 Further Evaluation

Features that needs to be further evaluated:

- Mood Tracking - how can the design be made to match the importance of the feature?
- Questions - how could this feature be designed so that the user is not forced to send the questions directly to a health care provider if he does not want to?
- Test Results - what could possibly be shown in the platform?

5

Prototyping

In this chapter, it will be described how an interactive hi-fi prototype was made. Examples from the prototype are shown and the user scenarios helping the process are described. The chapter begins with a presentation of the workflow.

5.1 Design Process

In Figure 5.1 the process for designing an interactive hi-fi prototype is shown. The vector graphics software Inkscape [17] was used to create the wire frames for the prototype. The first step of designing the prototype was to decide the design of the home screen and to decide what features that should be in the prototype. It was decided that not all features should be implemented in the prototype even though they should be in the design. Therefore, four user scenarios were created to help designing the functionality of the prototype (section 5.2). The scenarios were supposed to represent the most discussed features, both at EXINI and in the questionnaire. When doing the prototype the main focus was on how the features should work. In order to not make the design become the overhand when later testing the prototype it was made to be discreet with gray colors and known icons. The icons were downloaded from Google's *Material Design* [34]. The design was made to be user friendly and easy to learn for the patients, hence providing a positive UX for the user as described in section 2.2.2.1. The thought has been to make each feature easy to find and setting captions that describes what is possible in the platform, trying to create high discoverability (section 2.2.2). The examples shown in section 5.3 are pages from the prototype. Since all participants in the questionnaire had access to, and frequently used, a computer it was decided to make the prototype look like a web application. The prototype was made in the web application *InVision*. In the program it is possible to create interactive hi-fi prototypes with the most basic functionality that could be implemented in a real product, letting the user click around just like in a real web page. However, limitations in the program exists and functions like letting the user know when something is saved was not possible to implement. This means that there are limitations in making the design as good and user friendly as possible.

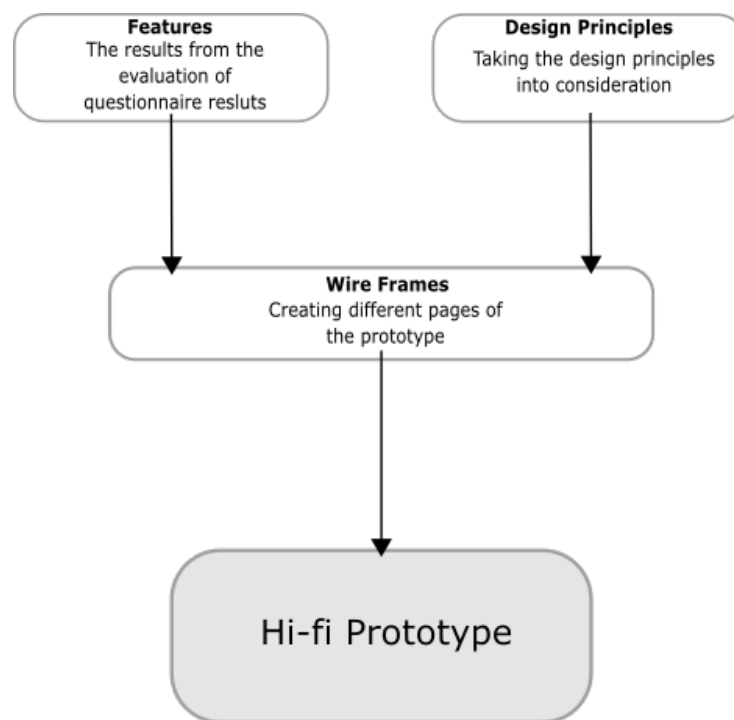


Figure 5.1: Design process for creating a hi-fi prototype.

5.2 User Scenarios

5.2.1 Scenario 1 - Mood Tracking

- Today you are feeling average. Save this in the platform, also leave a comment about your mood.
- Go check how your mood has changed lately. What was your comment on March 15?

5.2.2 Scenario 2 - Relatives

Ben is registered as your relative in the platform. Go change so that he could follow your mood updates.

5.2.3 Scenario 3 - Images

On March 2 your doctor registered images from a diagnostic examination. Go check how those images differ from the previous examination on November 7, 2017.

5.2.4 Scenario 4 - Test Results

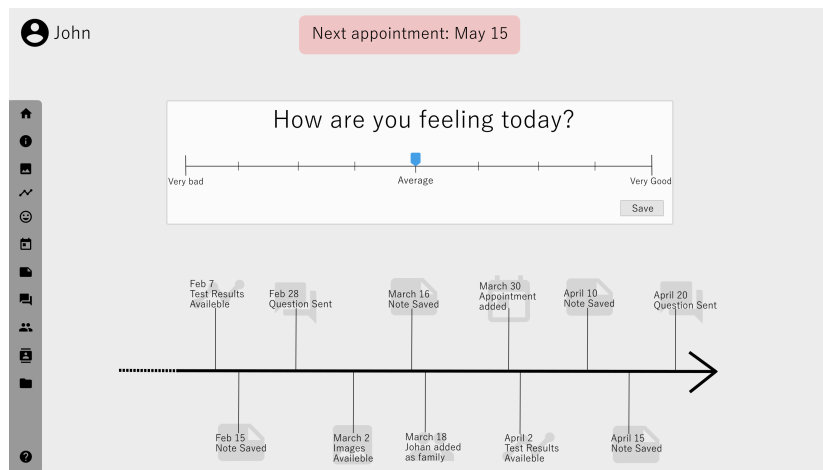
On April 2 new test results were registered. Go check what your PSA-value was at this time.

5.3 Examples

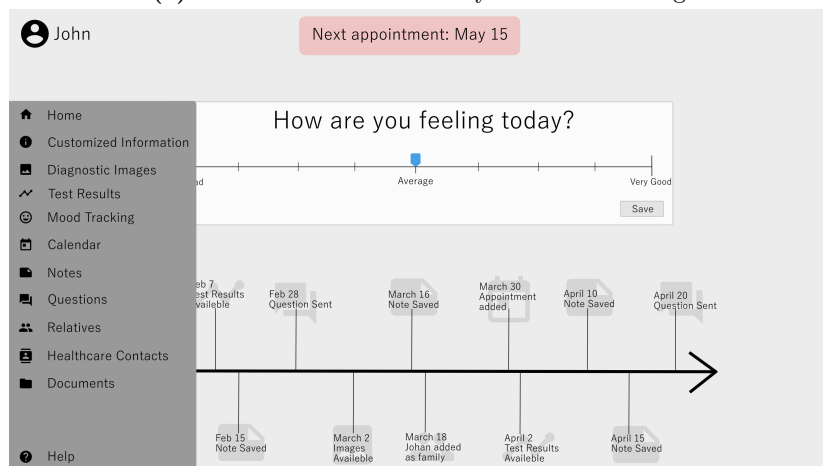
Below, examples from the prototype are shown for the home screen and two of the user scenarios. This is to present the ideas behind the design and to show how the prototype works. The design elements such as colors, pop-ups, fonts and layout is the same throughout the whole prototype to create consistency within the design. The chosen examples are the pages best showing this.

5.3.1 Home Screen

It was decided to design the home screen with a menu since this was the best alternative in the questionnaire. In Figure 5.2 it is shown how the menu is supposed to expand when the user is hovering with the mouse over the icons.



(a) The home screen with only the icons showing.



(b) The home screen with the menu expanded.

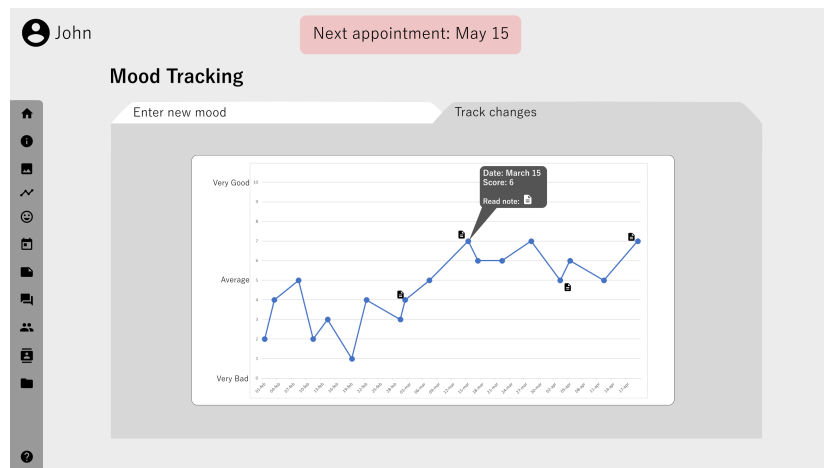
Figure 5.2: The home screen containing a timeline with the latest platform updates and a mood board for easy updating and mood tracking.

On the home screen there is also a timeline containing the latest updates in the platform. As background these posts have the same icons as the corresponding feature in the menu. The posts are clickable, taking the user directly to the right entry. There is also a mood tracking board where the user can save today's mood directly on the home screen. The mood board has been placed on the home screen since this is the only feature where the user has to make an entry, preferably each time visiting the platform. The timeline does not contain entries about mood updates. This is because the user is supposed to enter mood updates as often as possible and that would then be all that was shown in the timeline. The home screen also has a header with a reminder of the next appointment. This stays in the same place throughout the platform.

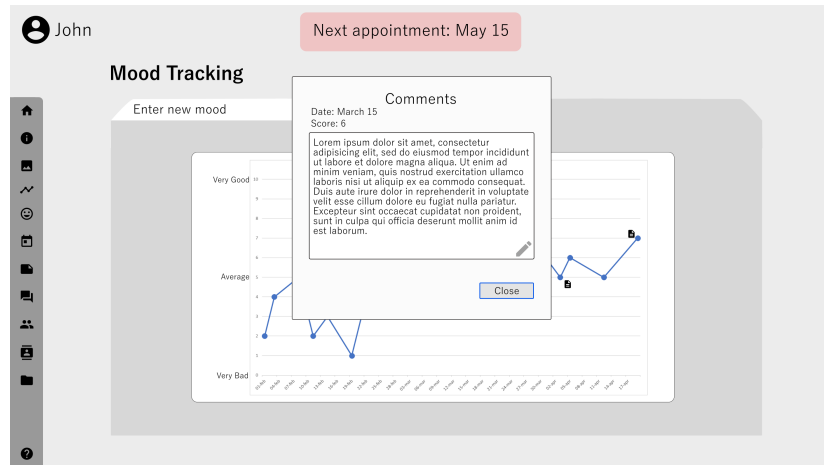
5.3.2 Mood Tracking

In Figure 5.3 the first thing to notice is that the design has been made with a tab bar that lets the user navigate within the feature. This is mutual for all feature screens and supposed to make it easy for the user to switch between different functions.

Since tracking moods were important to the participants in the questionnaire but the feature was dismissed, the new design for mood tracking was important. The thought has been to make it easier and quicker to add moods since this is a feature that supposedly is more usable the more entries the user makes. When adding a new mood in the platform the user can either use the mood tracking board in the home screen (Figure 5.2a) or use the same board but accessing it from the menu. When clicking save, the user is asked if he wants to add a comment about the mood. This is done by a pop-up screen. By clicking on *Track changes* in the tab bar these comments and the reported moods can be viewed, as in Figure 5.3a. As default the screen shows a graph with the reported mood scores and note icons where comments have been added. By hovering the mouse over a data point, specific information about that day is showed. If comments have been added, these can be read by clicking the note icon in the balloon. The user is then presented with the pop-up in Figure 5.3b containing the comment. In the prototype the text is Lorem Ipsum for typesetting purposes only [35]. In the prototype there is no way to actually edit the comment, but the design is there and the thought is that this could be a possibility in a future product. A limitation with this design is that it was not possible to add a confirmation to the user that the moods are saved when pressing *Save*, this results in poor feedback to the user since it feels like nothing has happened when pressing the buttons.



(a) The user can track the mood changes over time and see where comments have been made.



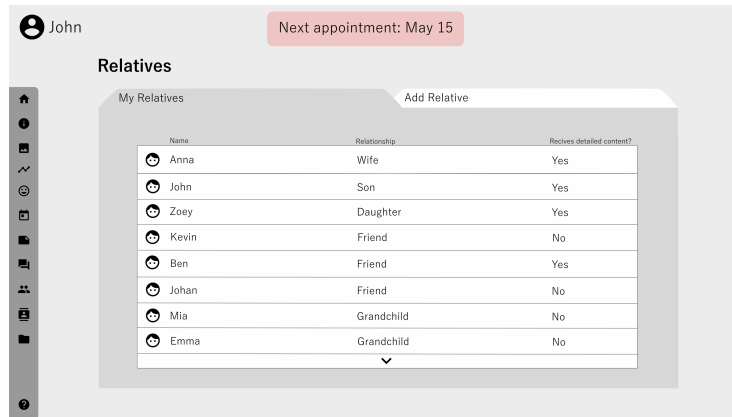
(b) When opening a comment it appears as a pop up on the screen.

Figure 5.3: The mood tracking has been made easier to follow compared to the sketches in the lo-fi prototype.

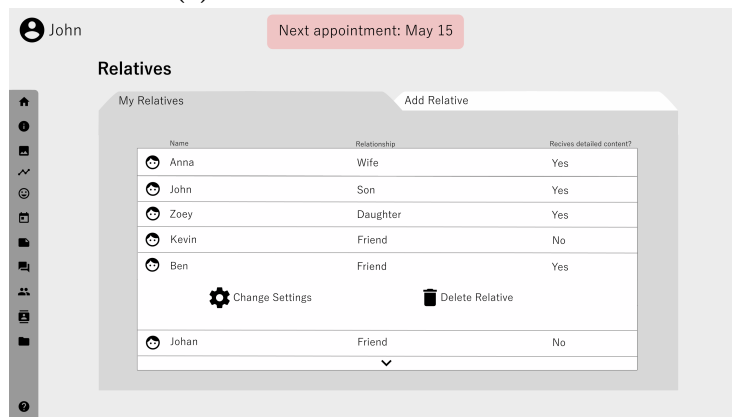
5.3.3 Relatives

In Figure 5.4 it is shown how the user would change settings for his friend Ben. The list in Figure 5.4a is designed to be simple with the most relevant information presented. When the user clicks on the field for a relative the field expands showing more alternatives, Figure 5.4b. Both changing settings and deleting relatives are functions that should be easy to find since the questionnaire showed that controlling who sees what is important. In figure 5.4c the different settings have been divided into *privacy settings* and *content settings*. This is to emphasize that the user could control what is shared and also control the amount of shared content. In the prototype there is no way for the user to get more information about this, however using the question marks would be a good way to inform the user about the differences in the different settings. Also in

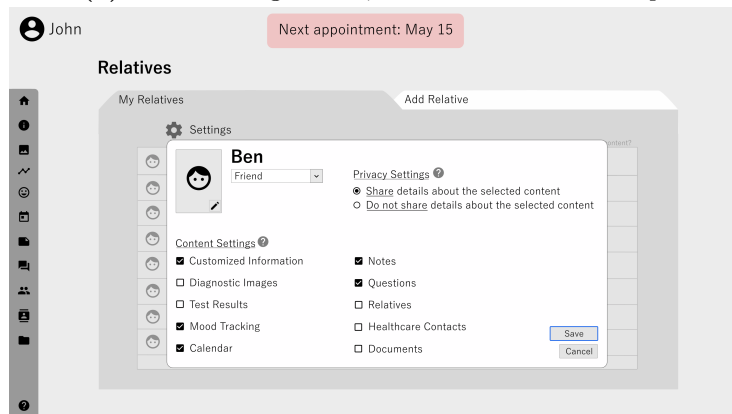
this design it would be better if the system would provide feedback to the user when pressing the buttons.



(a) The list with the added relatives.



(b) When clicking on Ben, more alternatives show up.



(c) Changing settings for Ben.

Figure 5.4: Changing settings for each relative is supposed to be easy.

5.4 Key Learnings

5.4.1 Features and Requirements

New features that were developed during the making of the prototype:

- Questions and Notes were divided into two separate parts of the platform in order to better distinguish between notes that the user keeps for his own sake and questions that he wants someone to answer.
- In order to let the user quickly save mood updates the new design lets this happen in only three clicks from the home screen.
- If something special has happened that affects the mood this could be described in the comments instead of specifying every single feeling in different bars (like in the lo-fi sketch in Figure 4.9c).
- The opportunity to delete relatives from the platform was added to the design.

5.4.2 Further Evaluation

Questions that should be further evaluated:

- Does the platform provide a positive UX?
- Are the icons understandable?

6

Evaluating

In this chapter, the evaluation of the hi-fi prototype is presented. First it will be stated how the evaluation was designed, then a short description of the evaluation process is presented. Last, the results from the evaluation are established.

6.1 Design Process

The process for designing the evaluation is shown in Figure 6.1. The evaluation was designed with the goal to find the most obvious problems with the patient platform. Since this project is only research for a possible future product it was decided to make the evaluation with EXINI coworkers. These coworkers are no experts in usability, but they work with similar problems on a daily basis and therefore have the knowledge required to do this first evaluation of the hi-fi prototype. The participants hold different competences within the company and could therefore provide useful feedback from different angles. Six heuristics were set up to fit the design of the hi-fi prototype. Four of these were taken from Jakob Nielsen's original heuristics [29]. One was taken from the *First Principles of Interaction Design* [36]. The last one was self created to fit the project. The heuristics that were evaluated against were:

1. *Match between system and the real world.* Designers should endeavor to mirror the language and concepts users would find in the real world based on who their target users are. Presenting information in logical order and piggybacking on user's expectations derived from their real-world experiences will reduce cognitive strain and make systems easier to use.
2. *Consistency and standards.* Interface designers should ensure that both the graphic elements and terminology are maintained across similar platforms. For example, an icon that represents one category or concept should not represent a different concept when used on a different screen.
3. *Help and documentation.* Ideally, we want users to navigate the system without having to resort to documentation. However, depending on the type of solution, documentation may be necessary. When users require help, ensure it is easily located, specific to the task at hand and worded in a way that will guide them through the necessary steps towards a solution to the issue they are facing.

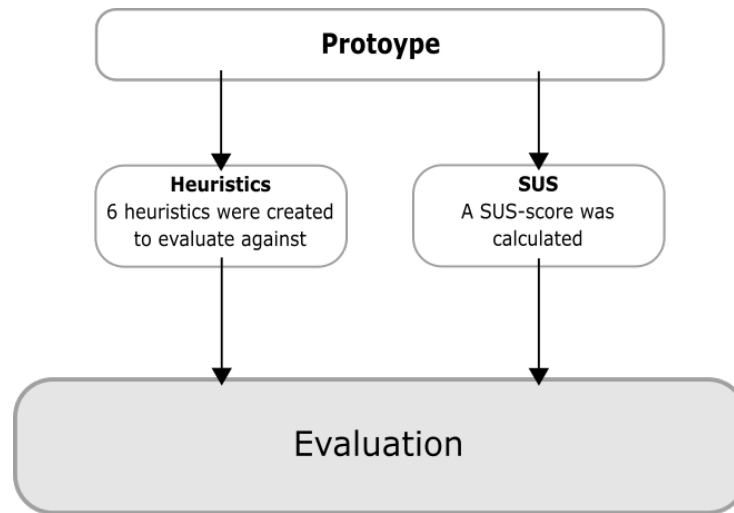


Figure 6.1: Design process for the evaluation phase.

4. *Flexibility and efficiency of use.* With increased use comes the demand for less interactions that allow faster navigation. This can be achieved by using abbreviations, function keys, hidden commands and macro facilities. Users should be able to customize or tailor the interface to suit their needs so that frequent actions can be achieved through more convenient means.
5. *Small visible structures, such as icons, symbols, buttons, scroll bars, etc.* The appearance of such objects needs to be strictly controlled if people are not to spend half their time trying to figure out how to scroll or print. Their location is only just slightly less important than their appearance. Where it makes sense to standardize their location, do so.
6. *Usefulness.* Does the feature feel useful in terms of easily keeping up with changes due to disease progress. Is there any functionality that is making this hard?

The ones that were excluded from Nielsen's original ten heuristics were the ones covering elements and principles that were unimplemented because of prototyping limitations. For example, the heuristic about providing the user with good feedback so that it is always possible to get confirmation of what each button click results in, was excluded since it was not possible to provide this kind of feedback in the prototyping tool used.

The results from this evaluation was then compiled together with the results from a SUS-questionnaire to create an understanding of how other people find the platform. The SUS-score also resulted in an understanding of how the UX (section 2.2.2.1) was found by the users.

6.2 Evaluation Process

The evaluation was preformed in 3 steps; using the prototype, discussions, and a SUS-questionnaire. Before the evaluation could start, the participants were

presented with information about the goal of the evaluation and the heuristics. Since the participants from EXINI were not experts in usability it was important that they knew what heuristics to evaluate against before the evaluation began.

6.2.1 Using the Prototype

The participants were presented with the four user scenarios that the prototype was designed with (section 5.2) and asked to perform these tasks in the prototype. While performing each scenario the participants were asked to evaluate each part against the heuristics and to take notes about what was good and what was not so good. It was pointed out that it was important that they were critical on the design when performing the scenarios. The heuristics were printed out so that each participant had access to them throughout the whole evaluation.

6.2.2 Discussions

All participants took part in a group discussion where each scenario was discussed in terms of what was good, what was not so good, and possible errors made. These discussions proceeded from the heuristics. Some time was also set aside to discuss the general feeling of the platform to find out what the participants figured needed to be improved on.

6.2.3 SUS

The evaluation ended with each participant answering the SUS-questionnaire in a digital form. The SUS was part of the evaluation since it seemed important to get an objective measure of the platform. The participants were asked to answer these questions as if they imagined to be a patient diagnosed with prostate cancer.

6.3 Results

The evaluation resulted in overall good feedback that will be of importance for the future work with the platform. 13 of the coworkers participated in the evaluation.

6.3.1 Positive feedback

The general feel of the platform among the participants was positive. The icons were found understandable by most participants and helped when trying to find the right things. The possibility to control what content that is shared with whom was found good even though it was a bit difficult to understand what the different settings actually changed. Since this was difficult, it was good that the design provided the opportunity to add help information. In the design there are both *save* and *cancel* buttons, which was found good since this probably is what the intended user expects. The participants thought it easy to navigate within the platform once the menu was found. The view for comparing images was especially liked. Discussion about whether the latest date should be presented

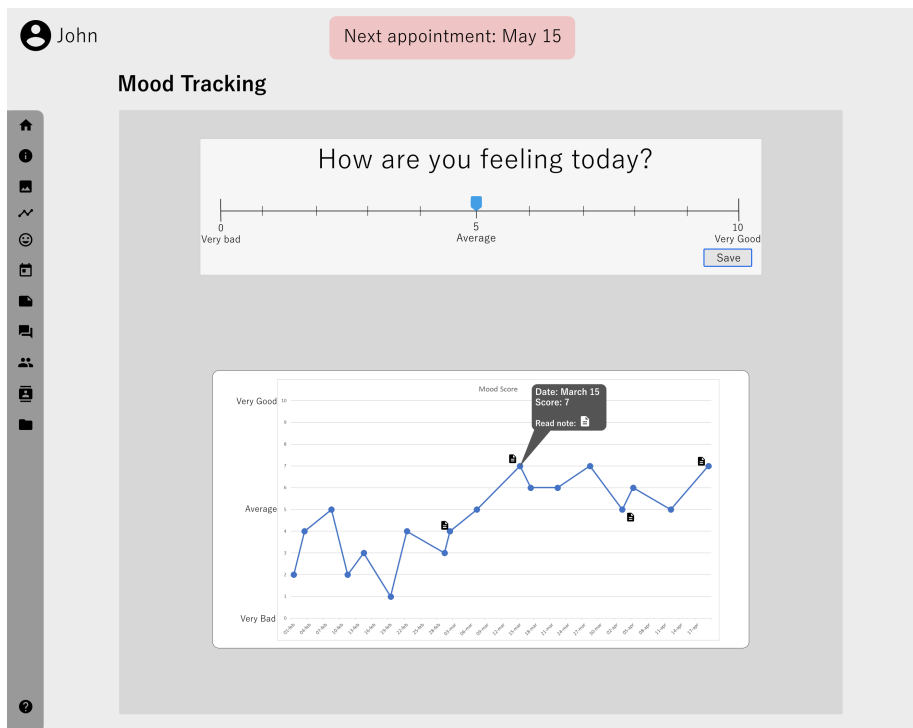


Figure 6.2: Based on the feedback, a new version of *Mood Tracking* was created.

to the right or to the left of the screen came up. Since the design lets the user choose this himself the question ended up being about what should be presented at the screen when first entering the feature. The possibility to customize the view and to present the images in whatever preferred way was found good. The timeline on the home screen was found good by most participants although some did find it annoying that the mood entries were not part of the entries on the timeline. Most thought that it was good to also have the entering of moods on the home screen but some thought that the user should be able to better specify what kind of specific mood (e.g. pain, fatigue, etc.) that is reported. That the design elements are big on the screen was reported to be very good, especially for the intended age group using the platform. The design with presenting the information in different tabs was good, but sometimes redundant. Like in the mood tracking feature, it would maybe be more beneficial to the user if all content were on the same page. In Figure 6.2 such a improvement has been made, removing the tabs and keeping all information in the same place. The tabs within the relatives feature could also be on the same page, with just an add-button for adding more relatives.

6.3.2 Improvements

Some of the wording did not match the participants expectations of the features. For example gave the word *relatives* a too strong association to blood family and *customized information* did not supply the right understanding for the feature. The items in the menu was by some of the participants found to be presented

in a strange order. At some places it was also found that there were too many clicks that had to be made to complete the tasks. It was also pointed out that the participants tried to go through the calendar to get to certain entries, since this function was not implemented this was not possible in the prototype. Like stated in section 4.6 this is something that would be a good feature and should work in a real product. There were also some concerns that the text was a bit hard to read in some places. The text over the icons in the home screen timeline was difficult to distinguish for some of the participants, so was the text in the different graphs. When it comes to the test results feature it was discussed that it would be good if there were an option to compare different test results in the same graph. There was also concern that the reporting of moods did not match the tracking of the same moods. When reporting the mood, no numbers are shown, but they exist in the graph which was confusing to the participants. In Figure 6.2 this is improved on. To keep the user from having to use the menu at every change of feature, it could be a good idea to keep shortcuts to the most used features in the home screen. That would also reduce the numbers of clicks. The need for adding comments to the moods were discussed, and it was figured that this depends on personal preferences on how to best report and track changes.

6.3.3 SUS

The result from the SUS was an average score of 73.75. When translating this with Aaron Banger’s adjective rating scale, it compares to a rating of a *good* feeling, Figure 6.3. The lowest score was of 60 which translates to *OK*. The best score was of 92.5, which is *excellent* [37]. This also corresponds to the general discussion about the feelings of the platform, which were overall positive.

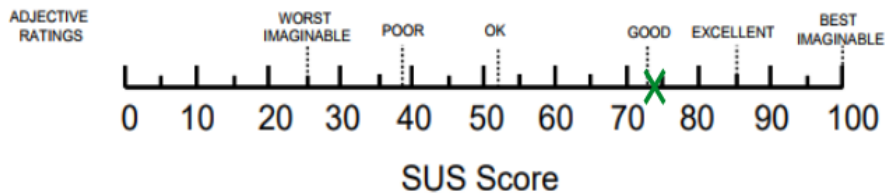


Figure 6.3: Translating SUS score to adjective ratings [37]. The green cross is the evaluation average for the prototype.

6.4 Key Learnings

6.4.1 Features and Requirements

Features that need improvement:

- The mood tracking needs to be fixed so that it uses the same scoring system in both reporting and tracking.
- The number of clicks for each task need to be minimized.
- Change wording of *customized information*. A better wording might be *cancer information*.

- Change the word *relatives* to match the fact that both family and friends can be added. *Family and Friends* might be better.
- Tabs needs to be removed on pages where they are redundant.

6.4.2 Further Evaluation

Features that needs to be further evaluated:

- The mood tracking needs to be further evaluated in terms of balancing entering moods quick and easy and entering enough information that is relevant to track.
- Number of graphs that are interesting to compare at once in *test results*.
- The places where the text is hard to read needs to be found.

7

Discussions

That a technical solution that helps the patients follow disease change is necessary has been clear during this project. In this chapter, discussions about the platform and the methods used will be presented together with my own comments and concerns. Some thoughts about the ethics concerning a patient platform are also discussed.

7.1 The Platform

The platform should be a place where the patient accesses all information that helps him keep track of his condition and how it changes over time. To do this the following features should exist in the platform.

7.1.1 Relatives and Close Ones

This is one of the most discussed features of the platform. Throughout the project it has shown that the use for this feature is not clear to everyone. Some really like having the option to share with close ones and some really dislike it. This probably depends on what kind of person you are and how you feel about sharing such personal information in general. Outside of the evaluations a concern about integrity has also come up and it was questioned whether it would be okay or not that a platform shared such details about the patient to others. It will therefore be very important that this is something that the patients control themselves and the option to decide who receives what information will need to be very clear to the users. The feature should be named *Family and Friends* so that no confusion on the wording is made.

7.1.2 Diagnostic Images

Viewing and comparing diagnostic images is one of the most important features to EXINI and also one of the features that was most liked in the questionnaire with the first sketches. When connecting this feature to different EXINI-products, different images could be available to the patients. Something that has stuck through the project was an early comment from one of the first interviewees about that it should be optional to the patient if he wants to access

images at home or not. I personally think this is a very good idea. A patient should never be forced to access something that he is not comfortable with, and that could increase personal worry. The patients connected with in this project have been positive to the possibility of having access to diagnostic images at home, but I think it is important for companies such as EXINI to really respect that this is something fairly new and something that could be scary to some people. For those liking to compare and follow up, I think this could be a very useful tool. It should therefore allow the comparison between dates and studies. It could also increase the possibility to get a second opinion if the feature allows the user to share raw image-data. This was not something that was one of the largest benefits reported in this project, but in the US where it is a lot more common to seek a second opinion this could be even more beneficial. Throughout the project it has been clear that the images need to come with a good explanation. This explanation should be of such kind that the images, and what they mean are clearly stated to the patient.

7.1.3 Mood Tracking

Since mood tracking was one of the features least liked, but at the same time found very useful, it was made more accessible in the platform. Instead of entering many different mood options, like in the first sketches, it was changed so that only one entry has to be made. This alteration was something that was found limiting in the heuristic evaluation. This tells that it is hard to balance between making it too time consuming to the user and entering enough data. On this, more user data has to be collected.

7.1.4 Calendar

The calendar feature was never a part of the final evaluation. However, it was most liked to have the reminder of the next appointment in all screens in the prototype. Since many also tried to use this route to access the different entries in the user scenarios, I think it will be important that this works as a storage space for everything happening in the patient journey, both when it comes to past and future events.

7.1.5 Information

The information feature should be called *Cancer Information* in the platform. It should contain information about the specific stage of cancer, the specific treatment, and received drugs. The information should be customized to the patient and minimize the time the patients spend searching the internet for the right information.

7.1.6 Test Results

The ability to follow changes in certain test results, such as PSA, was from the start considered important since this is something that reportedly every patients wants to know at every appointment. It was therefore a feature that was never discussed in the questionnaire. However the design of the feature was discussed in the heuristic evaluation, where it was concluded that it should be

possible to select more than one graph at a time in order to compare trends. The most intuitive might probably be to compare two results at a time since these could then be represented at the left and right axis. However, more research on whether this is enough and the best way to present test results needs to be done.

7.1.7 Health Care Contacts

Having access to a list with how to contact certain health care professionals seemed like a good feature when conducting the questionnaire. This could be a step in helping the patients store everything in the same place to make it easier to find the right information when needed.

7.1.8 Questions

Whether the user should be able to ask questions to a health care professional or not, needs more research. Since this is also a questions about whether the health care has the possibilities to answer such questions or not, this is depending on more than what the user wants.

7.1.9 Notes

Keeping notes that the patient could store until the next appointment is another feature that helps the user store everything that has to do with the cancer in the same place. This is a feature that the user could use to his own extent and preference, without affecting the platform structure. It is therefore not talked about a lot after the initial interviews where all participants agreed that it would be good to have a place to store such notes.

7.1.10 Documents

This is a feature that has not been discussed much during this project. It came up as an idea when discussing the platform with the EXINI coworkers as a safety, letting the patients scan and save documents that were not provided digitally. This feature is depending on whether the information will be automatically uploaded to the platform or not. It is therefore unclear how it could be of use in the future and hence no evaluation has been made on this feature. It is however appearing in all the designs just to show its presence. Further studies on how to upload entries into the platform will have to be made before this feature could be evaluated.

7.2 The Methods

7.2.1 Establishing Requirements

The interviews held during this part of the project helped a lot when building an understanding for the users. Interviewing with sound recording was easy since it was possible to focus on the answers without having to take notes at the same time. The structure of conducting a first interview and then basing the following interviews on these answers worked really well in this project. It

made it possible to step by step get forward and to base my understanding on the interviewees experiences. I also think it was good that the questions were designed to be opened, in a semi-structured way. This made it possible to actually talk freely about the interviewees experiences, which was the most important part of the interviews. After making the first two sketches, it was a lot easier to communicate my ideas. It would probably have been a good idea to have made sketches earlier to bring along when talking to the two patients. It was also good to end this phase of the project with a discussion with the coworkers at EXINI since this made it possible to take the ideas out of my own head and onto paper and create more sketches.

7.2.2 Designing Alternatives

Creating the alternative sketches for the lo-fi prototype helped in visualizing the concept of a patient platform. It also helped in communicating this concept to the participants answering the questionnaire. I think that this really helped when they tried to answer the questions and figure out if a feature was useful or not. Most answers were as expected and corresponding to theory. When it comes to designing questions to be leading, it can be found to have both positive and negative effects on the evaluation. I cannot be sure that all participants understood that they had the option to discard the features by selecting the option *Other*, and therefore there could be some bias in the answers. However, I think this was the best way to do the questionnaire since it was not possible to meet with all twelve participants in person and explaining each feature in detail. In this way the participants got a hint about what the platform could offer, and hopefully got to think about new ways to handle problems with technology. I think it was good to make the sketches digitally. Since I am not very good at drawing this allowed me to undo, and redo as many times as I liked without destroying each sketch several times.

7.2.3 Prototyping

InVision and Inkscape worked well together for producing the hi-fi prototype. Using design principles to place each design element in an intuitive way made the process easier. It was also good to have the four user scenarios as a basis for the work. This made it possible to early on state exactly what kind of elements that were needed to make the prototype, and move forward from those. I think that the four scenarios represented the platform well and, were good examples of how different parts of the patient journey can be stored in the same place. The only drawback with the prototyping tools used was that it was not possible to present the user with correct feedback. For me, the prototype would have felt more real if this was possible since I think feedback is one of the most important parts of the UI, especially when designing for older men.

7.2.4 Evaluating

The evaluation of the prototype generated good feedback and the most obvious problems were found, just like planned. It would have been good to receive feedback from the intended users as well but due to problems with connecting

to patients and getting them to participate in user studies, that was not possible. The six heuristics chosen for the evaluation worked well as to start the discussions about the different user scenarios and to find out what tasks that were hard to perform and which parts of the UI that did not match the expectations. The evaluation resulted in a good idea of what needs improvements if the platform ever is suppose to work as a real product. The SUS-score worked well in terms of creating an objective measure of the platform. From the answers it felt like it was possible for the evaluators to imagine to be the patients, and most participants had the same scoring.

7.3 Ethical Aspects

Ethical aspects that I think should be considered for this project are concerning the contact with patients and how to handle their data. On a further perspective the ethics about sharing medical images with patients, and also sharing their information with close ones should be considered.

When it comes to the patients who have participated in this study consideration has been taken to the fact that they are people who have suffered, or are suffering from a serious disease. Therefore it has been important to only talk to patients who willingly have chosen to participate and that feel dedicated to help out in making the future of prostate cancer better. All information resulting from their participation have been handled with great confidentiality.

When sharing information with patients consideration has to be taken to the fact that you are providing them with information that could potentially be found terrifying. The images in this report have been created to present a positive patient journey with improvements in the test results, but obviously this is not always the case and patients who get worse instead of better are common. Ethical aspects of actually providing patients with this information outside of the hospital has to be considered since you are taking the information away from the possibility of calming words from a health care provider. Comments from the doctor and contact with the health care will be important parts as to not make the platform potentially harmful.

Sharing information about themselves is something that many people do on a daily basis through different social media. When it comes to sharing medical data and updates about disease progress the control of shared information needs to be considered more clearly. I therefore think it is very important that the users get to decide the amount of shared information. Only the person actually affected by the prostate cancer should get to decide what he is comfortable sharing, and just like everything else that has to be respected by the close ones.

8

Conclusions

In this chapter, the conclusions drawn about the patient platform are stated.

It is clear that there are a lot of technical solutions existing on the market, trying to make the life of cancer patients easier. What seems to be missing is a technical solution that lets the patient store all information in the same place. The interest among the men participating in this report for accessing diagnostic images at home was great. The largest benefit would be to compare the differences between different studies, but the images could also work as a reminder of what the treating doctor said at the appointment. From the patients participating in this report it is clear that the platform needs to work on all kinds of systems, including computers, tablets and smart phones. This is to facilitate the large age span that the patients represent. The prototype made in this project works well as a model for the concept of a patient platform. The prototype clearly shows how the platform could work as a place that lets the user store and access all relevant information in the same place through relevant features.

8.1 Future work

In the future it will be important to figure out how all of the information will be collected into the platform. As a first step it might be an alternative that the users actually add all entries by themselves, but to make a really useful product it will probably need a way to automatically collect information and present it in the platform. More user studies need to be made, especially among the right age group evaluating the design. It will be important to implement more of the features into the prototype to test this, and to make the prototype look more like the EXINI products existing today. It will also be of importance to figure out how to initialize the platform to the patients, and who should be in charge and responsible for the content within it. In order to establish that it first needs to be established on which market the platform should be available, US and/or European.

Bibliography

- [1] Prostatacancerförbundet. Undersökning; (n.d.). Retrieved February 28, 2018. Available from: <http://www.prostatacancerforbundet.se/undersokning>.
- [2] Socialstyrelsen. Om PSA-prov; (2014). Retrieved February 28, 2018. Available from: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19489/2014-8-4.pdf>.
- [3] Liss MA, Ehdaie B, Loeb S, Meng MV, Raman JD, Spears V, et al. An Update of the American Urological Association White Paper on the Prevention and Treatment of the More Common Complications Related to Prostate Biopsy. *Journal of Urology*;198(2):329.
- [4] Ahmed HU, El-Shater Bosaily A, Brown LC, Gabe R, Kaplan R, Parmar MK, et al. Diagnostic accuracy of multi-parametric MRI and TRUS biopsy in prostate cancer (PROMIS): a paired validating confirmatory study. *Lancet (London, England)*;389(10071):815 – 822.
- [5] Javitt MC, Kravtsov A, Keidar Z, Abadi S, Amiel GE. Multimodality Image Fusion with PSMA PET/CT and High-Intensity Focused Ultrasound Focal Therapy for Primary Diagnosis and Management of Prostate Cancer: A Planned Research Initiative. *Rambam Maimonides Medical Journal*;8(4):1 – 13.
- [6] Office for Civil Rights (OCR). Summary of the HIPAA Privacy Rule; (2013). Retrieved February 28, 2018. Available from: <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>.
- [7] Muoio D. chemoWave app offers patients support during chemotherapy; (2018). Retrieved February 28, 2018. Available from: <http://www.mobihealthnews.com/content/chemowave-app-offers-patients-support-during-chemotherapy>.
- [8] Nationella prostatacancerregistret. Patientöversikt prostatacancer (PPC); (2012). Retrieved February 28, 2018. Available from: <http://npcr.se/rapporter/ppc/>.
- [9] Bjartell A. Professor in Urology, Dept of Translational Medicine, Medical Faculty, Lund University;. Personal conversation (2018, March 8).

- [10] Pfizer Oncology. INTRODUCING LivingWith; (n.d.). Retrieved February 28, 2018. Available from: <https://www.thisislivingwithcancer.com/livingwith-app>.
- [11] MyLifeLine Cancer Foundation. Create A Support Community; (2018). Retrieved February 28, 2018. Available from: <https://www.mylifeline.org/getstarted>.
- [12] lify io. Medical imaging collaboration made easy; (n.d.). Retrieved February 28, 2018. Available from: <https://lify.io/>.
- [13] MIM Software Inc . Mobile & Cloud; (n.d.). Retrieved March 1, 2018. Available from: https://www.mimsoftware.com/markets/mobile_cloud.
- [14] MIM Software Inc . VueMe™; (n.d.). Retrieved February 28, 2018. Available from: https://www.mimsoftware.com/mobile_cloud/vueme.
- [15] Samsung R&D Institute Bangladesh. Arctecture Draw, Sketch, Paint [Android app]; (2018). Google Play: First downloaded 2018, February 19. Last updated 2018, April 25 (version 5.1.1.0).
- [16] ©InVision. InVision Prototyping Tool [Web application]; (2018). Available from: <https://www.invisionapp.com/>.
- [17] Inkscape. Inkscape 0.92 - Draw Freely. [Open Source Software]; (2018). Available from: <https://inkscape.org/en/>.
- [18] Prostatacancerförbundet. Fakta om prostatacancer; (n.d.). Retrieved January 29, 2018. Available from: http://www.prostatacancerforbundet.se/fakta_om_prostatacancer.
- [19] Cancer NET. Prostate Cancer: Statistics; (January 2017). Retrieved January 26, 2018. Available from: <https://www.cancer.net/cancer-types/prostate-cancer/statistics>.
- [20] Cancer NET. Prostate Cancer: Stages and Grades; (January 2017). Retrieved January 26, 2018. Available from: <https://www.cancer.net/cancer-types/prostate-cancer/stages-and-grades>.
- [21] Nystrand A. Prostatacancer; (September 2016). Retrieved January 26, 2018. Available from: <https://www.cancerfonden.se/om-cancer/prostatacancer>.
- [22] Cancer NET. Prostate Cancer: Treatments Options; (January 2017). Retrieved January 31, 2018. Available from: <https://www.cancer.net/cancer-types/prostate-cancer/treatment-options>.
- [23] Preece J, Rogers Y, Sharp H. Interactive Design, beyond human-computer interaction. Chichester: John Wiley & Sons Ltd; (2015).
- [24] Norman D. The Design of Everyday Things. New York: Basic Books; (2013).
- [25] Arvola M. Interaktionsdesign och UX - om att skapa en god användarupplevelse. Lund: Studentlitteratur AB; (2014).

- [26] Technical Committee ISO/TC 159, Ergonomics, Subcommittee SC 4, Ergonomics of human-system interaction. Ergonomic requirements for office work with visual display terminals (VDTs) — Part 11: Guidance on usability; (1998, reviewed 2008). Retrieved February 1, 2018. Available from: <https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-1:v1:en>.
- [27] Johnson J. Designing with the mind in mind. Burlington: Elsevier; (2010).
- [28] Walker M, Takayama L, Landay JA. High-Fidelity or Low-Fidelity, Paper or Computer? Choosing Attributes when Testing Web Prototypes. Proceedings of the Human Factors and Ergonomics Society Annual Meeting;46(5):661.
- [29] Nielsen J. 10 Usability Heuristics for User Interface Design; (January 1, 1995). Retrieved May 7, 2018. Available from: <https://www.nngroup.com/articles/ten-usability-heuristics/>.
- [30] Wong E. Heuristic Evaluation: How to Conduct a Heuristic Evaluation; (April, 2018). Retrieved May 7, 2018. Available from: <https://www.interaction-design.org/literature/article/heuristic-evaluation-how-to-conduct-a-heuristic-evaluation>.
- [31] Brooke J. SUS - A quick and dirty usability scale; (n.d.). Retrieved January 29, 2018. Available from: <https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html>.
- [32] Sauro J. MEASURING USABILITY WITH THE SYSTEM USABILITY SCALE (SUS); (2011). Retrieved April 23, 2018. Available from: <https://measuringu.com/sus/>.
- [33] Bangor A, Kortum PT, Miller JT. An Empirical Evaluation of the System Usability Scale. International Journal of Human-Computer Interaction;24(6):574 – 594.
- [34] Google. Material icons [Web page]; (2018). Available from: <https://material.io/icons/>.
- [35] Rundqvist M. Lorem Ipsum (Svenska); (n.d.). Retrieved February 28, 2018. Available from: <https://sv.lipsum.com/>.
- [36] Tognazzini B. First Principles of Interaction Design (Revised & Expanded); (March 5, 2014). Retrieved May 8, 2018. Available from: <http://asktog.com/atc/principles-of-interaction-design/>.
- [37] Bangor A, Kortum PT, Miller JT. Determining What Individual SUS Scores Mean: Adding an Adjective Rating Scale. International Journal of Human-Computer Interaction;4(3):114–123.

Appendices

Appendix A

SUS Questions

System Usability Scale

© Digital Equipment Corporation, 1986.

| | Strongly disagree | | | | | Strongly agree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|----------------|
| 1. I think that I would like to use this system frequently | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 2. I found the system unnecessarily complex | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 3. I thought the system was easy to use | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 4. I think that I would need the support of a technical person to be able to use this system | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 5. I found the various functions in this system were well integrated | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 6. I thought there was too much inconsistency in this system | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 7. I would imagine that most people would learn to use this system very quickly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 8. I found the system very cumbersome to use | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 9. I felt very confident using the system | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |
| 10. I needed to learn a lot of things before I could get going with this system | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| | 1 | 2 | 3 | 4 | 5 | |

Appendix B

Interview About Patient Background

This interview was conducted on February 8, 2018. Since the interview was performed in Swedish, the following summary is also presented in Swedish to keep as much of the original data as possible.

Den intervjuade är forskningssjuksköterska på Urologiska kliniken på Skånes Universitetssjukhus i Malmö sedan 3 år tillbaka. Hon har innan dess jobbat inom både primärvård och akutvård. Hon har själv gett sitt medgivande till att medverka i denna rapport.

Vem är den typiska patienten och vem har han runt omkring sig?

Det är svårt att ange en typisk patient. Åldersspannet är stort men majoriteten av patienterna är äldre män. Patienterna som kommer till Urologiska kliniken har tidigare genomfört undersökningar på exempelvis vårdcentral där man hittat förändringar i prostatans storlek eller förhöjt PSA-värde. Det första besöket på Urologiska kliniken är till för undersökningar och det är ovanligt att anhöriga är delaktiga i undersökningsrummet vid detta besök. Vid andra besöket är det vanligare att anhöriga, oftast partnern, närvarar och är delaktig.

Hur mycket vill patienten veta om sin sjukdom?

Hur mycket man vill veta är väldigt olika mellan patienterna. Vilken typ och mängden av information som patienten behöver eller vill ha är också beroende på hur sjukdomsscenariot ser ut. De flesta patienterna vill gärna ha någon form av information och många har även sökt denna på egen hand före besöket hos sjukvården. Många patienter är oroliga. Att kunna förklara så att patienten förstår är viktigt. Den övergripande känslan är att sjukvården generellt blir bättre och bättre på att förklara och förmedla informationen till patienterna. Denna utveckling beror på en mängd olika faktorer som till exempel personalens sätt att förklara, men också att forskningen blivit tydligare och ger mer stöd till förklaringarna.

Vem ställer generellt mest frågor, patienten eller de anhöriga?

Det är väldigt beroende på vem den anhöriga är och vad denna har för bak-

grund. Patienterna är också väldigt olika kring vad de vill veta.

Finns det något hjälpmedel som idag används och som är till hjälp för patienten att följa utvecklingen av sin sjukdom, där de kan gå in och få information som kanske inte kunnat tas in vid läkarbesöket?

Det finns ett utlåtande från patologen samt ett Gleason-värde som patienterna får reda på. Det finns inget visuellt som används för att patienterna ska kunna följa och se detta utan det blir en allmän diskussion kring utlåtandet där patient och läkare pratar om vad utlåtandet betyder. Till hjälp har man en anatomisk bild där det finns möjlighet för läkaren att rita ut var tumören/tumörerna sitter, denna kan patienten sen få ta med sig hem. På 1177 kan patienten gå in och läsa sin journal, i denna syns inga labb- eller röntgenresultat. Som patient har man även möjlighet att ställa frågor genom att kontakta den kontaktsjuksköterska man blivit tilldelad i samband med diagnostiseringen. Detta sker via telefon eller via 1177. De flesta patienter som kommer nya till avdelningen får även en individuell vårdplan där information om behandlingar och möten finns med. Denna ska följa med patienten mellan avdelningar och ges även som utskrift till patienten att ta med hem. Hur vårdplanen sedan används i praktiken är inte helt etablerat. På nätet finns mycket bra information, till exempel har Prostatacancerförbundet och 1177 mycket information riktad till patienterna. Inom sjukvården ser man sällan problem med att det inte finns uppdelningar i informationen utan patienterna är generellt bra på att sondera själva. Patienterna upplevs också som duktiga på att prata med varandra om sin sjukdom och sina behandlingar och de gillar när de känner igen vad läkaren pratar om, till exempel från vad hört från andra eller läst på internet. För att patienterna ska få ut någonting av internetsökningarna är det viktigt att informationen från sjukvården är tydlig så att rätt information eftersöks.

Har du upplevt att det finns något som saknas i form av hjälpmedel för att patienterna ska kunna följa sin sjukdom? Finns det frågor som uppkommer från patienten gång på gång?

Patienterna frågar ofta om sitt PSA-värde. Även frågor om röntgenresultat är vanligt förekommande. Generellt är det dessa frågor som oroar mer än frågor som handlar om vad som händer närmast. Allmänt är det svårt inom sjukvården att veta vad man som personal saknar till patienterna. Tekniska lösningar är dock något som patienterna ofta konstaterar hade underlättat. Oftast handlar detta om situationer där olika enkätundersökningar ska genomföras. Patienterna vet själva bäst vad de saknar vilket är bra att tänka på i utformandet av en teknisk lösning.

Har du några tips på vad jag ska tänka på när jag pratar med patienter som kanske är eller har varit sjuka?

Generellt handlar det i dessa fall om väldigt öppna patienter. Det är bra att tänka på att låta patienten prata fritt. Att vara rak även vid känsliga frågor är viktigt. Om man är öppen för svaren man kan få så blir intervjusituationen lättare. För att patienten ska känna sig trygg är det viktigt att verka trygg själv.

Kan man märka att fokus hamnar på andra saker i till exempel ett samtal eller i en bild när man är sjuk jämfört när man är frisk?

Det är inget man märker av i sjukvården. Man kan märka av att människor

APPENDIX B. INTERVIEW ABOUT PATIENT BACKGROUND

är olika och att det påverkar hur man tar in information men det är svårt att ange något som är typiskt just för gruppen av patienter. För att undvika missförstånd är det alltid bra att koppla ihop till exempel en bild med text eller ett samtal.

Appendix C

Information Sheet

This is the information sheet used for the individual patient and the urologist interviews. Since the interviews was conducted in Swedish the information is in Swedish as well.

Information om intervjun

Syftet med intervjun

Syftet med denna intervju är att göra en behovsanalys kring efterfrågan av tekniska lösningar för män diagnostiserade med prostatacancer. Intervjusvaren kommer ligga till grund för en första prototyp av en sådan teknisk lösning. Intervjun sker som en del i mitt examensarbete på Lunds Tekniska högskola i samarbete med EXINI Diagnostics.

Frivilligt deltagande

Deltagandet i studien är frivilligt och som deltagare är du förbehållen rätten att när som helst, utan särskild förklaring, avbryta deltagandet. I sådant fall raderas all tidigare insamlad data och dina svar kopplas inte längre till undersökningen.

Insamling av data

Ljudupptagning kommer ske för att underlätta intervjun och insamlingen av data. Det insamlade materialet kommer att hanteras konfidentiellt och data kommer behandlas på så sätt att inga obehöriga kan ta del av dina svar. Inga personliga identiteter kommer att lämnas ut eller avslöjas i och med publicering av examensarbetet.

Kontaktuppgifter

Om du har frågor och funderingar kring intervjun eller vill lägga till något i efterhand får du gärna höra av dig till mig via mejl.

Emmy Sandwall

emmy.sandwall@exini.com



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Appendix D

Informed Consent

This is the consent form the interviewee was asked to sign before conducting the individual patient interviews. The same consent was used for the urologist interview. Since the interviews was conducted in Swedish the consent is in Swedish as well.

Informerat samtycke för medverkan i intervju

Härmed samtycker jag att min medverkan i intervjun dokumenteras enligt bifogad information kring insamling av data.

Jag är införstådd med att:

- Mitt deltagande är helt frivilligt och kan när som helst avbrytas
- Resultatet av mina svar kommer inte kunna kopplas tillbaka till mig som person
- Jag tillåter att intervjun spelas in (ljudupptagning) och att inspelat material endast kommer användas till examensarbetet

Underskrift:

Namnförtydligande:

Ort, Datum:



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Appendix E

Interview Questions - individual patient

These are the questions asked during the individual patient interviews. The interviews were conducted in Swedish and therefore the questions in this appendix is also presented in Swedish.

1. Kan du börja med att berätta lite om dig själv och hur din erfarenhet av prostatacancer ser ut?
 - (a) När fick du diagnosen?
 - (b) Under hur lång tid fick du behandling?
 - (c) Hur gammal är du?
2. Vilken roll har dina anhöriga spelat under tiden du varit sjuk?
 - (a) Vem är de?
 - (b) Har de hjälpt dig leta information och varit aktiva med frågor vid läkarbesök?
 - (c) Har du upplevt det svårt att förmedla vad läkaren sagt till de anhöriga?
3. Har du upplevt det möjligt att följa utvecklingen av prostatacancer från läkarbesök till läkarbesök?
 - (a) Vilken typ av möjlighet hade du möjlighet att följa?
 - (b) Fick du några hjälpmedel från sjukvården?
 - (c) Har det varit viktigt för dig att kunna följa konkreta utvecklingar, t.ex. hur PSA-värdet förändrats?
4. Det finns många appar där man kan rapportera hur man mår, dela med sig av sin resa med nära och kära och organisera sitt liv. Är det något du använt dig av?
 - (a) Hur har det fungerat, vad har varit bra respektive dåligt?
 - (b) Varför har du inte använt dig av något sådant?

APPENDIX E. INTERVIEW QUESTIONS - INDIVIDUAL PATIENT

Följande frågor är något kortare och handlar om din inställning kring olika möjligheter för någon form av teknisk lösning.

1. Kan du se någon fördel med att få tillgång till dina undersökningsbilder hemma?

| Ja | Nej | Kanske/Beror på |
|--|--|--|
| (a) Vad hade du velat se då? | (a) Varför inte? | (a) Vad beror det på? |
| (b) Vad hade du velat ha för information kring bilderna? | (b) Tror du dina anhöriga hade kunnat ha nytta av det? | (b) Hade detta kunnat hjälpa i dialogen med dina anhöriga? |
| (c) Vad hade du velat ha möjlighet att göra med bilderna? | | |
| (d) Kan du se några restriktioner på en sådan lösning? | | |
| (e) Hade detta kunnat hjälpa i dialogen med dina anhöriga? | | |

2. Har du någon gång önskat att du haft tillgång till alla dina bilder, tex för att få en andra åsikt eller visa någon?

| Ja | Nej | Kanske/Vet inte |
|--|---|----------------------|
| (a) Vem hade du velat visa? | (a) Varför inte? | (a) Kan du utveckla? |
| (b) Tror du dina anhöriga hade kunnat ha nytta av det? | (b) Är det något dina anhöriga hade haft större nytta av? | |

3. Vilken typ av information hade du velat ha tillgång till hemma?

- (a) Information om specifik behandling (vald för just dig)?
- (b) Allmän information om alla typer av behandlingar?
- (c) Information kopplad till ett specifikt cancerstadium?
- (d) Något annat?

APPENDIX E. INTERVIEW QUESTIONS - INDIVIDUAL PATIENT

4. Hade du velat ha tillgång till exempelvis en kurva med hur PSA-värdet förändras från undersökning till undersökning?
 - (a) Hade du kunnat tänka dig att ange detta själv efter vad läkaren sagt?
5. Hade du velat ha möjligheten att ange hur du mår (och följa detta)?
 - (a) Hade det varit ett verktyg som du tänker dig hade varit bra för din egen del eller hade det varit något du ville att din läkare skulle kunna ta del av?
6. Hur ställer du dig till olika typer av communities där man kan prata med andra i samma situation?
7. Hade du velat att personer utvalda av dig hade haft tillgång till samma tekniska lösning som du har?
 - (a) Hade du tyckt det var en bättre idé om du hade kunnat reglera innehåller som varje person får tillgång till?
8. Om du haft tillgång till någon form av teknisk lösning, vilket format tror du hade varit mest lämpligt och mest användbart?

| Internetsida | Smartphone | Både och |
|--|--|--|
| (a) Varför? | (a) Varför? | (a) Varför? |
| (b) På vilket sätt hade de andra gjort lösningen mindre användbar? | (b) På vilket sätt hade de andra gjort lösningen mindre användbar? | (b) På vilket sätt hade de andra gjort lösningen mindre användbar? |

9. Finns det något du känner att du saknat under din tid som patient som hade kunnat vara till hjälp, dvs om du hade fått drömma helt fritt, vilken funktion hade du sett till att ha tillgång till i en teknisk lösning?

Appendix F

Interview Questions - Urologist

1. Hur ser ditt arbete ut?
2. Patienten får reda på att man har hittat cancerceller i prostatan. Vilka testresultat får han ta del av och hur?
3. Om du hade haft tillgång till en bild, likt denna här (Figure F.1), där du får information om antalet tumörer i prostatan och hur aktiva/aggressiva de är, hade du då velat visa denna informationen för patienten?

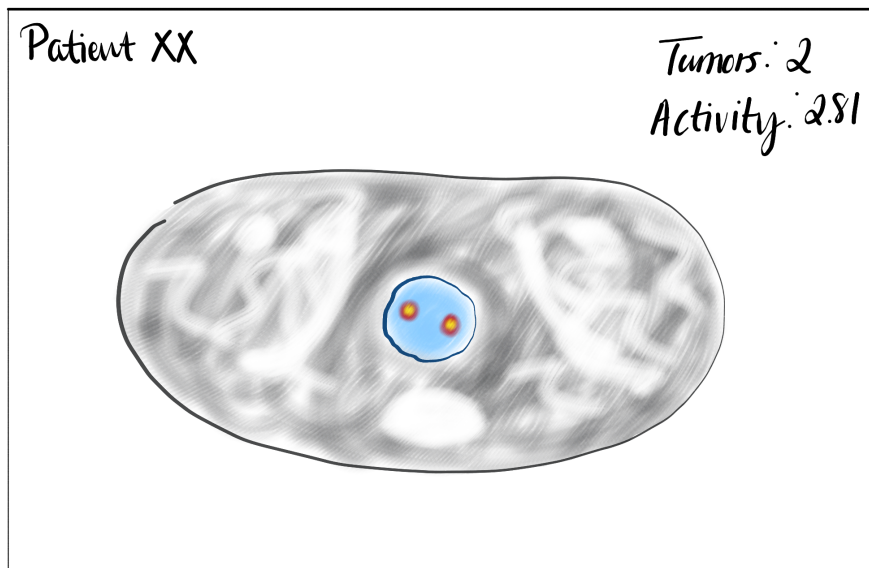


Figure F.1: Sketch to Question 3.

APPENDIX F. INTERVIEW QUESTIONS - UROLOGIST

| Ja | Nej |
|--|--|
| (a) Varför? | (a) Varför inte? |
| (b) Vad hade gjort det till en fördel? | (b) Hade man kunnat göra på något annat sätt så att du hade velat det? |

4. Tror du det finns en fördel med att visa bilder för patienterna för att understryka att det faktiskt inte finns några tumörer?

(a) Är patienterna bra på att tro på sådan information idag eller tvivlar de om man säger att de inte finns tumörer i ex skelettet?

5. Hade du kunnat tänka dig att även ge patienterna tillgång till en sådan bild hemma?

| Ja | Nej |
|---|--|
| (a) Varför? | (a) Varför inte? |
| (b) Vad hade gjort det till en fördel? | (b) Hade man kunnat göra på något annat sätt så att du hade velat det? |
| (c) Hade patienten haft möjlighet att tolka bilden? | |

6. Om vi tittar på denna bilden (Figure F.2):

(a) Är det någon funktion som du direkt tänker "ja, detta hade våra patienter verkligen haft nytta av"?

(b) Är det någon funktion du tänker att patienterna hade haft väldigt lite nytta av?

(c) Är det någon funktion du saknar?

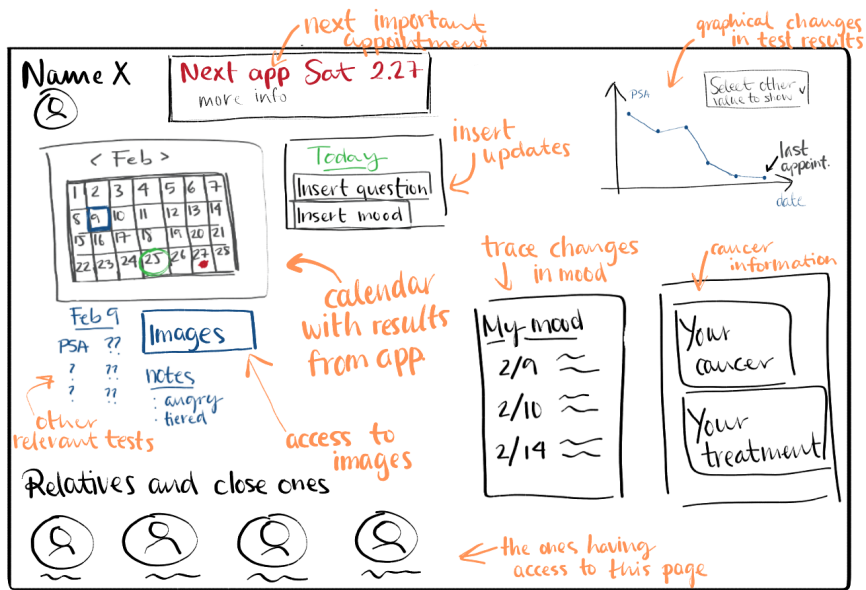


Figure F.2: Sketch to Question 6.

7. Hur är din inställning till att som urolog facilitera någon sådan här lösning?
8. Har du någon uppfattning om hur ofta man missar cancer vid biopsi?

Appendix G

Questionnaire

Undersökning angående patientplattform

Information om undersökningen:

Undersökningen sker som en del av mitt examensarbete på Lunds tekniska högskola i samarbete med EXINI Diagnostics. Arbetet är inom interaktionsdesign och målet är att undersöka ifall det finns ett behov av en teknisk lösning som skulle kunna underlätta vardagen för män som diagnostiseras med prostatacancer.

För att undersöka detta kommer du snart få se ett antal av mina skisser med tillhörande frågor. I skisserna finns förslag på olika funktioner som kommit på tal under tidigare intervjuer. Tanken med plattformen är att göra den enklare att följa utvecklingen av sjukdomen samt att underlätta vardagen med smarta funktioner.

Tänk dig att skisserna du ser är sidor i en telefon-app eller sidor på internet där du helt fritt kan bläddra dig fram och tillbaka. Fundera på vad du tycker om funktionerna som presenteras och om du tycker det är funktioner som hade kunnat vara till hjälp för just dig.

*Obligatorisk

Bakgrundsinformation

Dina svar är helt anonyma och kommer inte kunna spåras tillbaka till dig.

1. Jag ger mitt samtycke till att mina svar används i examensarbetet. *

Markera endast en oval.

- Ja
 Nej

2. Jag är införstådd med att de skisser som presenteras för mig i denna undersökning tillhör EXINI Diagnostics och får inte spridas utanför syftet med denna undersökning. *

Markera endast en oval.

- Ja
 Nej *Sluta fylla i detta formulär efter den sista frågan i detta avsnitt.*

3. Hur gammal är du? *

Markera endast en oval.

- <50
 50-60
 61-70
 71-80
 81-90
 >91

4. Vilka av följande har du hemma och använder regelbundet? (Markera alla som stämmer) *

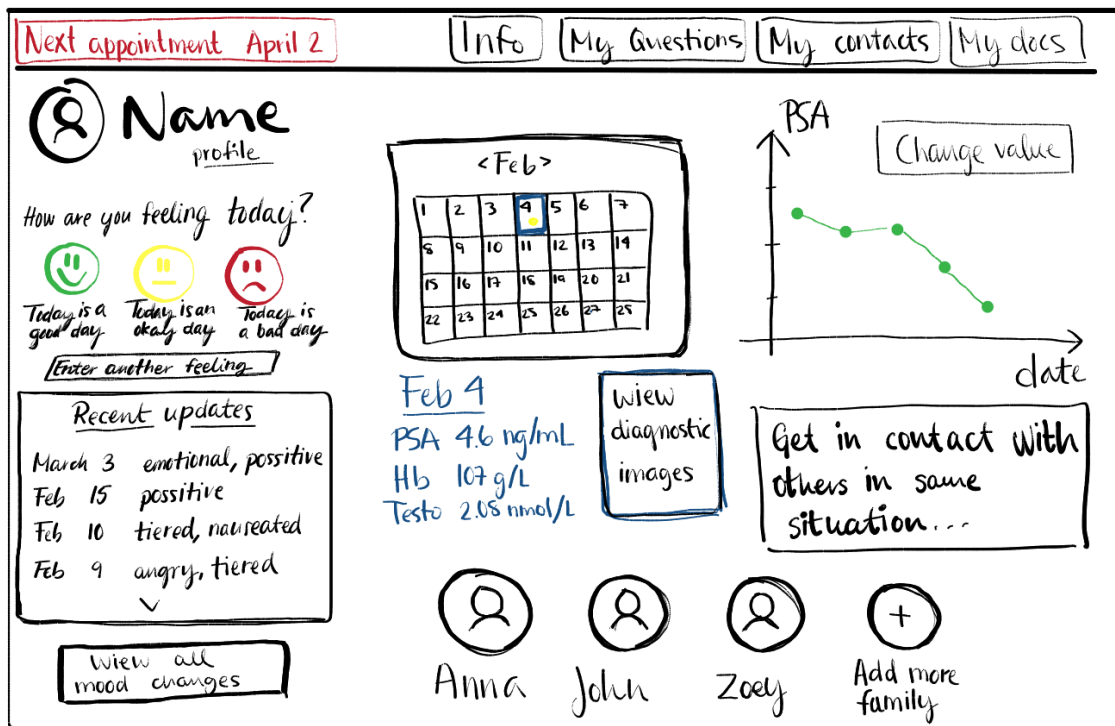
Markera alla som gäller.

- Dator
 Surfplatta
 Smartphone
 Inget av ovanstående

Hemskärmen

Här presenteras förslag på hur förstasidan (hemskärmen) skulle kunna se ut. Vad är ditt intryck?

Alternativ 1 - Allt innehåll direkt på hemskärmen



5. Alternativ 1 - hur stor överblick känner du att du får över de olika funktionerna? *

Markera endast en oval.

1 2 3 4

Dålig överblick Bra överblick

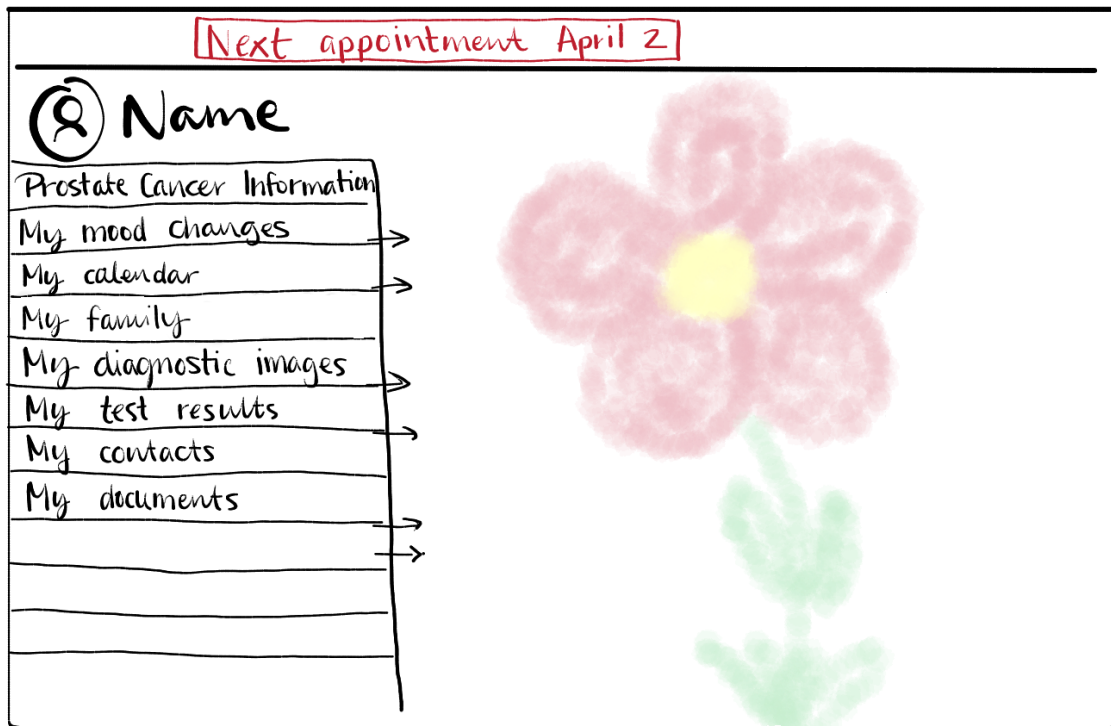
6. Alternativ 1 - till hur stor del känner du att designen ger dig förståelse för hur du ska använda plattformen? *

Markera endast en oval.

1 2 3 4

Dålig förståelse Bra förståelse

Alternativ 2 - Samlat i en meny, funktionerna visas sedan en och en



7. Alternativ 2 - hur stor överblick känner du att du får över de olika funktionerna? *

Markera endast en oval.

1 2 3 4

Dålig överblick Bra överblick

8. Alternativ 2 - till hur stor del känner du att designen ger dig förståelse för hur du ska använda plattformen? *

Markera endast en oval.

1 2 3 4

Dålig förståelse Bra förståelse

9. Vilket av alternativen tycker du ser lättast ut att använda? *

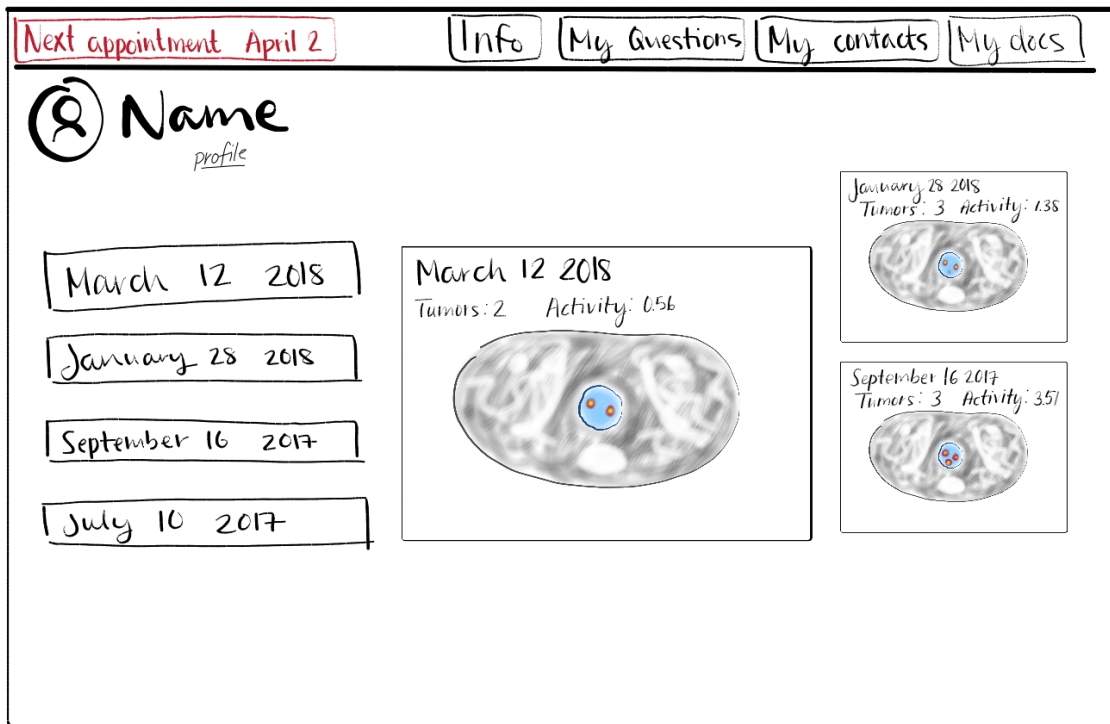
Markera endast en oval.

- Alternativ 1 - Allt innehåll direkt på hemskärmen
- Alternativ 2 - Samlat i en meny, funktionerna visas sedan en och en
- De är likvärdiga

Tillgång till diagnostiska bilder

Tanken med funktionen i bilden nedan är att du skulle kunna ha tillgång till dina diagnostiska bilder hemma. Du ska själv kunna gå in och visa de bilder som läkaren visat vid läkarbesöket. Från varje undersökning finns bilder med information som går att jämföra från tillfälle till tillfälle.

Undersökningsbilder



10. Hur stor användning tror du att du hade haft för denna funktion? *

Markera endast en oval.

1 2 3 4

Ingen användning Stor användning

11. Hade det varit viktigt för dig att det till varje bild fanns ett utlåtande från din läkare? *

Markera endast en oval.

1 2 3 4

Nej, det är inte viktigt Ja, det är mycket viktigt

12. Vad kan du se för nytta med denna funktion? (Flera svar är tillåtna) *

Markera alla som gäller.

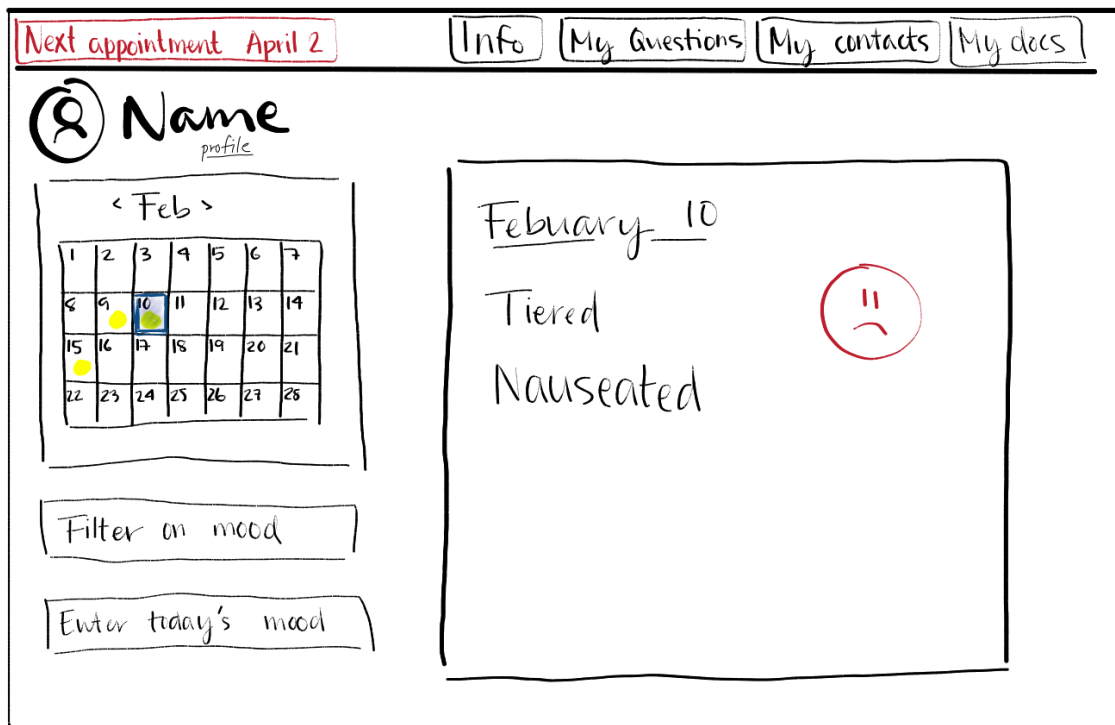
- Påminna mig själv om vad läkaren sagt och visat
- Visa för anhöriga
- Visa för en ny läkare för en andra åsikt
- Få en bra överblick av vad som förändrats mellan undersökningarna
- Övrigt: _____

13. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

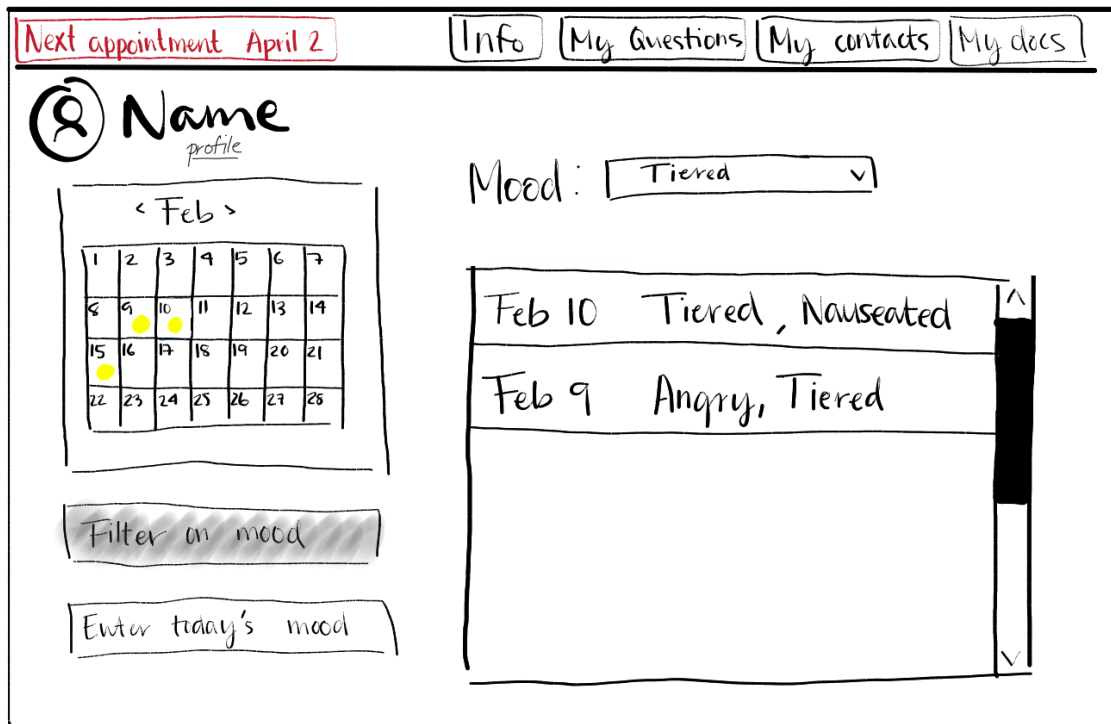
Uppföljning av humör

I denna funktion är tanken att du ska kunna följa hur ditt humör, biverkningar och känslor förändrats över tid. Tanken är att du skulle kunna rapportera detta direkt från startskärmen som det första du gör när du besöker plattformen och sedan gå in och följa upp hur det förändrats.

Hitta ett datum i kalendern och se vad du rapporterat



Filtrera och visa alla dagar du haft en viss känsla, ex trött



14. Hur viktigt anser du det är att du på ett enkelt sätt hade kunnat följa hur ditt mående förändrats över tid? *

Markera endast en oval.

1 2 3 4

Inte alls viktigt Jätteviktigt

15. Vad kan du se för fördelar med en sådan här funktion? (Flera svar möjliga) *

Markera alla som gäller.

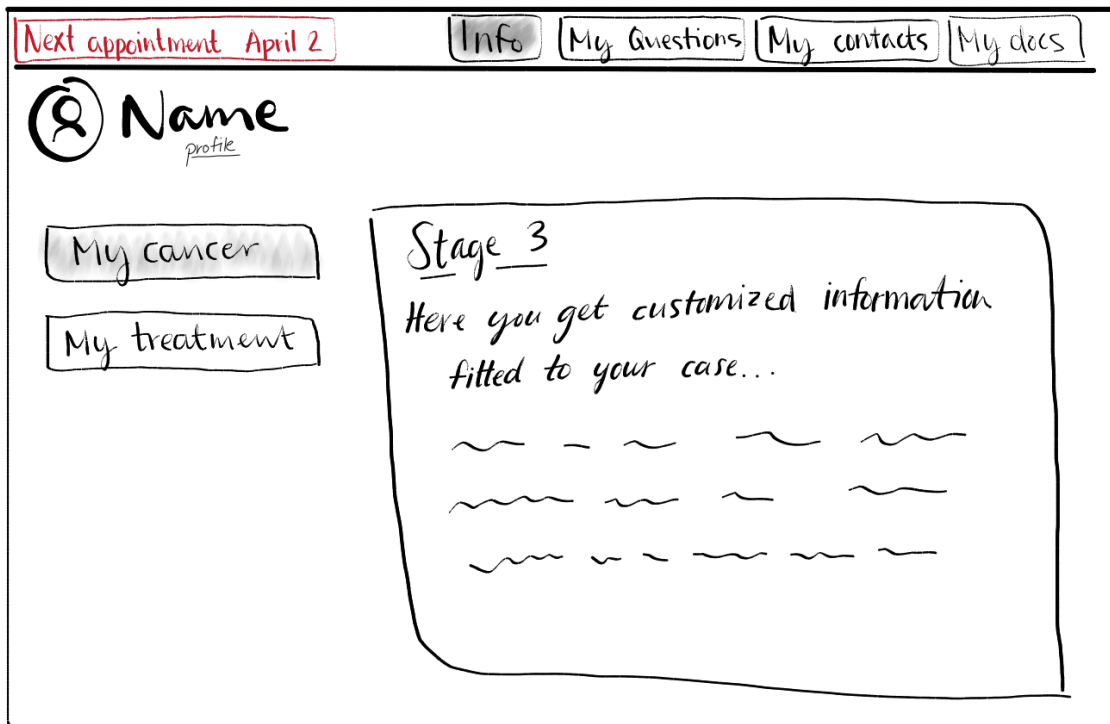
- Jag hade själv kunnat få en bättre överblick
- Jag hade haft lättare att kommunicera mina problem till sjukvården
- Det hade varit lättare att hålla anhöriga uppdaterade
- Övrigt: _____

16. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Information

Det finns mängder av information om prostatacancer på internet, här tittar vi på en lösning där du skulle kunna få specificerad information för just din typ av cancer och behandling.

Patientspecifik information



17. Hade du ansett att det var bra att få tillgång till mer skräddarsydd information på det här sättet? *

Markera endast en oval.

1 2 3 4

Nej, inte alls bra Ja, mycket bra

18. Vilken information hade varit viktig för dig att se här? (Flera svar möjliga) *

Markera alla som gäller.

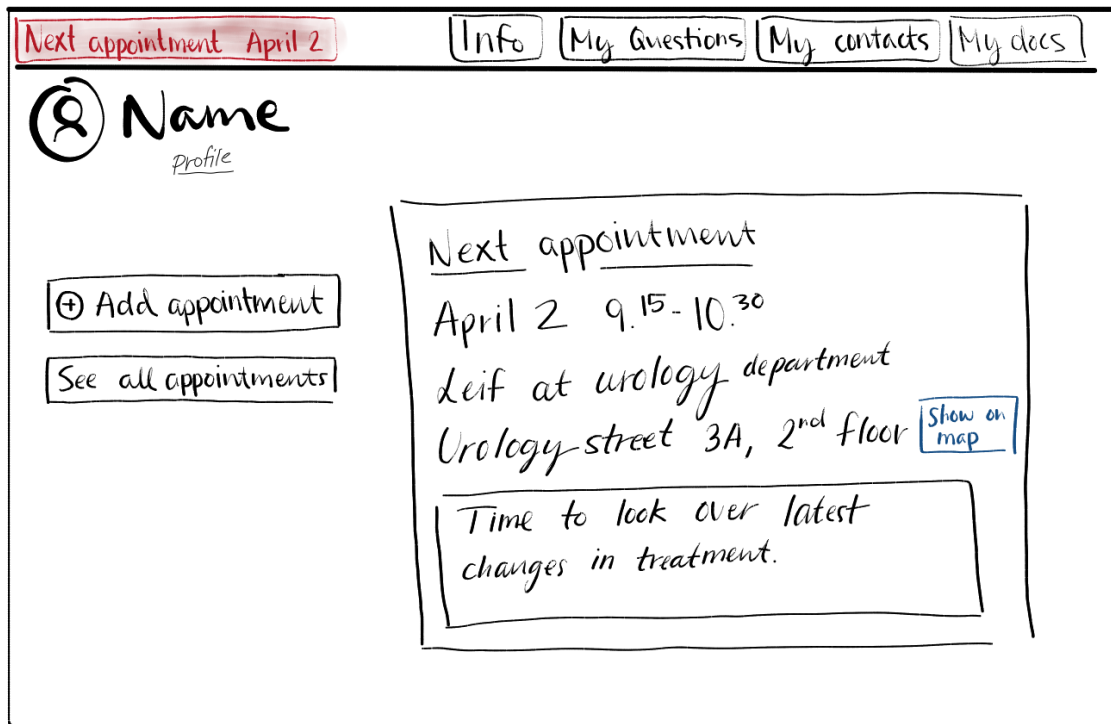
- Specifik cancerinformation
- Specifik behandlingsinformation
- Specifik läkemedelsinformation
- Information från psykolog
- Övrigt: _____

19. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Kalenderhändelser

Här skulle du kunna ha tillgång till en kalender med dina närmsta läkarbesök.

Nästa besök



20. Hur stor användning tror du att du hade haft för funktionen att kunna lägga till läkarbesök i en kalender? *

Markera endast en oval.

1 2 3 4

Ingen användning Stor användning

21. Hur viktigt hade det varit att händelserna las in direkt från sjukvården, det vill säga att du slipper lägga in händelserna själv? *

Markera endast en oval.

1 2 3 4

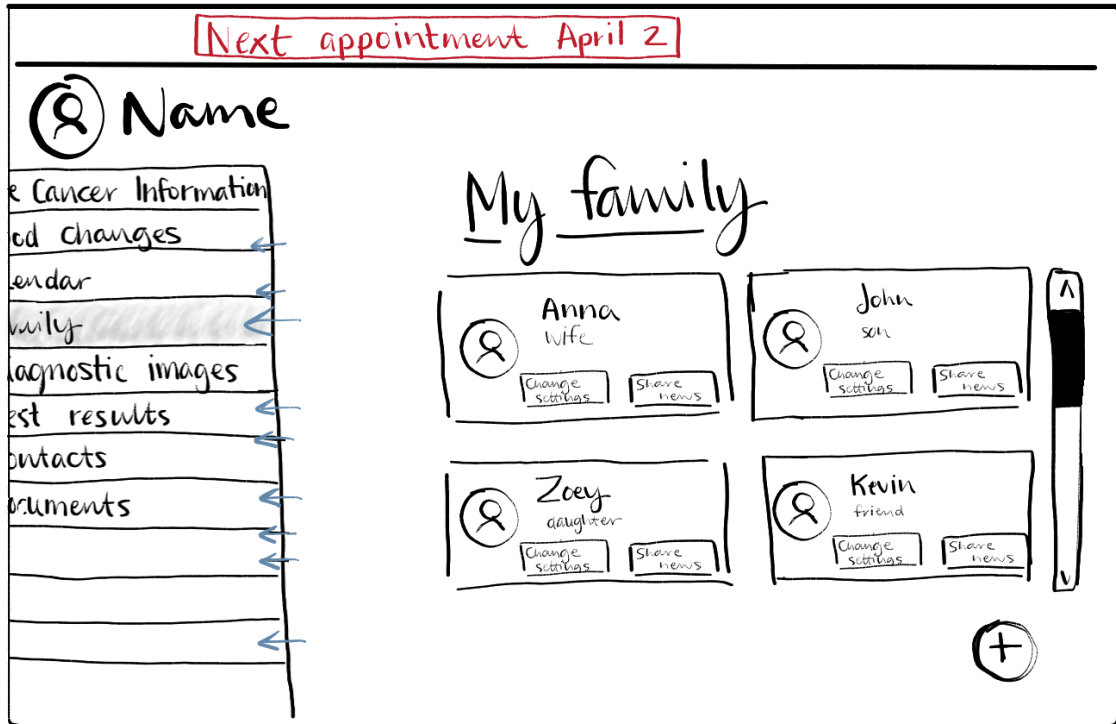
Inte alls viktigt Mycket viktigt

22. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

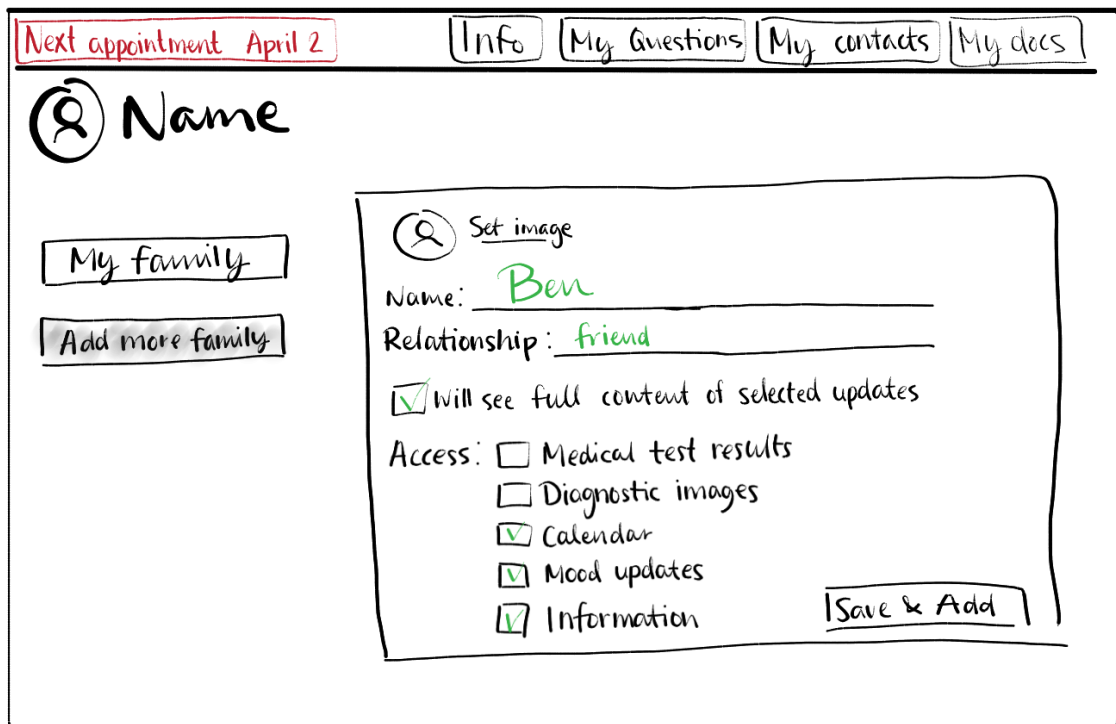
Min familj

I den här funktionen är tanken att du skulle kunna ha möjlighet att lägga till familjemedlemmar eller vänner som du vill ska ha tillgång till samma information som du. Är det någon du skulle vilja ge tillgång till mindre information skulle du kunna ställa in även detta. När något uppdateras i din plattform informeras anhöriga som då kan gå in och se förändringarna.

Lista över tillagda familjemedlemmar



Att lägga till en ny vän. Här skulle du kunna begränsa informationen vänner har åtkomst till.



23. Hur stor användning tror du att du hade haft för funktionen att kunna lägga till anhöriga som får ta del av din resa? *

Markera endast en oval.

1 2 3 4

Ingen användning Stor användning

24. Instämmer du med påståendet: Det är bra att jag själv kan välja vilka funktioner mina anhöriga får ta del av? *

Om du till exempel vill att vännen Ben endast ska kunna se att något uppdaterats, men inte innehållet i uppdateringen, skulle du kunna ställa in det. Du skulle också kunna ställa in vilka uppdateringar du vill att han ska få se.

Markera endast en oval.

1 2 3 4

Instämmer inte Instämmer helt

25. Vilken nytta hade du sett med den här funktionen? (Flera svar möjliga) *

Markera alla som gäller.

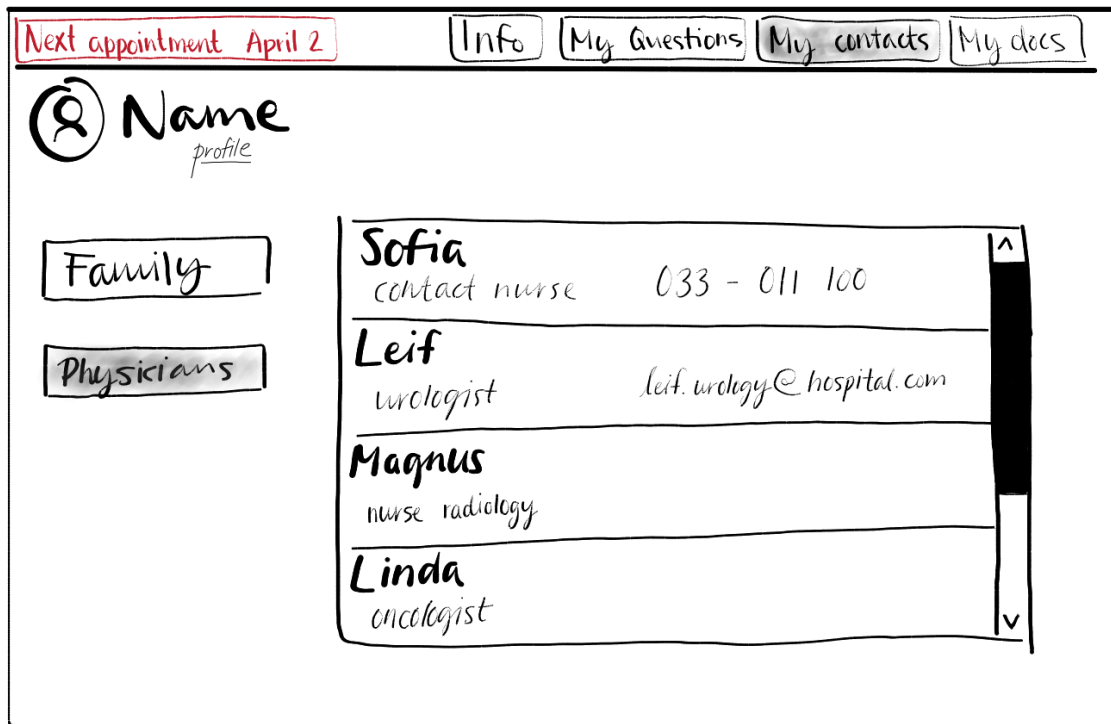
- Jag hade snabbt kunnat dela uppdateringar med mina anhöriga
- Det hade kunnat minska oron hos mina anhöriga
- Det hade underlättat kommunikationen med mina anhöriga
- Övrigt: _____

26. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Kontakter

På denna sida skulle du kunna samla kontaktinformation till dina sjukvårdskontakter.

Kontaktinformation till sjukvården



27. Hur stor nytta tror du att du hade haft av en funktion med kontaktuppgifter till sjukvården?

*

Markera endast en oval.

1 2 3 4

Ingen nytta alls Stor nytta

28. Hur viktigt hade det varit att kontakterna las in direkt från sjukvården, det vill säga att du slipper lägga in dem själv? *

Markera endast en oval.

1 2 3 4

Inte alls viktigt Mycket viktigt

29. Tycker du det är viktigt att du även hade kunnat lägga till kontaktuppgifter till de som lagts till som anhöriga? *

Markera endast en oval.

1 2 3 4

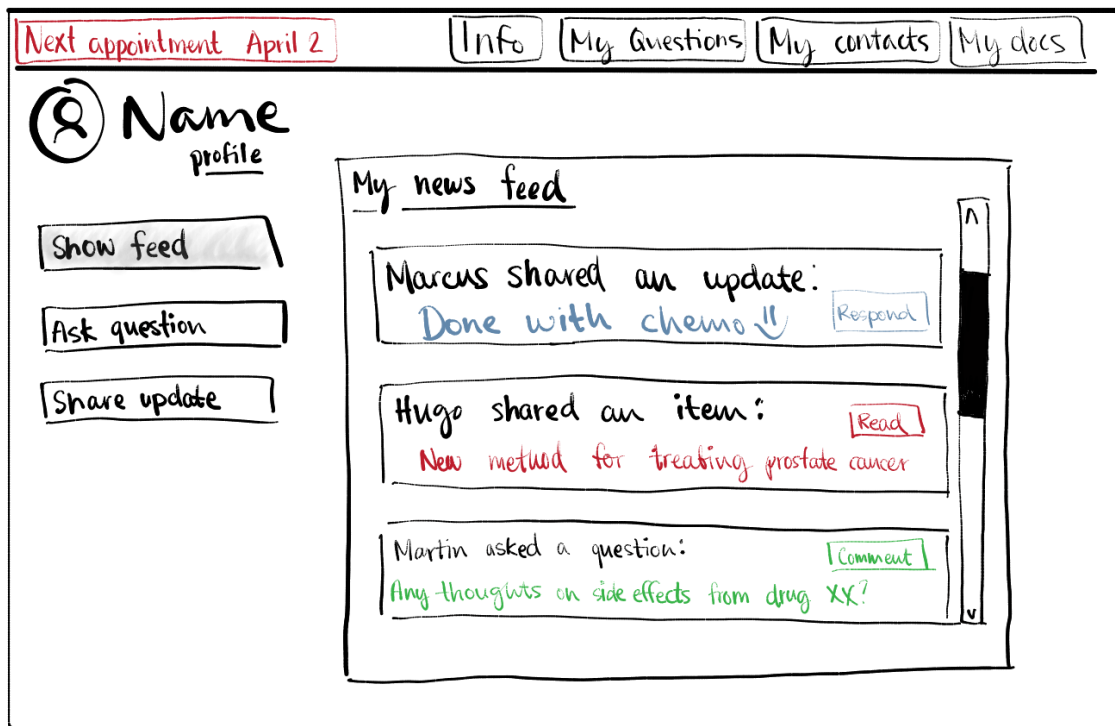
Nej, det är inte alls viktigt Ja, det är mycket viktigt

30. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Flöde

På denna sida kommer du få ta ställning till hur du känner kring att ha tillgång till en sida där du kan komma i kontakt med andra användare av plattformen.

Flödesuppdatering - här kan du bläddra bland inlägg gjorda av andra användare.



31. Hur stort känner du att behovet av att komma i kontakt med andra i samma situation är? *
Markera endast en oval.

1 2 3 4

Inte stort alls Mycket stort

32. Hade du kunnat tänka dig att denna kontakt skedde via en digital plattform? *
Markera endast en oval.

Ja

Nej

Övrigt: _____

33. Vilken nytta hade du sett av att sådan kontakt sker via en digital plattform? (Flera svar möjliga) *

Markera alla som gäller.

- Jag hade kunnat undvika att träffa personer i verkligheten och ändå vara uppdaterad
- Det hade kunnat vara ett komplement till att träffa personer i verkligheten
- Jag ser ingen nytta med att detta ska ske i digital form
- Övrigt: _____

34. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Frågor

I detta avsnitt presenteras alternativet att skriva in frågor till sjukvården.

Du skulle både kunna lägga till minnesanteckningar och skicka frågor.

The sketch shows a user interface for a patient's digital health record. At the top, there is a navigation bar with four tabs: 'Info', 'My Questions', 'My contacts', and 'My docs'. Below the navigation bar, on the left, is a profile section with a circular icon containing a person silhouette, followed by the text 'Name' and 'profile' underneath. To the right of the profile are two buttons: 'Add note' and 'Ask question'. Below the profile are two more buttons: 'My notes' and 'My questions'. The main area of the interface is a large rectangular box containing a 'To:' dropdown menu with a checkmark icon. Below the dropdown is a large text input area with several horizontal wavy lines representing text and a question mark at the end. At the bottom right of this input area is a 'Send' button.

35. Hade det varit viktigt för dig att frågorna skickades direkt till sjukvårdspersonal som kunde svara på frågorna? (Alternativet är att frågorna samlas så att du själv kan visa dem vid nästa läkarbesök) *

Markera endast en oval.

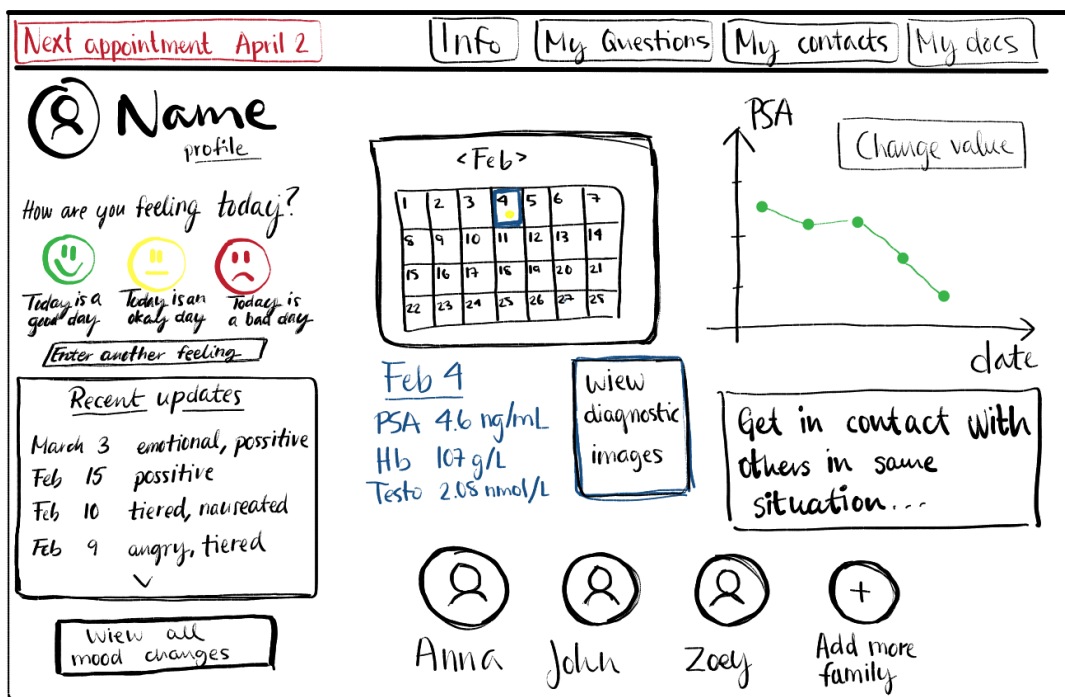
1 2 3 4

Nej, inte alls viktigt Ja, mycket viktigt

36. Om du har ytterligare tankar kring den här funktionen kan du skriva dem här, annars kan du gå vidare.

Avslutande frågor

37. Nu när du fått se de olika funktionerna, vad är din känsla angående plattformen? *



Markera endast en oval.

1 2 3 4

Negativ känsla, det verkar inte bra Positiv känsla, det verkar bra

38. Har du möjlighet att utveckla ditt svar? Om inte, gå vidare till nästa fråga.

39. Vilken funktion tyckte du BÄST om (mest nödvändig)? *

Markera endast en oval.

- Se diagnostiska bilder
- Kalenderfunktionen
- Feed
- Anhörigfunktionen
- Informaitonsdelen
- Humörsuppdateringar
- Tillgång till ett community med män i samma situation
- Kontaktinformation till sjukvården

40. Vilken funktion tyckte du SÄMST om (mest onödig)? *

Markera endast en oval.

- Se diagnostiska bilder
- Kalenderfunktionen
- Feed
- Anhörigfunktionen
- Informaitonsdelen
- Humörsuppdateringar
- Tillgång till ett community med män i samma situation
- Kontaktinformation till sjukvården

41. Finns det någon mer åsikt du skulle vilja lägga till angående plattformen?

Tack för din medverkan!

Tack för att du tagit dig tid att gå igenom frågorna!

42. Skulle du kunna tänka dig att bli kontaktad i framtiden för vidare undersökningar? *

Markera alla som gäller.

- Ja, för undersökningar kopplade till denna undersökningen
- Ja, för frågor angående prostatacancer
- Nej, det vill jag inte

43. Om du svarade ja på ovanstående fråga, hur vill du bli kontaktad?

Om du lämnar dina kontaktuppgifter nedan kan du kontaktas i framtiden för nya undersökningar. Observera att undersökningen då inte längre är helt anonym. Dina svar kommer fortfarande inte kopplas till dig som person.

Tillhandahålls av

