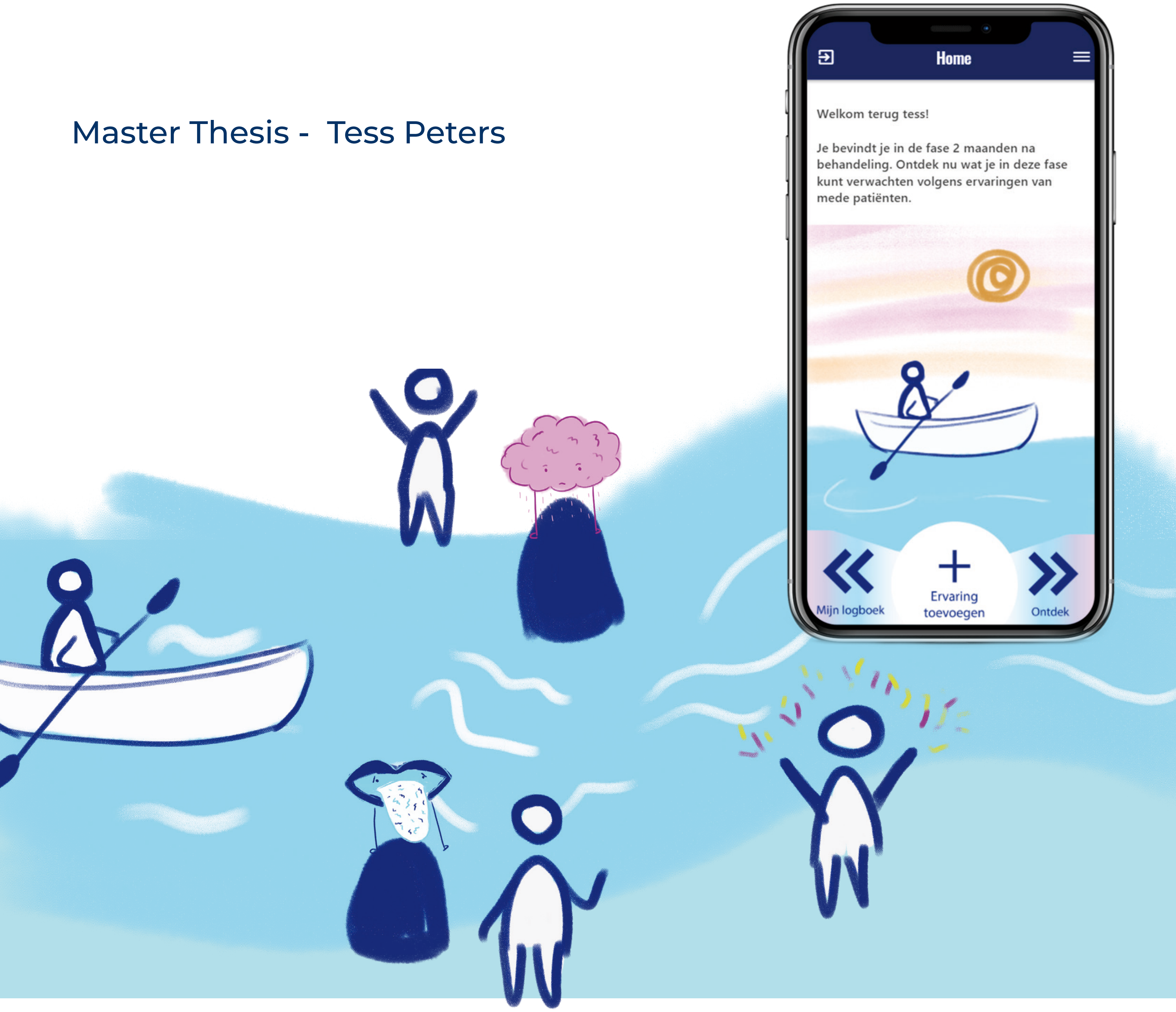
ExPEERience

Designing for Patient Empowerment for Head and Neck Cancer Patients in the Follow-up Phase

Master Thesis - Tess Peters



Welkom terug tess!

Je bevindt je in de fase 2 maanden na behandeling. Ontdek nu wat je in deze fase kunt verwachten volgens ervaringen van mede patiënten.

Erasmus MC
Universitair Medisch Centrum Rotterdam

zorg monitor
Erasmus MC

TU Delft

CardioLab

ExPEERience:
Designing for Patient Empowerment for Head and Neck Cancer Patients in the Follow-up Phase.

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> **“Experiencing a disease is different from knowing it.”**
>
> **Kees Ahaus, 2021, Conferentie Uitkomstgerichte Zorg**

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Abstract

In this graduation thesis I investigate how to design for patient empowerment in the context of head and neck cancer (HNC) patients in their follow-up phase (the first 5 years after treatment). This project is set up with the Erasmus MC and was initiated to elaborate on their current service called the Healthcare Monitor (HM).

Background
The HM is a structure of electronic patient-reported outcome measures (ePROs) filled in by patients before every follow-up consultation. The answers are shown in a dashboard to the treating physician and used during patient consultations (Dronkers et al., 2020).

The design problem
What the current HM lacks however, is insight for the patients themselves into their health and addressing their concerns in between the consultations. Therefore this project aims to develop an additional service to the HM that empowers patients in between consults whilst also providing the doctor with a more frequent and realistic insight into their wellbeing.

Designing for patient empowerment
Patient empowerment can ultimately lead to a better quality of life. In this project it is viewed as a process that can be influenced through design. Therefore an inspirational model is created in this thesis that designers can use when designing for patient empowerment.

The context
HNC patients in their follow-up need to deal with a lot of different physical and psychosocial side effects (Aguilar et al., 2017). I investigate their concerns using the double loop method of Jung (2021). I analyze the community context through a computational analysis of online cancer community platforms. The patient context is investigated through a focus group with 6 care professionals and interviews with 9 ex-patients. 4 main concerns are found. Patients want to:

- Be prepared for what they can expect and do
- Have the overview of how they are doing
- Be supported when they have a doubt
- Have a relevant service for them

Designing
The model for patient empowerment and patient concerns are combined to create a design vision. The vision is to provide patients with an overview that enables them to gain more control in dealing with issues that concern them. This overview was designed in a prototype application through 3 main elements; a logbook with previous experiences, a possibility to track current experiences and an overview of expected experiences based on peer experiences.

Prototype testing
This prototype was tested by 6 ex-patients who found value in the low threshold way to contact others, find trustworthy information and track their wellbeing. They valued peer experience exchange and better insight into themselves as this can ultimately lead to more reassurance in between consults. Based on this test further improvements, suggestions for the next steps and possibilities to scale the concept are presented.

Key learnings
When developing an app for patient empowerment the Erasmus MC should;

- Include peer patient experiences
- Provide the patient with insight into their wellbeing over time
- Integrate tools and databases in one complete overview

For designing in the field of value based healthcare, this project stresses the importance of incorporating experiences of the community and using a multidisciplinary approach.

Reading guidelines

This reading guideline is meant to guide the reader to understand the structure of the report.

Each chapter starts with a brief introduction and ends with a blue rectangle that provides the key chapter insights as a summary of the chapter (see the example rectangle below).

Text in the report is structured in the following way:

This is a main heading

Sub heading

Sub-sub heading

Main text

“Quotes.”

Key chapter insights

- Key chapter insight 1
- Key chapter insight 2
- Key chapter insight 3
- Key chapter insight 4
- etc.

Abbreviations

HNC	Head and Neck Cancer
MC	Medical Centre
HM	Healthcare Monitor
ePRO	electronic Patient-Reported Outcome measure
ENT KNO (in Dutch)	Ear Nose Throat Keel Neus Oor (in Dutch)
HPV	Human Papilloma Virus
TU	Technical University
VBHC	Value-Based Healthcare
PE	Patient Empowerment
MDO	Multidisciplinary meeting
HREC	Human Research Ethics Committee
EPF	Electronic Patient File
HCD	Human Centered Design
ICT	Information and Communications Technology
METC	Medical Ethical Research Committee

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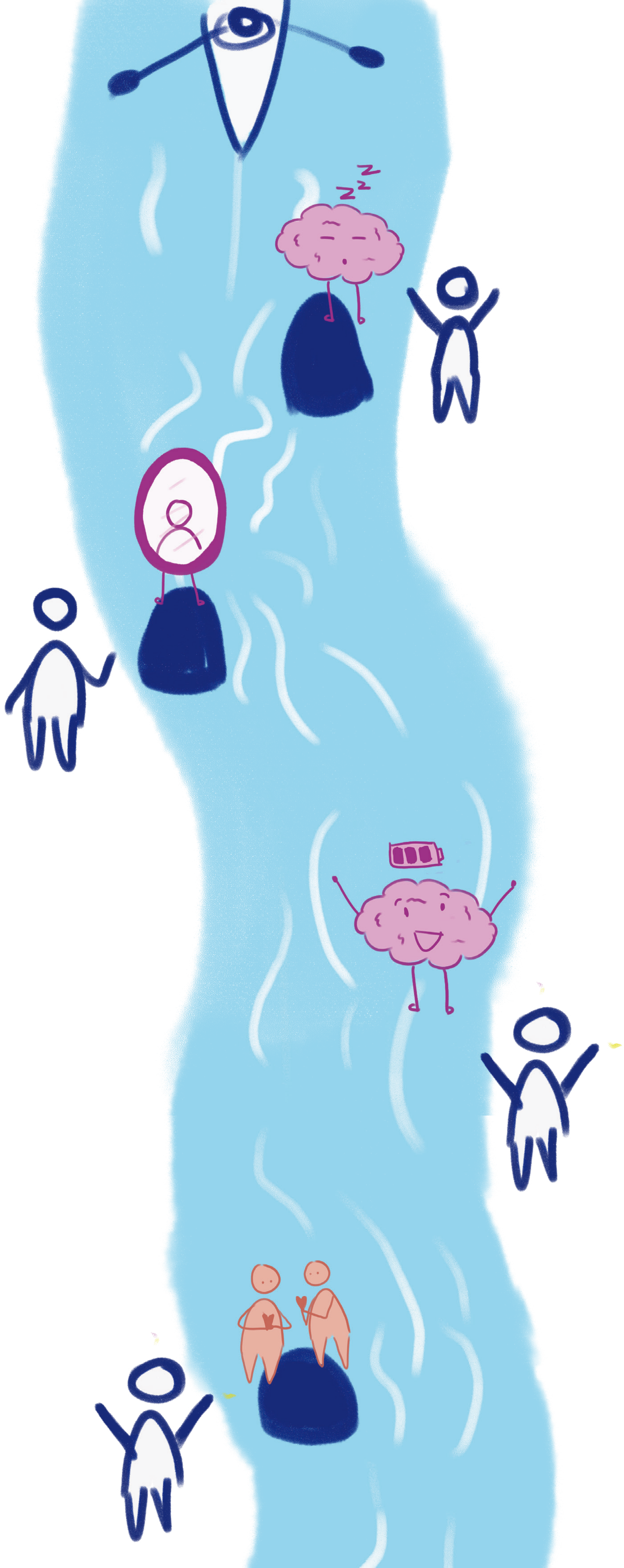


1. INTRODUCTION

This chapter aims to deliver an overview of this report and an introduction to the context of the project. Furthermore the project aim and approach are presented.

1.1 Thesis introduction

This graduation project is set up in a collaboration with the Value-Based Healthcare team of the Erasmus Medical Centre. The project was set up based on a previous research project done with the Ear Nose Throat (ENT) department of the Erasmus MC. In this research project we investigated how the Healthcare Monitor (HM) service of the Erasmus MC might be further improved. The result of this research provided the direction for this graduation project, which is to design a digital service that is linked to the HM that can increase patient empowerment for head and neck cancer patients in their follow up phase. Appendix A provides the project brief of this thesis.

This thesis consists of 8 big chapters. Figure 1 shows the structure of this thesis.

Chapter 1 provides the introduction of the project. It presents further explanation on the background, aim and approach of this design project.

Chapter 2 explores the theme of patient empowerment. Why do we want patient empowerment? What is it? And how can it be created? These questions will be answered by combining 4 relevant models of patient empowerment found in literature. I create my own inspirational model of patient empowerment in order to be able to design for it.

In chapter 3 I explore the context of head and neck cancer patients in their follow up phase more in depth using the double loop method of Jung (2021) where I also incorporate the community in my context research by analyzing posts on online cancer patient communities. Furthermore interviews with ex-patients and a focus group with care professionals are done to better understand the patient concerns.

In chapter 4 I combine the insights from chapters 2 and 3 to form a design vision.

This design vision is used in chapter 5 in order to create a prototype application. It is hypothesized that this designed prototype can increase patient empowerment and add value for head and neck cancer patients in their follow up phase.

The prototype is tested in chapter 6 by 6 ex-patients. This chapter also addresses the first improvements for the design that resulted from the prototype test. These are used to redesign the concept and provide a new system concept design.

In chapter 7 I look at how the designed concept might be further developed showing a development roadmap with the next steps and also looking at opportunities to scale the concept.

Chapter 8 provides the discussion and conclusion. It discusses the key learnings for designing an app for empowering cancer patients in their follow-up phase and for designing for the field of Value-Based Healthcare. It concludes with an overview of the thesis results.

To get a quick insight into the main research questions and answers of this graduation project I want to refer you to 2 visuals in this thesis.
Figure 11 on pages 24 & 25 shows an overview of the chapters of this thesis with their accompanying research questions.
Figure 115 on pages 182 & 183 shows the same overview with the found answers to these questions.

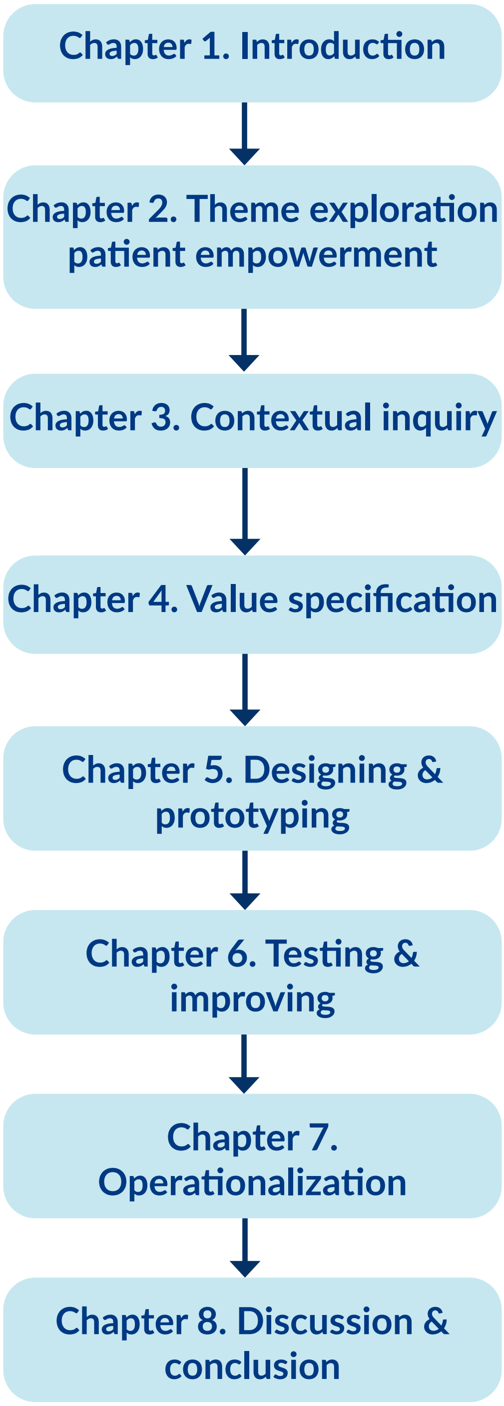


Figure 1. Thesis structure

1.2 Background

1.1.1 Head and neck cancer

Head and neck cancer (HNC) is a type of cancer that starts in the head and neck area. It includes different cancer diagnosis that can be seen in figure 2. In total around 3000 people are yearly diagnosed with head and neck cancer in the Netherlands and around 950 people die annually as a consequence of this disease (NKR Cijfers, n.d.). Around 2/3 of people diagnosed with head and neck cancer is male of which half is between the age of 60-74 (see figure 1).

The most common causes of this type of cancer are tobacco use, alcohol use and the Human Papilloma Virus (HPV) (Incidentie Hoofd-Halskanker, n.d.). The 5 year survival rate differs per cancer type, but overall it has been increasing over the years. This means that more people need to find a way to live with the consequences of this disease and its treatment.

HNC patients often need to deal with a lot of different physical and mental side effects in the years following treatment (Aguilar et al., 2017). Think of functional limitations that limit the quality of life such as speech issues and eating difficulties (Karnell et al., 2000). But also the psychosocial impact of life after cancer treatment such as fear of cancer recurrence, depression (Howren et al., 2013), goal disruption (Offerman et al., 2010) and change in spousal relationship (Offerman et al., 2015). Howren et.al. (2013) therefore advocate for more attention to long-term HNC survivorship and its effect on patient functioning.

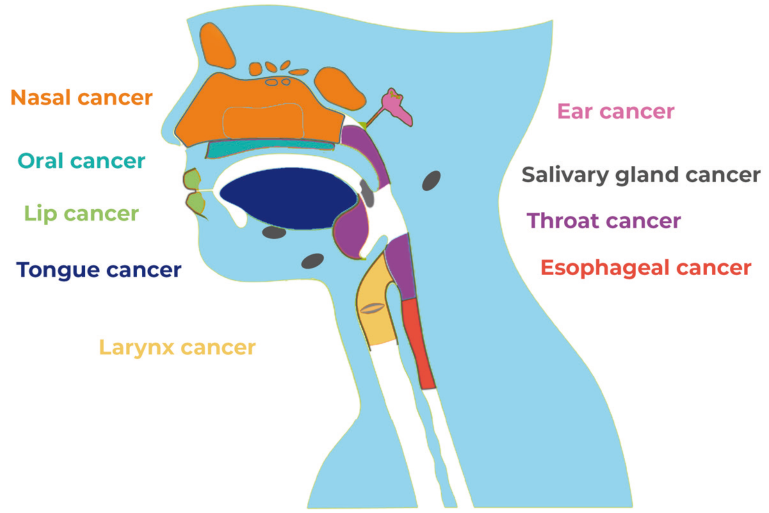


Figure 2. Head and neck cancer types

Figure 3. Average persona of target group based on NKR cijfers and personal communication with ENT doctors.

1.1.2 The Health Care Monitor

The physical and psychosocial side effects experienced by Erasmus MC HNC patients in their follow-up phase and their experienced quality of life, is currently measured using the Healthcare Monitor (HM). This is a structure of electronic patient-reported outcome measures (ePROs) that uses questionnaires filled in by patients before every outpatient clinic visit (Dronkers et al., 2020). Most patients do this at home two weeks before a consult. A few patients with less digital skills fill in the questionnaires right before their consult using an iPad provided by the hospital accompanied by a volunteer.

The treating physician looks at the results of the ePROs before a patient consultation to prepare the conversation.

Figure 4 shows an overview of the current follow-up process. It shows the 3 previously described steps of the patient filling in the questionnaires at home, the treating physician looking at the results in their dashboard and using them during the consult conversation. At the bottom of this visual you can also see a visual representation of the frequency with which the patient data is collected over the follow-up years. As you can see the frequency decreases over time.

The HM creates value in different ways. The values that are increased by this system according to NFU-Consortium Kwaliteit van Zorg (2020) are;
1. Increased quality care,
2. Strengthening the position of the patient
3. Future proof care

The position of the patient is currently strengthened by providing a better opportunity for patients to prepare their follow-up consultations. They think about their health and questions they have for the doctor in advance.

However, in a collaborative design research project of the Cardiolab TU Delft and the HNC department of the Erasmus MC, it was found that still, there is a need for more patient empowerment in the follow-up phase. How this was found and how this let to this graduation project will be explained in section 1.1.4. But first I want to address the concept of Value-Based Healthcare briefly since we worked together with the Value-Based Healthcare (VBHC) team of the Erasmus MC.

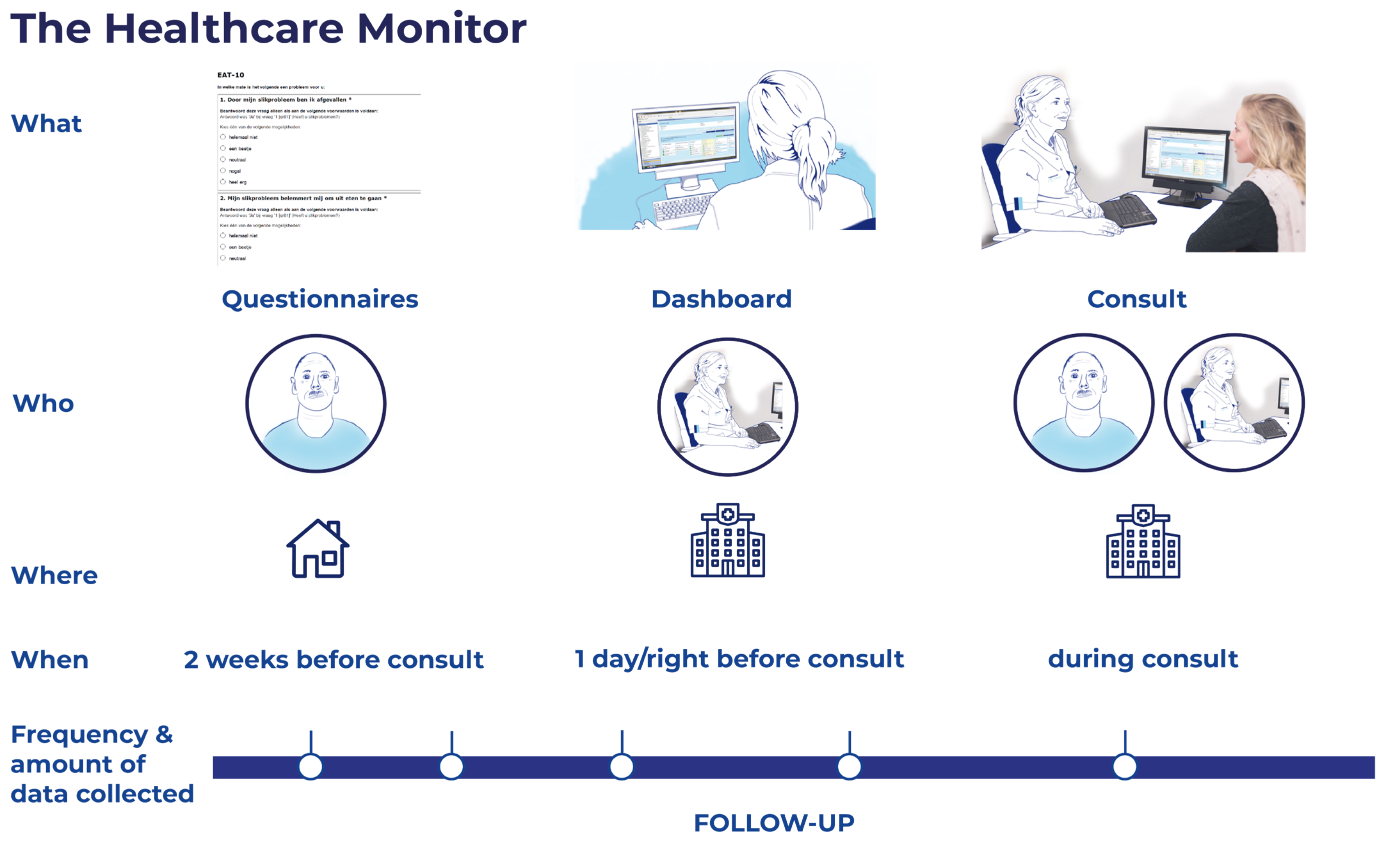


Figure 4. Current follow-up process using the HM

1.1.3 Value-Based Healthcare

Value-Based Healthcare (VBHC) can be interpreted in various ways. Some people refer to it as being cost-effective. However, the more appropriate use is referring to it as a way of working, where you include the values of different stakeholders. Lewanczuk et al., (2020) say that it includes dimensions of quality, the Quadruple Aim and feasibility.

The Quadruple Aim that they mention is a model for improving care (Feeley, 2017) that includes:

- Patient experience
- Care team wellbeing
- Reducing cost
- Clinical outcome

These 4 aims show very well that VBHC is about creating value in different ways.

According to Lewis (2019), VBHC can play an important role in meeting the evolving needs of our population. He says that VBHC is about doing the right thing at the right time. Supporting decision with data that comes from patient feedback.

We can thus see that involving the patient is important in VBHC and that the HM is a good example of VBHC. This was also confirmed when we talked to members of the VBHC in the research project.

1.1.4 Collaborative research project

Before this graduation project I have done a design research project with the HNC department of the Erasmus MC. In this research project we researched opportunities for improving the Healthcare Monitor. We did so by answering the 4 research question shown in figure 5.

RQ1: What is the **current use** of the Healthcare Monitor and what are **wishes for the future** from the VBHC team perspective?

RQ2: What are the **values** the Healthcare Monitor creates?

RQ3: How do **patients & family members posting on online communities** experience their cancer journey and what are their **main concerns**?

RQ4: What are the major **overlapping opportunities** when comparing the patient and family members experience of online cancer communities with the goals of the VBHC team?

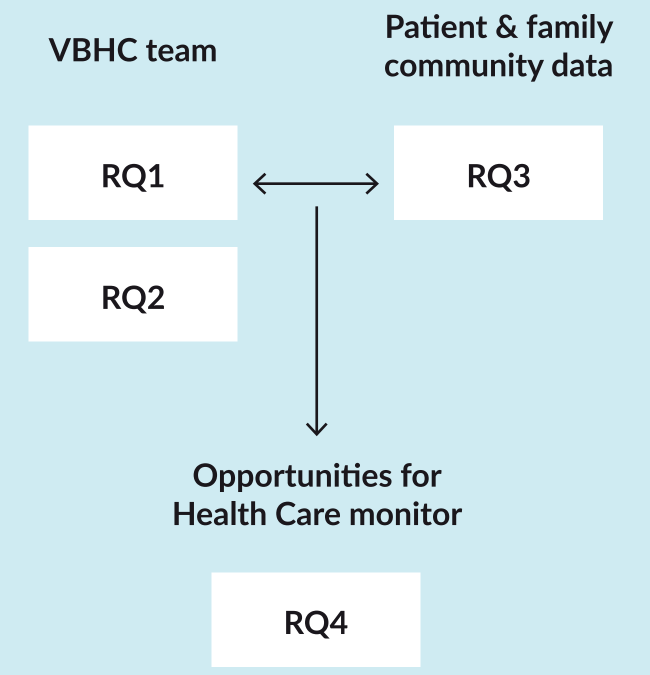


Figure 5. Research questions and approach for the research project done in advance of this graduation thesis.

These questions were answered through interviews with members of the VBHC team of the Erasmus MC, observations at consults and creating a patient concern journey from data gathered through online community platforms of cancer patients. In chapter 3.2 I explain the research of the online community data in more detail. For now, it is only necessary to know that we found 3 opportunities to improve the Healthcare Monitor. These 3 opportunities and how we found them is further explained in Appendix B.

Together with the members of the VBHC team of the Erasmus MC we chose to further investigate one of these 3 opportunities in this design graduation project. The opportunity chosen was the patient-driven opportunity that aims to increase the value patient empowerment. Figure 6 shows how this opportunity was found by comparing how the current dashboard creates this value and what members of the VBHC team wish for this value.

The opportunity is to create more insight and access for patients to track and view their data. Patients currently do not have insight into the results of the HM, other than what is shown during the consultation. Furthermore patients only track how they are doing every 2 weeks before they go to a consultation. These consultations become less frequent in the years after treatment, as was shown in figure 4 on the previous page. Therefore, it can take several months or at some point even half a year before patients can express how they are doing. We found that patients want more support and control in the follow-up phase. This was expressed both by clinicians (R. Baatenburg, personal communication, October 1, 2020) and patients posting on online forums (Kanker.nl, Canadian Cancer Society & Cancer Council).

Furthermore, other studies (Howren et al., 2013; Kondylakis et al., 2020) also report the need for psychosocial interventions and effective support of continuous and integrated care for (head and neck) cancer patients in the recovery phase. Therefore we decided to focus on the patient in this graduation project. This will further be explained in the next section which discusses the aim of this project.

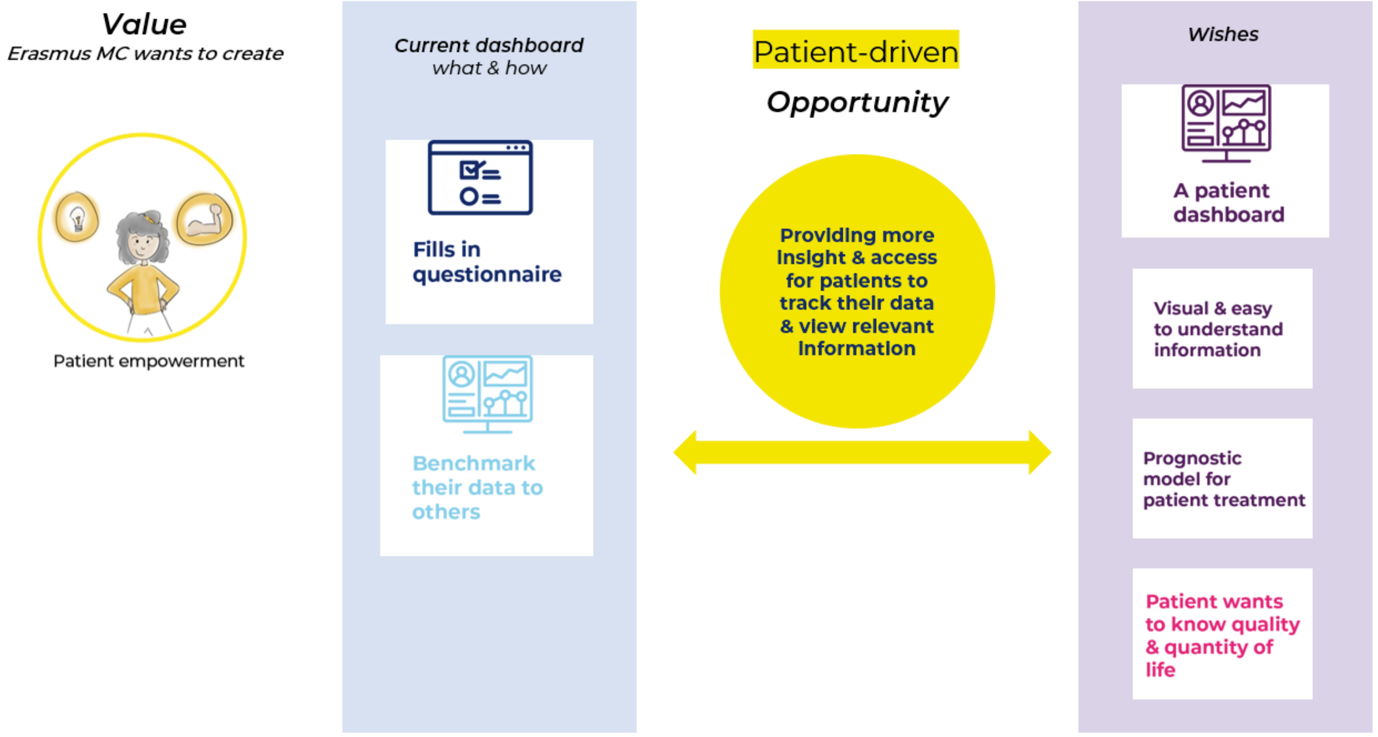


Figure 6. The patient-driven opportunity found in the preceding design research project: Patient empowerment

1.1.5 Project aim and scope

Based on the opportunity previously described, this project was set up as an extension to the interdisciplinary research collaboration between the TU Delft and Erasmus MC.

The aim of this project is to **design a digital service linked to the Healthcare Monitor that increases patient empowerment for head and neck cancer patients in their follow-up phase**.

The vision of this project is that an additional service to the HM, that addresses the continuous concerns of patients at home, will empower patients and lead to better quality care in the follow-up phase. Figure 8 shows this vision in a visual way. It shows how the added digital service is different in the what, who, where, when and the frequency of tracking.

The main differences between the current and envisioned scenario are that patients track their health more frequently through a smaller amount of questions asked per session. Furthermore they get insight into the results themselves and can decide with whom they want to share these results.

We start this project with this vision as a hypothesis. The hypothesis is; **a digital service for patients at home where they can track and view their health continuously will help to increase patient empowerment.**

The last step of the vision shows that the collected data can also be shared with the treating physician and perhaps even family members. This is added, since we found in the research project that the treating physicians want a more realistic insight into how the patient is doing and the family perspective is also important to incorporate. In the research project we concluded that the quadruple aim, as described in chapter 1.1.3, should be changed into a quintuple aim so that it also includes the family experience. Figure 7 shows this new model.

Due to the limited time of this project, I focus on the patient perspective in this thesis and give recommendations for including the family and doctor perspective in the final chapters. In the discussion I address how this project can create value for the 5 different aims of the quintuple aim.

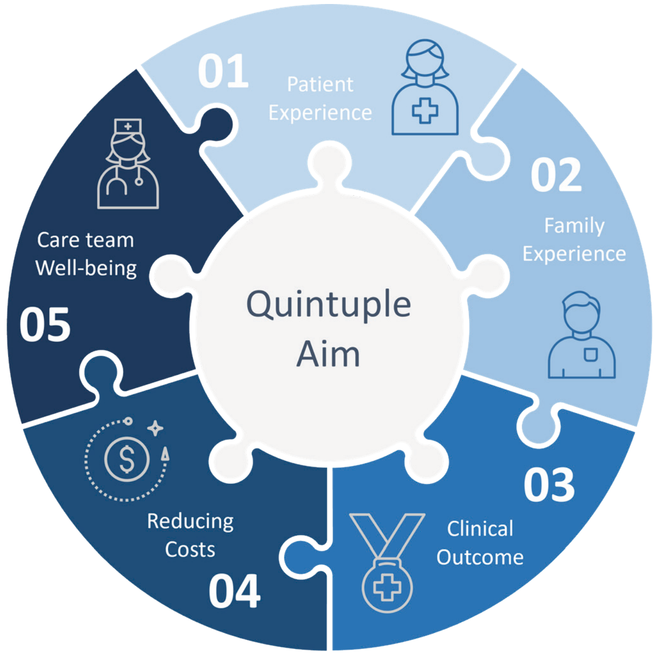


Figure 7. The quintuple aim which is based on the quadrupple aim but also includes the family experience

The main research question of this project following the aim, hypothesis and focus on the patient perspective is:
How should a digital service system be designed to empower head & neck cancer patients in their follow-up phase of their treatment?

This question is divided into the following sub-questions:

1. What is **patient empowerment**, why do we want it and how can it be created?

2. What are the **concerns** of head and neck cancer patients in the follow-up phase?

3. What should the design **offer** in order to address the concerns of head and neck cancer patients and increase patient empowerment?

4. How should the service system be **designed** in order to deliver the design promise?

5. What should be done to make this service system **operational** in the future?

6. What are the **key learnings** of this project for designing for patient empowerment and Value-Based Healthcare in general?

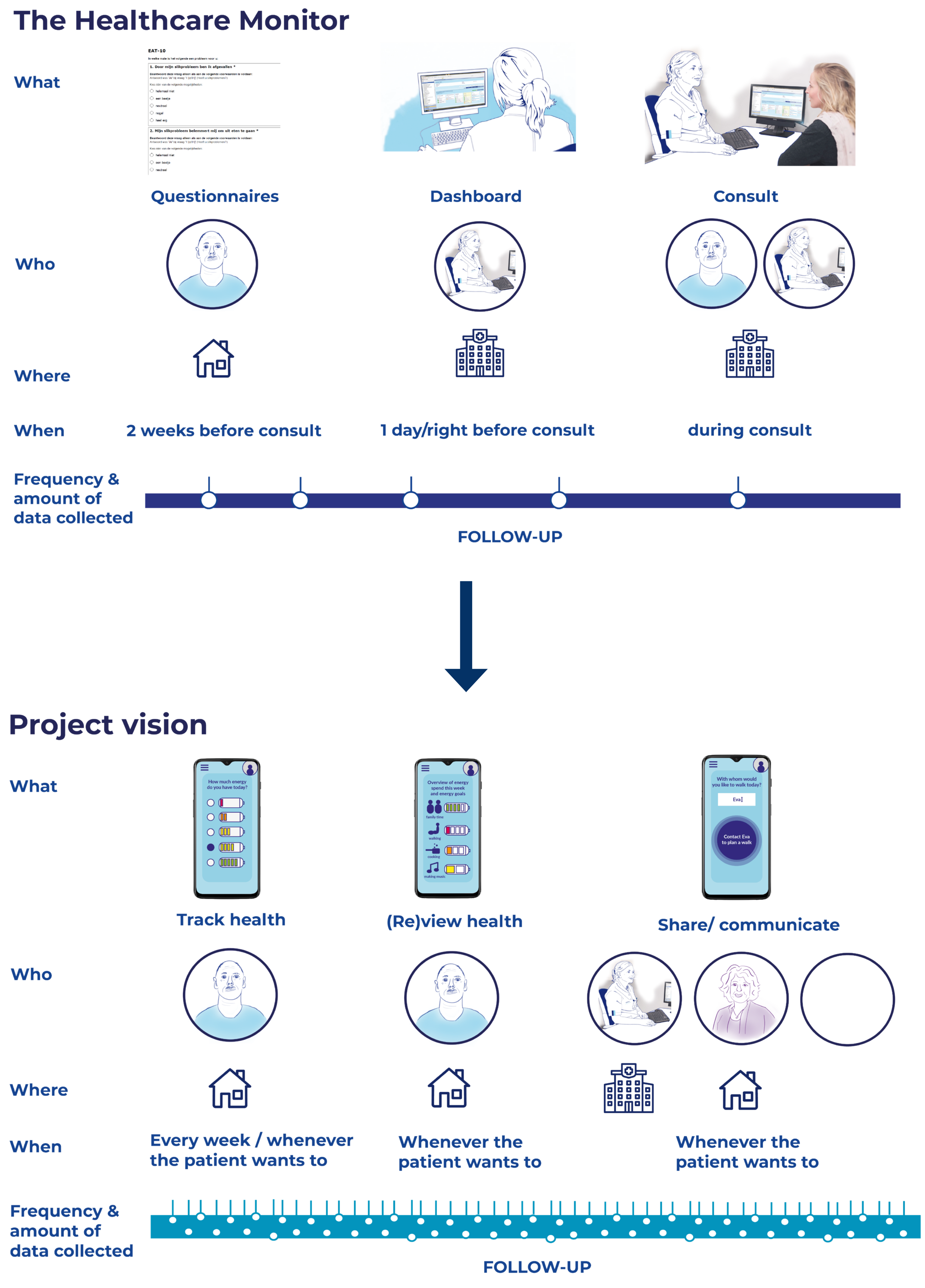


Figure 8. Project vision for an additional patient empowering service to the HM in the follow-up

1.2 Project approach

In order to answer the previously stated research questions and reach the aim of this project, a design approach was set up. The main approach of this project is doing Design Research that is informed by data (van Kollenburg & Bogers, 2019). This will be done using the double loop method of Jiwon Jung (2021) as can be seen in figure 9. This method incorporates both the user as well as the community context. It is an iterative design approach where data is used to inform and evaluate design decisions.

Following the recommended CeHRes roadmap for eHealth Research Innovations (van Gemert-Pijnen et al., 2011), this project will involve the different stakeholders in different phases of the design process. Figure 10 shows the CeHRes roadmap and how the chapters of this report link to it. This approach is adapted to fit this project.

An overview of this adapted approach for this project can be seen on the next pages in figure 11. Throughout these different steps the double loop will be used to iteratively inform and evaluate the outcomes. The steps illustrated in figure 11 on the next pages are an elaboration of the report structure presented in chapter 1.1. The overview shows how the different steps in the approach relate to each other and which research questions they aim to answer. I explain the steps of this approach in more detail below.

1.2.1 Theme exploration patient empowerment

In chapter 2 I explore the theme patient empowerment. Why do we want to create it? What is it? And how can we design for it? Since increasing the value patient empowerment is the starting point of this project, it should be clear what definition of patient empowerment we work with in this project. Therefore, a new comprehensive model for patient empowerment is created to provide inspiration for the design and a common understanding of the theme of patient empowerment. This model can be used by other designers who aim to design for patient empowerment

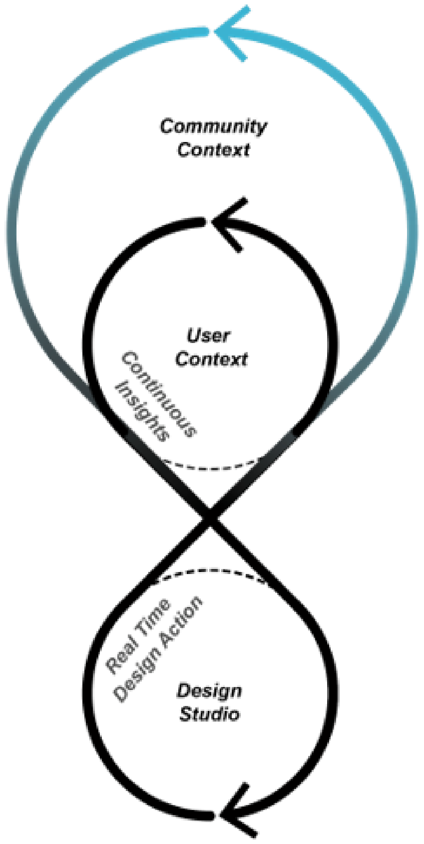


Figure 9. Double loop method using community context as well as user context for a continuous itterative design loop (Jung, 2021)

1.2.2 Contextual inquiry

Next to understanding the theme patient empowerment, I also need to have an understanding of the target group we are designing for; HNC patients in their follow-up phase. Therefore, in chapter 3 I research the concerns of HNC patients through different methods. These methods include an inquiry of the community data through analysis of blogs and forum posts on online platforms, a focus group with 6 care professionals and interviews with 9 ex-HNC-patients.

1.2.3 Value specification

The outcome of the theme exploration and contextual inquiry are linked to see overlapping opportunities to create value in chapter 4.1. These insights are then translated into a design vision and conditions in chapter 4.2.

1.2.4 Designing & prototyping

In chapter 5 the insights and design vision come together in an ideation for a new service system for HNC patients in the follow-up phase. A concept for an application is created and also prototyped in order to discuss it with the target group. By making the design tangible through prototyping it can start the discussion on how an application could create value. It can help patients to express what they like about the application and what they might miss or want to improve. In this way we involve the users again like stated in the double loop and CeHRes roadmap.

Through testing the prototype we gain insight into the thoughts of ex-patients with regards to the designed applications value. Chapter 6 includes the test set-up, outcomes and recommendations for improving the design.

1.2.5 Operationalization

In chapter 7 I provide recommendations for the operationalization of the design. What steps are needed in the future and what could be done to scale the design later on? This is done by doing a focus group session with ICT experts of the Erasmus MC in order to get insight into the technical possibility to incorporate this system in the Erasmus MC. Furthermore, I briefly elaborate on the needs of the other stakeholders as discussed in the quintuple aim; the care professionals and the family members.

On the next pages you find the overview of the approach used in this report. It shows how the different chapters link to one another and what research questions I try to answer in each chapter.

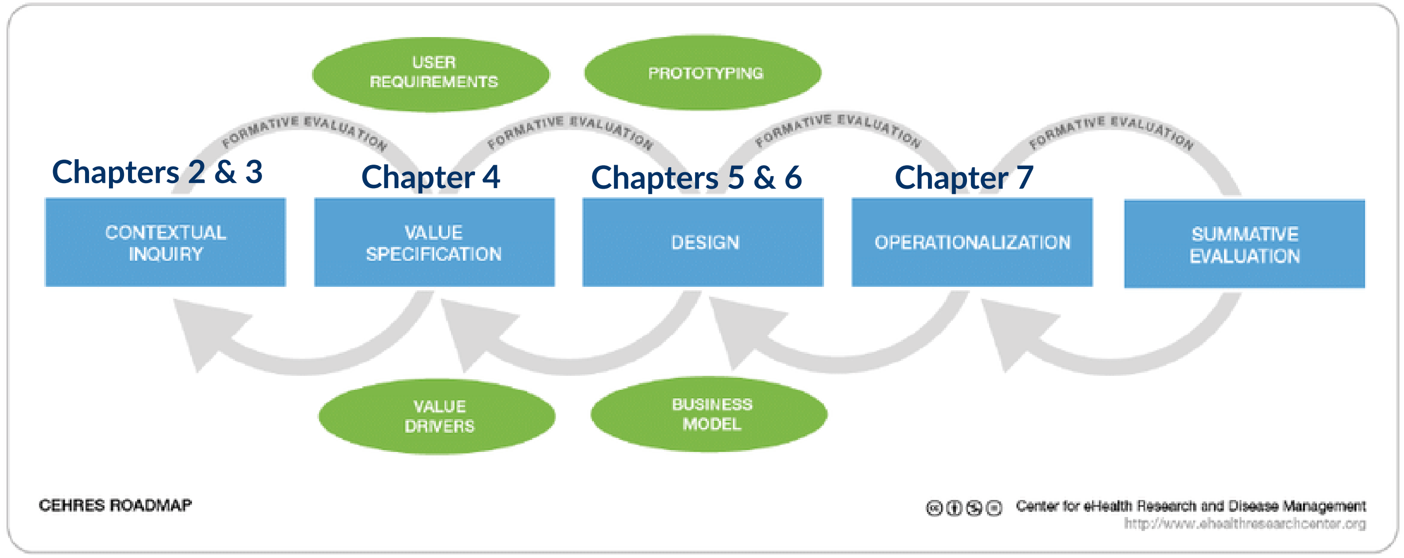
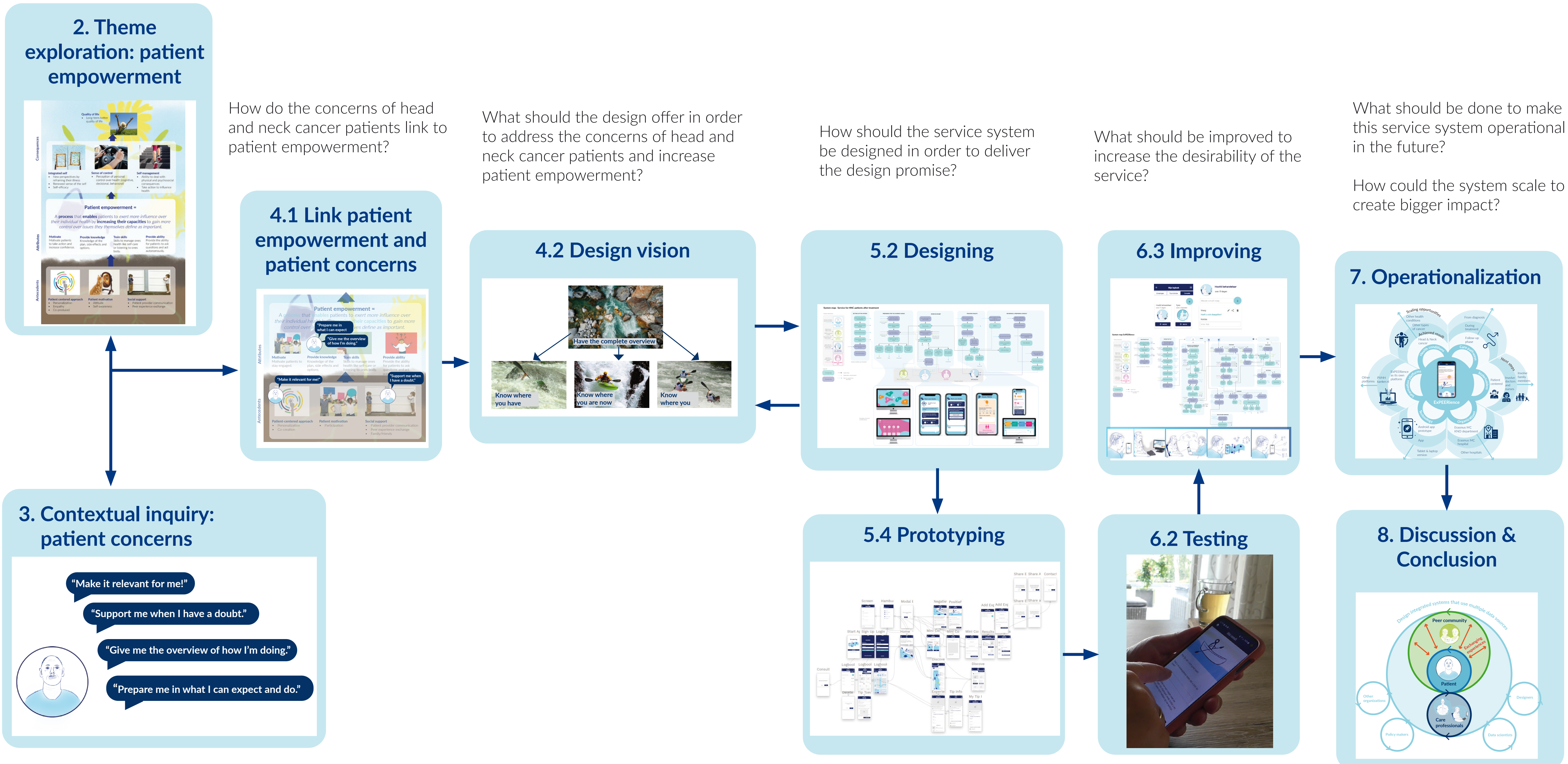


Figure 10. CeHRes Roadmap for eHealth Research

How can we design for patient empowerment?

What is patient empowerment, how can it be created and what are its consequences?



How do the concerns of head and neck cancer patients link to patient empowerment?

What should the design offer in order to address the concerns of head and neck cancer patients and increase patient empowerment?

How should the service system be designed in order to deliver the design promise?

What should be improved to increase the desirability of the service?

What should be done to make this service system operational in the future?

How could the system scale to create bigger impact?

What are the concerns of head and neck cancer patients in the follow-up phase?

How should the service system be prototyped in order to test its desirability?

What do ex-patients think of the desirability of the proposed concept for HNC patients in the follow-up phase?

What key learnings should the Erasmus MC take with them when developing an application for empowering cancer patients?

What is the value created by ExPEERience for the other stakeholders involved? How can it achieve the quintuple aim?

What can be concluded from the insights gathered in this project for designing for value based healthcare?

Figure 11. Project approach showing the different chapters, how they relate to each other and their research questions

Sub-question 1: What is **patient empowerment**, why do we want it and how can it be created?

2. THEME EXPLORATION: PATIENT EMPOWERMENT

This chapter aims to explore the concept of patient empowerment. Why do we want it, what is it and how can it be created?
An inspirational model that designers can use when they want to design for patient empowerment is presented.

2.1 Chapter introduction

The main aim of this project is to design for patient empowerment (PE) of head and neck cancer patients in their follow-up phase. In order to do so, this chapter will look at the first sub question as stated in chapter 1.1.5:

1. What is **patient empowerment**, why do we want it and how can it be created?

This sub-question is split up into the following 3 smaller research questions:

- Why do we want patient empowerment?
- What is patient empowerment?
- What is needed to create it?

These questions are answered one by one in the next sections of this chapter.

The theme of patient empowerment is explored in the scope of this project. I propose a model that can be used by designers who want to design for patient empowerment. I use this model myself to create a design vision in chapter 4.

Patient empowerment is a complex concept and therefore different studies try to capture this complexity in models. 4 of these models are compared to create an inspirational model for patient empowerment that can be used to design for. With this model I aim to provide the readers of this report with an understanding of how I use the concept of patient empowerment in this design project. The model addresses the 3 posed research questions.

The models for patient empowerment that I look at are from Fumagalli et al. (2015), Zimmerman (1995), Bravo et al. (2015) and Castro et al. (2016). These 4 models were chosen based on their validity and differentiating views. The models of Fumagalli et al. and Castro et al. incorporate meta-analyses of a large amount of scientific articles. They combine the definitions of all these articles into comprehensive models. Their models are thus created from a theoretical perspective. Bravo et al. combine a theoretical approach with qualitative research. They go through multiple iterative cycles for designing their model. They provide a more patient-centered approach. Therefore their model is interesting from a more practical perspective. Last but not least the model of Zimmerman is looked at, since it is used very often in scientific articles as 'the' model for patient empowerment. His psychologist perspective is interesting to incorporate.

I combine these models looking at how they answer the 3 research questions I pose and looking at where they overlap and differ. Furthermore I combine them by looking at the elements that I deem relevant in the scope of this design project. Since I want to use the model as an inspiration for my design process it should include elements that I can design for. Therefore I decide not to include certain elements such as personal characteristics (an example from the model of Bravo et al.). I thus formulate my model in a way that can lead to inspiration for designers and answers the 3 research questions.

I include the elements of a patient-centered approach, social support, motivation, knowledge & skills and providing the ability to ask questions and act autonomously as the elements that we can design for. Its consequences are an integrated self, a sense of control and more self-management, ultimately leading to a better quality of life. How I got to these elements is presented in the next chapters.

Figure 12 shows an overview of how this chapter is arranged in line with the research questions. In chapter 2.2 I look at why we want to create patient empowerment (its consequences). In chapter 2.3 I look at what patient empowerment is (its definition & attributes). Chapter 2.4 explores what is needed in order to create patient empowerment (its antecedents). Finally chapter 2.5 summarizes these insights into the proposed model of patient empowerment that can be used as inspiration to design for.

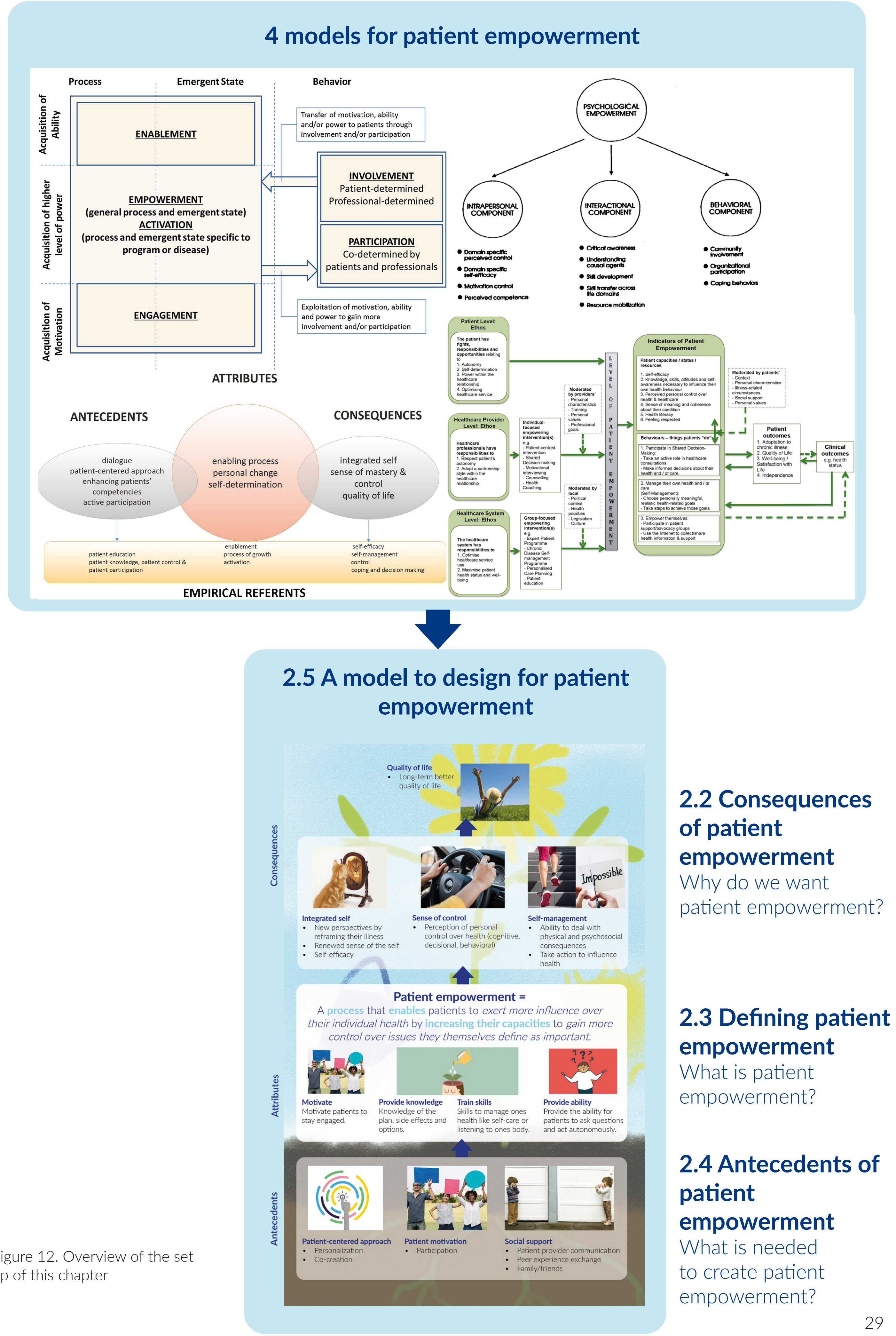


Figure 12. Overview of the set up of this chapter

2.2 Consequences of PE

2.2.1 Introduction

This chapter aims to answer the sub-sub-question: why do we want patient empowerment? With the aim to further explain the positive consequences of patient empowerment that make it desirable to increase it.

Figure 13 shows how the consequences of patient empowerment are structured and defined in the proposed model to design for patient empowerment. 3 consequences are defined that all lead to one bigger long-term consequence, namely increased quality of life. The 4 consequences are:

- Integrated self
- Sense of control
- Self-management behaviour
- Better quality of life

This chapter further elaborates on these 4 consequences to address why patient empowerment is desirable.

2.2.2 Consequences

Integrated self

Castro et al. (2016) define one of the consequences of patient empowerment as an integrated self. This means that patients reframe their illness and have a new perspective on themselves and/or their illness. Zimmerman (1995) describes this as the intrapersonal component, which refers to how people think about themselves, including their self-efficacy. Bravo et al. (2015) and Castro et al. (2016) both include self-efficacy as a consequence of patient empowerment. Self-efficacy means the perception of one's own ability to reach a goal. If a patient has more self-efficacy he or she has more confidence in their abilities to reach their goals and deal with changes. An integrated self means that patients start to think differently about themselves and their capabilities. They can get a more positive self-image.

Sense of control

Another consequence defined by Castro et al. is the sense of control that patients experience when they are empowered. This is on the cognitive, decisional and behavioral level. A patients perception of control is also discussed by Zimmerman (1995) and Bravo et al. (2015). Bravo et al. discuss the perceived personal control over health and healthcare as a consequence. Patients thus have the feeling that they are more in control of their life and health when they are empowered.

Self-management behaviour

Self-management is explained by Castro et al. as the ability to deal with physical and psychosocial consequences and lifestyle changes that are created by a chronic illness. This links to Zimmerman's behavioural component which includes taking action to influence ones health. A consequence is thus that patients are taking more action to manage and influence their health. This consequence is also described by Bravo et al. as the actual things patients do. Their examples link to self-management, participating in shared decision making and seeking support. A consequence of patient empowerment is thus that patients start to take action to deal with the consequences of their illness.

Better quality of life

A long-term envisioned consequences described by Castro et al. is the increased quality of life of patients. This can be seen as a combination of the previously described consequences. Booger et al. (2011) investigated the predictive role of empowerment in the quality of life of breast cancer patients. They found that more empowerment can significantly predict better quality of life. Bravo et al. also show that quality of life is a patient outcome that links to the indicators of patient empowerment. This further suggests that the 3 consequences described previously ultimately can lead to the outcome of better quality of life for patients.

Figure 13. The positive consequences of patient empowerment (Booger et al., 2011; Bravo et al., 2015; Castro et al., 2016; Zimmerman, 1995)

2.2.3 Conclusion

When looking at these positive consequences that patient empowerment can bring it becomes clear why we would want to design for patient empowerment. Patient empowerment can bring back a sense of confidence and control for head and neck cancer patients that need to deal with all the physical and psychosocial consequences in the follow-up phase. As described in the background chapter, HNC patients have to deal with a lot of side effects that influence their quality of life. If they can find a better way to deal with these side effects and take action to influence their health, their quality of life could ultimately increase creating patients that are more satisfied with their life.

Key chapter insights

- Patient empowerment can lead to the positive consequences of an integrated self, sense of control, self-management and eventually a better quality of life for patients.

2.3 Defining PE

2.3.1 Introduction

This chapter aims to answer the sub-sub-question: what is patient empowerment? As described in the introduction this chapter aims to provide a definition of patient empowerment for this design project. It also aims to provide an overview of the attributes of patient empowerment; what elements does it consist of that we can design for?

Chronic diseases, like cancer, and their burden on the health care system are increasing (World Health Organization, 2012b). This has led to a switch in our approach to healthcare, looking more at the role of patients in their health care process. Therefore in 2012 the first European Conference on Patient Empowerment was held (World Health Organization, 2012a). Since this conference the attention for this topic has increased.

This switch and an increasing interest in the topic patient empowerment has caused for an explosion of terms like empowerment, engagement, enablement, participation, involvement and activation (Fumagalli et al., 2015). There are so many different overlapping meanings in this field that people interpret the word patient empowerment differently when heard. Therefore I propose one definition that can be inspirational to designers.

2.3.2 PE as a process

Fumagalli et al. (2015) explore the definitions of patient empowerment that are used in literature in a meta-analysis of 286 scientific articles. They found that patient empowerment is used broadly and people refer to it as being a process, state or behavior.

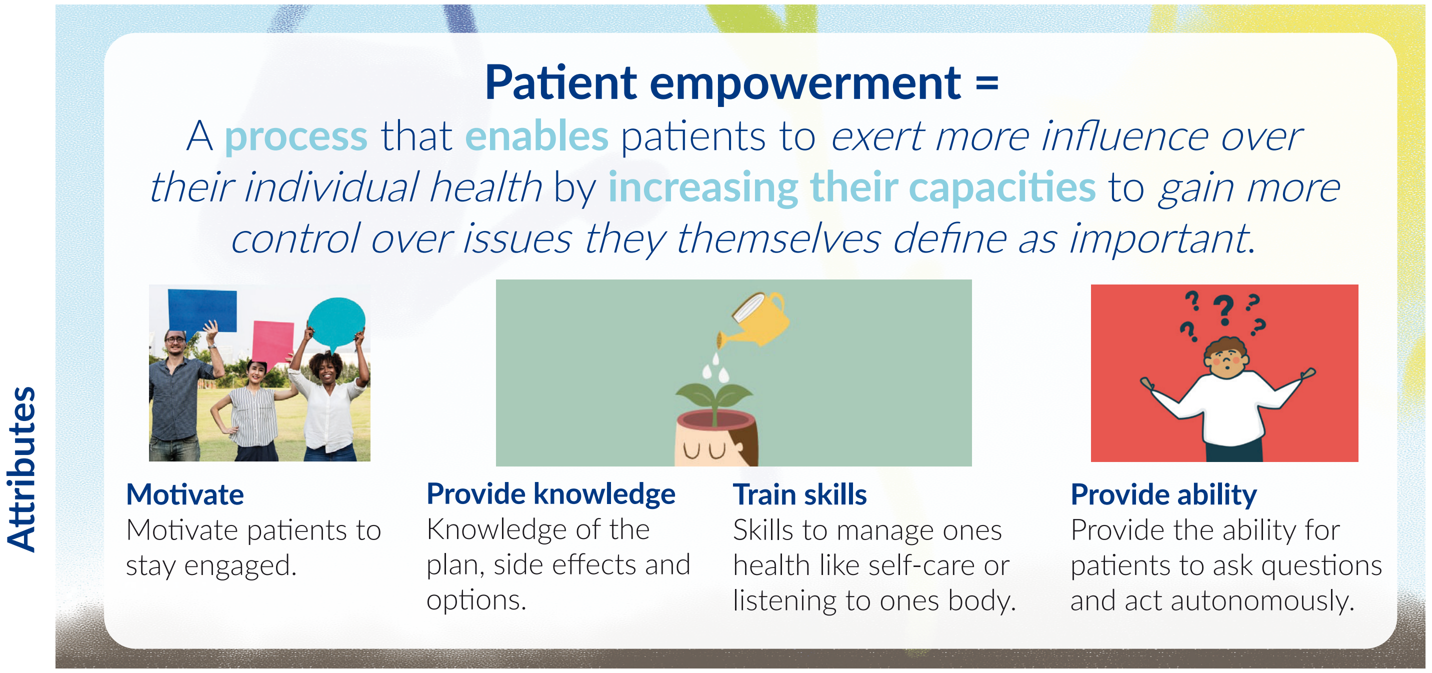
In this design project I define patient empowerment as a process. A state says something about an individual's ability and motivation. A behavior says something about the actions of an individual. However in order to achieve a state and trigger actions, certain activities and inputs need to be provided over time (Fumagalli et al., 2015). In other words, a process is needed. And this process is something that can be designed. An individual's state or behavior cannot be designed, but it can be influenced by a designed intervention that provides the patient with the right activities and inputs at the right time. Bravo et al. (2015) also use empowering interventions in their conceptual model of patient empowerment as a means to influence the empowered state and behaviors of patients.

Castro et al. (2016) propose a comprehensive definition of patient empowerment as a process based on an analysis they performed on 20 definitions used in different scientific papers, see figure 14. This definition of patient empowerment is the one used in this project. This definition is chosen because it looks at patient empowerment as a process and it is based on a thorough analysis of definitions.

In the definition we find the words 'enabling' and 'increasing their capacities'. These concepts are quite similar, especially when looking at the definition of enabling by Fumagalli et al. (2015) who define enabling as the acquisition of ability: "providing appropriate knowledge, skill and abilities to understand their condition and make decisions; and developing appropriate contexts that allow patients to learn such knowledge, skill and abilities." This leads to the different attributes that patient empowerment consists of when defined as a process that enables patients to exert more influence over their individual health. These attributes are discussed in the next section.

2.3.3 Attributes

Next to a definition of patient empowerment for this project it should also be clear what attributes patient empowerment consists of to have a more concrete understanding of how one might design for this process. As previously seen in the definition, patient empowerment is about increasing patient capacities. Looking at the different models and other literature, 4 important attributes to increase patient capacities are discovered. Figure 14 shows these capacities. I further elaborate on these attributes in this section.



Patient empowerment =

A **process** that **enables** patients to *exert more influence over their individual health* by **increasing their capacities** to *gain more control over issues they themselves define as important.*

Motivate
Motivate patients to stay engaged.

Provide knowledge
Knowledge of the plan, side effects and options.

Train skills
Skills to manage ones health like self-care or listening to ones body.

Provide ability
Provide the ability for patients to ask questions and act autonomously.

Figure 14. The definition and attributes of patient empowerment (Bravo et al., 2015; Castro et al., 2016; Fumagalli et al., 2015; Johnsen et al., 2017; Zimmerman, 1995)

Motivate

According to Zimmerman (1995) an important element of patient empowerment is the intrapersonal component. This refers to how people think about themselves. Some of the concepts this component includes are perceived control, self-efficacy and motivation. Fumagalli et al. discuss motivation as a combination of attitude and self-awareness. Motivation can be seen both as an antecedent needed for patient empowerment, as well as a component that needs to be created in the process. Patients need to be 'willing' to improve their life as Fumagalli et al. describe it, however attitudes and self-awareness do not emerge spontaneously but from processes where these attitudes are provided and evaluated. Engagement can be used as an acquisition of motivation. Patient empowerment depends on health interventions that stimulate this engagement in the healthcare system. So in order to increase patient capacities, their motivation to stay engaged should also be something that is stimulated.

As designers we can design systems that keep patients engaged and motivated to keep working on improving their life.

Provide knowledge

Knowledge is seen as an important component by Zimmerman, Fumagalli et al., Bravo et al. and Johnsen et al. (2017). Zimmerman describes knowledge and skills to be part of the interactional component. This refers to the understanding people have of their situation and options. Johnsen et al. investigated patient empowerment in cancer follow-up by interviewing 16 patients about these concepts. They state that: "Knowledge was mentioned repeatedly by the patients as being necessary to achieve control". Patients referred to knowledge as knowing about one's care plan and what to expect with regards to the side effects. However they also highlighted that not all patients are keen to know everything and the extent to which patients want to know about things differs per person.

As designers we can design systems to provide the right knowledge at the right time.

Train skills
In order to use this knowledge effectively patients also need relevant skills to manage their health. Again skills can be found in the different models of Zimmerman, Fumagalli et al. and Bravo et al. The patients interviewed by Johnsen et al. talked about the importance of having skills for self-care and listening to one's body. According to Zimmerman the skills of decision making, problem solving and leadership are needed for patient empowerment. Some patients already naturally have certain skills whereas others lack certain key skills to become empowered. It can be interesting to check this with a patient in order to understand their situation and needs better when it comes to acquiring skills for patient empowerment.

As designers we can design systems that recognize what necessary skills a patient misses and help in training these skills.

Provide ability
Next to the willingness, patients also need the ability to improve their life. For a certain part this ability is created by a combination of knowledge and skills (Fumagalli et al., 2015). However another component is needed to provide ability. Johnsen et al. (2017) found that it is about being able to make the health care system address one's concerns and being able to monitor one's care. Patients talk about the importance of influencing the timing of information, level of self-care and the possibility to ask questions. Therefore ability is also something that can be provided by the way the health care system interacts with its patients. It should provide patients with the ability to ask questions and act autonomously.

Designers can help to create systems that provide this ability to the patient.

2.3.4 Conclusion

In this chapter I explained which definition I will use as a designer to design for patient empowerment. In this project patient empowerment is seen as a process that we as designers can influence by providing the right attributes, in the right amount, at the right time. The attributes that patient empowerment consists of are motivation, knowledge, skills and the ability to ask questions and act autonomously. The process of patient empowerment itself is defined as:

> A **process** that **enables** patients to *exert more influence over their individual health* by **increasing their capacities** to *gain more control over issues they themselves define as important.*

Designers can design for this process and help to increase the capacities of patients through design.

Key chapter insights

- Patient empowerment is seen in this project as a process that we can design for.
- During the process of patient empowerment motivation, knowledge, skills and the possibility to ask questions and act autonomously should be provided at the right time in the right amount.

2.4 Antecedents for PE

2.4.1 Introduction

This chapter aims to answer the sub-sub-question: what is needed to create patient empowerment? Castro et al. (2016) describe several antecedents that are needed to create patient empowerment. The other reviewed models also address some aspects are prerequisites in order to create patient empowerment.

Figure 15 shows how 3 antecedents of patient empowerment are structured and defined in the proposed model to design for patient empowerment. The 3 antecedents are:
- Patient-centered approach
- Patient motivation
- Social support

This chapter further elaborates on these 3 antecedents to address what is needed to start the process of patient empowerment.

2.4.2 Antecedents

Patient-centered approach

Castro et al. describe a patient-centered approach as an antecedent for patient empowerment. This means that it is prerequisite for the empowerment process. A patient-centered approach contains different elements.

First of all a patient-centered approach requires personalization. Kondylakis et al. (2020) created an intervention called iManageCancer that incorporated self-management tools on different levels such as psycho-emotional monitoring and serious games. One of their key learnings was that a 'one-size-fits-all' approach does not work for cancer. It needs to be customized to the individual needs of patients. Breeman et al. (2021) also discovered the need for personalization and describe it as a need for a 'one-stop-shop' where different tools are provided to different patients. If attuned to people's health needs and expectations such technological interventions can help to achieve the empowerment process (Graffigna et al., 2013).
Furthermore a patient-centered approach asks for co-creation with the patients themselves. Kees Ahaus, professor at the Erasmus university, stresses the importance of co-creation in a podcast of the online conference of Uitkomstgerichte Zorg (Ahaus, 2021). He expresses that the patient should be included in the Value-Based Healthcare team that creates new interventions for patients. Their expertise on experiencing the disease can help in improving care. "Experiencing a disease is different from knowing it." Lu et al. (2021) also stress the importance of collaborating with patients in order to develop cancer-specific apps. Therefore in order to create an intervention that aims to empower patients, patients themselves should be involved in the design process of creating such an intervention.

As designers we can develop personalized systems and incorporate patients in our design process, for example through co-creation sessions.

Patient motivation

As previously discussed in chapter 2.2.3, patient motivation can also be seen as an antecedent for patient empowerment. A patient needs to be willing to try out the process of empowerment. If a patient does not want to exert more influence over their individual health they will not be open to a process that tries to enable this. Castro et al. describe this motivation as patient participation. Patient empowerment is a personal process that can only be supported but inherently comes from the patients willingness to have more control. Fumagalli et al. also see patient involvement and/or participation as a way to transfer motivation to the process of empowerment. We can thus say that initial motivation of a patient to gain more capacities is needed in order to increase them.

As designers we can design different ways to promote systems that can increase patient empowerment.

Social support

Castro et al. a describe a dialogue between health care providers and patients to be an antecedent for patient empowerment. The support from care providers is an important requirement to be able to enable the process of patient empowerment. Studies of different eHealth applications also found that it is important to support the patient-provider communication. Lu et al. (2021) found a need to enhance patient-provider communication through integrated technological solutions. Fillion et al. (2009) found that patients felt more empowered in the presence of a professional navigator. Hochstenbach et al. (2017) discovered that nurses could fulfill this role as they are often the bridge between patients and care professionals. The social support from care professionals is thus important when designing for patient empowerment. However other forms of social support are important as well.

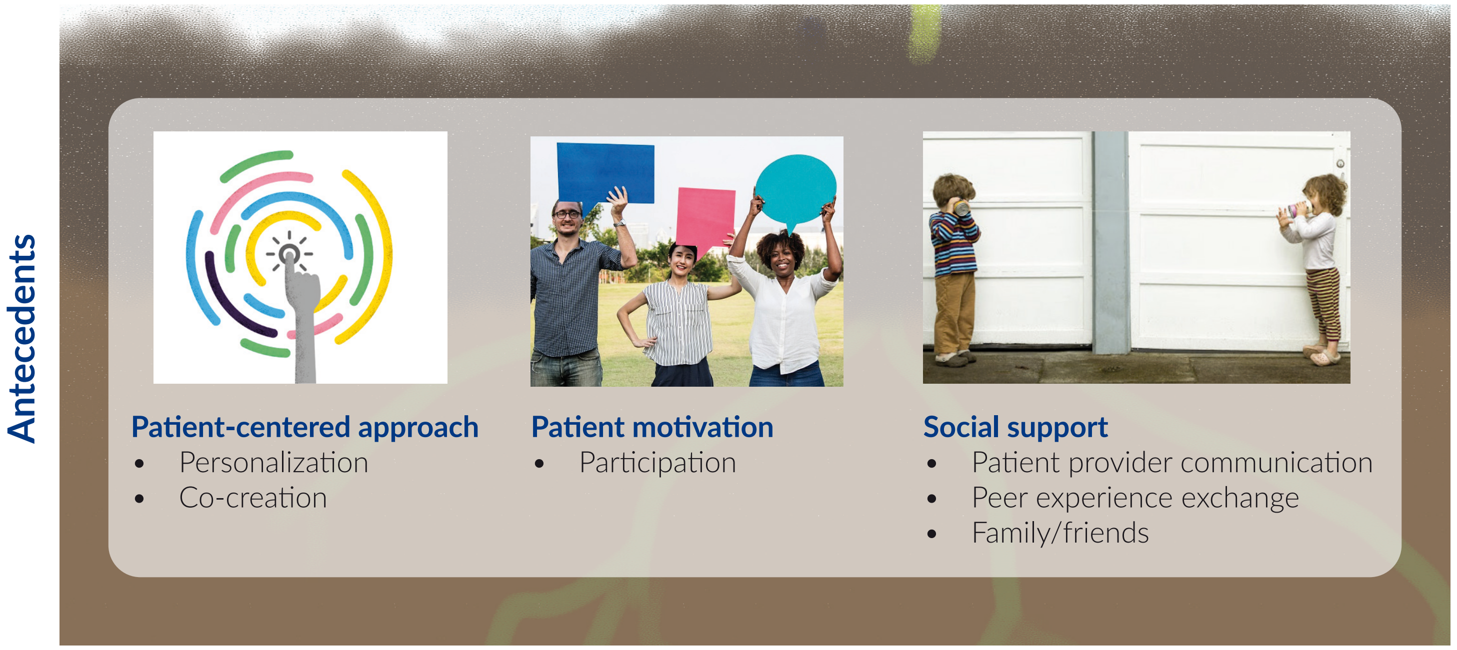


Figure 15. The antecedents for patient empowerment (Ahaus, 2021; Breeman et al., 2021; Castro et al., 2016; Fillion et al., 2009; Graffigna et al., 2013; Hochstenback et al., 2017; Kondylakis et al., 2020; Lu et al., 2021; Skribekk et al., 2018)

Another form of social support that is important for patients is peer support. Skirbekk et al. (2018) investigated what can be gained from peer support in cancer care. They found that it helps patients and their relatives with coping. This is done by providing hope and tips to deal with situations where otherwise stress would prevail. They have experienced something similar and can thus provide positive social comparison. It can thus be seen that peer support is an important requirement to create patient empowerment.

Social support from family and friends is also important, however I will not go into detail on this form of social support in this part of the project yet. The initial focus of this project is on the patient, however I see great potential and need to involve family members and possibly friends further on in this project. This will be discussed in the recommendations.

As designers we can design systems that provide this social support by developing ways for patients to interact with their care professionals and peers.

2.4.3 Conclusion

We have seen 3 important elements that are needed to start the patient empowerment process. These can be seen as requirements for the patient empowerment process and should therefore always be considered when designing interventions for patient empowerment. For patient empowerment a patient centered-approach is needed which means that the intervention should be personalized and co-created with patients. Furthermore a patient needs to be open to participate and be motivated to try out a new service. This can be achieved by designing the right way to promote the intervention. Finally social support is important to incorporate in designed interventions for patient empowerment. Especially patient-provider communication and peer-support should be encouraged through the design.

Key chapter insights

- In order to start the patient empowerment process a patient-centered approach, motivation and social support are needed.

2.5 Model for designing for PE

2.5.1 Introduction

This chapter proposes the complete model that can be used to design for patient empowerment. It is based on the content of the previous chapters that answered the first sub-question. It shows the answers to the 3 sub-sub-questions; why do we want patient empowerment (consequences), what is patient empowerment (definition and attributes) and what is needed to create it (antecedents). These were answered by comparing 4 models of patient empowerment presented in literature. The purpose of this model is to inspire designers who want to design for patient empowerment. Furthermore this model is used as the base for understanding patient empowerment in this design research project and provides evidence and inspiration when designing for patient empowerment.

2.4.2 PE as a process for personal growth

Figure 16 shows the combined model of patient empowerment including the previously discussed antecedents, attributes, definition and consequences. The combined model is represented as the process of growing a flower to make it understandable and inspirational for designers to use.

The right conditions
For growing a flower certain elements are necessary. One precondition is soil with the right nutrients. This soil with its nutrients can be seen as the antecedents that are needed for patient empowerment. In this case the nutrients needed are a patient-centered approach, patient motivation and social support as discussed in chapter 2.4. Without these conditions the seed will not hatch and the growing process will not start at all.

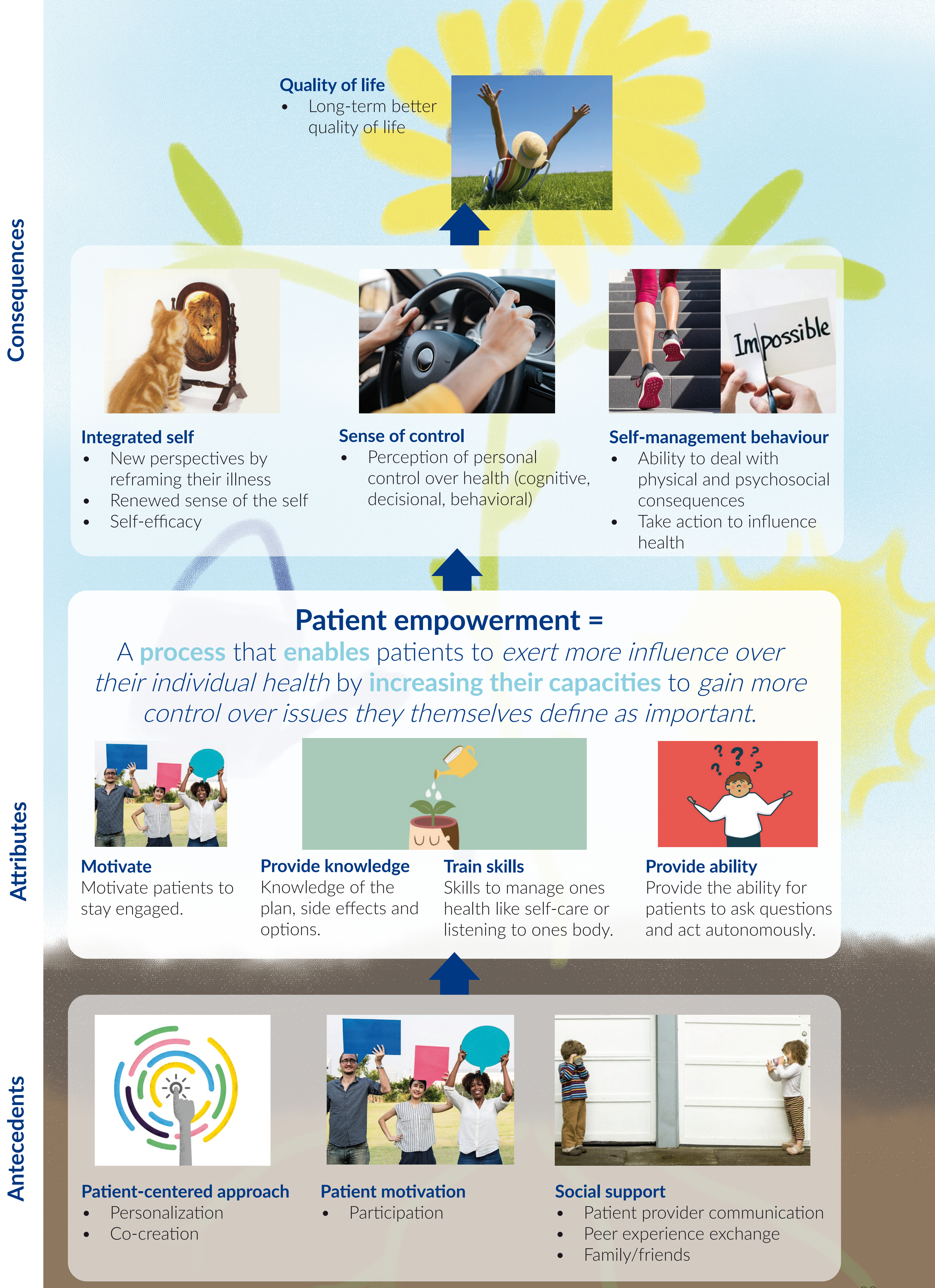
A process of timing and measuring
Patient empowerment itself is the process that is performed to make the flower grow. It is providing the flower with the right amount of water and sunlight at the right time. This enables the flower to grow. In the model this includes providing patients with motivation, knowledge, skills and abilities at the right time as explained in chapter 2.3. When provided at the right time and in the right amount this can enable patients to ‘grow’. In this case growing means gaining more control over issues they themselves define as important.

Seeing results
When the flower grows we can see the consequences of this process, the beautiful leaves and flowers. The leaves can be viewed as the positive consequences of patient empowerment which are an integrated self, sense of control and self-management. These in their turn help to create the flower, a better quality of life. These consequences were explained in chapter 2.2.

In this model patient empowerment is thus viewed as a process that enables personal growth. When designing for patient empowerment we must therefore first of all make sure that the conditions for growth are met, the antecedents. Next we can stimulate the growth process by providing the right attributes at the right time. We must enable the patient to grow by increasing their capacities to do so. This process can then create the desired positive consequences for patients’ lives in the follow-up phase.

Key chapter insights

- The proposed inspirational model for designing for patient empowerment shows patient empowerment as a process for personal growth.
- To start this process the antecedents are needed. During this process you need to provide the attributes at the right time in the right amount. Eventually if your designed intervention incorporates these aspects it can create patient empowerment and lead to the positive consequences.



Consequences

Quality of life
- Long-term better quality of life

Integrated self
- New perspectives by reframing their illness
- Renewed sense of the self
- Self-efficacy

Sense of control
- Perception of personal control over health (cognitive, decisional, behavioral)

Self-management behaviour
- Ability to deal with physical and psychosocial consequences
- Take action to influence health

Attributes

Patient empowerment =
A **process** that **enables** patients to *exert more influence over their individual health* by **increasing their capacities** to *gain more control over issues they themselves define as important.*

Motivate
Motivate patients to stay engaged.

Provide knowledge
Knowledge of the plan, side effects and options.

Train skills
Skills to manage ones health like self-care or listening to ones body.

Provide ability
Provide the ability for patients to ask questions and act autonomously.

Antecedents

Patient-centered approach
- Personalization
- Co-creation

Patient motivation
- Participation

Social support
- Patient provider communication
- Peer experience exchange
- Family/friends

Figure 16. A combined model of patient empowerment including its attributes, antecedents and consequences

Sub-question 2: What are the **concerns** of head and neck cancer patients in the follow-up phase?

3. CONTEXTUAL INQUIRY

This chapter investigates the concerns of head and neck cancer patients in the follow-up phase.
This is done through analyzing data from online community platforms, a focus group with care professionals and ex-patient interviews.

3.1 Chapter introduction

The main aim of this project is to design a digital service that increases patient empowerment of head and neck cancer patients in the follow up phase. In the previous chapter I explored the theme of patient empowerment to get a better understanding of this concept and how to design for it. In this chapter, I look at the second sub-question which is about head and neck cancer patients in the follow up phase. I want to understand their concerns in this phase, in order to be able to design a meaningful additional service for them, that can enable them to become more empowered.

Therefore, this chapter aims to answer the second sub-question posed in chapter 1.1.4:

> 2. What are the **concerns** of head and neck cancer patients in the follow-up phase?

In order to answer this question, several different design research steps are performed. Figure 17 shows these steps and how they built up on each other. By combining the evidence of the different studies a more accurate picture of the concerns of head and neck cancer patients is created. I do not only get to know the perspectives of a few head and neck cancer patients, but I also look at community data and insights from care professionals. This combination of quantitative and qualitative methods will provide the richest understanding (Shah & Corley, 2006).

By first performing research on concerns through online communities and a focus group with care professionals, I had a better understanding of the context and issues before actually talking to ex-patients. This made sure that the interviews could be more on point and I could better empathize with the patient's situation. In this way, I got more in depth information from the patient interviews on their experiences. They are the experts of their experiences and if you as a design researcher are already better aware of their context you can better understand the conversation and ask relevant questions.

At the end of this chapter I discuss the main HNC patient concerns that are found through combining the different studies.

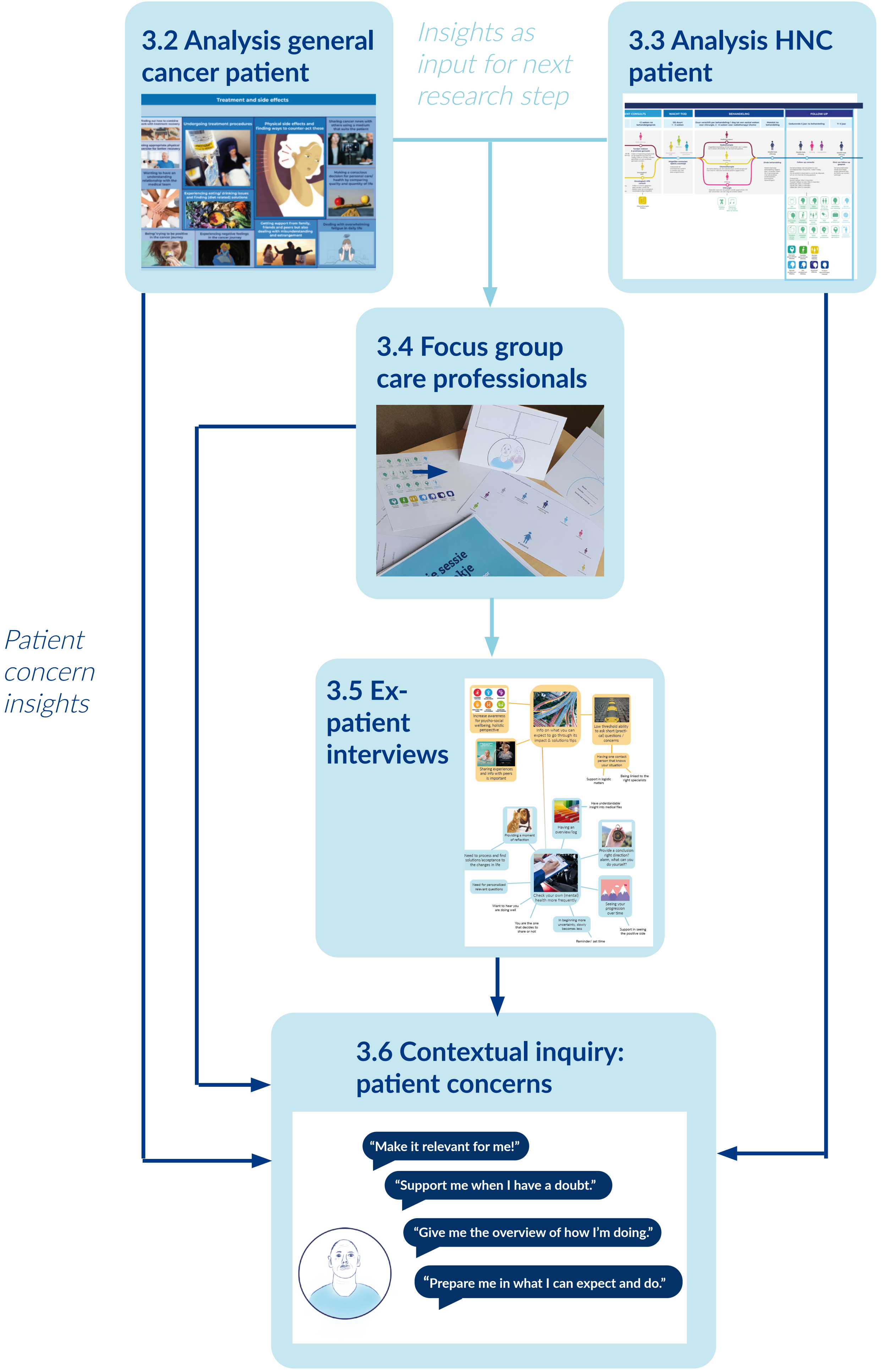


Figure 17. An overview of the chapter structure and interelation between the different research steps

3.2 Analysis general cancer patient

3.2.1 Introduction

Patients are using online forums to post their experiences and give advice to others. These online community platforms can be a valuable source for finding patient needs throughout their journey. McRoy et al. (2018) used an automated content analysis of posts written by breast cancer patients on online platforms to identify their needs over time. They confirm that texts from online forums can be analyzed effectively for identifying patient needs over time using automated methods.

Identifying the journey of patients over time is referred to as patient journey mapping in most literature. Patient journey mapping is deemed valuable for optimizing care processes and using a patient-centered approach (Kushniruk et al., 2020). Often these journeys are made to show the medical journey of patients and are created through interviews with patients and doctors.

However, the creation process of these journeys might lack in the following two aspects;

1. Interviews are created around the current medical care path and questions might steer the conversation. Patients might not be able to express their real experiences in this set up.
2. They are based on qualitative research looking at the experiences of just a few patients through interviews.

Creating a quantified map of patient experiences and needs through online community data analysis can be an interesting opportunity to get a more complete and evidence based journey of patient concerns. I explain these two aspects that make community data analysis interesting to use for designers more in depth in the next two paragraphs.

Gaining real insight into patient experiences

What makes the use of online forums so valuable, is that they provide more real insight into the actual lives and thoughts of patients. As Beusterien et al. (2012) describe it: “Patient web forums provide a unique opportunity for patients to spontaneously post their experiences and thoughts about diseases and treatments.” The way questions are formulated for interviews or questionnaires dictate the way that patients answer. Also the presence of a researcher can bias the reported experience. When wanting to gain honest and unbiased understanding of patient experiences it is therefore valuable to look at online forum posts.

Quantifying patient experiences

Online stories can be analyzed manually and then quantified using machine learning techniques. These machine learning techniques can show how many other posts talk about the topics found. In this way you can provide strong evidence as you analyze stories of thousands of people. Especially in the medical field this can be interesting, as care professionals are often more easily persuaded when using evidence from a larger set of people. Thus, when designing for the health care context it can be interesting to use online community data to get more acknowledgement of the validity of your data from care professionals. This is important for designers as they want to co-create and involve the care professionals in their design steps.

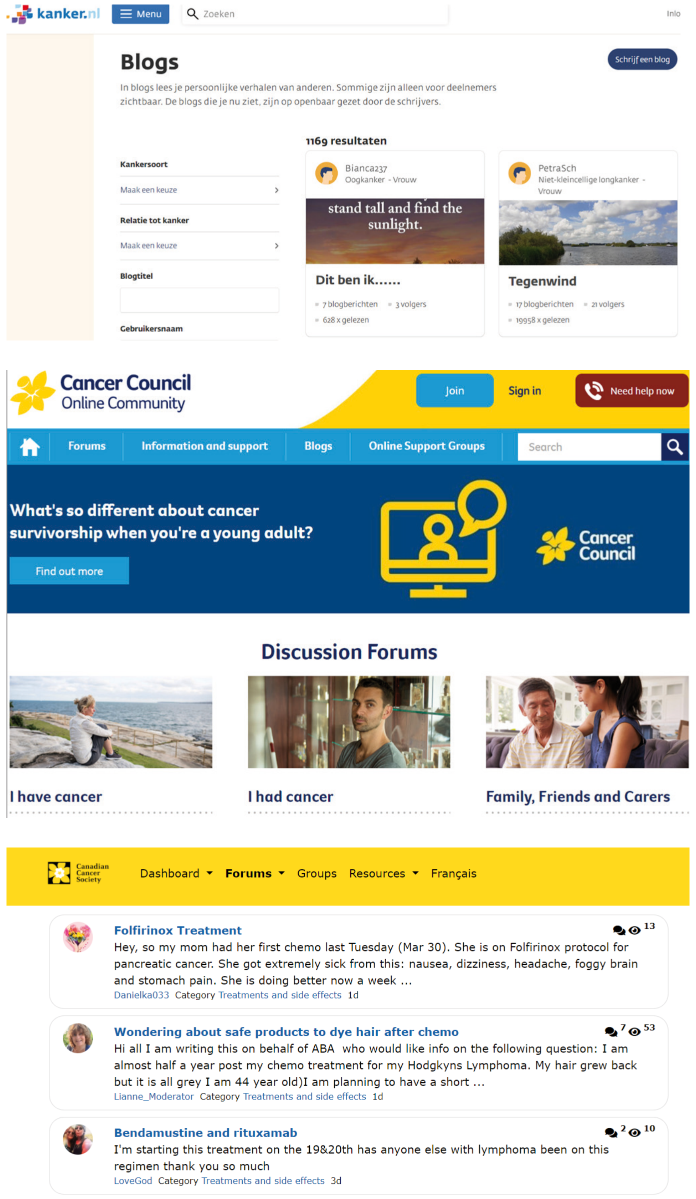
In this chapter, I therefore use online community data to create a complete and evidence based journey of cancer patient concerns over time.

3.2.2 Aim

The aim of this community data analysis is to find out what concerns cancer patients have throughout their cancer journey. I want to gain a better understanding of their daily life and struggles. This understanding serves two purposes as described in the chapter introduction. First of all, it will be used as input for identifying HNC patient concerns in the follow-up phase. Secondly, it is used to have a better understanding of the patient context before talking to care professionals and ex-patients. For the conversation with care professionals such an evidence based understanding can help to create confidence in your research and enthusiasm to participate.

The sub-sub-question, linking to sub-question 2, that will be answered in this chapter is: What concerns do cancer patients experience over time?

The focus is on the patient reported experiences, as these can be found through their blog posts and forum replies. The element of time is added to see what concerns are related to the follow-up and get a better understanding of the complete journey of cancer patients. When you are designing for a certain phase in someone’s journey, you need to know what their previous experiences and possible future experiences are. In order to communicate the answer to this research question effectively with the other stakeholders of this project, I use a visual translation of the online patient reported experiences in the form of an interactive patient experience journey.



In blogs lees je persoonlijke verhalen van anderen. Sommige zijn alleen voor deelnemers zichtbaar. De blogs die je nu ziet, zijn op openbaar gezet door de schrijvers.

Folfirinox Treatment 13

Hey, so my mom had her first chemo last Tuesday (Mar 30). She is on Folfirinox protocol for pancreatic cancer. She got extremely sick from this: nausea, dizziness, headache, foggy brain and stomach pain. She is doing better now a week ...

Danielka033 Category Treatments and side effects 1d

Wondering about safe products to dye hair after chemo 7 53

Hi all I am writing this on behalf of ABA who would like info on the following question: I am almost half a year post my chemo treatment for my Hodgkyns Lymphoma. My hair grew back but it is all grey I am 44 year old)I am planning to have a short ...

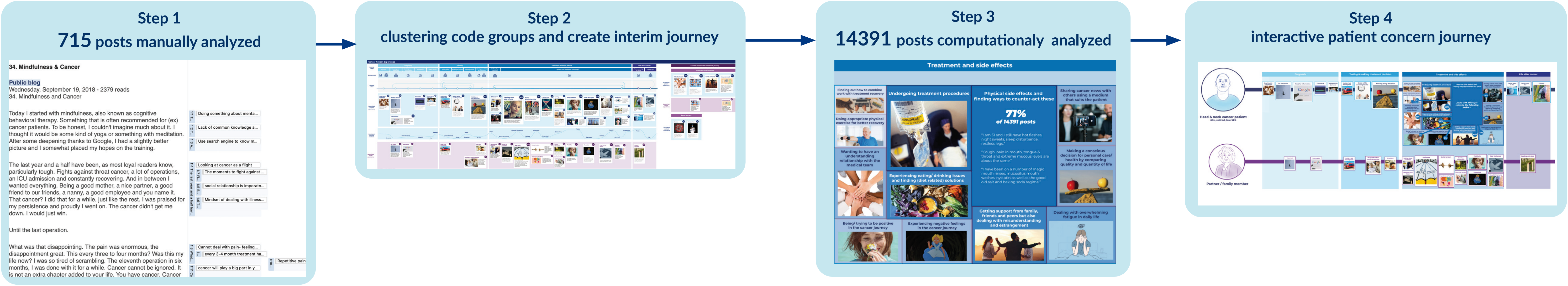
Lianne_Moderator Category Treatments and side effects 1d

Bendamustine and rituxamab 2 10

I'm starting this treatment on the 19&20th has anyone else with lymphoma been on this regimen thank you so much

LoveGod Category Treatments and side effects 3d

Figure 18. The 3 online communities used



34. Mindfulness & Cancer

Public blog
Wednesday, September 19, 2018 - 2379 reads
34. Mindfulness and Cancer

Today I started with mindfulness, also known as cognitive behavioral therapy. Something that is often recommended for (ex) cancer patients. To be honest, I couldn't imagine much about it. I thought it would be some kind of yoga or something with meditation. After some deepening thanks to Google, I had a slightly better picture and I somewhat placed my hopes on the training.

The last year and a half have been, as most loyal readers know, particularly tough. Fights against throat cancer, a lot of operations, an ICU admission and constantly recovering. And in between I wanted everything. Being a good mother, a nice partner, a good friend to our friends, a nanny, a good employee and you name it. That cancer? I did that for a while, just like the rest. I was praised for my persistence and proudly I went on. The cancer didn't get me down. I would just win.

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Figure 19. The 2 different analysis done, showing their input and translated output

3.2.3 Method

In this chapter I look at the concerns of cancer patients in general. In the next chapter I do research on online community data of HNC patients specifically. There are 3 main reasons to first do a general cancer patient online community research:

1. There are more stories to find online when looking at stories from different cancer patients. The big online cancer community platforms like Kanker.nl and CancerCouncil are meant for all types of cancer patients.
2. A lot of experiences are similar for patients with different types of cancer. They all go through the same stages of diagnosis, treatment and life after cancer. They often have similar treatments like surgery, chemotherapy or radiation therapy. Even though they have different side effects for different types of cancer, dealing with side effects is something almost all cancer patients experience.
3. I want to look at the difference between the general cancer patient concerns and HNC patient specific concerns. In what do they overlap and where do they differ? Looking at this difference can help to identify what needs to be adjusted to the designed service in later stages of this project, in order to expand it to different types of cancer.

To answer the research question I analyze the stories posted by patients in blogs and forums on 3 different platforms (see figure 18 on the previous page):

1. Kanker.nl (Dutch platform)
2. CancerCouncil (Australian platform)
3. Canadian Cancer Society (Canadian platform)

The platforms were chosen based on language and popularity. In order to analyze the posts correctly, it was important to have a good understanding of the native language that the posts were written in. Therefore, I choose Dutch and English platforms to work with.

The analysis of these posts is done in four steps:

1. A manual analysis of 715 posts was performed by 8 different design students using a thematic analysis that was executed by coding paragraphs and grouping these codes in the program Atlas.ti.
2. I clustered the code groups made by the different students into bigger themes and showed these in a preliminary patient concern journey.
3. Based on this journey, the most interesting phase is chosen to further investigate using a computational analysis. This analysis was done by Ki-Hun Kim, a data scientist, that uses a machine learning technique called topic classification and the association rule to analyze 14391 posts of the platform Canadian Cancer Society on their topics and relations.
4. The results of this computational analysis are combined with the manual analysis journey into one interactive patient concern journey. This interactive journey aim to communicate the results of the online cancer patient community analysis.

Figure 19 shows these steps visually. The first 2 steps were performed outside of this graduation project in a research project prior to this graduation. This research project was done by me and Jiwon Jung. In the next pages I discuss the details of the procedures and interim results of these 4 steps.

3.2.4 Procedures & interim results

In this section I address some important details of the procedures and intermediate results of these different steps, that led towards the final result of this analysis, an interactive journey map of cancer patient concerns.

Manual analysis procedure

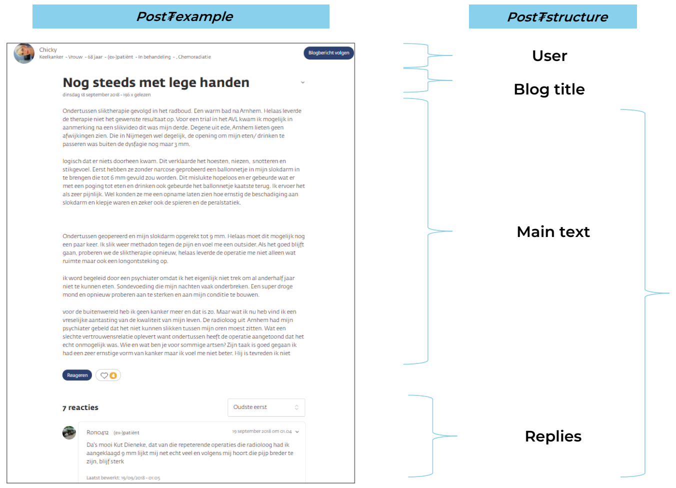
As previously explained, 8 different design students manually analyzed 715 different stories. This was done using a thematic analysis (Braun & Clarke, 2006). Texts were analyzed looking at the meanings of sentences/paragraphs in the main text (see figure 20). The student looked for themes in these sentences that they reported in the form of codes in the program Atlas.ti (see figure 21). These codes were then grouped by the students to form code groups. Dutch students analyzed the posts from kanker.nl, while English students analyzed the posts from the English platforms.

The 715 stories are mainly written by patients themselves, however we also included stories from family members as we also wanted to explore the concerns of family members in the journey. The insights from the family members perspective are discussed later in this report in chapter 7.3, where I look at how the designed concept could scale to include the family perspective.

The results of this step were 8 atlas.ti files with a total of 715 documents that together made up 4917 codes. These documents were merged to perform the next step.

Combining the files to form one preliminary patient concern journey

I combined the different atlas.ti files to form one big document. I restructured the code groups defined by the students in an excel file (see figure 22) into 51 code groups, of which 32 belonged to the patient and 19 to family members. In this process the names that students had given to code groups and the codes that belonged to a group, were restructured according to the newly defined bigger groups. A complete overview of the code groups that belong to the bigger 51 themes can be found in Appendix C.



Chicky
Keelkanker - Vrouw - 68 jaar - (ex-)patiënt - In behandeling - , Chemoradiatie
Blogbericht volgen

Nog steeds met lege handen
dinsdag 18 september 2018 - 196 x gelezen

Ondertussen sliktherapie gevolgd in het radboud. Een warm bad na Arnhem. Helaas leverde de therapie niet het gewenste resultaat op. Voor een trial in het AVL kwam ik mogelijk in aanmerking na een slikvideo dit was mijn derde. Degene uit ede, Arnhem lieten geen afwijkingen zien. Die in Nijmegen wel degelijk, de opening om mijn eten/ drinken te passeren was buiten de dysfagie nog maar 3 mm.

logisch dat er niets doorheen kwam. Dit verklaarde het hoesten, niezen, snotteren en stikgevoel. Eerst hebben ze zonder narcose geprobeerd een ballonnetje in mijn slokdarm in te brengen die tot 6 mm gevuld zou worden. Dit mislukte hopeloos en er gebeurde wat er met een poging tot eten en drinken ook gebeurde het ballonnetje kaatste terug. Ik ervoer het als zeer pijnlijk. Wel konden ze me een opname laten zien hoe ernstig de beschadiging aan slokdarm en klepje waren en zeker ook de spieren en de peralstatiek.

Ondertussen geopereerd en mijn slokdarm opgerekt tot 9 mm. Helaas moet dit mogelijk nog een paar keer. Ik slik weer methadon tegen de pijn en voel me een outsider. Als het goed blijft gaan, proberen we de sliktherapie opnieuw, helaas leverde de operatie me niet alleen wat ruimte maar ook een longontsteking op.

ik word begeleid door een psychiater omdat ik het eigenlijk niet trek om al anderhalf jaar niet te kunnen eten. Sondevoeding die mijn nachten vaak onderbreken. Een super droge mond en opnieuw proberen aan te sterken en aan mijn conditie te bouwen.

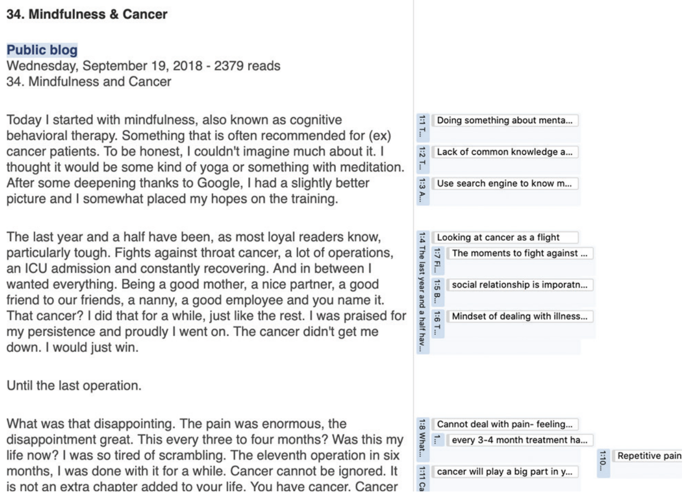
voor de buitenwereld heb ik geen kanker meer en dat is zo. Maar wat ik nu heb vind ik een vreselijke aantasting van de kwaliteit van mijn leven. De radioloog uit Arnhem had mijn psychiater gebeld dat het niet kunnen slikken tussen mijn oren moest zitten. Wat een slechte vertrouwensrelatie oplevert want ondertussen heeft de operatie aangetoond dat het echt onmogelijk was. Wie en wat ben je voor sommige artsen? Zijn taak is goed gegaan ik had een zeer ernstige vorm van kanker maar ik voel me niet beter. Hij is tevreden ik niet

Reageren 4

7 reacties
Oudste eerst

Rono412 (ex-)patiënt 19 september 2018 om 01.04
Da's mooi Kut Dieneke, dat van die repeterende operaties die radioloog had ik aangeklaagd 9 mm lijkt mij net echt veel en volgens mij hoort die pijp breder te zijn, blijf sterk
Laatst bewerkt: 19/09/2018 - 01:05

Figure 20. Post structure



34. Mindfulness & Cancer

Public blog
Wednesday, September 19, 2018 - 2379 reads
34. Mindfulness and Cancer

Today I started with mindfulness, also known as cognitive behavioral therapy. Something that is often recommended for (ex) cancer patients. To be honest, I couldn't imagine much about it. I thought it would be some kind of yoga or something with meditation. After some deepening thanks to Google, I had a slightly better picture and I somewhat placed my hopes on the training.

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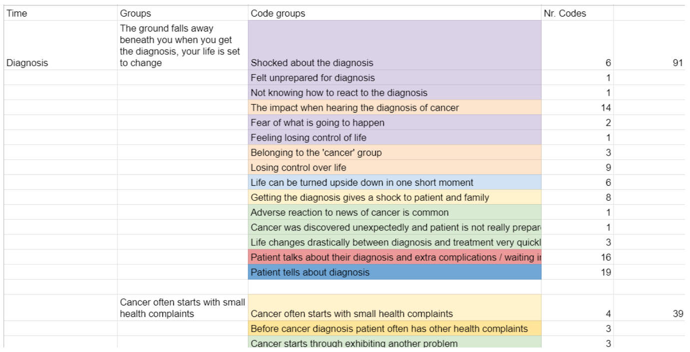
Figure 21. Codes created in Atlas.ti



Time	Groups	Code groups	Nr. Codes	
Diagnosis	The ground falls away beneath you when you get the diagnosis, your life is set to change	Shocked about the diagnosis	6	91
		Felt unprepared for diagnosis	1	
		Not knowing how to react to the diagnosis	1	
		The impact when hearing the diagnosis of cancer	14	
		Fear of what is going to happen	2	
		Feeling losing control of life	1	
		Belonging to the 'cancer' group	3	
		Losing control over life	9	
		Life can be turned upside down in one short moment	6	
		Getting the diagnosis gives a shock to patient and family	8	
		Adverse reaction to news of cancer is common	1	
		Cancer was discovered unexpectedly and patient is not really prepar	1	
		Life changes drastically between diagnosis and treatment very quickl	3	
		Patient talks about their diagnosis and extra complications / waiting i	16	
		Patient tells about diagnosis	19	
	Cancer often starts with small health complaints	Cancer often starts with small health complaints	4	39
		Before cancer diagnosis patient often has other health complaints	3	
		Cancer starts through exhibiting another problem	3	

Figure 22. Snap shot of the excel showing the clustering of the code groups into bigger groups. See Appendix C for the complete overview.

The themes could be linked to phases of the cancer patient journeys based on the categories in which the stories were posted on the platforms and by identifying reoccurring steps in patient blog posts. Table 1 shows the categories used on the different platforms and their link to the 4 bigger phases defined in the created concern journey which are; diagnosis, testing, treatment & side effects and life after cancer. These phases were defined using the platform categories and by reading the stories and distilling the different phases that reoccur in the different posts of patients. This led to the addition of the phase testing, which was not used as a separate category on the platforms but was seen as a relevant in between phase when reading the stories of patients.

I created an initial patient and family member concern journey based on this manual analysis by linking the code groups to the right phases. The complete visual result can be found in Appendix D. Figure 23 shows how this journey is build up. Some code groups could not be linked to a certain phase like 'support from family and friends', since they were relevant throughout the journey. These were therefore visualized separately as general concerns.

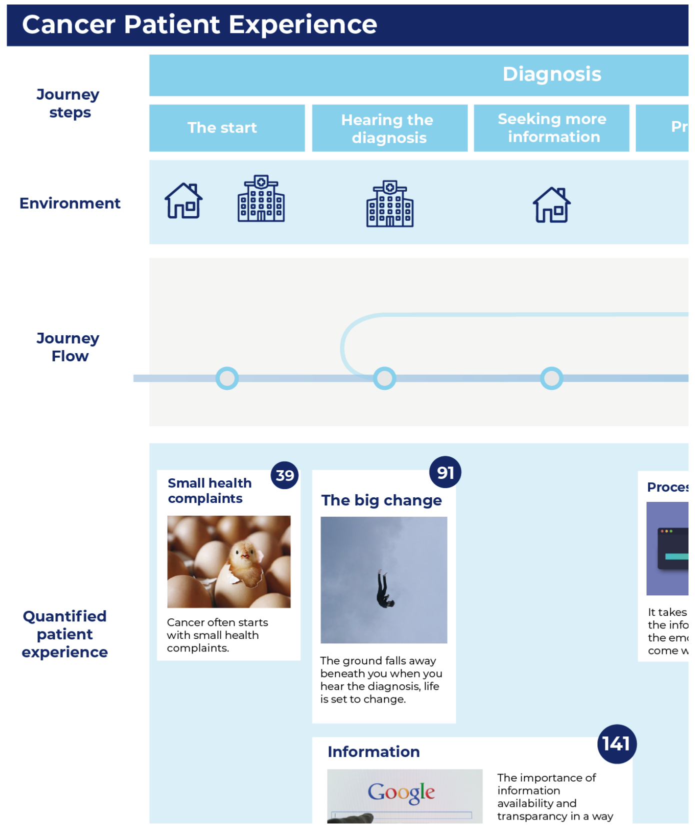


Figure 23. Snap shot of the interim patient experience journey

Defined phase	Kanker.nl categories	Cancer Council categories	Canadian Cancer Society categories
Diagnosis	When cancer comes into your life	Pre-diagnosis	I've just been diagnosed, diagnosis cancer and treatment
Testing		The emotional roller-coaster	
Treatment & side effects	Radiation (and consequences), Chemotherapy (and consequences), exercise sports and physical recovery, cancer pain, fatigue, nutrition, meaning	Treatments & side effects, money matters, caring for someone with cancer	Treatment and side effects, living with cancer, diagnosis cancer and treatment, coping with a loved one's cancer
Life after cancer	Continue with your life after the treatments, not getting better		Living with and beyond cancer, if cancer returns, facing end of life, grief and loss

Table 1. Phases used in the journey and their matching categories on the different online forums

Computational analysis

In order to quantify our manual results, I performed a computational analysis for one of the discovered phases. One phase had to be chosen, since creating a good input data set and code structure for the analysis is a time intensive process. In the limited time of this project it was therefore decided to analyze the phase of treatment and side effects more in depth. Of course focusing on the patient perspective, since the main aim of this project is to focus on how the patient can be empowered.

The phase of 'treatment and side effects' is chosen based on the following 2 reasons:

1. In the manual analysis it was found that this phase was the biggest patient concern group when compared to others. It includes a total of 2108 codes, whereas diagnosis has 330, testing has 397 and life after cancer contains 175 codes. It also includes the biggest code group; 'Dealing with side effects.' This code group alone already consists of 478 codes
2. The scope of this project is the follow-up phase where side effects have been shown to play a very important role (Aguilar et al., 2017).

The machine learning process used is called topic classification. In order to classify the topics the system needs a learning data set.

Creating a learning data set

The learning data set is created by taking the relevant manually analyzed posts in the category of 'treatment and side effects' from the online community Canadian Cancer Society (https://cancerconnection.ca/). This platform was chosen, since it already has a distinctive tab for 'treatment and side effects' on its website and contains a large amount of posts.

The learning dataset was iteratively constructed using a thematic analysis of the words in the sentences that would be processed by the computer. It was chosen to use sentences for the learning data, since posts contained multiple sentences with different topics. An example of a sentence changed into the words processed by the computer is shown in figure 24.

Sentence: "One of the things that kept me sane was exercising."

Processed words: ['one', 'things', 'keep', 'sane', 'exercise']

Topic: Doing appropriate physical exercise for better recovery

Figure 24. Example of how the sentences are processed

As you can see words such as 'of' and 'me' are taken out of the sentence, capitals are removed and verbs are used in the original form.

492 example sentences are used that were classified into 12 different topics. In table 2 you can see the topic labels. These topics were labeled by looking at the complete set of sentences clustered in the theme. Based on this a representative label in an active form was created.

Performing the topic classification

The data scientist, Ki-Hun Kim, performed the topic classification process to quantify the 12 themes. This was done by using the learning data as input to learn the classifier. The classifier was learned by applying non-negative matrix factorization (Févotte & Idier, 2011) and random forest (Breiman, 2001) to the learning dataset.

The data set used to analyze consists of all posts written between January 2012 and November 2020 in the seven relevant forums of the Canadian Cancer Society platform. In total this data set contained 14391 posts that together contained 112758 sentences.

The learned classifier was applied to all these 112758 sentences. Each of the sentences was put into the most likely of the 12 topics. Based on this sorting it could be identified in how many posts the 12 topics were discussed. Table 2 shows the topic with the found number of posts and percentage of posts that contained this topic.

Topic	Number of posts	Percentage of posts
Experiencing physical side effects from treatment and finding ways to counteract these	10282	71%
Undergoing treatment procedures	9454	66%
Experiencing eating/drinking issues and finding (diet)related solutions	6286	44%
Getting support from family, friends, and peers but also dealing with misunderstanding and estrangement	6320	44%
Dealing with overwhelming fatigue in daily life	5154	36%
Making a conscious decision for personal care/health by comparing quality and quantity of life	4877	34%
Sharing cancer news with others using a medium that suits the patient	4848	34%
Wanting to have an understanding relationship with the medical team (effective communication)	4712	33%
Experiencing negative feelings (of depression, anxiety and loneliness) in the cancer journey	4044	28%
Being/trying to be positive in the cancer journey	3356	23%
Doing appropriate physical exercise for better recovery	2723	19%
Finding out how to combine work with treatment recovery	1990	14%

Table 2. Results of the computational analysis of the themes in the treatment and side effects phase

Performing a topic co-occurrence rule mining

A topic co-occurrence rule mining analysis was performed to find relations between the different topics. Topic co-occurrence rules were mined by applying association rule mining (Agrawal et al., 1993) to the dataset. A topic co-occurrence rule is an if-then rule. It consists of an antecedent and consequence. If a set of topics (antecedent) is written in a post together, another set (consequence) of topics will probably also be discussed in this post. For example, if someone talks about experiencing negative feelings, there is an 80% chance that he also talks about dealing with physical side effects in this post and a 54% chance that experiences with eating/drinking issues are discussed.

The 12 topics found in the topic classification and their relations are combined with the previously created patient and family concern journey to form a complete interactive visual overview. The relations used in this interactive journey are the ones that included one antecedent and one consequence since these were possible to visualize as separate links between the 12 topics. In total 60 relationships are shown in the interactive overview. This overview is presented and further discussed in the next section, the results.

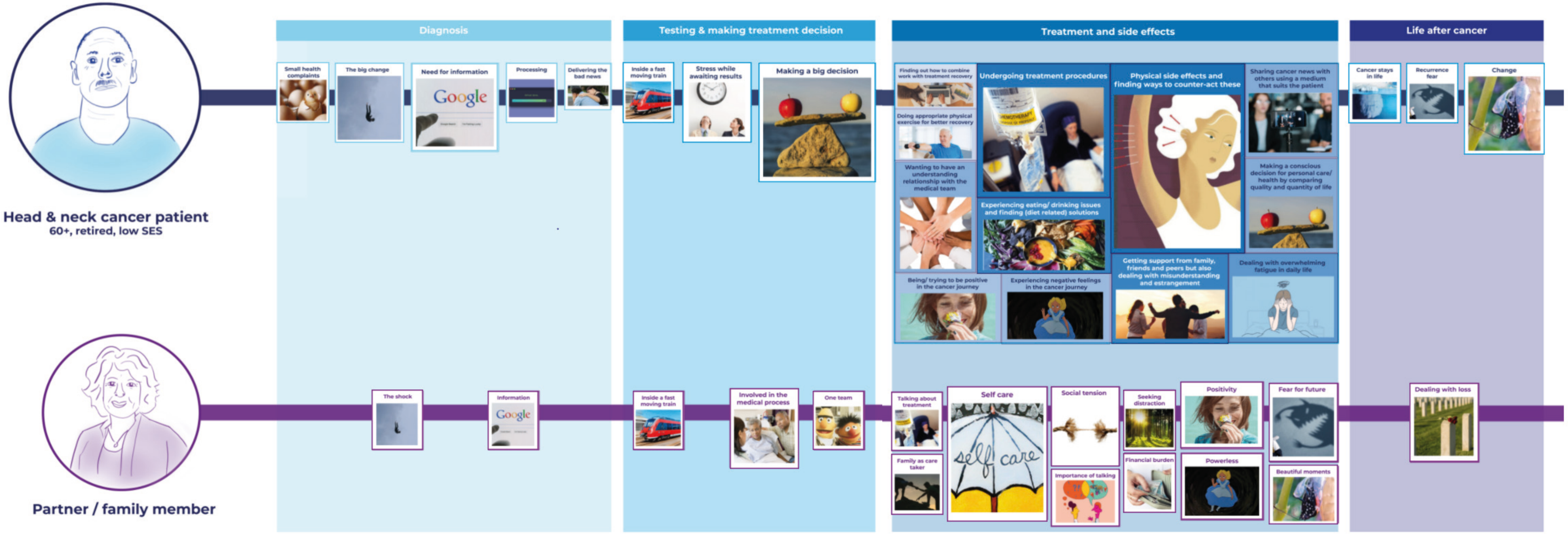


Figure 25. Interactive cancer patient and family member concern journey showing both the results from the manual and the computational analysis. Go to: https://ts26m3.axshare.com

3.2.5 Final result: an interactive cancer patient concern journey

The concerns discovered in the manual and machine learning analysis are translated into a visual interactive journey (see figure 25). This is done to create a coherent overview that is rich with data, but not overwhelming. This visual can be used to share with stakeholders and as a starting point for discussion. It includes quotes from the patient and family blogs to provide a more in depth understanding of the concerns. The part of the journey that includes the machine learning analysis, the treatment and side effects phase from the patient perspective, is highlighted using a different format. This part of the journey is elaborated upon by also showing the percentage of posts that addressed this concern and the relations between the different concerns (see figure 26). The interactive journey can be accessed through the following link: https://ts26m3.axshare.com

In this result section I discuss the main findings that are presented in this journey that answer the research question: What concerns do cancer patients experience over time?

Since the research question focusses on the patients experience I will only discuss the patient concerns over time in this section. The family member concerns will be discussed later in the recommendations in chapter 7.3. The different phases of the journey with the relevant patient concerns are discussed on the next pages.

"I am 51 and I still have hot flashes, night sweats, sleep disturbance, restless legs."

"Cough, pain in mouth, tongue & throat and extreme mucous levels are about the same."

"I have been on a number of magic mouth rinses, mucusitus mouth washes, nystatin as well as the good old salt and baking soda regime."

Figure 26. Interactive part showing the percentage of posts and quotes when you hover over (left) and the relationships between the topics when you click on it (right)

The diagnosis

Cancer often starts with small health complaints. It seems like nothing serious but when patients get to the doctor they can hear that they have been diagnosed with cancer whilst they are completely unprepared for this serious message. The journey of cancer patients starts here where they feel like falling into the deep unknown. Their life is set to change. Patients are looking for information on their diagnosis and need time to process this initial shock. However finding the right information can sometimes be hard as there is so much to find on the internet. They also need to tell their loved ones about it. Patients need time to process all this but often they don't have much time as they are thrown into the hospital mill of testing and deciding on a treatment.

Relevant concerns in this phase:
- Small health complaints
- The big change
- Need for information
- Processing
- Delivering the bad news

"It's the scariest thing to hear that you have been diagnosed with cancer and very much the fear of the unknown of what's going to take place to get rid of it."

"There's so little information out there even with internet and I also think the internet doesn't help so much either."

Testing and making a treatment decision

Patients are put into the fast moving hospital train together with their partner. They need to do a lot of different tests in a short time. Waiting for the results of the test is a stressful experience. How big is it? Where has it already spread? The answers to these questions are important for what treatment is possible and thus for a large part for the course of the patient's life. Waiting for an answer that has such a big influence on your life is very stressful. Another very important topic found in this phase is 'making a big decision'. This is the point where patients need to make a decision on their treatment. Some patients don't have much time in this phase to explore the different options or just have one option to choose from. Despite this lack of time, patients look for experiences of peers with their treatment to compare different treatment options and ensure that they make the right decision, balancing quality and quantity of life.

Relevant concerns in this phase:
- Inside a fast moving train
- Stress while awaiting results
- Making a big decision

"It's not always good to have an imagination when it comes to waiting and no one likes being in limbo. The longer you wait the more time you have to think of what-if scenarios."

"What is wisdom ... your feeling is very important. It is a decision that only you can make."

Treatment and side effects

As mentioned in the procedures chapter, this phase of the patient journey was further investigated using a computational analysis to quantify the findings and find relationships between the concerns. I first address the themes found in this phase and then elaborate on the relationships in a next paragraph.

Table 2 in section 3.2.4 shows the 12 concerns found in this phase with the percentage of posts that discussed these topics. When a decision is made the treatment starts. Patients talk a lot about the difficult time during treatment (66% of posts) but they talk even more about dealing with the side effects of the treatment and disease (71% of posts). Not only the physical side effects but also how it effects them mentally and how their social life is affected. They talk about eating difficulties (44% of posts), fatigue (36% of posts) and emotional ups (23% of posts) and downs (28% of posts). Furthermore they discuss the importance of support from family and friends (44% of posts) but also an understanding medical team (33% of posts). Moreover patients have different ways to keep their friends and family updated on how they are doing (34% of posts). Some use email, while others use Facebook groups. We can again see the theme of 'making a conscious decision' (34% of posts) as patients sometimes also need to make tough decisions in this phase like deciding to stop their medication. Furthermore the two smaller topics of doing physical exercise (19% of posts) and combining cancer with work (14% of posts) were also discussed by patients.

Patients ask each other for advise when it comes to dealing with side effects. Different tips & tricks and experiences with side effects are shared. It becomes evident that information about side effects and solutions are important topics to discuss with peers. Patients want to share their experiences, know if it is similar to other patients' experiences and discover what solutions peers use.

"I used to call it "chemo day", because I was literally there all day."

"I find that when the fatigue hits I can feel it coming and it is like walking into a wall."

"I only found sweet drinks tasted "normal" and even told the oncologist this process is going to make me diabetic at the same time!"

"This is where I found my team helped - being able to talk about the crappy stuff (literally sometimes) with the nurses and the therapist really helped."

Relationships between the different concerns

As mentioned before a co-occurrence rule mining was used to identify the relationships between the different concerns in this phase. 60 direct relationships were found that are presented in the interactive journey. Figure 12 on the previous page showed how these relationships are visualized. I will now briefly discuss the most interesting relationships found and my interpretation of why these relationships exist.

Most of the concerns were related to 'undergoing treatment' and 'physical side effects'. This is logical since these are the biggest groups and are therefore most often mentioned. The concern of 'finding out how to combine work' was too small to show a relation to another concern.

'Doing physical exercise' was highly related to 'physical side effects and finding ways to counteract these'. 80% of the time that physical exercise was mentioned they also mentioned physical side effects. This makes sense as doing physical exercise is a way to counteract physical side effects.

Whilst 'trying to stay positive' only linked to the two bigger concerns, 'experiencing negative feelings' also linked to 'experiencing eating/drinking issues' and 'getting support from family and friends'. Negative feelings arise from experiencing these eating and drinking difficulties or when a patient feels misunderstood by their family or friends.

'Having an understanding relationship with your medical team' also links to the 'eating' and 'support' concerns next to the two bigger groups. This shows that patients want their medical team to take these concerns into consideration.

'Making an important decision' also included the 'eating' and 'support' concerns in its relationships. Furthermore the concern of 'dealing with fatigue' was also linked to making a decision. We can see that the physical concerns of eating and energy are taken into account by the patient when making a decision for their healthcare. Furthermore social concerns are considered as they take their family and friends into account in this decision.

'Dealing with fatigue' also links with 'eating' and 'support'. Eating can influence your energy level and when you are tired this influences your social relationships.

We can thus see that concerns also influence one another and that dealing with physical side effects links to most concerns as it is the biggest group and relates to a lot of different concerns.

Life after cancer

If patients survive the cancer journey they need to find a way to deal with what has happened to them. Cancer stays in your life as you often still have fear for recurrence and some of the side effects last for the rest of your life. However patients also expressed that cancer can be a good change that teaches you how to focus on the things that really matter and enjoy every day.

Relevant concerns in this phase:
- Cancer stays in life
- Recurrence fear
- Change

"Living with cancer makes you a bit more laconic. It makes those things that matter more important, life itself, for example."

"Now that everything seems to be "okay" for me again, everyone wants to continue on the same footing and I won't. Time will tell how I will solve that."

3.2.6 Discussion

Looking at this journey, it becomes clear that cancer patients have to deal with a lot of uncertainties and changes. The journey is a rollercoaster of emotions where you can be very positive at one point in time and feel down at another point. It is all about dealing with the physical, social and emotional changes that you go through. Especially the physical consequences of the disease is a topic that peers like to discuss with each other on online platforms. Are others experiencing this as well? How do they deal with this? Social support from peers can help patients in dealing with these consequences. Knowing they are not the only ones and getting practical tips and solutions. Social support from the medical staff members is also very important. They need to have an understanding for the patient's situation.

By analyzing blog and forum posts of online communities, a good overview of patient experiences and concerns over time could be created. The blog posts show true patient experiences and often express the complete journey someone goes through. While the forums show the topics that patients have questions about, topics that patients want to discuss with their peers. Analyzing online community posts can thus be interesting when one wants to know the real concerns of patients over time. By quantifying this data, a stronger argument can be made for the importance and prevalence of certain concerns. The worth of first using a manual analysis and then a computational analysis is that supervised learning can take place, where the designer can find meaning first and then quantify this meaning by the computer. In this way the richness of the data and usability for creating a patient journey is secured.

Limitations
Several limitations were however found in doing this community data analysis. First of all, the manual analysis was done by 8 different students. Even though they were briefed to use a similar coding structure, people still have different ways of interpreting blogs and posts and create different code groups. This made it difficult to combine all the different code groups at the end. A second limitation was that the codes could not always be linked to a specific phase in the journey. For some it was easy since the posts came from a category on the online platform already, but for blogs it was harder to place them in the right phase. For blogs you would have to read the context of the complete blog to place the code in the right place. Furthermore, some of the code groups were discussed throughout or at different places in the journey. Making a big decision was for example mostly discussed in the phase before treatment but also in the phase after treatment. A recommendation for when one would want to create a patient journey from the online data, is to write down the phase in the code when creating the code. In this way you can place the code in the right context when reading the blog and better group them together later on.

Key chapter insights

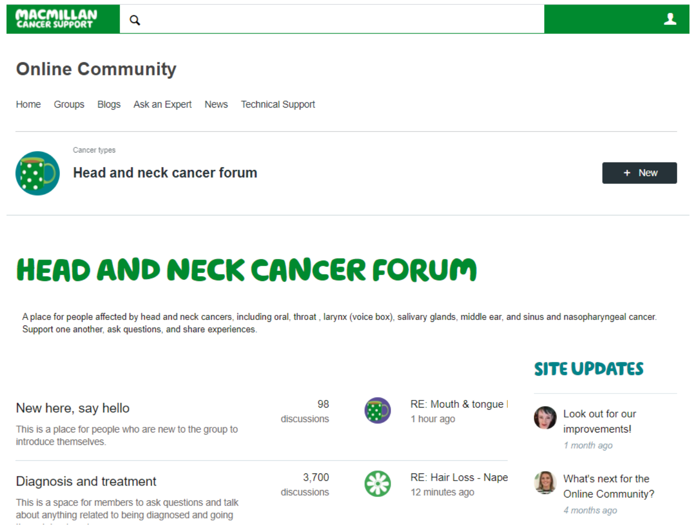
- Patients experience a lot of uncertainties and changes throughout their journey.
- Finding out how to deal with the physical consequences of the disease and treatment is the biggest concern for patients.
- Social support helps in dealing with the consequences of the disease whether it is from family members, friends, peers or the medical team.

3.3 Analysis HNC patient

3.3.1 Introduction

In the previous chapter I discussed the concerns of cancer patients in general, not specifying a cancer type. In this way I could gain a general understanding of the journey that cancer patients go through and their concerns throughout this journey. In this chapter I look at the concerns of head and neck cancer patients specifically, since this project focusses on HNC patients in their follow-up phase. I am interested to find out where the concerns of HNC patients overlap and differ when compared to the general cancer patient concerns as described in the previous chapter.

Community data is used once again to get a genuine insight into the concerns of HNC patients in a quantified way. The data used is taken from forum posts on the Macmillan Cancer Support head and neck cancer forum (see figure 27).



A place for people affected by head and neck cancers, including oral, throat , larynx (voice box), salivary glands, middle ear, and sinus and nasopharyngeal cancer. Support one another, ask questions, and share experiences.

This is a place for people who are new to the group to introduce themselves.

This is a space for members to ask questions and talk about anything related to being diagnosed and going

Figure 27. Macmillan Cancer Support head and neck cancer forum

3.3.2 Aim

The aim of this analysis is to get a better understanding of HNC patient specific concerns and their specific journey.

Therefore, the sub-sub-question, linking to sub-question 2, that is answered in this chapter is: What are the concerns that HNC patients express on the online community platform of Macmillan and how do they relate to their medical journey?

This research aims to get a better understanding of the issues that HNC patients face and how they relate to the medical journey that HNC patients go through at the Erasmus MC. This understanding will be used and checked in the next phases of the contextual inquiry.

3.3.3 Methods & intermediate results

Answering this research question is done in 4 steps:
1. Gaining an understanding of the care path of HNC patients at the Erasmus MC.
2. Gaining an understanding of HNC patient concerns through online community data.
3. Verifying and adding upon the HNC patient concerns with literature insights.
4. Linking the care path to the HNC patient concerns to see where the concerns are situated in this journey.

Figure 28 on the next page shows an overview of these steps.

Step 1. Gaining an understanding of the care path of HNC patients
In order to understand HNC patient concerns I first of all need to gain a better understanding of the medical journey they go through. This is done by visualizing the care path of patients at the Erasmus MC. The way this journey is visualized takes its inspiration from the metro mapping technique of Griffioen (2021). The documents used for creating the care journey were a patient journey excel flowchart created by ENT researcher and doctor Maarten Dorr, the Zorggids K.N.O. (Erasmus MC, 2020) and the diverse questionnaires used in the Healthcare Monitor. The goal of this visual is to place the patient concerns in the Erasmus MC context. It is not the goal to be perfectly accurate as in the scope of this project this was neither feasible nor wanted.

Step 2. Discovering HNC patient concerns through online community data
The next step is to use online community data again

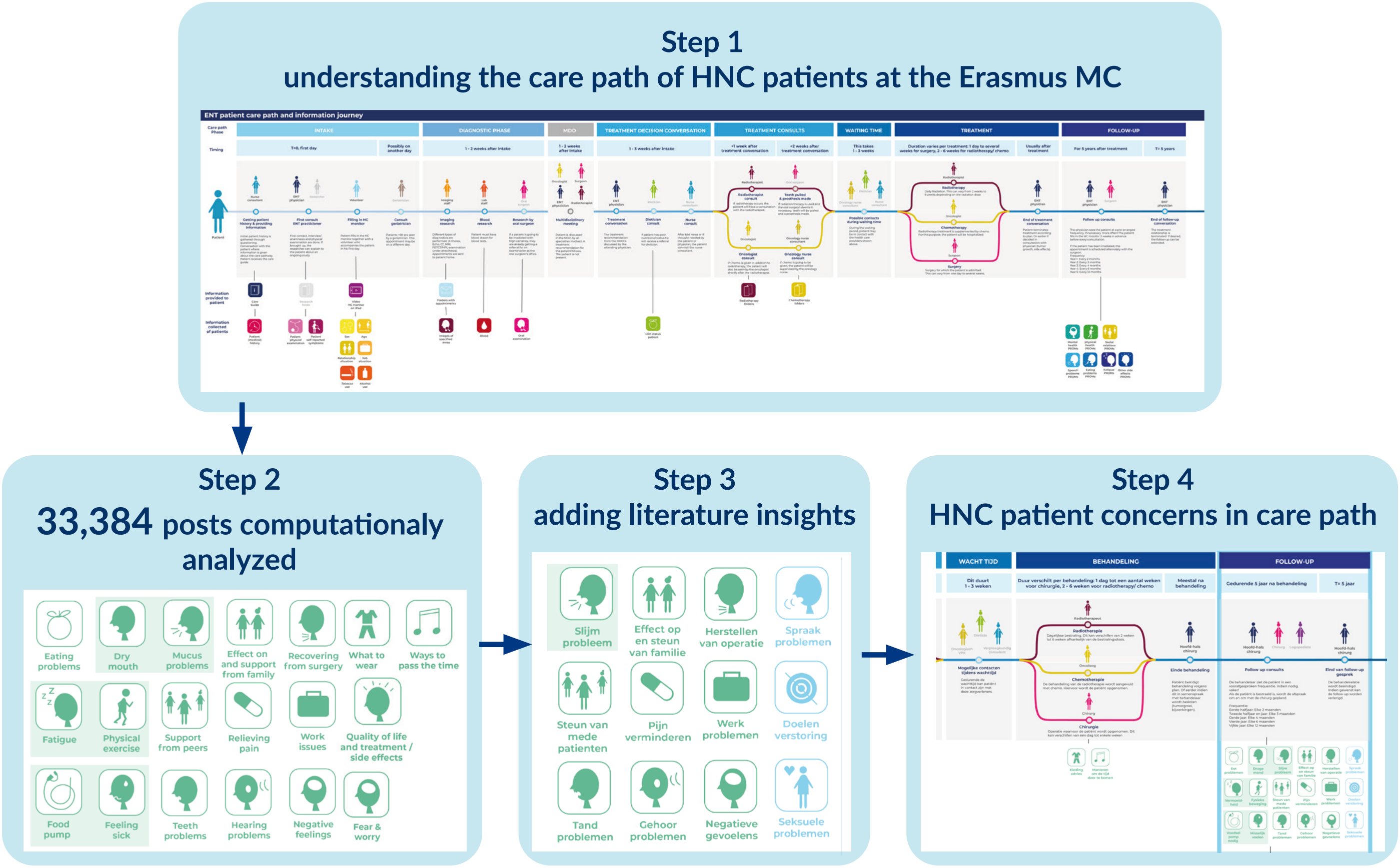


Figure 28. Steps of HNC patient analysis

to find out the concerns of HNC patients. This time however, the community data is analyzed using the computer immediately meaning that no manual analysis is done beforehand. This is also called unsupervised learning.

This analysis was again performed by the data scientist Ki-Hun Kim, who used the Latent Dirichlet Allocation method (Blei et al., 2003). This method can automatically discover sets of keywords that frequently appear in posts together. For example the key words: 'eat, food, drink, taste, manage'.

33,384 texts from forums and replies on the Macmillan Cancer Support Community for HNC patients were used. 4 iterative cycles were done with the data to find out what the optimal topic number is. The optimal number is the amount of topics that best represent the diverse concerns of HNC patients while having a good coherence score (Newman et al., 2010). During these iterative cycles mistakes in the input data were also filtered, such as repetitive sentences of users that used the same words without extra meaning. It was found that an analysis for 25 topics best represented the data.

The computer can identify these topic sets, however it cannot label these sets with an understandable topic name. Therefore, I performed the labelling by creating an understanding of the grouped key words through 50 representative texts per topic. The analysis of these representative texts let to a final description of 19 HNC patient concerns, as some of the labelled topics discussed a similar concern, a very specific concern or did not discuss a concern at all.

Step 3. Verifying and adding upon the HNC patient concerns with literature

In order to verify these concerns and to build upon these concerns a literature study was done. The searching tools semantic scholar, PubMed and google scholar were used to search for HNC patient concerns. Search terms were: 'head and neck', 'cancer', 'patient', 'concern', 'side-effects', 'psychosocial', 'quality of life'. 3 new concerns were added based on insights from literature.

Step 4. Combining insights using a metro mapping visual

Finally, the 19 HNC patient concerns found through the computational analysis and the 3 concerns found through literate are combined with the care path. Based on the analysis of the representative texts, the concerns could be placed at the right point in time in the journey. The result is a care path that shows HNC patient concerns next to the information provided and given to the patients. This visual will be further presented in the next section.

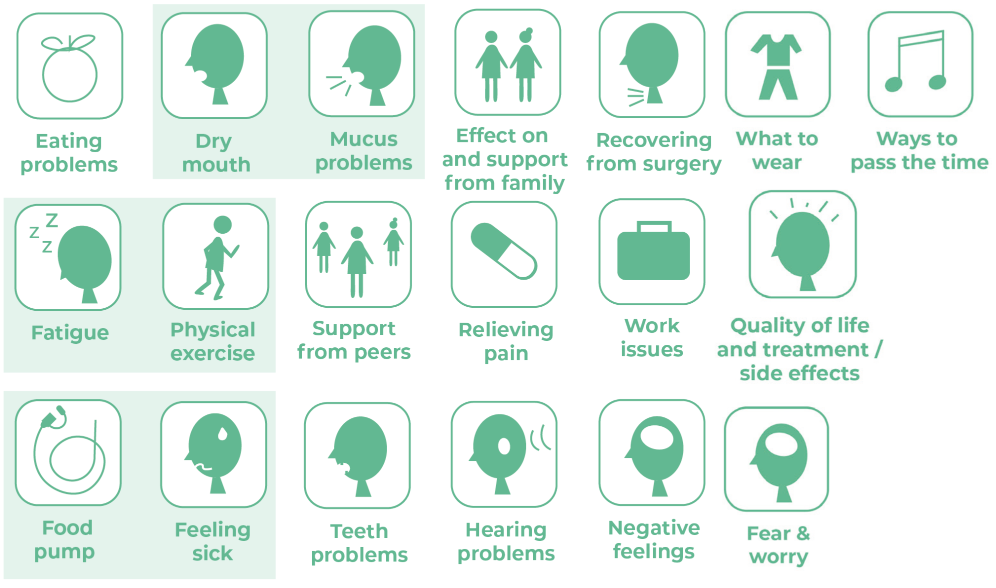


Figure 29. 19 HNC patient concerns found through computational analysis

Figure 30. 3 HNC patient concerns found additionally through literature

3.3.4 Result: care path with HNC patients concerns

HNC concerns through online community data

As previously described 19 specific HNC patient concerns were identified based on the topic descriptions formed by analyzing the representative texts. See Appendix E for a complete overview of the found topic keywords, topic descriptions and how these translate into these 19 concerns. Figure 29 shows a visual overview of these concerns.

The concerns with a green background behind them were discussed together in posts. A dry mouth was often discussed in combination with mucus problems. Fatigue in combination with physical exercise and food pump in combination with feeling sick.

Most of the found concerns relate to dealing with physical side effects of the recovery phase. Specific effects for head and neck cancer patients are eating problems, a dry mouth, mucus problems, recovering from surgery, a food pump, teeth problems and hearing problems. Patients asked about how others deal with these physical side effects and shared their experiences and practical tips and tricks with each other. For eating problems patients talked about different diet solutions like drinking mint tea or mashing food. For teeth problems they discussed different products to keep your teeth clean and different cleaning rituals. The focus of most posts was on finding recognition and helping each other with experiences and tips.

HNC patient concerns through literature

The literature research confirmed a lot of the concerns found in the community data analysis of HNC patients. In a study of Aguilar et al. (2017) it was found that issues with salivation, fatigue, eating, swallowing and fear of recurrence have the biggest prevalence (above 20%). The negative feelings felt by HNC patients was also confirmed in a study of Duffy et al. (2007) and Howren et al. (2013) where respectively 40% and 15-50% of HNC patients were found to suffer from depression in the course of treatment. Different side effects were found to have a different impact on the quality of life of patients. Karnell et al. (2000) found that speech and eating difficulties have the most impact on the wellbeing of patients whereas Terrell et al. (2004) found that a feeding tube has the most negative impact on the quality of life of patients. Speech difficulties was a concern that was not yet found in the community analysis. Furthermore, the concerns of goal-disturbance and sexual problems were found in literature. Offerman et al. (2010) found that patients experience goal-disturbance and need help in goal re-engagement. Melissant (2021) talks about the needs for supportive care to address concerns regarding body image and sexuality. Based on these findings the concerns of speech problems, goals disturbance and sexual problems were added to the concern list of HNC patients (see figure 30).

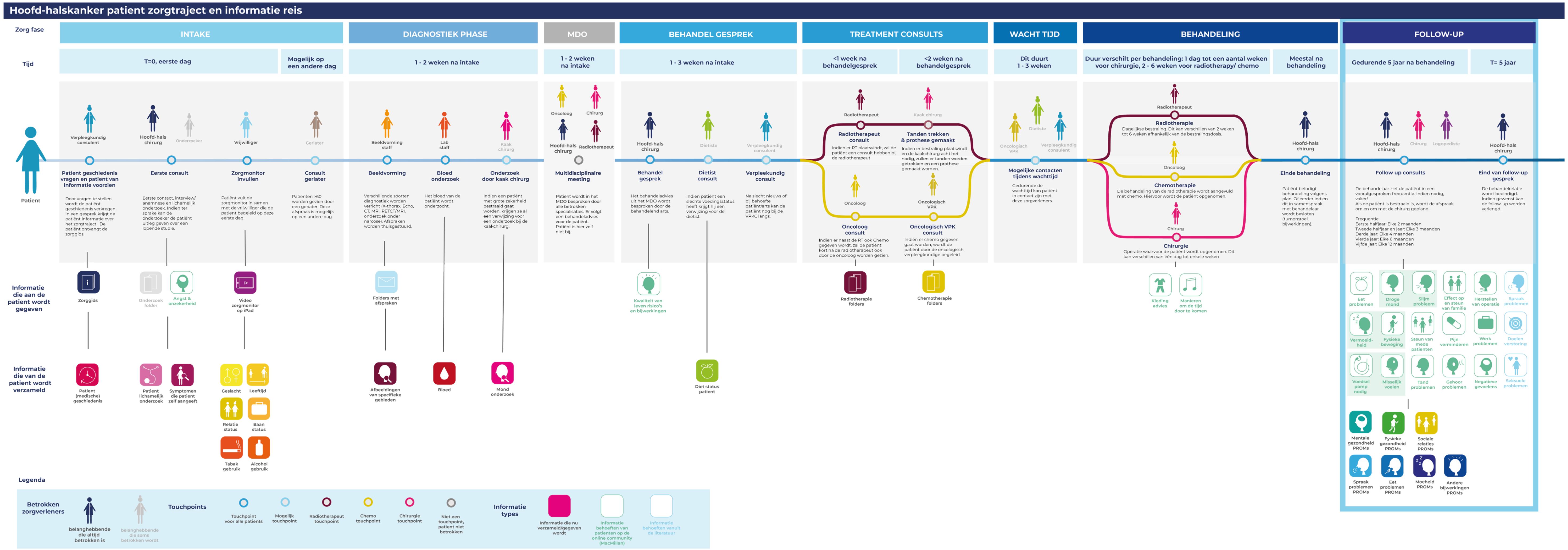


Figure 31. HNC patient care trajectory and information journey including the patient concerns found in the community data analysis and literature review

Combined insights in a metro map

Figure 31 shows the result of combining the metro map of the care journey created in step 1 with the HNC patient specific concerns found in steps 2 and 3. This visual is also showed bigger in Appendix F. The HNC patient care trajectory and information journey shows the different care phases the patient goes through: the intake, diagnostic phase, multidisciplinary meeting (MDO), treatment conversation, treatment consults, waiting time, treatment and follow-up. The patient is present in all phases except for the MDO where a multidisciplinary meeting is held to discuss the treatment of the patient. The journey shows the different stakeholders involved in the different phases and the different information that is given to the patient and collected from the patient. The follow-up phase is highlighted since this is the focus of this project. The frequency of follow-up consults decreases over time. In the first half year the patient goes to a follow-up consult every 2 months. In the final year, the fifth year after treatment, the patient only goes to a consult once. As you can see, most patient concerns found in the community data analysis and literature study are also situated in this follow-up phase.

3.3.5 Discussion

We can see that concerns of HNC patients overlap with the general cancer patient journey, in the sense that the biggest concerns discussed on the HNC forum are the side effects of treatment. Similar concerns such as eating difficulties, fatigue, effect on and support from loved ones, working problems and emotional downs were discussed. However, for HNC patients some very specific side effects were also found such as a dry mouth, mucus problems, recovering from surgery, teeth problems, hearing problems and dealing with food pumps. Therefore, we can say that for both groups it was found that dealing with side effects is a major concern. Both on the physical as well as the psychosocial level. And where the psychosocial level overlap some of the physical side effects differ per cancer type.

From the metro map it becomes clear that mostly at the beginning of the trajectory a lot of information is collected and provided to the patient. It also becomes clear that the biggest information gap is in the follow-up phase where patients have a lot of different concerns. Information is collected from the patients on most of these concerns through the questionnaires filled in by patients in the Healthcare Monitor. However, patients also want to be provided with information. We can see that patients use forums to share their concerns and ask advice from others. They are in need of recognition and practical tips from peers in this phase. They seek information themselves on how to deal with the side effects through these online communities.

Limitations

Since this literature study is not the main part of this project but just a source for extra understanding and inspiration of the concerns of HNC patients, it is likely that there is more relevant literature to be found on this topic. However, since the concerns will also be added upon by care professionals and ex-patients the current mapping of concerns was considered enough to use in the next phases of the contextual inquiry.

The metro map is created mostly on the information provided by one ENT researcher/doctor. Since the metro map is not a goal in itself but a means to get insight into the context and spark inspiration, it is however not perceived necessary to create the perfect real journey. If one would want to create a more accurate metro map, interviews with more care professionals are required.

Key chapter insights

- HNC patients have similar but also some very specific physical side effects to deal with compared to the general cancer patient.
- Patient information concerns are mostly situated in the follow-up phase where less information is provided and contact moments become less frequent.

3.4 Focus group care professionals

3.4.1 Introduction

The previous chapters explained how two different quantitative research methods have led to an understanding of (head and neck) cancer patient concerns. Shah & Corley (2006) show that the combination of quantitative and qualitative methods provides the richest understanding. Therefore the quantitative research is added upon by qualitative research. In this qualitative research part I will talk with the most important stakeholder groups for this project to get a richer understanding of the context. These groups are of course the head and neck cancer patients themselves, but also the care professionals that care for these patients.

Care professionals have met so many different patients that they have a broader understanding of head and neck cancer patient concerns. They have experience with many different cases and can thus provide a valuable insight into different patient concerns. They can also provide insight into their own needs and concerns as care professionals. To uncover these different concerns I did a focus group session with 6 care professionals.

In this chapter I explain the full procedure of the focus group, also including the parts that relate to uncovering the care professionals' needs. In this chapter I focus on the outcomes that related to the concerns of HNC patients that care professionals identify. These outcomes help to answer the main research question of this contextual inquiry which is about the concerns of the head and neck cancer patients. The outcomes that relate more to the concerns of care professionals themselves are further discussed in chapter 7.2 that looks at the next steps needed to further develop the suggested concept of this thesis.

3.4.2 Aim

The sub-sub-question, linked to sub-question 2, that I aim to answer in this chapter is: What patient concerns do HNC care professionals identify?

The focus group itself has the main aim to find out the opinions and concerns of a diverse group of medical professionals involved in the follow-up of HNC patients for a new patient dashboard service system. I want to uncover what information is important to collect and share in such a service, who has to be involved and how the information should be used according to care professionals.

3.4.3 Method

To uncover the needs of care professionals for a new service in the follow-up phase, the qualitative Focus Group method was used. It is a good technique for uncovering attitudes of care professionals regarding health care services (Papp et al., 2014). Furthermore, the group discussions that this method provides, allow participants to build upon each other, generating broader insights. (Wong, 2008)

Participant selection
Selecting the participants to join the session was done using the method Convenience Sampling. This method was chosen since I, the design researcher, had limited time and accessibility to get a more randomized sample of health care professionals (Etikan, 2016). Furthermore, using convenience sampling helped to get a diverse group of people around the table from the ENT department of the Erasmus MC in a short amount of time. Through contacts at the Erasmus MC, care professionals with different job functions related to the topic were selected.

The focus group session was held with the following 6 different HNC care professionals from the Erasmus MC:

- ENT doctor
- Nurse consultant
- HM volunteer
- Psychologist/researcher
- Head of ENT department
- ENT doctor/researcher

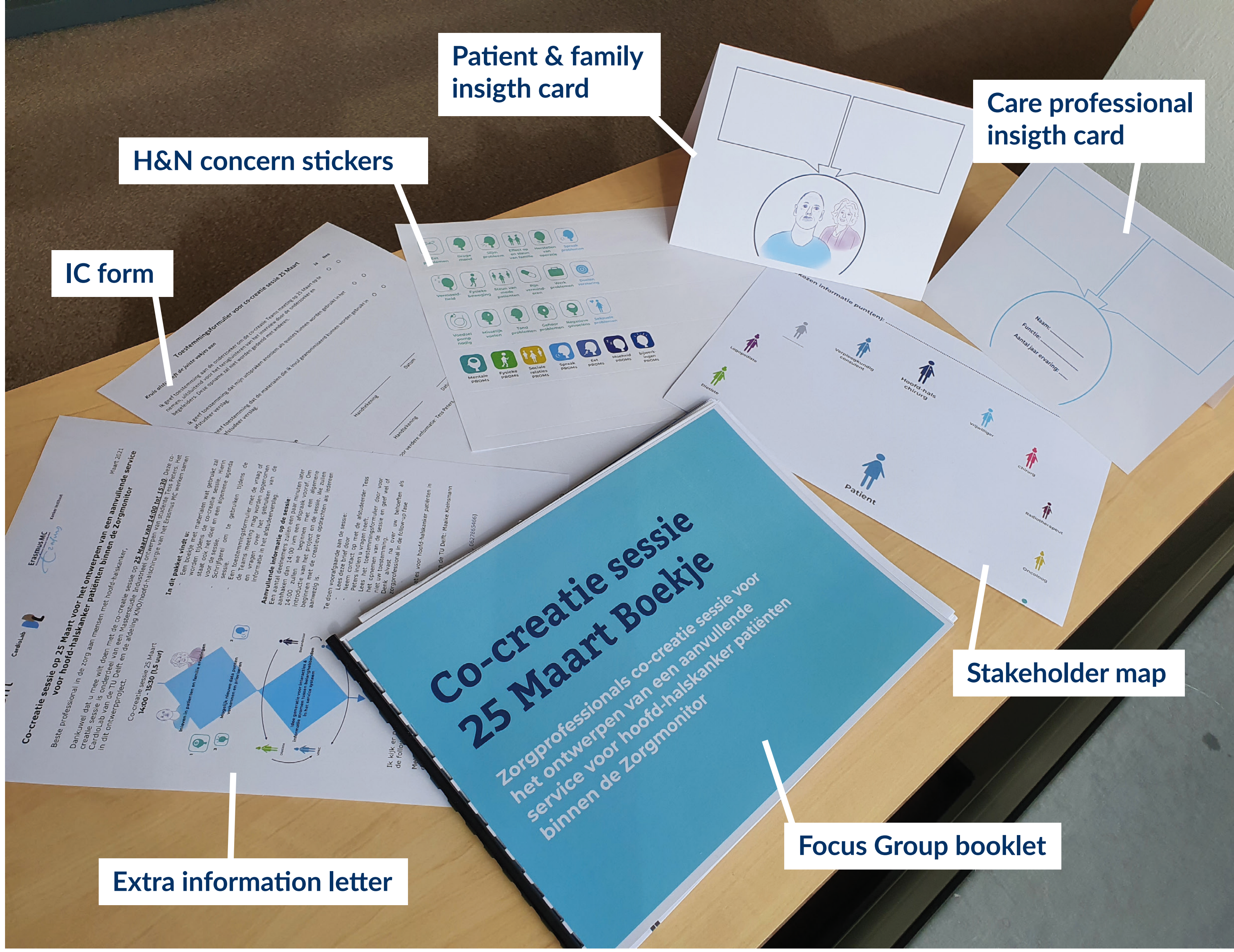


Figure 32. Focus Group session package send to participants including an information letter, IC form and a booklet with a diverse set of tools to use during the session

Procedure
One week before the Focus Group session a package was given to the participants. This package included a letter with extra information, an informed consent form to record the session and a booklet to be used during the session (see figure 32).

The booklet contains different exercises to be done during the session. Appendix G shows the complete booklet. In Appendix H you can find the stakeholder map. It was chosen to use a physical booklet since the session would be done using online video calling due to COVID-19. Using online video calling and online tools at the same time was deemed to be unpractical. Furthermore, from my previous facilitation experience I know that it is nice for participants to have some time off-screen during such sessions. Moreover, the physical booklets would provide a good insight into the individual thoughts of the participants next to the discussions.

The focus-group session consists of 4 main parts:

1. Insight into the needs of care professionals
2. Insight into the patient and family concerns from a care professionals perspective
3. Which information to collect?
4. How to use the collected information?

The session was supported with a presentation that explained the different exercises related to these parts and provided an introduction to the session. The session had a total duration of 1,5 hours. Further procedures per part are explained on the next page.

Part 1 (10 min): Insight into the needs of care professionals

For this part the care professional insight card was used from the physical booklet (see figure 32 on the previous page). Participants filled this in individually after which they shared their name, function and 1 concern in the group to introduce themselves and their concerns. They placed the insight card on the table to have it as a reminder during the session.

Part 2 (20 min): Insight into the patient and family concerns from a care professionals perspective

In this step the patient and family insight card was filled in by the participants (see figure 32 on the previous page). This was done by looking at the online patient journey map as presented in chapter 3.2. This insight card was also put on the table of participants to act as a reminder in the next steps.

Part 3 (25 min): Which information to collect?

In this step participants looked at the HNC patient follow-up concerns from the HNC journey as presented in chapter 3.3. Participants were first asked to add any data points/concerns that were not yet represented by the stickers (see figure 32 on the previous page). Next they were asked to prioritize the data points in 5 steps by placing the stickers in 5 boxes (see figure 33). Freedom was given to how many stickers were placed in one box, but a clear explanation of why these concerns/data points belonged together according to the participants was asked. The prioritized map made by the participants was used in a discussion to discuss about the importance of different data points from the different care professionals' perspectives.

Part 4 (30 min): How to use the collected information?

This part involved letting the participants ideate on new systems around the prioritized data points. Care professionals used the stakeholder maps provided in the booklet (see figure 32 on the previous page) to draw interactions and communication pathways between stakeholders. Participants also had the option to add a stakeholder that was not yet represented in the map. After individually filling in the stakeholder map one topic was chosen to fill in a stakeholder map together. This was used to spark discussion on what systems to create and which stakeholders to involve in what situations.

Data analysis

The collected data including the filled in booklets and the video recording of the Focus Group session were analyzed using the thematic analysis method. This is a method for identifying patterns (themes) in data relating to the research question (Braun & Clarke, 2006).

An inductive data-driven approach is used to uncover the most important themes in the entire data set of the session. This is done by clustering collected codes and searching for themes. A theoretical analysis is used for the specific question of what data points to add to the current set of HNC patient concerns (part 3). The same technique is used to make a summary of the possible systems discussed and drawn by participants in part 4.

3.4.4 Results

In this section I only discuss the results relevant to the research question: what patient concerns do HNC care professionals identify? Results that answer to the research question of the concerns of the care professionals themselves will be discussed in chapter 7.2. These are mainly the results of part 1 and 4.

The results of the focus group session include the filled in booklets and the discussions. Figure 33 shows some of the filled in booklet results. The results were analyzed using thematic analysis to come to 4 big themes. These themes are the result of an analysis of the complete session and include both patient concerns and care professional concerns. Furthermore, the results of part 3 of the focus group are 7 extra HNC patient specific concerns. The outcomes are further explained on the next pages.

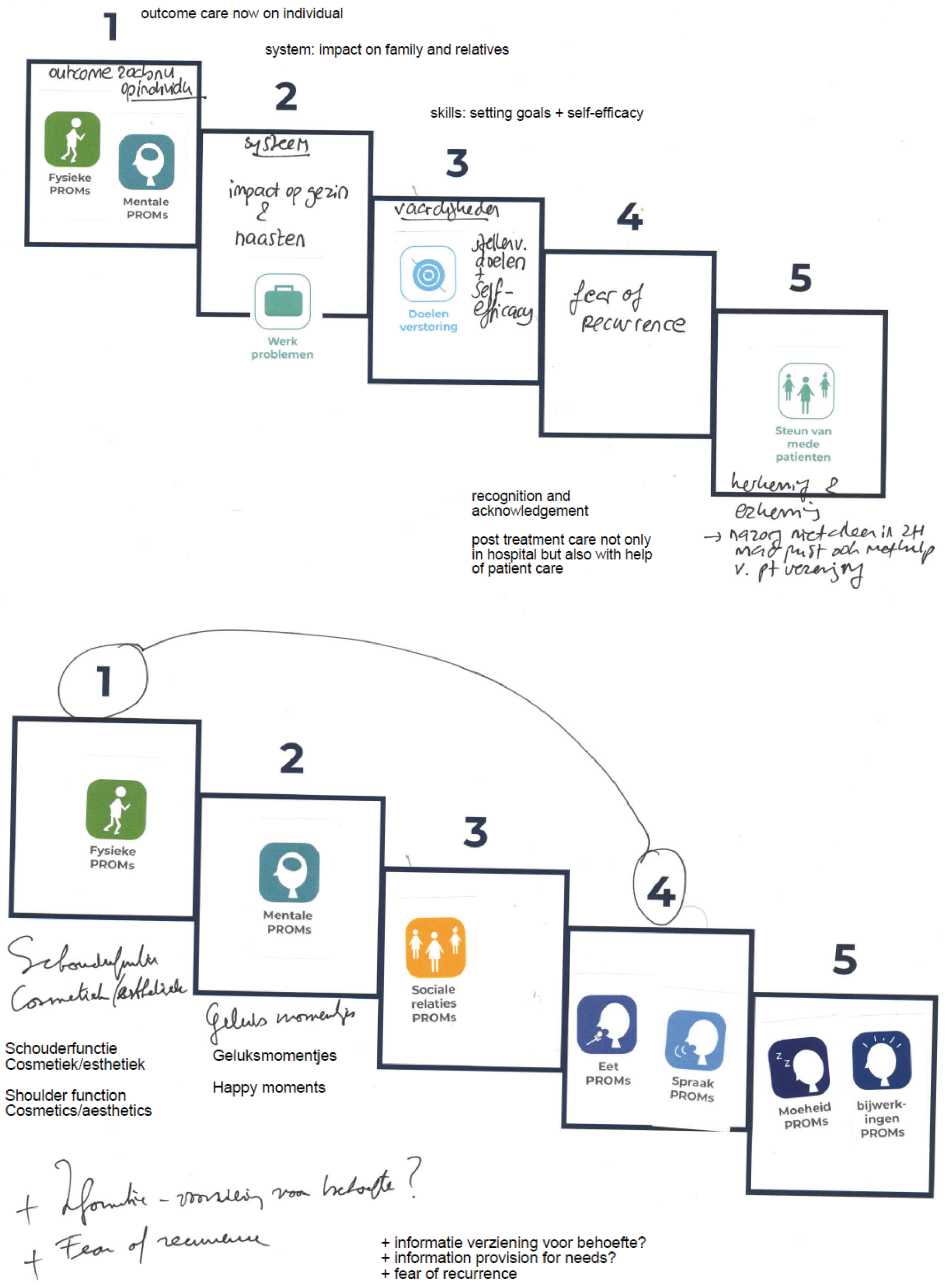


Figure 33. Some of the results of part 3 filled in in the focus group booklet

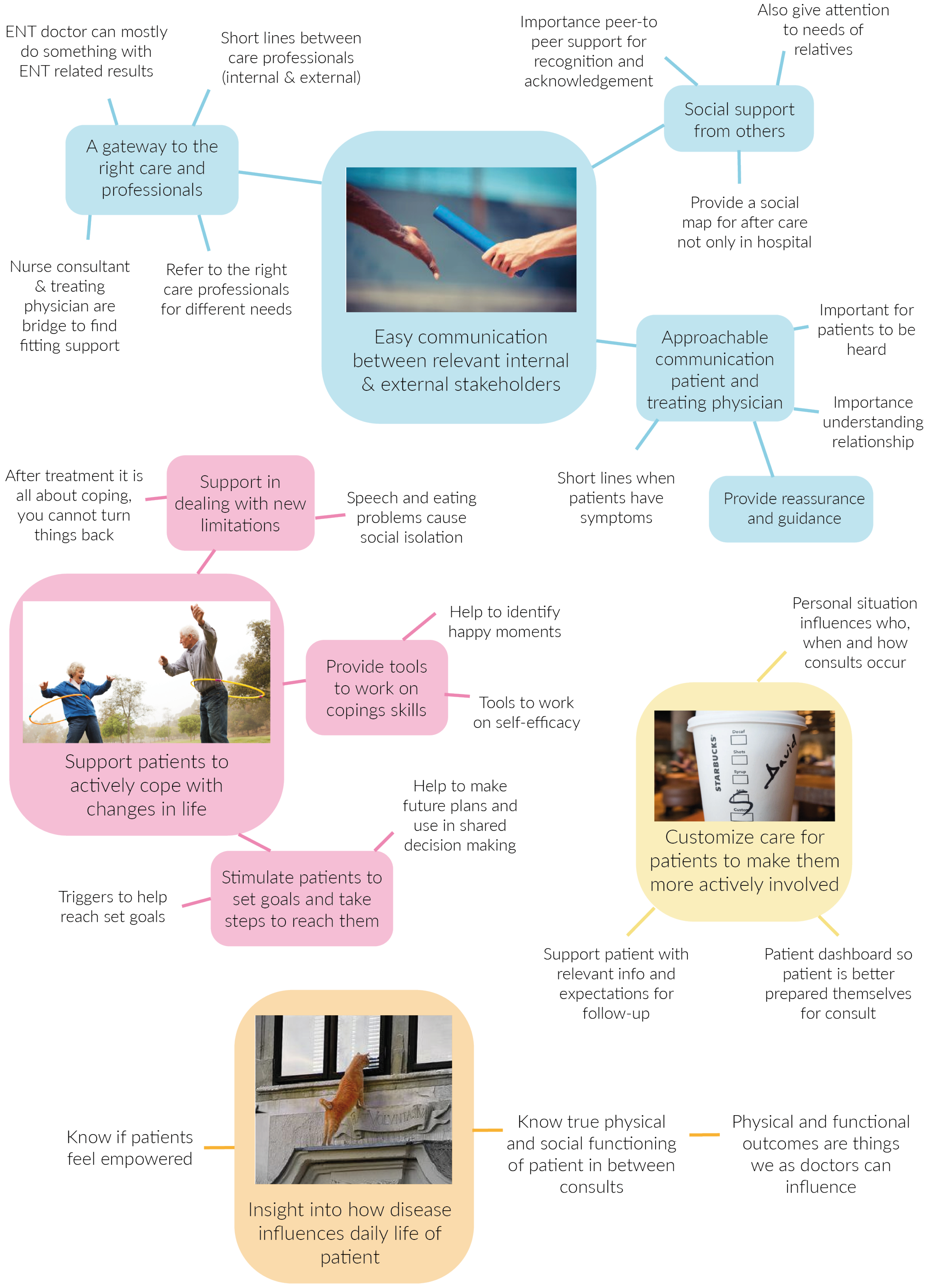


Figure 34. Thematic map: showing the themes that derived from the inductive thematic analysis of the Focus Group session

Thematic map

Figure 34 shows a thematic map that includes these 4 themes and their related smaller themes. The boxes with an image represent the bigger themes identified. Linked to these bigger themes, some smaller themes were identified (colored text boxes) linking back to the defined codes (plain text). The 4 biggest themes are further explained below.

Easy communication between relevant internal and external stakeholders

The healthcare professionals discussed the importance of short lines. They want short lines with the patient but also with other medical professionals when a link needs to be made between a patient and another professional. The nurse consultant and treating physician fulfill this role of a bridge between the patient and other care professionals at the moment.

Next to easy support from the medical team for the patient, care professionals also stressed the importance for easy support from peers. They also stressed the importance of taking the family members into account as well.

Support the patient to actively cope with the changes in life

The care professionals discussed the importance of coping. Patients cannot turn back to how things were, they need to learn how to deal with new limitations in life. They need to actively work on coping with these changes and seeing things from a positive perspective. This is an important patient concern.

Customize care for patients to make them more actively involved

From the discussions with the care professionals it became clear that the service needs to be personalized to support the patient with relevant information to become more actively involved themselves in their care process.

Insight into how disease influences daily life of patient

The doctors were especially curious to get a glimpse at how the patient is doing in their daily life. They want to know how they are truly doing physically as they have influence on the physical aspect. Furthermore, they are also interested in how the patient is doing overall and whether the patient feels empowered but the doctors feel like they have less influence on this part. This concern is more related to the concerns of care professionals themselves, however it also shows that the disease influences the patient's life on different levels. Therefore this theme is also seen as a concern of HNC patients. If they or their doctor get more insight into how their daily life is influenced by the disease, it can help to learn how to deal with the consequences of the disease and treatment.

HNC patient concerns

Figure 35 shows the 7 extra HNC patient concerns to be added. These concerns were added to the concerns discussed in the previous chapter to show during the ex-patient interviews.

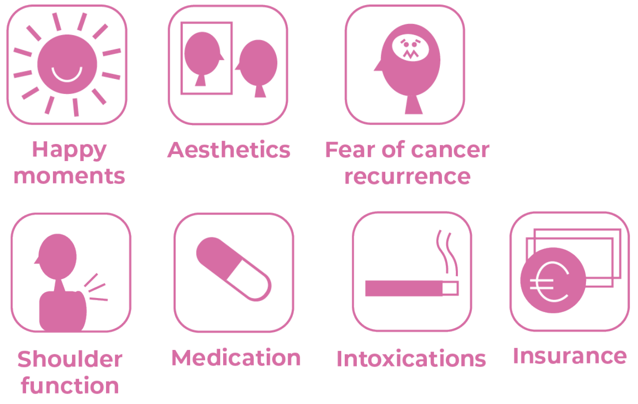


Figure 35. Extra HNC patient concerns/data points to collect that derived from the Focus Group session

3.4.4 Discussion

When looking at the results of the focus group in comparison with the quantitative analysis results and the theme exploration of patient empowerment, we can already see some overlap.

In both analysis the importance of social support was stressed. This is also one of the antecedents of patient empowerment as described in chapter 2.4. Social support is defined by patients and care professionals as the support of the care team, peers and family/friends. Especially the support from peers was stressed in the outcomes of the different studies.

Support in coping with the changes in life was one of the main themes found in the focus group session. This also came back in the quantitative analysis as dealing with side effects was the biggest concern found through the online platform analysis. A better insight into how the disease and treatment influence the daily life of the patient for care professionals and patients themselves could help in coping with these changes.

The need for personalized information for HNC patients was an important point discussed by the care professionals. This is also one of the antecedents for patient empowerment as discussed in chapter 2.4.

Limitations
One of the limitations was that due to an emergency situation one of the participants had to leave in the middle of the focus group session. However, the lost insights from this participant were caught up by doing an individual interview afterwards.

Another limitation was that since convenience sampling was used some of the participants were already more aware of the project than others. Their input might therefore have been a bit more biased in comparison to the participants that went into the focus group more blank.

Key chapter insights

- Care professionals think there should be short lines with patients.
- Patients should be supported in coping with the changes to their lives, sharing with peers and gaining more insight into how the disease and treatment influence daily life can help to do this.
- It is important to customize care for patients.

3.5 Ex-patient interviews

3.5.1 Introduction

An understanding of the needs and concerns of HNC patients was already found through community research and the focus group session as described in the previous chapters. However, a more in depth understanding of the needs and concerns of head and neck cancer patients themselves in the follow-up phase is needed to discover the specific necessities for a service in this phase. Therefore, the method contextmapping was used including interviews with 9 ex-patients.

3.5.2 Aim

The aim of this study is to find out the experiences, needs and concerns of HNC patients in their follow up phase through ex-patient interviews.

This chapter aims to answer the following 4 sub-sub-questions, linked to sub-question 2:

- What is it like to be a HNC patient in the follow up phase?
- What do they think is important to address in a new service?
- What value do they see in a patient dashboard?
- How and when would they want to interact with the system?

3.5.3 Method

In order to study the experiences, needs and concerns of HNC patients in the follow up phase the method contextmapping is used. Sleeswijk Visser et.al. (2005) describe the different steps of this generative method as: preparation, sensitizing participants, group sessions, analysis and communication. This study uses similar steps except for the session step. Instead of group sessions, individual semi-structured interviews will be done in order to get more personal and in depth experience insights. The steps; preparation, sensitizing, semi-structured interviews and analysis, are further explained in this section and section 3.5.4 'procedure'.

Preparation: Participant selection
One main criteria was used to select participants. They had to be ex-head and neck cancer patients. This means that the patient has been treated for their cancer and is now in the phase after treatment.

Participants were asked through 3 different channels:
- The klankbord group of the Erasmus MC
- The patient association pvhh
- The online platform kanker.nl

In total 9 ex-patients (and one partner) were included in this study. Since this study focusses primarily on the patient no additional partners were asked. However, to get a brief insight into the view of the partner on the follow-up phase, and because this couple works very well together, one interview was done with patient and partner together.

Preparation: Ethical considerations
Since this research includes human beings, ethical approval was gotten from the Human Research Ethics Committee (HREC) of the TU Delft.

Furthermore, the sensitizing booklet that I use was reviewed by 6 different care professionals who work with HNC patients including; an ENT doctor, a nurse consultant, two psychologists, a speech therapist and a clinical data scientist. Their feedback was used to improve the sensitizing booklet before sending it to the participants. Furthermore, as stated in the HREC approval the participants were given an anonymous ID so no data can be linked back to the actual persons.

3.5.4 Procedure

Participants were sent a sensitizing booklet in advance of the interviews. See figure 36 on the next page for an insight into the two steps used for contextmapping: the sensitizing booklet and interview. More in depth explanation on the procedures of the sensitizing booklet, the interview and the data analysis will be explained in this section.

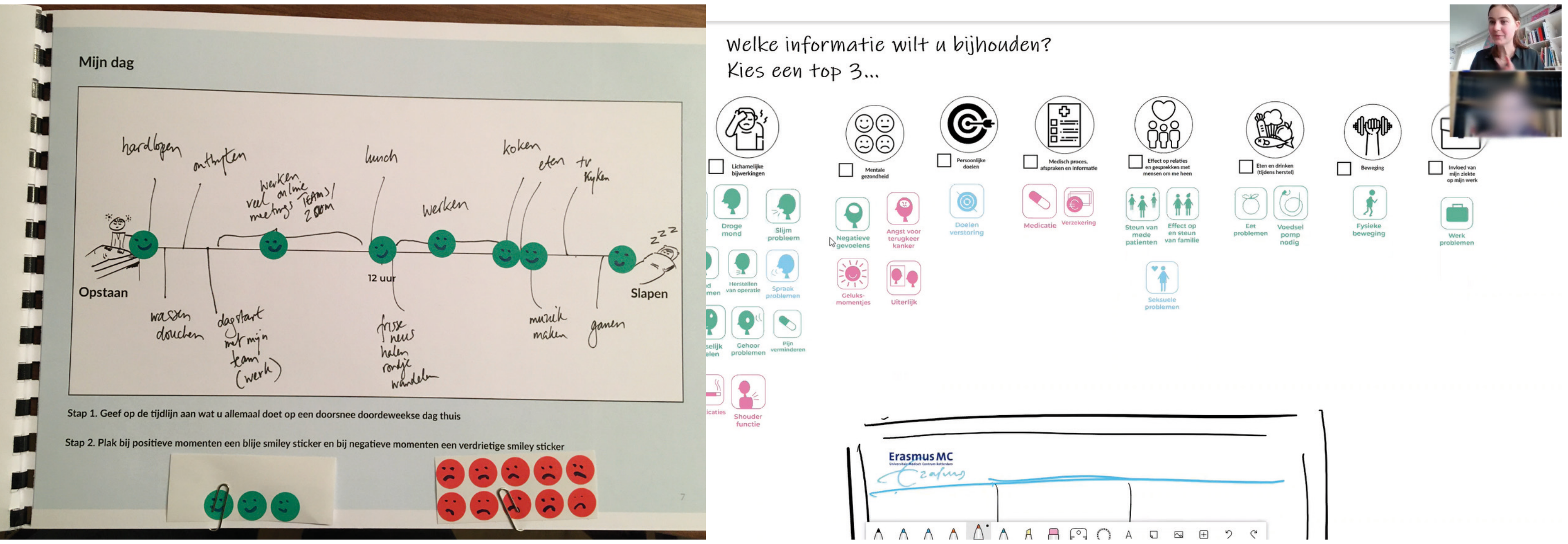


Figure 36. The two steps of contextmapping used; a sensitizing booklet (left side) and semi-structured online interview using visual tools (right side)

Sensitizing booklet

A sensitizing booklet was used for the preparation of both the interviewer and the interviewee. A sensitizing booklet is a workbook form of a cultural probe. As Gaver et al. explain, cultural probes are a collection of tasks that give clues about the lives and thoughts of people. In this way the researcher gets to know the patients, their thoughts and experiences before the interview. This helps in empathizing with them and preparing more in depth interview questions.

Next to the researcher the sensitizing booklet also helps the ex-patient to prepare for the interview. The ex-patient has the chance to think about past experiences so that he or she is more prepared to think about future possibilities, following 'the path of expression' from Sanders & Stappers (2012). As mentioned before the sensitizing booklet was created with the feedback of a diverse group of care professionals. It was set up using a conceptual model of patient empowerment and the choices that need to be made for the service system design as its backbone, see Appendix I. The booklet contains 7 tasks that give a better insight into the present and past experiences of ex-patients with regards to their lives, care and wellbeing in the follow-up phase. See Appendix J for a complete overview of the booklet. The booklets were send by post to the participants at least one week before the interview. The interviews were scheduled to be held after receiving the filled in booklets through post. Since 1 participant was not in the Netherlands, 1 booklet was filled in digitally.

Semi-structured interview

A semi-structured interview was used to get a more in depth understanding of the answers provided by the ex-patients in the booklets and to think together about the value and use of a patient dashboard. The semi-structured method was used to ensure similar questions were addressed throughout the interviews while maintaining the freedom to explore interesting topics more in depth. (Patton, 2002) The general structure of the interview can be found in Appendix K.

In short the interviews consisted of the following parts:
- Introduction of the project and introductory questions
- Part A: Asking more in depth questions on the answers given in the sensitizing booklet
- Part B: Thinking of a service system design together
  - o Step 1: Answering the WHAT
    What would you like to keep track of and why? What value does it bring? Do you have different tracking needs over time?
  - o Step 2: Answering the HOW & WHO
    How should the collected information be used? What action should be taken and by whom? How should the data be collected?
  - o Step 3: Answering the WHEN
    When would you like to keep track of and review your data? How frequent?
- Wrap up

Due to corona the interviews were done using video calling services. The videocall service used for the interview was chosen by the participants and varied from Zoom, to Microsoft Teams to WhatsApp video calling. 2 of the 9 participants had trouble with expressing themselves well through speech as a result of the treatment. These participants answered the questions by filling in a word document and answering some extra questions through email.

During part B of the interview supportive visuals were used to guide the conversation on the what, how, who and when. The set-up of part B is based on the service system design choices that need to be made as is shown in the model of Appendix I.

Data analysis

Written data was collected through the sensitizing booklets. Furthermore, the interviews were recorded so that they could be transcribed and no data would be lost. The interviews were transcribed following the general structure of the interviews.

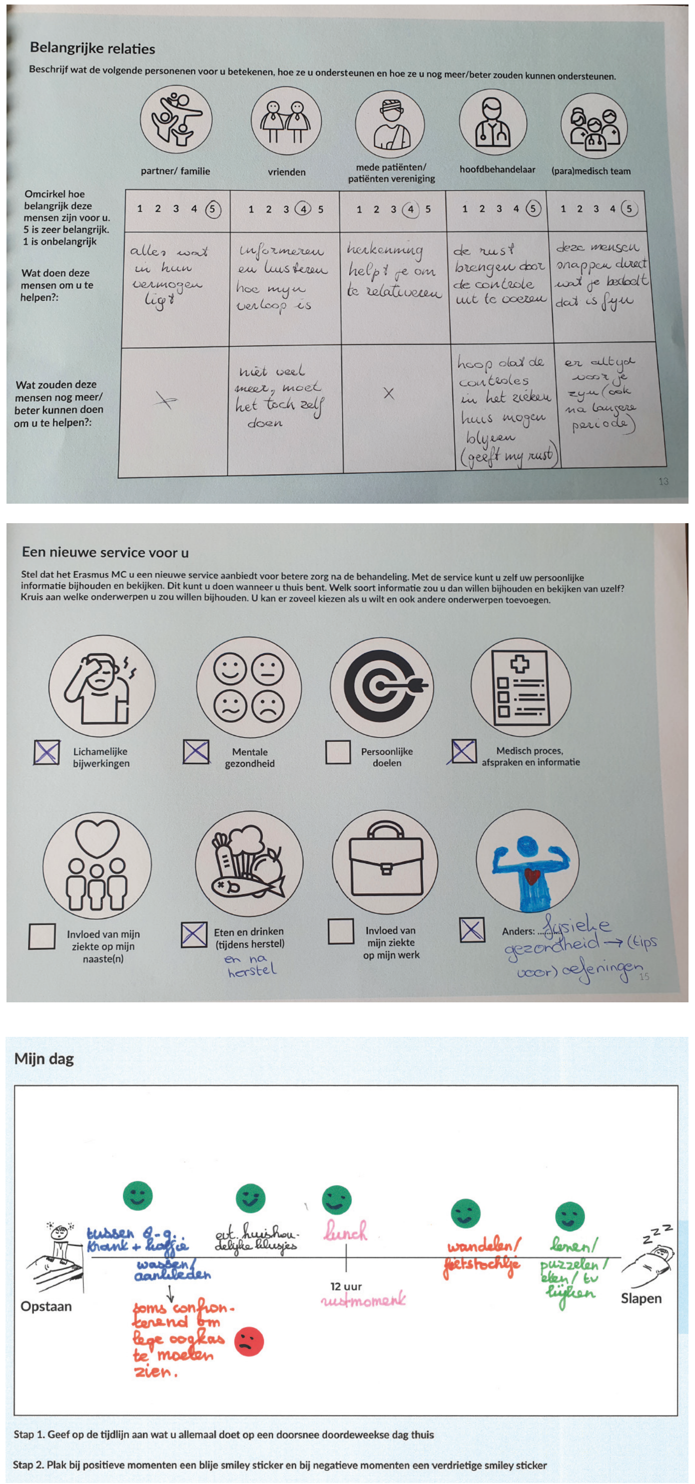
The transcripts and filled in sensitizing booklets were analyzed similarly to the data of the focus group session, using the thematic analysis method (Braun & Clarke, 2006).

Important quotes that helped to answer the research questions were highlighted in the transcript and put on post-it cards in mural. They were given a color so that they could be traced back to the participant ID. Then they were clustered to iteratively identify bigger overarching themes.

A theoretical thematic analysis is used for the data points participants missed in the overview, since the answers don't lead to more themes but rather to a direct insight into what is still missing in this overview.

3.5.5 Results

The results include both the filled in sensitizing booklets and the transcribed interview. Figure 37 shows some of the filled in booklets to give an impression of the results.



Belangrijke relaties

Beschrijf wat de volgende personenen voor u betekenen, hoe ze u ondersteunen en hoe ze u nog meer/beter zouden kunnen ondersteunen.

	partner/ familie	vrienden	mede patiënten/ patiënten vereniging	hoofdbehandelaar	(para)medisch team
Omcirkel hoe belangrijk deze mensen zijn voor u. 5 is zeer belangrijk. 1 is onbelangrijk	1 2 3 4 [✓ 5]	1 2 3 [✓ 4] 5	1 2 3 [✓ 4] 5	1 2 3 4 [✓ 5]	1 2 3 4 [✓ 5]
Wat doen deze mensen om u te helpen?:	alles wat in hun vermogen ligt	informeren en luisteren hoe mijn verloop is	herkenning helpt je om te relativeren	de rust brengen door de controle uit te voeren	deze mensen snappen direct wat je bedoelt dat is fijn
Wat zouden deze mensen nog meer/ beter kunnen doen om u te helpen?:	X	niet veel meer, moet het toch zelf doen	X	hoop dat de controles in het ziekenhuis mogen blijven (geeft mij rust)	er altijd voor je zijn (ook na langere periode)

13

Een nieuwe service voor u

Stel dat het Erasmus MC u een nieuwe service aanbiedt voor betere zorg na de behandeling. Met de service kunt u zelf uw persoonlijke informatie bijhouden en bekijken. Dit kunt u doen wanneer u thuis bent. Welk soort informatie zou u dan willen bijhouden en bekijken van uzelf? Kruis aan welke onderwerpen u zou willen bijhouden. U kan er zoveel kiezen als u wilt en ook andere onderwerpen toevoegen.

☒ Lichamelijke bijwerkingen
☒ Mentale gezondheid
☐ Persoonlijke doelen
☒ Medisch proces, afspraken en informatie
☐ Invloed van mijn ziekte op mijn naaste(n)
☒ Eten en drinken (tijdens herstel) en na herstel
☐ Invloed van mijn ziekte op mijn werk
☒ Anders: fysieke gezondheid → (tips voor) oefeningen

15

Mijn dag

Stap 1. Geef op de tijdlijn aan wat u allemaal doet op een doorsnee doordeweekse dag thuis

Stap 2. Plak bij positieve momenten een blije smiley sticker en bij negatieve momenten een verdrietige smiley sticker

Figure 37. Some of the results of the filled in sensitizing booklets

Thematic map

An overview of the identified themes can be found in figure 38. The larger themes have a color, the smaller themes linked to these larger themes are represented by plain text. The themes are clustered around the two most important themes:

- Information on what you can expect to go through, its impact and solutions/tips
- Check your own (mental) health more frequently

The 13 bigger themes (colored) are briefly discussed below. For better insight into what quotes led to these clusters see Appendix L, that includes a link to the Miro Board.

Information on what you can expect to go through, its impact and solution/tips

This was the biggest group found. Patients express that they want to know what to expect. They want to know what side effects can be so that they are better prepared for what might come.

Right now patients do not have a good idea of what the consequences of the disease and treatment are on their lives. They need to figure out everything themselves but they would like help in preparing themselves and solving issues after treatment. Even though doctors might talk about the consequences during a consultation, patients cannot remember everything and want to be able to look it over and respond to it at calm moments at home.

Patients that did get some information on what to expect from peers expressed the value this brought to them. Simply having the steps to come explained to you, helps to bear it better, you are more prepared and know what you can expect.

Patients also express the need for getting solutions/tips for dealing with the issues that arise after treatment. They would for example have liked to know tips for balanced eating; eating healthy while also eating comfortably (fluidity of foods).

"I would like a list with: this is what you can expect, this is what you can do about it, with this you have to go back to the doctor, this will go away etc."

"I want to know if I feel something if it is from treatment, if I can do something about it or need to accept it."

Increase awareness for psychosocial wellbeing, a holistic perspective

Patients do not only want to be prepared for the physical side effects to come, but would also like to become more aware of the psychosocial issues. They expected that this would be a standard topic discussed by the hospital, but instead they sometimes had to find out about it themselves the hard way. Especially since these are issues that can continue for a long time and can come very unexpectedly, they are important to address.

"Mental issues, fears, those are things that can continue for a long time."

"Before my friends told me about the hard process they had been through, I had never thought about how my disease affected them and that shocked me."

Sharing experiences and info with peers is important

Patients expressed that they like to ask other peers what problems they experience and how they deal with them. They like to share their experiences to help one another and share insights that they gathered along the way. This helps to have a positive perspective and get new inspiration for solutions and what to expect.

"We have a nose app where we ask peers: how do you do this? What is your experience?"

"Peer support is very important, they understand you, you are not alone, you can help others."

Low threshold ability to ask short questions/concerns

Patients expressed that often when they have a concern it is a small question and it can be hard to share this question. Calling and making an appointment can feel like a big unnecessary step if you just want an answer to a short question. Therefore, patients expressed that they would prefer more direct contact with a care professional when they have a question. Sending a message can already feel like a lower threshold. They want one place where they can go to, to share how they are doing and get simple and useful tips.

"If I have a small question I would like short lines."

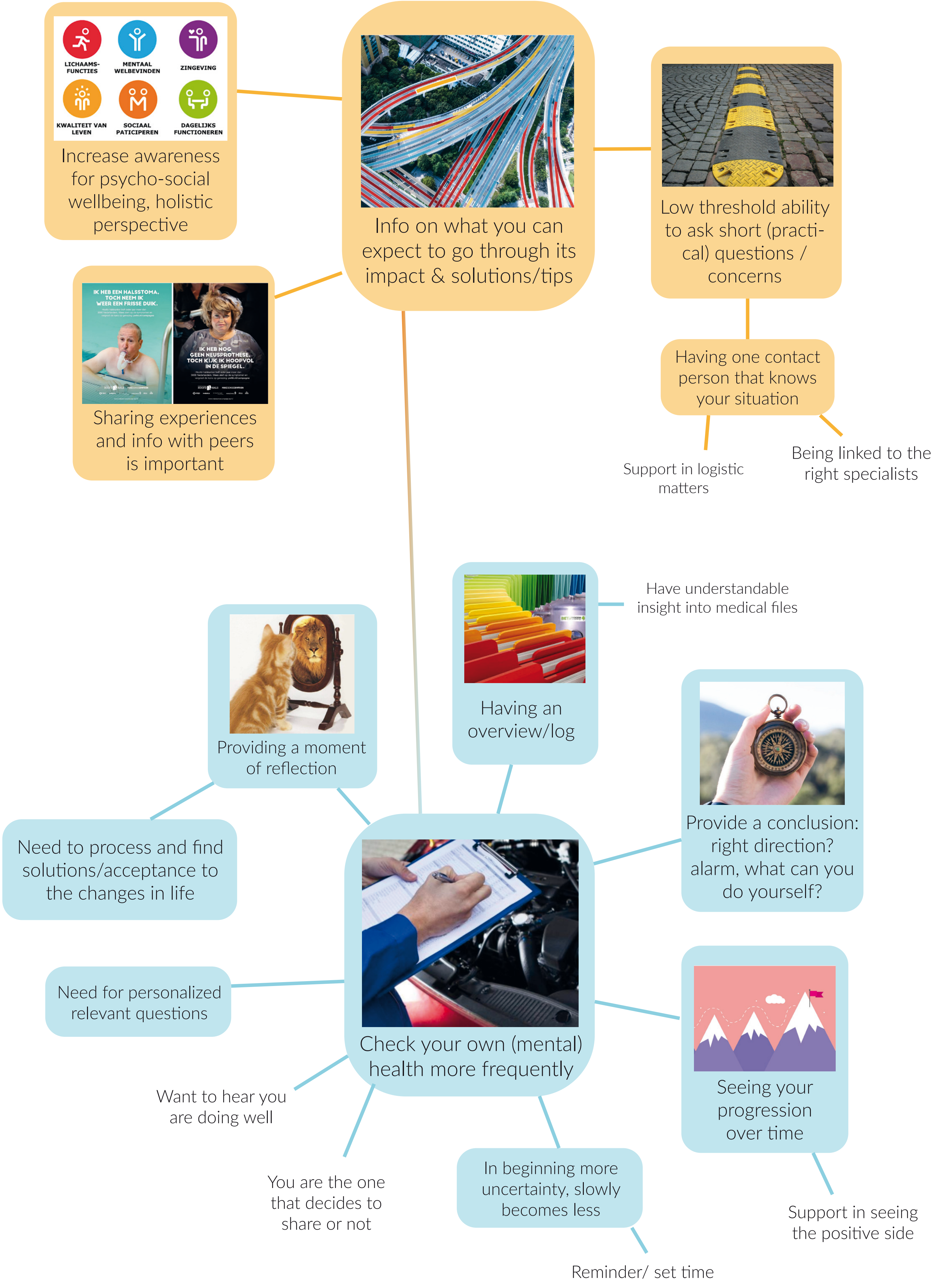


Figure 38. Thematic clusters overview

Having one contact person that knows your situation
This links to the theme of 'low threshold ability to ask short questions/concerns'. Patients express that they want one person that they can go to that knows their situation and functions as the bridge between other experts if needed.

"It would have been nice to have one contact person after treatment."

Check your own (mental) health more frequently
Patients want to have more regular check points in between the consults. Especially mental health is something that you need to track more regularly, as it can change significantly over time. Additionally, these checks make sure you do not forget how you felt. This also links to the next topic of having an overview.

"I would like to share my story in between consults."

Having an overview/log
Patients want to have an overview of how they are doing so that they can remember it, have it written down and can use it in conversations with others. They would like to have an overview of everything in one place. This includes their own health tracking, but also what they discussed with their doctor.

"I would use the app as a recall of how I felt. One week ago I know but otherwise it is hard to remember."

Provide a conclusion: right direction? Alarm? What can you do yourself?
Next to being able to look back at how you are doing, they would also like to see conclusions from their answers. When something they are experiencing is serious and needs to be looked at, they would prefer to receive an alert in between consults. They want to know if they are heading in the right direction and if not, what they can do about it. Do they need to discuss this with their doctor or can they do something about it themselves.

"If you can conclude things from your answers you can start doing something with it; go to a doctor or do something yourself."

Seeing your progression over time
This overview also helps to see your progression over time. You can record your highs and lows and see progress to give you hope and grip. They want to see their own improvement.

"I made photos and looked in the mirror to know this is how I am now and it will only get better. I could see my progress."

In the beginning more uncertainty, slowly becomes less
Patients expressed the need for such a check to be bigger in the beginning when you have a lot of insecurities. It depends on what phase you are in what you want to track and how often you want to track it. Therefore, patients would like to indicate themselves when and how frequently to track their health and be reminded about it.

"It depends on which phase you are in, in the beginning it is daily business but then the ghost disappears to the background."

Providing a moment of reflection
Patients expressed that the value of checking your own (mental)health more frequently was also that it will provide a moment of reflection. It helps to create awareness of how you are doing. You need a trigger to start thinking about how you are doing, as you do not always do this naturally. One ex-patient used the sensitizing booklet as an example. By filling it in the participant gained more insight into how she saw herself as a person.

"A quiz about your emotions can help to create awareness about how you are doing, you don't know yourself how you are doing so then questions can help."

Processing and finding solutions/acceptance to the changes in life
This reflection can help to process your feelings and find solutions/acceptance to the changes in your life. Finding acceptance is a continuous process, but it helps to frame and anchor things that have changed differently. You need to take small steps until you improve and it becomes normal. Talking to others can help this process.

"Dealing with side effects was a discovering journey, searching on internet, talking to peers and finally adapting."

New data points
15 new concern points were added to the HNC patient specific concerns. The results of all the HNC patient concerns will be discussed in the chapter 3.6.

3.5.6 Discussion

Using a sensitizing booklet really helped to get more in depth insights during the interviews. Furthermore, patients expressed that they had enjoyed filling it in and it had created a moment of reflection for themselves. Through the booklets and interviews the 4 sub-sub-questions posed at the beginning could be answered.

What is it like to be a HNC patient in the follow-up phase?
The ex-patients expressed that right after treatment when you enter the follow-up phase it can feel like you fall into a black hole. You need to figure out everything yourself and need to find ways to deal with the consequences of the disease and treatment. Either by finding solutions or acceptance. They can feel quite alone in this discovering journey. Sharing experiences with peers helps to see how others deal with similar issues.

What do they think is important to address in a new service?
In the sensitizing booklets as well as the interviews it was found that patients want to know about the possible consequences of treatment and how to deal with these. They want to have an overview of how they are doing and what they can expect, not only on the physical aspects but also on the psychosocial aspects. An overview of how they are doing over time can help them to remember what they felt and see progression. Furthermore, patients want to have short lines with one care professional as a contact person if they have a small question.

What value do they see in a patient dashboard?
The value they see in a patient dashboard that provides this overview is; preparation for what might come, insight into how they are doing and seeing progression. In short, it could show them where they stand and what they can expect. This information can provide the confidence to reflect on their wellbeing and to change something if necessary. Ex-patients expressed that the value of having an overview of how you are doing, brings the value that you can remember it, see improvement, act if necessary and have everything together in one place.

How and when would they want to interact with the system?
Ex-patients wanted to have both an application for the mobile phone as well as a dashboard on the computer. The phone provides flexibility, you can access it anywhere you are. The computer provides a better overview when you want to read longer things.

Almost all ex-patients stressed that the need for the frequency of use will slowly diminish after treatment. In the beginning there is a lot of insecurity and you would want to check it more often. After a while things become more normal and you are starting to find solutions or accept things, life goes on. Therefore, the timing and frequency of using the system should be able to adjust to the needs of the patient. Ex-patients did also mention the importance of a reminder so that you remember to keep track of your wellbeing.

Limitations
Due to the corona pandemic the interviews had to be done through online video calling services. This sometimes made communication more difficult with microphones that were not working properly or connections being lost. These technical difficulties caused for some of the interviews to take longer than the planned hour, however no parts of the interview were skipped so no information was missed due to this medium.

Since 2 of the 9 ex-patients participating in this study had difficulty with an oral interview, they answered the questions in writing. Even though this also provides a good insight, the gathered information was a lot less compared to the oral interviews since no follow-up questions could be asked which naturally happens in oral interviews.

Key chapter insights

- Patients want to be prepared for the physical and psychosocial consequences after treatment.
- Patients want to have an overview of how they are doing and see progression.
- Patients find peer support important.
- Patients want a low threshold ability to ask short questions.
- Patients want the system to fit their personal needs and concerns.

3.6 Summary patient concerns

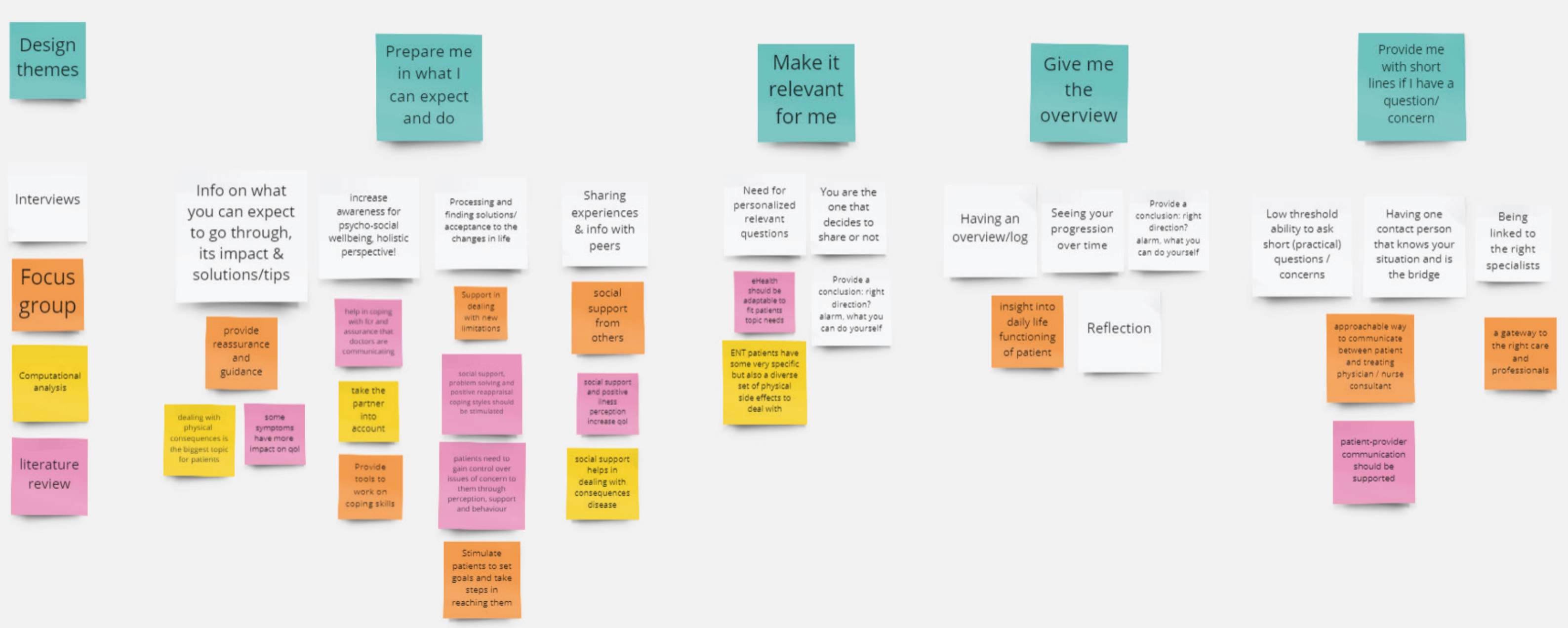


Figure 39. Overview of clustering process

3.6.1 Introduction

This chapter aims to summarize the contextual inquiry as described in the 4 previous chapters and answer sub-question 2: What are the concerns of head and neck cancer patients in the follow-up phase? Chapter 3.1 showed how these 4 different studies all contribute to answering this question.

The insights from these 4 different studies were clustered again using a thematic analysis (see figure 39). The outcome is 4 main patient concerns that I discuss in this chapter.

3.6.2 4 main HNC patient concerns

Figure 40 shows an overview of the 4 main concerns that were discovered:

1. Prepare me for what I can expect and do
2. Make it relevant for me
3. Give me the overview of how I am doing
4. Support me when I have a doubt

These concerns are explained in more detail below.

Prepare me for what I can expect and do
In chapter 3.2 it was found that the physical side effects are the point of greatest discussion for cancer patients in general. Also, for HNC patients specifically, most topics of concern belong to the physical concerns (chapter 3.3). It was seen that patients are looking for recognition, advice and solutions on these topics from peers. They ask questions on what they can expect and what they can do about it. This need for knowing what to expect was also found in the ex-patient interviews where it was the biggest topic discussed (chapter 3.5). This need comes from the uncertainty that the phase after treatment brings with it. Not only do they want to be prepared for the physical consequences, but also the psychosocial consequences are something they want to be aware about.

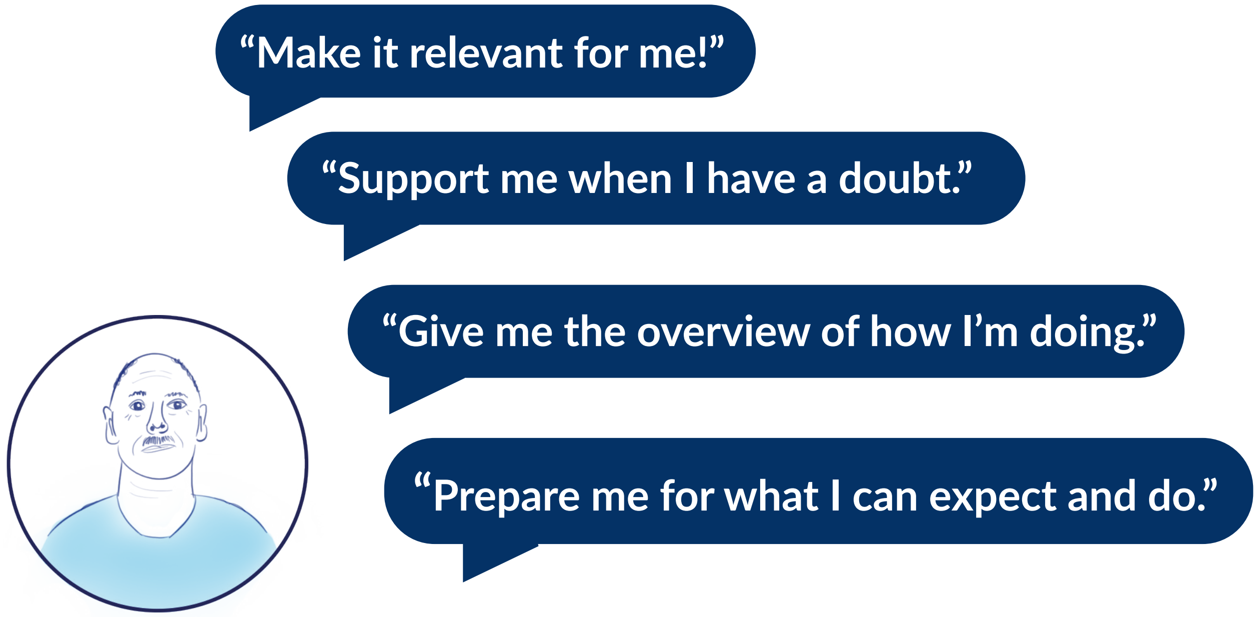


Figure 40. Overview of the 4 bigger concerns found for HNC patients

Make it relevant for me
In these 4 studies different topics of concern to HNC patients were found. An overview of all the topics found can be seen in figure 24 on the next page. It was found that patients experience concerns on different levels such as their physical functioning, their mental wellbeing and social relationships. All in all, HNC patients have a lot of different concerns as a consequence of their disease and treatment. However, it was also found that it differs greatly which concerns are experienced by a patient and which concerns are more important for the patient to address for their quality of life. Therefore personalization is of importance to patients. This was also found both in the focus group with care professionals (chapter 3.4) and the ex-patient interviews (chapter 3.5).

Give me the overview of how I am doing
In the ex-patient interviews (chapter 3.5), patients expressed the need to have an overview of how they are doing, to see their progression and check if it fits within the normal boundaries or whether they have to sound the alarm. Care professionals also expressed the importance of more insight into the wellbeing of patients in the focus group session (chapter 3.4).

Support me when I have a doubt
Patients find peer support important. This can be seen by the need for patients to ask questions to peers on online community platforms (chapters 3.2 and 3.3). This was also found in the ex-patient interviews (chapter 3.5) and focus group session (chapter 3.4). Ex-patients also expressed the need to have one contact person in the hospital that they can ask questions to. They want to have more direct contact if they have a doubt about something.

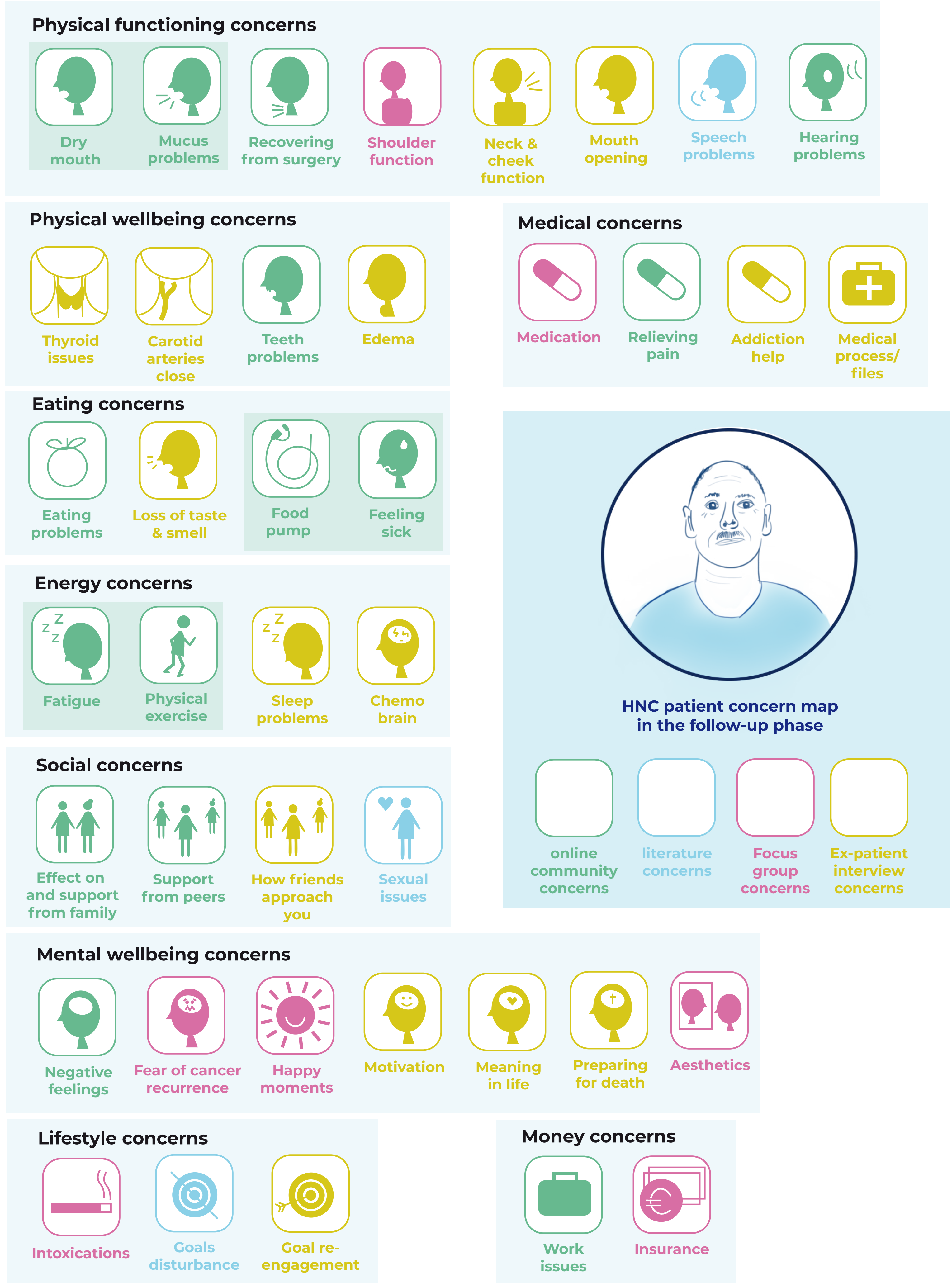


Figure 41. Overview of the HNC patient concerns found in the different contextual inquiry studies

3.6.3 HNC patient concern map

In chapters 3.3, 3.4 and 3.5 data was gathered on the different specific concerns for HNC patients. The insights from each research step were taken to the next step to be verified and added upon.

Figure 41 shows a patient concern map that shows the different concerns found in the different analyses. I created different categories for the concerns:

- Physical functioning
- Physical wellbeing
- Medical
- Eating
- Energy
- Social
- Mental wellbeing
- Lifestyle
- Money

This overview shows the diversity and scale of concerns that HNC patients have to deal with and creates a more in depth understanding of the different concerns through examples.

The overview is a general overview gathered from the different sources. It stresses again the importance of personalization, as not all patients have the same concerns.

3.6.4 Discussion

In this closing chapter, I have summarized the insights from the 4 different studies I conducted, described in chapters 3.2 to 3.5. These were summarized in 4 main HNC patient concerns and a patient concern map that shows specific examples of different categories.

By summarizing the concerns in this way, I have a good overview of the most important insights to use for creating a design vision. In the next chapter I link these insights with the patient empowerment model discussed in chapter 2. By combining these two chapters I can gain a better insight into what it means to design for increasing patient empowerment for HNC patients in their follow-up phase.

Limitations

I clustered the insights myself to create the 4 main patient concerns. Therefore, the results may be more biased compared to when such data is analyzed by multiple different researchers. Due to the time limitations of this project, it was chosen to do this analysis by myself.

Key chapter insights

- The 4 main concerns of HNC patients are being prepared, personalization, have the overview and get support if in doubt.
- HNC patients have a lot of different concerns. Some on the physical level others on the psychosocial level. This makes personalization key.

Sub-question 3: What should the design **offer** in order to address the concerns of head and neck cancer patients and increase patient empowerment?

4. VALUE SPECIFICATION

In this chapter a design vision is presented by combining the insights from chapters 2 & 3.

4.1 Link patient empowerment

4.1.1 Introduction

In this chapter I combine the insights from chapters 2 and 3. Both chapters explore a different part of the main aim of this project which is to increase patient empowerment for HNC patients in the follow up. Chapter 2 looked at patient empowerment and proposed a model that can be used when you want to design for patient empowerment, including a definition, attributes, antecedents and the positive consequences. In chapter 3 I looked at the concerns of head and neck cancer patients in the follow up phase and found 4 main concerns. By combining these chapters we get insight into how the concerns of HNC patients link to patient empowerment, where do they overlap? This overlapping point is important to keep in mind for the design process. In the next chapter I introduce my design vision which is based on this combination of insights.

4.1.2 Aim & method

This chapter serves as a first step to answer sub-question 3: what should the design offer in order to address the concerns of HNC patients and increase patient empowerment?

This is done by answering the sub-sub-question: How do the concerns of HNC patients link to the model created for designing for patient empowerment? This chapter aims to get insight into where concerns of HNC patients overlap with the created model to give focus for the design vision and requirements. In order to combine these insights I looked at how I could map the 4 main concerns found in the contextual inquiry on the model. By mapping these concerns the relation can clearly be seen in a visual way.

4.1.3 Results

Figure 42 shows the result of mapping the concerns on the model. As you can see, the 4 main patient concerns are either situated in the antecedents or attributes part of the model. This is logical, since concerns are focused on people's needs. Therefore, it makes sense that they are situated in the model at the parts where the things needed for patient empowerment are described. It is not about the outcome or consequence. The lower part of the patient empowerment model is also most interesting for me as a designer, since this is something that your design can contain. The consequences are the desired outcome of your design. The lower elements can directly be linked to designed elements that the service will need to incorporate. 3 parts of the patient empowerment model are highlighted by placing the 4 concerns. I discuss these below.

Patient-centered approach
The patient concern 'make it relevant for me' links to the antecedent of a patient-centered approach as described in chapter 2.4. Both personalization (Breeman et al., 2020; Graffigna et al., 2013; Kondyakis et al., 2020) and co-designing with patients (Ahaus, 2021; Lu et al., 2021) can help to make it more relevant for them. This can be seen as a requirement for the design as it is both a concern of patients and an antecedent for patient empowerment.

Social support & provide ability
Another requirement for the design is providing social support and the possibility to ask questions. Patients expressed this in their concern 'Support me when I have a doubt'. They want to be able to communicate with care professionals and peers. The antecedent of social support, as described in chapter 2.4, also addressed both patient provider communication (Fillion et al., 2009; Hochstenbach et al., 2017; Lu et al., 2021) and peer support (Skirbekk et al., 2018). Furthermore, the attribute of 'provide ability', as described in chapter 2.3, is about providing the possibility for patients to ask their questions (Johnsen et al., 2017). Providing this support and ability will be a requirement for my design as it comes back as an antecedent, attribute and concern.

Knowledge & skills
I think that the patient concerns 'Prepare me for what I can expect and do' and 'Give me the overview of how I'm doing' link to the attributes knowledge and skills (Bravo et al., 2015; Fumagalli et al., 2015; Johnsen et al., 2017; Zimmerman, 1995), that are described in chapter 2.3. Patients want to have the knowledge and skills to be prepared for what they might come across in the follow-up phase. Furthermore, they want insight into how they are doing as this can provide them with the knowledge they need to take action to change their health for the better. This overview and preparation can be seen as key elements that the design should include.

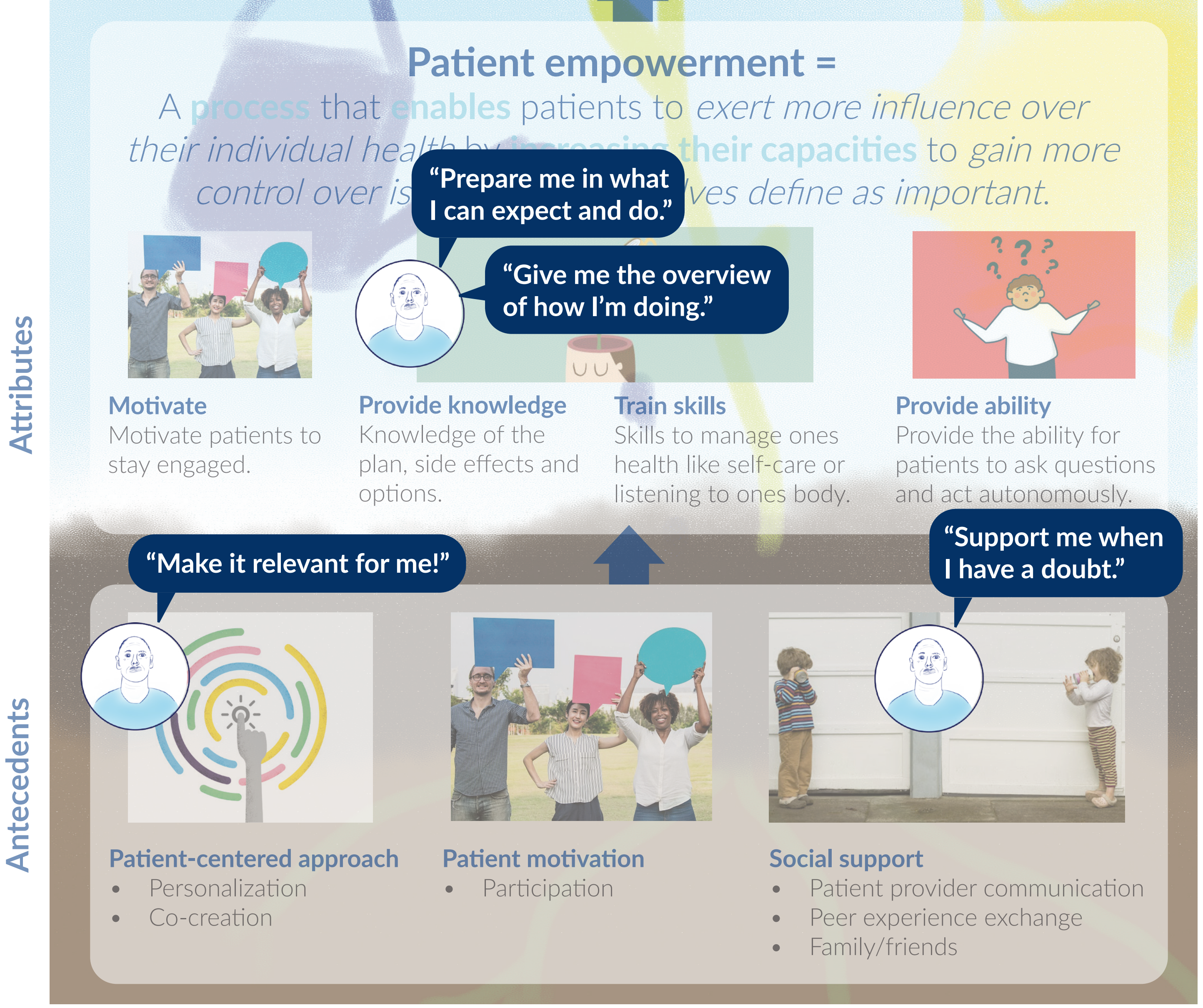


Figure 42. Overview of the 4 concerns found for HNC patients linked to the model of patient empowerment as shown in chapter 2

4.1.4 Discussion

By combining the found patient concerns with the created model of patient empowerment, we can see some important requirements for the design that can help to create a design vision.

It is interesting to see that patient concerns very much overlap with the antecedents and attributes of the patient empowerment model. All antecedents and attributes touch upon the patient concerns, except for motivation.

The topic of motivation is both an antecedent and attribute in the patient empowerment model, however it was not discussed much by the patients. It is interesting to see that patients did not mention motivation that much. Probably because it is something more intrinsic. The patients focused mostly on their extrinsic concerns. They talked about what information and opportunities they want from their environment. As designers, we should however not overlook the intrinsic antecedents and attributes needed for patient empowerment. This is harder to design for but it should be kept in mind especially considering the long term motivation to keep using a design. For the scope of this project the main focus will be on the elements that were also found to be patient concerns, so motivation will not be the focus. In the recommendations I will however briefly look at how this aspect might be incorporated in future development.

Key chapter insights

- Requirements for designing for patient empowerment are a 'patient-centered approach' and 'social support'.
- Providing knowledge and skills for preparation and insight into your wellbeing are important elements that the design should incorporate.
- Motivation is not the main focus of this project but is important to consider when designing for patient empowerment.

4.2 Design vision

4.2.1 Introduction

I created a design vision for this project by combining the insights of the contextual inquiry and the model of patient empowerment as seen in the previous chapter. With this vision I aim to answer sub-question 3: What should the design offer in order to address the concerns of head and neck cancer patients in their follow-up phase and increase patient empowerment?

This vision provides a promise that the solution should provide to the HNC patients in the follow up phase. It incorporates the definition of patient empowerment and the most important attributes that were also stressed in the contextual inquiry; prepare the patient and give them the overview. These link to providing the relevant knowledge & skills.

4.2.2 Design vision

The design vision will be used as inspiration for the design phase. It goes as follows:

An **OVERVIEW** that enables you to gain more **CONTROL** in dealing with **ISSUES OF CONCERN TO YOU** in the turbulent and uncertain phase after treatment.

To provide a better understanding of what this vision means a metaphor is used. The metaphor is going on a canoe trip (see figure 43).

The canoe represents the tool that I will design. Without a canoe you will be lost swimming in the turbulent stream of the water. The canoe provides the possibility to be above the water and have the overview. You can see where you have been, where you are now and where you might go. You can see where other people are canoeing and figure out what you might expect ahead. If you know you have a high chance of encountering a waterfall on your route, you can prepare yourself for the jump you need to make.

This is similar for the journey of a cancer patient after treatment. Patients suddenly have to deal with new issues, they enter unknown and turbulent waters. Therefore, they want to have an overview so that they know how they are doing, how others are dealing with these waters and can prepare themselves for the route ahead

Know where you have been
Clearly seeing where you come from can help you to understand where you are now. You can see your progression and get insight into your wellbeing. Based on this insight you can gain a better perception of your individual state and it can be a prompt to take action if needed.

Know where you are now
By checking where you are now, how your wellbeing is at this moment, you can sound the alarm if necessary and take action to follow a new route if necessary.

Know where you might go
Patients want to know what they might expect on the different routes ahead. What waters did their peers encounter? How did they deal with this? What solutions are out there? If patients know better what they can expect they can become more confident in knowing what is part of their disease and how to deal with it. Even though the side effects won't become less, they can bear them better if they know about them up front.

4.2.3 Conditions for the design

In order to be able to provide this design promise 3 conditions have to be provided by the eHealth solution that relate to the antecedents of patient empowerment. These are elaborated below.

Possibility to share your doubts
As discovered in the theme exploration of patient empowerment in chapter 2, but also in the contextual inquiry in chapter 3, it is important to have short lines when the patient has a question or doubt (Fillion et al., 2009; Hochstenbach et al., 2017; Johnsen et al., 2017; Lu et al., 2021).

- Having a log of your wellbeing
- Seeing your progression over time

- Insight into how you feel at this moment
- Sound the alarm or change your course if necessary

- Being able to prepare yourself for what might come

Figure 43. A mataphor for the design promise of providing the patient with overview

Content should be personalized to the patient
This condition was also found both in the contextual inquiry (chapter 3) as well as the theme exploration (chapter 2). The content should be relevant to the individual patient that uses the eHealth solution (Breeman et al., 2020; Graffigna et al., 2013; Kondyakis et al., 2020). A way to achieve this is co-creation with the patient (Ahaus, 2021; Lu et al., 2021). Another way is using intelligent systems to personalize the content.

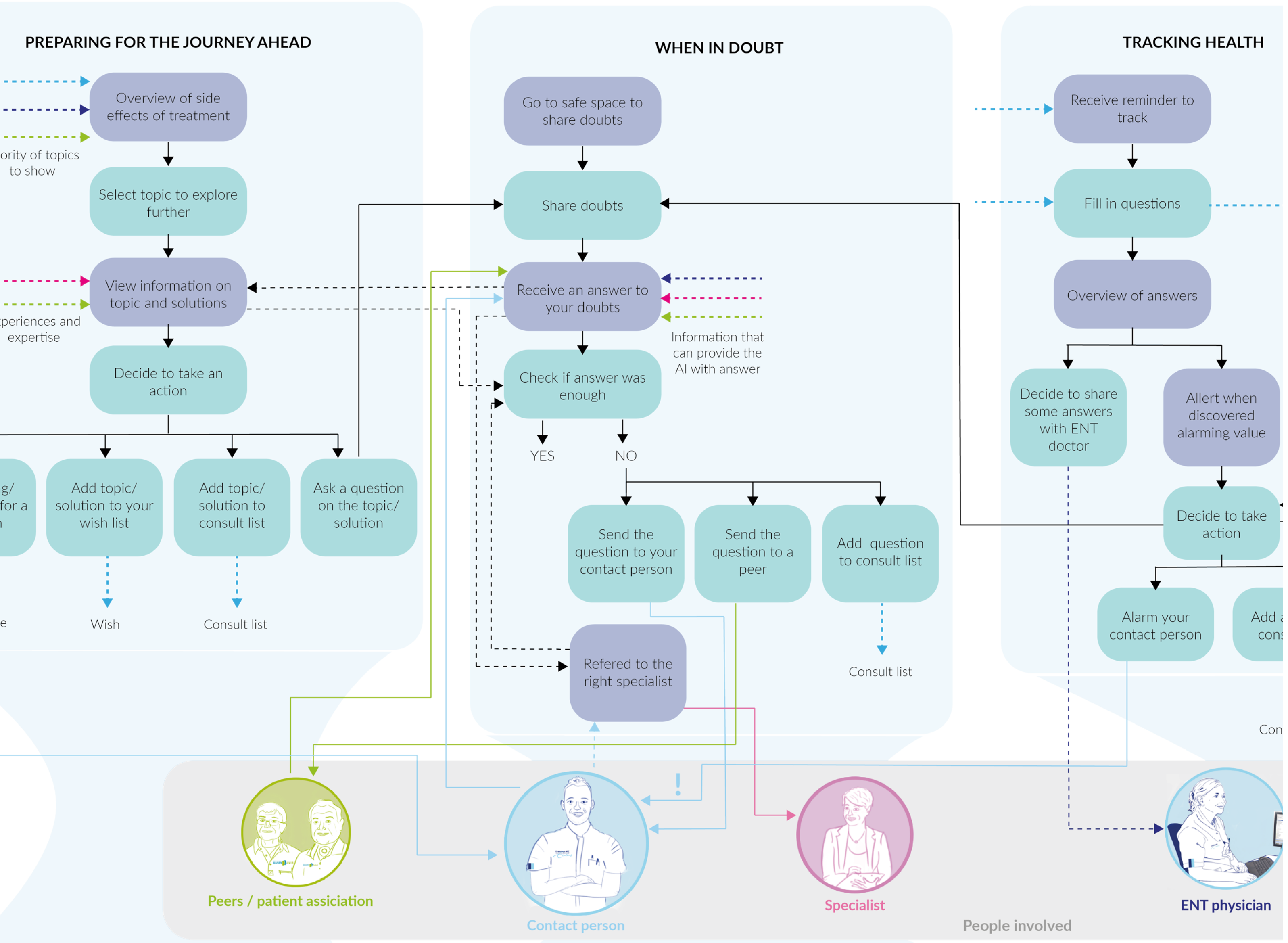
Peer experience exchanges should be included
In order to provide good expectations and increase patient empowerment, peer support is of great importance. This was also found in the contextual inquiry (chapter 3) where peers were found to help each other with providing expectations and solutions. It is also part of the social support antecedent as shown in chapter 2, where Skirbekk et al. (2018) found that is can provide positive social comparison.

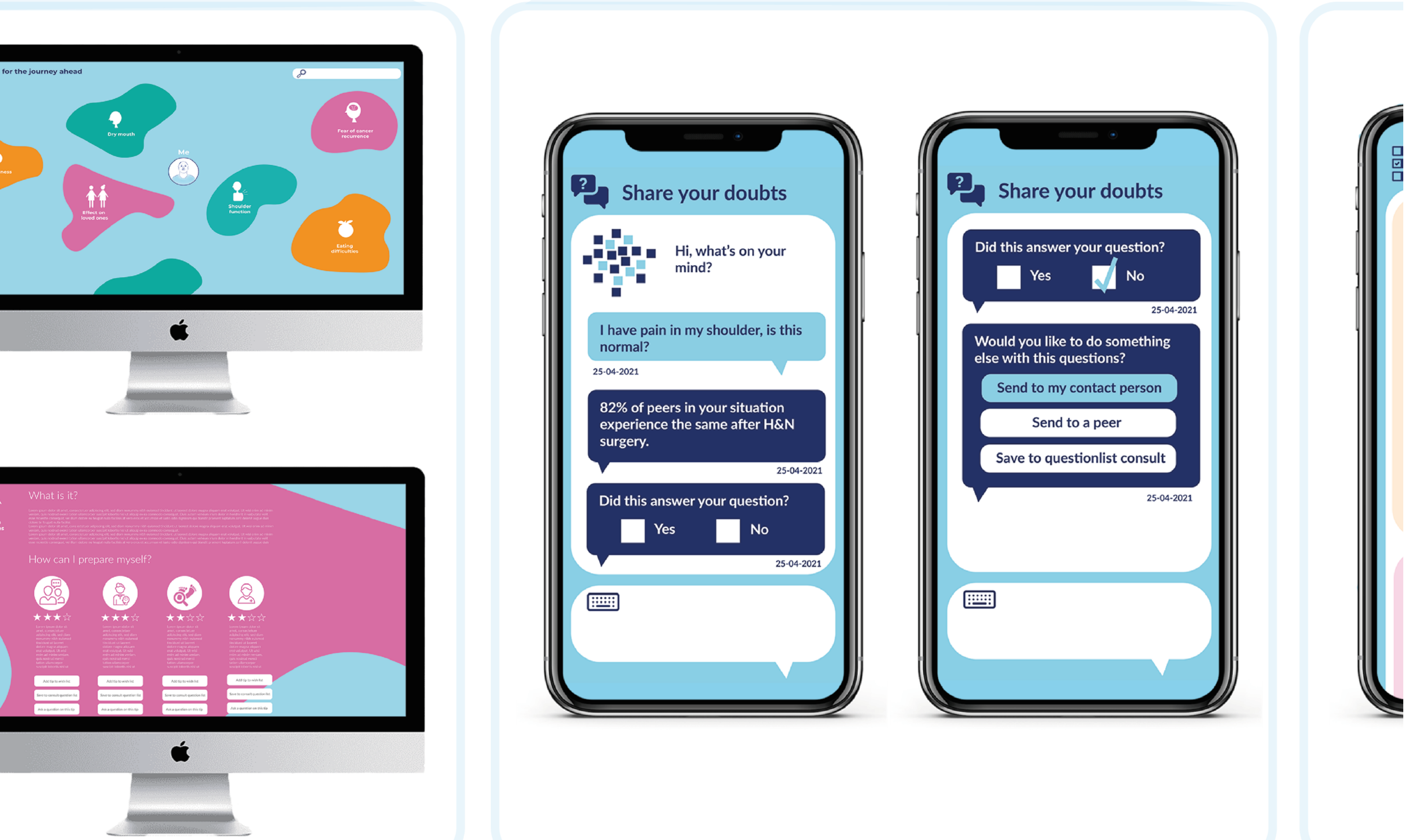
4.2.4 Discussion

The design vision and conditions for the design previously described will be used in the next phase of this project as input for the ideation. In the next chapter I look at how the service system can be designed in order to deliver this promise.

Key chapter insights

- The design promise for this project is to provide the patients with an overview that enables them to gain more control to deal with issues of concern to them.
- This overview should show where the patient has been, where he is now and where he might go.
- Conditions for the design are the possibility to share doubts, personalized content and exchanging peer experiences.





Share your doubts

Hi, what's on your mind?

I have pain in my shoulder, is this normal?
25-04-2021

82% of peers in your situation experience the same after H&N surgery.
25-04-2021

Did this answer your question?
☐ Yes ☐ No
25-04-2021

Share your doubts

Did this answer your question?
☐ Yes ☑ No
25-04-2021

Would you like to do something else with this questions?
Send to my contact person
Send to a peer
Save to questionlist consult
25-04-2021

Sub-question 4: How should the service system be **designed** in order to deliver the design promise?

5. DESIGNING & PROTOTYPING

In this chapter I ideate on how the service system should be designed based on the insights from the previous chapters and the design vision. I also show how a prototype is created to further investigate the desirability of the designed concept and discover things to improve.

5.1 Chapter introduction

In this chapter I aim to answer sub-question 4:

> 4. How should the service system be **designed** in order to deliver the design promise?

The way to answer this question is through an ideating process. In my first ideation I did not have my design vision yet, just the insights from the contextual inquiry and patient empowerment model. In this first ideation session I looked at designing a system that could integrate the different HNC patient concerns and increase patient empowerment. In chapter 5.2 I start with explaining this ideation phase in which I envisioned the design system for the first time to create a better understanding of what the design should deliver as a design promise.

By creating a first concept for a service system I could iterate upon my design vision. What was really the value that I wanted to create with my design? What does my design promise to its users? This was answered by looking at my first concept and the model that linked my contextual inquiry and patient empowerment exploration (chapter 4.1). I realized that an **OVERVIEW** is the most important and can lead to the other concerns if it incorporates the right things in the overview. I already explained in chapter 4.2 what this overview means and what it should include.

After having created a design vision, I could really start to ideate on how the application could convey this design vision. Therefore, in chapter 5.3 I answer the question: How can an overview be created that increases the capacity of patients to deal with issues of concern to them in the phase after treatment? The main design question here is how the application could show an overview of past, present and possible future experiences as explained in chapter 4.2. This chapter is more about the actual app design and less about the system. The system aspect will be incorporated once more after the prototype test when recommendations for improvement are provided in chapter 6.3.

Figure 44 shows an overview of the ideation process. However, ideation is not a linear process it is a cycle of constant iterations that happen in between. Going back and forth between designing and prototyping. This is also what I tried to show in figure 44 where you can see that iterative cycles are made.

The created idea in chapter 5.3 is used to create a prototype application to test. How and why this prototype is created, is discussed in chapter 5.4. As you can see in figure 44 the prototype test that is presented in chapter 6.2 leads to a new iteration for both the app ideation and service system ideation. This is discussed in chapter 6.3 where suggestions for improvements of the system design are discussed.

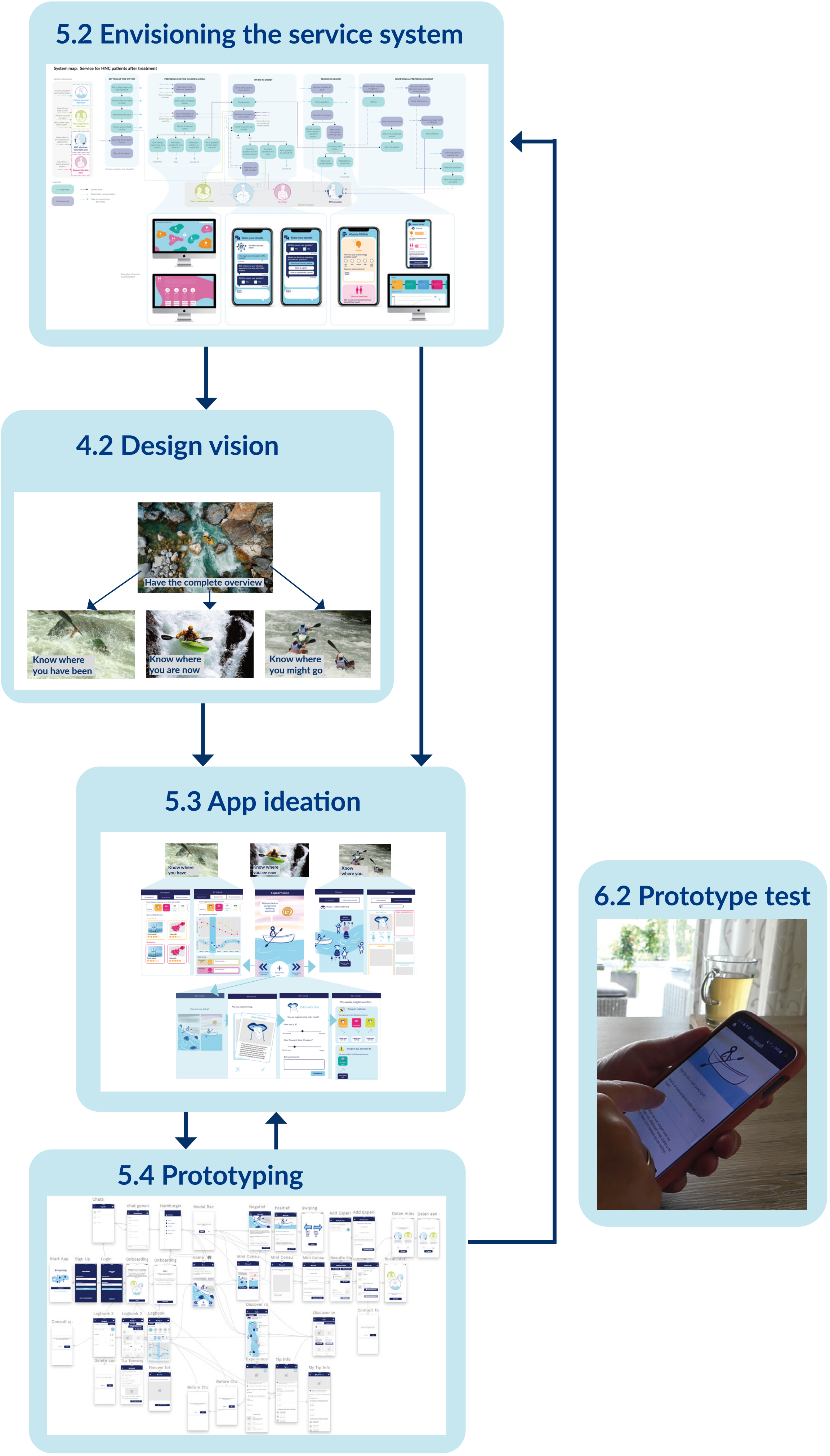
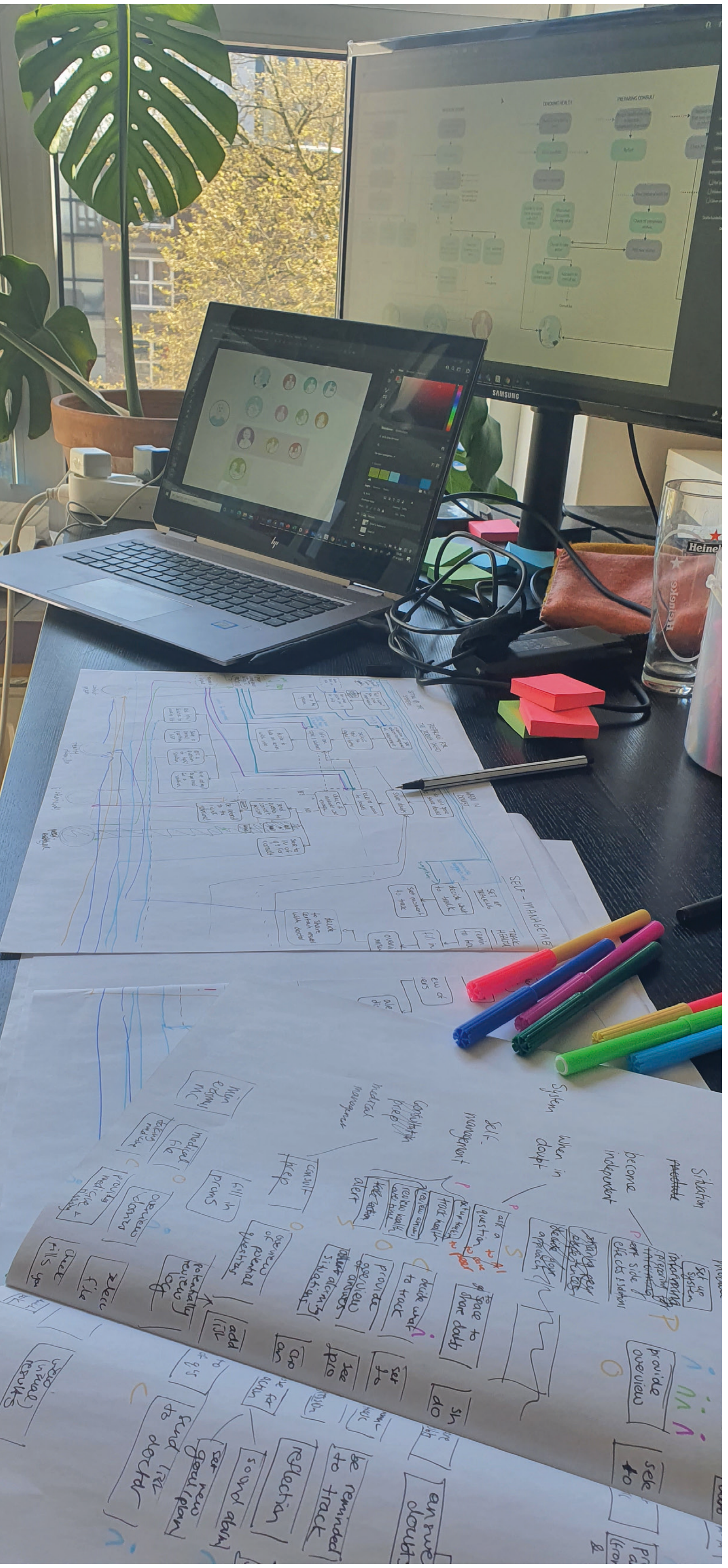


Figure 44. Ideation process overview

5.2 Envisioning the service system



5.2.1 Introduction

I started of my ideation process with the found patient concerns of the contextual inquiry and my exploration of patient empowerment. In order to translate these insights into a service system, I ideated on what data such a system should include and how the flow of use should be for the system. What data do you want to collect? What data do you want to provide? I then created some visuals to provide examples of how this abstract system could look like in the form of an app/desktop website. I presented this idea for a service system at my midterm and it was actually a starting point for discussion. It triggered the conversation to think of a design vision. This is how I got to the design vision as stated in chapter 4.2. I realized I needed to find focus for my design. By first thinking of what the service system should look like I had a better idea of the actual promise that I wanted to deliver. Creating this first idea of a system helped me to understand that providing an overview for the patient is the most important aspect of the system. And that this overview consists of previous, present and possible future experiences.

5.2.2 Data bases

I started ideating with thinking about what data would be needed in order to provide a personalized overview where patients can see how they are doing and what they can expect. Figure 45 shows an overview of the data bases that I think are needed to create a relevant overview for HNC patients in their follow up phase. These are:

- A medical data base with input from the treating ENT physician
- A personal patient data base with input from the patient themselves
- A data base with peer experiences with input from different peer platforms
- An expert info data base with input from different experts

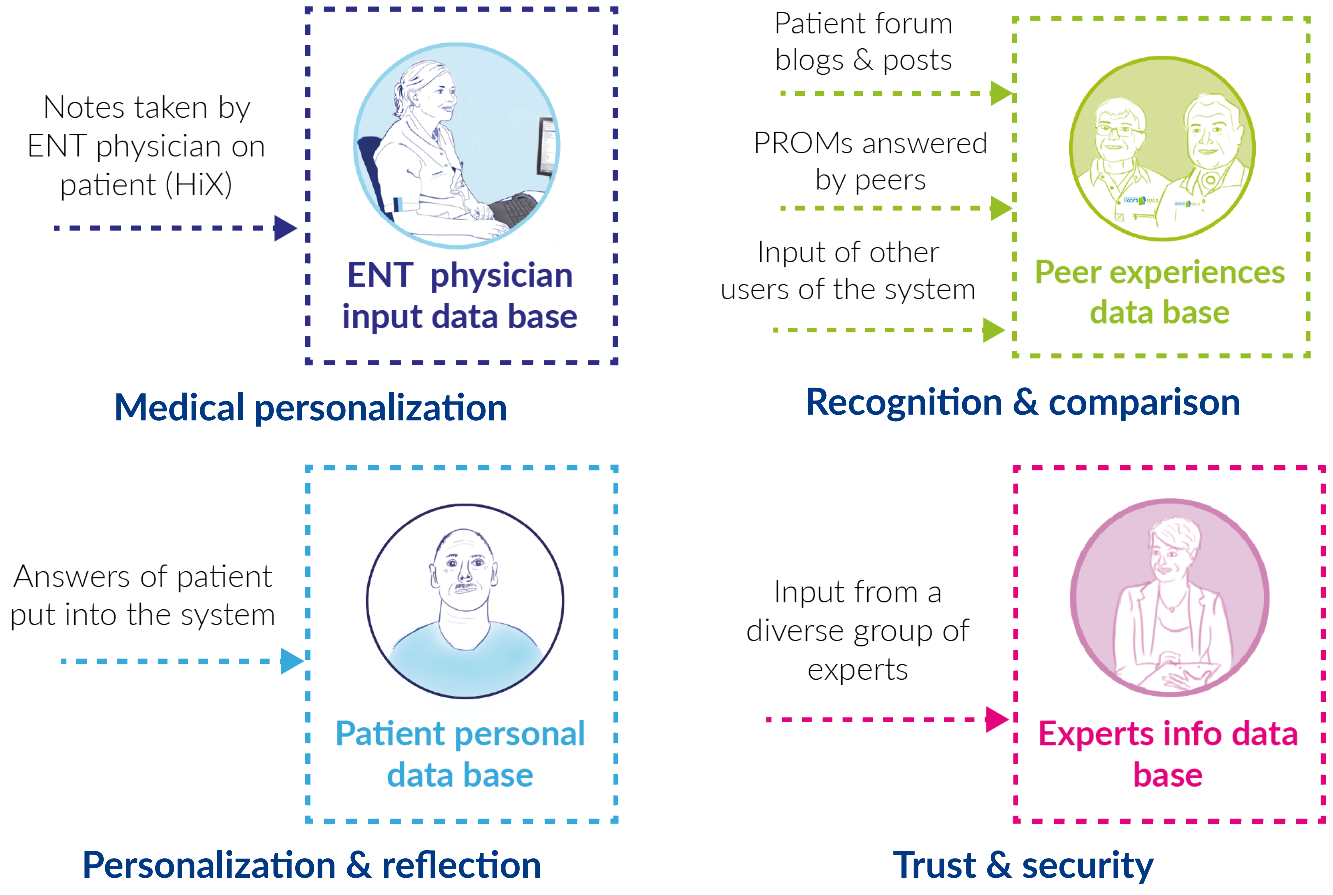


Figure 45. Data bases service system with their input and meaning

ENT physician input data base
A medical data base is needed to create the right medical personalization for the patient so that the system can be personalized based on the treatments and care a patient has had. This is necessary to predict relevant side effects in the future and experiences to track. The treating physician can put in a suggestion for what experiences the patient should track. When a patient has had surgery the treating physician can for example ask to track shoulder function. And when a patient has had radiotherapy he can put in a dry mouth in expected side effects. In this way the app can become personal to the medical situation of the patient. The input for this system can come from the EPF (electronic patient file) that already exists in the HiX system of the Erasmus MC.

Patient personal data base
By using the system the patient can create a personal data base of experiences and preferences. This is needed to personalize the app to the preferences of the patient and also to calculate possible future experiences. If a patient for example starts to experience fatigue more frequently the app can give more personal suggestions based on the patient input.

Peer experience data base
The system would also need input from peers so that it can make a realistic prediction for what patients might experience in the future and can provide a benchmark for the patient. Showing peer experiences can help for recognition and comparison. Patients can relate to the experiences of others, feeling like they are not the only one and can compare themselves to how others feel to see if what they feel is normal. The input can come from multiple sources. Experiences can come from online forums and blogs as explored in chapter 3.2 & 3.3. They could also come from the questionnaires filled in by patients through the Healthcare Monitor. Furthermore, patients can share their experiences within the system, in this way other user experiences shared in the application can also add to the peer database.

Expert info data base
I think that the system needs input from experts to provide trust and security in the sense that the information provided is correct and up to date. Different experts like dentists, physiotherapists and psychologists could help to make the information provided by the system actual.

During the ideation for the system I took into account that data from these different databases can be provided or collected by the system. During the ideation I looked at when this system should provide and collect which data and how it should do this.

5.2.3 System design

As mentioned before, when initially ideating for a service system I did not have my design vision yet. Instead I focused on incorporating the 4 needs of HNC patients as defined in chapter 3.5 and looked at when and how to provide/collect the data needed to provide a personal overview. This let me to create a system that includes 5 main parts:

1. Setting up the system
2. Preparing for the journey ahead
3. When in doubt
4. Tracking your health
5. Reviewing & preparing consult

'Setting up the system' and 'tracking your health' link to the concern 'make it relevant for me'. 'Preparing for the journey ahead' links to 'prepare me for what I can expect and do'. 'When in doubt' links to 'support me when I have a doubt'. 'Reviewing & preparing consult', 'Preparing for the journey ahead' and 'tracking your health' all provide for the need 'give me the overview'. In this way the different parts of the system link to the 4 main HNC patient concerns found. I discuss the 5 parts of the system briefly below.

Setting up the system

In order to make the system personalized, next to the input from the treating physician it is also important to collect some preferences of the patient when first accessing the system. Preferences on what patients find important in their life, what they want to track, when they want to track and their desired contact person are some examples of things that you would want to set up the first time you use the system. The contact person can be the treating physician, a nurse consultant or general practitioner for example. From the interviews it was found that different patients prefer different people as their contact person. The nurse consultant was most popular among the interviewees.

You also want to see the input data from your doctor this first time you log in to know what his/her recommendations are for tracking. Furthermore, a tour of the system can be good to show at the start to give insight into how the system works, what will happen with the collected data and how to use the system. Figure 46 shows the different steps of the set up. These different steps help to make the system more relevant for the patient and to provide a kick start to use the system.

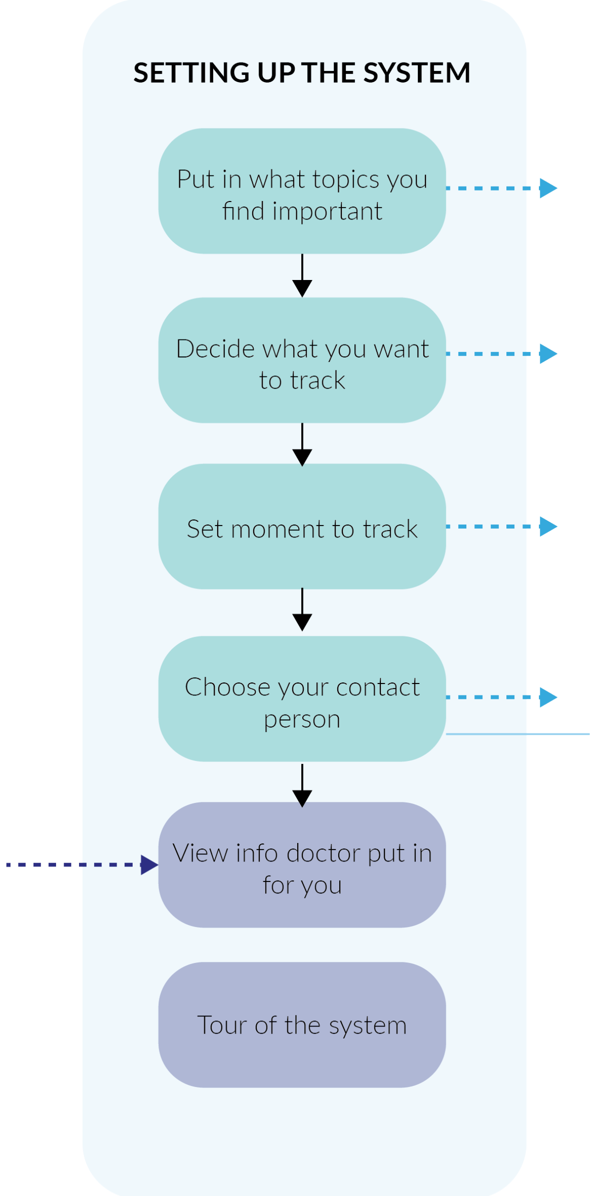


Figure 46. Setting up the system

Preparing for the journey ahead

One of the main concerns of HNC patients was that they want to be prepared for what they might expect. The system should provide an overview of relevant side effects based on the data input from peer experiences, the treating physician and the patients themselves. Based on these inputs, the system can prioritize which side effects are relevant to show to this patient at what time. Patients can then dive deeper into these topics and explore related information and tips provided by experts and peers. In the system I imagined for patients to have an easy possibility to take action on these topics by providing 4 different actions. Figure 48 show an example of how the dashboard could look like that provides this preparation possibility.

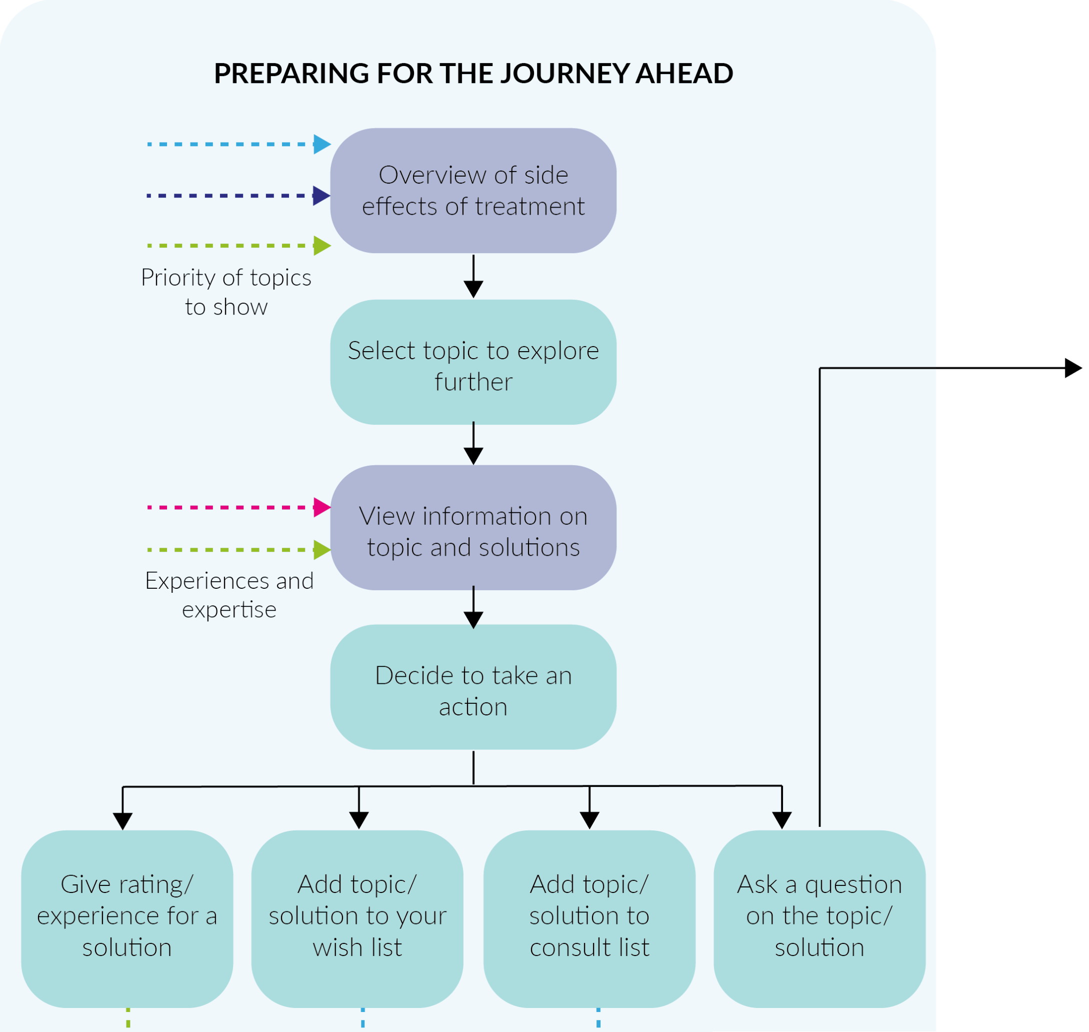


Figure 47. Preparing for the journey ahead system

I will now explain the 4 action buttons as shown in figure 47. You can rate the topic or solution to provide other peers with insight into the value/ importance of it. You can add a topic or solution to your wish list so that it is shown in your personal overview and you can more easily review it later on. You can add a topic or solution to your consult list so that you can immediately create a question about it for your next consult with your treating physician. You can also ask a question about the topic or solution going to the 'when in doubt' function.

Figure 48 shows an overview of how this could look like in an interface. In this example you can see that the possible physical and psychosocial side effects are presented as islands. Islands closer to the patient mean that they are more relevant for the patient in this stage. The different colors show that it is either about a physical, mental or social effect. When an island is clicked you see the screen presented at the bottom of figure 48. Asking a question links us to the next part of the system; 'when in doubt.'

Figure 48. Preparing for the journey ahead visual examples

When in doubt

When a patient has a doubt they should be able to share it in a safe space. This links to their need to get support when they are in doubt. In this system I have envisioned an AI to answer the questions posed by patients based on the different data it has from the system databases (see figure 49). First the answer is provided using this data, then the system checks whether the question of the patient is answered. If not it can send the question to a peer or to the preferred contact person.

Figure 50 shows an example of how such a chatting system with an AI could look like when the patient wants to share a doubt. It is chosen to first go for an AI, as it might filter a lot of questions that can be answered with the available information, and by doing so relief work pressure from the care professionals. The system or the contact person can then refer to the right specialist if needed.

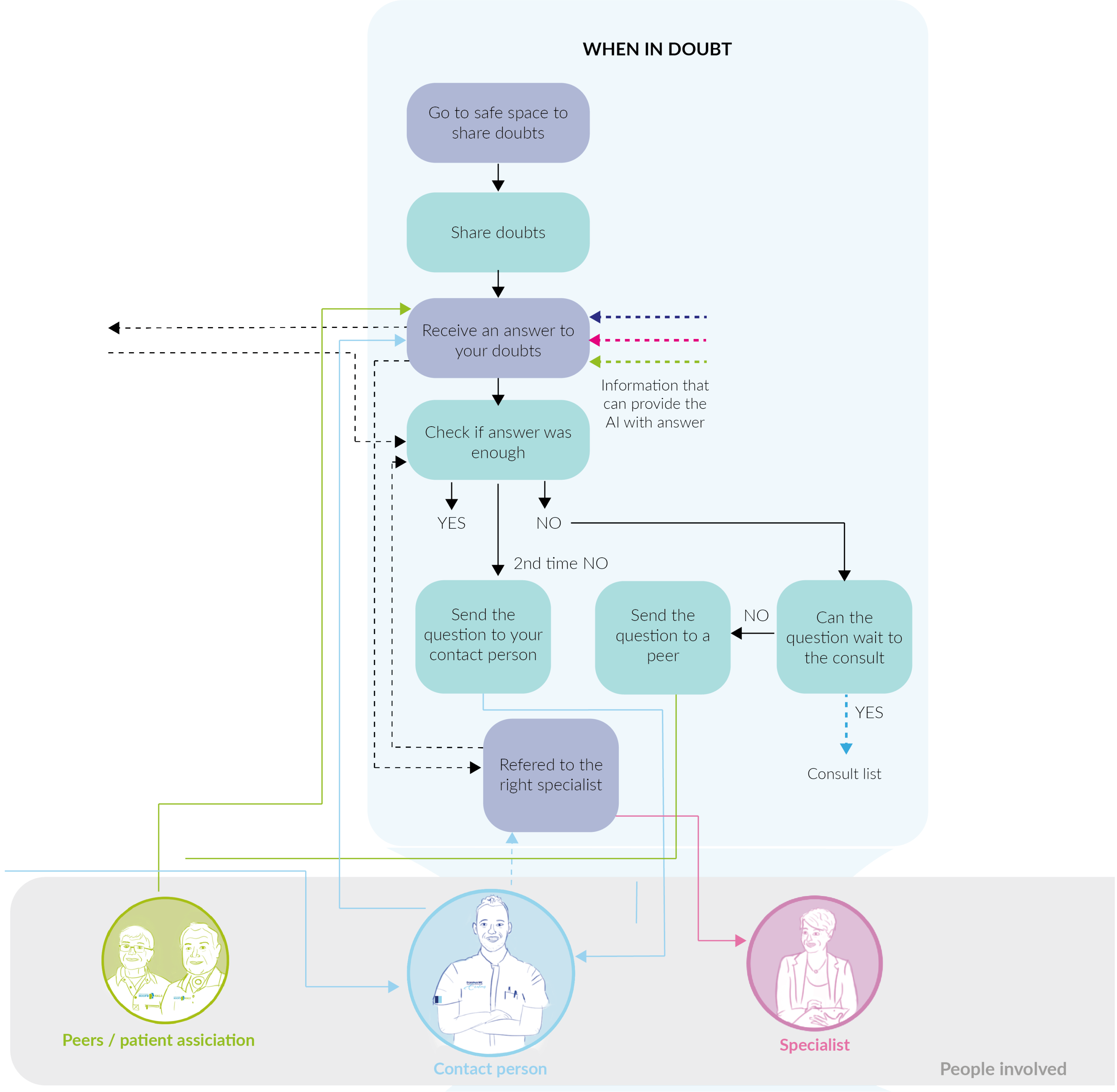


Figure 49. When in doubt system

Hi, what's on your mind?

I have pain in my shoulder, is this normal?

25-04-2021

82% of peers in your situation experience the same after H&N surgery.

25-04-2021

Did this answer your question?

☐ Yes ☐ No

25-04-2021

Did this answer your question?

☐ Yes ☑ No

25-04-2021

Would you like to do something else with this questions?

Send to my contact person

Send to a peer

Save to questionlist consult

25-04-2021

Figure 50. When in doubt visual example chat

Tracking health

This part of the system is about knowing how you are doing at this moment. Figure 52 shows how the flow of this part of the system works. First the system reminds you to check your own health by filling in some questions. The answers provide you an insight into your health and can be shared with your health care professional. If an alarming value or result is discovered, this should be notified and contact with the treating physician should be easily accessible. Figure 51 shows an example of how the tracking and insight overview could look like. Other low emergency options are also provided if the alarm is not too bad, but it does call for extra action from the patient, like asking a question about it during the next consult or finding solutions for this problem through the platform. This brings us to the final part of the system 'reviewing and preparing consult'.

Weekly PROMs

Fatigue

How was your overal energy level this week?

○ very low ○ low ○ neutral ○ high ○ very high

Leave an extra comment:

Effect on loved ones

Did you ask your loved ones how they felt last week?

Weekly PROMs

Overview

Fatigue

Your energy is already higher than last week! :)

Effect on loved ones

It looks like you have paid less attention to the effect on your loved ones this week. Here is what you can do:

View suggestions for this topic

Share your doubt

Alarm contact person

Figure 51. Tracking health visual example

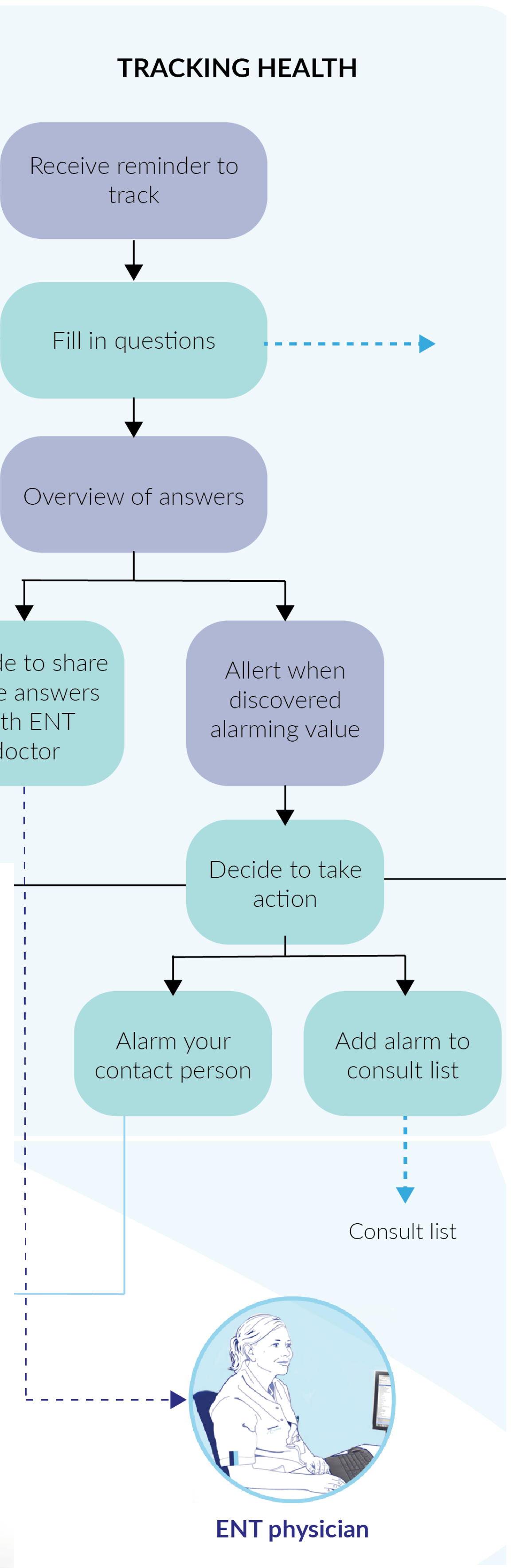


Figure 52. Tracking health system

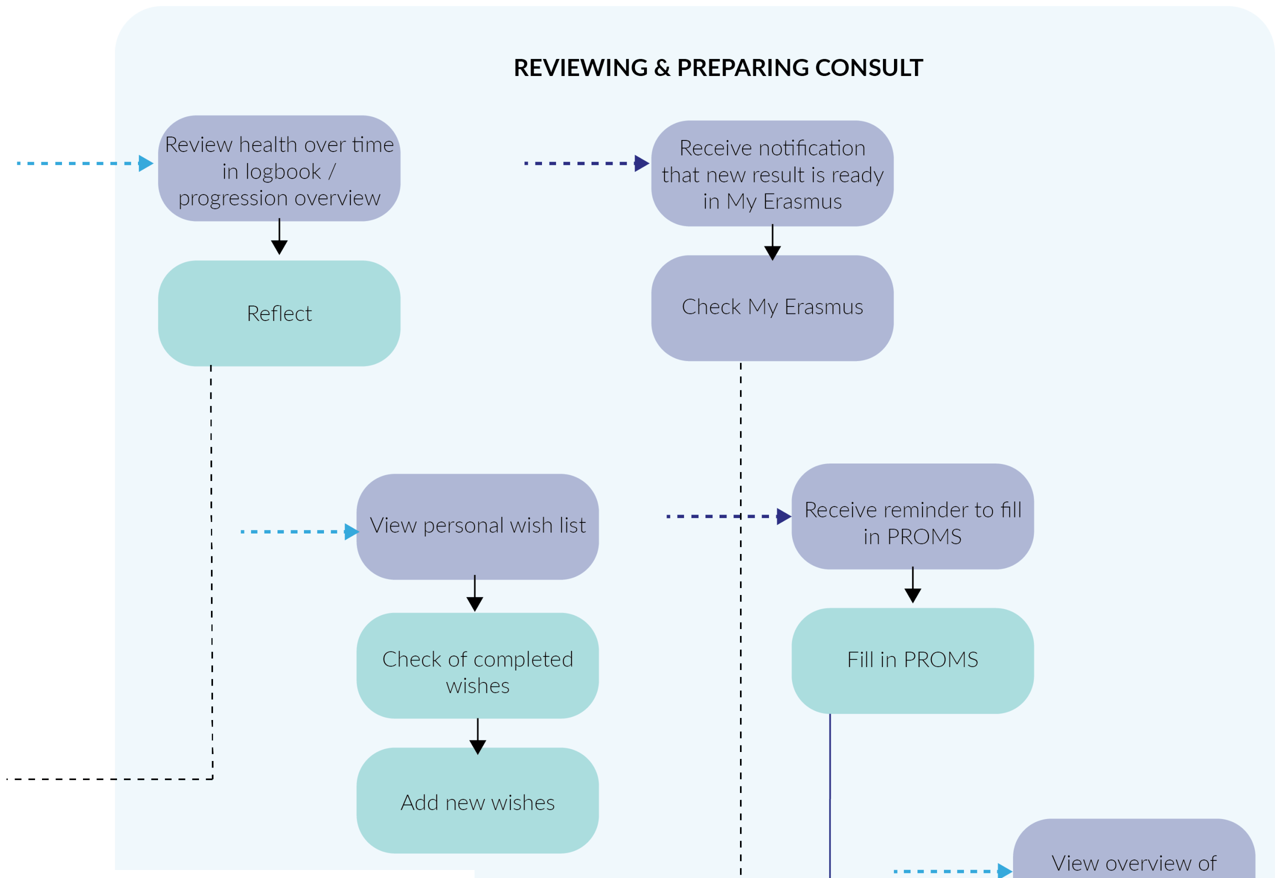


Figure 54. Reviewing system

Figure 53. Reviewing visual example

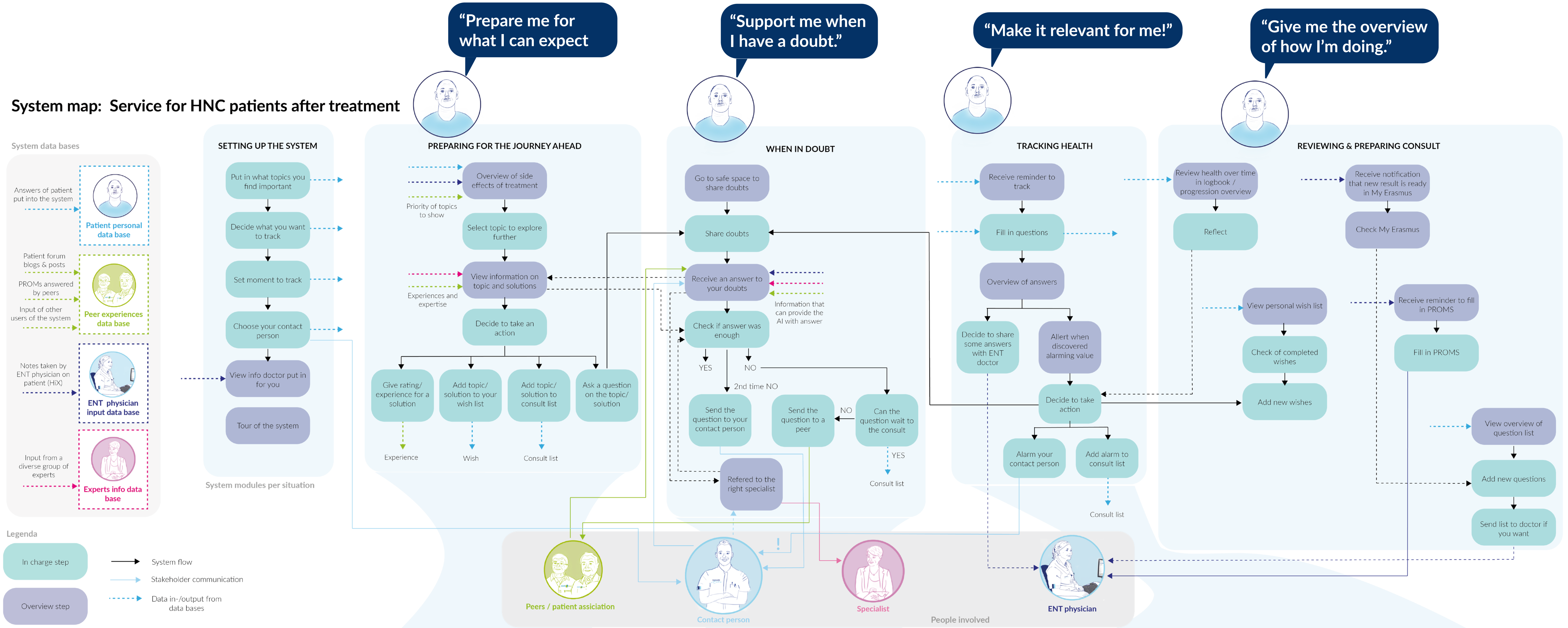
Reviewing and preparing consult

The last part of the system provides an overview of saved experiences, tips and questions. It is like a logbook that can show you how you have been doing over time and functions as a way to remember your questions and experiences. This part of the system also helps to prepare for your consultations by linking to other systems of the Erasmus MC like My Erasmus and the Healthcare Monitor. In this way, and by offering an easy way to collect your questions for the next consult, it can prepare patients for their consultation. Figure 54 shows an overview of the different elements this part of the system could contain. In figure 53 you can see an example of how an overview of experiences over time could look like.

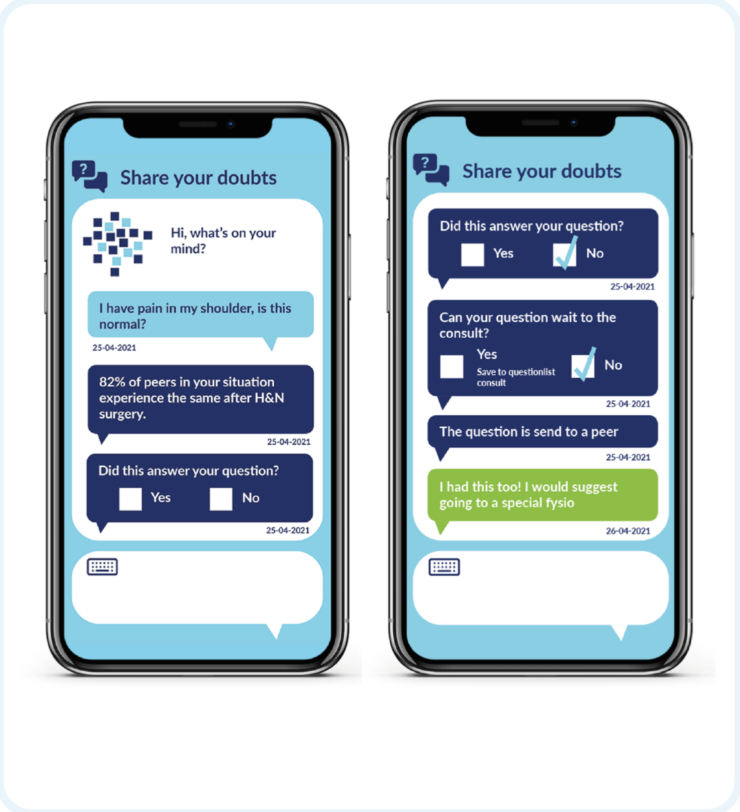
Complete system

The complete picture of the idea for the service system can be found on the next pages in figure 55. It shows the system service map including the data transmissions, relations between the different parts and which parts relate to which HNC patient concerns.

System map: Service for HNC patients after treatment



Examples of service manifestations


Share your doubts

Hi, what's on your mind?

I have pain in my shoulder, is this normal?
25-04-2021

82% of peers in your situation experience the same after H&N surgery.
25-04-2021

Did this answer your question?
☐ Yes ☐ No
25-04-2021

Share your doubts

Did this answer your question?
☐ Yes ☑ No
25-04-2021

Can your question wait to the consult?
☐ Yes
Save to questionlist consult
☑ No
25-04-2021

The question is send to a peer
25-04-2021

I had this too! I would suggest going to a special fysio
26-04-2021


Weekly PROMs

Fatigue

How was your overal energy level this week?
○ very low ○ low ○ neutral ○ high ○ very high

Leave an extra comment:

Effect on loved ones

Did you ask your loved ones how they felt last week?

Weekly PROMs

Overview

Fatigue

Your energy is already higher than last week! :)

Effect on loved ones

It looks like you have paid less attention to the effect on your loved ones this week. Here is what you can do:

View suggestions for this topic

Share your doubt

Alarm contact person

Figure 55. Complete overview of the designed system with visual examples and links to the 4 main patient concerns

5.2.4 Discussion

As mentioned before, ideating on a system based on the 4 main patient concerns finally led to creating a design vision. By visualizing the idea for this system, I realized that the main value that I want to bring to patients is having an overview. An overview of their previous experiences (reviewing and preparing consult), of their current experiences (tracking health) and their possible future experiences (preparing for the journey ahead). Whilst also incorporating the two important elements of making it relevant for the patients and providing them with social support. These are also two antecedents for patient empowerment as described in chapter 2.3.

So the vision described in chapter 4.2 was created by first ideating on the system. Now that I had created this vision, I could start ideating on how the app should provide this overview. This is what I discuss in the next chapter.

Key chapter insights

- The 4 patient concerns can be integrated in one system.
- Different databases are needed in order to personalize the system.
- If the system really provides the complete overview it should also include the data from the HM and EPF.

5.3 App ideation

5.3.1 Introduction

In this chapter I present how I tried to answer sub-question 4: How should the app be designed in order to deliver the design promise? The design promise, or vision, as described in chapter 4.2, is to provide patients with an overview. Therefore, the ideation question I started with was; how to create an overview? Where I specified the following three sub-ideation-questions:

- How to provide an overview of previous experiences?
- How to track how you are doing and show how you are doing at this moment?
- How to provide an overview of possible future experiences?

I decided to go for an application instead of a webtool for you laptop, since ex-patients expressed the value of having access to this overview and tracking system at all times in the ex-patient interviews (chapter 3.5).

5.3.2 Ideation

How to create an overview?
I started ideation on my own thinking about how the 3 different elements of previous, present and future could be incorporated in one app. Figure 56 shows a first idea of a home screen where the patient is on a boat. For this idea I imagined a gamified environment where the different elements on the boat represented the different functional elements. The cabin would hold the logbook with previous experiences. The crow's nest would allow you to look ahead for future experiences. In the end I figured this idea is a bit too abstract and the experience of patients in their follow up phase is not like steering a sailing boat but more like a canoe as explained in chapter 4.2. They don't have full control of where they are going, sometimes the current takes you somewhere else.

Figure 57 shows the next idea where an overview could be given from a top point of view like a map. This map includes where you are at this moment, where you have been and where you might go. Figure 58 shows some examples of games that also use maps. In this way you can look back and forward and explore different worlds like a physical, mental or social side effects world. Even though this overview

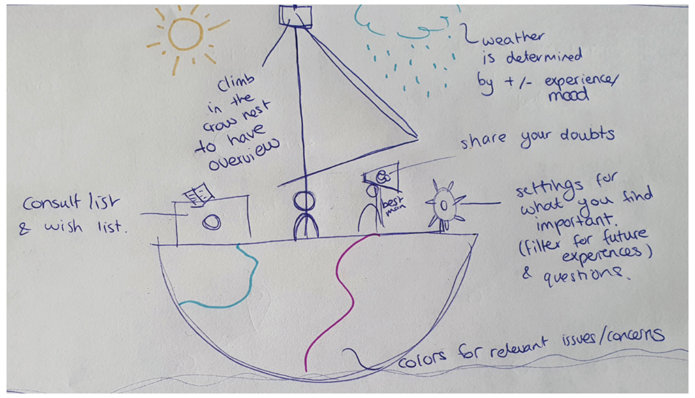


Figure 56. Idea for gamified home screen overview

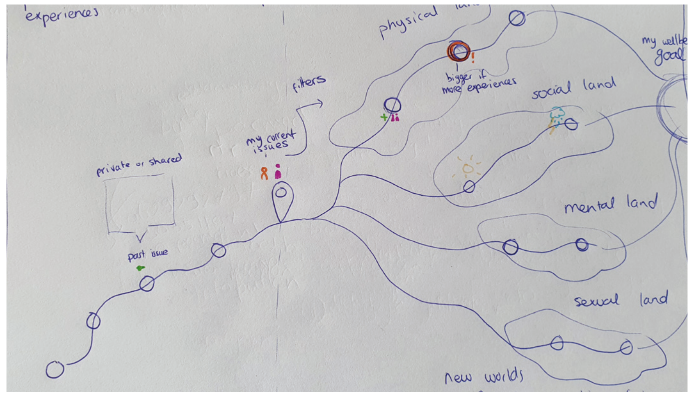


Figure 57. Idea for map overview

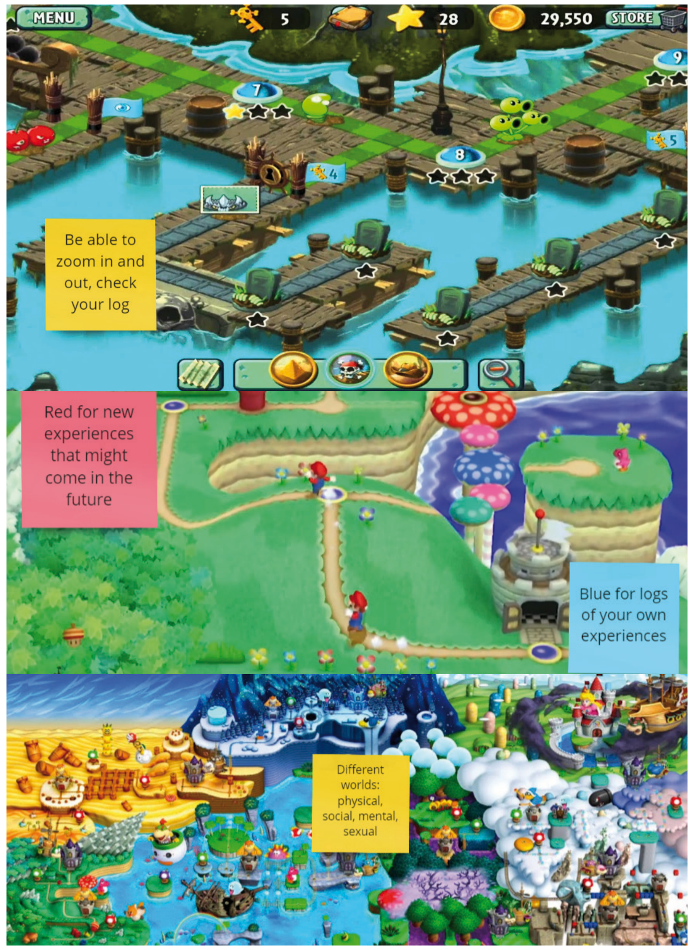


Figure 58. Examples of maps and their possibilities

would show everything in one glance and provide a fun element, it would become very chaotic. The overview could become very crowded. Furthermore, it suggests that there is a set path of levels (side effects) ahead while you are not sure whether you will come across a certain level. You only want to know what levels you might expect and how to play them, but you are not sure whether you will actually need to play them.

Therefore, I decided to go for a more simple home screen that provides you to go to your logbook, add an experience or explore what you might find in the future. Figure 59 shows some ideas for how this home screen could look like.

Figure 60 shows the home screen design that I used for my final concept of this phase in order to start prototyping. It uses the metaphor of the canoe, showing how turbulent or calm the stream is. This shows if you are having a good or bad period. Adding a new experience is in the middle and draws the most attention. Looking back is also visualized using a rewind symbol while looking ahead uses a fast forward sign to show that you will be looking ahead. These both suggest that you are currently in the presence and can look back or ahead.

How to show possible future experiences?

Next, I started to ideate on how to show the 3 main functions I did this simultaneously, but for the comprehensibility I explain each function separately. I start with an explanation of my ideation for showing possible future experiences.

When thinking about how to show these future experiences, I started to think about how these experiences should look like. I thought that perhaps you don't want to show real pictures, because they can be very confronting to see. To keep it a bit more lighthearted I thought of using drawn characters instead. Just like Pokémon characters, these can have different strengths and can belong to different categories. Figure 61 shows how I translated some of the side effects into initial ideas for characters. Their cards could show extra information, their impact on a patients daily life and tips about what to do with them. Using such characters can create a visual recognition of the side effect and provide a serious story in a more airy way.

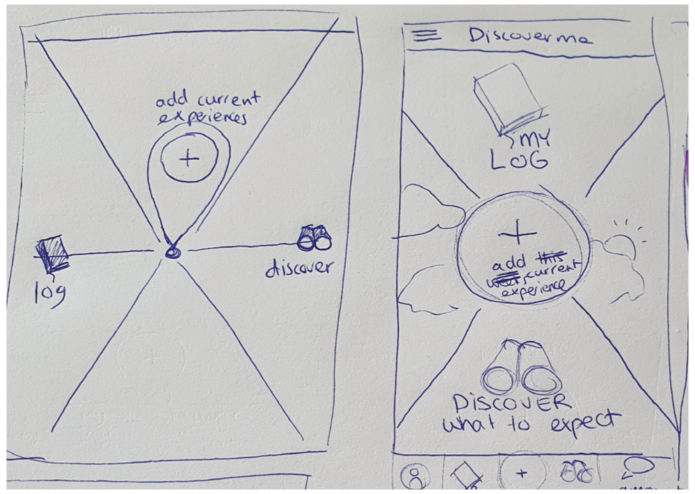


Figure 59. Ideas for a more practical home screen overview

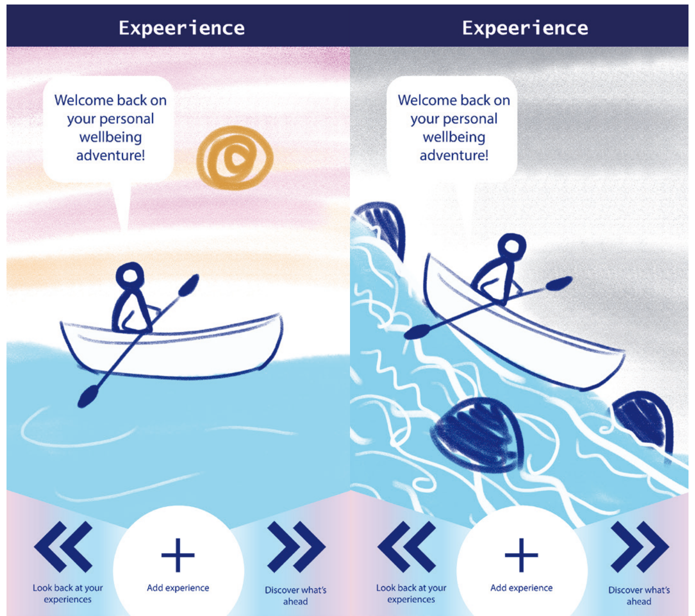


Figure 60. Final concept for the home screen

Figure 61. Characters as side-effects

Next, I thought about different ways of how these characters should be shown to the user who wants to know which characters he might expect in the future. Figure 62 shows 3 different ideas of presenting these characters. On the left you see an idea of showing them on a horizon that you can walk through. It shows that some characters (side effects) are closer to you and are more likely to appear in the near future. It is presented more in a storytelling way. In the middle I went for a more practical overview of all the cards with the most relevant shown on top. On the right I used the metaphor of the canoe again to show the characters as things you come across while sailing along the river.

In the end, I decided to go for both a storytelling and overview approach (see figure 63). The story telling approach can show you what to expect in the phase that you are in. You can see what's ahead in the near future. While the overview also provides you with the possibility to see all possible relevant experiences and search for an experience when you want to.

How to track experiences?

The next part to ideate on was how to track the experiences of patients. I figured you want to include several different questions. First of all, you want to know how the patient is feeling in general. Did they feel good or not the past few days. This asks for a general reflection of their wellbeing. Then you want to know what physical/psychosocial side effects they experienced.

This can be asked in several different ways. The two main ways I ideated were a swiping deck and a checklist. Either you can swipe whether you have had a certain effect. In this way you can also ask some follow up questions directly about a side effect if they say they experience it. The other option I thought of is checking boxes with the side effects you've experienced. Figure 64 shows some of my sketches when ideating how to collect experiences.

While ideating I realized that collecting these experiences can be seen as a mini consult. You want to create the same empathy as you experience in a conversation with a doctor. Start with the more general question of: How are you feeling? And then diving deeper into the relevant side effects and experiences.

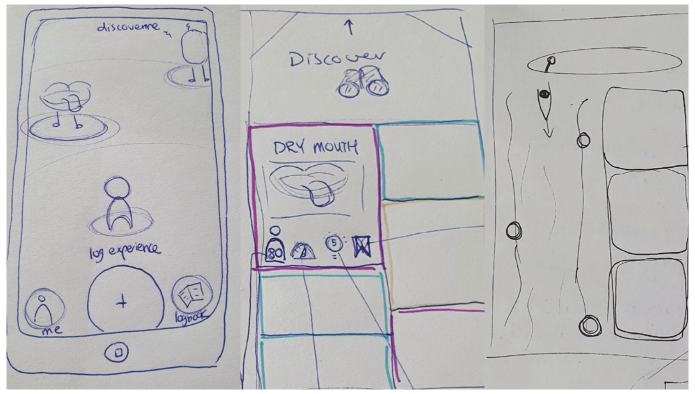


Figure 62. Ideas for discovering what is ahead

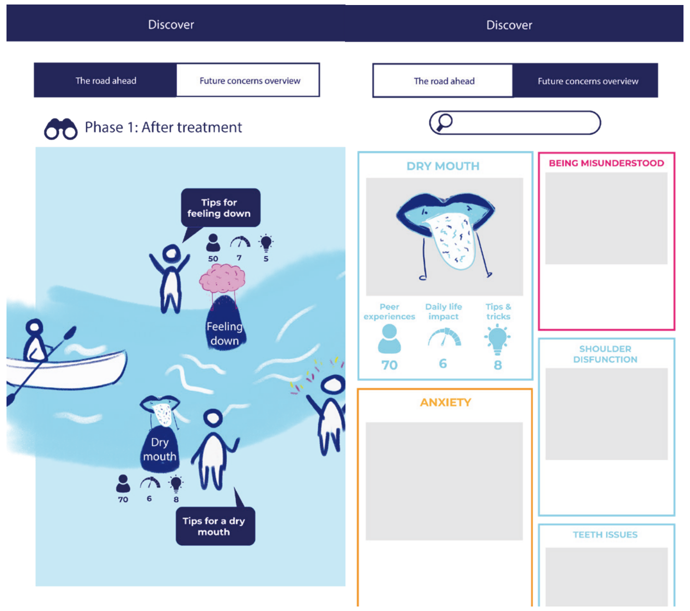


Figure 63. Final concept for discovering what is ahead

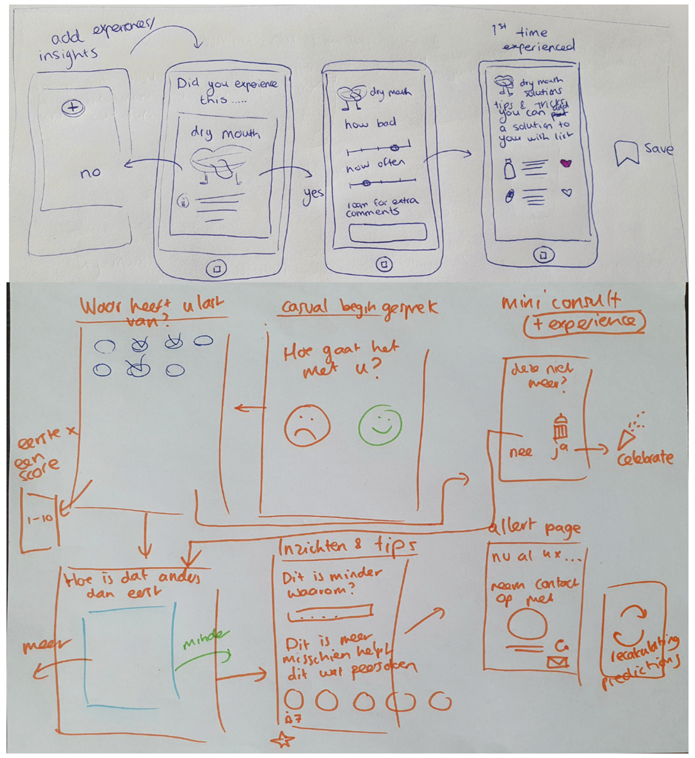


Figure 64. Ideas for tracking experiences and seeing insights

At the end of the tracking it would be nice to show a brief overview of insights from this tracking activity. How did the patient improve or regress? This is also what ex-patients mentioned in the interviews. They want to also receive an interpretation of the results, so that they know what the insights mean and can take action. In order to make taking action more easy I would also like to show a relevant action according to the insights. For example, when someone's shoulder function has regressed an action could be to watch physio videos or contact your physio therapist.

Figure 65 shows an overview of some of the different screens envisioned for the final idea of the mini consult. This was used to create the prototype. As you can see when you say that you experience a certain side effect, the system will ask you 3 extra questions: How bad is it? How frequent is it? And do you have extra comments? These first 2 questions relate to how the questions in the Healthcare Monitor are asked. The third question leaves space for patients to provide extra comments as they mentioned that they want to have this option in the interviews.

How to show previous experiences?

The final part of the application should show an overview of your previous experiences. I wanted to create a logbook that can show your experience but where you can also keep track of tips that you find interesting or the questions that you have for a consultation. In this way you have everything together in one application. Figure 66 shows some sketches of how these elements could be presented to the user.

Another question was how to present the overview of the experiences. You want to show the progression of patient experiences over time. Did they improve on their dry mouth? Figure 67 shows some different sketches of how to provide insight into the change over time. Either with line graphs or by showing whether a symptom has decreased, increased or stayed the same. Another idea was to provide insight into how the different symptoms link together so that you could for example show that whenever a patient feels tired they also often experience headaches. Such relations could provide an insight into what experiences are linked.

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Figure 65. Final concept for tracking experiences: a mini-

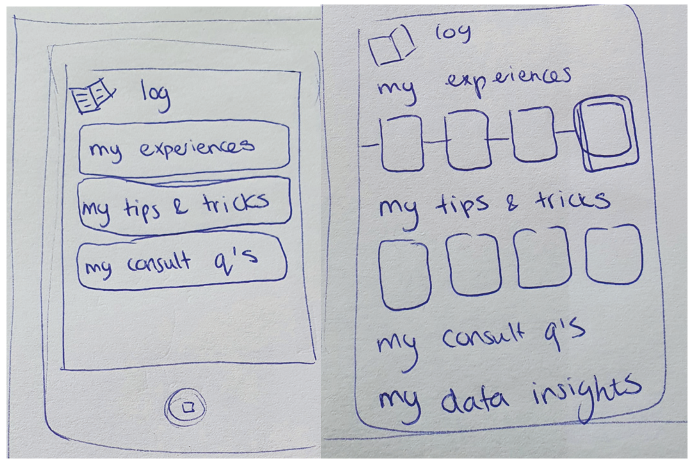


Figure 66. Ideas for how to show a logbook

Figure 68 shows some examples of how you can show progression over time. I wanted to let the general feeling that patients filled in when they track their experience come back in the overview of previous experiences. I linked it to the metaphor of the canoe. Showing a turbulent stream when patients indicated they were not doing too well and a calmer stream when patients say they generally felt good. Figure 69 shows how I envisioned this stream to look like. It also shows that you can select which experiences you want to see in the graph and that you can select a week to also look back at the individual answers that you put in. Furthermore, it shows how past experiences, tips and tricks and consult questions can be put in one logbook.

All these 3 different parts that together create the complete overview, are integrated in one coherent app that uses the canoe metaphor to distinguish between turbulent and calm phases and uses characters for the different physical and psychosocial side effects. The complete overview of this app and how it links to the different parts of creating an overview, is shown on the next pages.

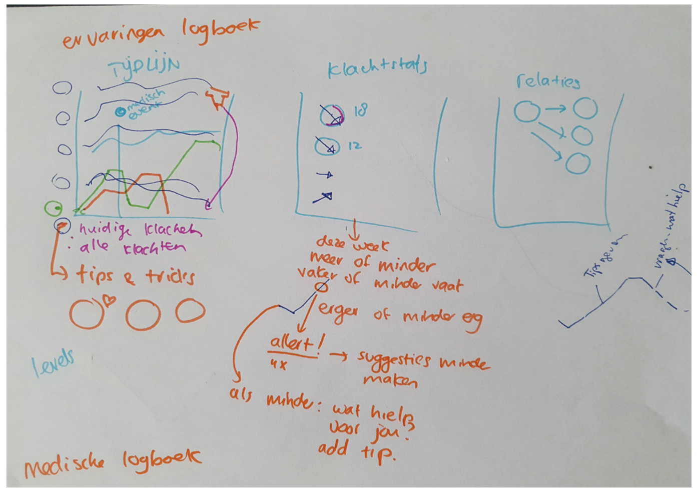


Figure 67. Ideas for showing progress and insights

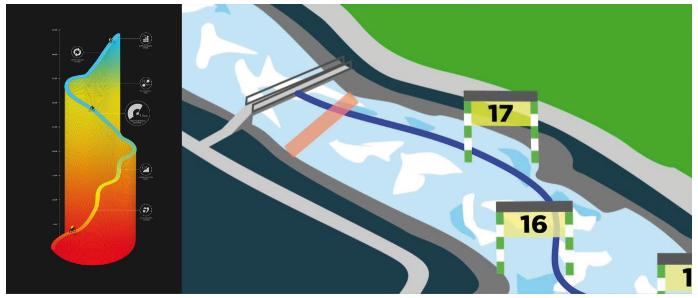


Figure 68. Examples of how you can show progress over time

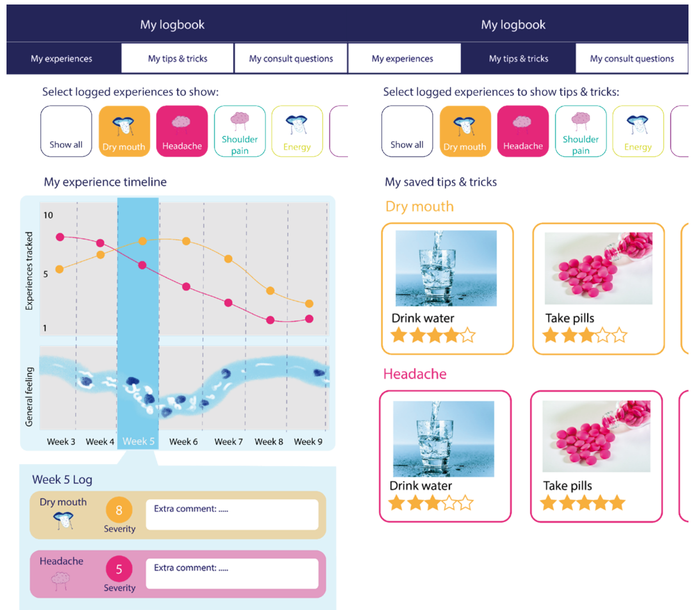


Figure 69. Final concept for logbook

5.3.3 The complete idea

Figure 70 shows an overview of how the complete app would look like and how it links to the 3 defined parts that are needed to create the complete overview.

As you can see the logbook links to ‘know where you have been’. Tracking your experience and seeing your current status on the home screen link to ‘know where you are now’. Finally, the discovering pages link to ‘know where you might go’.

The interfaces and overview seen in figure 70 are used as a basis to create the prototype. How this prototype is created and for what purpose is explained in the next chapter.

Key chapter insights

- The 3 different parts of the overview should be provided in different screens that are accessible through the home screen.
- Adding an experience should feel like a mini consult, personal and empathic.
- The app should contain buttons that can help to create a direct action based on an insight.
- The app should contain an overview with all side effects that one might expect and an overview of phase specific side effects.

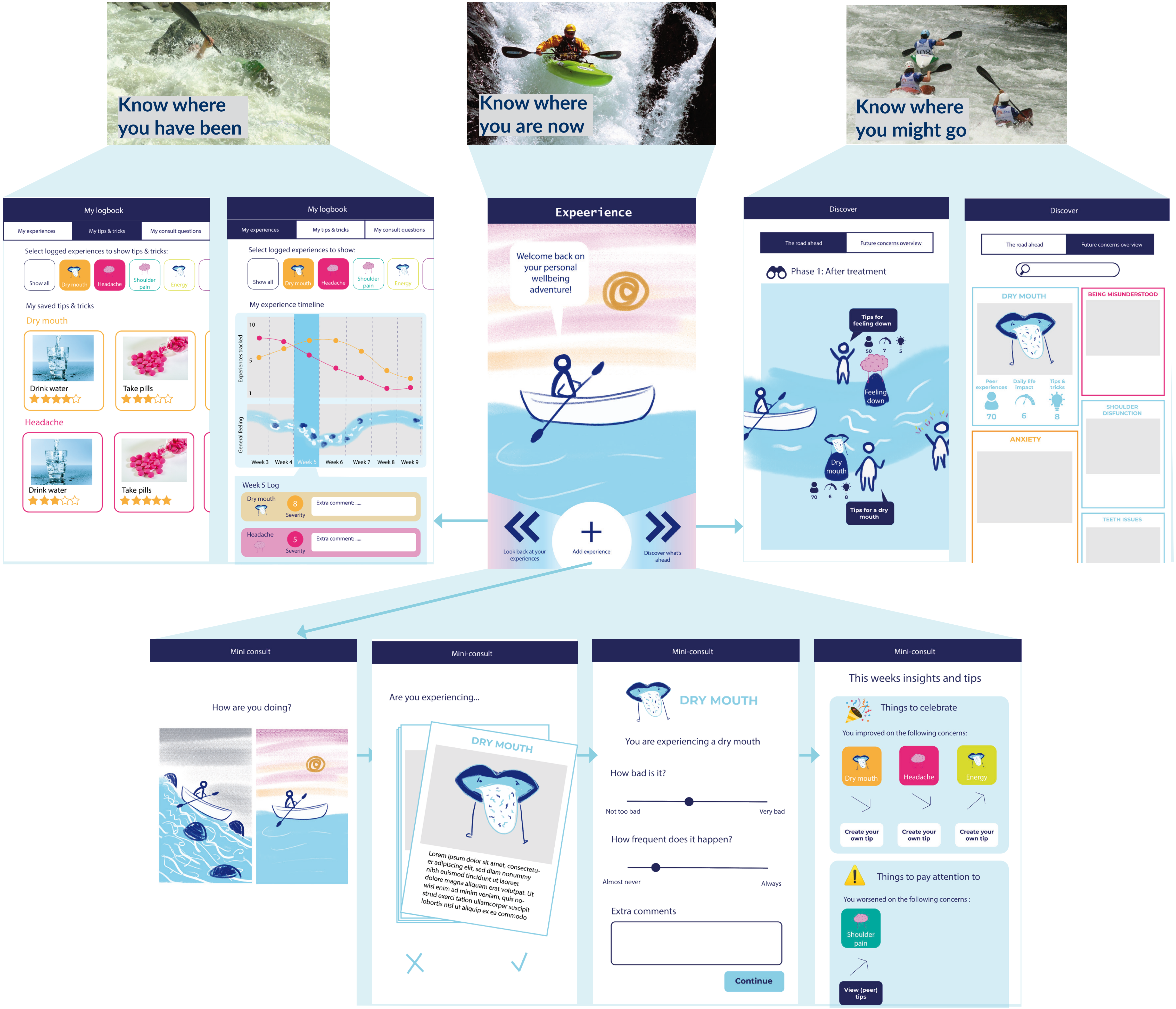


Figure 70. Complete overview of the concept application and how it links to the 3 parts of the overview

5.4 Prototyping

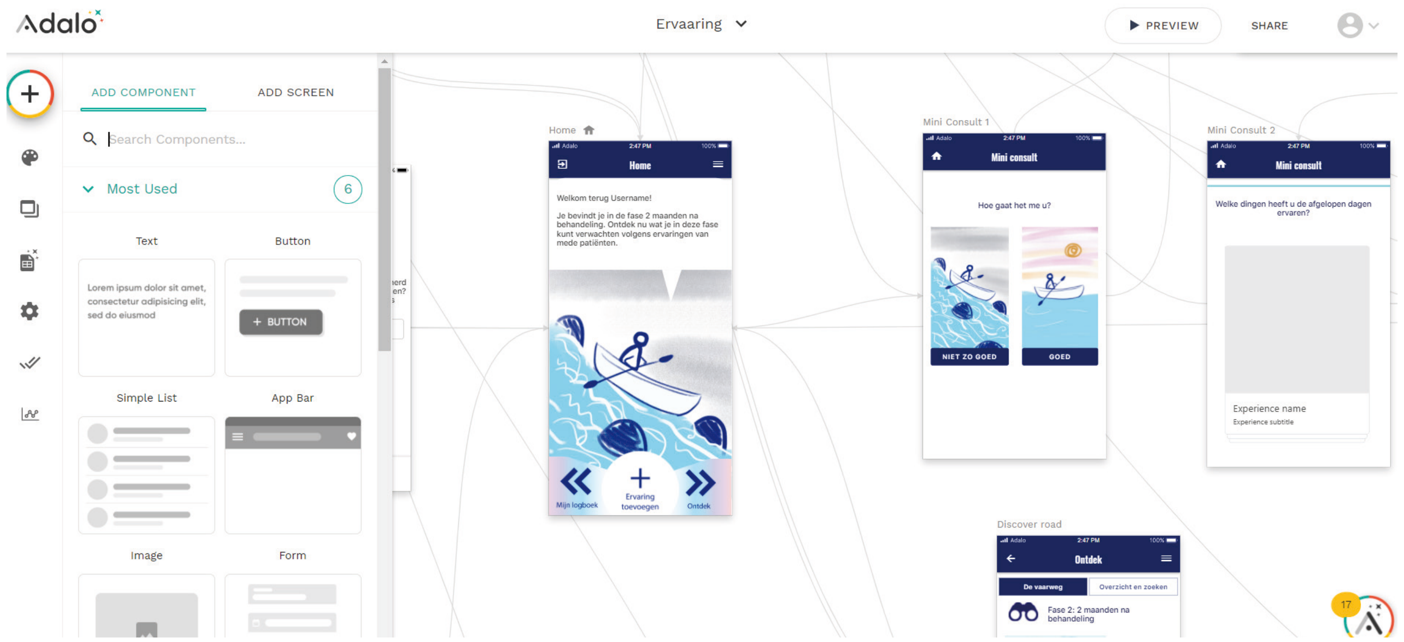


Figure 71. Prototyping tool Adalo where you can add components, screens and links between screens

5.4.1 Introduction

Prototyping is one of the co-creative design methods that advocates Human Centered Design (HCD) and is often used in the iterative design process of eHealth applications (Hochstenbach et al., 2017). HCD focusses on the needs and requirements of users, and by doing so enhances effectiveness and user satisfaction (Grimaldi et al., 2020). Therefore, a qualitative prototype test actively involves the users by letting them test and evaluate the prototype, as recommended in the data-enabled design 8-shape model of van Kollenburg & Bogers (2019).

Prototyping can thus be seen as a good way to co-create with your users. This is also important when you want to design for patient empowerment as it is part of the antecedent 'patient-centered' as described in chapter 2.4. By prototyping you can make your idea more tangible and show it to your users for discussion. By discussing it you can together explore the value that your idea could create and what is currently still missing or should be changed.

In this project the prototype is used to show to ex-HNC-patients. Patients can explore the prototype and it helps to start a discussion on what an application in the follow-up phase could mean for patients and how the current design can be improved.

5.4.2 Aim

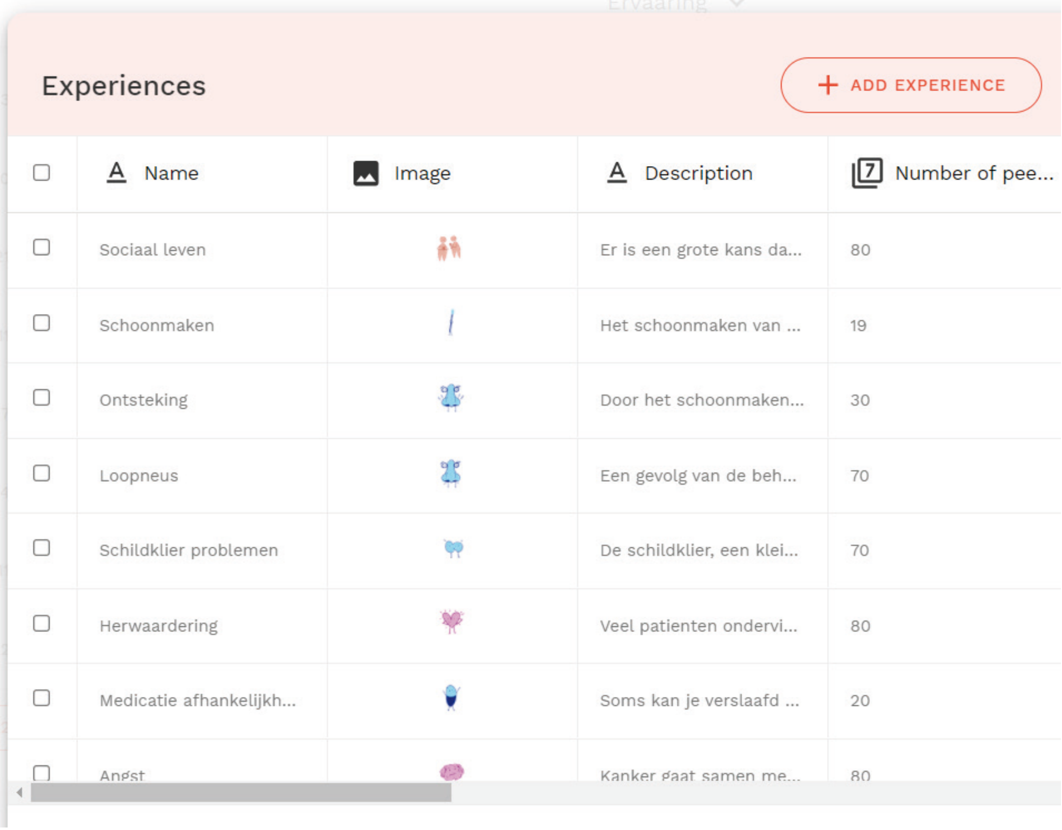
The aim of this chapter is to show how a prototype of the idea explained in the previous chapter is developed in order to show the idea in a tangible way to ex-patients in an explorative session.
This chapter still aims to answer sub-question 4 by asking the smaller sub-sub-question: How should the service system be prototyped in order to test its desirability?
With this prototype I want to start a discussion on the desirability of the concept and how it could be made more desirable for patients in the follow up phase. The answers to this question will help to improve the design and answer sub-question 4.

With desirable I mean 3 things:
- It adds value for patients in the follow-up phase
- This value is created in an appropriate way
- Patient empowerment is increased

5.4.3 Selecting a prototype tool

There are different tools available to create an application prototype. Like Bubble, Buildfire, AppGyver, Adalo, Adobe XD and Axure.

When selecting a tool I looked at a tool that uses easy visual construction, instead of too much coding.



Experiences

+ ADD EXPERIENCE

☐	Name	Image	Description	Number of pee...
☐	Sociaal leven		Er is een grote kans da...	80
☐	Schoonmaken		Het schoonmaken van ...	19
☐	Ontsteking		Door het schoonmaken...	30
☐	Loopneus		Een gevolg van de beh...	70
☐	Schildklier problemen		De schildklier, een klei...	70
☐	Herwaardering		Veel patienten ondervi...	80
☐	Medicatie afhankelijkh...		Soms kan je verslaafd ...	20
☐	Angst		Kanker gaat samen me...	80

Figure 72. An example of the databases in Adalo where you can add different properties to a record

I choose a more visual app as I am not skilled enough to create a quick prototype by just using coding. By using a program that uses visual elements to play with, I could create a more complete application in a shorter time, so that I was able to test the complete idea of the application in the scope of this project.

Another consideration I made when choosing a tool, was how easy it was to adapt it to different users. Since personalization is one of the antecedents for patient empowerment and it is also part of my concept, I wanted to convey this personal aspect in my prototype. I wanted to be able to show side effects relevant for the different patients that used my prototype.

Furthermore, when this prototype would be used for further research and development it should be able to scale to more users. Therefore, it needs to be able to remember data and create databases. Since a request is send to the medical ethical committee (METC) of the Erasmus MC for a longer test of 3 weeks with patients that are actually in the first 5 years after treatment, this should be taken into account. When this request is approved the prototype should be able to be adopted so that it can be used for 3 weeks effectively by different users.

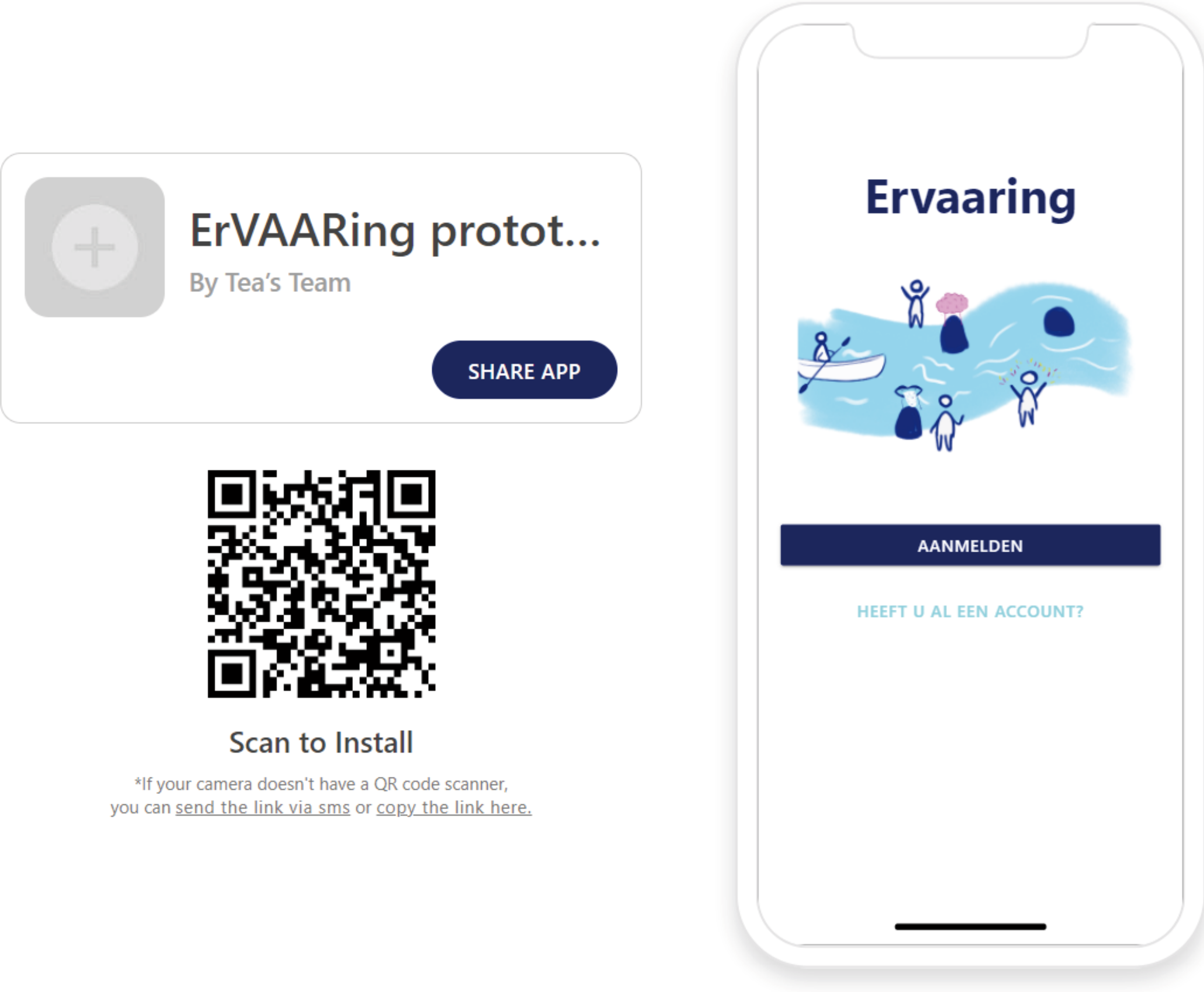
Based on these criteria I choose to work with the program Adalo. This is a web based program that provides you with the possibility to create an app visually, using different components that you can choose from (see figure 71). Furthermore Adalo has the possibility to create databases. These databases can be created very easily and can contain different elements (see figure 72). I, for example, could create a database for experiences where I could also select for which users this was relevant and how many peers also experienced this. By using these databases personalized content could be created.

5.4.3 Prototyping & iterating

While prototyping the design I had to make a lot of design choices in between. I iterated my design while prototyping. Thinking about what information should be included and how to present it. Also based on some small user tests with friends and the interviews with ex-patients, I constantly improved my design until the testing.

The databases I created, were created based on my knowledge created in the contextual inquiry and knowledge from online relevant platforms like the patient association for head and neck cancer patients (pvhh). I could use tips and quotes that I had found on the online platforms to make the experience more realistic. Furthermore, I used the insights from the ex-patients interviews as input for what side effects were relevant for patients.

Figure 73. Complete overview of the screens and links build in Adalo



Scan to Install

*If your camera doesn't have a QR code scanner,
you can send the link via sms or copy the link here.

Figure 74. QR code to try out my prototype app

Figure 73 shows a complete overview of the screens and links between the screens that I prototyped. You can try out the prototype yourself by scanning the QR code in figure 74. Log in with username: tess, password: test. This allows you to go through the prototype yourself in a web based app. For the test I created an android application from the prototype so that I could test it as a real app, without the website bar. However, this link is only for the test participants since there is a limited number of people that can use it as internal testers.

In the next paragraphs, I highlight some of the parts of the prototype that are different or new compared to the concept shown in the previous chapter.

Language

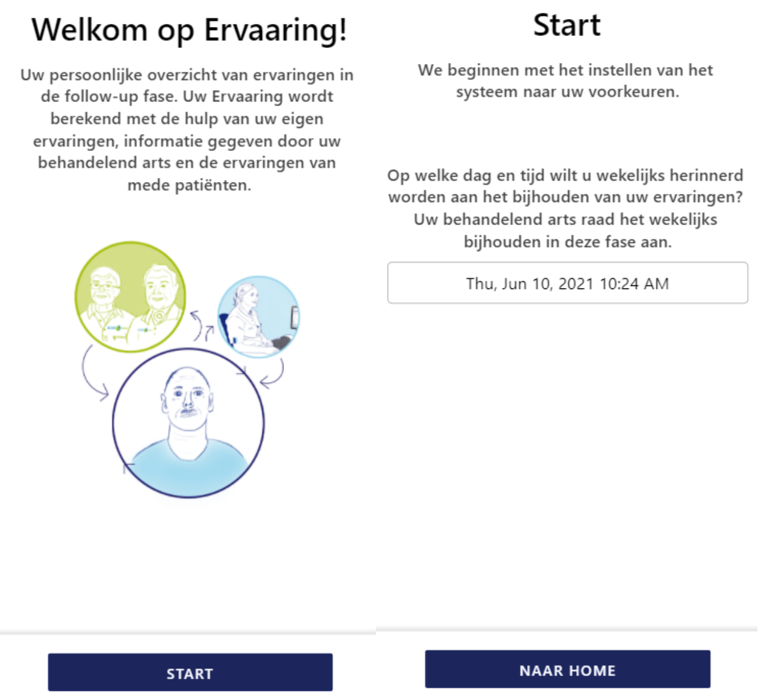
Since the app is tested with Dutch ex-patients the language of the prototype is also Dutch, in this way the test participants will better understand the texts and functions.

Extra explanations

I used extra screens in the beginning to explain how the app works. Figure 75 shows these extra screens. They tell the user with what information their experiences are calculated. Furthermore, it provides the full experience by also asking to set in a time for a reminder. This allows the patients to really imagine how the app could work in their daily life.

Figure 76 shows some other elements added. The added text on the home screen is there to show that the app is personalized to you and the phase that you are in. The text tells you in which phase you are and can change based on where you are in the process. Furthermore, an extra page was created in the mini consult to ask for the reason why someone feels a certain way. This was created to show empathy for how the user feels and explain why the mini consult can help patients.

Another extra explanation, is a screen that asks you with whom you want to share your experiences. This screen also explains why you would want to share your results with your treating physician or peer patients. This option appears when you want to share all your experiences, but you can also share your experiences individually. This is used so that you can decide what you share. This was an important point discussed in the ex-patient interviews. Some experiences are personal and you just want to review for yourself. Figure 77 shows these two screens, one to share all experiences and one to shar individual experiences.


Welkom op Ervaaring!

Uw persoonlijke overzicht van ervaringen in de follow-up fase. Uw Ervaaring wordt berekend met de hulp van uw eigen ervaringen, informatie gegeven door uw behandelend arts en de ervaringen van mede patiënten.

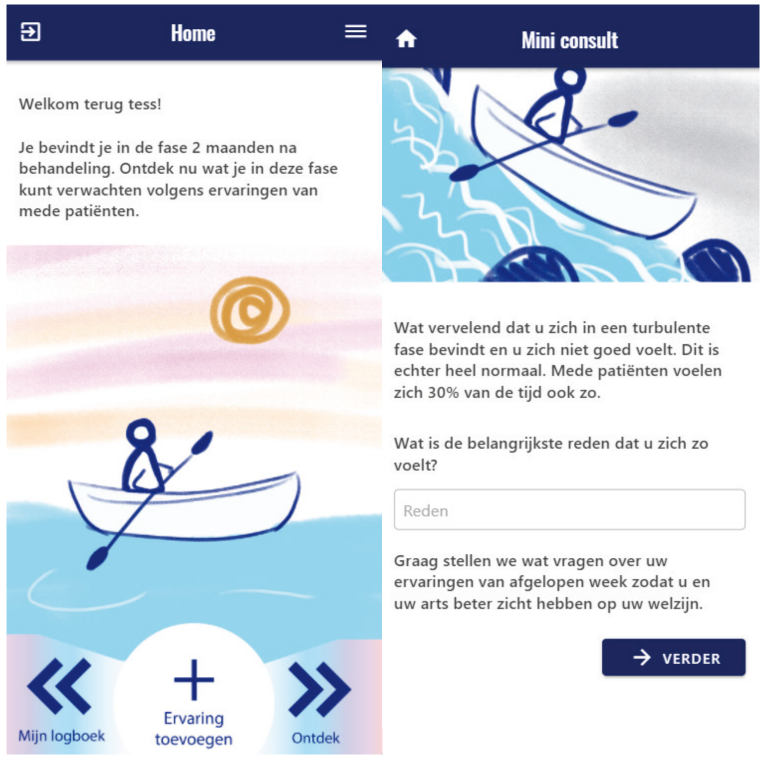
Start

We beginnen met het instellen van het systeem naar uw voorkeuren.

Op welke dag en tijd wilt u wekelijks herinnerd worden aan het bijhouden van uw ervaringen? Uw behandelend arts raad het wekelijks bijhouden in deze fase aan.

Thu, Jun 10, 2021 10:24 AM

Figure 75. Onboarding screens


Home

Welkom terug tess!

Je bevindt je in de fase 2 maanden na behandeling. Ontdek nu wat je in deze fase kunt verwachten volgens ervaringen van mede patiënten.

Mini consult

Wat vervelend dat u zich in een turbulente fase bevindt en u zich niet goed voelt. Dit is echter heel normaal. Mede patiënten voelen zich 30% van de tijd ook zo.

Wat is de belangrijkste reden dat u zich zo voelt?

Reden

Graag stellen we wat vragen over uw ervaringen van afgelopen week zodat u en uw arts beter zicht hebben op uw welzijn.

Figure 76. Extra explanations on home screen and mini consult


Al uw ervaringen van deze week delen met:

Uw behandelend arts: voor meer persoonlijke zorg ☐

Mede patiënten: om anderen op weg te helpen ☐

Uw ervaring met Eetbeleving delen met:

Uw behandelend arts: voor meer persoonlijke zorg ☐

Mede patiënten: om anderen op weg te helpen ☐

Figure 77. Extra screens to share experiences

Information and tips for experiences

Some screens were not yet addressed in the concept explained in the previous chapter, like the screens that provide the information on the experiences and tips that relate to these experiences. These screens could be created with the databases, making them change according to the experience you select.

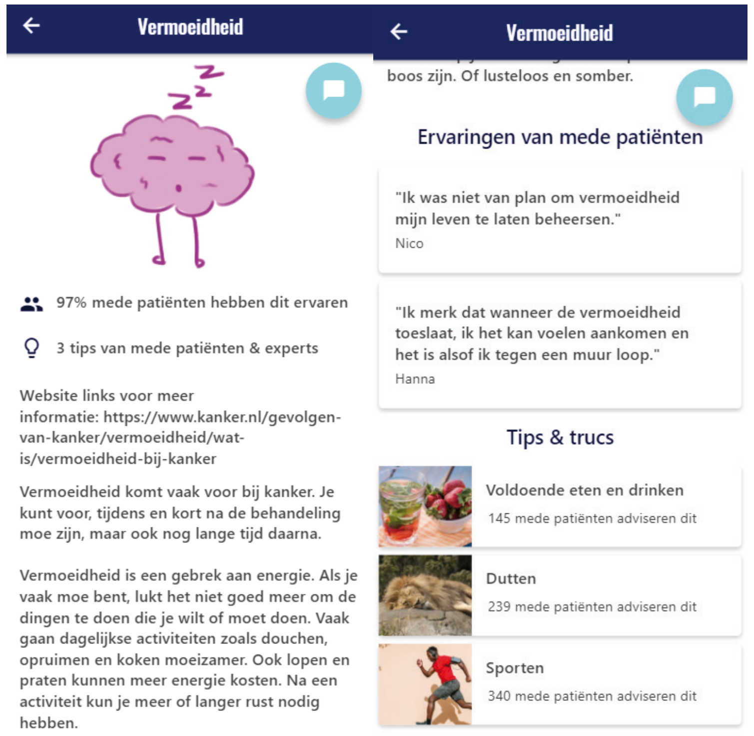
Figure 78 shows what is shown on the information page. The character is shown on top to give a visual idea of the topic it is about. It also shows how many other patients experience it and the amount of tips added for this experience. A website link to a relevant website on this topic is shown and some general information. When you scroll down you can see experiences of peers. This can show some real stories to make it relatable and realistic. Furthermore, there is a section for tips and tricks. If you click on this you will go to selected tips and tricks page as shown in figure 79.

On the tips and tricks page you can find how many other patients advice this tip. This can show you how good a tip is. Again a website link, extra information and experiences from peers are shown. Furthermore, it shows people who you can contact to provide the possibility to take action and ask questions if you want to know more about this tip.

Mini consult

I already explained some extra screens that were added to the mini consult. Another change is the way in which the severity and frequency are asked. Figure 80 shows how these are asked in the prototype. The severity can be selected on a scale from 1-10 and the frequency can be selected from 4 options. I based these options on the options used in the questionnaires of the Healthcare Monitor. The HM questionnaires often use 5 options. I removed one option, never, since if you say that you experience something the frequency cannot be never.

Other changes are made to the screens that show the results and insights, see figure 81. You can see your logged experiences that you just logged in your mini consult and can add an experience that was not in the list of experiences you swiped through. The insights show things to celebrate and things to watch out for. This should provide the user with a better understanding of what the results mean for them and provides a link for direct action.



97% mede patiënten hebben dit ervaren

3 tips van mede patiënten & experts

Website links voor meer informatie: https://www.kanker.nl/gevolgen-van-kanker/vermoeidheid/wat-is/vermoeidheid-bij-kanker

Vermoeidheid komt vaak voor bij kanker. Je kunt voor, tijdens en kort na de behandeling moe zijn, maar ook nog lange tijd daarna.

Vermoeidheid is een gebrek aan energie. Als je vaak moe bent, lukt het niet goed meer om de dingen te doen die je wilt of moet doen. Vaak gaan dagelijkse activiteiten zoals douchen, opruimen en koken moeizamer. Ook lopen en praten kunnen meer energie kosten. Na een activiteit kun je meer of langer rust nodig hebben.

boos zijn. Of lusteloos en somber.

Ervaringen van mede patiënten

"Ik was niet van plan om vermoeidheid mijn leven te laten beheersen."
Nico

"Ik merk dat wanneer de vermoeidheid toeslaat, ik het kan voelen aankomen en het is alsof ik tegen een muur loop."
Hanna

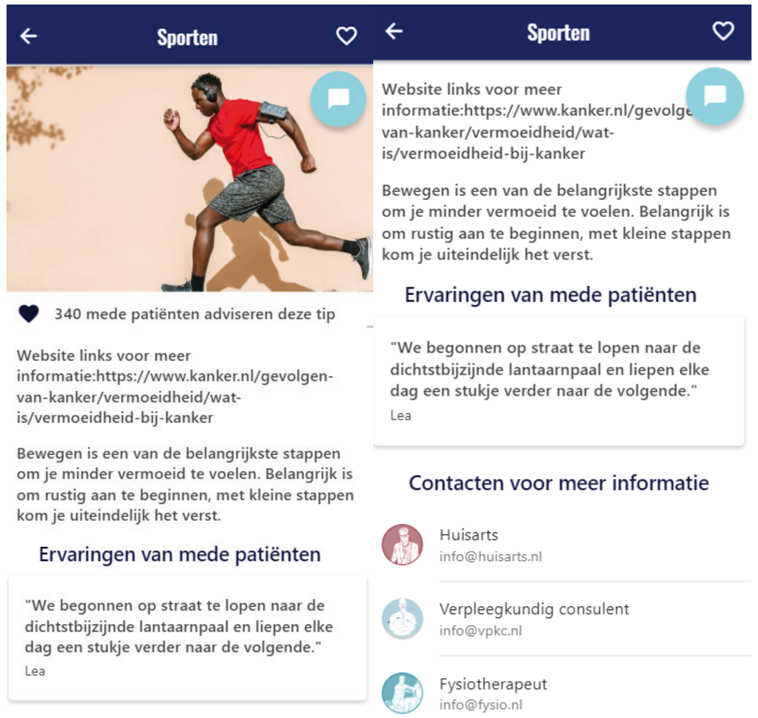
Tips & trucs

Voldoende eten en drinken
145 mede patiënten adviseren dit

Dutten
239 mede patiënten adviseren dit

Sporten
340 mede patiënten adviseren dit

Figure 78. Information screen for experiences



340 mede patiënten adviseren deze tip

Website links voor meer informatie:https://www.kanker.nl/gevolgen-van-kanker/vermoeidheid/wat-is/vermoeidheid-bij-kanker

Bewegen is een van de belangrijkste stappen om je minder vermoeid te voelen. Belangrijk is om rustig aan te beginnen, met kleine stappen kom je uiteindelijk het verst.

Ervaringen van mede patiënten

"We begonnen op straat te lopen naar de dichtstbijzijnde lantaarnpaal en liepen elke dag een stukje verder naar de volgende."
Lea

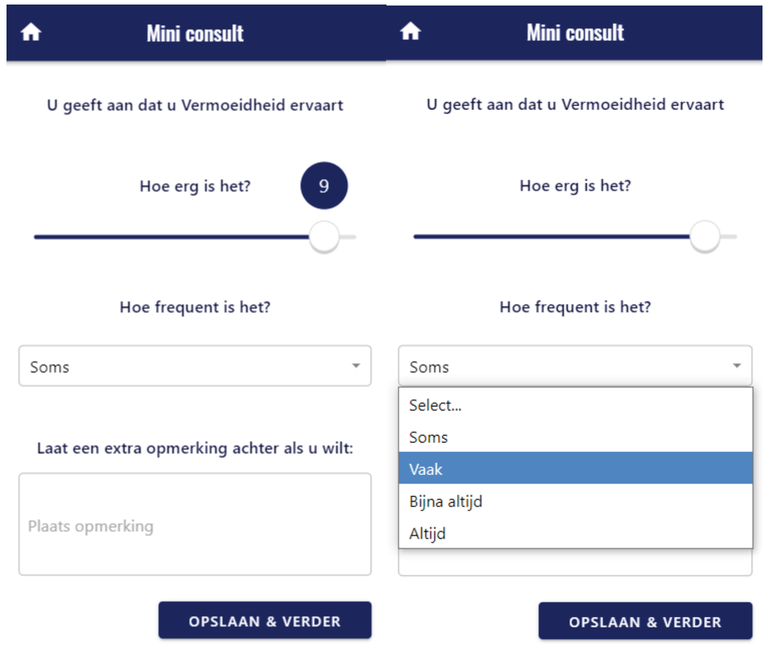
Contacten voor meer informatie

Huisarts
info@huisarts.nl

Verpleegkundig consulent
info@vpkc.nl

Fysiotherapeut
info@fysio.nl

Figure 79. Tip screen



U geeft aan dat u Vermoeidheid ervaart

Hoe erg is het? 9

Hoe frequent is het?

Soms

Laat een extra opmerking achter als u wilt:

Plaats opmerking

U geeft aan dat u Vermoeidheid ervaart

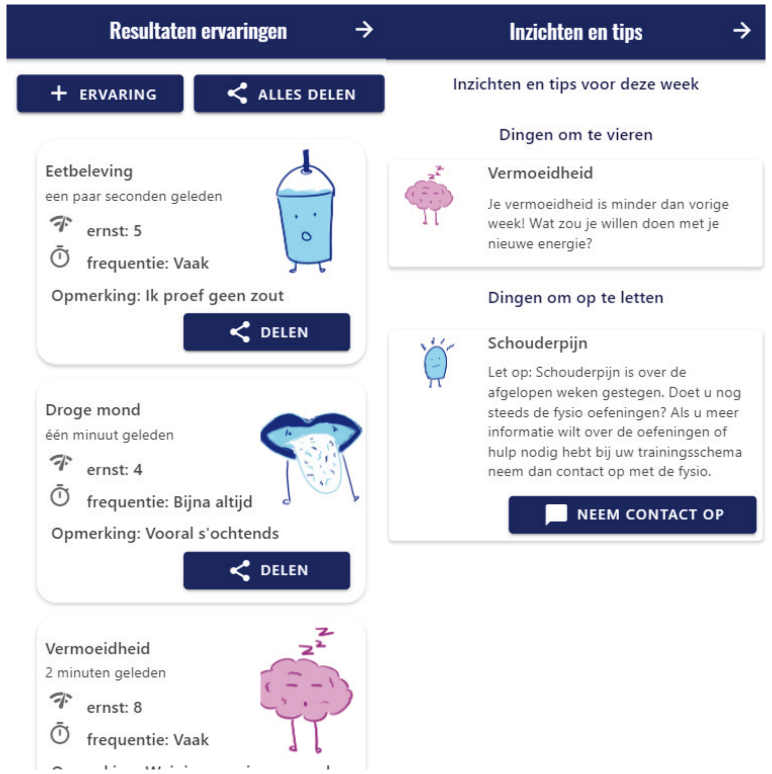
Hoe erg is het?

Hoe frequent is het?

Soms

Select...
Soms
Vaak
Bijna altijd
Altijd

Figure 80. Mini consult extra questions for an experience



Eetbeleving
een paar seconden geleden
ernst: 5
frequentie: Vaak
Opmerking: Ik proef geen zout

Droge mond
één minuut geleden
ernst: 4
frequentie: Bijna altijd
Opmerking: Vooral s'ochtends

Vermoeidheid
2 minuten geleden
ernst: 8
frequentie: Vaak

Inzichten en tips voor deze week

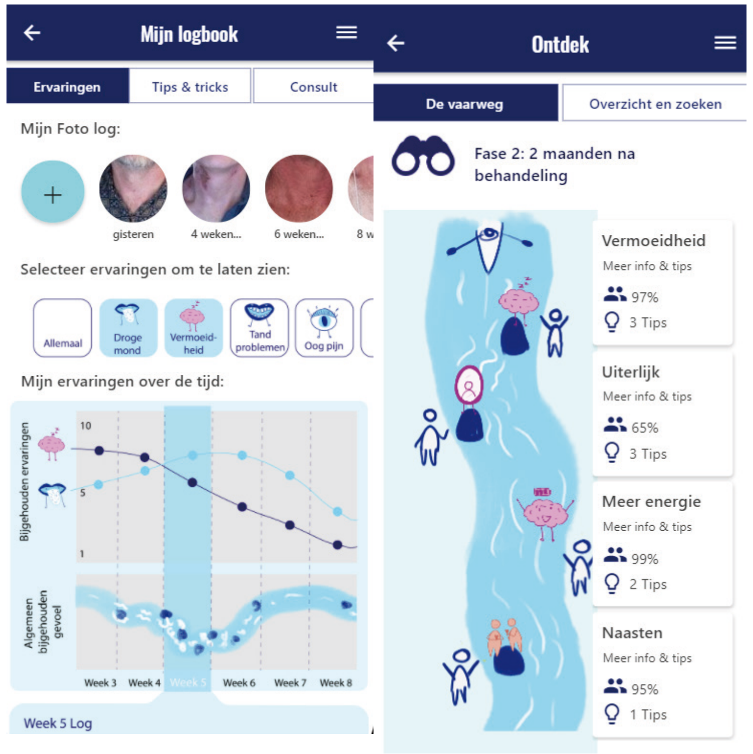
Dingen om te vieren

Vermoeidheid
Je vermoeidheid is minder dan vorige week! Wat zou je willen doen met je nieuwe energie?

Dingen om op te letten

Schouderpijn
Let op: Schouderpijn is over de afgelopen weken gestegen. Doet u nog steeds de fysio oefeningen? Als u meer informatie wilt over de oefeningen of hulp nodig hebt bij uw trainingsschema neem dan contact op met de fysio.

Figure 81. Mini consult results and insights



Mijn Foto log:

Selecteer ervaringen om te laten zien:

Mijn ervaringen over de tijd:

Fase 2: 2 maanden na behandeling

Vermoeidheid
Meer info & tips
97%
3 Tips

Uiterlijk
Meer info & tips
65%
3 Tips

Meer energie
Meer info & tips
99%
2 Tips

Naasten
Meer info & tips
95%
1 Tips

Figure 82. Logbook and discover screen

Logbook photos

Another change is that I added the option to add photo's, see figure 82. Some patients expressed the value of taking photos over time to see your physical progression. I incorporated this feature to test if this could really bring added value and how it should be included in the app. It is a point that I want to discuss with the ex-patients that will test the app.

Changed view discover page

Another small change is the lay out of the discover page, see figure 82. I made the river vertical so that you could easily scroll down to see more future experiences. This was also a design choice made because of the limitations of the prototyping tool where horizontal scrolling was not possible. To still create a similar effect and test whether an overview of possible future experiences this way works, I created a vertical stream.

5.4.4 Discussion

Adalo worked out to be a good tool to visually construct a working app that can make your app concept tangible. While working on the prototype I was also iterating on the design. Some things for example turned out to be a bit chaotic so I made them more simple. Also, by creating the screens, I got insight into what I want to show on a page and what I still missed. Creating the prototype was therefore also a designing activity in itself, where you constantly iterate and create new design choices.

The final prototype to use for the test has a lot of elements that are already working to really let the test participant experience what it would be like to use the app during the follow up phase. Furthermore, I wanted to test what elements could be created using the prototype tool Adalo. I for example tried to made a working graph from the inputs of the mini consult. This turned out to be difficult in Adalo. This is something to take into account when further developing the app. Such elements might have to be created with code. By testing the limits I can tell more about when you would want to use this program and where it lacks for the future developers of the application.

Some elements do not work yet, like the graph on the logbook page as mentioned before. Therefore, this is something to tell ex-patients before testing the prototype. They should have the right expectations about the prototype, knowing that some parts of the app do not work yet.

The created prototype is used for an explorative test with ex-patients, as explained in the beginning of this chapter. The set up and results of this test are explained in the next chapter.

Limitations

The prototyping tool had some limitations. As previously discussed, one of the limitations was that you could not easily scroll horizontally. Furthermore, some things had to be added in the prototype to make it work. Like a final card to the slide deck that says to swipe left. This is added so that when swiped right on the previous experience you can go to the screen with additional questions on that experience. If this card is not added, you will directly go to the results and cannot add the additional information. This is something that should be taken into account when further developing the prototype. Another limitation was that the home screen cannot be shown on the full screen. I have tried multiple ways to make it fit, but it depends on the phone you use. This is something that I need to consider during my prototype test. I have to let ex-patients know to scroll down to view the complete home page if they do not do this naturally.

Key chapter insights

- A prototype is used as a tool to co-create with patients.
- While prototyping the design was iteratively adjusted.
- Adalo can be used as a prototype tool when you want to use different data bases to personalize the prototype experience for the test participants.

Sub-question 4: How should the service system be **designed** in order to deliver the design promise?

6. TESTING & IMPROVING

This chapter I show how the prototype test is executed and used to test the desirability of the proposed concept. Initial suggestions for improving the design are also provided.

6.1 Chapter introduction

This chapter is a continuation of the previous chapter. It still aims to answer sub-question 4:

> 4. How should the service system be **designed** in order to deliver the design promise?

This question is answered in this chapter by investigating the value that the design can bring through a prototype test. This prototype test shows what is needed in the design. What aspects of the design add value for the patient? It also addresses what can be improved in the design to deliver the design promise in a more appropriate way. A new concept design is suggested based on these findings.

Figure 83 shows the structure of this chapter. First of all, the prototype test with the prototype that was shown in the previous chapter is explained. The results are visually communicated and used in the next section to make some initial suggestions for improving the design of the application. Furthermore, an iterated version of the system is presented through a system map and story board.

The suggested improvements are recommendations to take into account for the further development of the system. How to develop this system further is discussed in the next chapter: 'operationalization'. Since these recommendations often link to these next steps, I will refer to the next chapter in this chapter several times.

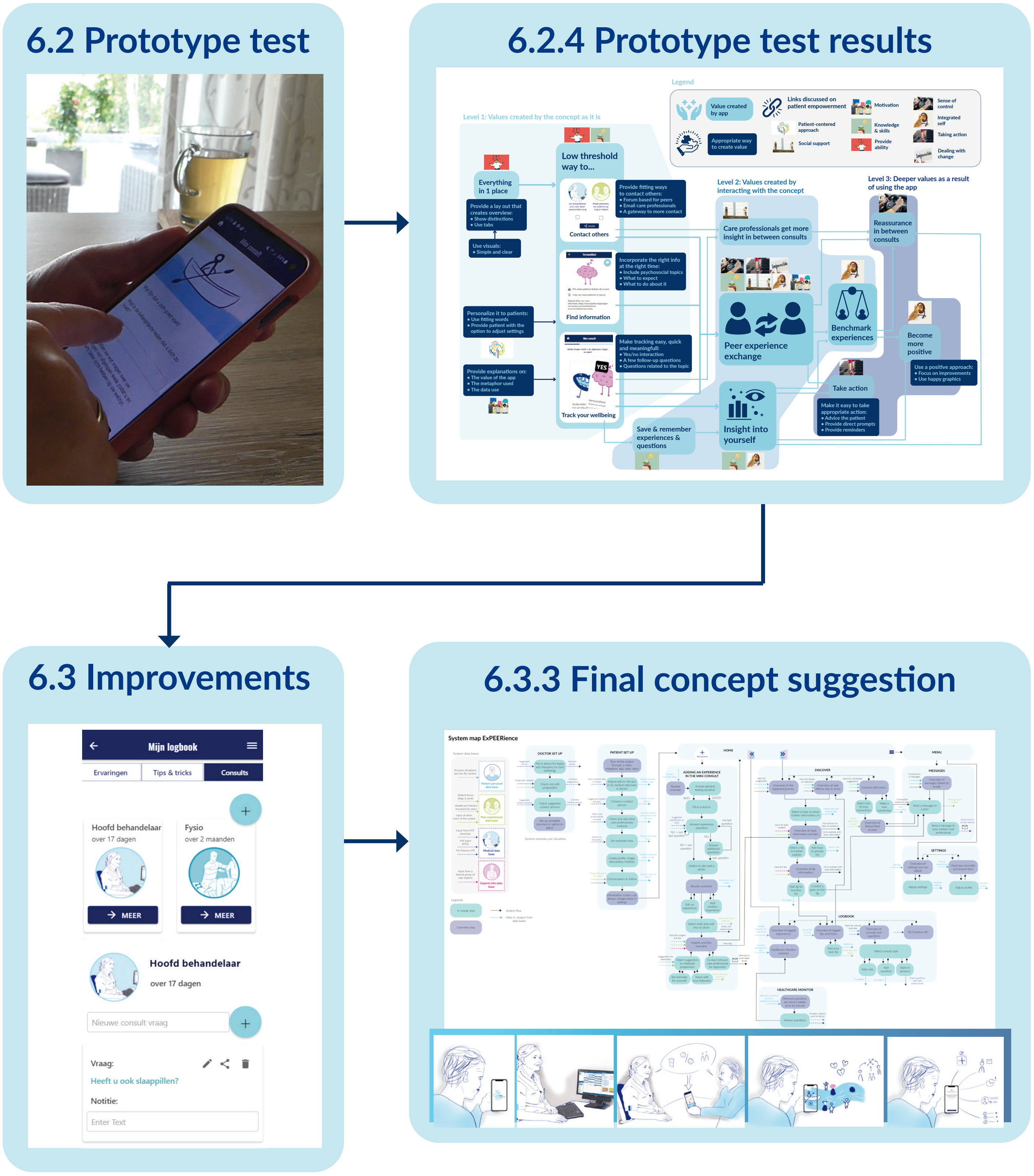


Figure 83. Chapter structure

6.2 Prototype test

6.2.1 Introduction

This chapter explains how the prototype that was shown in the previous chapter is tested by ex-patients. As mentioned before, testing a prototype with users helps to actively involve the users by letting them test and evaluate the prototype. This is recommended in the data-enabled design 8-shape model of van Kollenburg & Bogers (2019) and the CeHRes roadmap for eHealth Research Innovations (van Gemert-Pijnen et al., 2011). It is a way to involve the users in the design process and serves as a generative method for improving my design.

In this chapter I explain the set up and results of the prototype test.

6.2.2 Aim

The aim of the prototype test is to gather ex-patient-reported experiences on the desirability of the proposed concept for HNC patients in the follow-up phase. In order to answer the sub-sub-question: What do ex-patients think of the desirability of the proposed concept for HNC patients in the follow-up phase?
Answering this sub-sub-question will gain new insights for sub-question 4 on the design of the concept.

As mentioned in the previous chapter, I include 3 main topics under desirability:
- Value
- Appropriateness
- Link to patient empowerment

Figure 84 shows an overview of the objective, sub-objectives and related research questions.

6.2.3 Method

In order to gather ex-patient-reported experiences on the desirability of the proposed concept, a qualitative prototype test was done that uses think aloud and a semi-structured interview to capture the experiences of ex-patients.

Thinking aloud is a method used both in design and medical research. It is a method where the test participants say what they think while exploring a tool. According to Bolle et al. (2016) this is a great method for evaluating user experiences with an eHealth solution.

Next a semi-structured interview (Patton, 2002) is used to ask questions related to the research questions shown in figure 84.

Participants
6 ex-patients participated in this prototype test. Since it is a qualitative study that is used mostly as a generative evaluation, this amount was deemed appropriate.

The study population consists of ex-Head and Neck cancer patients. They were included using convenience sampling (Etikan, 2016).

2 ex-patients also participated in the ex-patient interviews, as described in chapter 3.5. 4 participants were new.

Table 3 shows an overview of the different types of cancer and the platforms through which the participants were included.

Cancer type
- 1 eye
- 2 nose
- 3 throat/mouth

Platforms for contact
- 2 klankbord
- 2 kanker.nl
- 2 whatsapp group

Table 3. More information on selected participants

Test objective: To gather **ex-patient-reported experiences on the desirability** of the proposed concept application for HNC patients in the follow-up phase.

Main RQ: What do **ex-patients think of the desirability** of the proposed concept for HNC patients in the follow-up phase?

Sub-objective 1: VALUE
Identify the value of the application for patients in their follow-up phase.

Sub-objective 2: APPROPRIATENESS
Identify the appropriateness of the application for patients in their follow-up phase.

Sub-objective 3: LINK PATIENT EMPOWERMENT
Investigate the link between the application and patient empowerment.

RQ 1.1: What **value** is currently created by the application according to ex-HNC-patients?

RQ 1.2: What **value** do ex-HNC-patients **miss** that they would want to have in an application in the follow-up phase?

RQ 2.1: Does the app create the desired value in an **appropriate way** for HNC patients in the follow-up phase?

RQ 2.2: How could the value be delivered in a **more appropriate way**?

RQ 3.1: To what extend are the **antecedents** of patient empowerment provided by the app according to ex-patients?

RQ 3.2: To what extend are the **attributes** provided by the app according to ex-patients?

RQ 3.3: To what extend do ex-patients think that the **short term consequences** of patient empowerment could be created by the app?

Figure 84. Overview of prototype test objectives and research questions

Study procedure

The study procedure differs for ex-patients that have already participated in the previous interviews and the new participants. For the new participants an extra introduction conversation is planned before the prototype test.

This introduction conversation takes 15 minutes and is planned to get to know each other. I explain the project and the goal of the prototype test and ask a few questions to get to know the patient better. An overview of the procedure for this introduction conversation can be found in Appendix M. The questions are about the issues patients experienced in their follow-up phase, so that I can personalize the prototype according to their context. This conversation is not necessary with the 2 participants that already had an interview, as they are already aware of the project and have already shared their concerns in the follow-up phase.

With the results of the introduction conversations, the prototype is personalized for the different users, adding different things to track and different expected experiences per participant.

The prototype test itself takes 1,5 hours. An overview of the procedure of this test can be found in table 4. An overview of the material used can be found in figure 85. The test could either be done online or offline, based on the preference of the participant.

In short, patients sign the informed consent form and are explained why the prototype test is done. The prototype app is set up. For offline tests my phone is used, for online tests a bit more time is needed to install the app. Ex-patients are asked to think back to a situation in their follow-up, around 2 months after treatment, so that they can also express how the application could be of value to patients who are still in this phase. The participant explores the prototype while thinking out loud and answering some in between questions. After this the semi-structured interview is held. The test protocol and questions can be found in Appendix N. The last step of the interview is discussing the topics of patient empowerment based on topic cards, see figure 85. At the end of the test participants receive a small thank you present.

Data analysis

The feedback provided by patients is used to iteratively improve the design. The method used for analyzing the feedback is the thematic analysis method (Braun & Clarke, 2006). Patterns in the feedback that relate to the research questions are identified by clustering collected codes (feedback) and searching for common themes.

What	Details	Duration
Introduction	• Explain meaning of a prototype; work in progress, some things work with real input data, others are examples. • Explain test goal/focus; your experiences with a designed application for patients in their follow-up phase (value & ideas for improving the value). • Set up the system • Download link & log in	10 min
Sensitizing	• Ex-patient is asked to think back to a situation in the phase around two months after treatment.	5 min
Exploring the prototype using think aloud	• Ex-patient is asked to explore the prototype. While doing so the ex-patient is asked to think out loud. The researcher also observes the actions taken by the ex-patient. This is all captured using video and/or audio recording. • Tasks can be given in between in case the participant did not explore all the functions yet. E.g.; Explore your logbook. • Questions can be asked in between by the researcher to ask a question about a specific thought or action of the ex-patient.	45 min
Semi-structured interview	• After using the prototype, questions are asked about the 3 sub-objectives: value, appropriateness and link to patient empowerment. The link to patient empowerment is discussed using cards as a conversation starter.	25 min
Closing	• Close the prototype test by explaining what will be done with the results. Give a thank you present.	5 min

Table 4. Study procedure prototype test

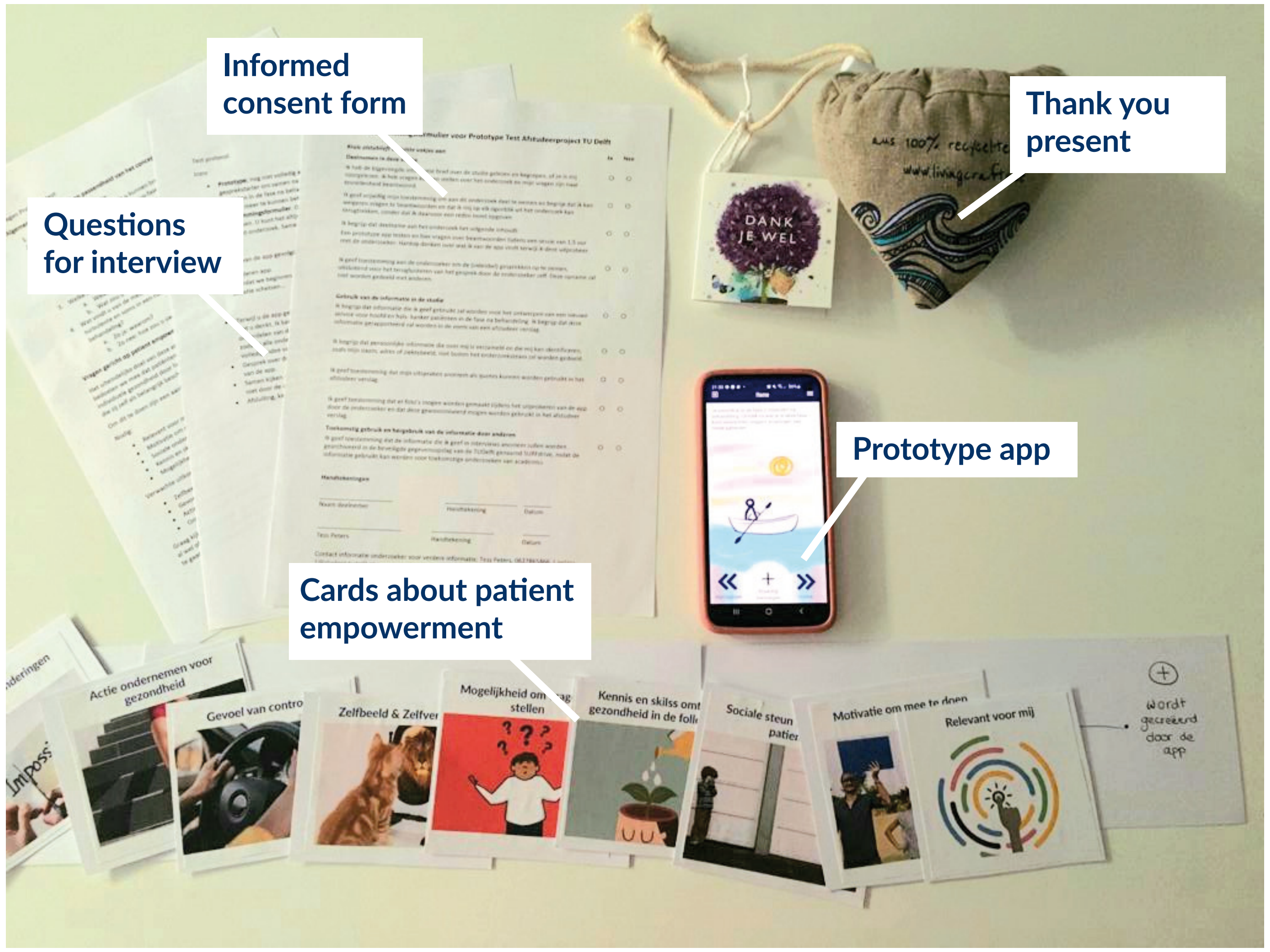


Figure 85. Overview of the materials used for the prototype test

6.2.4 Results

The results of the prototype test are the transcribed conversations that include the thinking out loud and answers to the questions. Codes were gather from these conversations looking at quotes that can help to answer the 3 research questions of value, appropriateness and link to patient empowerment. These codes were then clustered to discover common themes for these 3 research questions. The codes and clusters can be found in Appendix L.

Between these clusters relationships were found. Ex-patients discussed that certain values created by the app create other deeper values. Furthermore, the appropriateness and patient empowerment cards could also be linked to these values. An overview of the themes found for the different research questions and their links can be found in figure 88 on page 128.

I will now discuss the results in the following order:

- Values created by the application
- Appropriate ways to create these values
- How the application links to the patient empowerment cards
- Other insights related to the system development

As you can see the 3 research questions are answered in order, followed by more general insights that were gathered outside of the scope of the research questions. Ex-patients expressed some concerns related to the system development which I think are interesting to briefly discuss as well. The themes are discussed in order of importance, starting with the cluster with the largest amount of codes.

Values created by the application

Exchanging experiences with peers
This was seen as an important value as ex-patients see their peers as the experts in this phase. The doctors are the experts in the treatment phase but after treatment peer experiences are most important. They are the ones that really understand what you are going through and can provide practical tips and tricks. In figures 86 & 87 you can see tips that participant wanted to share with peers. You can learn from each other and help each other. Moreover, ex-patients discussed that exchanging tips with peers is important so that you do not have to invent the wheel again. There are so many patients who have already experienced this and have discovered practical tips, that it would be a shame if you have to figure it out again from scratch.

Peer experience exchange was therefore seen as one of the most important values this application can create.

“You do not have to invent the wheel again and can share your tips with others.”

“Contact with peers is important, only they understand what you are going through.”

“Peers can provide the most trustworthy information in this phase.”

Low threshold
Ex-patients discussed that the application provides a low threshold way to contact others, find information and track your wellbeing. The integration of these different elements in one tool helps to create this low threshold. Furthermore the medium, a phone application, creates a low threshold as you always have it with you and is easy to access.

Contacting care professionals through such an app is seen as more low threshold then when you have to call them. Sometimes speaking is literally more difficult for these patients, as they have problems with their voice box. But also, it can feel like a barrier to call someone when comparing it to sending an email. Getting into contact with peers could also be more easy through such an integrated tool that is used by peers and provided by the hospital. Reporting problems to peers or care professionals is thus made easier when combining it in one app.

Furthermore, the threshold to find information is lowered since you can search for peer experiences and can trust the information more than when you would google on a topic.

Finally, tracking your wellbeing is made easy by the short questionnaires that provide the possibility to more frequently check how you are doing, to create a more realistic image then when you would only do it 2 weeks before a consult.

“On your phone it is relatively easy in this way to have a lot of trustworthy information and tips.”

“I like that the questionnaire is short, nothing worse than filling in 4 pages of questions and you are not sure why you are doing it.”

“It is a good way to get into contact with peers, less threshold then with Facebook for example.”

Insight into yourself
Another value created by the application is more insight yourself over time. This is created by tracking your health and being able to look back at it in the logbook through graphs. Insight into yourself can help you to take the right action or become more positive over time as you can see progression. When you can see these improvements it can give you hope and provide you with courage. Being able to look back at how you are doing over time helps you to remember these improvements.

“It helps me to be positive by making me aware of improvements, however small.”

“Logbook with graph serves as a reminder that you are improving, that is nice to look back at.”

Benchmarking experiences
Ex-patients expressed that an important need answered by this application is the need to benchmark their experiences to others. They want to know that they are not alone and know what ‘normal’ experiences are for their situation. The percentages in the application that showed how many peers experienced this, helped to create this feeling. It confirmed that they are not the only ones experiencing this.

“When I feel something I would like to search for it, do others also experience this? Percentages work well in that case.”

“I like to see how many others experienced it gives you the feeling that you are not alone.”

Care professionals get more insight in between consults
Another value created by the low threshold way to be in contact with the hospital, is that the care professionals get better insight into your wellbeing in between consults. Ex-patients expressed that they would like to share what they track with care professionals so that they can intervene when necessary. They could, for example, decide to ask the patient to come to a consult earlier or decide to skip a consult. Patients would rather be in contact with a nurse consultant in this phase then a doctor, since they expressed the need for practical tips and reference to the right specialists.

“Doctor can intervene when necessary based on the data.”

“Need to be in contact with hospital is answered, best would be a nurse consultant.”

Figure 86. Test participant showing a tip for cleaning to share with peers

mede patiënten adviseren deze tip

Website links voor meer informatie:

Ga vanaf dag 1 naar de buurman en zeg hallo daar ben ik weer.

Figure 87. A tip created by a participant to share with peers

Save and remember experiences and questions
Ex-patients expressed that they have a need to remember their experiences and questions. This need is answered by being able to track their experiences and write down questions in between consults. By having this saved they expressed that they could better prepare themselves for the next consult.

"The value I see is that you create your own dossier."

"Useful to write down your questions for things that do not need immediate action. Always bad to think of these last minute before a consult."

Reassurance in between consults
Being able to contact your peers and care professionals, seeing how you are doing and benchmarking your experiences can provide reassurance in between consults. You do not have to wait until a consult and get the reassurance that you are not alone. Furthermore, the availability of trustworthy information provides reassurance, as you often do not register everything during a consult with the doctor.

"In the beginning you are uncertain and easily isolated this helps to open up the world a little bit."

"The app can be great to use in between consults if you have questions you don't need to wait."

Everything in one place
The value of 'a low threshold' is created by the value of 'having everything in one place'. The combination of different possibilities in one application provides a valuable resource and overview. This can provide a feeling of control.

"The feeling of overview created by the app, having everything in one place, is what can give me a feeling of more control."

Appropriate ways to create this value
The values explained before are created by the design of the prototype application. Ex-patients expressed how the prototype created this value and whether this was an appropriate way to do so. They expressed what elements and interactions they deemed appropriate. In figure 88 you can find the links between the appropriate ways to create value and the values.

Provide fitting ways to contact others
As seen in the previous chapter, exchanging experiences between peers is one of the biggest values that the application could provide according to the ex-patients. However, in order to enable these exchanges between peers a fitting way should be provided to be able to contact one another.

When discussing the chat function in the prototype, some of the ex-patients were enthusiastic, while others expressed that they would prefer a forum based contact platform. They expressed that they just wanted to be able to ask a question to peers and have a large reach, not expecting anyone to answer immediately. Furthermore, there are enough applications that provide a way to chat with others. They would see this application more as a platform where you can get into contact with peers and then exchange phone numbers if you would like to talk with each other further. Patients expressed that they liked the concept of a peer buddy. They expressed two concerns for this peer buddy. On the one hand, they would want to be the ones to choose who is their peer buddy, as they can find out with whom it fits. On the other hand, they expressed that in the first stages after treatment you have very little energy and it is nice if things are made as easy as possible for you.

Ex-patients did express that they liked the possibility to discuss matters within certain topics and also have a general space to express themselves. Furthermore, one of the participants expressed that she would like to see if one of her peers is in need of help or cheering up. It can thus be concluded from the different conversations, that an iteration step is needed on the way that patients can get into contact with each other.

Another stakeholder to contact is the medical care professionals. Patients expressed that most questions can be answered by peers. However, the more medical questions might be better asked to a chatbot, nurse consultant or doctor. Patients were okay with a chatbot that used previous questions and answers to answer their questions. If they really needed to talk to a care professional, they often preferred to talk to a nurse consultant through email and be referred by him/her to the right care professional if needed.

"With a chat you expect someone on the other hand. Perhaps make it a contact request."

"Perhaps you could see when someone else is in a dip and help him out of it."

"Link to email for care professionals. More realistic that they will respond."

Use visuals
Ex-patients expressed that they liked the simple and clear visuals. It can help people to better understand the information and can make them more positive. However, the visual of the 'general feeling river' was not understood by everyone. This had two main causes. First of all, even though the patients expressed that they found the metaphor to be very fitting to their situation, they did not grasp it solely from the prototype and would need some initial explanation at the beginning of the app. Explanation is another cluster that I will address later on. Secondly, the y-axis can be defined better. Some participants did understand that up means positive and down negative, but it was not immediately clear. Visuals are important and should be investigated more when further developing the prototype.

"I like the visuals, it is calm and you know immediately what it means."

Personalize it to the patient
Participants liked the concept because it felt like it was specifically made for them. To make it even better in its personalization the following 2 things were discussed:

1. Provide the patient with the option to edit their choices

Ex-patients liked the fact that they could decide with whom they would share their experiences and whether they wanted to log photo's. Providing patients with the option to decide for themselves and edit their choices later, was stressed by some of the participants. They want to be reassured that they can change their settings later and can adjust information put into the system.

"If I can adjust/add to the information about me and my settings I could make it more relevant for me and feel more in control."

2. Make sure you use fitting words

Another way to make the application more appropriate is to use the right wordings. The use of the canoe metaphor worked very well and resonated with all of the participants. However, not all participants could appreciate the word 'celebrate'. Further research with patients and nurse consultants might help to make the wordings of the final prototype even more appropriate.

"I like the metaphor you use. It fits the reality. You are in a rapid stream with ups and downs"

Incorporate the right topics at the right time
Ex-patients expressed the importance of incorporating psychosocial topics in the application. They found it important to ask a question about fear, for example, and to incorporate the effect on social relationships in the information part of the application. Participants gave tips for what topics they missed in the application. Intimacy and sexuality are examples of topics mentioned by the patients. These are important to include so that it is taken out of the taboo zone. Furthermore a concern mentioned was to provide these topics at the right times. In the beginning you might not want to think about your appearance yet, as you are more focused on the physical recovery. It should be investigated further what the right topics are at the right time.

"Add intimacy and sexuality and let patients know where to go with this topic."

"You need to time when you share what information."

Make tracking easy, quick and meaningful
The mini consult was appreciated by the ex-patients, because it made tracking their health easy and quick. Opinions on the swiping were divided. Some liked the easy interaction, for others it provided complications and they would prefer a yes and no buttons. The extra questions were also liked. They fitted with what they would expect and the option to leave an extra comment was appreciated. The following tips were provided to improve these extra questions; add numbers to the scale and discuss with the nurse consultant what questions to ask per topic.

"I like the swiping aspect, it's not another list."

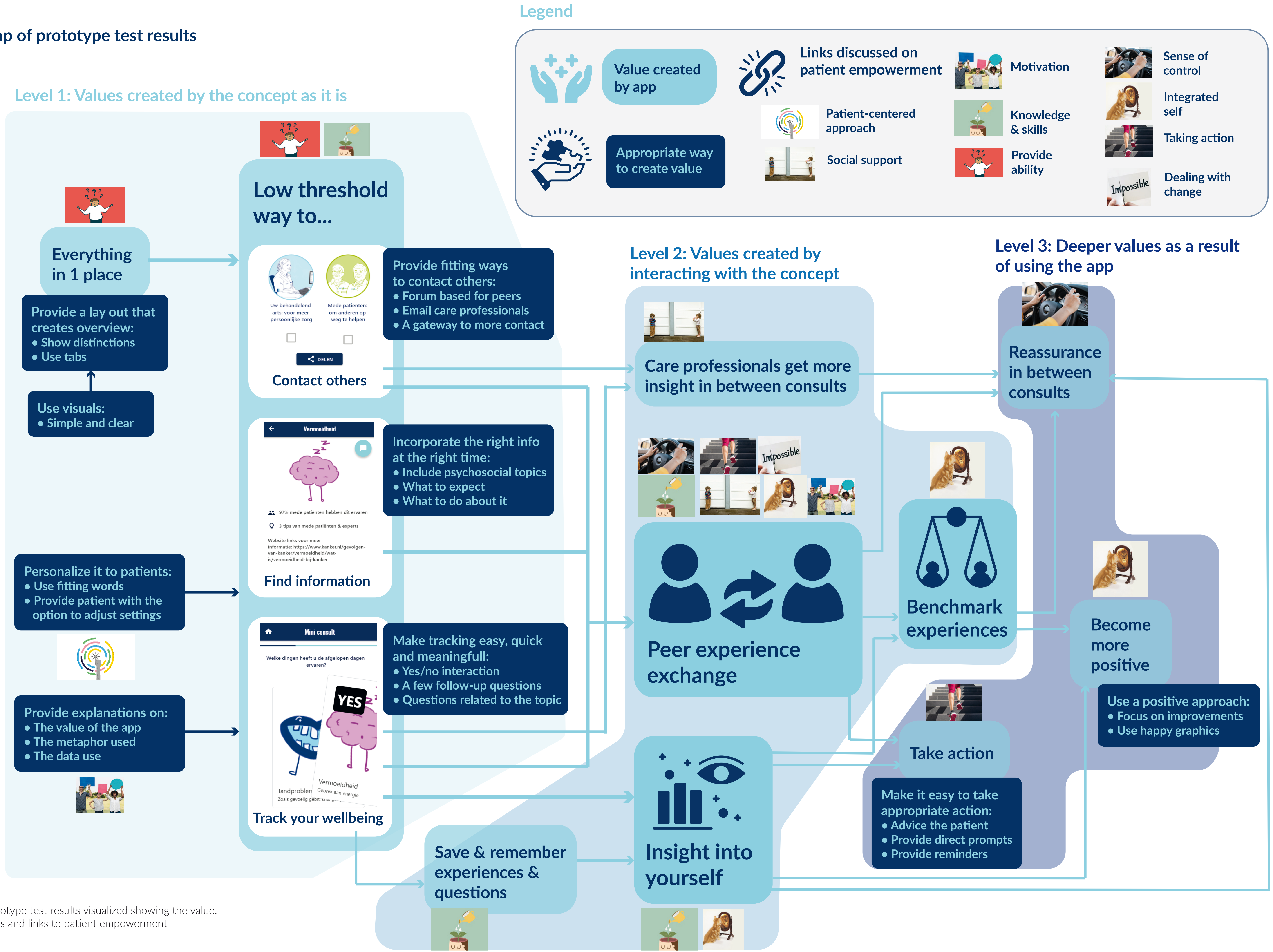
"Swiping is difficult perhaps a button is easier for my age category."

"The 3 follow-up questions are good, a peer used to ask me the exact same things."

Provide a lay out that creates overview
As previously seen, visuals are important and can help in creating understanding. They can be used to create overview. However, one also needs to make visual distinction between elements to create overview. Ex-patients expressed their need for such a distinction in showing what things they have shared and differentiating between different consults.

"Consult page could be improved; put into categories of departments/ people."

Visual map of prototype test results



Legend

Value created by app

Appropriate way to create value

Links discussed on patient empowerment

Patient-centered approach

Social support

Motivation

Knowledge & skills

Provide ability

Sense of control

Integrated self

Taking action

Dealing with change

Level 1: Values created by the concept as it is

Everything in 1 place

Provide a lay out that creates overview:
- Show distinctions
- Use tabs

Use visuals:
- Simple and clear

Personalize it to patients:
- Use fitting words
- Provide patient with the option to adjust settings

Provide explanations on:
- The value of the app
- The metaphor used
- The data use

Low threshold way to...

Uw behandelend arts: voor meer persoonlijke zorg

Mede patiënten: om anderen op weg te helpen

☐ ☐

DELEN

Contact others

Provide fitting ways to contact others:
- Forum based for peers
- Email care professionals
- A gateway to more contact

Vermoeidheid

97% mede patiënten hebben dit ervaren

3 tips van mede patiënten & experts

Website links voor meer informatie: https://www.kanker.nl/gevolgen-van-kanker/vermoeidheid/wat-is/vermoeidheid-bij-kanker

Find information

Incorporate the right info at the right time:
- Include psychosocial topics
- What to expect
- What to do about it

Mini consult

Welke dingen heeft u de afgelopen dagen ervaren?

YES

Tandproblem

Zoals gevoelig gebit,

Vermoeidheid

Gebrek aan energie

Track your wellbeing

Make tracking easy, quick and meaningfull:
- Yes/no interaction
- A few follow-up questions
- Questions related to the topic

Level 2: Values created by interacting with the concept

Care professionals get more insight in between consults

Peer experience exchange

Save & remember experiences & questions

Insight into yourself

Level 3: Deeper values as a result of using the app

Reassurance in between consults

Benchmark experiences

Become more positive

Use a positive approach:
- Focus on improvements
- Use happy graphics

Take action

Make it easy to take appropriate action:
- Advice the patient
- Provide direct prompts
- Provide reminders

Figure 88. Prototype test results visualized showing the value, appropriateness and links to patient empowerment

Provide explanation

As previously mentioned there is need for further explanation of the metaphor at the beginning of the app. Next to this, ex-patients also mentioned that they would like an explanation in the beginning on how the app works, what the care-professionals do with the information and what value the application can bring them as patients. Such an explanation can help to create more motivation to use the app.

“I want to know what happens at the back, what does the doctor do with it.”

Make it easy to take appropriate action

Ex-patients liked the buttons that prompted to take action like the ‘contact your physio’ button. They also appreciated the reminders to take action and even opted for more of these prompts, like push notifications for topics that they are interested in or providing suggestions on how to celebrate.

“I like the button to take direct action and that tells me what to do.”

Use a positive approach

Ex-patients stressed the importance of using a positive approach. They mentioned three things that helped to create a positive feeling; using happy visuals like the characters, phrasing sentences in a positive way and highlighting improvements. One tip to even increase the positivity was to end the mini consult on a positive note, asking what you want to work on next week.

“You provide a positive twist, focus on things that are improving not only bad things.”

“The enjoyable thing is that it does not look somber. The graphics are happy and clear.”

How the application links to the patient empowerment cards

Participants talked about the patient empowerment cards in relation to the prototype they explored. They sorted them on relevance for the application (see figure 89) and some even created links between them (see figure 90). By discussing these cards, links could be made between the values created by the prototype as previously explained, and these concepts.

Figure 89. Test participant sorting the patient empowerment

Figure 90. Different outcomes of discussion with patient empowerment cards

Figure 88 on the previous page shows an overview of how the different patient empowerment cards were linked by ex-patients to the different values. It is interesting to see that exchanging experiences with peers was believed to contribute most to patient empowerment. Ex-patients explained that this exchange leads to different aspects of patient empowerment. For example, some participants expressed that their self-image and self-efficacy could improve by talking to peers and seeing that others experience similar things.

“I would be motivated to use the app to help others and to be in contact with others.”

A few aspects of patient empowerment could be improved more through a redesign of the concept. Ex-patients expressed that it is a good initial data base of knowledge that can grow over time. One participant provided the idea to add videos to convey information in a low threshold way. Furthermore, taking action could be stimulated more. It is already created through tracking and reviewing your wellbeing. However, by providing even more concrete to do’s when something is regressing and providing the possibility to set goals, you could perhaps increase this aspect. Finally, as discussed before, providing a better explanation of the value of the app at the beginning can increase the motivation to start using it.

“Knowledge and skills could be better in the app; like videos of how to clean (self-care) or how a treatment will go. Showing is easier than describing.”

“When you can translate symptoms and questions into concrete to do’s and steps it is easy to take action.”

On the concepts of self-image, dealing with change and motivation, ideas of the participants differed. Some said these could not be created by an application and are inherent to a person’s attitude. Others said that by exchanging experiences with peers these concepts could be created.

“Dealing with change is something personal, can not be created by the app.“

System concerns of participants

Unintendedly, ex-patients also expressed their concerns for how the system should be developed and how it might be expanded. I discuss these concerns in this paragraph and use them in the next chapters.

The following concerns were addressed by the patients:

- There needs to be a moderator/manager of the system.
- The Healthcare Monitor should be integrated in such a way that you do not have to answer questions twice.
- Security of the system is important.
- Create links to the relevant websites/platforms that already exist.
- Good promotion is important.
- You could also use this application during treatment.
- You should test your application with a diverse group to make it inclusive for everyone.
- For expansion you could make it work for other devises as well.
- You could use this application for different kinds of patients or other hospitals.

Even though the research questions do not link to these concerns, they are valuable to take into account for the next chapters.

6.2.5 Discussion

Clusters were formed, using a thematic analysis, that answer the 3 research questions, as stated in the beginning. By looking at the experiences with the prototype that ex-patients reported, I could link different values, appropriate ways and patient empowerment elements together in one overview. Figure 88 on page 128 shows this overview that can be seen as the conclusion of this prototype test. This overview helped to answer the three research questions.

1. Value of the application

I could distinguish 3 different levels of value created by the prototype. The first level as shown in figure 88, is the value that the concept creates as it is. This means that the patient does not have to interact with the app over time to get these values, but they are inherent to the application itself. The biggest value in this level is the value that the application provides a low threshold way to contact others, find information and track your wellbeing. This is created through the value of having everything in one place.

This low threshold creates the next level of values; values that are created by interacting with the concept. These values are created when the patient interacts with the system over time. The biggest values in this level are; exchanging experiences with peers, insight into yourself and the possibility to benchmark experiences. The low threshold to track your wellbeing creates the value of saving and remembering your experiences and questions. This value in turn helps to create the value of getting insight into yourself. The combination of the different elements of the application help to exchange your experiences with peers. Which in turn provides the value to benchmark your experiences with those of others. Furthermore, you have the value that care professionals also get more insight into your wellbeing in between consults.

As a result of using the application over time, you will experience deeper values that are shown in level 3. It can help you to take action and become more positive. Ultimately, it can help in providing the patient with reassurance in the time between consults.

2. Appropriateness & things to improve

The dark blue boxes in figure 88 show the answers of ex-patients on how the previously described values can be created in an appropriate way. These were discussed in detail in the results section. Some of the points were already addressed by the prototype while others could be improved to increase the appropriateness. Some initial improvements that are suggested through these insights will be discussed in the next chapter, chapter 6.3.

The metaphor used was found relatable by all 6 participants and the visuals were appreciated, since they create a more positive view.

3. Link to patient empowerment

When looking at figure 88 it is interesting to see that the deeper values link to the consequences of patient empowerment while the values created by the concept and the interaction with the concept link mostly to the antecedents and attributes. An exception is exchanging experiences with peers. This was linked to many different aspects of patient empowerment. This stresses once again the importance of exchanging experiences with peers. The greatest link with patient empowerment was found through this value of exchanging experiences.

Desirability

By combining the answers of these three different questions, I can make an initial conclusion on the desirability of the concept. Ex-patients reported that they think this concept is desirable for head and neck cancer patients in their follow up phase, since it answers a diverse set of needs of patients in this phase in an appropriate and low threshold way. The most important needs answered are to exchange experiences and tips with peers and get a better insight into your own wellbeing. The concept is desirable since it provides everything in one place. The concept can help to increase different elements of patient empowerment especially by providing peer experience exchanges.

Limitations

Since this prototype test was done with a small group of participants that were selected using convenience sampling it should be seen as an initial qualitative study on the desirability of the concept. It is not a completely representative group of patients, since these patients were already interested in innovations for health care. In the next research a more diverse group of people should participate in the study. 3 of the prototype tests were done offline and 3 online. In the online prototype tests it differed how participants used the prototype. One of the participants used a tablet for example, while another used the interface of Adalo on the laptop. Therefore, the interaction with the system might have differed slightly for these participants. However, they could all see and experience the different screens and therefore discuss the value and appropriateness of this concept.

Key chapter insights

- According to ex-patients the created prototype is desirable for head and neck cancer patients in their follow-up phase, since it answers the needs of exchanging experiences with peers and getting better insight into your own wellbeing in a low threshold way.
- Eventually these created values can lead to more reassurance for patients in the time in between consultations.
- There are a couple of things to improve to make the prototype deliver these values in an even more appropriate way.
- Exchanging experiences with peers can lead to many different elements of patient empowerment.

6.3 Recommended improvements

6.3.1 Introduction

In this chapter I address the recommended improvements to make to this application based on the insights of the prototype test.

The improvement suggestions are mainly based on the dark blue boxes that are shown in the result overview of the prototype test in figure 88 on page 128. These show the appropriate ways to create the desired value. As discussed in the results of the prototype test some of these values could be created in a more appropriate way. Suggestions for how to do this are provided in section 6.3.2.

Based on the insights from the prototype test and the made improvements a new concept is suggested. This concept is illustrated with a new system map and a scenario to show the use of the concept in context.

6.3.2 Suggested improvements

I explain the suggested improvements according to the dark blue boxes as shown in the results overview.

Provide explanation

One of the things discussed was to provide a more clear explanation at the beginning of the app on the value, the metaphor and the data use. This could create more motivation to start using the app. My suggestion is to create a short video that can be shown at the beginning of the application, the first time it is used by the patient. Figure 91 shows this suggestion visually.

Provide explanations on:
- The value of the app
- The metaphor used
- The data use

Figure 91. Explanation video suggestion

Personalize it to patients:
- Use fitting words
- Provide patient with the option to adjust settings

Eetbeleving
een paar seconden geleden
ernst: 5
frequentie: Vaak
Opmerking: Ik proef geen zout

Figure 92. Suggestions for more personalization

Personalize it to patients

Another improvement is providing the patient with more options to adjust settings. This will help to make it feel more personal. A suggestion is to show more options when the patient uses the application for the first time (see figure 92). The patient should be able to see and adjust the information that the treating physician has put into the system. They should be able to choose their contact person and time to track. Furthermore, they could set up their profile and choose peer patients to connect with. All these settings should be adjustable later on in a settings menu.

Not only at the beginning of the application but also while using the application, you should provide the option to adjust input. An example of this is the possibility to edit your tracked experiences when you see them in the results overview (see figure 92).

Another suggestion to improve the personalization, is to look at the words used in the application. This is something to do in the next steps of the development process of this application and will therefore be further explained in the next chapter, chapter 7 ‘operationalization’.

Create overview

In order to create a good visual overview several improvement suggestions are shown in figure 93.

One suggestion is to show a distinction between experiences that you have shared and those that you did not yet share in the results overview. You could also provide option to more easily select different experiences to share.

Furthermore, it is suggested to provide an overview of the different consults in the logbook. Your questions often relate to consults with different care professionals. Therefore, it can help the patient if the different consults are shown separately and questions can be added per consult. Another option added is the option to also place notes underneath the questions, so that you can really have everything together in an organized way in one place.

Provide a lay out that creates overview:
- Show distinctions
- Use tabs

Eetbeleving
een paar seconden geleden
ernst: 5
frequentie: Vaak
Opmerking: Ik proef geen zout

Hoofd behandelaar
over 17 dagen

Fysio
over 2 maanden

Hoofd behandelaar
over 17 dagen

Vraag:
Heeft u ook slaappillen?
Notitie:

Figure 93. Suggestions for more overview

Provide fitting ways to contact others

This is a very important point as it is linked to one of the most important values of exchanging experiences with peers. This point is really something that should be paid more attention to in the next stages of the design process. For now, my suggestion to improve this, based on the insights from the prototype test, is to provide different ways to contact others.

For looking at experiences on a certain topic, it might be best to use a forum format. This can be done by working together with the platform of Kanker.nl, who already use forums, but do not have forums placed in distinctive categories relevant for different types of cancer. Therefore, my suggestion is to create an ExPEERience part of this website that uses the experiences tracked in the application as categories for the forums. The application can have an in app referral to these forums that makes it look like they are part of the application. This provides the possibility to have everything together in this one app, without having to reinvent the wheel of forum contact between peers. Figure 94 shows an example of how this forum could be represented within the application.

Furthermore, in the prototype test it was discovered that ex-patients see this application as a way to get into contact with peers but not the medium for further contact in itself. This means that patients want to connect with peers via this platform and then want to have further contact through other platforms such as WhatsApp or email. In order to answer to this need for making connections with relevant peers I suggest to add a 'connect' section to the discover part of the application (see figure 95). In this section patients can discover peers that are looking to connect with others and have similar experiences. When you make a connection you send a request to your peer to follow their shared experiences. In this way you have a more closer connection with a few peers and can see and respond to their shared experiences. If someone is not feeling well, you can comfort them or share your tips. You can send a first message through this platform and then arrange further contact through another platform. This creates the possibility for more personal contact next to the tips and tricks and the forum.

Provide fitting ways to contact others:

- Forum based for peers
- Email care professionals
- A gateway to more contact

Forum vragen en antwoorden over Eetbeleving

mk66
(ex-)patiënt
8 mei 2021 om 20.47, gewijzigd 8 mei 2021 om 20.47

Opnieuw leren eten

Hallo,

Eind februari is bij mij een tumor in mijn mond/keel geconstateerd, vlak naast mijn huig. Het bleek een kanker te zijn veroorzaakt door het HPV virus. Na een traject van drie chemo's en 35 bestralingen middels een protonentherapie ben ik nu één week na mijn laatste bestraling. Nu kan ik nagenoeg niet meer eten o.a. door de pijn in mijn mond en keel. Maar ook alles staat me tegen terwijl ik enorme trek heb in van alles en nog wat. Heb een sonde gehad maar deze kon ik niet verdragen. Van de beruchte flesjes ga ik alleen bij het aanblik al van over m'n nek. Ik eet nu zo goed als niks, gelukkig heb ik nog wat reserves maar ik mis wel de voedingstoffen die nodig zijn voor een goed en snel herstel. Wanneer ik in de ochtend een klein schaaltje vla neemt dan zit ik de hele dag tot over m'n oren vol. Alsof ik de kerstdish van de hele familie heb weg gewerkt. Ik heb ook nagenoeg nooit honger.

Persoonlijk denk ik dat het voor 80% tussen m'n oren zit. Zijn er lotgenoten die hetzelfde ervaren als ik?

Stel een vraag over Eetbeleving

Figure 94. Suggestions for kanker.nl forum in application

Bea
Mijn chemotherapie voor keelkanker is net een maand geleden geëindigd. Nu ben ik opzoek naar een keelkanker patiënt die al verder in het proces zit zodat ik een mede patiënt maatje kan vinden die mij kan helpen. Neem contact op als jij diegene bent.

Gert
Hi, ik sta open om andere patiënten te helpen. Voor mij is het nu 5 jaar geleden sinds ik tongkanker heb gehad en ik heb veel ervaringen over hoe je om kunt gaan met de bijwerkingen. Mijn hobby's zijn puzzelen en wandelen. Neem contact met mij op als je een vraag hebt.

Figure 95. Suggestions for kanker.nl forum in application

Other stakeholders to contact are the relevant care professionals. Ex-patients suggested to use email as a way to contact them, as this was low threshold and often seen as a medium that allowed for the best response. Therefore the contact buttons should lead to the email application. A partly automated mail can be provided to make it even easier for patients to share their concerns with care professionals.

The right information at the right time

Another thing to look at in the further development of the application, is to provide the right information at the right time. How to further design for this will be discussed in the chapter 7. In order to provide good information the Erasmus MC could work together with the patient association 'Patiënten Vereniging Hoofd Hals' (see figure 96) and other information organizations that have already gathered a good data base of information. The application could link to these websites so that you do not need to reinvent the wheel again.

Make tracking easy, quick and meaningful

It is important that the tracking of experiences is easy, quick and meaningful so that patients keep tracking their experiences over time. To do so, the interaction should be easy and feel fast. Furthermore, the questions should be relevant. I provide some initial suggestions for improvements for the interactions here. Suggestions for how to make the questions even more relevant are provided in chapter 7.

Figure 97 shows some initial suggestions to improve the tracking experience.

From the prototype test it became clear that the swiping interaction can be difficult for some patients. It is however a quick way to track your experiences and therefore some patients liked it. It should be further investigated whether you want to use the swiping interaction with some more explanation or whether you want to change it to two simple Yes and No buttons.

For the convenience you could show the numbers of the scale underneath the scale questions of how bad the experience is.

Furthermore, it could be interesting to provide the option to take a photo for the photo log at the end of the mini consult. It should be optional, but it is good to prompt it during the mini consult to make it more low threshold to track your appearance over time.

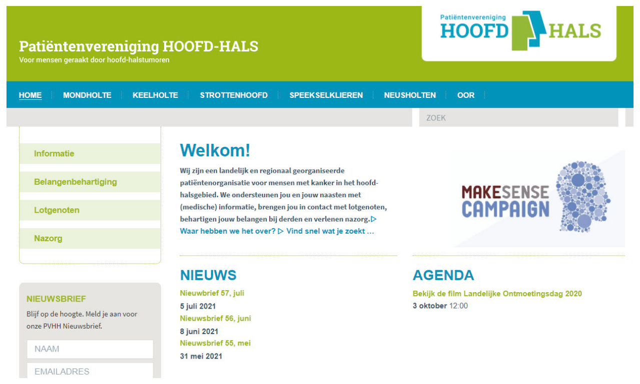
97% mede patiënten hebben dit ervaren

3 tips van mede patiënten & experts

Website links voor meer informatie: https://www.kanker.nl/gevolgen-van-kanker/vermoeidheid/wat-is/vermoeidheid-bij-kanker

Incorporate the right info at the right time:

- Include psychosocial topics
- What to expect
- What to do about it



Welkom!

Wij zijn een landelijk en regionaal georganiseerde patiëntenorganisatie voor mensen met kanker in het hoofd-halsgebied. We ondersteunen jou en jouw naasten met (medische) informatie, brengen jou in contact met lotgenoten, behartigen jouw belangen bij derden en verlenen nazorg.▷
Waar hebben we het over? ▷ Vind snel wat je zoekt ...

NIEUWSBRIEF
Blijf op de hoogte. Meld je aan voor onze PVHH Nieuwsbrief.

NIEUWS
Nieuwbrief 57, juli
5 juli 2021
Nieuwsbrief 56, juni
8 juni 2021
Nieuwsbrief 55, mei
31 mei 2021

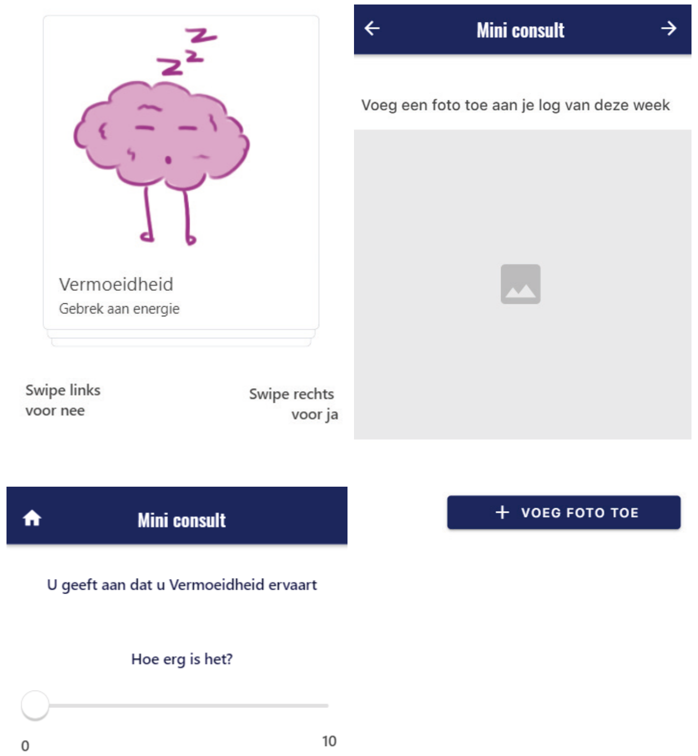
AGENDA
Bekijk de film Landelijke Ontmoetingsdag 2020
3 oktober 12:00

Figure 96. Suggestions for using information from the patient association

Welke dingen heeft u de afgelopen dagen ervaren?

Make tracking easy, quick and meaningfull:

- Yes/no interaction
- A few follow-up questions
- Questions related to the topic



Voeg een foto toe aan je log van deze week

U geeft aan dat u Vermoeidheid ervaart

Hoe erg is het?

Figure 97. Suggestions for improving tracking experiences

Make it easy to take appropriate action and focus on improvements

Participants liked the buttons that prompted to take direct action and provided some suggestions to do this even more. One suggestion is to also use the prompt to celebrate an improvement. By providing suggestions based on the hobbies of a person you can stimulate the patient to do something fun to celebrate improvements. This helps to see things from the positive side. Figure 98 shows this action button underneath the section of things that have improved.

Another suggestion to focus more on the positive things, is to end the mini consult with the question: 'What would you like to work on next week?' This question asks the patient to take action for their health in the following week while focusing on that you can improve your wellbeing.

Another added button in the overview of insights, is the button to view tips. In this way you not only provide the direct action to contact a care professional if necessary, but also provide the patient with a prompt to take action themselves to improve their health.

Another way that can help in taking action yourself more easily, is to provide the patient with the option to follow a topic. If a patient is interested in tips for shoulder pain they can say that they want to get a notification whenever there is a new tip for this topic.

These suggestions for improvements where used to create a suggestion for a new concept. This will be presented in the next section in the form of a new system map and a story board that shows how the application is used.

Make it easy to take appropriate action:
- Advice the patient
- Provide direct prompts
- Provide reminders

Use a positive approach:
- Focus on improvements
- Use happy graphics

Inzichten en tips →

Inzichten en tips voor deze week

Dingen die verbeterd zijn

Vermoeidheid

Je vermoeidheid is minder dan vorige week! Wat zou je willen doen met je nieuwe energie?

Dingen om op te letten

Schouderpijn

Let op: Schouderpijn is over de afgelopen weken gestegen. Doet u nog steeds de fysio oefeningen? Als u meer informatie wilt over de oefeningen of hulp nodig hebt bij uw trainingsschema neem dan contact op met de fysio.

Figure 98. Suggestions for more direct promts to take action and focus more on the improvements.

6.3.3 Final concept suggestion

Based on the findings of the prototype test and the recommended improvements, I present a final concept suggestion in this section. This suggestion is meant as a starting point for a new iterative design process where the prototype is redesigned and tested again with a more diverse group of patients. It is meant as inspiration for this new design phase, reflecting the insights from the previously tested concept. The concept will be explained through a system map and a story board.

System map

A new system map of this concept is created to show the different parts and interactions that the system should include and how the data is used within the system. Figure 99 on the next pages shows the overview of the system map. It includes 9 different parts that I will briefly describe below.

Doctor set up

In order to set up a good initial data base for the system to start with, the doctor sets up initial recommendations for the topics and frequency for the patient to track. An advice is provided to the doctor by the system, but the doctor can add or change this advice. The doctor checks the prognosis made by the system to show to the patient in the discover module of the app and can adjust it. Furthermore, the doctor can check the suggested care professional contact persons and adjust these. If the doctor for example knows that the patient has a good relationship with a specific nurse consultant, he or she can be put in the suggestions. At the end of the set up the doctor can see an overview of what the system will show to the patient and has a final chance to make some adjustments. This set up is done to provide a valid and relevant start of the system for the patient.

Patient set up

The first time that the patient uses the application, an initial patient set up sequence is run. It starts with showing the introduction explanation video of the system. Next, the patient can check, adjust and choose several options to set up the system to his or her preference. In this set up the patient can also already choose some peer patients to follow and connect with. This set up is done once at the first time use, but the choices can always be adjusted in the settings menu.

Home

This is the screen that the application opens on every other time the patient opens the app. It is a gateway to the other modules and shows the last mood that the patient has been in.

Adding an experience in the mini consult

Through the plus button on the home screen patients are referred to the mini consult where they can track their general mood, experiences and appearance. The results are shown in an overview that can be adjusted, added upon or shared with peer followers or the medical contact person. From these results some insights are shown to the patient with suggested actions to take based on how the experiences of the patient has changed over time.

Discover

This part of the applications shows the expected journey as prognosed by the system, based on the data it collects from the patient and his or her peers. It also shows an overview in which patients can search for experiences and check how many other peers have experienced this. A new added feature is the possibility to connect with peers. In this overview you can find peers that have similar experiences. You can decide to follow them to view their experiences and see how they differ or match with yours. Furthermore, you can connect with them and send them a message to have further contact through other platforms.

Logbook

Here you can review the experiences you have tracked, the tips you have saved, your consults and link to My Erasmus MC. The consults page shows which consults you have planned and provides the opportunity to add questions per consult. The link to My Erasmus MC is created in this logbook to provide the complete overview of important medical data in one application. This makes it easy to look back at this data, reflect on it and write questions based on the insights you get from reviewing the data. This will help patients to be better prepared for their consults.

Messages

The messages part is limited and serves mostly as a gateway to start talking with people through other platforms. You can ask patients to have further communication through email or phone for example. For the medical contact person, it serves as an easy way to send them an email through this application.

System map ExPEERience

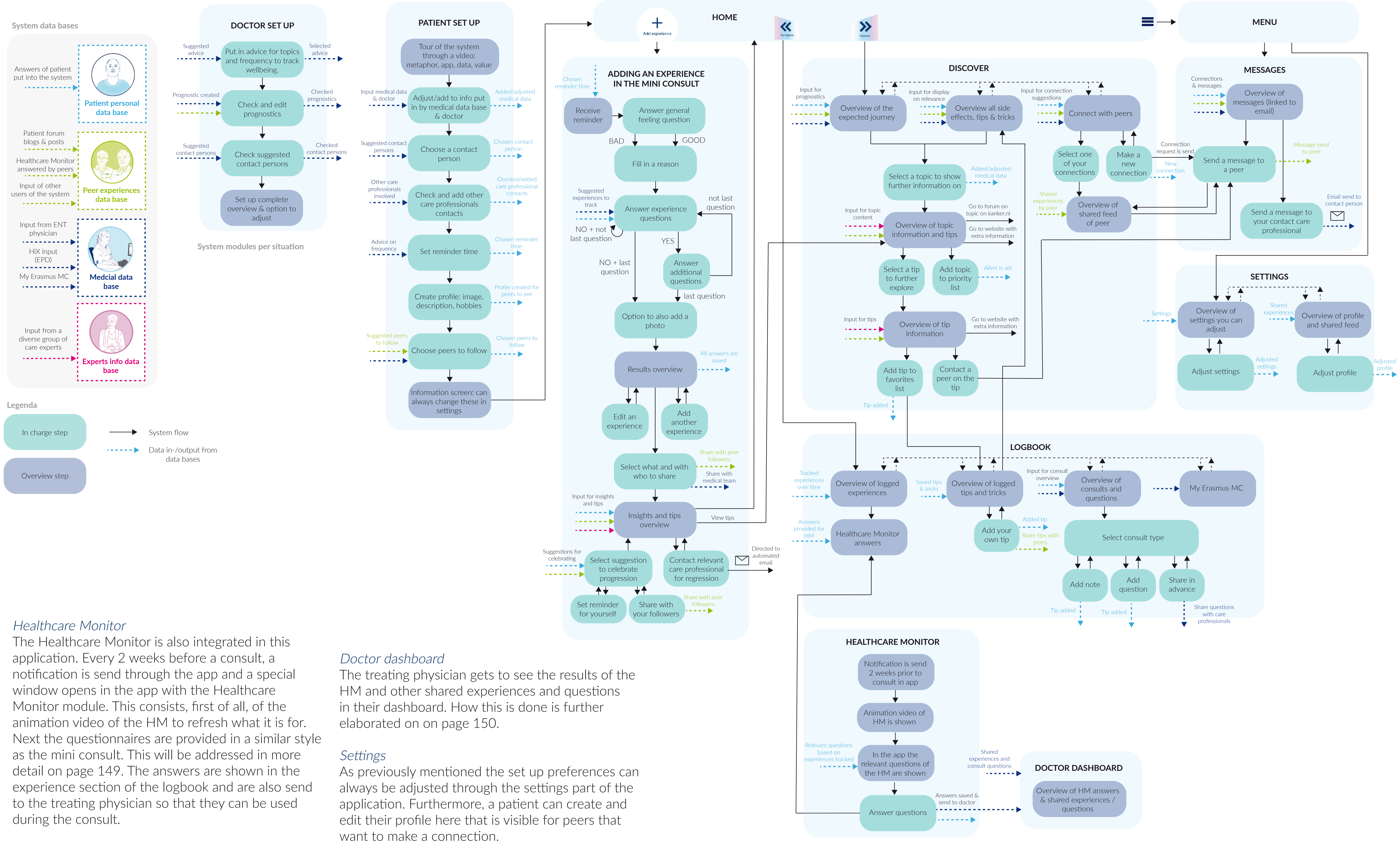


Figure 99. System map of ExPEERience with the suggested improvements

Healthcare Monitor

The Healthcare Monitor is also integrated in this application. Every 2 weeks before a consult, a notification is send through the app and a special window opens in the app with the Healthcare Monitor module. This consists, first of all, of the animation video of the HM to refresh what it is for. Next the questionnaires are provided in a similar style as the mini consult. This will be addressed in more detail on page 149. The answers are shown in the experience section of the logbook and are also send to the treating physician so that they can be used during the consult.

Doctor dashboard

The treating physician gets to see the results of the HM and other shared experiences and questions in their dashboard. How this is done is further elaborated on on page 150.

Settings

As previously mentioned the set up preferences can always be adjusted through the settings part of the application. Furthermore, a patient can create and edit their profile here that is visible for peers that want to make a connection.

Story board

On the next pages a story board shows how this system map actually works in the use context, to provide a more concrete example of the previously explained modules in a visual way.

First time use, introducing and setting up the system

Visual scenario

Time

Location

Description

System module

2 weeks before first follow-up consult

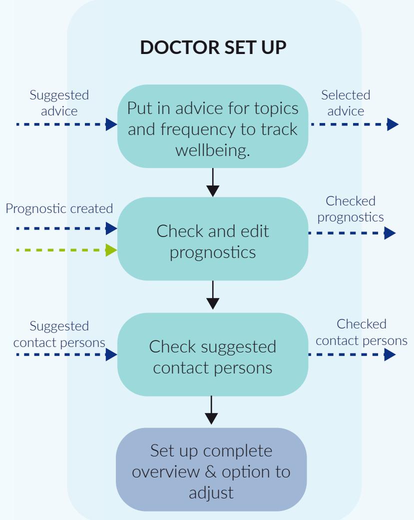
Follow-up HM filled in by patient

2 weeks before the first follow-up consult, the patient fills in the Healthcare Monitor. This data will be used by the ExPEERience system to provide suggestions for the experiences to track to the treating physician in the doctor set up.

Just before first follow-up consult

Doctor sets up system

Before the first follow-up consult the treating physician checks the set up of the system. The system provides an overview of the suggested set up for this specific patient. The treating physician can adjust the set up if necessary.



DOCTOR SET UP

Suggested advice → Put in advice for topics and frequency to track wellbeing. → Selected advice

Prognostic created → Check and edit prognostics → Checked prognostics

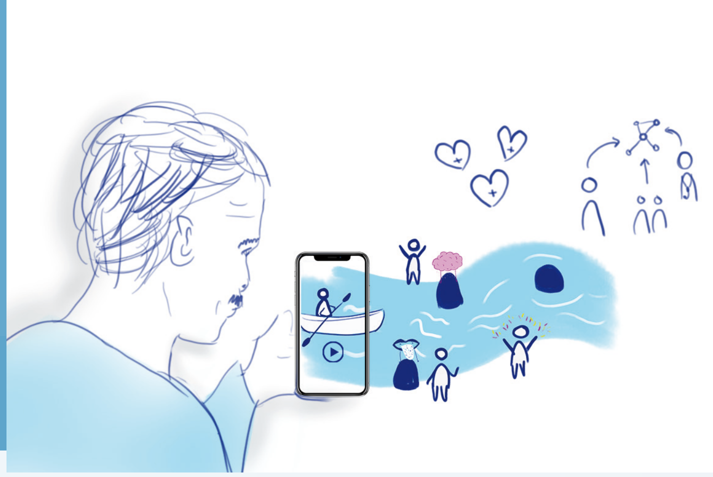
Suggested contact persons → Check suggested contact persons → Checked contact persons

Set up complete overview & option to adjust

During first follow-up consult

App presented to patient

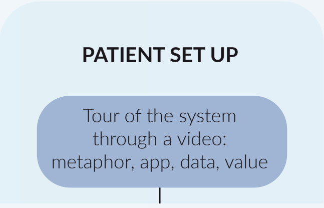
During the first follow-up consult the application is presented to the patient by the treating physician. The treating physician briefly explains what the app does and what it means for the patient and their follow-up period.



First time patient opens the app

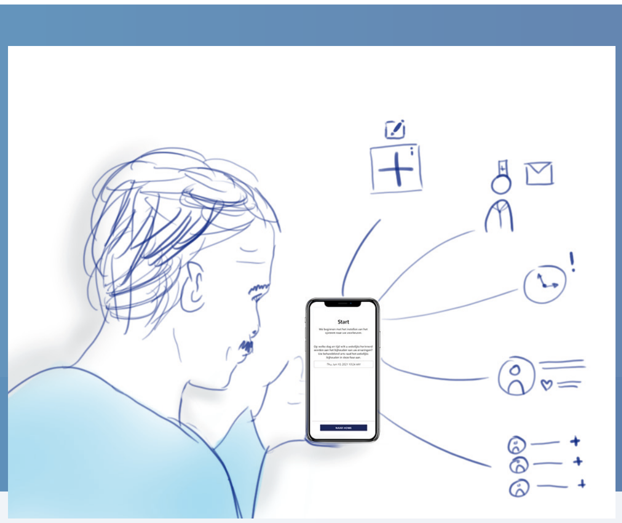
Explanation video first time use

The first time the patient opens the app at home, an explanation video is shown to further explain the app, the value it can create and what is done with the data it collects.



PATIENT SET UP

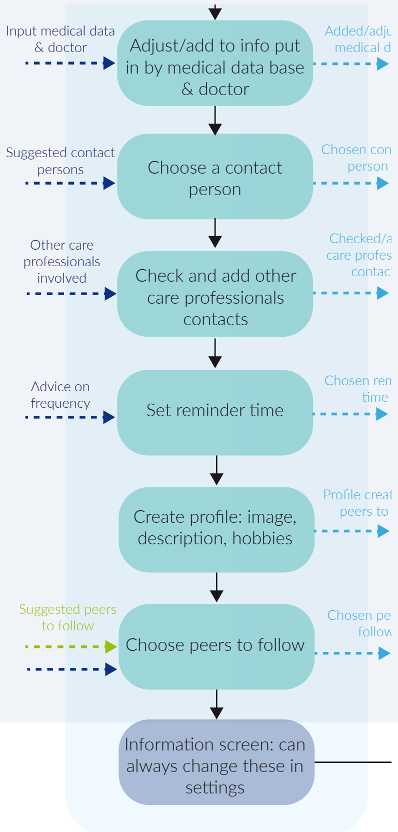
Tour of the system through a video: metaphor, app, data, value



First time patient opens the app

Patient system set up

After the explanation video the patient gets to see several screens with questions about setting up the system.



Input medical data & doctor → Adjust/add to info put in by medical data base & doctor → Added/adju medical d

Suggested contact persons → Choose a contact person → Chosen con person

Other care professionals involved → Check and add other care professionals contacts → Checked/a care profes contac

Advice on frequency → Set reminder time → Chosen ren time

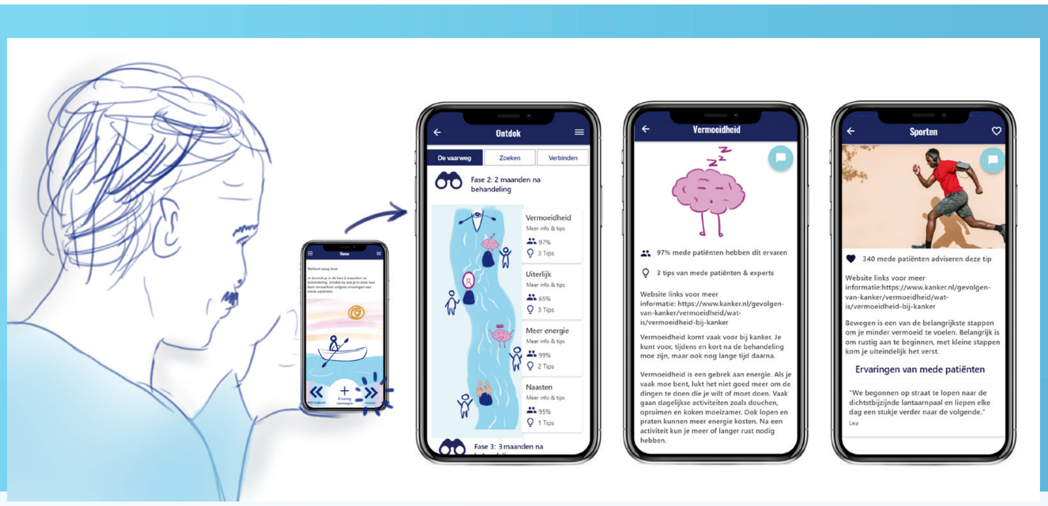
Create profile: image, description, hobbies → Profile creat peers to

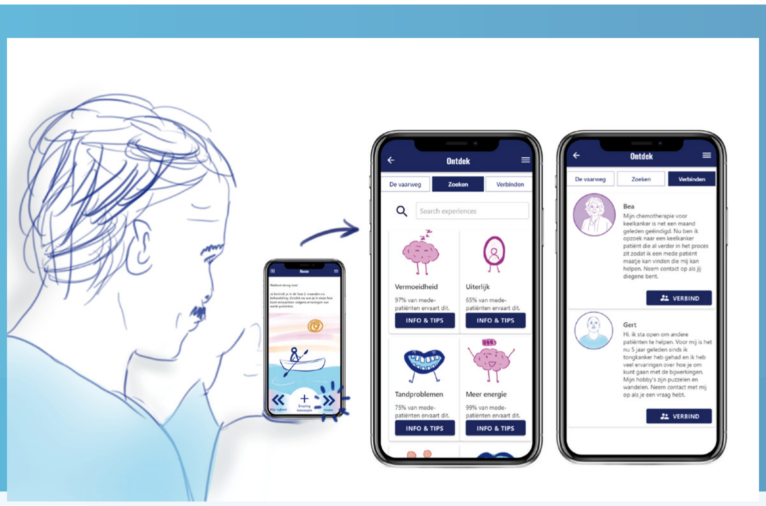
Suggested peers to follow → Choose peers to follow → Chosen pe follow

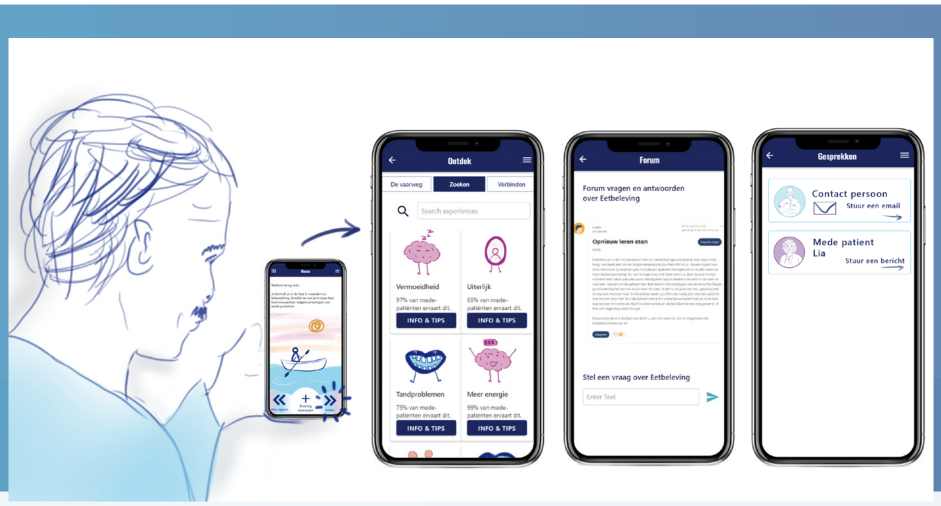
Information screen: can always change these in settings

Regular use during 5 years of follow-up

Visual scenario







Time

Location

Whenever the patient wants to or when a new phase begins

Discovering what to expect
Whenever the patient feels like it or when a new phase begins, he or she can discover what they can expect in the next phase of the follow-up process. These phases and their expected experiences are based on the different data sources that the system uses. The patient can explore these experiences to prepare for what might come and read experiences, tips and tricks of peers.

Whenever the patient wants to search for an experience and benchmark it with peer experiences

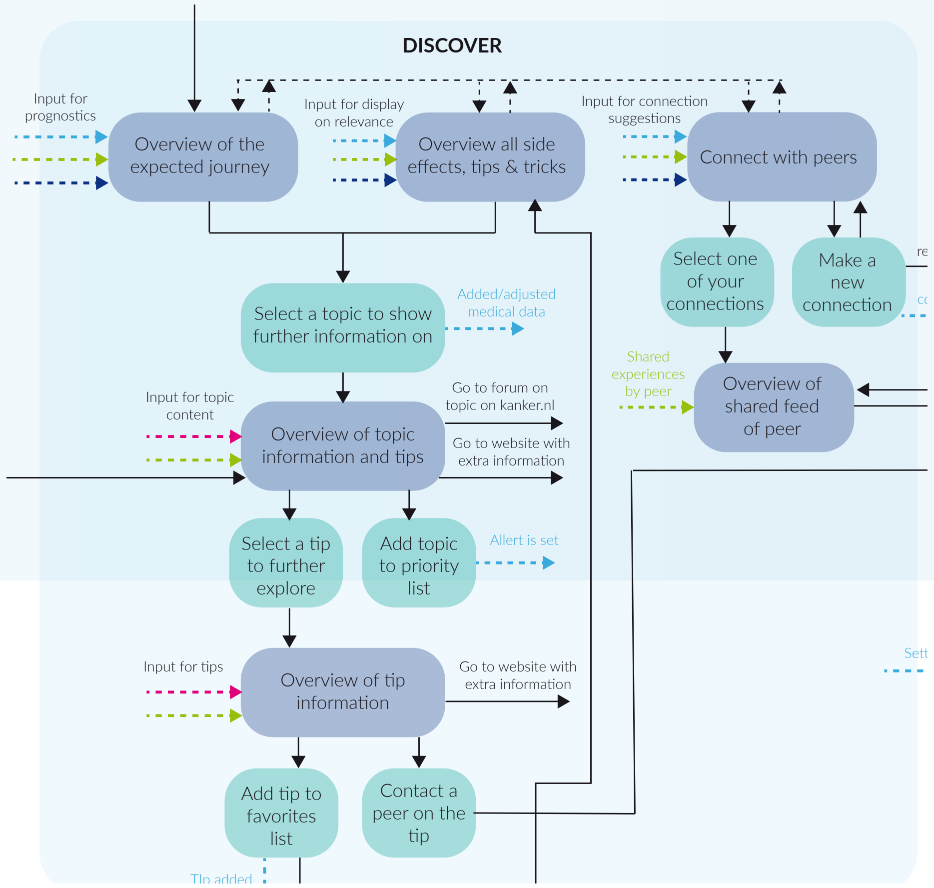
Searching for experiences and peers
Whenever the patient is experiencing something, they can search for the experience in the overview to find extra information on it and tips. They can also connect with peers and follow their experiences to benchmark their experiences to their own experience.

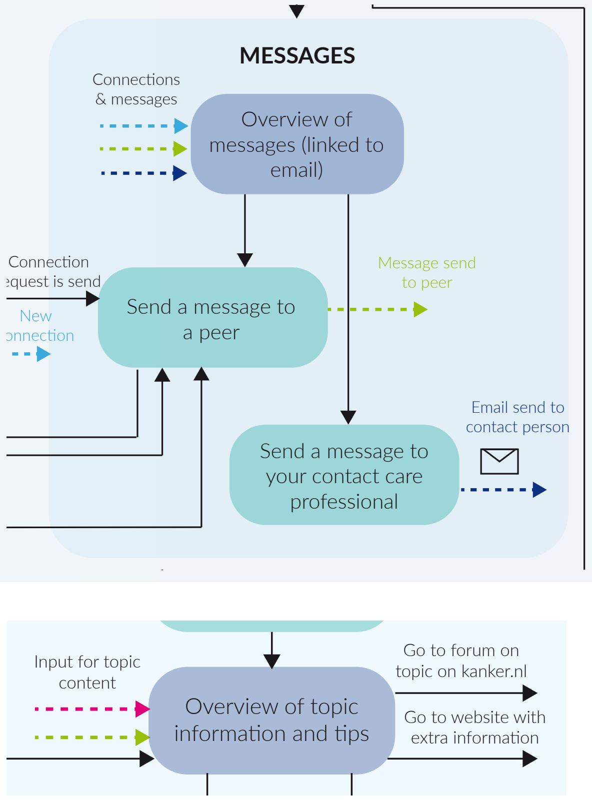
Whenever the patient has a question

Asking a question
When the patient wants to ask a question about a certain topic, they can ask it through the kanker.nl forum that is presented within the app. When they want to have a conversation with a peer, they can send a message through the app to discuss further contact options. If they have a question for their contact care professional, they can send an email message through this platform. Through these different options patients can receive answers to their questions from different people.

Description

System module





Regular use during 5 years of follow-up

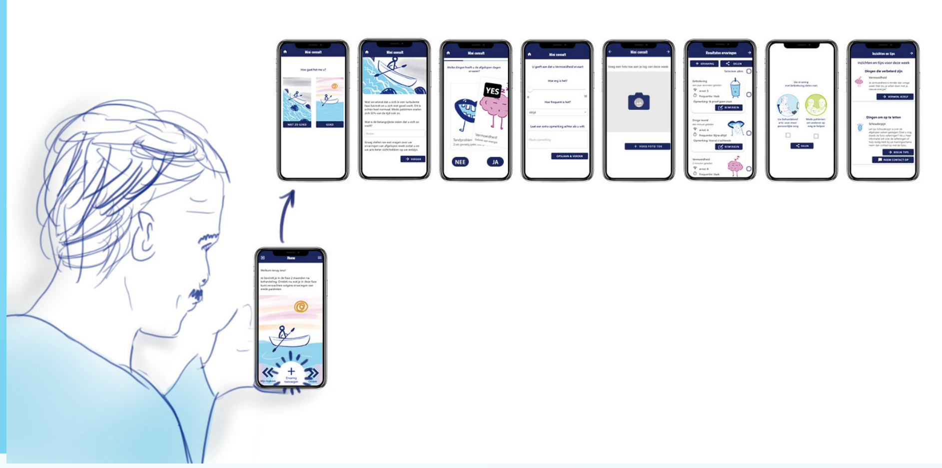
Visual scenario

Time

Location

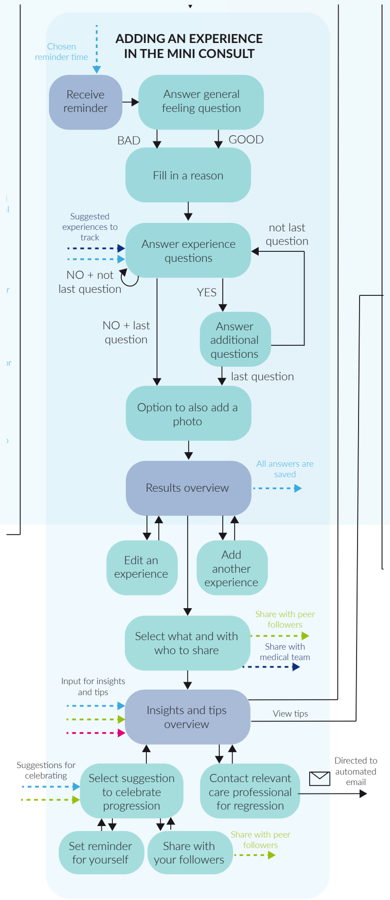
Description

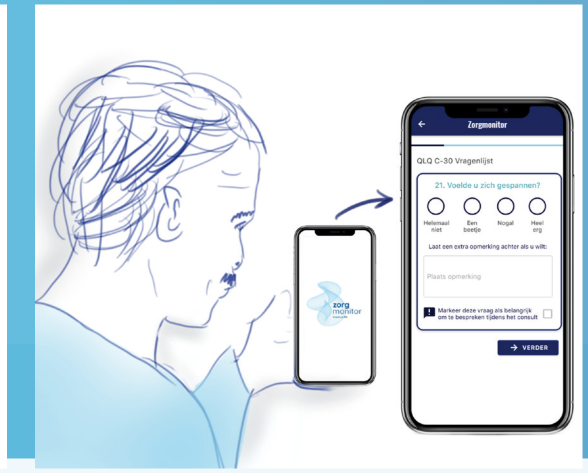
System module



Weekly tracking experiences

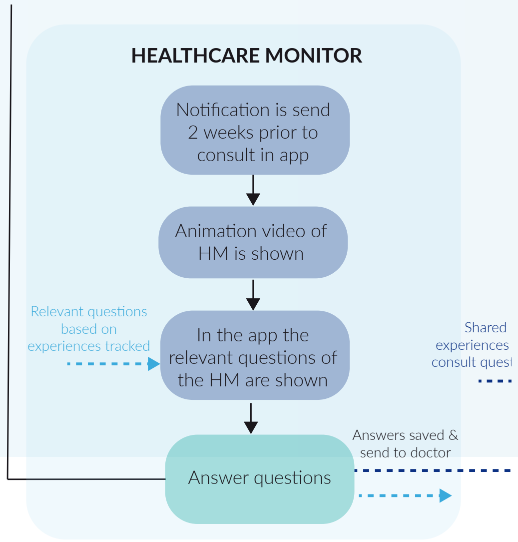
Adding an experience in the mini consult
In the first follow-up year, the patient gets a reminder to track their experiences every week. The patient fills in the questions and can see his or her results of this week and the insights when compared to the previous weeks. Based on these insights, the patient can decide to take action; celebrate improvements, view tips or contact the relevant care professional. Furthermore the patient can share their tracked experiences with peer followers and/or their treating physician if they want to. The frequency to track experiences can be reduced over the years.

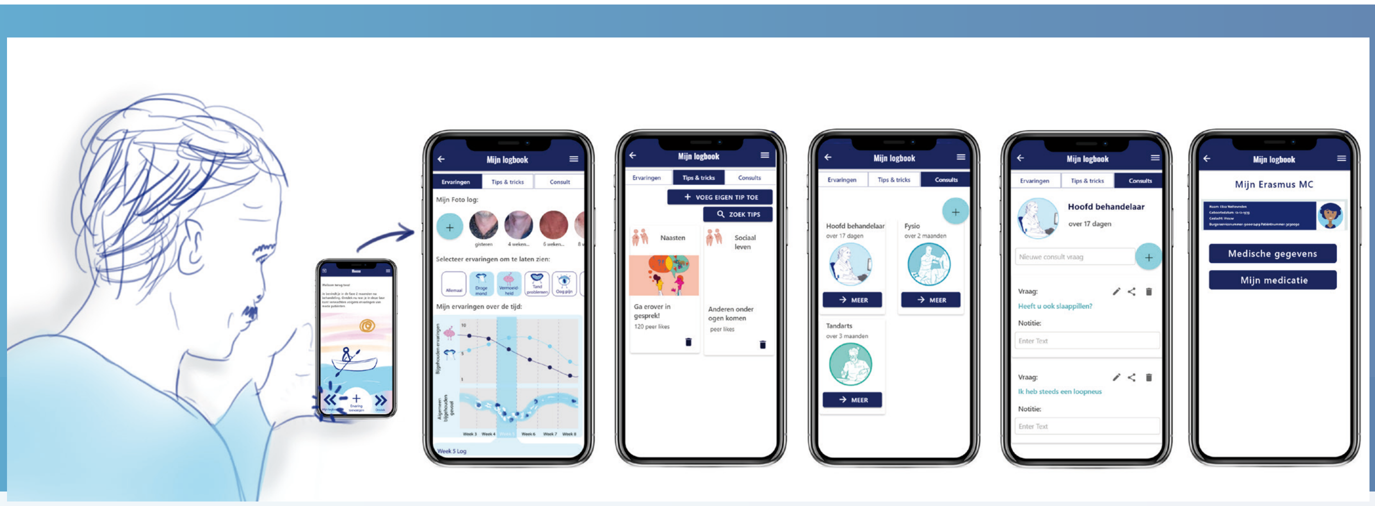




2 weeks before a consult

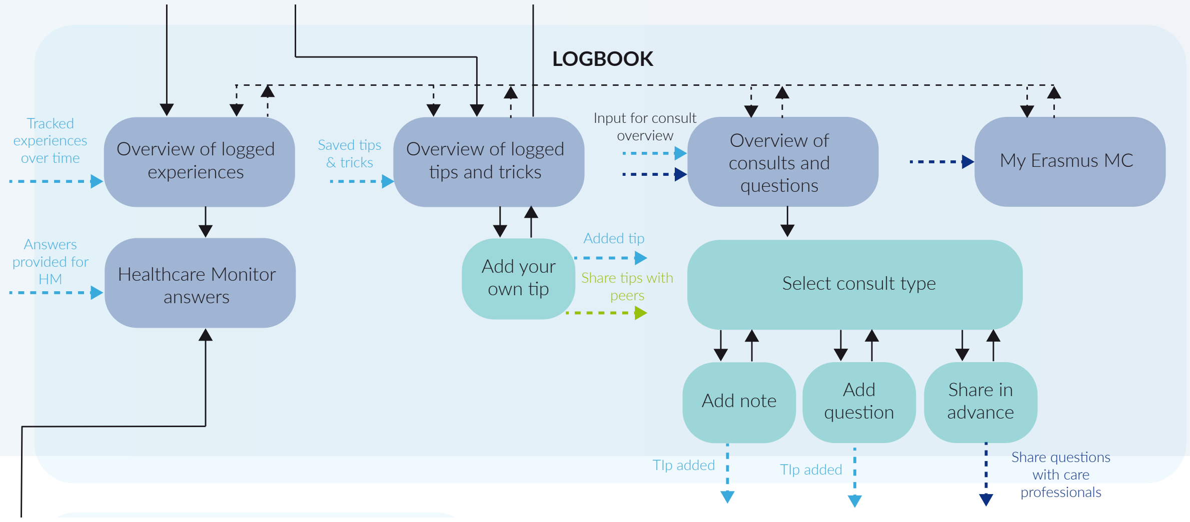
Filling in the Healthcare Monitor
2 weeks before the next consult with the treating physician, the patient receives a notification in the application to fill out the Healthcare Monitor within the app. The patient answers the questions which are selected based on the relevance when looking at the patient data. The results are forwarded to the doctor.



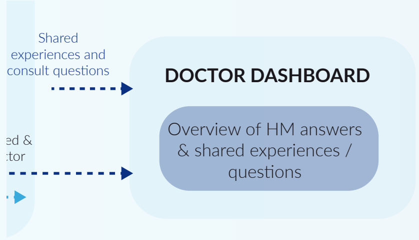
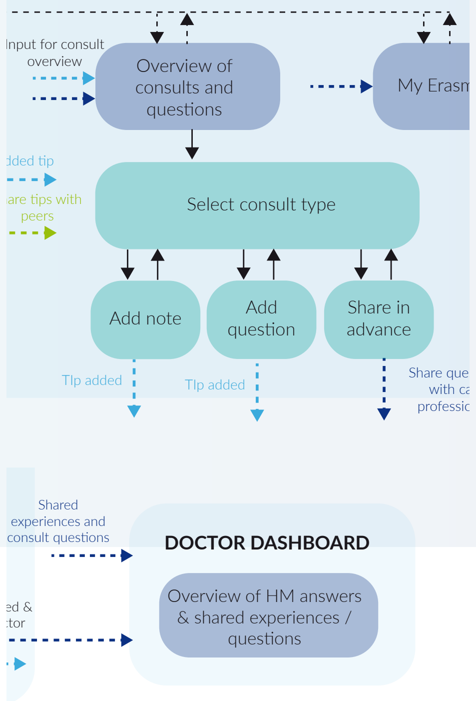


Whenever the patient wants to review their experiences and 2 weeks before a consult

Reviewing logged experiences, tips and consults
Whenever the patient wants to, they can review the trends of their logged experiences or look at their saved tips and tricks. Furthermore, they can see an overview of the consults and add questions to ask during these consults. Right after filling in the HM, the patient is asked to look back at their logbook, including their 'My Erasmus MC', in order to prepare for their consult and add consult questions based on their insights from looking back. The patient can decide to share some of the logged consult questions in advance with the doctor.



Regular use during 5 years of follow-up

Visual scenario		
Time	**Right before consult**	**During a follow-up consult**
Location		
Description	*Reviewing patient data in dashboard* The shared experiences, questions and answers to the healthcare monitor can be seen in a trend overview in the dashboard of the treating physician. The treating physician can use this to better prepare for the consult.	*Using the insights in the consultation* During a follow-up consult both the patient and treating physician are better prepared and have a better insight into the health of the patient. They both have their dashboard with insights and questions to use during the consult. The patient can use the application to review his or her questions and make notes within the consult page.
System module		

Healthcare Monitor integration

As seen in the story board, the concept idea is to also integrate the Healthcare Monitor questions in the application. Based on the experiences that the patients have tracked, the questionnaires and questions are filtered on relevance. Figure 101 shows which questionnaires will always be asked (darker blue) and which ones are only asked if relevant (lighter blue). The questions on psychosocial problems and quality of life are always good to ask patients. However, since not every patient experiences specific physical problems, such as voice issues, these questionnaires need to be filtered for their relevance.

The order shown in figure 101 is a suggestion. Further research should be done on the desired order of questionnaires in the application.

Figure 100 shows an example of how these questions could be asked within the ExPEERience application. Further design and research should be done to create a format that fits best with the user needs. I have added the option to add a comment, since this was liked by the prototype test participants in the mini consult. Furthermore, there is an option to highlight the question as important to discuss with the doctor. This could help both patient and doctor to get a fast understanding of the important topics to discuss during the consult.

QLQ C-30 Vragenlijst

21. Voelde u zich gespannen?

○ Helemaal niet
○ Een beetje
○ Nogal
○ Heel erg

Laat een extra opmerking achter als u wilt:

Plaats opmerking

Markeer deze vraag als belangrijk om te bespreken tijdens het consult ☐

Figure 100. HM question example in app

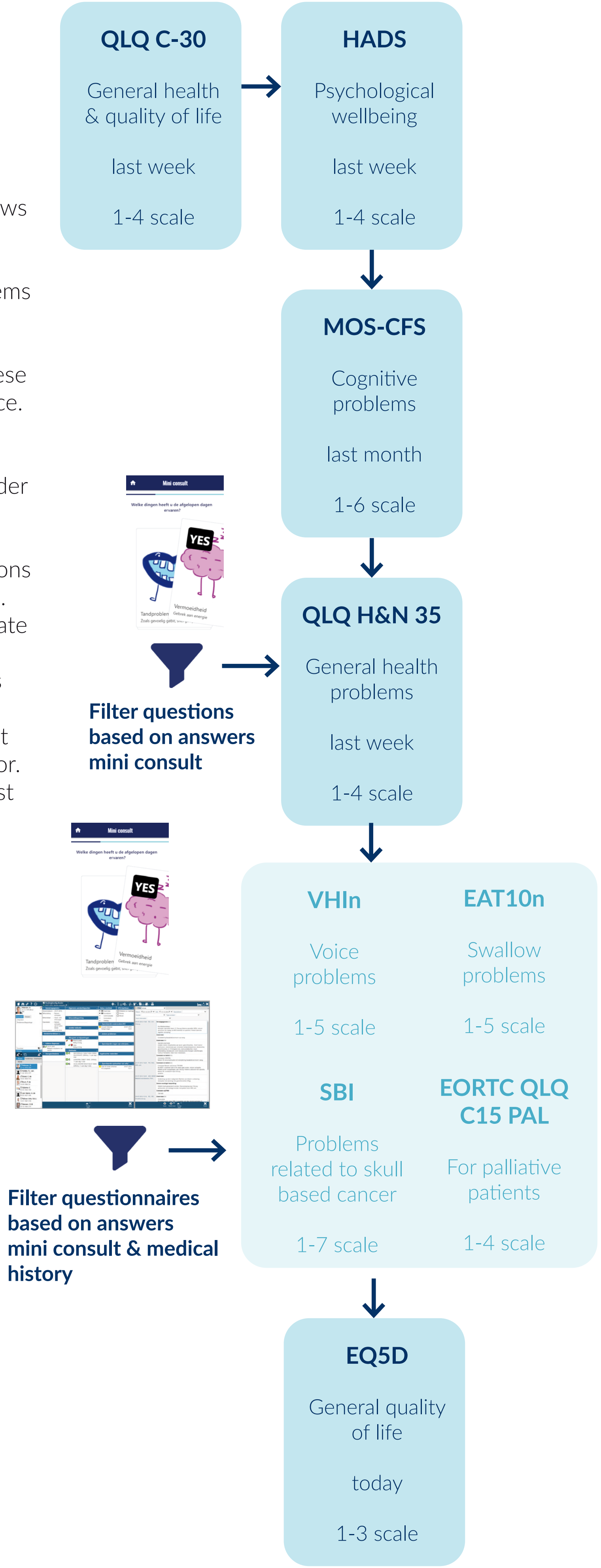


Figure 101. Questionnaires HM flow in application

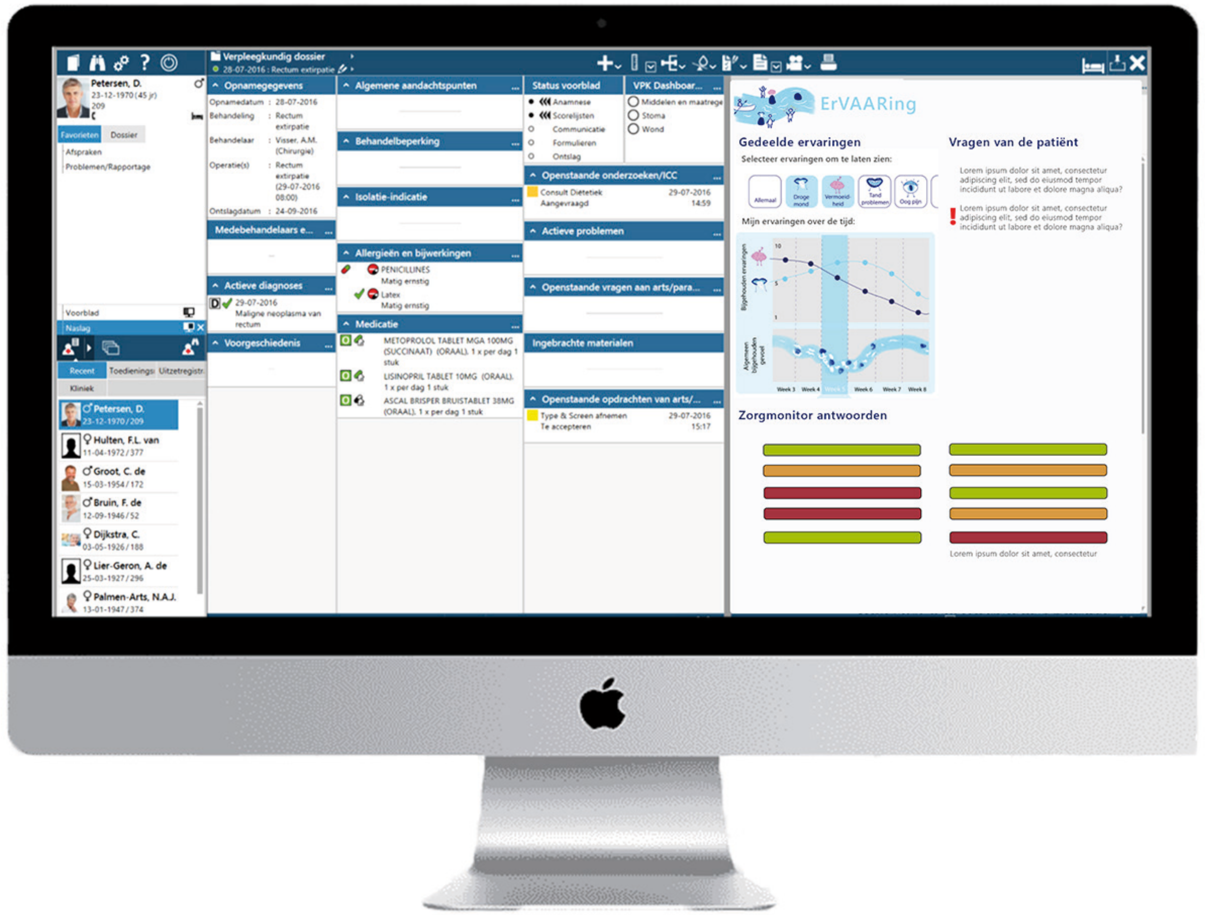
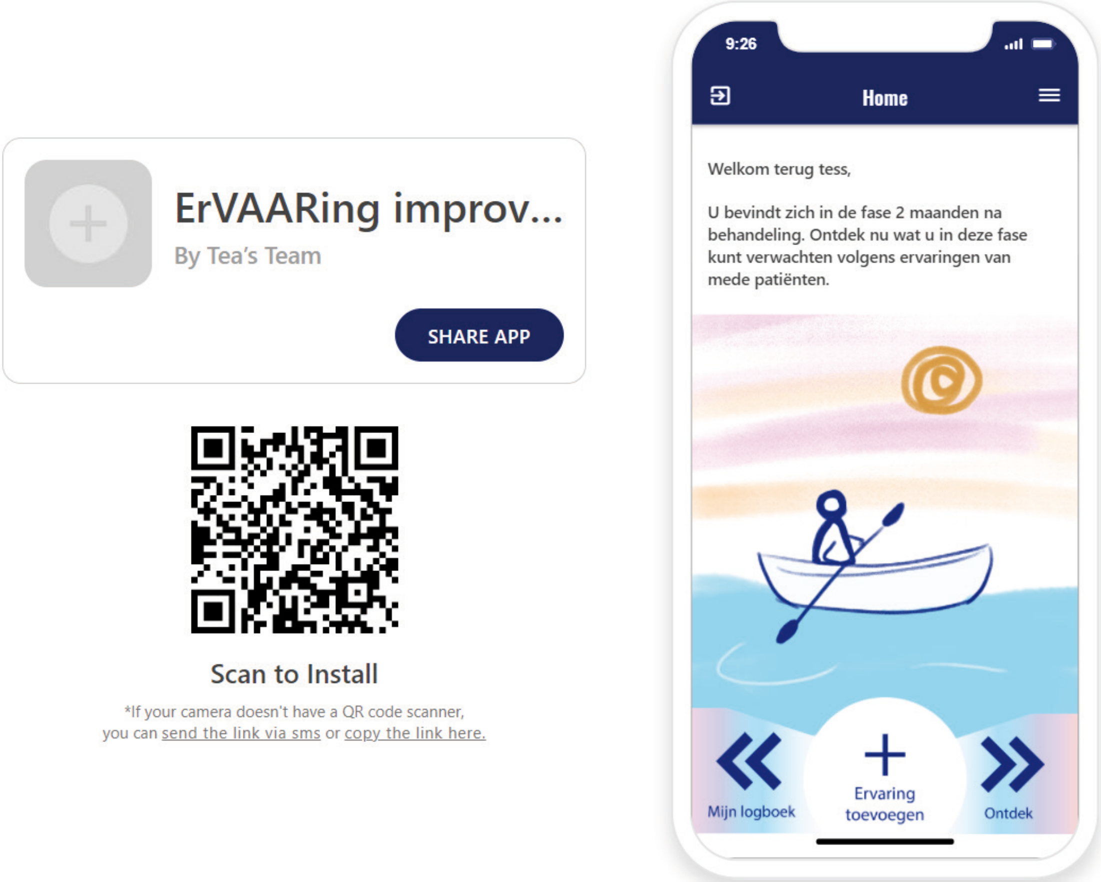


Figure 102. Treating physician dashboard example

A dashboard for the treating physician
The story board also showed a dashboard for the treating physician. This dashboard will need to be designed in order to fit with the needs of the care professionals. This is something to do in the next steps and will therefore be further discussed in the next chapter; chapter 7 'operationalization'. For now figure 102 shows a first simple visualization of the idea that the data collected through the application should be presented inside HiX. HiX is the system that doctors currently use to view patient information. The data from ExPEERience can be viewed in a separate tab in combination with the Healthcare Monitor. This tab can be opened by the treating physician before and during consult to be better prepared and have a quick overview and insight of the health situation of the patient.

Alert when it goes over a threshold
Furthermore something that should be incorporated in the system is an alert if the values of the tracked experiences go over or below a certain threshold value. This value should be decided upon together with doctors and nurse consultants and is also one of the next design steps.

When such a limit is broken, an alert is sent to the medical contact person, who checks the values and if needed takes necessary action such as asking the patient to come to a consult sooner.



*If your camera doesn't have a QR code scanner, you can send the link via sms or copy the link here.

Welkom terug tess,

U bevindt zich in de fase 2 maanden na behandeling. Ontdek nu wat u in deze fase kunt verwachten volgens ervaringen van mede patiënten.

Figure 103. QR-code to the design prototype that includes some of the suggested improvements

6.3.4 Chapter conclusion

In this chapter a value map was presented based on the findings of the prototype test. Furthermore, the insights of the prototype test let to some suggestions for improving the application design. Based on these insights, a suggestion for a new system concept was shown through a system map and story board.

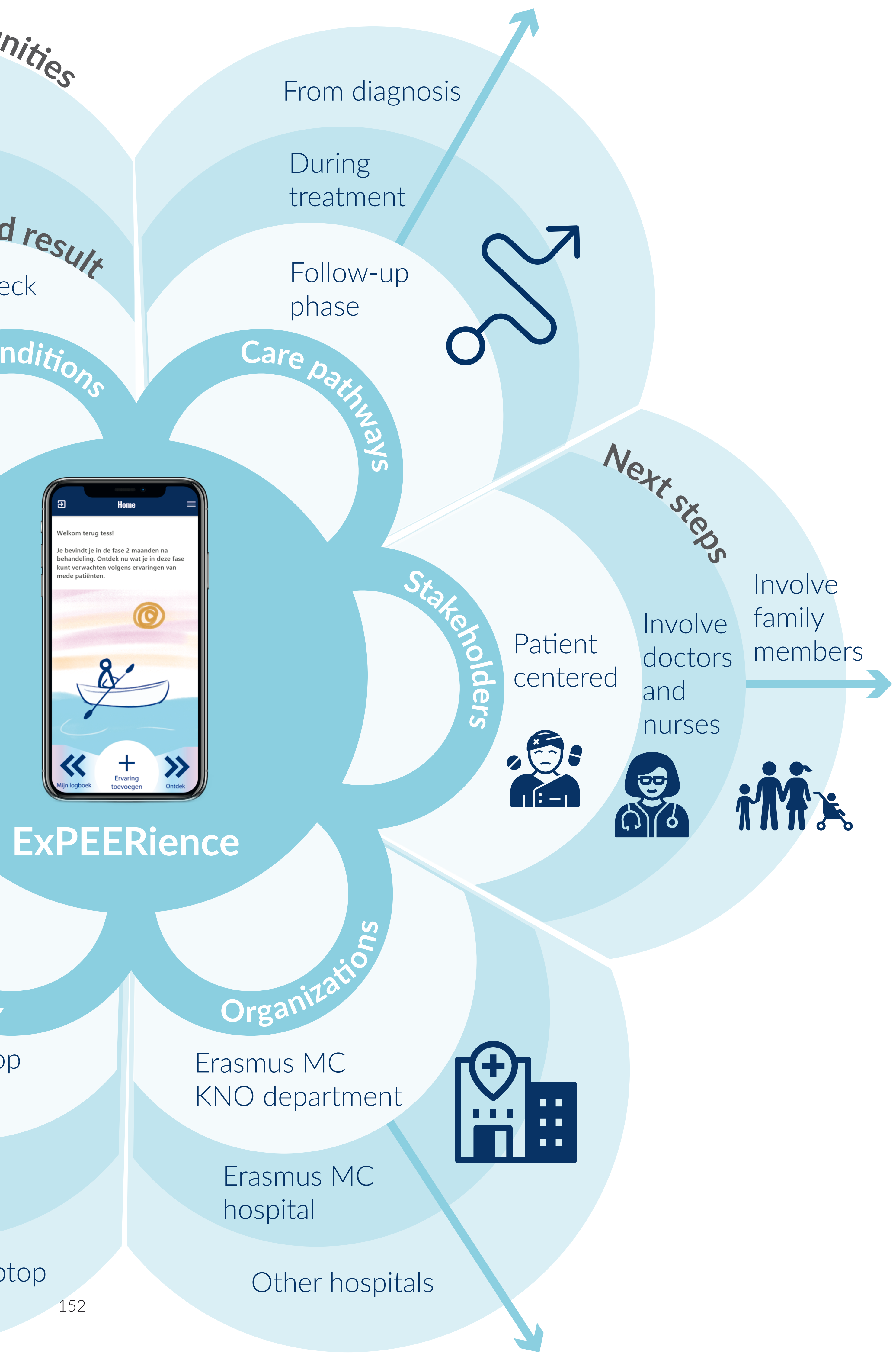
These suggestions are recommendations to take into account in the next developing steps of this concept. They can be used for designing a new prototype to test with patients for a longer time. Some of these improvements have already been added to the prototype. They can be viewed by scanning the QR-code shown in figure 103. (Use username: tess, password: test)

In the next chapter I discuss the next steps to take in this development in more detail and I also look at how this system could eventually be scaled.

In chapter 8, the value map shown in chapter 6.2 is used once more, as input for the discussion for designing for patient empowerment and Value-Based Healthcare.

Key chapter insights

- Several improvements are recommended to increase the appropriateness of how the application delivers the desired values.
- The Healthcare Monitor should be integrated in the system in a way that is seamless for the patient in its use.
- Further attention should be given to designing the interface for care professionals in the next development steps.


Welkom terug tess!

Je bevindt je in de fase 2 maanden na behandeling. Ontdek nu wat je in deze fase kunt verwachten volgens ervaringen van mede patiënten.

Sub-question 5: What should be done to make this service system **operational** in the future?

7.
OPERATIONALIZATION

In this chapter I present a development roadmap that shows the next steps needed to further develop this concept. I also present a model that shows different ways how to scale this concept in the future.

7.1 Chapter introduction

In the previous chapter, the value that the ExPEERience concept can create was explored through a prototype test. Based on this prototype test, some recommendations for improving the design of the concept were discussed, leading to a suggestion for an improved concept. In order to further develop this concept and make it work in the context of the Erasmus MC, further research and design steps are needed. In this chapter I will highlight the next steps needed in the development of this system and steps that can be taken later to scale the service.

The aim of this chapter is to answer sub-question 5:

> 5. What should be done to make this service system **operational** in the future?

This sub-question is divided into the 2 following sub-sub-questions:

- What are the next steps needed to further develop this concept?
- How could the system scale to create bigger impact?

Figure 104 shows how this chapter builds upon the concept suggestion to suggest steps for further development and scaling of the service. First, I talk to ICT staff members of the Erasmus MC to get a better understanding of the technical feasibility of the concept and the next steps needed in order to further develop this concept in the Erasmus MC context. Based on these findings, I provide a further development roadmap in chapter 7.2, that shows the next steps to take in the development of an application for HNC patients of the Erasmus MC in their follow-up phase. In chapter 7.3 I will provide some suggestions for scaling this service in the future.

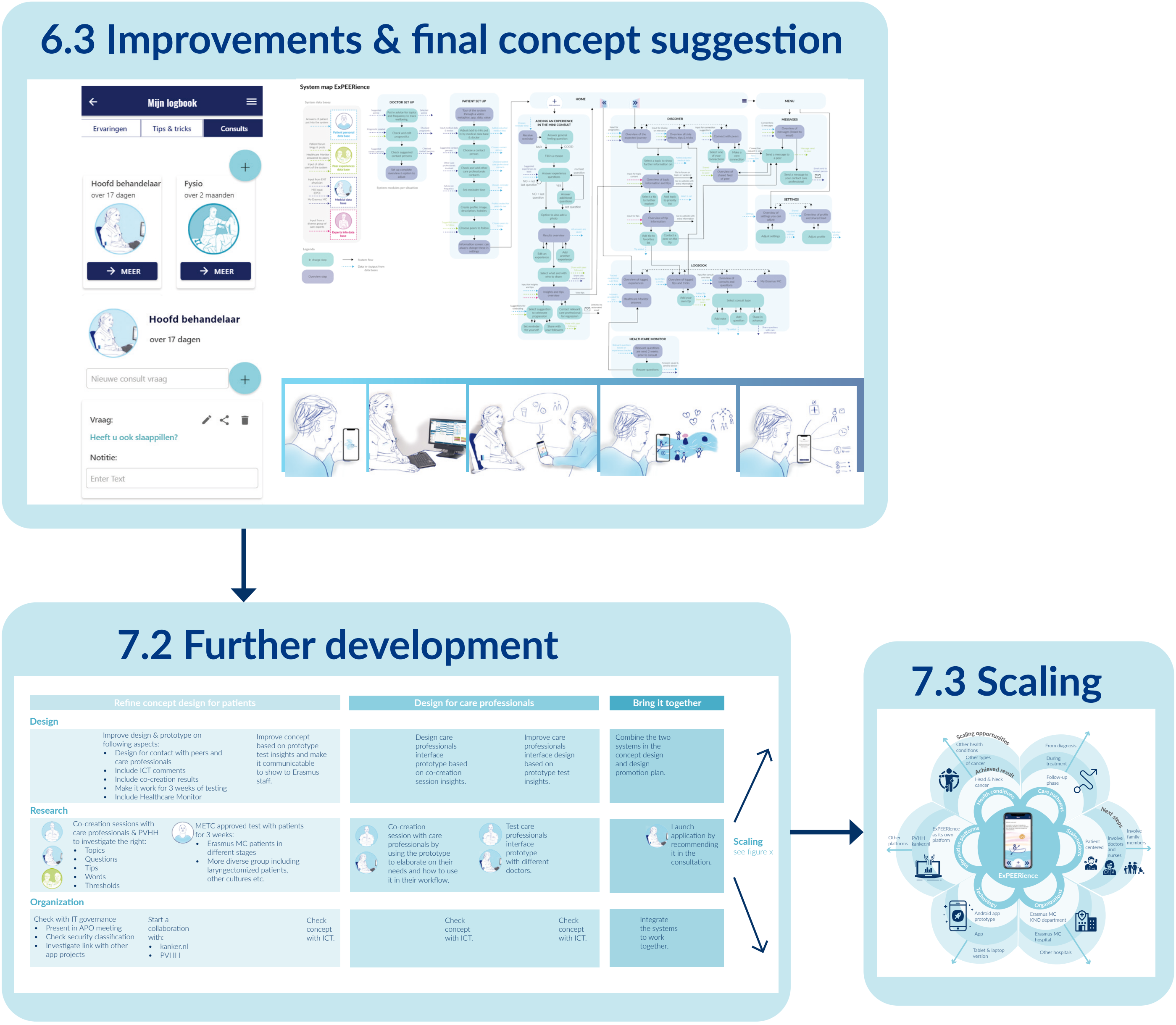


Figure 104. Chapter structure

7.2 Further development

7.2.1 Introduction

In this chapter I discuss the feasibility of developing this system and what is needed to get it towards implementation, answering the sub-sub-question: What are the next steps needed to further develop this concept?

I first talked to ICT staff members of the Erasmus MC in order to get insight into the feasibility of the technology and discuss the development with them. In chapter 7.2.3 I show the first steps envisioned to further develop this application, including looking at ICT and care professional needs. In the next chapter I show what could be possible in the future to scale this system.

7.1.2 Involving ICT staff

Since the idea revolves around data it is important to involve the ICT staff first, before further developing the concept. Therefore, I took an initial step in this involvement by meeting 4 ICT staff members from the Erasmus MC.

In the meeting we discussed the feasibility of integrating my concept into the digital systems of the Erasmus MC. We discussed topics like data security, integration of different systems and app development. I will discuss the most important insights from this meeting below.

Technically it is feasible

The techniques to integrate different systems are available. Especially for integrating the system in the doctors dashboard, since they have created a framework where you can put in inputs from different systems in different tabs.

Security is the biggest concern

The system needs to be able to be trusted by the different users. It should only show information when it is confirmed that it is shown to the right person. Often double verification or DigiD is used for this.

It is important to do a test on the security classification of your app before starting to further develop it. This classification will determine the requirements for security and determine whether, for example, a double verification is needed.

Start small

It was mentioned multiple times that you should start small. Start in one hospital. This is easier since the Erasmus MC use their own servers. If you want to incorporate other organizations, you will need to find a server outside that is trustworthy. Therefore, it is best to start with the patient doctor communication within the hospital. Furthermore, they recommended to start with one department as it takes a lot of effort and time to bring an idea to different parts of the organization.

Integrate systems

Currently the Erasmus MC is looking at creating a patient dashboard application that can be used throughout the journey of the patient. There are different dashboard apps that they could use as an underlaying building block. It is possible to integrate different applications and change the look and feel to create one coherent application. Therefore, if you find a feature that already works somewhere else, why reinvent the wheel when you can fit it into your app with your own look and feel? Thus, integrating systems is recommended.

By involving the ICT staff it became more clear what the next steps should be when you would want to further develop this idea in the Erasmus MC. One important thing for me to do is to differentiate where my project adds value to the market that already exist. What key insights should be taken and integrated within a bigger patient dashboard? This is what I address in the discussion in chapter 8. But first I explain the envisioned roadmap for further development based on my conversation with the ICT staff of the Erasmus MC and the lean development model.

7.2.3 Development roadmap

Figure 105 on the next pages shows a roadmap for the first steps to further develop the concept. This roadmap is meant to guide the next steps for the concept development when this project would continue. It works towards the first launch of a working concept within the context explored in this project, head and neck cancer patients of the Erasmus MC in their follow up phase. As discussed before you should start small before expanding. Therefore this roadmap focusses mainly on providing a first mobile app to launch withing the ENT department of the Erasmus MC. Opportunities for scaling will be discussed in the next chapter.

As you can see the roadmap is divided into 3 main stages:
1. Refine the concept design for patients
2. Design for care professionals
3. Bring it together

I will now elaborate on the steps described in these different stages.

Refine the concept design for patients

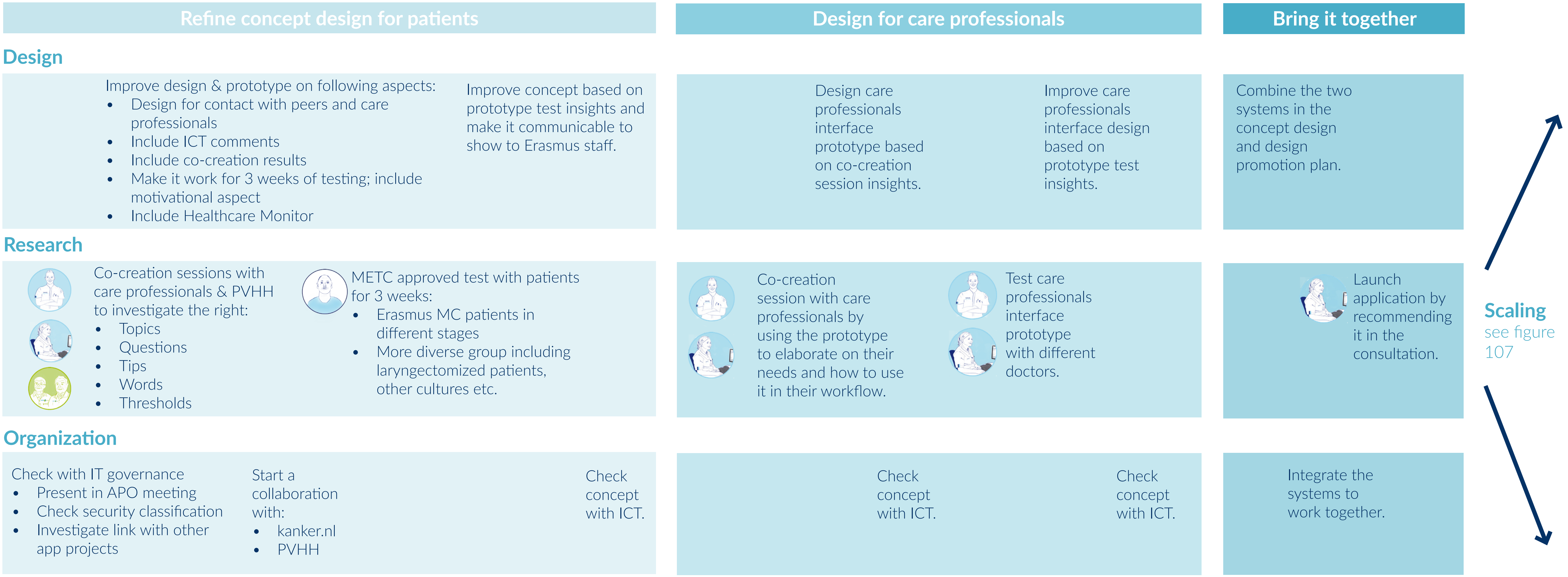
As seen in the previous section, it is important to closely work together with the ICT staff in the development process. Therefore the first next step should be to check the concept idea with IT governance of the Erasmus MC. This can be done by presenting it during one of their meetings. Furthermore, the security classification should be checked and it is good to investigate the link with other projects so that the wheel does not have to be reinvented again. The insights gathered from these meetings can help in creating a feasible design for the next prototype.

In order to use the right content in the application, I suggest to do co-creation sessions with different experts including nurse consultants, treating physicians, other care professionals involved in the care process and the patient association 'Patienten Vereniging Hoofd Hals' (PVHH). A collaboration with the PVHH can be sought, since they already have a lot of good information and tips to use in the platform. These co-creation sessions can be done before a next prototype test in order to provide valid content to the test participants. However, it could also be done after the next prototype test, when it would serve more as a finalizing step after having investigated the value of the concept over a longer period of time with patients who are in a more early stage in their follow-up. During the co-creation sessions things such as the topics and information to show, the questions to ask per topic, the tips to show and words to use can be discussed. In a session with the treating physician the thresholds for sending alerts can also be discussed. This can also be done in the next stage where the design for the care professionals is more closely investigated.

Based on the insights from the ICT and perhaps also already from the co-creation sessions, the prototype design can be improved to be tested by patients for a longer period of time. Since it will be tested for a longer period of time, the design should also include some elements to stimulate the motivation of patients to keep using the system, as suggested in chapter 4.1. Examples of elements that can be used in the design to stimulate motivation throughout the process are notifications and reminders. Further design and research is needed to see what works best.

When designing this prototype the suggested improvements shown in the previous chapter can also be integrated including the new ways to contact peers and care professionals. For the contact with peers through forums, the Erasmus MC could collaborate with the platform kanker.nl. The set-up of this platform could be integrated in the prototype test to use a forum structure that already works. Furthermore, the data of peer experiences and tips that is already shared on the platform kanker.nl, could be used to create a start of the database for the application. As shown in the previous chapter, the link with the Healthcare Monitor should also be simulated in the next prototype to test what patients think about integrating it in this way.

The next step is to test the improved prototype with patients for 3 weeks. This prototype test already has an approval from the Medical Ethical Committee (METC) of the Erasmus MC. This test can be done with a more diverse group of patients and patients that are all familiar with the Healthcare Monitor of the Erasmus MC. In this test the improved aspects of the design can be tested. Moreover, the concept can be tested for a longer time. This provides better insight into the value that is created by using this concept over time. It also provides the opportunity to test different iterations that are based on in between data during these 3 test weeks.



	Refine concept design for patients	Design for care professionals	Bring it together
Design	Improve design & prototype on following aspects: • Design for contact with peers and care professionals • Include ICT comments • Include co-creation results • Make it work for 3 weeks of testing; include motivational aspect • Include Healthcare Monitor Improve concept based on prototype test insights and make it communicable to show to Erasmus staff.	Design care professionals interface prototype based on co-creation session insights. Improve care professionals interface design based on prototype test insights.	Combine the two systems in the concept design and design promotion plan.
Research	Co-creation sessions with care professionals & PVHH to investigate the right: • Topics • Questions • Tips • Words • Thresholds METC approved test with patients for 3 weeks: • Erasmus MC patients in different stages • More diverse group including laryngectomized patients, other cultures etc.	Co-creation session with care professionals by using the prototype to elaborate on their needs and how to use it in their workflow. Test care professionals interface prototype with different doctors.	Launch application by recommending it in the consultation.
Organization	Check with IT governance • Present in APO meeting • Check security classification • Investigate link with other app projects Start a collaboration with: • kanker.nl • PVHH Check concept with ICT.	Check concept with ICT. Check concept with ICT.	Integrate the systems to work together.

Figure 105. Suggested first steps for further development

The final step is to make a final iteration based on the prototype test insights and make the concept presentable to show to care professionals in the next stage. The concept should be checked with the ICT to remain critical on the technical requirements. This concept is then taken to the next stage.

Design for care professionals
During this project my main focus has been on the patient experience. However, the care professional experience is also very important to take into account for developing this application, as is also seen in the quintuple aim shown in chapter 1. Therefore the next stage is to include their perspective more in the design process and start designing an interface for them to work with. This should be done by co-creating with the care professionals. The concept can be used as a starting point for discussing their needs and how to use the new data gathered by this system in their workflow. Based on these insights an interface can be designed to test with care professionals. The technical feasibility of this concept is checked with the ICT before doing a prototype test with care professionals. Based on the insights the concept is improved. This cycle can continue for a couple of times as is also seen in the lean development model, in order to create a concept that fits with the care professional needs.

A first start in uncovering the needs of care professionals was already done in the focus group session as described in chapter 3.4. A brief representation of the most important results of these needs will be discussed in the next section, 7.2.4.

Bring it together
The final stage is to bring these two interfaces together in one system and make a working app that can be launched with a first batch of patients. After this first launch the lean development model can continue and iterations can be made continuously, to improve the design based on feedback provided by both patients and care professionals who use the system.

At the end of the development roadmap you can see that steps after launching the application can be steps to start scaling the service system. The envisioned steps that can be taken to scale this service are explained further in the next chapter using figure 107.

But first, as described before, an initial idea of care professional needs that was uncovered during the focus group session is elaborated upon in the next section.

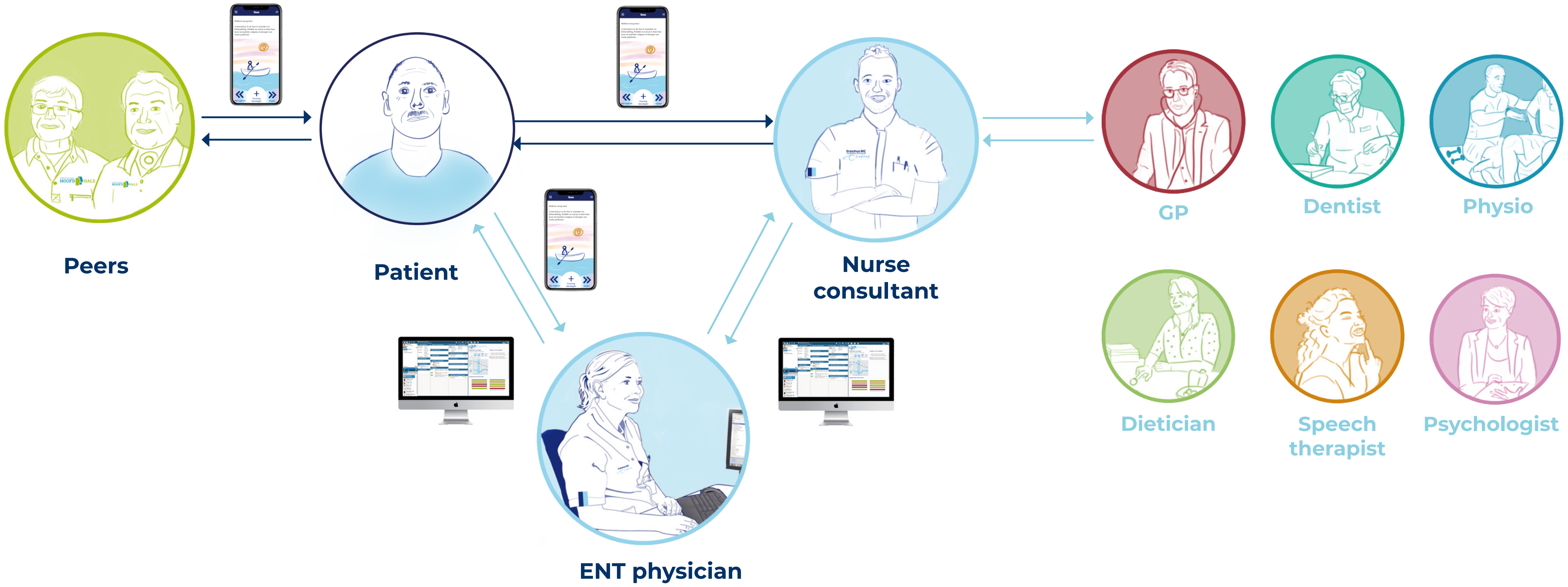


Figure 106. Initial vison for communication between the different

7.2.4 Care professional concerns

Chapter 3.4 describes how the focus group session for care professionals was set up and executed. It also describes the two parts of the focus group session that lead to insights into the concerns of care professionals. These are part 1 (insight into the needs of care professionals) and part 4 (how to use the collected information). Their results were not discussed before since the focus was on the patient. In this section I will briefly discuss the results of these parts to give an initial insight into what to take into account when designing for care professionals, which is an important stage for further developing this concept as described in the previous section. More elaborate results on the summaries of the system maps created in part 4, are shown in Appendix O.

Different concerns for different care professionals

In the focus group session it became clear that the doctors and head of department were mostly concerned with the physical wellbeing of the patient since this was their area of expertise with which they could help the patient. The nurse consultant, psychologist, volunteer and researchers however, were more interested in the psychosocial wellbeing of the patient.

Communication and insight

Important topics for the care professional concerns are found in the thematic analysis (see chapter 3.4, figure 34). When it comes to the care professionals themselves, they want to have low threshold internal and external communication and have a better insight into how the patient is really doing.

Low threshold communication with the patient means to have direct contact when they have symptoms. This could be provided by the application. When designing the care professionals interface it should be clear for them which symptoms are important to address. This links back to defining these threshold values for symptoms. A care professional should be able to see in one glance and be alerted if they need to take action based on the logged symptoms. This also links to the second need of having a better insight into how the patient is really doing. By showing graphs with highlights that show the more frequently tracked experiences of the patient, we could provide a more real image of the patients wellbeing for the care professionals to use in their care.

Nurse consultant as a gateway

When looking at the system maps created in part 4 of the session (see Appendix O) it becomes clear that the treating physician is the most important contact person when it comes to physical concerns. However, the nurse consultant is more important when it comes to psychosocial concerns and settings goals. The nurse consultant can function as a gateway to other relevant care professionals. This links to the needs of the patients who described the importance of nurse consultants in this phase for them, since they can help with practical tips and advice. Furthermore, Hochstenbach et al. (2017) also found that nurse consultants are seen as the best gateway by patients themselves. Taking this into account, it is a logical step to say that the nurse consultant could probably best fulfill the contact person role in this application and can help to link to other care professionals or to the treating physician if necessary.

A vision for interacting with the system

Based on these first insights I present an initial vision for the interaction between the different stakeholders in figure 106. As you can see the application provides the first communication gateway for patients with peer patients and the nurse consultant.

The care professional interface can be used to internally communicate about a patient between the nurse consultant and the treating ENT physician.

Furthermore, it can be used during the consult by the ENT physician to communicate with the patient. The patient can use the application during the consult themselves to have their questions and notes at hand.

If needed the nurse consultant can serve as a gateway to other care professionals in between the consults. When the system detects, for example, an increase in shoulder pain, the nurse consultant can link the patient to a special physio for head and neck cancer patients.

In this way the data gathered is used for enhancing meaningful information exchange between the different stakeholders. However, the patient only has to deal with communication with the nurse consultant and peers through the app.

7.2.5 Chapter conclusion

In this chapter we have seen the importance of involving ICT experts in the development process of this application. Furthermore, the importance of looking at care professional concerns in the next steps was stressed. An initial insight into these concerns was presented in section 7.2.4.

In order to make this service system operational we should start small in one department of the Erasmus MC, focusing on the interaction with peers and care professionals.

Once this system is operational within a smaller context it can be iteratively improved and we can start to look at scaling the service in different ways. These will be discussed in the next chapter.

Key chapter insights

- Involve ICT staff members of the Erasmus MC throughout the development process.
- Further design and research is needed to explore how this system can be integrated in the workflow of care professionals.
- Start small and make the system operational in a small system before scaling it.

7.3 Recommendations for scaling the service

7.3.1 Introduction

In the previous chapter we have seen a roadmap of concrete next steps that can be taken for further developing the system concept. In this chapter I look at steps that might be taken in the further future in order to scale the service. I look at the sub-sub-question: How could the system scale to create bigger impact? I do this by presenting possibilities to scale the service on six different levels. These show how this system could have impact on a greater scale in society. One of the levels presented will be elaborated on in a bit more detail, since some initial research on how to scale on this level was already done in this project.

7.3.2 Scaling ExPEERience

Figure 107 shows how the concept of ExPEERience can scale on 6 different levels. The visualization idea of using a flower shape came from previous work of Valeria Pannunzio, a PhD candidate at the Industrial Design Engineering faculty of the TU Delft.

The presented scaling levels are:
- Care pathways
- Stakeholders
- Organizations
- Technology
- Information platforms
- Health conditions

Steps to scale can be taken in these separate levels, either simultaneously or separately. In this section I further explain how scaling within these different levels is possible.

Care pathways
In this project I have focused on designing for patients who are in their follow-up phase; the last phase of the care path where patient and care professional focus on dealing with different side effects and checking for recurrence. However, through the online community analysis, patient interviews and prototype test, I also got to know that such an application could create value for patients who are in earlier stages of their care path. During treatment patients could also benefit of tracking their health and seeing peer experiences. Furthermore, if it can be taken to even right after diagnosis it could be used as a tool for making shared decisions for treatment. Patients have the need to benchmark their experiences with others throughout the journey to understand if what they are experiencing makes sense. However, as seen in the patient journey created from the online community data (chapter 3.2), patients also have different needs in these different phases of the care path. Therefore when you would want to scale this service to these other phases, you would need to do more user needs research with patients who are in these phases of their journey.

Stakeholders
A seen in the previous chapter the next step in the development process is to involve the care professionals perspective, creating an interface for them. Patient and care professionals are needed in the first version of the application. A stakeholder group that could be explored further in the future are the family members. In my research of online communities and in the focus group held with care professionals, it became clear that it is important to take this group into account. Therefore, a next step in scaling this service could be to further investigate the needs of family members and see how they can contribute and value from this system. A first research into their insights was done by also analyzing the blogs and posts of family members shared on online communities. I share the results of this analysis in the next section.

Figure 107. Vision for how the concept of ExPEERience can be scaled on different levels

Organizations
As mentioned in the previous chapter we should start small. In this project the focus has been on the ENT department of the Erasmus MC. This is a good place to start the development of such a system, as they have the relevant knowledge and skills of developing systems such as the Healthcare Monitor in their VBHC team. The next scaling step would be to deploy the system throughout the entire Erasmus MC hospital. This is similar to what has happened with the HM. It started small in the ENT department and is slowly finding its way to the other departments of the hospital. After scaling to other departments, the next step could be to scale to other hospitals. This is a more difficult step since you would need to start integrating different systems of different hospitals. You would have to find a way to securely store the data for these other hospitals. Either on their own servers or by finding one common secure server that you could use.

Technology
In this project I designed an application to use on a smartphone. The prototype I built was created for Android phones. Therefore a next step for further testing and implementation is an application that can be used on different types of smartphones. After the first smartphone app has launched we can scale to also deploy the app in different formats. Making it compatible for a tablet or laptop. During my prototype test I already had one participant who preferred working with a tablet. In order to address the different types of users we would therefore want to scale in the technological devices that can host the system interface.

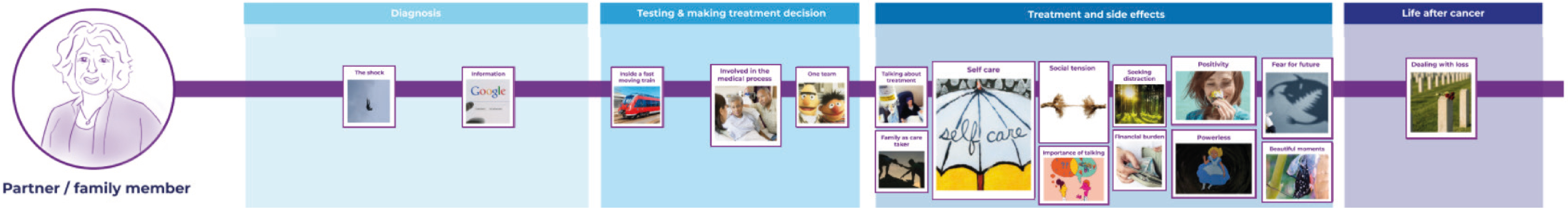


Figure 108. Interactive concern journey of family members of cancer patients, go to: https://ts26m3.axshare.com

Information platforms

As previously discussed in the development roadmap, it can be interesting to start a collaboration with the platforms kanker.nl and the patient association PVHH. These platforms already have a good starting data base of peer experiences, information and tips. Furthermore they can be integrated within the application such as the forum format that is used by kanker.nl. These are just two interesting platforms that could be integrated in this system. Other platforms might also contain valuable information or formats that could be used inside the application so that the content that is shown has valid sources and the wheel does not have to be reinvented again. In the future different information platforms could therefore be added to add to the completeness and validity of the database used by the system.

Health conditions

My target group for this project was head and neck cancer patients in their follow-up phase. I did not look at palliative patients however. This could be an interesting scaling step. Furthermore, this application could also be valuable for other types of cancer patients. If you would want to scale to other types of cancer, you would have to do more research into the relevant things to track for this target group and their needs in their care path. You could use a similar approach as I used in my project, but then with other types of patients. Since I already investigated the general cancer patient concerns through an online community data analysis (chapter 3.2), you can say that cancer patients in general have similar concerns. They can all benefit from keeping track of their health and exchanging experiences with peers in the follow-up phase. Taking it another step further, you could even use it for other health conditions. For this however more initial research is needed as there is a bigger difference in concerns and care paths.

Scaling steps

The diagram presented in figure 107 does not show the order in which to scale. This depends on the preference of the different stakeholder involved and the organizational and technical feasibility of the scaling steps. You could argue that scaling to other hospitals is important since it will create a larger data base of patients that use the system and therefore, a larger network of peer experiences and connections. However, as described by the ICT staff members scaling to different hospitals brings technical and security difficulties. Furthermore, political differences might also influence this scaling step. As we can see, different scaling steps bring new problems to solve and new research and design to perform. The order of scaling should therefore be discussed with the different people involved in the development of the system. But let's start with the further development of this concept, as described in the previous chapter. Bringing a first concept into operation to be used as a learning project for further design and development.

As previously discussed in the stakeholders section, an initial insight into the family members' concerns was gathered by doing an online community data analysis. These will be briefly presented in the next section.

7.3.3 Family member concerns

In chapter 3.2, I already explored the concerns of cancer patients through an interactive journey. In this interactive journey I also created a line for the concerns of family members of the patient (see figure 108). These are based on the forum posts and blogs written by family members, often the partner, of the patient. The interactive journey can be found here: https://ts26m3.axshare.com

I briefly discuss the biggest topics found below.

Caring for another vs caring for yourself

We can see that for family members the biggest topic found is self-care. In the treatment and side effects phase family members spend a lot of their time taking care of the patient, forgetting about their own needs. Especially partners express that they can lose themselves in this process and advice other partners to take time to care for yourself as well. When designing for family members, we should therefore look at how we can design something that helps to create this balance between caring for yourself and caring for the patient.

> "Caring for someone you love is bloody hard, but like the air stewardess' tell us when they give the safety talk on the plane, you have to put your own oxygen mask on first before you try to help anyone else."

Social tension and the importance of talking

When this balance in caring for each other is not found social tension can occur. Therefore the importance of talking to each other is stressed. Patient and partner should have the opportunity to express their feelings and needs to one another.

> "However it is quite difficult to hold a conversation of any length and he certainly isn't telling us how he is feeling."

Emotional rollercoaster

Not only the patient goes through a rollercoaster of both positive and negative emotions. The partner and family members are also dragged into this rollercoaster. Sometimes feeling positive, sometimes feeling powerless, other times being fearful for the future. They can also benefit in this process from exchanging experiences with their peers or gaining a better understanding of how they feel.

> "Yet optimism predominates. My wife is recovering, healing, getting stronger, still has her downs, but the ups are starting to take over. I am also getting stronger."

Involved in the medical process

Partners often accompany patients in their medical journey and want to be involved in the medical process, so that they can help their partner and make important decisions together. Therefore, it can be interesting for the partner and family members to also have a good insight into the medical journey and decisions of the patient.

> "In any case, we were nicely called back after 15 minutes. And as a partner I want to crawl through the phone so that I can hear everything and say everything."

Dealing with loss

When the patient does not make it, the family members are left to deal with the loss of a loved one. In this grieving phase it can help to talk to others who have experience similar situations. It is a difficult but important phase to provide support. This could be done through design. The palliative phase is something that is not addressed in this project but is important to take into account when scaling this service. You could also design this application for palliative patients and their family members. They will have different needs but could possibly also benefit from gaining insight into their wellbeing, quality of life and exchanging experiences with peers.

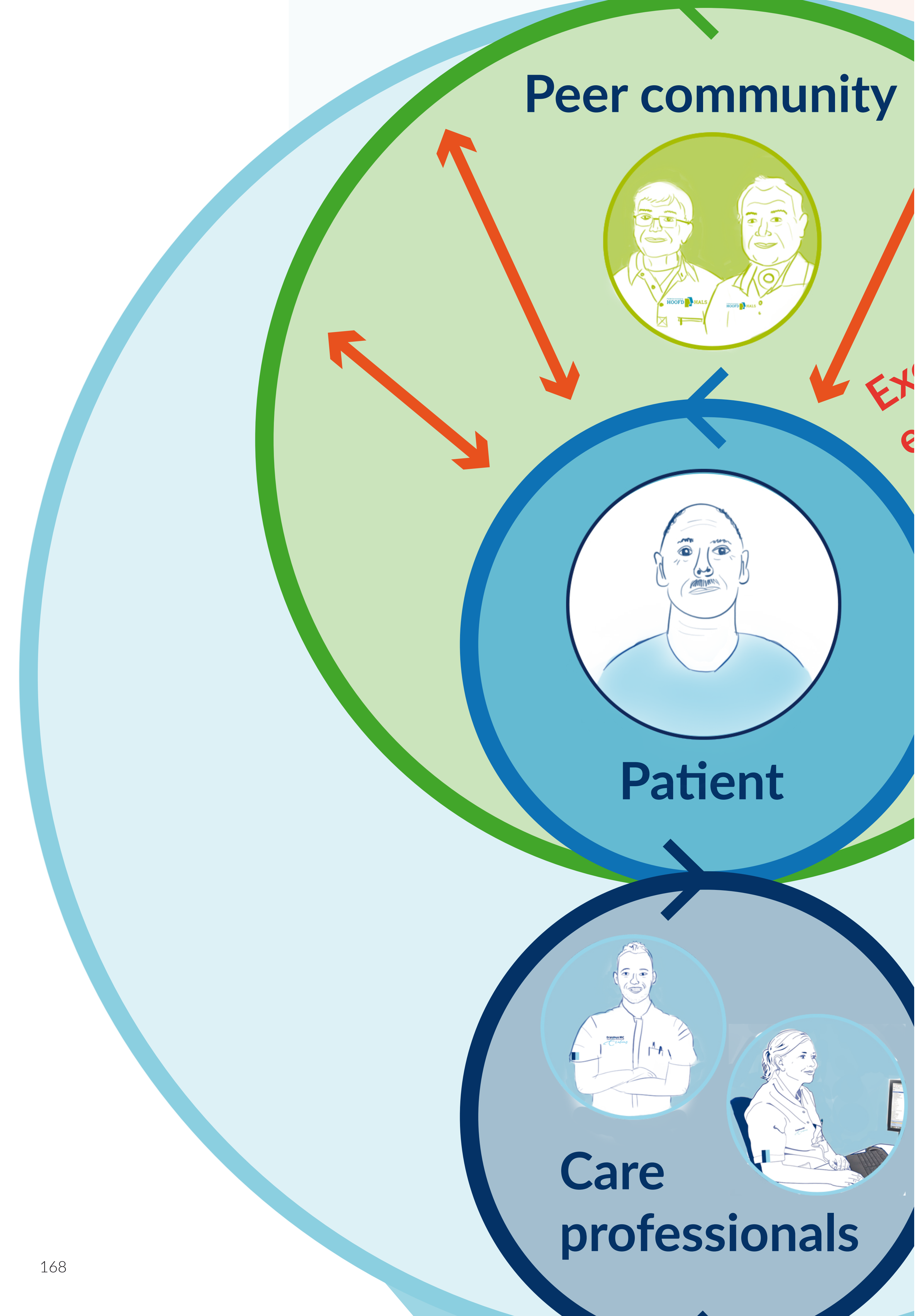
> "I learned a lot in my grief support group. ..... How to deal with the different and torturous emotions that were eating me alive."

7.3.4 Chapter conclusion

After the concept has been further developed and implemented on a small scale you can start to think about the different ways to broaden the impact of the system. This can be done on a care-path, stakeholder, organization, technology, platform and health condition level. In which order to take these scaling steps, needs to be decided by the developing team of the system. Decisions can be made by weighting technical and organizational feasibility with the potential amount of positive impact the step can create. Involving family members in the system is definitely an interesting scaling step to take in the future. It could help them to take better care of the patient and themselves which ultimately might decrease healthcare costs made by both patients and their family members.

Key chapter insights

- Scaling the concept of ExPEERience is possible on different levels; care-path, stakeholder, organization, technology, platform and health condition level.
- When scaling the concept to also include family members, the balance between caring for the patient and caring for yourself as a family member should be taken into account.



Sub-question 6: 6. What are the **key learnings** of this project for designing for patient empowerment and Value-Based Healthcare in general?

8. DISCUSSION & CONCLUSION

In this chapter I present the key learnings of this project that the Erasmus MC should take into account when developing an app for patient empowerment. Furthermore I discuss learnings for designing in the VBHC field. At the end of this chapter I provide a conclusion by showing the answers to the different sub-questions.

8.1 Chapter introduction

In chapters 8.2 and 8.3 of this chapter I answer sub-question 6:

> 6. What are the **key learnings** of this project for designing for patient empowerment and Value-Based Healthcare in general?

This sub-question is divided into two levels; a project level and a more broader level. On the project level I discuss the key learnings for the Erasmus MC when they want to develop an application to empower cancer patients. Project 8.2 includes these key learnings as well as an overview of the values that can be created for all the stakeholders involved. These values are linked back to the quintuple aim as discussed in chapter 1. In chapter 8.3 I discuss what can be learned for designing for value based healthcare in general from this project.

In chapter 8.2 I explore the following questions:

- What key learnings should the Erasmus MC take with them when developing an application for cancer patients?
- What is the value created by ExPEERience for the other stakeholders involved? How can it achieve the quintuple aim?

In chapter 8.3 I address the question:

- What can be concluded from the insights gathered in this project for designing for Value-Based Healthcare?

The answers to these questions are based on all the gathered insights during this project and mainly based on the value map as shown in chapter 6.2.4 (see figure 109).

In chapter 8.4 a conclusion is provided that answers the 6 sub-questions posed in chapter 1. I also present a visual overview of the answers found to the different sub-sub-questions as posed in the visual overview in chapter 1.3. This serves as a visual summary of this graduation thesis.

The final chapter, chapter 8.5, includes a personal reflection on the design process.

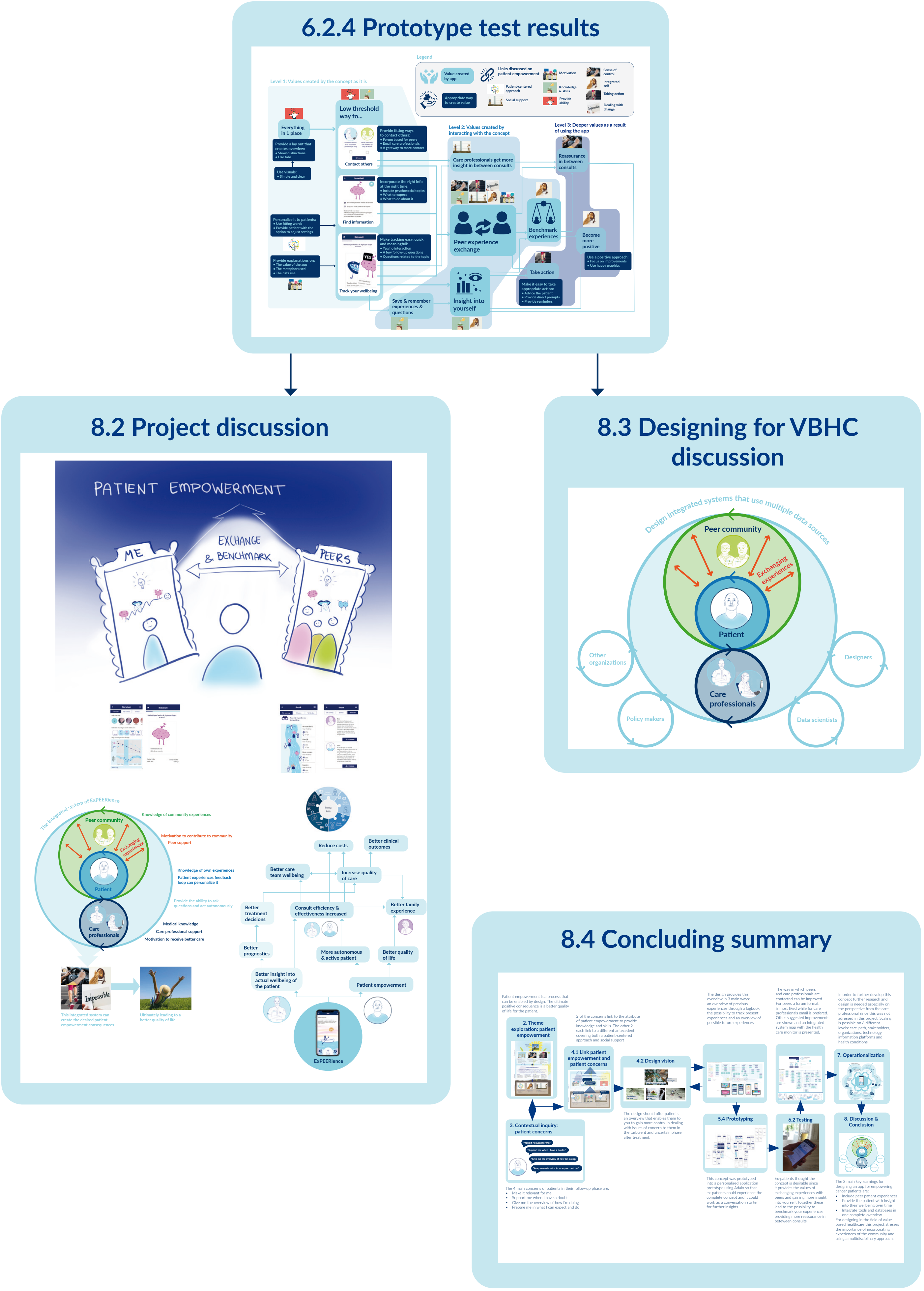


Figure 109. Chapter structure

8.2 Project discussion

8.2.1 Key learnings for designing an app for Erasmus MC patients

In this chapter I will answer the question:
What key learnings should the Erasmus MC take with them when developing an application for empowering cancer patients?
The answers will be based on the insights gained from the prototype test as presented in chapter 6.

Include peer patient experiences

Usually eHealth applications focus on self-management purely from a patient perspective. The examples shown in figure 110 of other patient dashboard applications, only show the care path of the patient, their health progression or provide the possibility to ask questions to an Artificial Intelligence system. The focus is on providing the patient with medical information from a clinical perspective to help with self-management. This can also be seen in the intervention called iManageCancer of Kondylakis et al. (2020). Their eHealth solution incorporated self-management tools on different levels such as psycho-emotional monitoring and serious games. However, they focused on the 'I' manage cancer perspective, not on the 'we' manage cancer perspective.

What I have found in my project however, is that the greatest need of cancer patients in their follow-up phase is to exchange experiences with their peers. Peer patients are the experts in this phase. They have been through a similar process and can help with both the practical tips as well as the emotional support. In the value map that was created as a result of the prototype test in chapter 6, it also became clear that patients see peer experience exchange as the most important value that an application could provide in the follow up phase. With this experience exchange they meant connecting with peers, sharing practical tips but also just simply seeing how many other peers experience something. The percentages that showed how many other peers experienced something helped them to benchmark their own experiences. If others are experiencing this too, then it is probably normal to feel this way. This can provide reassurance in between the consults and can emotionally help since you see that you are not the only one going through this tough process.

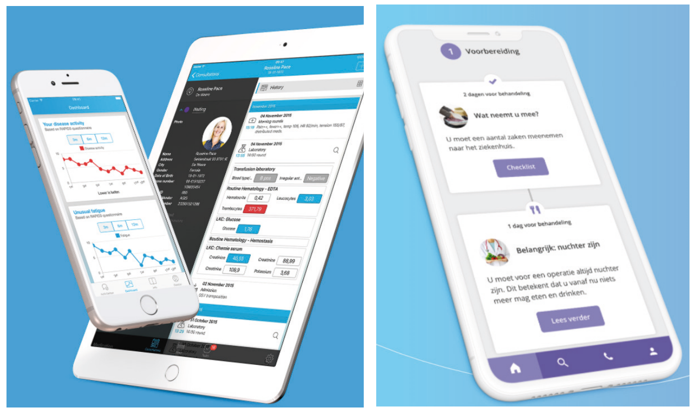


Figure 110. Examples of other patient dashboard apps

In chapter 2.4 we already got a glimpse of the importance of peer support. Skirbekk et al. (2018) already found that peer support helps patients with coping by providing hope and tips to deal with difficult situations. They can provide positive social comparison. Therefore, peer support was considered as part of the social support antecedent for patient empowerment.

What I want to stress is that this topic is much more important for cancer patients in their follow-up phase than initially imagined. In the value map created from the prototype test, we have seen that exchanging peer experiences might on itself lead to the different desired consequences of patient empowerment. In the context of head and neck cancer patients in their follow up phase, involving peer experience exchange in the eHealth solution is therefore a must have. Looking at the results of the general cancer patient journey from the online community data analysis, I could also conclude that this peer experience exchange is important for all cancer patients and might also benefit patients in different stages of their care path.

Provide patients with insight into their own wellbeing over time

In order for patients to be able to benchmark their experiences to others, as can be seen in figure 111, they also need to have insight into their own experiences. Therefore, the application should also provide the more common part of eHealth solutions where patients can track and review their health over time.

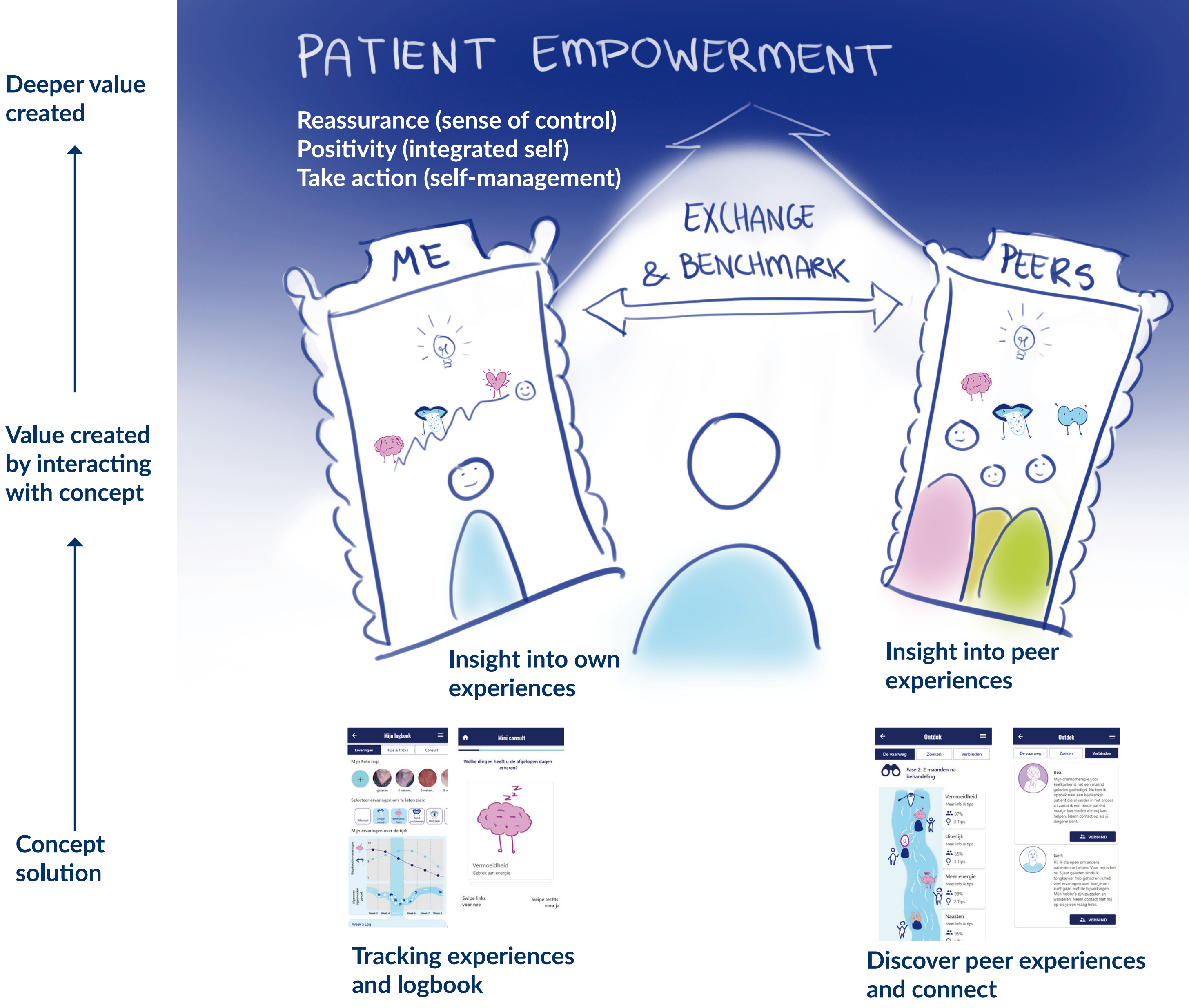


Figure 111. How the concept of ExPEERience can lead to patient empowerment

This tracking should be made easy by only providing topics that are relevant for the patient. Furthermore, the interaction with the app can be designed to make it feel easy and quick for the patients. In my prototype test I found that patients liked the swiping interaction since it felt easy and quick. Even though a lot of questions were asked, this was not experienced by the patients. One patient mentioned: "I like the swiping aspect, it's not another list." Even though the swiping interaction in itself was not liked by all patients, it did provide a feeling of a short questionnaire, since only for the relevant experiences follow-up questions were asked. Such an interaction should be provided to patients in the application to motivate them every week to keep track of their wellbeing.

As seen in the results section of the prototype test, patients liked to see their progression over time. It helped them to take a more positive look. Therefore, an overview of their experiences over time should also be provided by the application. Furthermore, the patients really liked the direct insights and actionable advice. Therefore, I suggest to also include direct actions with the insights provided to the patients.

Integrate tools and databases in one complete overview

As explained in the previous sections, we need both the possibility to exchange experiences with peers and the possibility to track and review our own health to create the most value. Different tools need to be integrated into one application to provide the complete overview through one interface. That is an overview of past, present and possible future experiences. By doing so and also integrating different databases, more trustworthy prognostics and suggestions can be created.

You should thus provide the patient with a tool that includes the different aspects needed to create patient empowerment in one application. When taking ExPEERience as an example, we can see that patients particularly valued it since it incorporated a way to contact others, also including the care professional, find information and track your wellbeing in one application. This makes it very low threshold to use it. A patient can find trustworthy information provided by the patient association, whilst also asking questions to peers on a forum of kanker.nl, all through the same interface. Furthermore, when you gain better insight into your own wellbeing you can also better benchmark it to experiences of others. This combination of low threshold tools and trustworthy platforms in one place through the same simple interface, is what can contribute to patient empowerment and provide reassurance in between consults.

This system is different from a platform like kanker.nl, since it integrates these different tools and can also interpret the tracked experiences to show it as comprehensible percentages, progression lines and concrete actions. The patient can thus really gain insight into their wellbeing and get direct relevant suggestions to take action in one system.

When comparing this integrated system to a platform like kanker.nl, another main difference will be that this system is provided by the hospital as part of the follow-up phase. In this way more patients will take part in the system and therefore there is more chance for patients to connect with relevant peers. Moreover, a larger set of users will cause for a more accurate data set to make predictions. Furthermore, the connection with the hospital could increase the motivation of patients to use the system, since the data they track can help to improve the care they get from the hospital and is used by their treating physician in the consult. So, the connection with the care professionals is an important differentiator when comparing it to a platform like kanker.nl.

As mentioned before, more trustworthy prognostics and suggestions can be made through an integrated system. The system has a broad range of data it can use since it integrates tracked experiences of peers, forums and the electronic patient file. This combination of data from different sources could help to make interpretations of the data and predictions more accurate.

8.2.2 An integrated system that creates patient empowerment

To conclude, when developing an application for cancer patients, the Erasmus MC should provide an overview of patient and peer patient experiences by integrating different tools, platforms and data sources in one portal. Figure 112 shows how such an envisioned system could look like. Instead of just looking at the interactions between the patient and care professionals an important interaction between patient and peers is added. The extra value of this system is that the various interactions are all provided by one system that can use data from multiple sources to create a more accurate image of the patients wellbeing and compare this with peers. It combines medical knowledge, knowledge of the patient experiences and knowledge of the community experiences.

When looking at how this links back to patient empowerment, we can see that this integration of the possibility to contact others, find trustworthy information and track your wellbeing in one system can help to create patient empowerment. Figure 112 also shows how this integrated system and the different data loops, provide the antecedents and attributes needed for patient empowerment. First of all, the low threshold created by this integrated system provides the ability for patients to ask questions and act autonomously. Furthermore, motivation to use the system is created by both the wish to contribute to the community as well as the desire to receive better care. Social support is stimulated both through contact with peers and care professionals. A patient-centered approach is used by continuously using patient reported experiences as data for personalization. Knowledge is created and shown on different levels; the patient experience, community and medical level. Together these elements can support patients in getting insight into their own health and benchmark this to experiences of others, so that they can feel more reassured and supported in the time in between consultations. This combination can help to create the desired consequences of patient empowerment, ultimately leading to a better quality of life (Castro et al., 2016).

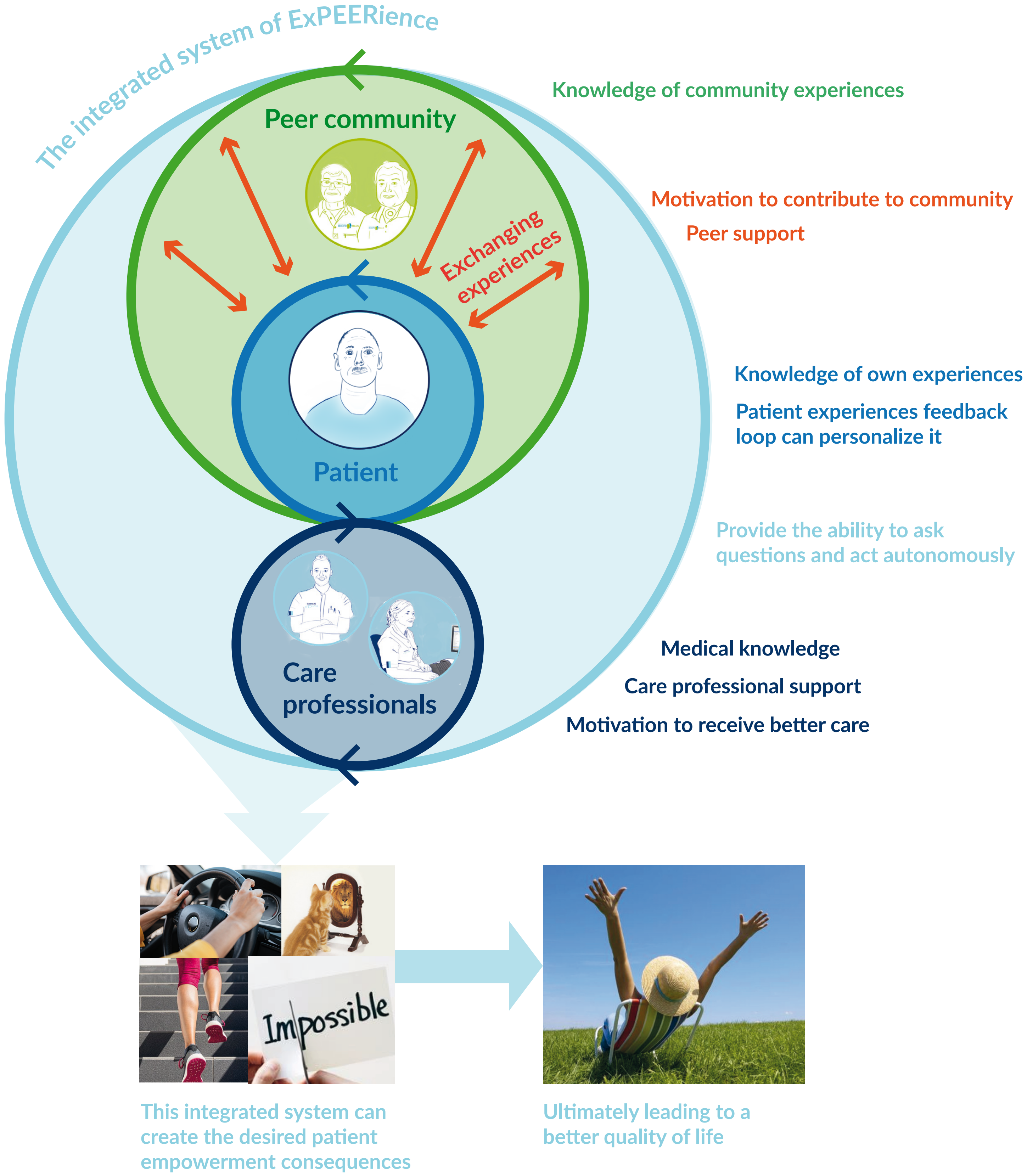


Figure 112. Envisioned integrated system of ExPEERience with its links to the different elements of patient empowerment

8.2.3 Value for everyone

In chapter 1 I introduced the quintuple aim. A model that shows what values you should aim to create with new healthcare interventions. In this chapter I explain how these different aims are reached through the ExPEERience concept. I show that this concept not only brings value to the patient, as described in the previous chapters, but also adds value for the care professionals, family members and healthcare sector in general.

Figure 113 shows how the various values created by ExPEERience ultimately lead to the different aims of the quintuple aim.

First of all, as argued in the previous chapter, ExPEErience can create patient empowerment. In chapter 2.2 we have seen that there are multiple consequences of patient empowerment. One of the consequences was increased self-management. The patient becomes more autonomous and active since they have their own tool to track their health, find information and take action based on the insights. They have the ability to find practical tips and explanations in between the consults. Furthermore, they are better aware of how they feel and what they have questions about for the treating physician. This will make them experts of their own health and thus better prepared for the consult.

Furthermore, the care professionals also have a better insight into the actual wellbeing of the patient. They can see data spread over time to have a more accurate image of the patient's progression. This makes them better prepared for the consultation as they know what points to address during the consult.

A better prepared patient and care professional will make the consult more efficient and effective. They can address the real questions and issues of the patient, while leaving time for some small talk. Moreover, if needed the treating physician can decide to advance, postpone or skip consultations based on the data and needs expressed by the patient.

A more efficient consult can lead to reducing costs, as less consults might be needed and less time is needed from care professionals to answer questions in between consults. Furthermore, a more efficient consult can increase the wellbeing of the care team, as they might have more time to take a break and feel more satisfied with the effectiveness of their talk with the patient. Moreover, a more effective consult will increase the quality of care, which benefits both patient and care professional.

I will now go back a step to the increased insight into the actual patient wellbeing by the care professionals. This can also lead to better prognostics, as more frequent data on patient wellbeing on different levels is tracked. This can help to make more accurate predictions and can be used for patients in their earlier phases of the care path to make a better shared decision together with the care professional. When a better shared decision can be made the quality of care can also increase.

An increased quality of care can lead to the different aims of the quintuple aim. It can help to create better clinical outcomes since better care can lead to better clinical results. Together this can help to reduce costs since less unnecessary treatments or consultations are performed.

Furthermore, an increased quality of care together with a more effective consult and a better quality of life for the patient, can lead to a better experience for the family members of the patient. Family members often accompany the patient to consults. If this is more efficient and effective, they also benefit from it and perhaps have time to ask some more questions themselves. Furthermore, if the quality of life of the patient increases the family members also benefit. They have to care and worry less about the patient and have more room to gain a balanced life of self-care and caring for the patient.

An integrated system that creates patient empowerment therefore not only provides value for the patient, but also for the other stakeholders involved.

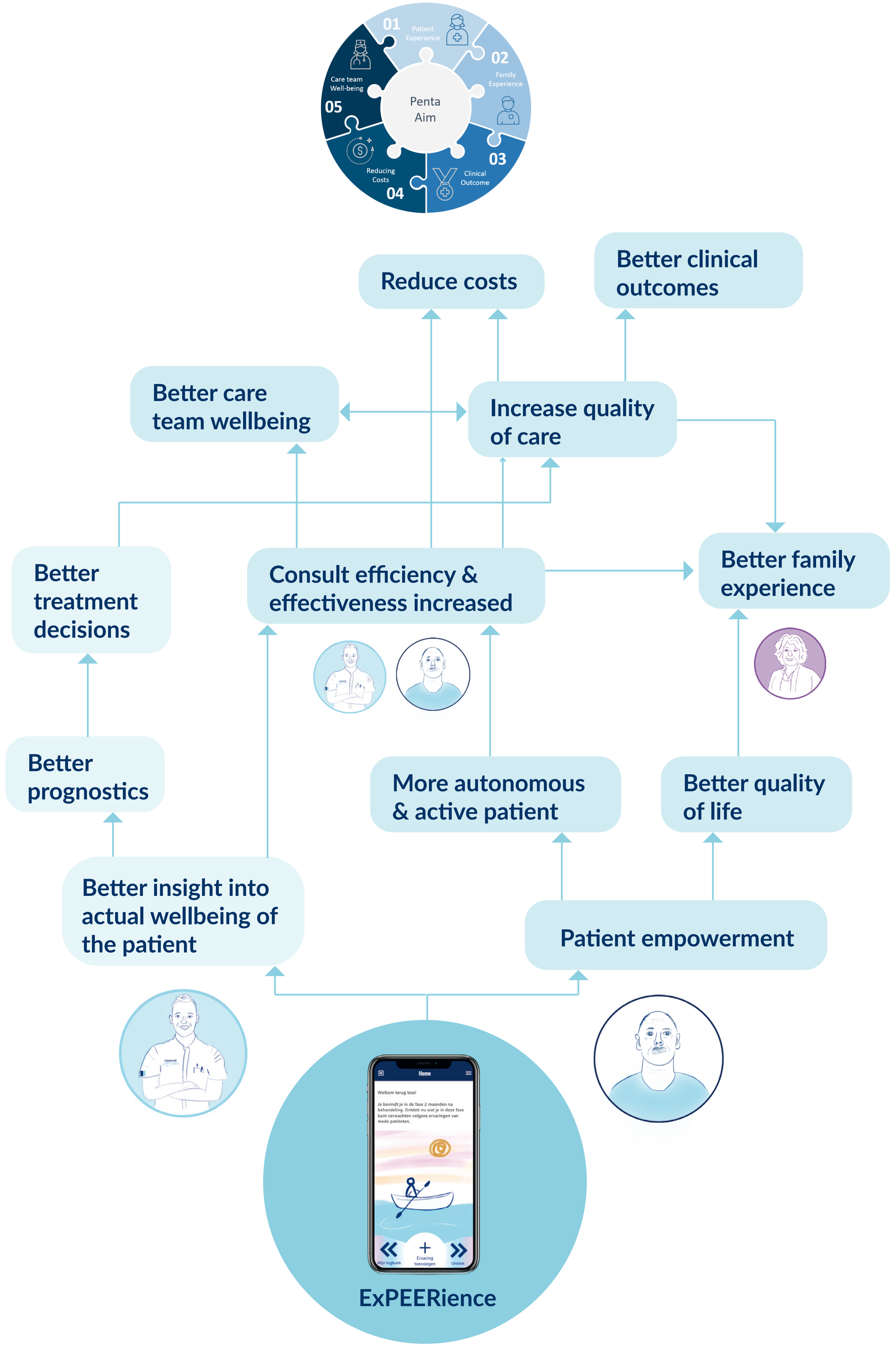


Figure 113. Value map for other stakeholders involved including the quintuple aim

8.3 VBHC discussion

8.3.1 Learnings for the Value Based Healthcare field

In this chapter I answer the question:
What can be concluded from the insights gathered in this project for designing for value based healthcare?

Include both the patient and the community in the process

In chapter 1.1.3 the concept of value based healthcare was introduced as a way of working where you include the values of different stakeholders. Currently, the focus mostly lies on including patient feedback in the care services provided (Lewis, 2019) and by doing so generating value for both patients and the healthcare system (Lewanczuk et al., 2020). In a recent conference of 'Uitkomstgerichte Zorg' (2021) professor Kees Ahaus also talked about including the patient in the Value-Based Healthcare team when creating new interventions. I agree that the patient has to be incorporated in the design process if you want to create value. In my project I have seen that including patients throughout the process helps to identify the needs and values and leads to a more fitting and valuable solution.

However, next to the patient I also believe the community data should be incorporated in the design process when designing for VBHC. By looking at the community data in the research phase, it can become more clear what values should be created for the bigger community. In this sense, I think that the community should also become part of the VBHC team. This can already be realized by looking at online available community data like I did in my project. I therefore think that the double loop method of Jung (2021) should be used when you are designing for VBHC. Both the patient and community should be included in this process to create interventions that truly create value.

Include designers in a multidisciplinary approach

In my design project it became clear to me how important a multidisciplinary approach is when designing for value based healthcare. To create value your intervention should be feasible, thus for my project I needed ICT personnel and data scientists. Furthermore, care professionals should be incorporated as they understand the patient and their own needs that should be met in order to be able to add value.

A member that is however not always part of the VBHC team, but could add value, is the designer. The designer can bring the different views of the multidisciplinary team together with user and community research.

Together these different stakeholders and organizations can create systems that enable patient empowerment through meaningful interactions and data use. Figure 114 shows how this multidisciplinary team iteratively and continuously works on providing this system that can create value for the healthcare sector. Some members of the multidisciplinary team are provided as examples, also including policy makers. The final composition of the team should be determined based on the project.

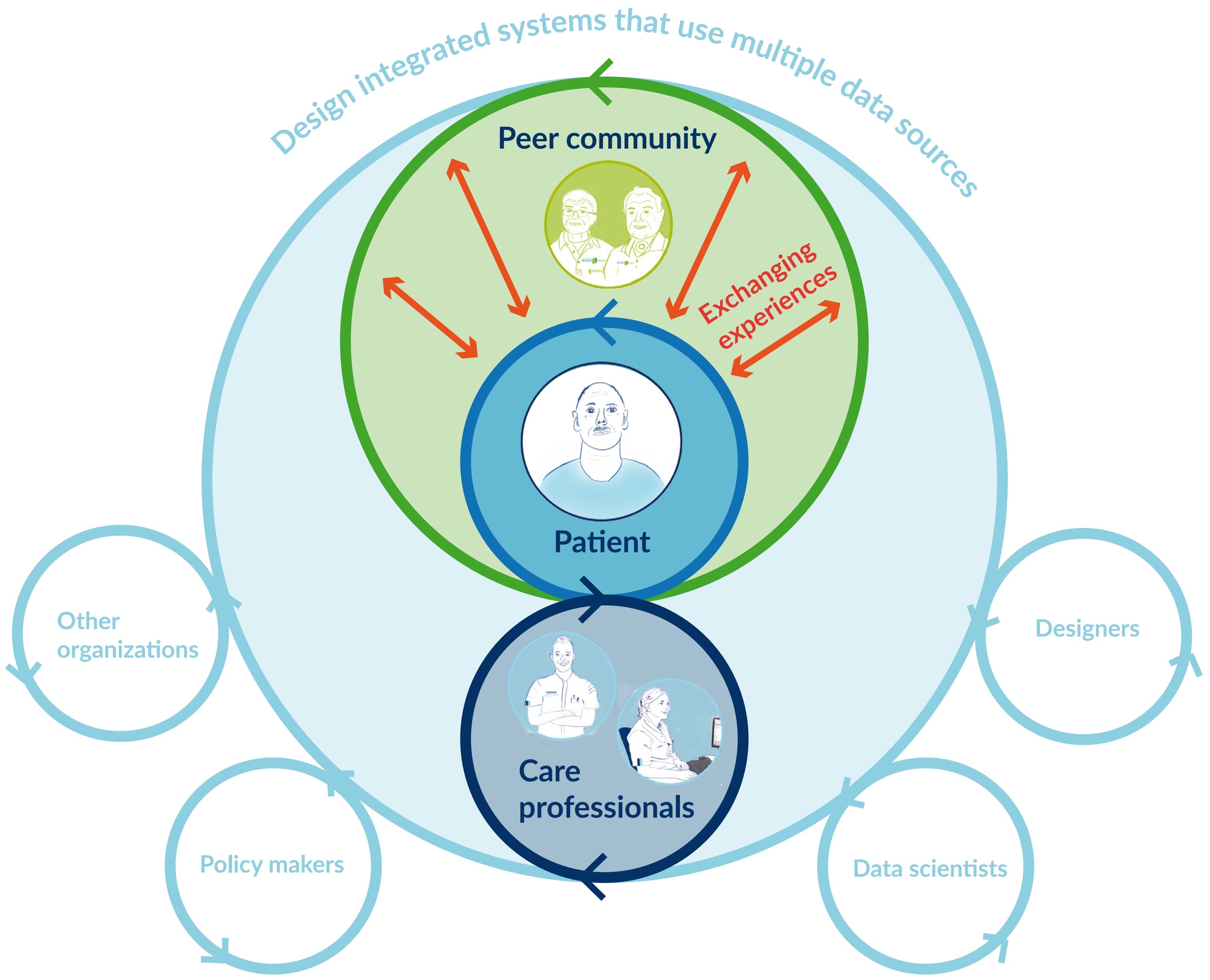


Figure 114. A double loop and multidisciplinary approach to design for Value Based Healthcare

8.4 Concluding summary

In this final chapter I provide a summary of the findings of this project. This is done by providing a recap of the main aim, research question and hypothesis of this project. Furthermore, the answers to the 6 sub-questions posed in chapter 1 are presented. Additionally, figure 115 on the next pages shows an overview of the various answers to the sub-sub-questions as presented in the overview in chapter 1.3.

In this graduation thesis I investigated how to design for patient empowerment in the context of head and neck cancer patients in their follow-up phase.

This project started with the aim to **design a digital service linked to the Healthcare Monitor that increases patient empowerment for head and neck cancer patients in their follow-up phase**.

The main research question that this thesis tried to answer is: **How should a digital service system be designed to empower head & neck cancer patients in their follow-up phase of their treatment?**

The hypothesis was that: **a digital service for patients at home where they can track and view their health continuously will help to increase patient empowerment.**

As described in chapter 8.2, this project found initial evidence that a digital service for patients at home where they can track and view their health continuously, can indeed help to increase patient empowerment, if combined with the possibility to exchange peer experiences. This addition of peer experiences is one of the main insights of this project.

The following sub-questions were posed in chapter 1:

1. What is **patient empowerment**, why do we want it and how can it be created?

2. What are the **concerns** of head and neck patients in the follow-up phase?

3. What should the design **offer** in order to address the concerns of head and neck cancer patients and increase patient empowerment?

4. How should the service system be **designed** in order to deliver the design promise?

5. What should be done to make this service system **operational** in the future?

6. What are the **key learnings** of this project for designing for patient empowerment and Value-Based Healthcare in general?

In chapter 2 I provided an answer to the first sub-question by presenting a model that designers can use to design for patient empowerment. In this model patient empowerment is defined as a process that can be influenced through design. If you provide the right starting conditions (a patient-centered approach, motivation and social support) you can start the patient empowerment process. During this process you want to provide patients with the right amount of motivation, knowledge, skills and abilities at the right time. So that eventually patients can get a better quality of life.

In chapter 3 I provided the answer to the second sub-question by investigating the context of head and neck cancer patients in their follow-up phase through 3 different types of design research. 4 main patient concerns are found. Patients want to:

- Be prepared for what they can expect and do
- Have the overview of how they are doing
- Be supported when they have a doubt
- Have a relevant service for them

In chapter 4 I answered sub-question three by combining the insights from chapters 2 & 3. The patient concerns 'prepare me for what I can expect and do' and 'provide me with the overview' were linked to the patient empowerment attributes 'knowledge and skills'. 'Support me when I have a doubt' could be linked to the antecedent 'social support' and the attribute 'providing the ability to ask questions'. The concern 'make it relevant for me' linked to the antecedent 'a patient-centered approach'.

These links created the basis for the design vision: to provide the patients with an overview that enables them to gain more control to deal with issues of concern to them. This overview should show where patients have been, where they are now and where they might go. Conditions for the design are the possibility to share doubts, personalized content and exchanging peer experiences.

In chapters 5 & 6 I answered sub-question 4 by ideating and prototyping the application. It was found that the system should provide the possibility to track your own wellbeing through a mini consult that feels quick, personal and positive. Furthermore, the app should provide insight into your progression over time and give suggestions for actions to take to improve your wellbeing. Finally, the app should include an overview of the physical and psychosocial side effects that you might expect based on peer experiences and provide the possibility to exchange experiences, tips and tricks with peers.

In chapter 7 I addressed sub-question 5 by presenting a development roadmap with the next steps to take and a model for scaling the concept in the future. Next steps include a closer collaboration with the ICT members of the Erasmus MC, further improving and testing the app from the patient perspective and also including how the system can be incorporated in the workflow of the care professionals. The development should start small in the ENT department of the Erasmus MC. It can scale later on, on six different levels; care-path, stakeholder, organization, technology, platform and health condition level. When scaling the concept to also include family members, the balance between caring for the patient and caring for yourself as a family member should be taken into account.

In the previous chapters of this final chapter, chapter 8, I presented the answer to sub-question 6, by discussing the key learnings for the Erasmus MC, the possible value for the different aims of the quintuple aim and the general learnings for the VBHC field.

The 3 main key learnings for the Erasmus MC for designing an app for empowering cancer patients are:

- Include peer patient experiences
- Provide the patient with insight into their wellbeing over time
- Integrate tools and databases in one complete overview

ExPEERience could also add value for the care professional and family member experiences by creating more efficient consults and providing better quality of care.

For designing in the field of VBHC this project stresses the importance of incorporating experiences of the community and using a multidisciplinary approach.

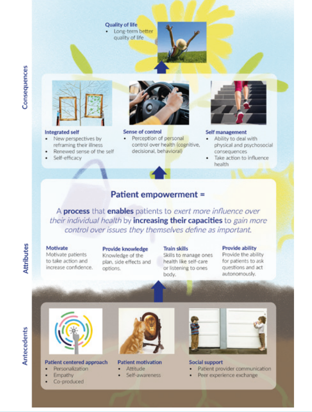
On the next pages a visual overview of these results is presented linking back to their chapters.

To conclude this project, figure 115 aims to provide a visual summary of the presented work in this graduation thesis.

The visual of the project approach as presented in chapter 1.3 is used. In this visual, shortened versions of the answers to the research questions are presented. If you want to see more details of these conclusions you can go to the relevant chapters and look at the key chapter insights.

Patient empowerment is a process that can be enabled by design. The ultimate positive consequence is a better quality of life for the patient.

2. Theme exploration: patient empowerment



3. Contextual inquiry: patient concerns

“Make it relevant for me!”

“Support me when I have a doubt.”

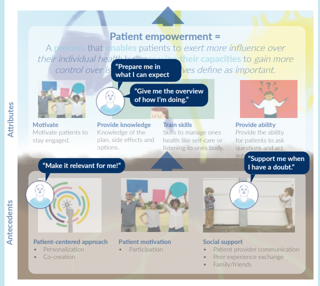
“Give me the overview of how I’m doing.”

“Prepare me in what I can expect and do.”

The 4 main concerns of patients in their follow-up phase are:
- Make it relevant for me
- Support me when I have a doubt
- Give me the overview of how I’m doing
- Prepare me for what I can expect and do

2 of the concerns link to the attributes of patient empowerment to provide knowledge and skills. The other 2 each link to a different antecedent covering both a patient-centered approach and social support

4.1 Link patient empowerment and patient concerns

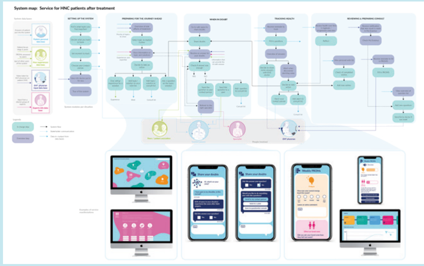


4.2 Design vision

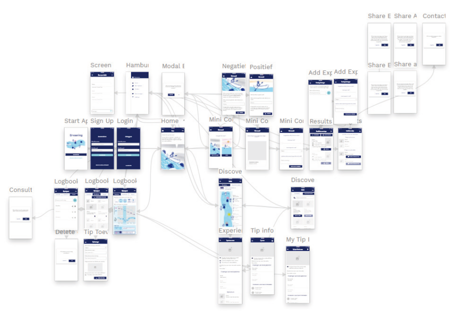
The design should offer patients an overview that enables them to gain more control in dealing with issues of concern to them in the turbulent and uncertain phase after treatment.

The design provides this overview in 3 main ways: an overview of previous experiences through a logbook, the possibility to track present experiences and an overview of possible future experiences.

5.2 Designing



5.4 Prototyping

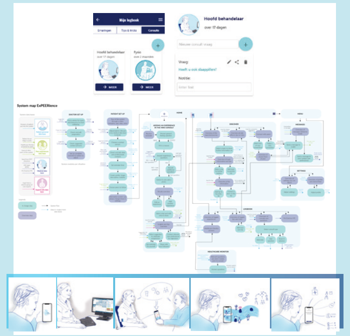


This concept was prototyped into a personalized application prototype using Adalo, so that ex-patients could experience the complete concept and it could work as a conversation starter for further insights.

6.2 Testing

Ex-patients thought the concept is desirable since it provides the values of exchanging experiences with peers and gaining more insight into yourself. Together these lead to the possibility to benchmark your experiences, providing more reassurance in between consults.

6.3 Improving

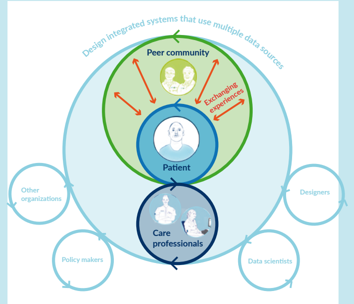


The way in which peers and care professionals are contacted can be improved. For peers, a forum format is most preferred, while care professionals prefer email. Other suggested improvements are shown and an integrated system map with the healthcare monitor is presented.

7. Operationalization

In order to further develop this concept, further research and design is needed especially on the perspective from the care professional, since this was not adressed in this project. Scaling is possible on 6 different levels: care-path, stakeholders, organizations, technology, information platforms and health conditions.

8. Discussion & Conclusion



The 3 main key learnings for designing an app for empowering cancer patients are:
- Include peer patient experiences
- Provide the patient with insight into their wellbeing over time
- Integrate tools and databases in one complete overview

For designing in the field of VBHC this project stresses the importance of incorporating experiences of the community and using a multidisciplinary approach.

Figure 115. Showing the conclusions per chapter to create a complete overview of the discovered results

8.5 Personal reflection

In my initial project brief (Appendix A) I described why I choose this project as my graduation project. My main reason was that I wanted to learn how to design for the medical context. The Design Research Project that I did with the CardioLab before this graduation project, sparked my interest in designing for healthcare and using community data in the design process.

Designing and researching in the medical field
I learned a lot in this project about designing for the medical field. Especially when it comes to involving the different stakeholders and doing research. I found that it is necessary to have connections within the hospital that can help you with setting up your research and finding participants. Without these connections I could never have managed to find the amount of participants for my tests that I now had. Furthermore, doing research with patients is more sensitive than with usual users, therefore the view of care professionals on your research materials can be valuable to take into account.

When it comes to doing research, I also discovered there is a lot of time and effort needed to get an approval for your research in the medical world. During this project I applied for approval from the METC of the Erasmus MC for doing a prototype test with patients for 3 weeks. In the beginning I was rather optimistic about getting approval, but it turned out to take quite some time. Even though I did not get the approval in time to use it during this graduation project, I learned how to create such a proposal and near the end of my project I did get an approval that can be used for future research. In the end, I think that the prototype test done during my project, with ex-patients for a shorter time, was even a better first step to test the concept. It helped to see whether there is value in the designed concept for the patients and was also used as an ideation step for further improvement.

I also learned the importance of scoping your project. This is always important, but especially in the medical field, since there are often so many different stakeholders and perspectives that you could include. It really helped that I made a decision to focus on the patient perspective. Of course designing for the care professional perspective or family perspective are also important, but these are graduation projects in themselves.

Using community data
I really enjoyed working with the community data. It provided me with the confidence that my project is something desired by a larger patient community. I definitely want to use such a method in my future design work, as I think it provides new ways of doing user needs research on a larger scale and can provide more genuine insights for designers. Communicating the results through an interactive journey map worked really well. It provided people with an overview of the gathered data in a way that is not too overwhelming, but does contain the necessary details if needed. I think that the combination of designers and data scientists can be really valuable. Designers can help to give meaning to, and communicate the results of machine learning techniques.

Creating inspirational models from theory
In the beginning of this project I struggled to define patient empowerment since there are so many different definitions for this concept. I found good models, but none of them gave me the complete inspiration that I needed to use this abstract concept in my design process. I learned that it can help to create own models for designers to use. Theory provides evidence, but it can be overwhelming. Designers need a visual and clear model that shows how they can bring these theoretical concepts into their design.

Using metaphors in your design process
I also learned that it takes time to come up with a good metaphor that you can use as your design vision. However, once you have a metaphor that really connects with the context, it can help to bring your design a step further. I noticed that the ex-patients who tried out the prototype really connected with the metaphor once I explained about the visuals I used in the app. I am not yet sure whether you want to literally use your metaphor in your design like I did, but I am sure that it helps to understand the context on a deeper level and can help to communicate the feelings and concerns of your stakeholders.

Design for effective meetings
I learned a lot on other aspects of communication as well. When I had my mid-term presentation, I put a lot of effort into presenting the intermediate outcomes in a visual way. This really helped to convey my message in the limited time. However, I noticed that for coach meetings, I did not always think thoroughly enough about the best way to communicate my work and questions. This often did not matter too much, but sometimes extra explanation was required and miscommunication could also take place. Therefore some meetings took longer than expected and sometimes extra meetings were necessary. In this process I learned that it can help a lot of you visualize what you want to say in one overview that you can use during your meeting. Furthermore, you should really think about the viewpoint of the other person, who comes into the meeting with a lot less knowledge of the project than you do.

Zooming in and zooming out
Another thing I learned in this project is switching between a helicopter and pedestrian view. As a designer you need to switch between thinking on the system level and thinking on the more detailed level throughout your design process. I noticed that sometimes you need to go into the details to make it concrete and tangible. Next, you need to zoom out again to create insights for the system and vision level. As a Design For Interaction student I have mostly been trained to look at the more detailed level. Therefore, I really enjoyed and learned from this project that forced me to also look at the bigger insights.

To conclude, I really enjoyed working on this project. Of course there were highs and lows, as every graduate student will notice, but I enjoyed working together with the different stakeholders and learning so many new things in this final project that I did as a student at the TU Delft.

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